



## Professional development

## Review of 2024



# Webinars

In 2024 we delivered six live webinars and two pre-recorded webinars, with over 836 health and social care professionals attending.

All webinars are recorded and available post event within the webinar section of the Association website, with subtitles added to each recording to ensure accessibility. We follow up with all attendees with a post 6 month questionnaire about how they have applied the webinar and resources shared to practice.

All our webinar recordings are available on our website at:  
[www.mndassociation.org/webinars](http://www.mndassociation.org/webinars)

You can view the webinars by clicking the “watch” buttons below.



WATCH

## The MiND B project – identifying and managing behavioural change in MND

**Aim:** To introduce and explain the MiND-B, a tool to detect behavioural symptoms in MND, and the MiNDToolkit, a novel online psychoeducational intervention to manage behavioural symptoms - and their application to practice.

**Speaker:** Professor Eneida Mioshi, University of East Anglia



WATCH

## Anticipatory grief – the challenges presented by a progressive condition for people living with and affected by MND

**Aim:** To consider the nature and possible presentation of anticipatory grief in people affected by MND, and ways to support them.

**Speaker:** Carol Bradley Advanced Nurse Practitioner, St Mary’s Hospice



WATCH

## “If it affects one of us, it affects us all”: the Whole Family approach, effective support for a household living with a diagnosis of MND

**Aim:** To explore the Whole Family Approach when caring for people affected by MND.

**Speaker:** Samantha Holden-Smith, Manchester MND Care Centre Coordinator and Specialist Nurse



WATCH

## “You matter because you are you, and you matter to the end of your life” – dispelling the myths of hospice care

**Aim:** To develop increased understanding of the role of hospice care for people living with and affected by MND.

**Speaker:** Claire Stockdale, Palliative Medicine Consultant, Severn Hospice and Lisa Sievwright, MND and Neuropalliative Specialist Therapist



WATCH

## NHS Continuing Healthcare (CHC) and MND

**Aim:** Hayley Koumas will explain how to apply for CHC for patients with MND, and discusses considerations and implications of the process.

**Speaker:** Hayley Koumas CHC Improvement Coordinator, MND Association



**WATCH**

## Anticipatory Medicines for MND

**Aim:** To explore the area of anticipatory medicines and why good communication is very important to help people understand why anticipatory medicines are prescribed.

**Speaker:** Dr Trish Sealy, Consultant in Palliative Medicine, South Tees Hospitals NHS Foundation Trust



**WATCH**

## Exercise in MND: When, what and how?

**Aim:** To explore appropriate exercise for people with MND

**Speakers:** Charlotte Massey, Specialist Physiotherapist and NIHR doctoral fellow, University of Sheffield and Sheffield Teaching Hospitals NHS Trust and Kelly Smith, Advanced Physiotherapist, Newcastle MND Care Centre



**WATCH**

## A focus on tube feeding in MND: current evidence, managing risks and exploring good

**Aim:** To develop increased understanding about the use of tube feeding for people with MND and the implications for provision of person-centred care.

**Speakers:** Dr Saba Bokhari, Consultant Respiratory Physician, Manchester University NHS Foundation Trust, Thomas Welbank, M.Nutr, Enteral Nutrition Service Lead / Advanced Clinical Practitioner, Sheffield Teaching Hospitals NHS Foundation Trust and Aritka Datta, Advanced Specialist Dietitian

*"I found the resources included in the presentation and sent post-webinar very helpful to give information to both me, and friends and relatives of people living with MND."*



**Click to view  
and book  
onto 2025  
webinars**

# Workshops

In 2024 three one-day workshops focussed on posture management and orthotics across England and a one-day workshop on respiratory failure in MND in Exeter. 87 professionals attended the workshops.

## Posture management and effective use of orthotics for people with MND

**Aim:** To introduce non specialist members of the MDT to principles of posture management, common problems experienced by people living with MND, and equipment and orthotic solutions.

**Workshop 1:** 13 March 2024 at Weston Home Stadium, Peterborough United Football Club. Delivered by Jenny Rolfe, Consultant Occupational Therapist, Accora UK and Lauryn Campbell Orthotist / Prosthetist at Addenbrookes Hospital and UCLH.

**Workshop 2:** 18 June 2024 at St Mary's Stadium, Southampton Football Club. Delivered by Jenny Rolfe, Consultant Occupational Therapist, Accora UK and Phillippa Sharpe, Specialist Occupational Therapist, Oxford University Hospitals NHS Foundation Trust.

**Workshop 3:** 19 November 2024 at Salford Community Stadium, Salford, Greater Manchester. Delivered by Jenny Rolfe, Consultant Occupational Therapist, Accora UK and Phillippa Sharpe, Specialist Occupational Therapist, Oxford University Hospitals NHS Foundation Trust.

## Respiratory failure in MND: options, solutions and issues

**Aim:** To introduce non respiratory specialist members of the MDT to respiratory failure and the different types of respiratory interventions.

**Workshop:** 5 March 2024 at Royal Devon and Exeter Hospital, Exeter. Delivered by Tracy Thomas, Lead Care Coordinator/Specialist Nurse, Jon Palmer, Consultant Nurse for Home Ventilation, Mike Thynne, Senior Clinical Respiratory/Sleep Physiologist, Rebecca Hall, Advanced Physio Practitioner in Acute NIV, Jane Smith, University Hospitals Plymouth, Charlie Hardaker, Respiratory Physiotherapist and Charlotte Kirby, Senior Respiratory Physiotherapist.



*"Fills a gap in training! So little available on posture and orthotics – good networking opportunity."*

# Competency builder sessions

2024 saw us trial competency sessions. These sessions will provide tuition by an expert, or experts to build proficiency, knowledge and ability in a defined area of practice, to then implement and develop skills. 22 health and social care professionals attended our pilot event about genetics. We got great feedback and will be offering more competency builder sessions in 2025.

## Understanding genetics, genetic testing and counselling, and how to talk about them effectively with the people in your care.

**Aim:** To support health and social care professionals to understand the process of genetic testing in MND, and the potential impact of it.

**Workshop:** 10 September 2024 – online

**Delivered by:** Dr Amina Chaouch, Clinical Lead for MND - Manchester Centre for Clinical Neurosciences at Salford Royal, Dr Rhona Macleod, Consultant Genetic Counsellor – Manchester Centre for Genomic Medicine, Kate Dack, Genomic Medicine Service Alliance St Mary's Hospital, Manchester, Georgia Brown Genetic Counsellor

**Workshop:** 23 September 2024 – online

**Delivered by:** Dr Rhona Macleod, Consultant Genetic Counsellor – Manchester Centre for Genomic Medicine, Kate Dack, Genomic Medicine Service Alliance St Mary's Hospital, Manchester, Georgia Brown Genetic Counsellor, Laura Furness - Manchester University NHSFT.



*“Very informative, in a clear way. Presented at the right level for specialist healthcare professionals working within MND. New knowledge not often covered at previous study days. Certainly will be very relevant and required going forward as genetics progresses”.*

# Information and Knowledge Exchanges



In 2021, we launched our Community of Practice, a peer led group of health and social care professionals encouraging and supporting the development of good care for people living with, or affected by, MND.

It now has over 1,600 members. We delivered three dedicated Information and Knowledge Exchange events for the Community in 2024, featuring presentations and networking opportunities, which attracted 299 attendees.

We have a dedicated members' area on our website with shared resources and recordings of the presentations. We also have an online forum hosted on Facebook with over 310 members, where professionals can get immediate peer to peer support. Find out more about the Community of Practice at [www.mndassociation.org/cop](http://www.mndassociation.org/cop)

**Our Information and Knowledge Exchange events (IKEs) are networking opportunities throughout the year. They bring members of the Community of Practice together to explore a particular topic or theme. They feature presentations from members of the Community, an opportunity to ask questions, and networking in breakout groups.**

Links to the Information and Knowledge Exchange recordings below and their accompanying resources can only be accessed by members of the Community of Practice. Email [COP@mndassociation.org](mailto:COP@mndassociation.org) if you are a member and need a password reminder. If you haven't joined yet, click the link below to join and get access to all the resources and Community activities.

[Join the Community of Practice](#)

[Visit members' area](#)

## Through thick and thin - Managing saliva

- Shauna Sheridan, Specialist Respiratory Physiotherapist provided an overview of the key considerations for Secretion Management in MND.
- Jan Clarke from the National Hospital for Neurology and Neurosurgery shared a Saliva Management Pathway. Knowing how to take informed action when a patient is choking or experiencing sensations of choking is vital when such episodes occur.
- Dorinda Moffatt, Specialist Neuro-Respiratory Physiotherapist/Frailty Therapist, Prospect Hospice shared the practical Choking pathway she has developed for use in her area.



*"Having been the MND Programme Lead for Marie Curie for 2 years now, I feel the Community of Practice is now a place where I feel I can grow my knowledge, confidence and understanding of MND enabling me to keep up to date."*

## Managing high tone

- Vivien Horton, Advanced Clinical Pharmacist explained what the various medications recommend by NICE guidelines can do, when they might be contraindicated and how prescribers settle on the most effective in Effective medication for cramps and spasms.
- Kelly Smith, Advanced Physiotherapist explored how physiotherapists can help people living with MND to manage this symptom and how physiotherapy can help with increased muscle tone in people with MND.
- Jenny Rolfe, Occupational Therapist talked through effective postural management including static and wheelchair seating, bed positioning and how these can be utilised to manage symptoms such as cramps and spasms, with useful and simple solutions.



*“The event provided access to a wealth of information and follow-up support, making it a very comprehensive learning experience. I liked that it covered pharmaceuticals, physiotherapy and positioning and included some evidence-based reasoning. The breakouts were a good opportunity to discuss with other services across the country to ask questions about how they manage certain challenges.”*

## Coping with complexity

This information and knowledge exchange gave attendees an opportunity to hear others candidly share examples of demanding cases they have managed.

- Anthony Hanratty, MND Advanced Nurse Specialist used a case from his area to explore the importance of understanding the motivations, expectations and such specific needs of the person living with MND and their family and carers in the provision of effective care.
- Rachael Marsden, Nurse Consultant for MND at John Radcliffe Hospital reflected on a case in which the patient discharge from hospital was complicated by systemic health care issues and how in this instance her team, overcame the problem.
- Phillippa Sharpe, Specialist Occupational Therapist, explored an example in which providing care when significant cognitive change is involved and when issues of this nature arose and various considerations and actions that they and their team took to provide appropriate care.



*“These sessions offer so much learning and show how sharing information as experts and learners grows our care and support to all patients and loved ones.”*



**Click to view  
and book  
onto 2025  
events**

# Annual Community of Practice Networking event

## What Matters Most? - Optimising quality of life for people living with MND, individual priorities and effective, person-centred care

The day started with a keynote speech to inspire and a short knowledge session to cement some concepts. Attendees were then moved into four stimulating competency sessions led by the expert core. In these sessions, members discussed and explored risk and the significant things 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.

Sessions included maintaining a sense of self, the fundamentals: eating and breathing, everyday challenges: novel solutions and MND and relationships.

**Keynote speech:** Professor Eneida Mioshi, University of East Anglia presented *Behavioural symptoms triangulated: perspectives from the family, the view of healthcare professionals, and the evidence from the research literature.*

**Knowledge session:** Doctor Caroline Barry, Consultant in Palliative Medicine, Norfolk MND Care and Research Network presented *Understanding risk, Best interest decisions and mental capacity.*

**Practical demonstrations included:** PEG and RIG insertion, respiratory equipment, orthotics, equipment solutions, safe exercise for people with MND, communication aids and syringe drivers.

**Exhibitors included:** REMAP, SpecialEffect, Neater Solutions, Liberator UK, Beagle Orthopaedic and Munevo.

Over 170 health and social care professionals attended the event from across England, Wales, Northern Ireland and Isle of Wight.

**Save the date: Our next Annual Network Event will take place on 7 October 2025. Further details coming soon.**



*"It's wonderful to find that no matter what level experience you can always learn more from new research and from expert peers."*

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

*"Amazing to be amongst large group of professionals dedicated to learn about and helping to improve care given to people living with MND and their families."*





# Annual Stephen Hawking MND Lecture

## Motor neurone disease – the importance of psychological care Acceptance and Commitment Therapy (ACT) – a proven intervention that supports quality of life.

Each year the Association holds the Annual Stephen Hawking MND Foundation Lecture, delivered by a subject authority, designed to highlight current research with members of the multidisciplinary team and demonstrate how this might feed into their practice.

Over 1,200 professionals from a wide range of disciplines and across the world registered for the 2024 event and over 700 attended live on 12 November 2024.

The lecture was led by Rebecca Gould, Professor of Psychological Therapies in the Division of Psychiatry at University College London, and also an Honorary Clinical Psychologist at Camden and Islington NHS Foundation Trust.

During this insightful and interesting lecture, attendees gained a deeper understanding of the importance of psychological support for people with MND, including the relevant recommendations outlined in NICE Guideline NG42. They were also introduced to the principles of ACT and how these can be applied to their practice in MND care.

All of the past lectures are available on our website at [www.mndassociation.org/hawkinglecture](http://www.mndassociation.org/hawkinglecture)



**Click to view  
2024 lecture  
recording**

## Coming up in 2025...

### 2025 Events

All of our 2025 webinars, workshops and information and knowledge exchange events are available to book on the events calendar. Additional events will be added soon, so please check our calendar regularly.

[www.mndassociation.org/education-events](http://www.mndassociation.org/education-events)

### Your views

If you have any suggestions about a training event or topic you would like covered within our education provision then please get in touch while we continue to plan for next year.

Please email your suggestions to [education@mndassociation.org](mailto:education@mndassociation.org)

### Get involved

If you are interested in presenting your experiences, a case study, or action you took to improve your services we want to hear from you!

Please contact [cop@mndassociation.org](mailto:cop@mndassociation.org) to share your presentation idea.



**Please email [education@mndassociation.org](mailto:education@mndassociation.org) if you  
have any questions about our education programme.**

# New information resources in 2024

We have a wide range of publications, resources and tools for health and social care professionals working with people with MND. View the full range on our website at [www.mndassociation.org/propublications](http://www.mndassociation.org/propublications)

## Professional information finder tool

We offer a wide range of resources to support health and social care professionals, as well as people living with MND. With nearly 200 resources available, finding the right one can be challenging.

This helpful new tool makes it easy to locate resources by topic or profession, providing links for both professionals and those affected by MND. Links can be quickly emailed to oneself or others.



[View the information finder tool](#)

## Advance care planning for MND booklet

This guide provides valuable information and practical strategies to help professionals facilitate advance care planning effectively for individuals with MND.

It covers key topics such as the benefits and challenges of advance care planning, how to approach discussions, essential decisions and documents, planning for urgent situations, and recording and communicating decisions.

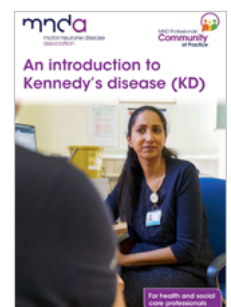


[View the advance care planning booklet](#)

## An introduction to Kennedy's disease booklet

This comprehensive guide is tailored to help health and social care professionals understand and meet the complex needs of individuals living with Kennedy's disease.

It gives an in-depth overview of the condition, including information on diagnosis, the role of gene inheritance, and effective approaches to symptom management. It also explores the range of support options available to individuals affected by Kennedy's disease.



[View the Kennedy's disease booklet](#)

## We also reviewed a number of our publications in 2024:

- Wheelchairs for people with MND
- Occupational therapy for MND
- Respiratory symptoms in MND
- MND: Information for social care services
- Using our care information
- Respiratory pathway
- MND Association support for professionals
- Wheelchair pathway

[View our publications for professionals](#)