



RHN Clinical PDOC Conference

The Royal Hospital for Neuro-disability, Putney

25 June 2024

Programme

09:00 Registration and refreshments

09.20 Welcome and Introduction

Paul Allen, CEO, Royal Hospital for Neuro-disability

Chair (AM) Dr Andrew Hanrahan, Consultant in Neuro-rehabilitation, Royal Hospital for Neuro-disability

09.30 PDOC setting the scene

Dr Ashraff Ali, Medical Consultant, Royal Hospital for Neuro-disability

09.45 Approaches to Tracheostomy Management in PDOC in the acute setting

Gemma Jones, Clinical Lead SLT for Critical Care and lead SLT for tracheostomy team, Cardiff and Vale UHB

Nicki Wimberley, Specialist SLT for Major Trauma, Cardiff and Vale UHB

10.20 Emerging and Evolving: The Prolonged Disorders of Consciousness Service at the National Rehabilitation Hospital, Dublin

Dr Raymond Carson, Consultant in Rehabilitation Medicine, National Rehabilitation Hospital, Dun Laoghaire, Dublin.

10.55 Coffee Break

11.10 Botulinum Toxin in the Management of Sialorrhoea for People with Prolonged Disorders of Consciousness

Teresa Clark, Consultant Physiotherapist, Royal Hospital for Neuro-disability

11.30 Prescribing in PDOC: Anticonvulsants

Dr Catherine O'Mahony, Clinical Fellow, Royal Hospital for Neuro-disability

11.50 Why do we prescribe antidepressants for people with PDOC?

Dr Lloyd Bradley, Consultant in Rehabilitation Medicine, Royal Hospital for Neuro-disability

12.20 Questions and Answers

12.30 Lunch



Chair (PM) Dr Sophie Duport, Associate Director of Research, Royal Hospital for Neuro-disability

13.20 Prolonged Disorder of Consciousness (PDOC) Provision in the North East and North Cumbria (NENC) ICB Region: report of a task and finish group

Emma Lever, Clinical Lead Speech and Language Therapist, Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust

Louise Thompson, Advanced Occupational Therapist, Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust

13.50 Prolonged Disorders of Consciousness and complex physical management in the community

Dr Stephen Ashford, Consultant Physiotherapist and Honorary Reader, London North West University Healthcare NHS Trust, Regional Hyper-acute Rehabilitation Unit & King's College London, Department of Palliative Care, Policy and Rehabilitation, London

14.20 Coffee break

14.35 RHN's evolving controlled sensory environments and assessments for our PDOC patients- from our level 1 Rehabilitation wards across to Continuing Care services- the before and now

Lucy Van Der Neut, Occupational Therapist, Royal Hospital for Neuro-disability

15.00 Outcome measurement in PDOC: the Putney FOCUS tool

Dr Sarah Crawford, Consultant Clinical Psychologist, Royal Hospital for Neuro-disability

15.20 CANH decision making for people in PDOC - learning and reflections

Erin Probert, Clinical Lead Speech and Language Therapist, Royal Hospital for Neuro-disability

15.40 Assessing communication in patients emerging from PDOC: from research to practice

Amy Pundole, Clinical Lead Speech and Language Therapist, Royal Hospital for Neuro-disability

16:00 Prolonged Disorders of Consciousness, the Neuropalliative perspective

Dr Andrew Hanrahan, Consultant in Neurorehabilitation, Royal Hospital for Neuro-disability

16.20 Questions & Answers

16:30 Conference Close



Speaker Biographies

Dr Stephen Ashford

Consultant Physiotherapist and Honorary Reader, London North West University Healthcare NHS Trust, Regional Hyper-acute Rehabilitation Unit & King's College London, Department of Palliative Care, Policy and Rehabilitation, London

Stephen has incorporated clinical practice with research and implementation science to develop research outputs which are clinically relevant and applied to people following acquired brain injury. He delivers the regional specialised outreach service for North West London and surrounding counties, including the management of spasticity and complex physical management (including for those with Prolonged Disorders of Consciousness). He has developed with local, national, and international colleagues a programme of research, which builds strongly on his clinical expertise in management of spasticity and the physical aspects of neurological rehabilitation.

The programme has incorporated development of outcome evaluation using Goal Attainment Scaling in conjunction with measures such as the Arm Activity measure, with robust psychometric testing. During a National Institute for Health Research (NIHR) lectureship Stephen developed the Leg Activity measure, Leg Therapy recording Schedule and Goal Attainment Scale Legs, which are now being used in practice nationally and internationally. During his involvement in the NWL ARC fellowship programme Stephen developed implementation approaches for some of these tools to achieve better measurement and improved outcomes for people with stroke and brain injury.

Stephen edited the national guidelines on spasticity management published in 2018 by the Royal College of Physicians, UK and has contributed to a number of other national guidelines on Stroke (2016 & 2023), Contracture management and Splinting (2016) and Prolonged Disorders of Consciousness (2020). He was awarded a Fellowship of the Association of Chartered Physiotherapists In Neurorehabilitation, UK in 2016 and of the Chartered Society of Physiotherapy, UK in 2018. He became Senior Clinical Lecturer and Hon. Associate Professor (University College London) in June 2019 and Honorary Reader in April 2023 (King's College London). Stephen is currently working on research projects in arm and leg spasticity, rehabilitation goal setting and planning for people with spasticity, clinician (physiotherapy, medical and other MDT members) practice development for spasticity management and the wider application of goal setting and measurement tools in rehabilitation. He also has a developing programme of work on contracture development, prevention, and management.

Dr Lloyd Bradley

Consultant in Rehabilitation Medicine, Royal Hospital for Neuro-disability

Dr Lloyd Bradley is a consultant in rehabilitation medicine. He has worked at the RHN for just over a year now having previously worked in specialist neurorehabilitation in Sussex. He has a PhD in molecular biology and genetics from the University of London and underwent medical training in London and the East of England. He has previously been on NICE guideline committees for the management of multiple sclerosis and adult cerebral palsy and worked with NCEPOD in developing evaluations of transitional care from paediatric to adult services. Dr Bradley's current research interests include looking at prescribing practices in individuals with acquired brain injury, factors impacting on outcomes of specialist rehabilitation and staff experiences in long term care working with patients with disorders of consciousness.

Dr Raymond Carson

Consultant Physician and Medical Director, Brain Injury Programme, National Rehabilitation Hospital, Dublin, Ireland

Dr Raymond Carson is a graduate of Trinity College, Dublin, and trained in general, geriatric medicine and palliative care before specialising in rehabilitation medicine. He has been a consultant at the National Rehabilitation Hospital since 2016 and is the present medical director of the Brain Injury Programme and



joint lead physician for the Prolonged Disorders of Consciousness Unit. His specialist clinical/research interests include complex neuro-disability, palliative care, spasticity management and transitional care for young people with acquired brain injury. Dr Carson has a strong interest in undergraduate & postgraduate medical education and holds adjunct academic appointments with the schools of Medicine at University College Dublin and the Royal College of Surgeons in Ireland. He has been awarded Fellowships of the Royal Colleges of Physicians of London, Edinburgh, Glasgow and Ireland. He is also a fellow of the European Board of Physical and Rehabilitation Medicine and is a member of the Board of the Irish Institute of Clinical Neuroscience.

Teresa Clark

Consultant Physiotherapist, Royal Hospital for Neuro-disability

Teresa Clark is a Consultant Physiotherapist at the RHN. She has worked with people in DOC and their families for approximately 15 years. Her clinical and teaching practice focuses on areas that increase complexity within a disorder of consciousness, including; spasticity and contracture, postural management, tracheostomy, and sialorrhoea.

Teresa completed a Masters in Clinical Research (at St Georges University London) exploring the feasibility and acceptability of including people with reduced decisional capacity in randomised trials. She is now a PhD candidate at the University of Nottingham, investigating philosophical and methodological methods of improving research participation and equitable research outcomes for those in a DOC.

Dr Sarah Crawford

Consultant Clinical Psychologist, Royal Hospital for Neuro-disability

Dr Sarah Crawford is a Consultant Clinical Neuropsychologist at the Royal Hospital for Neuro-disability in Putney. She is the professional lead for Clinical Psychology within the Brain Injury Service, an NHS England funded Level 1 neuro-rehabilitation service for patients with complex neuro-disability. Dr Crawford has a particular interest in supporting families, and chaired the RHN's steering group for improving services for our patients' and residents' families and friends.

She has previously worked in the NHS, providing specialist outpatient neuropsychological assessments. She has also worked as a Clinical Psychologist within other specialist neuro-rehabilitation settings, including a transitional rehabilitation service and a unit for patients with severe challenging behaviour secondary to brain injury.

Dr Crawford has a BA degree in Experimental Psychology from the University of Oxford, a PhD in Psychology from University College London, and a Doctorate in Clinical Psychology from Kings College London. She has completed post-doctoral training in clinical neuropsychology and is listed on the British Psychological Society's Specialist Register of Clinical Neuropsychologists.

Dr Andrew Hanrahan

Consultant Physician in Neuro-rehabilitation Clinical Lead in Neuropalliation, Royal Hospital for Neuro-disability

Dr Andrew Hanrahan has been at the RHN since April 2014 having spent the previous six years in Cork, setting up specialist rehabilitation services for the region and national clinical pathways through the National Rehabilitation Hospital, Dublin.

Andrew has been on the Specialist Register for Rehabilitation Medicine since 2008 after having trained within the Oxford Deanery. After undergraduate training and formative experiences as a missionary doctor in Southern India, he did his postgraduate training in Internal Medicine and further research in Stroke at Bournemouth, completing a Fellowship in Cerebrovascular Disease in 1997.



Andrew now specialises in neurological rehabilitation and neuro-palliative management of complex neurological disabilities and disorders of consciousness. He is on the national guideline development group (RCP PDOC 2020). He did an MA in Medical Ethics and Law at King's College London is extensively involved in the clinical, ethical and legal aspects of these conditions, and is the clinical End of Life Care Lead.

Andrew lectures at and is the external advisor to the MA Programme (CBET Centre for Bioethics and Emerging Technologies) at St Marys University Twickenham, and is on the editorial board of New Bioethics. He also lectures annually on the MSc programme at University College Cork, having helped set up the module on amputee rehabilitation. He is involved in many quality improvement projects at the RHN, medical undergraduate teaching, the Putney Nurse programme, and various Hospital and Board Committees.

Gemma Jones

Clinical Lead SLT for Critical Care and lead SLT for tracheostomy team, Cardiff and Vale UHB

Clinical Lead Speech and Language Therapist Critical Care and Tracheostomy Team, University Hospital of Wales, Cardiff

Gemma is an experienced SLT working in the acute hospital setting, specifically Intensive Care. She is a specialist advisor to the RCSLT for Critical Care. Gemma is the SLT lead for Tracheostomy services within her Health board and Chair of the UK National Specialist interest Group for SLTs working with patients with tracheostomies. She has helped develop a number of national policies and guidelines, including ICS SLT Pillar, RCSLT Tracheostomy Competencies for SLT and NHS Elect AHP Critical Care Capability framework. Gemma is passionate about improving patients outcomes, MDT working, effective leadership and making our professions great!

Emma Lever

Clinical Lead Speech and Language Therapist, Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust

Emma is the Clinical Lead Speech and Language Therapist for Neurological and Specialist Services within Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust. She works into Walkergate Park, Centre for Neurorehabilitation and Neuropsychiatry in Newcastle upon Tyne. She started developing her passion and clinical specialism in the field of Prolonged Disorders of Consciousness (PDOC) in 2002 and is now an Expert SMART Assessor. As well as working with individuals in PDOC as part of her inpatient caseload, she is part of the PDOC Outreach Team alongside her colleague Louise Thompson. This provides in reach assessment and advice to referring units, as well as follow up monitoring and ongoing support for patients in PDOC and their families following their specialist assessment and in line with the current RCP guidelines. Emma regularly provides education and training to all members of the MDT and care providers on the assessment and management of individuals in PDOC.

Catherine O'Mahoney

Clinical Fellow, Royal Hospital for Neuro-disability

Amy Pundole

Clinical Lead Speech and Language Therapist, Royal Hospital for Neuro-disability

Amy Pundole is an experienced Clinical Specialist Speech and Language Therapist working with communication and swallowing disorders in patients with severe and complex acquired neurodisability. Amy graduated from Sheffield University in 2001 and has worked with adults in a range of settings, in the NHS and Charitable sector. Amy's particular interests include complex dysphagia and tracheostomy management and she is an experienced FEES assessor and endoscopist. She uses a holistic approach



and is trained in the use of Facial Oral Tract Therapy (FOTT) in the management of swallowing and communication disorders.

Amy is highly skilled in working with adults in a Prolonged Disorder of Consciousness (PDOC) and their families. She is an RCSLT advisor in this field and has contributed to national guidelines. She is currently completing a PhD at University College London investigating how best to assess patients emerging from PDOC.

Erin Probert

Clinical Lead Speech and Language Therapist, Royal Hospital for Neuro-disability

Erin has been Clinical Lead Speech & Language Therapist for the Continuing Care service at RHN since 2021, however has been at RHN since 2013. Erin has a strong interest in complex mental capacity assessments and best interests decision making, supporting patient autonomy and advocacy, future care planning for people with progressive neurological disorders, and neuro-palliative care.

Erin is passionate about optimising quality of life for people with severe brain injuries. Some of her time is currently seconded into the role of 'CANH in PDOC Lead', where she is supporting the clinical teams with best interests decision making about Clinically Assisted Nutrition and Hydration for patients in PDOC at RHN.

Dr Alexandra Rose

Principle Clinical Psychologist, Royal Hospital for Neuro-disability

Dr Alexandra Rose has diverse work experience in the field of clinical psychology and neuropsychology. In 2023 she completed a PhD in Psychological medicine with the University of Glasgow supervised by Professor Jonathan Evans. Her PhD examined the assessment of mood after severe brain injury. Dr Rose has a strong background in working with patients psychiatric difficulties, people with brain injuries and neurodegenerative processes. She currently holds the roles of Honorary Research Fellow at the University of Glasgow and Principal Clinical Psychologist at the Royal Hospital for Neuro-disability. Dr Rose also has experience in private practice, providing psychotherapy, supervision and case management.

Louise Thompson

Advanced Occupational Therapist, Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust

Louise is an Advanced Occupational Therapist with Neurological and Specialist Services within Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust. She has worked at Walkergate Park, Centre for Neurorehabilitation and Neuropsychiatry in Newcastle upon Tyne since 2008. She trained as a SMART assessor in 2015 and now works into the PDOC Outreach Team alongside her colleague Emma Lever. Louise provides in-reach assessment and advice to referring units, support to the inpatient team to carry out comprehensive PDOC assessment and follow up monitoring and ongoing support for patients in the community. She provides education and training to professionals and care providers on the assessment and management of individuals in PDOC. Louise is involved in both regional and national service development and is an active member of the UK PDOC OT Network.

Lucy Van Der Neut

Occupational Therapist, Royal Hospital for Neuro-disability

Lucy is currently a Band 7 Occupational Therapist who has worked at the RHN since 2009, initially working as an OTA during her OT training and then returning in 2016 as a Senior Occupational Therapist. Since her return she has progressed to a Band 7 role gaining experience in the different areas of the hospital including our NHS funded level 1 Rehabilitation Unit, Continuing Care Services and Behavioural Unit. She helped to develop our annual MDT review process and database in line with RCP guidance for Prolonged



Disorders of Consciousness, to support thorough assessment and management of our patients in our longer term care services.

Lucy has a special interest in prolonged disorders of consciousness (PDOC), sensory programmes and supporting our patients to access controlled sensory environments particularly patients in Disorders of Consciousness whose sensory environments are not always in place or regulated.

She is part of a sensory working party to support the setup of these areas with specialist equipment, as well as to train staff in their use to ensure a 24 hour approach.

Nicki Wimberley

Highly Specialist Speech and Language Therapist, Major Trauma, University Hospital of Wales, Cardiff

Nicki has worked in the University Hospital of Wales since 2016 initially as team lead of acute services, and since 2020 SLT lead for major trauma. Nicki provides highly specialist assessment and intervention for a variety of caseloads including spinal cord injury, neurosurgery, polytrauma and critical care. Nicki has a specialist interest in acquired brain injury and is passionate about providing high quality care, MDT working, improving patients outcomes and making every contact count!