

Module 1: Pre-course virtual learning

Introduction to neuro-palliative care

Dr Ed Richfield, Consultant in Elderly Medicine, North Bristol 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, consultant neurologist and Dr Irina Kinchin both Global Brain Health Atlantic Fellows
- **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 Dening, 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 Dening
- **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 (DO), clinical lead for psychiatry, South London and Maudsley NHS Foundation Trust, Jennifer Casson (JC), occupational therapist, End of Life Partnership, Dr Zena Aldridge (ZA), independent dementia nurse consultant and regional clinical lead in dementia, NHS England & Dr Clare Ellis-Smith (CE-S), lecturer in palliative care, King's College London (TBC)

Individual talks using case studies to outline (30 mins):

- Pharmacological management of BPSD (DO)
- Non-pharmacological management of BPSD (JC)
- Identifying unmet needs (CE-S)
- Managing dementia in the hospice (ZA)

12:30 Lunch

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

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

Individual talks using case studies to outline:

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

15:15 Break

15:45 Spirituality

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

- Introduction to spiritual care in neuropall car
- 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

Cases to discuss will include:

- Pain (JT)
- Caregiver burden and support (ZA)
- Identification of terminal phase and medicines management (VH)
- Speech and communication difficulties (AT)
 - assistive technology

17:45 Final remarks

18:00 Close for day 1

19:00 Pre-dinner drinks

19:30 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 (GC), CEO, Neurological Alliance, Dr Jon Tomas (JT), & Sue Thomas (ST), independent healthcare consultant

- Practicality of service delivery (JT)
- Pathways and commissioning (ST)
- Policy in practice: an update on Patient-initiated follow up (PIFU), NHS England priorities, NICE rehabilitation guidelines and more (GC)

10:00 Break

10:30 Theme 3: Multiple sclerosis (MS)

Dr Emma Husbands, palliative care consultant, Gloucestershire Hospitals NHS Foundation Trust & Prof Eli Silber TBC, & Sarah Roderick (SR), 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 (EH)
 - Dysphagia
 - Respiratory changes
 - Pain
 - Other
- Spasticity (ES) and complex case management in advanced disease
 - Management in palliative stages (ES)
- The MS journey - key points for palliative discussions (SR)
 - End of life care provision across primary and secondary care divide

12:00 Lunch

13:00 Theme 4: Motor neurone disease (MND)

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

Individual talks using case studies to outline

- Palliative care in MND: when, why and how? (EH)
- Respiratory support including withdrawal of ventilation (RM)
- Advance care planning in MND: principles and challenges (EH)
- Nutritional management of people with MND (SW)
 - Dietetic management

- Decision-making and changes through a person's journey

15:00 Break

15:15 Unpaid carers

Mobilise, speaker TBC

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

15:45 Panel discussion part 2: Managing common advanced and end of life symptoms across neurology:

Dr Ed Richfield & Ruth Stross (co-chairs)

- Dr Emma Husbands
- Professor Eli Silber TBC
- Rachael Marsden
- Sarah Roderick
- Sean White

Case-based discussion with cases to include covering:

- Recognition of those approaching end of life (DO)
- Spasticity and dystonia - overview across all conditions (ES)
 - Spasticity, rigidity, high tone and dystonia - when it is which?
 - How does management differ?
 - Treatment options and therapeutic management
- Mobility and pressure ulcers (SR)
- Bladder and bowel symptoms (SR)
- Swallowing difficulties and dysphagia (SW)
 - enteral feeding plans through the course of the disease

17:00 Close for day, evaluations

Dr Ed Richfield & Ruth Stross (co-chairs)

17:15 Depart