

Candidate Pack for Engagement & Income Committee Members

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



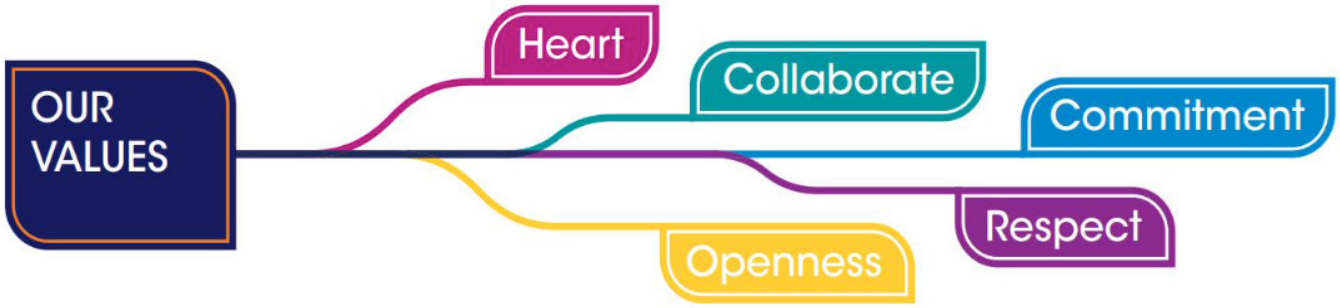
Our vision and values

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



Job description

Job title: Committee Subject Matter Expert

Reports to: Engagement and Income Committee Chair

Role Purpose

To act as a Non-Voting Member of the Engagement and Income Committee. The overall purpose of the Engagement and Income Committee is to provide governance and scrutiny on the strategic direction of the Association's engagement and fundraising work.

The Committee Subject Matter Expert (SME) plays a critical role in providing specialised knowledge and expertise to support the decision-making and strategic direction of the Committee.

Main responsibilities

Provide Expert Guidance

- Offer expert advice and insights on specific areas such as engagement and income generation.
- Serve as valuable resource for the Committee on technical or specialised issues, offering evidence-based recommendations.

Support Decision Making

- Attend Committee meetings (in-person or virtually) and contribute to discussions by offering expert opinions on relevant topics.
- Help the Committee understand complex issues and assist in evaluating potential solutions or strategies based on expert knowledge.

Contribute to Strategy Development

- Provide input to the development and refinement of the Association's strategic initiatives, ensuring that plans align with the latest research, trends, and best practices in the field of MND and care services and research.
- Assist in identifying emerging trends and innovations that could impact the Association's work and future direction.

Collaborate with Committee Members

- Work closely with other Committee members to share knowledge and build consensus on recommendations and decisions.
- Foster collaboration and open communication, ensuring that all perspectives are considered and integrated into Committee planning.

Monitor Industry Developments

- Stay current with developments in your area of expertise, including research, policy changes, and technological advancements, and communicate relevant updates to the Committee.
- Provide advice on how these developments might influence the Association's activities and strategies.

Support External Relations

- Assist in fostering partnerships or collaborations with external organisations, researchers, or specialists to further the Association's mission.

Assist in Fundraising and Advocacy (if applicable)

- Support fundraising and advocacy efforts with specialised knowledge or by providing high-level content for communications, campaigns, or presentations.
- Contribute to donor relations by providing technical content or updates that showcase Association's impact and future goals.



Person Specification

Required Skills and Experience

Specific Skills (one or more of the following)

- Significant expertise in fundraising development and strategy ideally in a large/complex organisation with many different "routes in" when it comes to fundraising mechanisms.
- A charity FR Director.
- Governmental knowledge - holding relationships, strong influencing, policy lens.
- Advertising end of marketing.
- Access to treatments, experience of regulatory environment and/or policy environment.

General Skills

- Experience in advisory roles, demonstrated experience in providing specialised advice in a professional or voluntary capacity.
- Strong communication skills, ability to communicate complex ideas clearly to a variety of audiences, including non-experts, and to work collaboratively within a team.
- Commitment to the Association's mission, with a passion for supporting people affected by or living with MND.
- Problem-solving ability, with a proven ability to analyse information, think critically, and provide actionable solutions or recommendations.
- Willingness to stay informed about advancements in your field and share that knowledge with the Committee.



Terms of appointment

Remuneration
This is a voluntary position, with reasonable expenses paid.

Location
Meetings are predominately virtual. Any in person meetings will be held at either our Northampton or London offices.

Time Commitment
The Committee meets quarterly. Meeting during 2-4 hours within standard office hours.

Term
Two years with a possibility of renewal.



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-eng-inc-com-mem/** 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**

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.

Closing date: Monday 9th June 2025

Preliminary interviews: w/c 16th June 2025

Final Panel interviews: mid July 2025

