

2023 MND Professionals' Community of Practice Networking event

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

Disclaimer: This is not a conference! You will not sit theatre style listening to presentations! What you *will* do is participate in sessions where ideas and concepts will be 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 learn through doing and exploration.



This is Adam.

Throughout the day you will follow Adam, and his family's, journey with MND. In groups, led by MND experts, you will consider how to effectively approach the sometimes challenging process of advance care planning.

No one can treat MND on their own – it is always a collaboration. So here, with your colleagues you will **discuss** and **explore** the significant things health and social care professionals, Adam, and his family might want to talk about at different stages in his disease progression. You will **reflect** on how you can best encourage and support the crucial thinking and decision making needed to ensure that best care takes place.

Date: Monday 9 October 2023

Time: 9.30 – 4pm

Location: National Conference Centre, Birmingham

Cost: £35 early bird rate until end of August, £50 thereafter

Keynote speaker:

To set the scene for the day, Dr Trish Sealy Consultant in Palliative Medicine, South Tees Hospital Trust, will deliver out keynote presentation: *Advance Care Planning: Who, When and How Much?*

Biography

Trish is a Specialist Palliative Care Consultant in the diverse community setting covering Middlesbrough, Redcar and Cleveland. She is Clinical Lead for South Tees Specialist Palliative Care. Trish works within a broad-based multidisciplinary team including allied health professionals and clinical psychology, supporting patients with any life limiting illness within home, care home and community hospital settings.

The sessions for the day - Adam's journey

Session 1: Diagnosis and first conversations

This is a time which may be dominated by shock and disbelief. There may be further examinations and questioning from health professionals in order to understand the person more specifically. There is a need to navigate the fine line between giving sufficient information and information overload. It is important to create an open and trusting connection with the person, so they feel able and confident to reach out if they need to.

Key question:

How much information does the person and their family want?

Session 2: Living with motor neurone disease

During this part of the MND journey the person may live for some time with just the symptoms they presented with at diagnosis. They may deal with the disease using some minimal coping strategies. Life may not change much but the person and their family will be aware that this could alter at any time. There is a need to balance supporting the person to make decisions and plan for the future, whilst not detracting from the relative normality they have.

But the nature of MND means that the disease can progress rapidly and in this stage the person could find they are adjusting to new challenges fairly regularly. They may start to lose independence and ease of communication. These unwelcome changes – both physical and cognitive may cause frustration and an alteration in their sense of self. Typically, there is a focus on finding solutions to new presenting problems, which preserve the person's self-determination and dignity.

Key questions:

What does the person seem ready to plan?

What does the person think are the best options for them?

Session 3: End of life

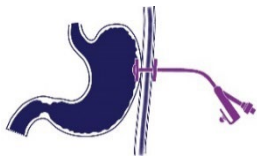
By this point the person has limited time left to live. As practitioners there are specific things to consider about therapy interventions and there may unfortunately be an emergency admission. But in this stage the aim is support the person to have a good death. There may be emotional conversations to have and as health care professionals there is a need to protect yourselves and maintain resilience when dealing with emotion and distress.

Key question:

What do we need to do to ensure that this person achieves a good death?

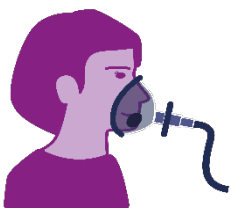
Demonstrations

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 gastroonomy 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.



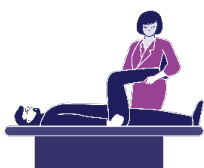
Orthotics

Orthotics can improve quality of life by reducing pain, promoting mobility, and supporting where muscles have weakened. You will be introduced to a wide range of splints, neck supports and more. Find out what solutions they offer, and how they can be put to best use to support the person in your care.



Equipment solutions

Get hands on with and discuss a range of equipment solutions to common problems faced by people living with MND, from profiling beds to eating and drinking aids.



Safe exercise for people living with MND

Learn about exercise, its benefits for people living with MND and specifically how it can be used without causing h



Communication aids

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.



Syringe drivers

A syringe driver is a small, battery-powered pump that delivers medication at a constant rate throughout the day and night. Familiarise yourself with this essential piece of kit used often used in the last few weeks and days of life when people find it difficult to swallow medicines.

We hope you can join us.

By the end of the day, you will have further developed confidence to support your patients to consider some of the significant topics and issues which arise during advance care planning. You will have discussed practice with national colleagues and have new ideas to take back to your workplace. You will also have had the opportunity to explore some of the key therapies and interventions for people living with MND.

Last year's attendees gained a lot from the networking day:

"What an amazing first face to face CoP event! So beneficial to be able to talk to so many therapists and build connections - Loved it!"

"Wonderful to see a group of experienced HSCP coming together with a common purpose. Thanks, a great day."

"Thank you for an amazing day – truly inspirational!"

Please join us for what will be another fantastic networking day. Visit www.mndassociation.org/education-events to book your place. If you have any queries in advance of the event, please email CoP@mndassociation.org

The Venue

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.

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

Birmingham City Centre – 20 minute drive
Central Manchester – 2 hour drive
Central Leeds – 2 hour drive
Central Bristol – 2 hour drive
Central London – 2 hour drive

By train

Nearest station: Birmingham International – 5 minute taxi journey

Other stations:

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