

Module 1: Pre-course virtual learning

Introduction to neuro-palliative care

Dr Ed Richfield, consultant in elderly medicine, North Bristol NHS Trust

Module 1a: The basics of neurology

(This content is intended primarily for individuals with a background in palliative or end of life care.)

- **Parkinson's: Scene setting and basic science: epidemiology, genetics, anatomy, pathology**
Dr Lara Teare, consultant neurologist, University Hospital Coventry and Warwickshire
- **An overview of Parkinson's medication**
Dr Richard Genever, consultant physician and movement disorders lead, Chesterfield Royal Hospital NHS Foundation Trust
- **Palliative care and Parkinson's disease**
Dr Alice Rogers, internal medicine trainee, University Hospitals Sussex NHS Foundation Trust
- **An overview of MS**
Daisy Cam, MS specialist nurse and Dr David Paling, consultant neurologist, Sheffield Teaching Hospitals NHS Foundation Trust
- **Introduction to dementia: prevalence, cause and impact**
Prof Iracema Leroi, associate professor of geriatric psychiatry, Trinity College Dublin & faculty, GBHI, Dr Clara Dominiguez-Vivero, senior atlantic fellow for equity in brain health, GBHI and Dr Irina Kinchin, health economist with expertise in quantitative and qualitative research, GBHI
- **An introduction to MND: pathophysiology and approach to care**
Rachael Marsden, MND consultant nurse, Oxford University Hospitals NHS Foundation Trust
- **Medication management – an overview in neurology**
Viv Horton, advanced clinical pharmacist for neurosciences, South Tees Hospitals NHS Foundation Trust

Module 1b: The basics of palliative care

(This content is intended primarily for individuals with a background in neurology or medicine for the elderly.)

- **Principles of neuro palliative care**
Dr Jessica M. Besbris, palliative neurologist, Cedars-Senai
- **Advance care planning (ACP) in neurology**
Dr Tim Jackson, consultant in palliative medicine, Northern Care Alliance NHS Trust
- **Adapting your communication for those with cognitive impairment**
Prof Karen Harrison Denning, professor of dementia nursing, De Montfort University & director of research and publications, Dementia UK
- **Admiral nursing – adapting practice in light of COVID-19**
Prof Karen Harrison Denning
- **How is palliative care delivered, what services do they offer, who are the team involved and how can they be accessed?**
Sarah Roderick & Ellie Garlick, MS nurse specialists, Cambridgeshire and Peterborough NHS Foundation Trust

Module 2: Residential MasterClass

Day 1 – 12th November 2024

09:00 Registration

09:30 Welcome & introduction

Dr Ed Richfield, consultant in elderly medicine, North Bristol NHS Trust

10:00 Theme 1: Dementia

Dr David Okai, clinical lead for psychiatry, South London and Maudsley NHS Foundation Trust, Jennifer Casson, occupational therapist team leader, End of Life Partnership, Dr Zena Aldridge, independent dementia nurse consultant and regional clinical lead in dementia, NHS England & Dr Clare Ellis-Smith, lecturer in palliative care, King's College London

Individual talks using case studies to outline:

- Pharmacological management of BPSD [40 mins]
- Non-pharmacological management of BPSD [40 mins]
- Identifying unmet needs [30 mins]
- Managing dementia in the hospice [30 mins]

12:30 Lunch

13:30 Theme 2: Parkinson's disease (PD)

Dr Ed Richfield, Anna Tucker, speech and language therapist, North Bristol NHS Trust & Viv Horton, advanced clinical pharmacist for neurosciences, South Tees NHS Foundation Trust

Individual talks using case studies to outline:

- Diagnosis and beyond - the principles of palliative care throughout a person's journey [25 mins]
 - Includes timely conversations throughout condition timespan
- Managing dysphagia [30 mins]
 - Eating and drinking with accepted risks (EDAR)
 - Impacts of dysphagia
- Palliative assessment and evidence for unmet palliative care need in Parkinson's [20 mins]
- Medicine management [30 mins]
 - De-escalation of existing medication and use of anticipatory medications to support end of life

15:15 Break

15:45 Spirituality

Rev Andrew Goodhead, lead chaplain and visiting lecturer, King's College London

- Introduction to spiritual care in neuropall care
- Addressing change in purpose and loss in long term neurological conditions
- The concepts of “multiple deaths” in chronic neurological conditions
- Exploring the overlapping roles of spiritual care / psychological care and how these may complement within a service
- Self-care for clinicians practising in this area

16:45 Comfort break

16:50 Panel discussion part 1

Managing common advanced and end of life symptoms across neurology

Panel discussion with interactive audience participation (MDT-style)

Chair: Dr Ed Richfield

Dr Jon Tomas, consultant in palliative medicine, University Hospitals Coventry and Warwickshire, Dr Zena Aldridge, Viv Horton & Anna Tucker

Matthew, a 77-year-old man with Parkinson’s disease and Parkinson’s disease dementia, also has chronic kidney disease, heart disease, hypertension, and leg oedema. He is no longer speaking meaningfully and often appears agitated, which concerns his wife and daughter, who are his primary caregivers. He struggles with swallowing, sometimes choking on food and finding it difficult to take medication, particularly Sinemet, which no longer seems effective. Matthew had previously expressed a desire for comfort-focused care, avoiding invasive treatments like a feeding tube.

- Pain
- Caregiver burden and support
- Identification of terminal phase and medicines management
- Speech and communication difficulties
 - assistive technology

17:45 Final remarks

18:00 Close for day 1

19:00 Pre-dinner drinks

19:30 Informal dinner

Day 2 – 13th November 2024

08:30 Registration

08:45 Welcome and overview day 2 objectives

Ruth Stross, head of nursing, Neurology Academy and neurology specialist nurse, Kingston Hospital NHS Foundation Trust

09:00 Developing neuro-palliative care services

Georgina Carr, CEO, Neurological Alliance, Dr Jon Tomas & Sue Thomas, independent healthcare consultant

- Practicality of service delivery [15 mins]
- Pathways and commissioning [15 mins]
- Policy in practice: an update on patient-initiated follow up, NHS England priorities, NICE rehabilitation guidelines and more [15 mins]
- Group Q&A [15 mins]

10:00 Break

10:30 Theme 3: Multiple sclerosis (MS)

Dr Emma Husbands, palliative care consultant, Gloucestershire Hospitals NHS Foundation Trust & Prof Eli Silber, consultant neurologist, King's College Hospital NHS Foundation Trust & Sarah Roderick, MS nurse specialist, Cambridgeshire and Peterborough Foundation Trust

Individual talks using case studies to outline:

- Unmet needs - identify what these are to go into detail [30 mins]
 - Dysphagia
 - Respiratory changes
 - Pain
 - Other
- Spasticity and complex case management in advanced disease [30 mins]
 - Management in palliative stages
- The MS journey - key points for palliative discussions [30 mins]
 - End of life care provision across primary and secondary care divide

12:00 Panel discussion part 2

Managing common advanced and end of life symptoms across neurology

Panel discussion with interactive audience participation (MDT-style)

Chair: Ruth Stross

Multiple sclerosis (MS)

Dr Emma Husbands, Prof Eli Silber, Sarah Roderick

Charlie 50yrs old male, diagnosed 19yrs old with PPMS, married to Jane with a 14yr old son Sam, now has advanced MS (EDSS 8.5), extensive care package, living at home, family are struggling with his increased needs, he has had multiple admissions with urine infections and now has pressure sores secondary to the spasticity and dystonia.

- Spasticity and dystonia - overview across all conditions
 - Spasticity, rigidity, high tone and dystonia - when is it which?
 - How does management differ?
 - Treatment options and therapeutic management
- Mobility and pressure ulcers
- Bladder and bowel symptoms

12:30 Lunch

13:30 Unpaid carers

James Townsend, Mobilise

- How can clinicians identify and supporting unpaid carers
- The impact of 'Mobilise' on carer support
- Carer assessment and legal support available to carers

14:00 Theme 4: Motor neurone disease (MND)

Rachael Marsden, MND nurse consultant, Dr Emma Husbands, Sean White, NIHR Clinical doctoral research doctoral fellow & MND dietitian, Sheffield Teaching Hospitals NHS Foundation Trust

Individual talks using case studies to outline:

- Respiratory support including withdrawal of ventilation [25 mins]
- Advance care planning in MND: principles and challenges [25 mins]
- Nutritional management of people with MND [25 mins]
 - Dietetic management
 - Decision-making and changes through a person's journey
- Group Q&A [15 mins]

15:30 Break

16:00 Panel discussion part 2

Managing common advanced and end of life symptoms across neurology

Panel discussion with interactive audience participation (MDT-style)

Chair: Dr Ed Richfield

Motor neurone disease (MND)

Dr Emma Husbands, Rachael Marsden, Sean White & James Townsend

During a MND support group the topic of discussion moved to how MND impacts on every aspect of the lives of people living with MND and that of their families. Living with MND affects the previous relationships and roles people have within their family homes at a physical, environmental and emotional level. The consequences of MND can make intimacy a challenge whether that be in relation to the ability to express themselves or changes to the physical environment of the home. People living with MND can perceive a loss of agency but expressed how they still want to have control over their care and how they wish to live their lives with MND. The group discussed how supporting HCPs can both support and hinder their ability to make choices that are aligned with their values, including the option to accept/take risks.

- How to support people with MND to make positive risk choices.
- Supporting people with MND to continue to engage in intimate relationships.
- Facilitating people with MND to make choices about their lives and care that are aligned with their own values.
- Recognising the support that caregivers need to meet the needs of people with MND and themselves.

16:30 **Close for day, evaluations**
Dr Ed Richfield & Ruth Stross

16:45 **Depart**