

# Could you be a Trustee?



**mnda**

motor neurone disease  
association

**INFORMATION GUIDE**

# Could you be a trustee?

For more than four decades the MND Association has been at the heart of the global fight against MND, offering advice and support when it is needed most and driving forward research towards effective new treatments and ultimately, a cure.

The MND Association is a charity that is growing, in terms of our research portfolio, our income and our voice to shout louder about MND, to make sure the voices of people with MND are heard by those who can make a difference. We have never been in a better place to beat MND - once and for all.

Back in 2022, we launched five overarching promises to our members and every person, living with and affected by MND, to help to guide our work in the coming years.

We will not rest until:

- 1. MND is treatable and ultimately curable.**
- 2. You get the care you need when you need it.**
- 3. Every day counts.**
- 4. You are heard.**
- 5. No one faces MND alone.**

## What is a trustee?

Charities are required to have trustees and trustees are volunteers who have the overall legal responsibility of the charity. We are a membership organisation and our governing documents require that our members have a say in the running of the Association.

Trustees play a vital role in pushing our work forward, ensuring we continue to do all we can to support people living with MND and their families while the search for effective treatments continues.

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

The Charity Commission for England and Wales, the regulatory body of the Association, outlines the six main duties of a trustee as:

1. Ensuring your charity is carrying out its purposes for the public benefit.
2. Complying with your charity's governing document and the law.
3. Acting in your charity's best interests.
4. Managing your charity's resources responsibly.
5. Acting with reasonable care and skill.
6. Ensuring your charity is accountable.



**“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*

# What does a trustee do?

Being a trustee means that 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 Fundraising Committee
- Governance Committee
- Finance and Audit Committee
- People, Culture and Inclusion Committee

Trustees are supported on committees by Committee 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 have a duty to act collectively, which means that they are collectively responsible for decisions made by the Board. Individual trustees may need to occasionally 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 the Executive Leadership Team ensure decisions are implemented.

## 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. 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 that 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.



**“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*

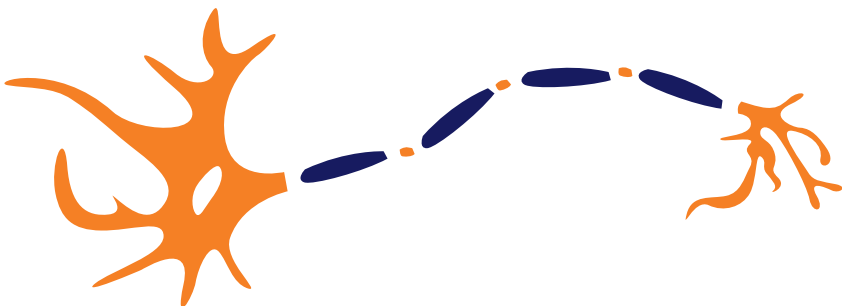
# How do I become a trustee of the Association?

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. The Annual General Meeting usually occurs in early summer.

Elected trustees serve for an initial three-year term. They can then stand for re-election for a consecutive second term of three years, after which time they must stand down for at least one year.

The Association also has up to six co-opted trustees, who are appointed by the Board and bring specific skills and experiences. The Board identify the skills needed by undertaking 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. Co-opted trustees can serve for up to three two-year terms.

The Chair is elected by the trustees and serves for one term of four years. The Board elects a Vice-Chair from their members.



## 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 to 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 that 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 (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.



**“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*

## Support for trustees with MND and other long-term conditions or disabilities.

Having lived experience within the membership of the Board is extremely valuable as it helps bring an important focus to our discussions. We particularly welcome applications from people living with MND, other long-term condition or a disability.

We will always be as flexible and supportive as we can. All meetings can be hybrid, allowing trustees with MND to join online if it suits their needs.

Every effort is made to accommodate requirements. We will help with transport, travel and accommodation. While we make every effort to ensure that the hotels and buildings, we use are fully accessible. However, they will not necessarily have all the facilities that you have at home so there may be an element of compromise required.

## Our commitment to diversity, equity and inclusion

We also particularly encourage nominations from under-represented groups and communities including, BAME, LGBTQIA+ and young people (over 18 years of age).





## Do trustees receive training and support?

All newly elected trustees 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 done online.

Trustees are also required to undertake e-learning training. External and internal training is also offered to support trustees. 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 do I find out more?

If you would like to find out more about the role of a trustee, please contact our Governance Manager at [governance@mndassociation.org](mailto:governance@mndassociation.org).

If you would like to find out about other volunteering opportunities at the Association, please visit [www.mndassociation.org/get-involved/volunteering](http://www.mndassociation.org/get-involved/volunteering).

# 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 50% of people with MND experience some form of cognitive change, this can affect their thinking or behaviour. The percentage rises to 80% for people who are in the advanced stages of the disease.
- It can leave people locked in a failing body unable to move, talk and eventually breathe.
- It affects up to 5,000 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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