Review of 2023

Education for health and social care professionals
Webinars

In 2023 we delivered five live webinars and two pre-recorded webinars, with over 862 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

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

A focus on oral nutrition in MND: current evidence, managing risks and exploring good practice.

Aim: To develop increased understanding about nutritional and dysphagia management of people with MND and the implications for provision of person-centred care.

Speakers: Sean White, Dietitian and NIHR Doctoral Fellow, University of Sheffield and Erin Probert, Clinical Lead Speech and Language Therapist, Royal Hospital for Neuro-disability.

Expiratory muscle strength training (EMST) for people with MND

Aim: To develop an understanding of Expiratory muscle strength training (EMST) and the evidence to support its use in people living with MND.

Speaker: Jodi Allen, Clinical Specialist Speech and Language Therapist, The National Hospital for Neurology and Neurosurgery, Queens Square, London

Equipment Solutions – your questions answered

Aim: To explore potential equipment solutions to presenting challenges for people living with MND.

Speakers: Phillippa Sharpe, Occupational Therapist, Jenny Rolfe, Occupational Therapist, and Malabika Ghosh, Occupational Therapist.

Let’s talk about Sex and Relationships

Aim: To highlight the importance of discussing sex and relationships with people with MND, using the Ex-PLISSIT model.

Speaker: Rachael Marsden – Nurse Consultant for MND, John Radcliffe Hospital, Oxford
Strengthening and improving multidisciplinary care for people with MND

Aim: To highlight the key clinical messages from the world’s largest study examining the lived experience of people with MND - the TONiC-ALS study, which has 36 sites in the UK.

Speaker: Professor Carolyn A Young, Consultant Neurologist – The Walton Centre

Maximising communication in MND: thinking outside of the tick

Aim: To explore the meaning of ‘communication’ and consider what is really important in MND.

Speaker: Jennifer Benson – Independent Speech and Language Therapist specialising in MND

Pain Management for MND

Aim: To increase understanding of how pain may be experienced in MND and potential methods to treat it.

Speaker: Dr Rhys Roberts, Consultant Neurologist at Addenbrooke’s Hospital – Cambridge

“Really informative, great use of evidence base tied in with clinical and practical everyday use. Has given me a great starting point to start using in my clinical setting.”

Click to view and book onto 2024 webinars
A Conversation with...

In 2022 we launched our new series, *A conversation with...* This series give attendees an opportunity to listen to subject matter experts being interviewed on Zoom, using questions submitted by you. We ran three drop-in sessions in 2023.

Recordings of our *A conversation with...* events can be found on our webinars web page at [www.mndassociation.org/webinars](http://www.mndassociation.org/webinars)

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**A conversation with... Alexa**
Presented by Richard Cave Specialist Speech and Language Therapist.
Richard discussed how off the shelf tech such as Alexa and mobile phone apps might be used by people living with MND to support their care.

**A conversation with... MND Association financial and equipment support services**
Presented by Pauline Matheson-Marks, Head of National Care at the MND Association
Pauline answered questions on various grants and equipment services that the Association can provide for people living with and affected by MND and how to apply for them.

**A conversation with... an MND Network Coordinator**
Presented by Caroline Bidder, MND Network Coordinator, Swansea Bay.
Caroline answered questions about how an MND network operates, what makes this dispersed model of care the appropriate one, and the impact it has on people living with and affected by MND

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**Masterclasses**

Two online masterclasses were run in 2023. Our 2024 masterclasses will be available on our [Calendar of Events](http://www.mndassociation.org/education-events) soon at [www.mndassociation.org/education-events](http://www.mndassociation.org/education-events).

**Let’s talk about end of life in motor neurone disease**

*Delivered by:* Dr Idris Baker and Becky Whittaker.

*Aim:* To help professionals gain confidence in discussing death, dying and advance care planning with people with MND.

“The trainers were engaging and helped me feel more confident and engaging with people around end of life and future care planning. The training did what it said, and achieved all the learning outcomes for me.”
Workshops

In 2023 we ran our second and third workshops focused on the critical area of MND care – Respiratory failure in MND. 138 health and social care professionals attended across the four workshops.

**Workshop 2: Options, solutions and issues**

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

**North workshop:** 7th March 2023 at Newcastle United Football Club. Delivered by Alison Armstrong, Kelly Smith, Helen Ashcroft-Kelso, Verity Ford and Jane Rodger.

**South workshop:** 14th March 2023 at the National Council for Voluntary Organisations (NCVO), London. Delivered by Catrin Emery, Rebecca Hall, Charlie Hardaker and Jonathan Palmer.

**Workshop 3: Secretion management and airway clearance**

**Aim:** To introduce non respiratory specialist members of the MDT to secretion management and airway clearance.

**North workshop:** 7 November 2023 at Newcastle United Football Club
Delivered by Alison Armstrong, Kathy George, Liam Campbell, David Derry, Aoife Stone-Ghariani.

**South workshop:** 21 November 2023 at the National Council for Voluntary Organisations, London.
Delivered by Catrin Emery, Charlotte Massey, Jodi Allen, Dorinda Moffatt and Michelle Chatwin.

**Respiratory workshop: Northern Ireland**

**Aim:** To introduce non respiratory specialist members of the MDT to secretion management and airway clearance.


“The whole trilogy of workshops has been very useful. Great for practical day to day management of MND patients, especially in the community.”
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 1,300 members. We delivered three dedicated Information and Knowledge Exchange events for the Community in 2022, featuring presentations and networking opportunities, which attracted 349 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 240 members, where professionals can get immediate peer to peer support. Find out more about the Community of Practice at 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 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

IKE: Effective multidisciplinary team working

**Effective multidisciplinary working** - Presented by Debbie Quinn, Queen’s Nurse PCCNS, Northamptonshire Healthcare NHS Foundation Trust, Specialist Advisor to the CQC.

**Effective Multidisciplinary working: the barriers** - Presented by Dorinda Moffatt, Specialist Neuro-Respiratory Physiotherapist/Frailty Therapist, Prospect Hospice.

“The breakout groups were great to hear about the working practises of colleagues across the UK who have a shared interest in continuing to promote best practise in this area. It was apparent that it is often difficult to change current practise due to financial restrictions, but we were given encouragement by Debbie to - ‘keep trying, don’t give up.’”
IKE: Psychological Care for people living with MND

Dr Rachel Woolrich, Principal Clinical Psychologist, the Oxford Psychological Medicine Centre.

Psychotherapy for people living with MND - Dr John Ashworth, Counselling Psychologist, South West Neuromuscular Operational Delivery Network, Bristol

“I don’t need or want a hoist”: what refusal could mean and how to support decision making for people living with MND and their carers – Presented by Dr Rachel Woolrich, DClinPSy, AFBPsS, Oxford MND Care and Research Centre.

“Brilliant presentations and super relevant to my team, so I really appreciate having access! Thank you again!”

IKE: Optimising decision making and the use of adaptations and equipment to enhance quality of life of people living with MND

When and what? Some possible equipment solutions to common challenges for people living with MND – Presented by Phillippa Sharpe Specialist MND Occupational Therapist, Oxford MND Care and Research Centre.

“I don’t need or want a hoist”: what refusal could mean and how to support decision making for people living with MND and their carers – Presented by Dr Rachel Woolrich, DClinPSy, AFBPsS, Oxford MND Care and Research Centre.

“So accessible for a range of professionals, opportunity for reflection on own practice and opportunity to take something new into your practice.”

Click to view and book onto 2024 events
Annual Community of Practice Networking event

Supporting people living with MND through advance care planning – A role for the whole MDT

Following the tremendous success of the first networking event last year, we repeated the event again this year bigger and better!

Throughout the day attendees followed Adam, a person living with MND and his family’s journey. In groups led by the export core they considered how to approach sometimes challenging process of advance care planning and how professionals can best support the crucial decision making needed to ensure the best care takes place.

Keynote speech by Dr Trish Sealy, Consultant in Palliative Medicine, South Tees Hospitals Trust. Trish delivered an inspiring speak on Advance care planning: who, when and how much?

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

Exhibitors included: Accora, Contour886, MND Association, Precise Health Ltd and tobii dynavox.

Over 130 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 9 October 2024. Further details coming soon.

“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. Thank you MND Association for organising this and all your other educational events.”

“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.”

“Excellent day - great to be able to network in person, learn from other professionals and share tips.”
Annual Stephen Hawking MND Foundation Lecture

Advance Care Planning what you need to know, and how to put it into practice

Each year the Association holds the Annual Stephen Hawking MND Foundation Lecture, designed to highlight current research with members of the multidisciplinary team and demonstrate how this might feed into their practice, delivered by an expert in their field. This year it was delivered as part of our partnership with the Royal College of Speech and Language Therapists (RCSLT).

Over 1,200 professionals from a wide range of disciplines registered for the 2023 event, which took place virtually on 21 November. The lecture was led by Professor Bee Wee CBE, Consultant in Palliative Medicine at Sobell House and Katharine House Hospice, Oxford University Hospitals NHS Foundation Trust and Associate Professor at University of Oxford.

Professor Wee explored advanced care planning for people living with MND, and its positive impact for the patient and for care. It included practical examples of how professionals can support advance care planning in their own role and environment.

The MND Association is grateful for the financial support received from the Stephen Hawking Foundation to make this lecture possible, and to the RCSLT for their partnership.

All of the past lectures are available on our website at www.mndassociation.org/hawkinglecture

Coming up in 2024...

2024 Events
All of our 2024 webinars and information and knowledge exchange events available to book on the events calendar. Our masterclasses, Conversations with... and workshops will be added soon, so please check our calendar regularly.

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

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 to share your presentation idea.

Please email education@mndassociation.org if you have any questions about our education programme.