

Could you be a Trustee?



mnda
motor neurone disease
association

INFORMATION GUIDE

Our vision is a world free from MND

Dear Reader,

This guide aims to answer your questions about what it means to be a trustee and explain who can stand for election.

Being a trustee is a great way of making a real difference to the lives of people living with motor neurone disease.

Being a trustee brings many rewards including the opportunity to support our vital work by planning the Association's future, developing your own skills of decision making, seeing the bigger picture and meeting new people.

The role also brings responsibilities and commitments, including attendance at board meetings, joining one of the Association's committees (and all the reading that goes with these) and the work can sometimes be challenging. Trustees are legally responsible for making sure the Association does what it was set up to do, and to ensure that it is well run.

If you are inspired to find out more about this fulfilling volunteering role, we would be delighted to hear from you.

The MND Association Board of Trustees

How do trustees make decisions?

The Board

The Board of Trustees meets up to five times a year. An agenda, minutes and information papers are sent to trustees about ten days before each meeting to allow time for reading and assimilation of information and the opportunity to ask for clarification from directors before topics are debated and decisions reached.

Trustees have a duty to act collectively, which means that they are collectively responsible for decisions made by the Board. Individual trustees may therefore need occasionally to put to one side any personal views about a particular issue and once the debate has been had, to support the decision that has been made.

The Chief Executive and directors ensure decisions are implemented.

Committee and panels

Some specialist tasks are delegated to smaller committees and panels that meet between two and four times a year and comprise trustees, staff and others with specialist knowledge. These focus on areas such as care, research, finance, governance and volunteering policy.

During periods of social restriction, all Board and Committee meetings have been held as virtual meetings, using Microsoft Teams. However, this approach is changing to become a mixture of physical and hybrid meetings. Committee meetings will most likely be held in the Association's central office in Northampton while Board meetings will be held in a variety of locations chosen for ease of access.

Trustees are expected to sit on one or more committees/panels.



“Being a trustee is the very best type of challenge: but all within a supportive community of dedicated people truly passionate about the cause we serve.”

Dr Shaun McGee, trustee

Support for trustees with disabilities

We particularly welcome applications from people living with MND, other long-term condition or a disability. Every effort is made to accommodate requirements and help with transport, travel and accommodation is of course provided.

As you will see in a later section of this brochure, elected trustees serve an initial term of three years. For someone living with MND, other long-term condition or a disability, this might feel somewhat daunting, but having lived experience within the membership of the Board is extremely valuable as it helps bring an important focus to our discussions. We would far rather you only serve one or maybe two years than not put yourself forward for election. We will always be as flexible and supportive as we can.

Board meetings can be quite long and tiring and membership of board committees increases your commitment, so if you are thinking about becoming a trustee and are concerned about the commitment required, do talk to existing trustees about the time commitment to help you decide whether the role it is right for you. An informal chat with a senior member of the care directorate will be offered to explore areas where you may need support now and in the future.

We make every effort to ensure that the hotels and buildings we use are fully accessible. However, they won't necessarily have all the facilities that you have at home so there may be an element of compromise required. We will do everything we can to facilitate your full participation and comfort.



Our commitment to Diversity Equity and Inclusion (DEI)

Motor neurone disease is an inclusive condition. Although it is more prevalent amongst older people it does not discriminate directly or indirectly on the grounds of sexuality, ethnicity, religion, disability, sex or age.

As an Association, we are committed to equity, value diversity and are determined to be fully inclusive in order that we can help ensure that people with and affected by MND get the best possible care and support in their particular circumstances. We have a very simple three-part DEI strategy:

1. Extending our reach into different communities and ensuring that our products, services and support are accessible
2. Identifying and addressing MND specific health and social care inequities
3. Becoming a truly inclusive organisation



“It is a privilege to support the Association by using my skills and experience and to help make a difference to those affected by MND.”

Jim Marshall, Trustee and Honorary Treasurer

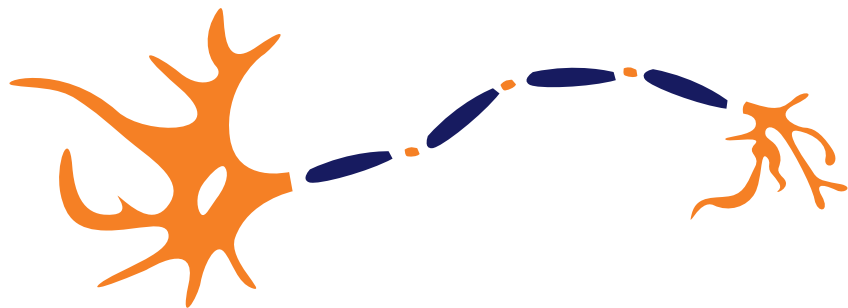
Why does the Association have trustees?

We are a membership organisation and therefore it is vital that members play a key role in the running of the Association.

Under our governing document, we are required to have a Board of Trustees. Trustees take overall responsibility for the proper running of the Association and work collectively to make decisions and ensure that we are doing what we were set up to do. Trustees have to consider not only the current needs of the Association but also plan for the future to make sure we are able to carry on our work on behalf of people with MND not just today but over years to come.

Our trustees are responsible for ensuring the mission and long-term aims of the MND Association are met. They have a responsibility to make sure the Association is well run, solvent and complies with the latest company and charity legislation.

The trustees must work within the Charities Act and Companies Act and accept the responsibilities and risks that flow from these pieces of legislation.



What do trustees do?

- Take a national perspective in ensuring the Association works towards meeting the needs of people affected by MND.
- Ensure the Association's resources are used appropriately.
- Agree the Association's direction and long-term plans.
- Evaluate how well the Association is meeting its commitments.
- Ensure the best interests of the Association as a whole are taken into account - taking an overall rather than a local perspective.
- Take legal responsibility for the proper running and governance of the Association.

Our Board of Trustees currently comprises the chair, up to nine elected and up to six co-opted trustees.

Our Chief Executive who is head of the Association's paid staff, reports to the Board of Trustees.



“Being a trustee is a huge privilege giving the opportunity to make a real difference to the Association and therefore people affected by MND.”

Catherine Knights, Trustee

Who can be a trustee?

To volunteer as a trustee, you must be:

- be willing to become a member of the Association
- over 18
- willing to comply with Disclosure and Barring Service (DBS) and any other relevant checks
- willing to comply with the Association's procedures relating to our Code of Conduct and declarations of interest
- able to confirm that you are not 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 dishonesty or deception (such as fraud)
- are bankrupt or have entered into a formal arrangement (eg 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.

How do I become a trustee?

Elected trustees stand for election in the spring and our members vote during the summer. Those receiving the greatest number of votes fill the vacancies on the Board and are announced at our Annual General Meeting.

Elected trustees serve for an initial period of three years. They can then stand for election for a consecutive second term of three years after which time they must stand down for at least one year. We also have up to six co-opted trustees who bring specific skills to the Board. We identify the skills we need by undertaking a regular skills audit among the members of the Board.

Co-opted trustees do not stand for election but go through a selection and interview process carried out by existing Board members. Co-opted trustees can serve for up to three two-year terms. These do not have to be consecutive, and they can continue for an additional term of two years in very exceptional circumstances if invited to do so by the Board.

The Chair is elected by the trustees and serves for one term of four years.

Do trustees receive training?

All newly elected trustees and co-opted trustees are required to attend an induction day focusing on their role and the Association's mission.

We also provide opportunities for ongoing training and support.

Trustees have a one-to-one discussion each year with the Chair to reflect on their experience and contributions and consider future opportunities.

Further knowledge can be gained by attending one of our Regional Focus events as well the AGM.

Anything else I should know?

- All reasonable expenses are paid.
- All trustees are required to act in accordance with the trustees' 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 within the Association's policies and procedures.
- Trustees are covered by the Association's liability insurance while carrying out their duties.

How do I find out more?

If you'd like to find out more about the role of a trustee, have any questions to ask or would like a nomination form to stand for election, our Chief Executive or Governance Officer would be delighted to hear from you. You can also access information online at www.mndassociation.org/get-involved/volunteering/becoming-a-trustee

Please contact us by emailing governance@mndassociation.org



“As a trustee, I want to use my personal experience and healthcare and social care background to help improve care for people living with MND.”

Siobhan Rooney, Trustee

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.

Motor neurone disease

- MND is a 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, sound feeling etc.
- Around 35% of people with MND experience mild cognitive change causing difficulties with planning, decision-making and language. A further 15% show signs of a form of dementia resulting in more pronounced behavioural change.
- It can leave people locked in a failing body unable to move, talk and eventually breathe.
- It affects up to 5000 adults in the UK at any one time.
- It kills six people every day in the UK.
- A third of people die within a year of diagnosis and half within two years.
- It has no cure.



MND Association

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