

MND Association End of Life Masterclass

Let's talk about end of life in motor neurone disease – June 2023

Session 1: What happens as MND progresses

- End of life: a guide for people with motor neurone disease (MND)
<https://www.mndassociation.org/support-and-information/information-resources/information-for-people-with-or-affected-by-mnd/end-of-life-a-guide-for-people-with-motor-neurone-disease>
- Professionals End of Life Guide - <https://www.mndassociation.org/sites/default/files/2022-11/Professionals%20guide%20to%20end%20of%20life%20care.pdf>
- Professionals guide for GPs and primary care teams -
<https://www.mndassociation.org/sites/default/files/2022-11/Guide%20for%20GPs%20and%20primary%20care.pdf>
- Cognition change and frontotemporal dementia and MND
[Cognitive change and frontotemporal dementia | MND Association](#) (webpage)
- Professionals - Cognitive change, frontotemporal dementia and MND booklet -
<https://www.mndassociation.org/sites/default/files/2022-11/Cognitive%20change%20and%20FTD.pdf>
- Care information - about palliative care services
<https://www.mndassociation.org/sites/default/files/2022-11/3D%20Hospice%20and%20palliative%20care.pdf>
- MND Just in Case Kit: Information for professionals -
<https://www.mndassociation.org/sites/default/files/2022-11/P4%20Just%20in%20case%20kit.pdf>

Section 2: Advance care planning and advance decisions – care information

- Section 9 of the EoL guide - <https://www.mndassociation.org/sites/default/files/2022-11/9%20Advance%20care%20planning%20and%20advance%20decisions.pdf>
- Care info - Advance decision to refuse treatment and advance care planning ADRT
<https://www.mndassociation.org/sites/default/files/2022-11/14A%20Advance%20Decision%20to%20Refuse%20Treatment%20and%20advance%20care%20planing.pdf>
- Care Info - Withdrawal of ventilation with MND -
<https://www.mndassociation.org/sites/default/files/2022-11/8C%20Withdrawal%20of%20ventilation%20with%20MND.pdf>

Reading publications referenced:

- A Short History of Falling: Everything I Observed About Love Whilst Dying by Joe Hammond
<https://www.amazon.co.uk/Short-History-Falling-Joe-Hammond/dp/0008339902>
- Joe Hammond article - <https://www.theguardian.com/books/2019/dec/03/joe-hammond-author-of-acclaimed-motor-neurone-disease-memoir-dies-aged-50>
- With the end in mind: How to live and die well by Dr Kathryn Mannix <https://withtheendinmind.co.uk>
- Listen: how to find the words for tender conversations by Dr Kathryn Mannix
<https://www.waterstones.com/book/listen/kathryn-mannix/9780008435431>

Education opportunities:

- **Webinar recording:** Dr Mannix ran an MND webinar based on her 'Listen' – Talking about dying book <https://youtu.be/K8ElfTwMBsl>
- **MND online learning modules** in-depth courses - <https://www.mndassociation.org/professionals/professional-education-and-development/online-courses/>
- **e-ELCA online learning session.** To register for free access please complete a short registration process. The MND Pathway is session 5.6 <https://www.e-lfh.org.uk/programmes/end-of-life-care/>

Section 3: Communication workshop – Real Talk

Real talk www.realtalktraining.co.uk

A recent example of conversation science can be seen in the **Rob Burrow documentary** recently shared on the BBC. At around 9minutes into this, there is a fascinating 2-minute conversation between Rob and his MND consultant which illustrates a pattern we see in Real Talk of a patient blocking talk about planning for the end of life and how the consultant deals with it

- Rob Burrow: Living with MND (round 9ish – 11mins) <https://www.bbc.co.uk/iplayer/episode/m001d9r8/rob-burrow-living-with-mnd>

If you would like to discuss the real talk videos in further detail, please contact Becky Whittaker at bwhittaker.consultancy@gmail.com