

All Wales MND Study Day

27 April 2023

Presentation 1: An overview of NCIG's approach to delivering on psychological and wellbeing needs to people living with neuro conditions across Wales - Rhiannon Edwards

- Comisiwn Bevan Commission - Planned Care Innovation Programme
<https://www.bevancommission.org/programmes/planned-care/>
- Improving the journey from symptom onset to diagnosis for people with neurological conditions
<https://www.bevancommission.org/projects/improving-the-journey-from-symptom-onset-to-diagnosis-for-people-with-neurological-conditions/>

Presentation 2: Why access to clinical psychology is so important for patients with MND – Dr Sian Hocking

- Emotional and psychological support -
<https://www.mndassociation.org/app/uploads/2020/07/Emotional-and-psychological-support.pdf>
- ECAS – Edinburgh Cognitive and Behavioural ALS Screen

MND Association webinar recordings: MND Patient and care perspectives

1. MND and the impact on carers and their families
<https://www.youtube.com/watch?v=pmxXZ1NGHdU>
 2. 'This is my journey' – people with MND and their carers share their perspectives
<https://youtu.be/ifaqqp3XSs6U>
 3. "That can't be right – I want a second opinion" – patients' reactions to a diagnosis of
<https://youtu.be/UNELI29HYcl>
- Cognitive change, frontotemporal dementia and MND
<https://www.mndassociation.org/app/uploads/px018-cognitive-change-ftd-mnd.pdf>
 - Changes to thinking and behaviour with MND
<https://www.mndassociation.org/app/uploads/2020/07/Changes-to-thinking-and-behaviour-with-MND.pdf>

Information to help adult carers and family members (care resources)

- <https://www.mndassociation.org/support-and-information/for-carers/>
- Psychological support for people with MND and professionals – please see this section of our webinar recordings <https://www.mndassociation.org/professionals/professional-education-and-development/webinars/> It includes: 1) Psychological support for people with MND, 2) Avoiding burnout – caring for yourself when you are supporting people affected by MND

Presentation 3: Neurological Conditions Recovery College "The Niwrostiwt" Linda Tremain

- NERS – National Exercise Referral Scheme
- Bevan exemplar: [#The Niwrostiwt / Neurostute Recovery College: 'Tredegarising' Healthcare 2.0 - Bevan Commission](#)

Presentation 4: Positivity within the lived experience of MND: A qualitative approach – Kathryn Sigsworth

- Living with MND (Care resource) <https://www.mndassociation.org/support-and-information/information-resources/information-for-people-with-or-affected-by-mnd/living-with-mnd-guide/>

Presentation 5: Introduction to Schwartz Rounds – The Point of Care Foundation

- The Point of Care Foundation - <https://www.pointofcarefoundation.org.uk>
- Supporting health and care staff - <https://www.pointofcarefoundation.org.uk/topic/supporting-staff/>
- About Schwartz Rounds - <https://www.pointofcarefoundation.org.uk/our-programmes/staff-experience/about-schwartz-rounds/>

Presentation 6: NHS Continuing Healthcare - Michelle Evans

- Michelle.Evans@HughJames.com
- Continuing NHS healthcare: Decision Support Tool (DST) for practitioners
<https://www.gov.wales/sites/default/files/publications/2022-03/continuing-nhs-healthcare-decision-support-tool-for-practitioners.pdf>
- NHS Continuing Healthcare for MND <https://www.mndassociation.org/app/uploads/2023/01/P7-CHC-for-MND-2022.pdf>
- Disabled Facilities Grants and home accessibility
<https://www.mndassociation.org/app/uploads/2022/06/10C-Disabled-Facilities-Grants-and-home-accessability.pdf>
- The Multidisciplinary Team (MDT) for MND infographic
https://www.mndassociation.org/app/uploads/2021/09/77401_MNDA_Infographic_MDT_v4_HR.pdf
- Hugh James Nursing Care website: www.hughjames.com/service/nursing-care/Other
www.hughjames.com/nursingcare

Presentation 7: MND SMART South Wales – Randa Magdalene

- **MND-SMART** <https://www.mnd-smart.org>
- **SMART** - Systematic Multi-Arm Randomised Trial
- Register interest <https://www.mnd-smart.org/contact/register-interest>