

fighting
motor
neurone
disease

Chief Executive

A message from the Chair

Dear Colleague,

Thank you for your interest in becoming the next chief executive of the Motor Neurone Disease (MND) Association. This is a truly pivotal time in our journey – after a decade of leading the organisation through considerable change and growth, Sally Light is set to step down at the end of the year and this is a significant opportunity for someone to lead the charity through the next stage in its transformation.



We are looking for an experienced, outward facing, influential senior leader who will ensure we deliver on our five Promises to best support for people with MND and their families. Supported by a highly dedicated, experienced and professional senior leadership team you will play a crucial part in ensuring we continue to deliver exceptional services to our MND community as we drive the research agenda towards the development of effective treatments and new care models. Collaborative, with high emotional intelligence, you will be at ease engaging with and maintaining strong relationships with a very wide range of key stakeholders, from donors, politicians, to the media, industry and senior clinicians, and, most importantly to our community.

MND Association is a national membership organisation with a local feel – our 90 branches and groups are run by incredibly dedicated and experienced volunteers who deeply understand and support their local MND community, and you must be able to demonstrate a real understanding of what motivates people to work or volunteer with us.

We are entering a very exciting and potentially life changing time for people with MND. With new funding of £50m secured towards research, we are on the cusp of being able to develop effective treatments for some if not all, of our community.

Although you don't need to have a health background, you will need to be able to demonstrate you understand the complex, often highly challenging and emotive environment we operate in, and be able to understand and engage credibly with stakeholders in the medical and pharmaceutical worlds as well as the research community.

We are an open, non-hierarchical and inclusive organisation and as our next chief executive you will actively embrace and look to maintain the positive organisational culture that exists here. We want our employees, volunteers and Trustees to represent the diversity of the communities of which we are a part, and for our research, services and influencing work to reflect the diverse needs of all those living with MND.

If this role sounds exciting and you are driven to lead us through the next stage of our journey, I look forward to hearing from you.

Usman Khan
Chair

About the MND Association

The MND Association focuses on improving access to care, research and campaigning for those people living with or affected by MND in England, Wales and Northern Ireland. We are a membership organisation with over 10,000 members forming a powerful national and local network that provides information and support. We have over 7,000 active volunteers in England, Wales and Northern Ireland and nearly 200 paid staff, all dedicated to improving the lives of people affected by MND, now and in the future. We improve care and support for people with MND, their families and carers.

Our Vision

A world free from MND.

We promise...

The MND Association is harnessing the hope within our community to speed up progress towards a world free from MND, by committing to five promises.

After more than 40 years' work, there is more knowledge, more co-ordinated care and more support than ever. But it's not enough. Our five promises give us a renewed focus to work faster and fight harder to strive for better – together with our community.

These promises have been shaped by our community and they will power everything we do

Promise 1: MND is treatable and ultimately curable

We are seeking new collaborative drug discovery and development projects, helping to fund and facilitate the research that is taking us ever closer to uncovering the causes of MND, effective treatments and ultimately a cure.

Promise 2: Everyone gets the care they need when they need it

Co-ordinated multi-disciplinary care is the very best way to ensure a person with MND has access to all the healthcare professionals they need, at the right time. Our 22 care networks across the country provide this. But not everyone with MND has access to the same level of support. That must change.

Promise 3: Every day with MND counts

For people with MND, technology can help life be the best it can. The MND Association Think Tank is working with tech giants from around the world to find solutions to real-life problems.

Promise 4: You are heard

If we shout louder and to the right people, things will change. If we all join together we can't be ignored.

Promise 5: No one faces MND alone

We will work to break down barriers that prevent people with and affected by MND from accessing the help and support they need.

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.

Click below to view the latest impact report



To find out more please visit <https://www.mndassociation.org/about-us/who-we-are/>

To read our strategy and annual reports please visit: <https://www.mndassociation.org/app/uploads/2022/07/Annual-Report-2021.pdf>

<https://www.mndassociation.org/app/uploads/2022/06/Impact-Report-2021.pdf>

Diversity, Equity and Inclusion

Motor neurone disease is an equal opportunities 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.

At the 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.

<https://www.mndassociation.org/about-us/who-we-are/diversity-equity-and-inclusion/>



Role Profile

Role title:	Chief Executive
Reports to:	Board Chair
Responsible for:	Director of Fundraising, Director of Research Development, Director of Care Improvement, Director of External Affairs, Director of Engagement, Director of Finance. Current revenue of £20M, staff c. 200 and services delivered across England and Wales and Northern Ireland.
Key relationships:	People living with or affected by MND and their representative groups Trustees Peers within the charity and medical research sectors Relevant government, healthcare and policy networks High value donors, funders and partners Staff and volunteers

The Senior Leadership Team (SLT), led by the CEO, are expected to:

- Be leaders for MND Association first and their areas of expertise and responsibility second
- Provide clear, confident articulation of purpose and direction of travel
- Role model and actively embed our values and behaviours across all of our activities
- Actively champion our brand values with energy and dynamism
- Be visible when and where needed both internally and externally
- Inspire, motivate, support, challenge and develop our people
- Seek out, support and act on the input and recommendations of expert leads.

Role purpose:

This role is accountable for providing the strategic leadership and direction that enables the MND Association to fulfill its Promises, vision and purpose. As CEO you will ensure the organisation continues to meet the needs of people living with MND, their families and their carers by growing our impact, building our brand, leading campaigns and ensuring our financial sustainability. In doing this you will ensure the MND Association remains a great place to work and volunteer, and a fantastic charity to support.



Overall organisational performance

- Leadership and management of the charity in the execution of its activities within the framework set by the Board of Trustees.
- Ensuring organisational performance is to agreed standards and measures.
- Ensuring the organisation effectively discharges its governance, constitutional and legal responsibilities.

Strategic development and delivery

- Give dynamic, innovative leadership and vision to the Association as it works to fulfil its mission.
- Develop and drive the overall strategic Promises and priorities securing the support of a highly skilled and dedicated organisation with best practice and good corporate governance built into all services.
- Work with the Board and Directors to achieve business strategy, plans and to comply with the legal and governance responsibilities of the role.

Organisational culture

- Leading by example in terms of prioritisation and delivery, setting goals and being measured against them. Setting clear expectations and following up transparently for optimum impact.
- Ensuring issues of diversity and inclusion are at the heart of the MND Association's culture and central to all organisational developments, including by ensuring the organisation is delivering against an agreed strategy and action plan for diversity and inclusion.
- Be a clear leader for issues of diversity and inclusion, personally role modelling our commitment to this.
- Be a visible leader for wellbeing, personally role modelling our commitment to this and ensuring it is at the core of how we work or volunteer together.

Leadership and management

- Leading and managing the SLT, collectively and individually, ensuring performance against agreed measures and supporting the ongoing professional development of the team and individuals within it.
- Be a visible and accessible leader across the organisation, accessible to staff and volunteers and working to inspire, motivate and support them in experiencing the MND Association as a great place to work and volunteer.
- Build effective relationships with the membership of the Association, for example, through the work of Branches and Groups, and lead in the development of related strategies and plans to increase income generation.
- Build, maintain and develop effective networks and relationships with key supporters, stakeholders and influencers and develop further the public profile of the Association.

Advocacy and influencing

- Creating, developing and leveraging a strong external network in support of the MND Association's ambitions, including through engagement in relevant sector, policy and research communities.
- Enhancing our brand and facilitating work to grow our supporter base, by acting as the senior media spokesperson for the MND Association and by being a visible and passionate advocate for our work and ambition.
- Take a lead role in establishing effective engagement with potential and existing major donors and Trusts and represent the Association at relevant events with external stakeholders and the media.
- Actively seek opportunities to expand the influence of the Association's role with key individuals and groups such as Government, relevant Agencies, academic institutions and other charities.
- Promote the values and ethos of the Association and be a positive ambassador for the charity.

Governance and accountability

- Ensure that the Association discharges its constitutional and legal obligations with sound financial management and effective delivery of services, in accordance with the Board's expectations, to ensure long-term sustainability.
- To build and maintain a positive working relationship with the Chair and other Trustee members of the Association Board and sub-committees.
- Overall responsibility for compliance with the Data Protection Act (DPA) and organisational health and safety responsibilities.
- To undertake any other duties commensurate with the post of Chief Executive.

Essential criteria

Knowledge and experience

- Significant experience of successful senior leadership and management within a large, complex organisation or chief executive of an organisation of similar scale or breadth on a national and/or international stage.
- Proven, extensive and successful cross-functional leadership experience, managing a senior team, and of leading organisational development and change management programmes.
- Good understanding of the role of data and digital in driving organisational development particularly in relation to supporter engagement.
- Ideally understands or has lived experience of the impact of a life limiting health condition, either personally or through a close connection, and ability to draw upon insights to lead with passion and authenticity.
- Demonstrable understanding of health and social care system working and meeting the clinical support requirements of people with multiple complex health needs.

Skills and abilities

- Open, authentic and empathetic leadership with an accessible and engaging style with the ability to get the best out of people.
- A skilled and inspiring communicator and campaigner, able to effectively influence and engage diverse stakeholder groups internally and externally including media, Government, staff, volunteers, and partners and funders within the health, social care and research communities.
- Commercial acumen and an ability to effectively utilise this in a charity context.

Personal behaviours

- A strong commitment to our five Promises, our vision and values of the MND Association and our community.
- Collaborative and collegiate approach with the ability to inspire and motivate all colleagues, including volunteers, at all levels.
- Actively role model and promote a commitment to diversity, equity and inclusion and proactively seeks out diverse views to inform thinking and decision making.
- Strong ambassadorial leadership, able to represent the Association in front of volunteers, staff, trustees and stakeholders and the public.
- Excellent judgment and high levels of integrity.

Desirable

- Experience of working to improve the lives of people with MND.
- Experience of working in health or social care, or associated basic or clinical research/sciences.
- Experience of media engagement and acting as an organisational spokesperson.

Terms of Appointment

Salary

Up to £130,000.

Contract

This is a permanent full-time appointment.

Location

Flexible location. Regular presence in Northampton (approximately two days a week) and London will be required, as well as travel nationally across the three countries we serve and internationally.

Pension

5% employee and 8.1% employer which is run on a salary sacrifice basis.

Holidays

28 days, rising to 33 after 5 years.



How to Apply

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

- your CV (no more than three sides)
- a short supporting statement (maximum two sides) that sets out why you believe you are ideally suited to take up the role of Chief Executive for the MND Association.
- We would be grateful if you would share any dates when you are not available to attend interview.

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

Closing date: Friday 2nd September 2022

First stage interviews with Starfish Search: w/c 12th September 2022

Second stage interviews with the MND Association: w/c 3rd October 2022

