

# 2024 MND Professionals' Community of Practice Networking event

**National Conference Centre, Birmingham**  
**Wednesday 9 October 9am-4:30pm**

## What Matters Most?

**Optimising quality of life for people living with MND,  
individual priorities and effective, person-centred care.**

**This is not a conference.** You will not sit theatre style listening to presentations! What you *will* do is extend your competencies by participating in sessions where ideas and concepts are shared to get you thinking and, importantly, questioning.

The aim 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. You will gain valuable skills and learn through doing and exploration.

*"It was a really interesting day with so many topics covered. I'm taking a lot of new knowledge with me, plus ideas of other aspects to delve further into."*

*"Good MND care is based on input from multiple healthcare disciplines. This event was a great opportunity to catch up with colleagues and meet new people working in MND."*

- **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 session to cement some knowledge. You will then split into groups, which you will stay in all day, getting to network closely with colleagues, and move through **four stimulating sessions** together. Each group will have a lead from the Community of Practice Expert Core who will make sure you are in the right place at the right time!

Every session will be an opportunity to consider the implications for **quality of life** in a key area for people living with MND. You will discuss and explore **risk** and the significant things health and social care professionals need to bear in mind when supporting people with the **critical thinking** and **decision making** needed to ensure that **best care** takes place, and that quality of life is maximised.

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



## Keynote speaker: Professor Eneida Mioshi

**Behavioural symptoms triangulated: perspectives from the family, the view of healthcare professionals, and the evidence from the research literature.**

Behavioural symptoms such as apathy, rigidity and disinhibition affect at least 50% of people with MND, with important consequences to care planning and family wellbeing. This talk will present an overview of the research evidence of these behavioural symptoms.

We will examine how families perceive these changes and how these symptoms affect them. We will then explore how healthcare professionals manage these symptoms in their practice, and which tools they could consider utilising to provide greater support to those affected by behavioural symptoms in MND.



## Knowledge session: Doctor Caroline Barry Understanding risk, Best interest decisions and mental capacity

At least half of people with MND will experience cognitive change, with 15% developing frontotemporal dementia. This talk will explore the Mental Capacity Act in the context of MND, including managing risks and making decisions in a person's best interests if they lack capacity to make an informed decision themselves.



## The sessions

### Maintaining a sense of self

What makes us human? What are the concepts of identity? People are not their diagnosis – they are people living with MND – the same people they were before the diagnosis. With the same likes and dislikes, irritations and things that delight. By actively listening to what really matters to them we can collaborate to find solutions and hacks to help them preserve and share their unique individuality. From the basic need to communicate, tasks of daily living, through to hobbies and interests there is much we can do but sometimes that involves risk. This session will explore these ideas and how it can impact you as professionals.

## The fundamentals: eating and breathing

Identifying and acknowledging risk is a key factor in the discussion of therapies and patient decision making. Some interventions are time dependent, with risk increasing as MND progresses. This has implications for the person living with MND and the practitioner. In this session we will explore patient and practitioner approaches and attitude to risk and the effect it has on care in two critical areas of MND care: **nutrition** and **respiration**. Subjects covered will include gastrostomy, eating with acknowledged risk, choices and decisions about breathing and withdrawing treatments at end of life.

## Everyday challenges: novel solutions

In this session you will meet inspiring organisations and people who are actively working to find tailor made answers to individual problems:

- **REMAP** design and custom-make equipment to help people with disabilities live more independently. The equipment and adaptations are made by volunteers with the aim to support mobility and at home, manage personal care or enjoy sports and hobbies.
- **SpecialEffect** don't want anyone to miss out on the fun and social inclusion that video games can offer. Our team of specialist occupational therapists and technologists work, free of charge, with individuals across the UK, to help them find ways to play when the standard controls are too tricky. Our equipment loan service and on-going support ensures we can keep people playing if their abilities and circumstances change over time.
- **Loughborough University, School of Design and Creative Arts** - Got a challenge? Talk with a design expert from Loughborough University! Bring along any tricky challenges, big or small you have come across within your MND case load that need an innovative 'out of the box' solution. This is a chance to put your problem to a top design brain who will go through the problem with you, identify the main issues, and come up with, and sketch, a novel solution for you. Dr George Torrens has over 30 years' experience in research and design of assistive products and may just have the answer!

## MND and Relationships

When asked 'What matters to you?', a common response from people living with MND is a call to ensure that their family and carers are looked after and that the effect of MND on them is minimised. People express the desire 'not to be a burden'. Without question, MND alters the dynamics of relationships from sexual, intimate connections through to bonds with children, the wider family and friends.

In this session we will consider how we can best support people living with MND, their carers, and families to retain the balance of their relationships and so called 'normal life' as much as is possible.



## Schedule of the day

<b>Welcome and coffees</b> Informal networking	8.30 - 9.00am
<b>Official welcome</b>	9.00 - 9.05am
<b>Keynote speaker - Professor Eneida Mioshi, UEA</b> Behavioural symptoms triangulated: perspectives from the family, the view of healthcare professionals, and the evidence from the research literature.	9.05 - 10.00am
<b>Understanding risk, Best Interest decisions and Mental Capacity - Dr Caroline Barry, Norfolk MND Care and Research Network</b> Overview of the Mental capacity Act in the context of MND.	10.00 - 10.30am
<b>Break</b>	10.30 - 11.45am
<b>Session 1</b> The first of four sessions giving you an opportunity to consider the implications for quality of life in a key area for people living with MND with your colleagues.	10.45 - 11.45
<b>Comfort break</b>	11.45 - 12.00pm
<b>Session 2</b> The second of four sessions giving you an opportunity to consider the implications for quality of life in a key area for people living with MND with your colleagues.	12.00 - 1.00
<b>Lunch, networking and demonstrations</b>	1.00 - 2.00pm
<b>Session 3</b> The third of four sessions giving you an opportunity to consider the implications for quality of life in a key area for people living with MND with your colleagues.	2.00 - 3.00pm
<b>Break</b>	3.00 - 3.15pm
<b>Session 4</b> The last of four sessions giving you an opportunity to consider the implications for quality of life in a key area for people living with MND with your colleagues.	3.15 - 4.15pm
<b>What is possible!</b> Hear about an inspirational project which demonstrates where focussing on quality of life for people living with MND can lead.	4.15 - 4.30pm
<b>Conference close and evaluations</b>	4.30pm



## 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 the MiND-B assessment tool for behavioural symptoms, how you can use it in clinic/home visits and be aware of possible strategies and actions which will 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.

### **Hydrotherapy for people living with MND**

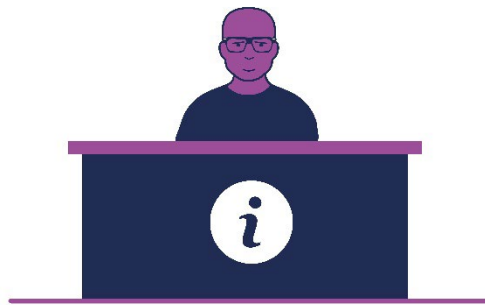
Learn about hydrotherapy, its benefits for people living with MND and specifically how it can be used without causing harm.

### **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 including:

- SpecialEffect
- Beagle Orthopaedic
- Munevo
- Design experts from Loughborough University
- and **many more** to be confirmed!



### 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@mndassociation.org](mailto:CoP@mndassociation.org)