

Community of Practice – Information and Knowledge Exchange event Psychological Care for people living with MND.

Publications and references

Presentation 1: Psychological Care for people living with MND by Dr Rachel Woolrich.

- Emotional and psychological support - <https://www.mndassociation.org/sites/default/files/2022-11/Emotional%20and%20psychological%20support.pdf>
- What us ACT? The Hexaflex Model and Principles Explained - https://positivepsychology.com/act-model/?utm_content=cmp-true
- Viktor Frankl - https://en.wikipedia.org/wiki/Viktor_Frankl
- Cognitive change, frontotemporal dementia and MND - <https://www.mndassociation.org/sites/default/files/2022-11/Cognitive%20change%20and%20FTD.pdf>
- Changes to thinking and behaviour with MND (care resource) <https://www.mndassociation.org/sites/default/files/2022-11/Changes%20to%20thinking%20and%20behaviour%20with%20MND.pdf>
- Frontotemporal dementia (FTD) – what does it mean for practice? Infographic <https://www.mndassociation.org/sites/default/files/2022-11/Infographic%20Frontotemporal%20Dementia.pdf>
- Edinburgh Cognitive and Behavioural ALS Screen (ECAS) - <https://ecas.psy.ed.ac.uk>

Presentation 2: Psychotherapy for people living with MND by Dr John Ashworth

- A professional's guide to end-of-life care in MND - <https://www.mndassociation.org/sites/default/files/2022-11/Professionals%20guide%20to%20end%20of%20life%20care.pdf>
- End of life: a guide for people with MND (Care resource) - <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>
- Finding your way with bereavement (care resource) - <https://www.mndassociation.org/sites/default/files/2022-11/Finding%20your%20way%20with%20bereavement.pdf>

Psychological resources and services available

- The Reality Slap by Russ Harris (book)
- Facing the Storm by Ray Owen (book)
- With the End in Mind by Kathryn Mannix (book)
- Further training - <http://contextualscience.org/> - introduction to ACT
- Further training - www.praxiscet.com – access ACT training
- MND Association www.mndassociation.org:
 - Offer counselling for children via Barnardos.
- Charity – Winston's wish www.winstonswish.org – UK child bereavement charity
- Charity - Widowed and Young www.widowedandyoung.org.uk
- End of Life Doulas. <https://eol-doula.uk>
- Free online resource www.psych.ox.ac.uk/talkingtochildren
 - 4 step guide to help you talk to your patients about telling children about serious illness
- Exercise –
 - Map out professional psychological network in your area?
 - Community neuro-rehab team?
 - Palliative care team?
 - MND Care Centre – nurses, OT, psychology?
- As big as it gets supporting a child when someone is seriously ill. A Winston's wish publication