

# 2025 MND Professionals' Community of Practice Networking event

National Conference Centre, Birmingham  
Tuesday 7 October, 9am-4:30pm

## Supporting Choice and Control for people living with and affected by MND

***"Everyone deserves an opportunity to make choices."***

- (attendee at last year's event)

People are supported to have choice and control over their own care and to make decisions about their care, treatment and wellbeing. People are supported to understand their rights by using different ways to communicate. Their understanding is reviewed throughout their care and treatment.

### Watch words:

- Choice (Choosing)
- Needs
- Preferences
- Wellbeing

### **choice**

/tʃɔɪs/

#### **noun**

An act of choosing between two or more possibilities.

### **control**

/kən'trəʊl/

#### **noun**

The power to influence or direct people's behaviour or the course of events.

**The aim of this event is to give you a unique opportunity to take time out to network with fellow professionals, talk, probe, ask questions and get hands on with equipment. There will be sessions led by experts in their field and you will gain valuable skills and learn through doing and exploration.**

*First time at event, excellent opportunity to network and learn from other HCP's, well balanced day with interactive sessions, I will be recommending to everyone.*

*It was amazing to meet so many likeminded clinicians who share the same values when caring for MND patients.*

- Participants at last year's event

### **How it will work**

We kick off the day with all attendees together for a keynote speech to inspire and a short self-care session to ground and reflect before launching into a day full of information, knowledge and networking. You will then have choice of stimulating competency sessions led by subject experts covering key areas for people living with MND.

You will choose which competency sessions you attend from the programme when you book your place.

**Find out more about the programme and the sessions on the following pages.**

## Keynote speaker: Dr Brian Dickie MBE Chief Scientist at the MND Association



### Choices and research

Brian has worked within research at the MND Association since 1997. In this session, he shares reflections into the evolution of the research strategy at the Association and in particular how research has shaped care and vice versa.

Research is an area of interest for many affected by MND and Brian will also present an overview of the types of research currently funded from understanding the mechanisms behind clinical progression to improving standards of care.

### Self care session:

#### Awareness, choice and connection

**Dr Emily Mayberry**, Senior Clinical Psychologist at Sheffield MND Care Centre and Clinical Neuropsychology Services, Sheffield Teaching Hospitals NHS Trust, and **Dr Rachel Woolrich**, Clinical Psychologist at Oxford MND Care and Research Centre will invite us to leave our professional armour at the door, and to practice awareness and reflection to foster self-care for the day ahead.



### The competency sessions



**These interactive sessions will be delivered by subject matter experts. You will choose which three you want to attend when you book.**

#### I know what would be good to know!

**Session lead:** Professor Eneida Mioshi, University of East Anglia

Have you ever thought, "It would be really good to do some research on that..."? This session is your chance to hear from clinicians who've done exactly that. We all have a stake in expanding the evidence base and shaping how research is designed and delivered.

Professor Eneida Mioshi, who originally trained as an Occupational Therapist, will explore how clinical practice can inspire research questions and how research methods can guide the collection of meaningful evidence.

### **New pathways for eating and drinking (with acknowledged risk) and management of secretions**

**Session leads:** Anthony Hanratty, Advanced Nurse Specialist and Clinical Lead, Middlesbrough MND Care Centre and Victoria Edwards, MND Care Coordinator, Cambridge MND Care Centre

This session explores the management of two common and complex issues in MND: swallowing difficulties and secretion management. These challenges affect quality of life, nutrition, hydration, and emotional wellbeing. Victoria and Anthony will present new pathways to support best practice, highlighting the multidisciplinary team's role. You'll hear how issues like fatigue, aspiration risk, thick or thin secretions, and a person's dignity can be better addressed - and how to adapt this care in your local setting.

### **"Crisis is a legitimate decision..."**

**Session lead:** Rachael Marsden, Consultant Nurse, Oxford MND Care Centre

***"How we feel when patients make unwise decisions..."*** - quote from last year's event

Clinical experience can help identify common traits among people with MND who choose not to plan ahead, despite prompts. This session offers space to consider whether 'crisis' might be a valid, even deliberate, choice. Rather than focusing solely on prevention, we'll explore how the multidisciplinary team can become more skilled at recognising early signs and responding with sensitivity - supporting people through crises rather than feeling pressure to eliminate them entirely.

### **I didn't sign up for this! Caring for Carers**

**Session lead:** Rosie Bamber, Specialist Neuro Occupational Therapist and Doctoral Fellow, University of Sheffield and Sheffield MND Care and Research Centre

Informal carers play a vital role in supporting people with MND, often balancing this with their own health and wellbeing. Providing them with the right support is not only best practice - it enables them to sustain high-quality care and reduces the emotional burden on everyone involved. In turn, this can ease feelings of guilt or anxiety for the person with MND. This session explores practical approaches to supporting carers within your service.

### **Assisted dying - ethical, emotional and professional challenges.**

**Session lead:** Dr Claire Stockdale, Palliative Medicine Consultant, Severn Hospice, Shropshire

The Terminally Ill Adults (End of Life) Bill raises important and often complex questions for people living with MND, their families, and the professionals supporting them. This session provides a space to explore the implications of the Bill, consider its potential impact on practice, and reflect on the ethical, emotional and professional challenges it presents. Attendees will be encouraged to share experiences and perspectives in a supportive and thoughtful environment.

## **Genetic toolkit: Developing patient decision aids around genetic testing for people living with and affected by MND.**

**Session leads:** Dr Alisdair McNeill, Senior Clinical Lecturer in Neurogenetics & Hon Consultant Clinical Geneticist and Jade Howard, postdoctoral researcher at Sheffield Institute for Translational Neuroscience, University of Sheffield.

This session introduces decision aids developed to support people with MND considering genetic testing, and family members exploring predictive testing. You'll hear directly from the team behind the tools, with the opportunity to explore how they work in practice. We'll also discuss the ethical, emotional and practical issues surrounding testing, and reflect on how these tools can support informed decision-making and influence your approach in clinical practice.

## **Let your yes be yes... Supporting choices when mental capacity is impaired**

**Session lead:** Dr Caroline Barry, Consultant in Palliative Medicine, Norfolk and Norwich University NHS Foundation Trust

Led by Dr Barry, who has a special interest in the Mental Capacity Act 2005 and MND, this interactive session uses group work to explore common challenges in MND care. Topics include managing risk, supporting decision-making with impaired capacity, and interpreting best interests. Delegates are encouraged to submit real-world case examples ahead of time, offering a chance to explore practical solutions together. If attending, please share any relevant cases with your booking form.

## **Competent and in control of your CPD!**

**Session lead:** Sal Hastings, Occupational Therapist and Lead for the Community of Practice at the MND Association

This session introduces a new framework of competencies for allied health professionals working in MND care. Designed for dietitians, occupational therapists, physiotherapists, and speech and language therapists, it outlines essential skills and knowledge across all levels of practice. The resource also supports managers and commissioners in planning services. Join us for a first look at this streamlined tool - developed to enhance care for people with MND while supporting your professional development and career progression.



## Schedule of the day

<b>Welcome and coffees</b>	8.30 - 9.00am
<b>Official welcome - Jan Clarke, Community of Practice Chair</b>	9.00 - 9.05am
<b>Keynote speaker - Dr Brian Dickie, Chief Scientist at the MND Association</b> Choices and Research	9.05 - 10.00am
<b>Self care: Awareness, choice and connection</b> Presented by Dr Emily Mayberry and Dr Rachel Woolrich.	10.00 - 10.30am
<b>Break and move into first competency session</b>	10.30 – 10.55am
<b>Competency session 1</b>	11 – 12pm
<b>Lunch, networking and exhibitor demonstrations</b>	12.00 – 1.30pm
<b>Competency sessions continue – including a comfort break</b>	1.45 – 4.00pm
<b>Expert core reflections and close</b>	4.10 – 4.25pm



## Demonstrations

At the start of the day, during breaks and in an extended lunch break, you will be able to talk to therapy experts, see demonstrations of various equipment and get hands on with it. There will be opportunities to find out more about:

### **PEG and RIG insertion**

Discuss the process of how a PEG or RIG gastrostomy tube is inserted. Examine first-hand the equipment your patient may have in place that you might not get to see otherwise.

### **Respiratory equipment**

Respiratory failure is the most common cause of death in MND. Here you will have the opportunity to handle equipment related to respiratory management, such as a cough peak flow metre, cough augmentation, lung-volume recruitment, and non-invasive ventilation including a range of interfaces.

### **Behavioural and cognitive changes in MND**

An opportunity to talk to researchers actively working on this important area. Discover more about assessing and managing behavioural symptoms to support the people in your care.

### **Orthotics**

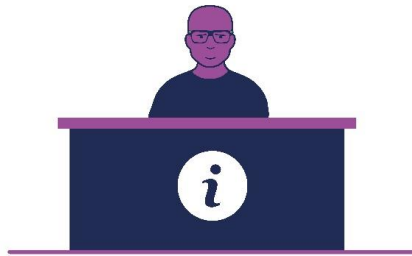
Orthotics aims to support, position and enhance the alignment of the body to enhance function and reduce the risk of deformities. Orthotics can improve quality of life by reducing pain, promoting mobility, and supporting where muscles have weakened. Be introduced to a wide range of splints, neck supports and more.

### **Communication**

There is a wide range of ways in which we can support communication for people living with MND. This is an opportunity to try out effective techniques from the simplest E-Tran frame, through to high tech solutions.

### **The ABC of ACP: who, when, how**

Advance care planning (ACP) is central to good care for people living with MND. This stand gives you opportunity to discuss the processes of ACP with palliative care experts, explore best practice and consider how you might incorporate it into your practice.



## Exhibitors

As in previous years, we will be joined by a range of exhibitors, giving you a chance to become familiar with products which may be useful for people with MND.



### National Conference Centre

Coventry Road,  
Bickenhill, Solihull,  
West Midlands B92 0EJ

## Directions

### By car:

J6 of the M42, follow signs to The National Motorcycle Museum from all approach roads.  
Postcode B92 0EJ.

Free parking on site, including charge points for [electric cars](#) and disabled parking.

Birmingham City Centre – 20 minutes drive  
Central Manchester – 2 hours drive  
Central Leeds – 2 hours drive  
Central Bristol – 2 hours drive  
Central London – 2 hours drive

### By train:

Nearest station is Birmingham International – 5 minute taxi journey

### Other stations:

Birmingham New Street – 25 minute drive  
Birmingham Snow Hill – 20 minute drive  
Solihull – 10 minute drive

## We look forward to meeting you!

If you have any queries in advance of the event, please email

[CoP@mindassociation.org](mailto:CoP@mindassociation.org)