The Leeds Teaching Hospitals
NHS Trust

The Rob Burrow Centre for Motor Neurone Disease

Strategy

A Centre of Care, Hope and Change

FOREWORD

Whilst the Motor Neurone Disease (MND) service at Leeds Teaching Hospitals NHS Trust has been running for more than ten years, it is really only over the past few years that MND has moved to a central point in our national conversation. From what was once a largely hidden condition, to now people knowing about it across all sports, in news headlines, and in the hearts of their communities across the country. A large part of this shift has been driven by the courage of people living with MND, and by advocates and brave leaders such as Rob Burrow CBE, whose openness, humour and unrelenting determination have given a voice to thousands.

The Rob Burrow Centre for Motor Neurone Disease is the embodiment of that visibility and courage. It began as a conversation, an idea shared between Dr Agam Jung and her patient Rob Burrow to create a better space for MND patients in Leeds that matched the clinical care. Supported by a fundraising appeal led by Leeds Hospitals Charity and largely bolstered by Kevin Sinfield, generosity and solidarity spread across West Yorkshire and beyond. In just four years, the shared dream has become a physical landmark achievement, with an innovative, purpose-built centre here at Seacroft Hospital for patients from Leeds and the surrounding area.

This strategy sets out a vision that reflects the scale of that achievement. It acknowledges that MND is complex, progressive and devastating, and that the people it affects deserve care that is compassionate, expert and centred around them as a person and also care for those who support them. The model of care will focus on integrating care with education, research and holistic support and bringing it under one roof to be a centre for excellence and a model that other centres might copy.

This centre has been shaped by the voices of people living with MND, by dedicated staff and volunteers, by charity voices and the thousands of people who generously donated to make it a reality.

As this strategy looks ahead, it does so with a defined sense of purpose. The Rob Burrow Centre for Motor Neurone Disease stands as a beacon of hope, compassion and ambition. It is a place where people can find space to breathe, to connect, to learn, to care, to innovate, and above all, to Live in the Now.

Robert Hakin
Director of Healthcare Planning

Dr Jonathan Bilmen
Clinical Director, Neurosciences

November 2025 marked an extraordinary moment: the opening of The Rob Burrow Centre for Motor Neurone Disease. As I reflect on the journey since March 2020, it feels almost surreal. What began as a conversation with my patient Rob Burrow about simple care and support for those living with MND, has grown into this striking purpose-built sanctuary that now stands proudly in Leeds and with a beautiful vision to change the way we support not only those living with MND, but their families and all those around them. This centre is a tribute to Rob's courage and a sign of hope and change for every family living with MND.

Shaped by five years of listening to patients, families, and staff, and with steadfast support from Rob and his family, it is a space where holistic care, research, education, and compassion sit side by side and are intertwined. Nature, permanence, and impermanence are woven gently into its design, offering dignity, hope, and love. I am profoundly proud of our multidisciplinary team, our architects and builders, our partners and fundraisers, and the generosity of the public. So much work has gone into building this centre, and now the real work begins. I look forward to working with so many talented and dedicated specialists as we continue the task of shaping pioneering care for MND. This is through our own example, through education and through the research projects and partnerships. We are energised by the journey ahead. Thank you.

Dr Agam Jung

Director, The Rob Burrow Centre for Motor Neurone Disease

Leeds Hospitals Charity exists to champion, support and give thanks to our NHS. We're also here to fund innovations that improve the hospital experience for patients and their families. In 2020, we were approached by Dr Agam Jung in the hope we could help with a refurbishment of N ward at Seacroft Hospital. From a clinician wanting to make the hospital environment better for her patients, a vision grew – a dream of a place where patients were treated as people and the whole family could be supported.

Thanks to thousands of people across Yorkshire and beyond, that dream is now a reality in The Rob Burrow Centre for Motor Neurone Disease. This strategy sets out how, together, we can go further thanks to charitable support. Through better education, innovative research and holistic support for everyone impacted by MND, together, we can provide hope, dignity and comfort.

Together we can transform lives, this is just the beginning.

Esther Wakeman

CEO, Leeds Hospitals Charity

When Rob was diagnosed with MND in 2019, it was a devastating time for our family. MND takes so much away - your independence, your freedom, your hopes for the future. But what it cannot take away is love, or the determination to fight for a better tomorrow.

What got us through those early days was the kindness and support of others - the medical team who cared for us, the friends and teammates who stood by Rob, and the incredible community who rallied around our family.

We soon realised that while MND changes lives, it also reveals extraordinary strength. Rob showed us what it means to face adversity with unwavering spirit. His determination, his refusal to be defined by his diagnosis, and his incredible ability to inspire others has helped to create this beautiful centre.

The centre represents hope for families like ours - hope that people living with MND will have the support, dignity, and specialist care they deserve. It is a symbol of courage, compassion, and community.

This strategy outlines how the centre will act as a catalyst for further improving the MND service in Leeds, through better education, research and holistic support for the whole family.

It's our hope that no person living with MND faces the journey alone.

Lindsey Burrow

Patron, Leeds Hospitals Charity

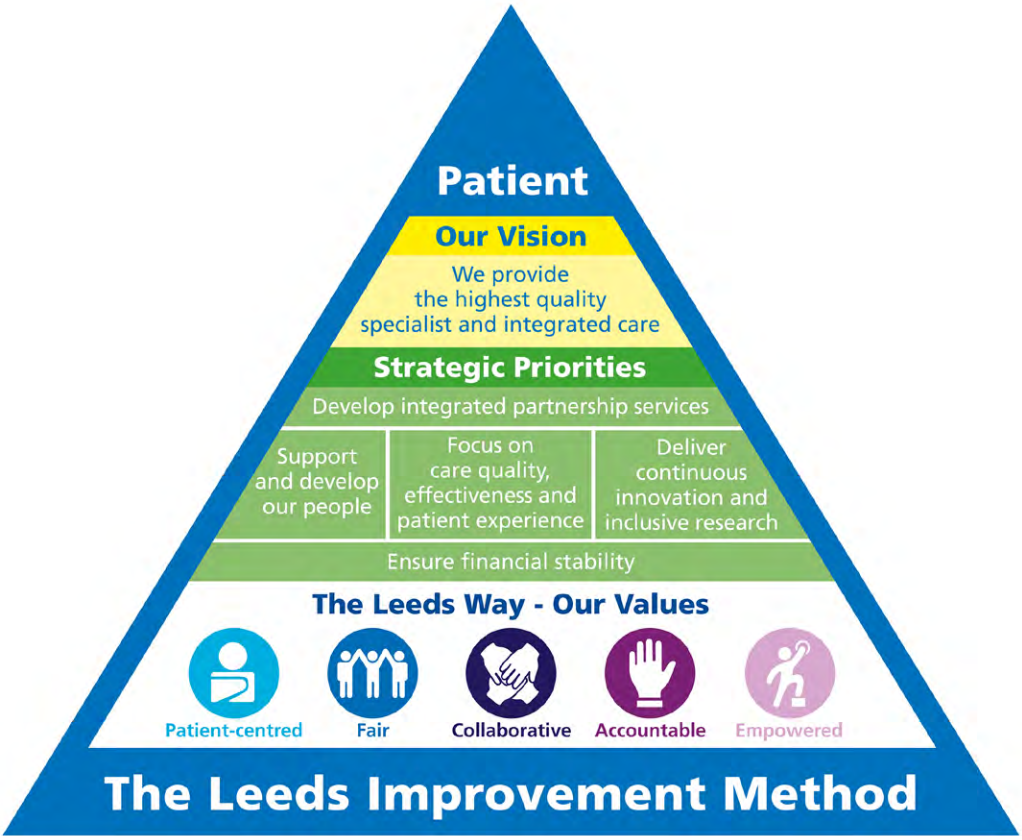
L:R Esther Wakeman, Chief Executive, Leeds Hospitals Charity,
Lindsey Burrow, Dr Agam Jung, Centre Director

OVERVIEW

Leeds Teaching Hospitals NHS Trust is an ambitious organisation with a clear vision to provide the highest quality specialist and integrated care.

- One of the **largest teaching hospitals** in the country
- A **regional and national centre for specialist treatment** and the **local hospital for the Leeds community**
- **Seven hospitals** across **five sites** in the city
- Treats around **1.8 million patients** every year
- Spends around **£2.1 billion** each year
- Almost **20,000 staff**
- Established **Centre of Excellence** for Research and Innovation and a top recruiter for clinical trials

Our vision, values and strategic priorities are summarised in our strategic triangle below, which shows patients at the centre of everything we do.



Our mission:

To be an internationally renowned academic healthcare institution, working in partnership to deliver the highest quality, safe, effective and innovative care which improves outcomes.

Our multi-year goals are:

- Support our patients to get home a day sooner.
- Recognise and act upon moments that matter to our patients.
- Be in the top 25% for patient experience and efficiency in outpatients.
- Support each other to act with kindness and compassion.
- Support our staff to manage every pound wisely.
- Make best use of our estate, equipment and digital assets.
- Reduce our carbon footprint by creating greener patient pathways.

The Leeds Way

The Leeds Way is what we stand for and what we want to achieve. It is how we do things around here and what makes Leeds Teaching Hospitals different to other organisations. The Leeds Way is described in our strategic triangle; it encompasses our ambition through our vision and strategic priorities and our culture through our values, as created by our staff. It sets out what our stakeholders can expect from us as a Trust.

Patient-centred
Fair
Collaborative
Accountable
Empowered

The Leeds Improvement Method

The Leeds Improvement Method (LIM) is our philosophy of continuous improvement that underpins all our organisational strategies. It brings the principles of daily management methods, improvement methodology, respectful behaviours and the removal of waste from processes together.

Our strategy framework

This strategy for The Rob Burrow Centre for Motor Neurone Disease sets out the aspirations of the Trust for the holistic care of patients with Motor Neurone Disease (MND) as well as our commitment to research, innovation and education into and of this disease.

As an enabling strategy it forms part of our framework of strategies, setting out our aims for the future. Our strategy framework enables us to ensure our strategies align and are updated appropriately to reflect and support the overall Trust strategy.

INTRODUCTION

> “In a world full of adversity,
> we must dare to dream”
>
> *Rob Burrow CBE*

The Rob Burrow Centre for Motor Neurone Disease is the embodiment of a dream, a first-of-its-kind facility to support Motor Neurone Disease (MND) patients, their families, friends and carers, and the staff and volunteers who are with them through their journeys. The centre started as an idea from a conversation between lead clinician Dr Agam Jung and Rob Burrow CBE. Following the BBC Documentary “My Year with MND”, highlighting the impact of MND and showcasing the work of the Leeds MND team, a plan was created to make the dream of the centre a reality. An appeal was launched by Leeds Hospitals Charity in 2021 to raise £6.8M. Inspired by Rob, his wife Lindsey and close friend Kevin Sinfield CBE, the community across West Yorkshire and beyond responded to the appeal, and just four years later The Rob Burrow Centre for Motor Neurone Disease will open at Seacroft Hospital in Leeds.

MND is a devastating, life-limiting, progressive neurological condition without a cure. It is a particularly debilitating and aggressive disease affecting multiple body systems, that requires a multidisciplinary team approach to provide the best possible care for patients. A hospital-based approach does not meet the complex, often challenging and ever evolving needs of the MND patients facing a terminal incurable condition. The care for MND spans hospital, home and hospice.

The dedicated, purpose-built Rob Burrow Centre for Motor Neurone Disease provides a socially and environmentally friendly space that will improve patient experience, reduce multiple hospital visits and reduce travel across sites for patients. It will enable the nationally renowned Leeds MND Team to deliver high quality clinical care at a single centre which includes holistic care and well-being therapies and activities. Delivering the services from one centre will also enable enhancements to out-of-hospital care with increased opportunity for virtual care and consultations.

The centre also offers dedicated spaces for patients and their families and carers to access therapeutic care, family support, and spiritual and end-of-life care. Supported by charities, including the Leeds Hospitals Charity and the MND Association, and dedicated staff and volunteers, this non-clinical support provides an opportunity for those affected by MND to find time and space to not only take time out for self-care and to support others in similar situations, but to create lasting memories with those closest to them. This presents a unique opportunity to research the impact of a holistic approach to care and family support, all under one roof.

Providing clinical services within one dedicated location provides greater opportunity for research and innovation. The centre gives the opportunity for Leeds to be recognised as a leader in MND research as the team develops research themes in reducing time to diagnosis, participates in national drug trials, explores carers' experiences and assesses how MND affects the whole body.

The Journey to The Rob Burrow Centre for Motor Neurone Disease - Key Moments

December 2019
Rob Burrow diagnosed with MND

Spring 2020
Idea of The Rob Burrow Centre developed between Dr Jung and Rob Burrow

2020
Partnership between MND Team and Leeds Hospitals Charity develops

October 2020
BBC documentary "*My Year With MND*" featuring Rob Burrow is aired, raising awareness of MND

September 2021
Appeal launched by Leeds Hospitals Charity

The centre has a bespoke facility which enables the development, not only of the team working within the Centre for MND, but also those working with them either in Leeds or in neighbouring services, and those in MND centres across the country.

It is these four pillars, Clinical Excellence, Holistic and Family Care, Research and Innovation, and Education, Workforce Development and Empowerment, supported by the dedication of staff and underpinned by patient and public involvement, strategic partnerships, a world-leading environment and a commitment to governance, that will turn a building into a centre of hope, care and change for all those affected by MND. The centre gives an opportunity for those affected by MND to "Live in the Now".

May 2023
The first Rob Burrow Leeds Marathon unites a community

December 2023
£5M raised

January 2024
Rob Burrow and Kevin Sinfield awarded CBE for "Services to MND"

June 2024
Rob Burrow dies

Groundbreaking at Seacroft Hospital

December 2024
Initial funding target reached

Ongoing
Additional funding of £1.1M over four years secured from MND Association

November 2025
The Rob Burrow Centre for Motor Neurone Disease opens

Ongoing
Fundraising and support from the community continues

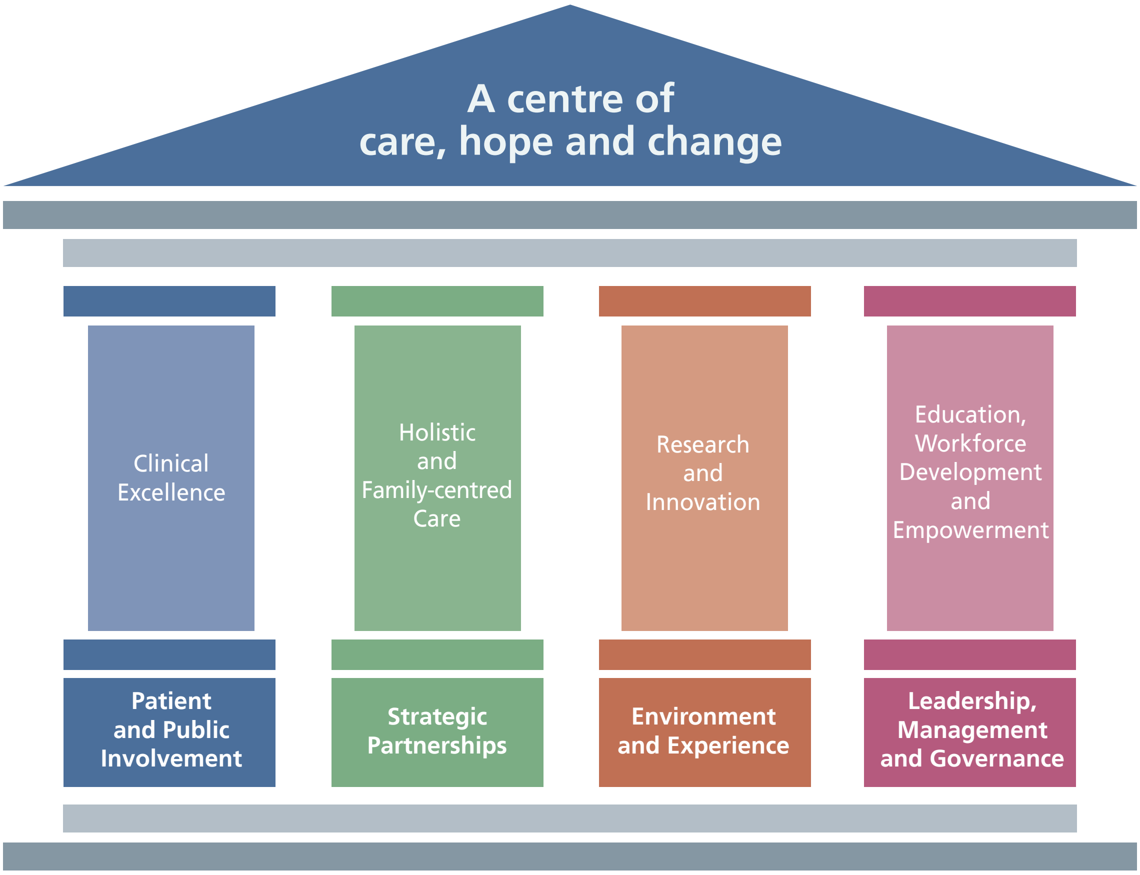
OUR VISION

To revolutionise holistic care for patients with Motor Neurone Disease, locally and nationally, empowering patients to "Live in the Now"

OUR MISSION

Four Pillars

The four pillars supporting The Rob Burrow Centre for Motor Neurone Disease are all equally important in fulfilling this vision and provide the basis for the hope, care, and potential for change, allowing patients to live in the now.



A centre of care, hope and change

Clinical Excellence

Holistic and Family-centred Care

Research and Innovation

Education, Workforce Development and Empowerment

Patient and Public Involvement

Strategic Partnerships

Environment and Experience

Leadership, Management and Governance

Clinical Excellence

To deliver a world-class MND clinical service.

Delivering evidence-based multidisciplinary services, in a purpose-built environment, provides the opportunity for seamless care, enhancing the patient's experience.

Holistic and Family-Centred Care

To create an environment offering a range of holistic therapies, activities and events for patients and families living with MND.

Working with Leeds Hospitals Charity and other charity partners, local businesses, and engaging volunteers, the centre will become a hub for people affected by MND, where they can experience a range of therapies in a familiar and friendly environment with people they know and love.

Research and Innovation

To become recognised as a leader in MND research.

The centre provides the opportunity to participate in national and international MND research studies and through this we will develop and lead our own patient-focused research into supporting those living with MND.

Education, Workforce Development and Empowerment

To provide recognised MND specific education, empowering our staff as leaders in the field.

With a bespoke education facility, the centre provides the ideal opportunity to expand the Leeds MND team's role in developing and delivering education and training sessions for staff in Leeds, regionally and nationally. We will embrace international partners, learning from the best and supporting those in the early stages of MND understanding.

The ethos of the centre is built on all four pillars developing equally and each is dependent on the others; as all four become individually stronger and integrated, the centre itself becomes stronger and more able to support the global MND community.

Pillar 1: Clinical Excellence

To deliver a world-class MND clinical service

Delivering evidence-based multidisciplinary services in a purpose-built environment provides the opportunity for seamless care, enhancing the patient’s experience.

The team at Leeds is nationally recognised as providing excellent care for patients with MND. The Rob Burrow Centre for Motor Neurone Disease gives the team the opportunity to enhance this care in a specialist clinical setting and supporting environment. In turn the team is committed to developing and supporting a model of holistic care encompassing all aspects of the patient’s life with MND.

Supporting patients with MND, a multi-system disease, requires a strong multidisciplinary team approach and the centre provides the unique opportunity to build on the care pathways that currently exist in Leeds and the region. The centre will provide a range of clinics, care and support for patients; however, it is neither an inpatient nor a 24-hour facility.

Currently the diagnosis of MND is a lengthy process and involves the elimination of other causes of symptoms. Reducing the time to diagnosis by providing easier access for potential patients as well as through research and education is a key aim of the clinical team working with MND in Leeds. The centre will provide early access for referrals and second opinion diagnoses.

The MND clinical team is supported by colleagues in other clinical disciplines, notably respiratory, gastroenterology, psychology, and community palliative care. Building on these successful relationships and integrating the care pathway is key to the clinical success of the centre.

The co-location of services within the centre will allow prompt referral to aligned services. This will not only reduce the need for multiple appointments; through recognition and diagnosis of illness more timely interventions will, in some instances, reduce the need for admission and lengthy hospital stays. The team’s responsive and proactive approach helps patients maintain autonomy at home.

The centre provides the ideal conditions for supporting and learning from other local regional MND clinical services. Services across the health community are provided in different ways and the specialisation and level of clinical service provided in Leeds is not replicated everywhere. The team is proud that no person referred to it has ever been turned away and will continue to support colleagues across the region. This will be in the form of shared learning through health professionals attending clinics, specialist referrals and providing options for patients to come to Leeds for procedures which cannot be provided in other services across the region.

Ian and Rachel Flatt attend the planting of the National Trust Tree of Hope sapling, November 2025

The dedicated MND centre will raise interest amongst clinicians, and it is hoped it will encourage more awareness of, and involvement in, the management of the disease. The West Yorkshire Association of Acute Trusts (WYAAT) has an agreement in place that allows clinicians to work in associated Trusts without changes to contracts. This will allow clinicians to consider careers as a specialist in MND and provide the opportunity to work in this environment. Giving access to all things needed to deliver a good service will further promote the rewards of working within this specialty.

In the future there is the potential for services to be transferred to the centre. Botulinum toxin (Botox) treatments are, for example, a key part of patient care, also supporting dignity. The ability to provide these on site at the centre for MND would be a significant advantage for MND patients.

For Allied Health Professionals, having dedicated equipment within the centre provides the opportunity to test with patients the different types of equipment that will ultimately support them at home, understand which will be most appropriate for their needs, and match their environment. It is envisaged that this will grow from MND specific equipment such as wheelchairs, mobility aids, communication aids, to equipment supporting other specialist care such as ventilation and respiratory aids. Whilst not every piece of equipment provided by specialties will always be available at the MND centre, a coordinated approach to care will improve the ability to arrange for the right equipment to be available for the patient at the time of their visit, reducing the need for visits to multiple sites. It is envisaged that the centre will use advancements in technology to provide custom-built equipment e.g. 3-D printed neck supports and voice banking.

Patients are not always able to attend clinics and the MND team provides services directly in the community. The centre provides the potential to add to this through virtual clinics and consultations. The service will grow in reach and patient numbers and thus enable clinicians in neighbouring services to access the benefits of the specialised service and centre for their patients.

1 The team’s aims for **Clinical Excellence** provided in and through the centre are:

Short Term:

- Successful transfer of existing services to the new centre
- Provide opportunities for colleagues around the region to visit the centre and experience clinics and the MDT approach
- Provide dignity and private space for patients and families immediately post diagnosis
- Ensure psychological support for acceptance and grief management

Medium Term

- Reduce the time to diagnosis for a regional cohort of patients
- Introduce additional clinical services provided from the centre e.g. neurophysiology assessments
- Attract more clinical staff to work as MND specialists across a range of disciplines
- Improve care with innovations based on the findings from research and patient feedback
- Introduce virtual clinics

Long Term

- Develop MND cognition clinics
- Improve saliva management by setting up Botox clinics
- Early palliative care input via dedicated palliative care clinics
- Palliative care led domiciliary clinics
- Embed a genetics service to support patients with genetic forms of MND

Our success in delivering clinical excellence will be measured through:

- Enhancements to the care pathway
- Reduction in the need for multiple visits by patients
- The range of available treatments offered through the centre
- Evidence based clinical excellence
- Number of patients accessing the centre
- Reduction in hospital admissions and length of stay

Pillar 2: Holistic and Family-Centred Care

To create an environment offering a range of holistic therapies, activities and events for patients and families living with MND

Care is at the heart of The Rob Burrow Centre for Motor Neurone Disease; the importance of holistic therapies and family-centred care sitting alongside excellent clinical care is not underestimated. MND patients quite often feel isolated and marginalised. The recent awareness campaign led by Rob Burrow and Kevin Sinfield has shone light on the cruelty of a forgotten illness and has created an "MND Community".

The centre will have a dedicated Centre Manager, funded by Leeds Hospitals Charity, to coordinate all the services and volunteers who will support patients and their families.

The centre also has a dedicated Family Support Worker, funded by the MND Association, with further family support workers to be appointed. Working together, the team at the centre will embrace the opportunities to provide therapeutic care that directly supports MND patients, as well as those services which patients and carers may now find more difficult to access.

The centre provides a welcoming environment that reduces the potential for social isolation for patients' families and carers, and it is planned to hold a range of events to bring this community together.

Patients, families and carers will be encouraged to design this offering, and with the support of volunteers and local organisations, a way will be found to deliver them wherever practical.

Holistic therapies can play a significant role in the care for those affected by MND and may include for example, massage, aromatherapy, acupuncture, chiropody, talking therapies, low-intensity exercise, and art and music therapy. These services are often provided by charities such as the MND Association, Leeds Hospitals Charity and the Leeds Rhinos.

In some cases, the provision of these may be at the centre, creating a community within a community and giving patients the experience of being with others in similar situations. This can often lead to friendships and peer support that would not be there otherwise. In other circumstances, for example where the patient cannot travel, it may be that these services are provided in a local setting. In all circumstances the centre will provide a focal point for patients, families and carers to learn about services that are available and how to access these. The services will be provided through service level agreements (SLAs) and strong quality assured contracts.

In addition to this, there are opportunities at the centre to work with local organisations to offer services to patients that they may now feel less comfortable about accessing. This could include personal services such as hairdressing, manicure and make up services, and spiritual services in a respectful environment.

The impact of MND on families and carers is significant and the centre will provide a place for families to meet and engage in activities of their own. It is envisaged that the range of activities will grow and develop to accommodate the changing needs of families.

These family-centred services will include practical support, including emotional support, access to care support services, and a variety of dedicated support for children. Everyday activities will be offered providing MND community support for family members. Special events will be celebrated in the centre, and MND patients and families will welcome each other in this unique environment.

The centre will provide opportunities for memory-making for patients and families and will have space for a lasting memorial to remember patients.

Volunteers will play a crucial role in this aspect of the centre, and over time a dedicated volunteer team will be established with education and training provided to deliver these services in the most compassionate and empowering way possible.

The centre will also become a repository of knowledge and information for patients, families and carers, with routes to access financial and professional services, carer and support groups or agencies providing support specific to the MND community. The links to these services can prove invaluable to many navigating their journeys.

Access to support for grief and end-of-life care will be provided through the centre and a complementary offer of support and understanding for those affected by this will be available. Links with Chaplaincy will grow to provide spiritual, pastoral and religious support when required.

Lindsey Burrow with the Burrow children Maya, Macy and Jackson

2

The team's aims for **Holistic and Family Support** through the centre are:

Short Term:

- To provide access to therapeutic offerings within the centre
- To provide a range of information to support those living with the impact of MND
- To provide space for activities and events
- To provide support groups and a study environment for children and young people
- To build a volunteer portfolio to provide support for patients, families and carers

Medium Term

- To provide a dedicated, structured volunteer portfolio and training programme
- To build a portfolio of personal and professional services, with local partners
- To grow engagement with the wider community to support our services

Long Term

- To provide a range of programmes through a range of media to our MND patients and families to support their living in the now
- To maintain a strong cohort of volunteers caring for our patients, families and carers
- To support other centres in growing their own local offerings

Our success in providing holistic therapies will be measured through:

- Number of patients, families and carers taking part in therapies and events
- Number of volunteers engaged
- Number of partnerships developed with local and national organisations
- Qualitative feedback from patients and carers on the programmes and events they attend.

Pillar 3: Research and Innovation

To become recognised as a leader in MND research

The focus of research and innovation for The Rob Burrow Centre for Motor Neurone Disease will be "living in the now", with a priority of improving the quality of life for patients, families and carers.

The centre, with co-location of services and an integrated environment, will mean that there is more opportunity to engage and expose patients and carers and staff to research and innovation. This will provide further impetus to grow research in four key ways:

1. Providing eligible patients with the opportunity to understand and join suitable trials, enabling them to be a catalyst of change for themselves and others
2. Providing patients and carers with information about ongoing national and international trials
3. Developing innovative and collaborative research at Leeds to improve understanding of the disease for symptom management to improve daily living, and provide assurance that this is of the best academic standards
4. Improving the potential to implement the learnings from research into care pathways from diagnosis to end of life.

The capacity to undertake research within MND in Leeds is growing with NIHR, Leeds Hospitals Charity and MND Association funded awards, positions and projects.

The journey to diagnosis of MND is long and a process of elimination. It causes significant anxiety, and reducing the time to diagnosis can significantly improve a patient's quality of life. An earlier diagnosis allows immediate support for patients and their families, and this is a key focus of the current research team. The research is led by a growing multidisciplinary team of clinicians and allied health professionals.

Clinical studies and trials that the team is involved in include trials looking at muscle twitching through an MRI scanner (FINALSUM) to improve the time to diagnosis; an international pilot study looking at upper motor neurones, focusing on how these differ between MND and healthy patients; participation in the MND SMART drug trial, which is testing multiple drugs to understand their

Dr Stuart Currie, Consultant Neuroradiologist, with Dr Agam Jung

impact on MND patients; participation in the DENIM Trial to improve breathing support provided to patients with MND; and a project to understand how artificial intelligence can support the diagnosis through assessing muscle twitching in the tongue and the body.

The MND team has also expressed an interest in developing new research into the links between MND and dementia, immersive technology to aid decision making by patients on assisted nutrition, as well as exploring and enhancing the carers' experience.

Aspirationally, the team also plans to explore qualitative projects relating to the effect of health inequality on MND patients and how this can be reduced, the impact of constipation on MND patients, and end of life care. The research team also hopes to deliver further research opportunities that will arise through the appointment of a palliative care consultant.

The driven and pragmatic approach from the MND team creates a huge potential for research and innovation and this is now being channelled through regular, formal research meetings and the introduction of a PPIE group for MND. The research team meetings include a dedicated time slot for new ideas to be presented for research and quality improvement by anybody interested in this area, including industry partners.

This research will lead to innovations in both diagnostic and care pathways, ensuring that the right treatment and support is offered at the right time and at the earliest time possible.

Through hosting MND research events, the team at Leeds is planning to create a community of interest and strengthen its involvement in research and innovation. This will strengthen links with universities and research centres and garner support for the potential for Leeds-led collaborative MND studies.

3 The team's aims for becoming **recognised as a leader in MND research** include:

Short Term:

- Supporting patient and carer participation in national and international MND studies
- Membership of the R&I leaders' group at Leeds Teaching Hospitals NHS Trust and access to the Trust's R&I Academy education package
- Develop a PPIEP group with support from the Trust's R&I team
- Developing Leeds hosted MND studies
- Encouraging peer reviews and becoming professionally self-critical
- Accessing pump-priming grants for new research projects from Leeds Hospitals Charity, the MND Association and other charities and institutions
- Hosting of MND research events

Medium Term

- Creating increased dedicated time for research
- Integrating research so that it becomes part of routine practice
- Generating income for a sustainable research team
- Securing support to create larger grant applications to:
  - Fund positions in research
  - Participate in studies
  - Develop further studies in Leeds with local participation

Long Term

- Developing collaborative studies led from Leeds
- Securing long term programme grants (e.g. from NIHR)
- Positioning Leeds as a leader in MND research diagnosis and care

Success in Research and Innovation will be measured through:

- Percentage of patients involved in studies
- Proportion of staff involved in research related activity, measured at appraisal
- Grants submitted and approved
- Funding received
- Scientific dissemination through journal publications and conference presentations
- Number of active collaborative academic partnerships
- Number of collaborative studies invited to participate in; and leading
- Feedback from patients and carers on
    - The power of joining studies
    - The impact on the quality of their lives

4

Pillar 4: Education, Workforce Development and Empowerment:

To provide recognised MND specific education, empowering our staff as leaders in the field.

The Leeds MND team has a strong history in education, workforce development and empowerment.

The team led the way with the production of an MND Nurse competency framework which was formally recognised and has been informally shared with colleagues around the country. Based on this and other inputs, this curriculum is now being developed nationally with support from the MND Association.

The bespoke seminar facility within The Rob Burrow Centre for Motor Neurone Disease now provides the environment to build on this, whilst the co-located provision of services in the centre gives greater scope for providing education to colleagues and learning opportunities for the team itself.

The scope for education and training is broad and encompasses all groups involved with the MND care pathway; medical, nursing and allied health professionals, family support workers, community nursing, palliative care, pharmacy and inpatient and community disciplines including hospice and care staff.

Such a broad scope means that creating a centre of excellence in education will take careful thought, planning and commitment. The support of the Leeds Teaching Hospitals Medical and Professional Education department working with the new Centre Manager is key to this success.

Working through the Trust's Learning, Education and Training (LET) Committee the MND team can understand how they can gain recognition and funding for the work that they are doing in the education and workforce development arenas.

To move along this journey the team will continue to provide education opportunities for colleagues from neighbouring MND and supporting services in clinics and through experiencing the multidisciplinary team approach adopted by the service in Leeds.

The next step is to develop and build evidence-based education programmes with short courses that are open to all colleagues caring for patients with MND and which, through a charging mechanism, become self-sustaining.

Examples of the types of programmes that can be developed include:

- Clinical education in suspecting, investigating, diagnosing and managing MND
- Breaking bad news
- Providing insights into patients' lives
- Management of symptoms and complications of living with MND for patients and carers
- The use of assisted home technology
- Coping with grief
- MND specific education for GPs, non-neurologists and hospice teams
- Caring for MND patients as inpatients
- Running an MND MDT meeting
- Developing role-specific curricula

The MND team needs to be offered the time to develop and deliver these courses; however, they would be facilitated by the Medical Education team.

Recognising that global health inequalities exist, the team is committed to sharing knowledge and learning opportunities with others in less developed health economies. This will be done through the Trust's own programmes and global MND communities.

Further to this, developing roles for the team members provides opportunities for staff development. These roles may include, for example, professional advocacy and clinical educator or clinical coordinator as well as training opportunities for doctors with recognised pathways to MND consultancy and specialist MND roles in nursing and allied professions. This will not be limited to clinical staff, with development opportunities for both staff and volunteers working in supporting roles.

The creation of an environment in which staff have space to talk to each other, share experiences and connect with others in similar roles is paramount to the success of the service. The dedicated centre provides an environment to empower staff to learn with, and from, each other and to develop in a safe place.

L-R: Dr Amr Tageldin, Neurology Registrar, Emelda Veraque, Research Nurse, Sam Oakes, MND Family Support Worker, Gary Jevon, Centre Manager

4

The team's aims in **Education, Workforce Development and Empowerment** include:

Short Term:

- Establishing an MND education working group
- Linking to the Trust's LET Committee
- Providing training sessions for care agencies and families
- Developing a professional advocacy role
- Creating an MND specific curriculum for the Family Support Worker role

Medium Term

- Move to digital delivery to increase audience reach
- Explore the creation of MND specific apprenticeships and professionally accredited courses
- Submit application for funded clinical leadership through medical education
- Run a national study day inviting others to present initiatives whilst showcasing the best of the service
- Reduce health inequalities through specialist education sessions

Long Term

- Create global health and academic partnerships across MND specialists
- Grow the Leeds offer through evidence-based education
- Position Leeds as a leader in MND research, diagnosis and care

Our success in Education, Workforce Development and Empowerment will be measured through:

- The number of students undertaking Leeds MND courses
- The number of staff developing and delivering MND Courses
- Accreditations received for courses
- Participation in study days
- The range of offering
- Feedback from participants
- Changes in practice
- Feedback from patients and carers on improvement in their quality of life

The Foundations

Underpinning the pillars are four key foundations ensuring that The Rob Burrow Centre for Motor Neurone Disease will operate effectively and efficiently:

Patient and Public Involvement and Experience

Patients will be at the heart of everything we do

Strategic Partnerships

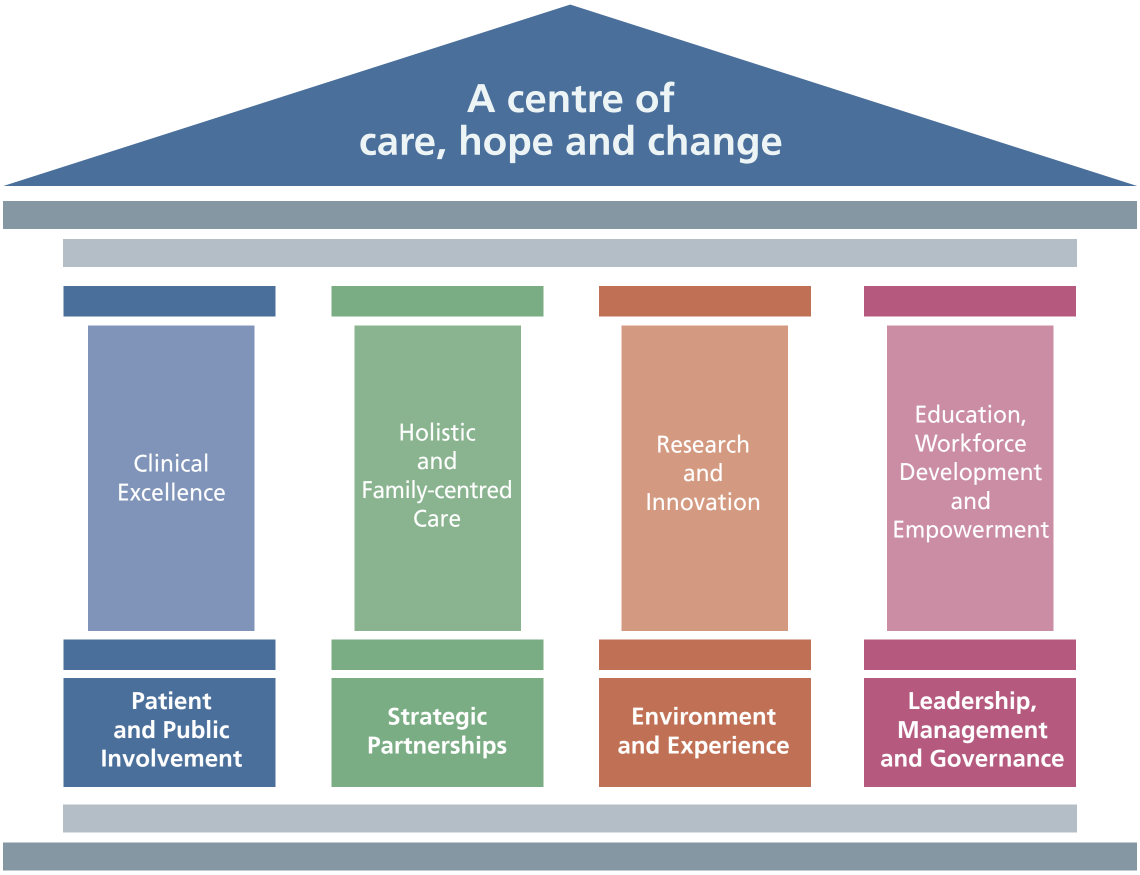
For the centre to succeed and thrive a partnership approach is essential

Environment and Experience

We will use the environment of the centre to improve the experience of all users

Leadership, Management and Governance

We will ensure through governance that the highest clinical, operational, research and education standards are maintained, remaining accountable to our communities of users and supporters



Patient and Public Involvement and Experience

Patients are always at the heart of everything we do, and the opening of The Rob Burrow Centre for Motor Neurone Disease gives us a platform to be national leaders for MND patients. Our vision of providing holistic care focused on the patient not the disease will be the theme for our patient involvement.

We have worked with patients to design the centre and will continue to do so. In the practical operation of the centre, understanding directly from patients, their families and carers how the centre can evolve to best support their needs will enable us to provide this care across a spectrum of clinical and non-clinical services.

Patients will be encouraged to participate in suitable research programmes to provide the opportunity to contribute to understanding of the causes and impacts of MND. Patients and their carers will also be involved and engaged in the research projects that we are participating in.

All users of the centre will be encouraged to share their views on what is working well and what can be improved, what they would like to see in the centre and what services remain better provided out of the centre. Through this feedback we will improve the experience of users and continually evolve the centre to remain the place of care, change and hope that it is designed to be. Doing this in a robust, scientific, unbiased way with appropriate methods and analysis will enable peer reviewed publication of this work.

We recognise that not all patients are always able to come to the centre, and we will find ways to involve them in the development of our services and care.

Creating a PPIE group is the first step in ensuring that the centre develops, building on rich conversations to provide the best possible experience for all users.

The first stakeholder meeting to plan the new Rob Burrow Centre for Motor Neurone Disease

Strategic Partnerships

The realisation of the centre has been made possible, through the inspiration and dedication of Rob and Lindsey Burrow and Kevin Sinfield CBE, with the support of the community and charity funding. Whilst not a fundraising centre, these partnerships must continue to grow and develop to enable the services within the centre to meet the expectations of our funders.

The partnership with Leeds Hospitals Charity has been fundamental to the building of the centre and through continued close working will become an integral part of the sustainability of the centre. The charity also supports the centre with appropriate staff and volunteer roles and with grant funding for research and equipment. Maintaining this relationship through events and close partnership working will allow us to develop the centre and our links to national and international research projects whilst also providing the best possible care for our patients.

We will also continue our strong partnership with the MND Association. A national charity, with regional services dedicated to MND, the MND Association provides funding for staff and research, as well as running valuable volunteer, patient and family groups. We will be able to ensure that all our patients and families are aware of the support that the MND Association provides either directly or through partnerships with organisations they work with. Within the centre, easy access to the MND Association’s own library of over 70 resources and signposting to further useful information, will be invaluable to patients and their families.

Partnerships with other charities that have supported us on our journey, including the Leeds Rhinos, The My Name’5 Doddie Foundation, the Darby Rimmer Foundation and Carers Leeds, will continue, enabling us collectively to expand knowledge about MND and support research and innovation in a coordinated way.

We will further engage with the community in meaningful ways, providing opportunity for education and learning, volunteer roles and local partnerships. Growing the public understanding of MND will ultimately lead to improved patient experience. To do this, we need to maintain the awareness of MND and the overwhelming support that has been generated through the appeal for the centre. It is our responsibility to lead and support this and we envisage the centre being the focal point for the ongoing community engagement.

We anticipate that our key charities will identify suitable local service providers. Through SLAs, and with our support, they will commission these services and add to our vision of holistic care.

Communication about, and awareness of, the centre will also be a critical success factor. A communication plan will be developed in conjunction with our key strategic partners and through this we will grow the identity and brand of the centre.

Environment and Experience

Ultimately the true measure of the centre is the experience of our patients. The new centre will be much more than the services that are provided within the building; the centre is a symbol of hope, care and change for the MND community. The opportunity to change their own personal experience and improve the experience of others is a key driver for many patients, and through involvement, research and innovation we must translate this into meaningful change.

The centre has been designed with a high level of input from patients, carers and staff, and features:

- Drop off point at entrance
- Wheelchair accessible parking to enable easy access for our patients
- Clinical and therapy spaces designed to be fit for purpose by patients and staff
- Sensory rooms and quiet spaces for patients and families
- Space for privacy and dignity in grief
- A dedicated education facility
- Clinical research space
- A garden to provide a connection to the world beyond the centre
- Garden paths which can be used to build confidence in wheelchair navigation on different surfaces
- Plans for a lasting memorial to those patients no longer with us

A growing team of staff and volunteers will provide the support that is needed to ensure that patients, families, carers and our clinical teams are able to use the centre to best effect and to maintain our focus on the patient and their needs.

The provision of activities in the centre both for patients and families is seen as a key part of the care for those affected by MND, and the integration with local partners will expand the horizons, not only of users but also of the centre.

> “My vision is that people diagnosed with MND hear the news in a calming and tranquil sanctuary. I envisage a beautiful, welcoming building that is user and family friendly. A place where patients feel comfortable to bring family members into a safe and homely environment for them, with signs of hope and optimism.”
>
> *Rob Burrow CBE*

We retain the commitment to this vision and will continue to work with patients, families, our staff and partners to make this a reality.

His Royal Highness The Prince of Wales officially opens the Centre on 20 November 2025

Governance

The Rob Burrow Centre for Motor Neurone Disease is owned and operated by Leeds Teaching Hospitals NHS Trust, and we commit to ensuring that strong governance is in place to enable us to realise our ambitions. The centre will be managed by the MND team working within the Neuroscience Clinical Service Unit, and usual Trust-wide clinical, research and corporate governance will apply. Safeguarding for patients, staff and volunteers will also be a key factor in our management of the centre and will be governed through the Trust's policies and procedures.

A Centre Manager has been appointed with funding from Leeds Hospitals Charity, and they will ensure the smooth running of the centre.

Recognising the special nature of the centre, we will set out a framework to ensure that we have the best possible mechanisms to provide the support needed for the team to deliver. This will include an annual plan, and a three year forward look to align strategy and delivery.

To ensure that the centre stays true to its primary objective of supporting patients with MND, the plan will be developed with the input of a range of stakeholders, including the Burrow family, patients and families, the key charities, and an academic partner supporting the centre and the Trust's clinical and management team.

This comprehensive annual plan will provide the detail on our activities through the coming year in the key areas outlined within this strategy. This will include:

- The objectives for the centre for the coming year
- How success will be measured
- Planned expenditure, including that which will fall outside the MND team Trust budget
- Funds required to achieve the plan and how these will be raised
- Service developments, including clinical, holistic and non-clinical care, research, innovation, education, workforce development and empowerment
- Plans for Patient and Public Engagement and Involvement
- Charity engagement and events
- Details on partnership working planned in year

A mechanism of engagement and reporting on the annual plan will be put in place to maintain accountability and ensure sustainability of the centre.

SLAs between the Trust and partners, and between charities and partners, and Memoranda of Understanding (MoU) between charities will be established and these will be managed in line with the governance of the lead organisations.

Through a cycle of planning, delivery, and monitoring of progress we will continue the development of the centre to support future generations of MND patients.

The Rob Burrow Centre for Motor Neurone Disease
Seacroft Hospital
York Road, Leeds
LS14 6UH

www.leedsth.nhs.uk
Facebook **@leedsthtrust**
Instagram **@leedshospitals**

Published December 2025