

Candidate Pack for Co-Opted Trustee

mnda
motor neurone disease
association

Starfish

About MND and the work of the association

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 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 provide 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.

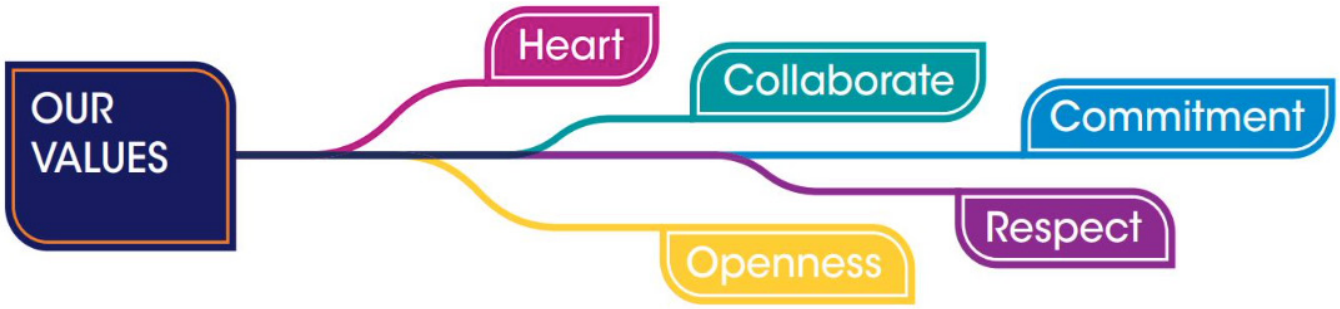
People with MND, their families and carers are at the heart of everything we do

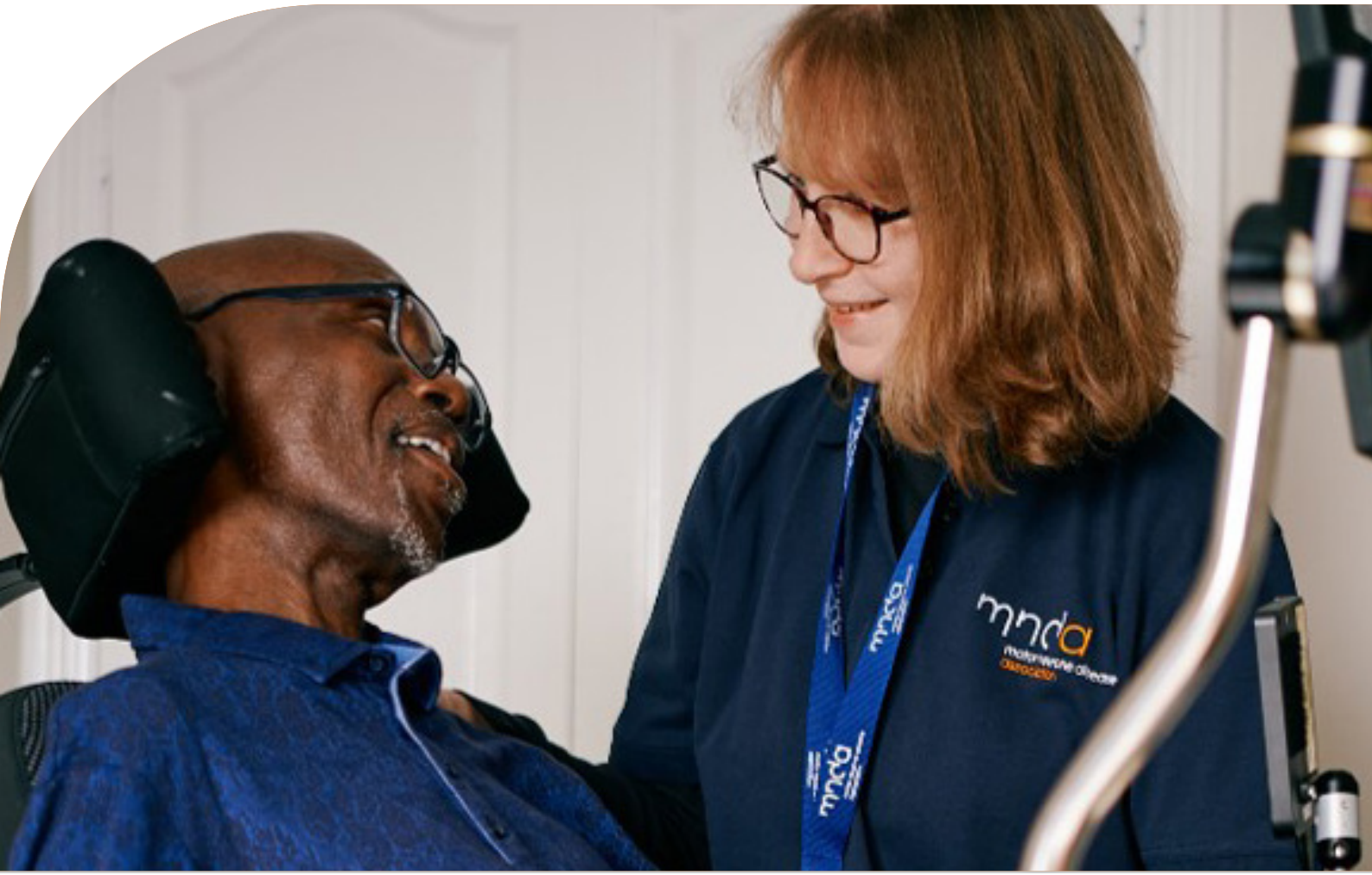


Our vision and values

Our vision
A world free from MND.

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.





Be a part of our growing charity

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. We now need to build on our success and ensure we are well positioned for further growth, elevating our profile and extending our reach and impact.

We have developed our new strategy and are working towards a launch date of April 2025 – we are ambitious, bold and unapologetic in our pursuit of excellence in every aspect of our work on behalf of people with MND.

To view our annual report, impact report and strategy, please click the links below:

Annual report 2023

2024 Impact report

2025-3030 Strategy



Become a Trustee

These are exciting times for our Association, and in 2025 we are looking for a new Co-Opted Trustee - who feels just as passionately about our work as we do – to help us take the next steps towards achieving our vision of a world free from MND.

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. They serve for initial three-year term and can serve for a maximum of three consecutive terms.

Trustees are volunteers who have overall legal responsibility for the charity and play a vital role in shaping our work. Their leadership ensures we continue to support people living with MND, their carers, and families while research into effective treatments progresses.

Summary of the role

A Trustee is expected to:

- Support the MND Association's mission and values with commitment and dedication;
- Engage constructively with the opinions of other Board members and staff contributions during discussions and meetings;
- Act reasonably and responsibly in fulfilling the role, while understanding and accepting their legal duties;
- Maintain confidentiality on sensitive and confidential information; Identify and address conflicts of interest appropriately, in line with legal obligations;
- Understand the purpose of meetings, prepare thoroughly, and attend regularly to contribute effectively;
- Exercise independent judgment in decision-making;
- Analyse information, including financial data, and challenge constructively when required;
- Make collective decisions and take responsibility for explaining and supporting those decisions;
- Collaborate effectively as part of a team; Champion equality, diversity, and inclusion within the organisation;

What does the Board of Trustees do?

The Board of Trustees has ultimate responsibility for what we do. The role of the Board is to:

- Provide appropriate oversight, governance and leadership to the charity in the pursuit of its strategies to fulfil its charitable purposes;
- Scrutinise the performance of the management in meeting agreed goals and objectives and monitor the reporting of performance in key areas;
- Satisfy themselves as to the integrity of financial and other information, and that financial and other quality controls and systems of risk management are robust and defensible.

As the Board is responsible and liable for the governance and functioning of the charity, they are accountable in varying degrees to a variety of stakeholders, including members, beneficiaries, funders, the Charity Commission, and other regulators (e.g. Companies House).

Above all else, Trustees must adhere to any legal and regulatory requirements applicable to the charity's activities.

What does a Trustee do?

Being a Trustee means you will play a critical role in helping the Association set its strategic direction, support and challenge the Chief Executive and the Executive Leadership Team. The Board is also responsible for monitoring the charity's performance, setting budgets and ensuring the Association complies with regulatory and statutory requirements. This is done by attending Board and committee meetings throughout the year, hearing reports and reading papers from the Chief Executive and the Executive Leadership Team. The Association has five committees which oversee the work of the charity. They are:

- Care Services and Research Committee;
- Engagement and Income Committee;
- Governance Committee;
- Finance and Audit Committee;
- People, Culture and Inclusion Committee.

Trustees are supported on committees by Committee Subject Matter Experts, people who bring a particular knowledge and experience to the committee by offering advice and insight.
The Chief Executive and members of the Executive Leadership Team attend committee and Board meetings.

How do Trustees make decisions?

Trustees make decisions collectively as a Board, following the principles of charity law, Charity Commission guidance, and the charity's governing documents, focusing on the charity's best interests and public benefit, while managing risk and conflicts of interest. The Chief Executive and the Executive Leadership Team ensure decisions are implemented.

Person Specification

The following characteristics, knowledge and experiences (or commitment to gaining them) would be advantageous to the role of charity Trustee:

- A high level of understanding and interest in the issues the charity seeks to address/represent;
- A commitment to the values and principles of the charity;
- Good business and financial acumen;
- Experience of committee work;
- Highly developed interpersonal and communication skills;
- Ability to understand complex strategic issues, critically assess, analyse and resolve difficult problems;
- Sound, independent judgement, courage, common sense and diplomacy;
- Politically astute, with the ability to grasp relevant issues and understand relationships between interested parties;
- Clear understanding, and acceptance, of the legal duties, liabilities and responsibilities of trustees;
- Sound knowledge of charity governance;
- Sufficient time and commitment to fulfil the role;
- Resilience;
- Ability to listen to and welcome alternative opinions and experiences;
- Flexibility in thinking;
- A desire to implement the highest standards of governance.

Specific Skills and Experience

The Association is looking for Trustees who have skills and experience within one of the following areas:

- Governance and/or legal;
- People and culture;
- Transformational change;
- Clinical service delivery;
- Healthcare;
- Charity CEO.

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.

Motor neurone disease 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.



What is the time commitment for being a Trustee?

Becoming a Trustee is a serious time commitment and Trustees are expected to attend around ten to twelve meetings per year.

- Each Trustee will be expected to attend four board meetings at our offices in Northampton or London. Board meetings are all day meetings and occur on a Friday.
- An in-person Board Away Day also occurs once per year, usually in September.
- Trustees will also be invited to sit on two committees. Committees meet online four times a year for a few hours in the work week.
- Trustees are expected to read and review any papers which will be discussed during the Board and committee meetings ahead of time.
- Trustees might also be asked to attend other meetings and events, to represent the Association, meet volunteers, members and donors.

We expect the time commitment for the role to be two to three days per month, spread over a 12-month cycle.

Committee meetings operate in a hybrid format to ensure inclusivity and accessibility.

While Board meetings are predominantly face-to-face, Trustees may be able to join remotely. Our central office is situated at Francis Crick House in Moulton Park, Northampton. We also have a managed office space in London.

Who can be a Trustee?

To volunteer as a Trustee, you must be:

- Over the age of 18;
- Be willing to become a member of the Association;
- Be willing Comply with Disclosure and Barring Service (DBS) and any other relevant checks;
- Be willing to comply with the Association's procedures relating to our Code of Conduct and declarations of interests;
- Able to confirm you have not been disqualified from acting as a Trustee.

You must not act as a Trustee if you are disqualified under the Charities Act, including if you:

- Have an unspent conviction for an offence involving dishonest or deception (such as fraud);
- Are bankrupt or have entered into a formal arrangement (e.g. an individual voluntary arrangement) with a creditor;
- Have been removed as a company director or charity trustee because of wrongdoing.

It is not a requirement to be involved with an MND Association branch or group although some Trustees hold a position within their local committee. However, it is important to remember that as a Trustee, you will be 'wearing a different hat' and working in the interests of the Association as a whole, not representing a local branch or group.

Do Trustees receive training and support?

All Elected and Co-Opted Trustees are required to take part in an induction programme. This involves meeting members of the Board, the Chief Executive and members of the Executive Leadership Team. The majority of this is completed online.

Trustees are also required to undertake e-learning training. External and internal training is also offered. Trustees are invited to have an annual review, a one-to-one discussion, each year with the Chair where they can identify further areas of support and training.

Anything else I should know?

- The role of a Trustee is an unpaid voluntary role. To help Trustees fulfil their duties all reasonable expenses are paid for by the Association.
- All Trustees are required to act in accordance with the Trustee's Code of Conduct, including declaring any potential conflicts of interest or loyalty.
- Trustees are required to abide by our policy on confidentiality and to work with the Association's policies and procedures.
- Trustees are covered by the Association's liability insurance while carrying out their duties.



How to Apply

We hope you will consider making an application. If you have questions about the appointment and would find it helpful to have an informal conversation, please contact **katy.giddens@starfishsearch.com** and we will be happy to arrange a call. To make an application, please go to **https://starfishsearch.com/jobs/mnda-co-opt-trus/** and click on the apply now button, with the following prepared:

- Your CV (no more than three sides).
- A supporting statement (no more than two sides) that sets out why you think this role is the right move for you and how you meet the knowledge and experience criteria.

Alternative application process

- To support an inclusive application process, we are open to receiving alternative applications. If you would like to apply via video or audio file, please send your recorded expression of interest to **chris.milo@starfishsearch.com**

Closing date: Monday 9th June 2025

Preliminary interviews: w/c 16th June 2025

Final Panel interviews: w/c 30th June 2025

