



PSPA Study Day for Health and Social Care Professionals

Introducing the
'Care Pathway'
for Progressive
Supranuclear Palsy
(PSP)

Governor's Hall, St Thomas' Hospital,
London SE1 7EH

Monday 24th September, 9am-4pm

PSPA Study Day for Health and Social Care Professionals

Introducing the
'Care Pathway'
for Progressive
Supranuclear Palsy
(PSP)

Chaired by **James Rowe**, Senior Clinical Research Associate,
Department of Clinical Neurosciences, University of Cambridge.

**Governor's Hall, St Thomas' Hospital,
London, SE1 7EH**

Monday 24th September, 9am-4pm

The study day is aimed at professionals involved in the care and support of people with PSP and CBD. The content of each lecture will be aimed at the multidisciplinary team and will highlight best practice within those areas. As these conditions are rare, many professionals may not be familiar with the complex needs of people living with PSP/CBD. The annual study day will provide the opportunity for MDT to get a clearer view of the services available to help them support people living with PSP/CBD.

This event is specifically relevant to: **Parkinson's Nurse Specialists, Neuro Nurses, District Nurses, Community Matrons, GPs, Hospital Doctors, Neurologists, Speech & Language Therapists, Social Workers, Continence Advisors, Care Home Workers, Hospice Teams.**

The aim of the learning and development resource:

- To help the MDT become aware of the impact of living with PSP/CBD.
- To provide information on the recently developed the Care Pathway for PSP/CBD.
- To understand the role of the MDT in supporting people living with PSP/CBD, allowing access to available services.

Key learning outcomes:

Participants will be able to:

- Identify the need for palliative care involvement and at what stage in the disease process.
- Outline best practice guidance within their speciality.
- Identify the services provided by the PSP Association to its members and the professionals involved in their individual care.

The event will qualify for 7 study hours (1 day)

Key stakeholder views are included in the development and ongoing quality assurance process. Feedback forms are given out to attendees at the event and followed up by a management review at PSPA. Feedback is incorporated into future planning. Professional members are targeted each year to see which subjects they wish to be covered, including Neurologists and MDT members with whom the PSPA Specialist Care Advisors have regular contact.

Content is relevant to the target audience and includes: Overview of PSP , The Care Pathway for PSP: responding to the needs of people with PSP, Cognition and PSP, Enabling social inclusion in PSP, Palliative Care and Advance Care Planning, The role of the Parkinson's Nurse / PD Specialist in supporting people with PSP and CBD.

Booking:

£40 early bird rate to 30 June, (thereafter £50) to include lunch and refreshments.

Programme

Monday, 24th September 2012

Venue: The Governor's Hall, St Thomas' Hospital, London, SE1 7EH

Chair: **James Rowe**, Senior Clinical Research Associate, Department of Clinical Neurosciences, School of Clinical Medicine, University of Cambridge, and Consultant Neurologist at Addenbrooke's Hospital

9.00 Coffee on arrival / registration

- 9.30 – 10.15 **Overview of PSP** – the impact of Progressive Supranuclear Palsy and Cortico Basal Degeneration on sight, speech, swallow, mobility and behaviour; supportive strategies and the importance of research – Huw Morris, Senior Lecturer in Neurology, Cardiff University, and Honorary Consultant at the University Hospital of Wales and the Royal Gwent Hospital
- 10.15 – 11.15 **The Care Pathway for PSP: responding to the needs of people with PSP** – An overview of the new Care Pathway for PSP, and how the supporting documentation gives best practice guidance to aid health and social care professionals in meeting the Standards of Care for people with PSP – Charlie Peel, Project Manager, Neuro Commissioning Support, and Debra Chand, Director of Programmes, PSP Association

11.15 – 11.45 Refreshment break

- 11.45 – 12.30 **Cognition and PSP** – the effects of PSP and CBD on cognitive function and the importance of specialist assessment and support for families affected – James Rowe
- 12.30 – 13.15 **Enabling social inclusion in PSP** – the role of Speech & Language Therapy in supporting people with PSP – Tricia Gilpin, Senior Speech & Language Therapist, the National Hospital for Neurology & Neurosurgery Queen Square, London

13.15 – 14.15 Lunch (Sandwiches/fruit)

- 14.15 – 15.00 **Palliative Care and Advance Care Planning** – why early palliative care and planning in PSP is so important; the role of neuro-palliative assessment and Advance Care Planning – Liz Garrod, Coordinator and Project Lead for Rare and Rapidly Progressing Neurological Conditions, Hertfordshire Neurological Service
- 15.00 – 15.30 **The role of the Parkinson's Nurse / PD Specialist in supporting people with PSP and CBD** – Liz Williams, Parkinson's Specialist Practitioner, South West Essex
- 15.30 Thanks and close

This event is accredited

Publications

We have a full range of publications and information on PSP and CBD available free of charge. To receive copies please tell us which you would like to receive by ticking the relevant box.

- A Guide to PSP and CBD**
Information to assist health and social care professionals in the support of people with PSP and CBD.
- A Guide to PSP and CBD for Occupational Therapists**
- A Guide to PSP and CBD for GPs and Community Nurses**
- Best practice in PSP**
This document looks at four stages of PSP, early, mid, advanced, end of life and describes best practice for social care professionals at each stage
- Living with PSP**
Information on the Care Pathway for PSP, Model of Care for best practice, and symptom snapshots.
- Membership Form**
Membership is free to people with PSP/CBD and carers.
- Carers Information Pack**
A comprehensive guide containing information on managing PSP and CBD.
- PSPA Befriending Scheme**
Information on the recently launched befriending service.

All of our publications can be downloaded at www.pspassociation.org.uk

**If you have any questions about PSP and CBD
our free Helpline number is
0300 0110 122**

The Speakers

James Rowe



James Rowe is a Wellcome Trust Senior Research Fellow in Clinical Science and Reader in Cognitive Neurology at the University of Cambridge. He is a consultant neurologist at Addenbrooke's Hospital with specialist clinics for Progressive Supranuclear Palsy, Corticobasal Degeneration and Frontotemporal Dementia. His research interests include understanding and restoring cognitive function in neurodegenerative disease, using brain imaging with network modelling and psychopharmacology. James' main research interests can be divided into theoretical and clinical. The theoretical work focuses on the organisation and control of voluntary behaviours - how we select, change or inhibit our actions. This work uses fMRI and MEG to study anatomical networks including prefrontal cortex, striatum and parietal cortex. The clinical work relates to the effects of FTD, PD and PSP on cognitive functions; the impact of disease on functional brain networks; and the ability of drug treatments to improve the control of cognition and action. In addition to the Department of Clinical Neurosciences, much of James' work is carried out at the MRC Cognition and Brain Sciences Unit (<http://www.mrc-cbu.cam.ac.uk/people/james.rowe/>) and in collaboration with the MRC Behavioural Neuroscience Institute (<http://research.psychol.cam.ac.uk/~bcni>) within the umbrella of Cambridge Neuroscience (<http://www.neuroscience.cam.ac.uk/directory/profile.php?jamesrowe>).

Huw Morris



Dr Huw Morris is a senior lecturer in neurology at Cardiff University and an honorary consultant at the University Hospital of Wales, Cardiff and the Royal Gwent Hospital, Newport. He trained in neurology and neurogenetics at the Institute of Neurology, Queen Square, London; Mayo Clinic, Jacksonville, Florida; the Western Pacific island of Guam and South London. Huw's main research interest is neurogenetics, particularly applied to neurodegenerative diseases such as fronto-temporal dementia, Alzheimer's disease, Parkinson's disease and Progressive Supranuclear Palsy, and he was a PSP Association clinical research fellow. His clinical practice focuses on movement disorders, early onset dementia and neurogenetics. His research is funded by the Parkinson's Disease Society, Progressive Supranuclear Palsy Association and the Medical Research Council.

Charlie Peel



Charlie Peel works as a Project Manager for Neurological Commissioning Support (NCS), a non-profit organisation developed to ensure that service users are at the centre of the commissioning process. During her four years at NCS she has been involved in commissioning and policy work both locally and nationally. She was involved in the creation, training and rollout of Neuronavigator (a commissioning webtool) and has led on the research and development for year of care models in multiple sclerosis (MS), and progressive supranuclear palsy (PSP). She has contributed to a number of publications and articles including a mid-term review of the National Service Framework for Long-Term-Neurological Conditions. Charlie is currently developing a transferable resource to encourage Integrated Care Pathways, initially for Parkinson's, as well as managing NCS's new programme which supports other charities to develop their skills and expertise in commissioning.

Liz Williams



Liz is a Parkinson's Specialist Practitioner in South West Essex. An Occupational Therapist by profession, Liz has worked extensively in both physical and mental health. She worked in the role of Case Manager for Long Term Neurological conditions before gaining an MSc in Advanced Clinical Practice (Long Term Conditions). Liz subsequently completed the Parkinson's Specialist Nurse course and for the last five years has been working in the role of a Parkinson's Specialist Practitioner, seeing

people with Parkinson's and related conditions. Liz recently set up the Essex PSP support group with another volunteer, to support people with PSP, their friends and family.

Debra Chand



Debra Chand is Director of Programmes for The PSP Association. Debra led on the development of the PSP Pathway of Care, launched this year, and has contributed to working groups such as the Department of Health End of Life Neuro Guide, published articles on care issues, and is a member of the NCPC neurological conditions group. Debra gained an MBA with Henley Management College and attained programme management practitioner status

while working in change management with Kent Police. Prior to this, Debra worked for many years in the voluntary sector, latterly as Director for Support and Development with The Leprosy Mission International, and in a voluntary capacity with Age UK and Carers'Voice, which deepened her interest in palliative and care issues and in delivering effective frontline services. Debra joined PSPA in July 2007 as Deputy Director of Care, became Director of Care in 2008, and Programmes Director in 2012.

Tricia Gilpin



Tricia Gilpin obtained a BSc Honours degree from City University in Clinical Communication Studies, as a mature student, in 1994. She had previously worked in Classical Music Administration and had run a catering company for ten years.

Since qualifying she has worked exclusively with adult neurology patients. Firstly, on a stroke rehabilitation unit for two years, and then, for the past fourteen years, at the

National Hospital for Neurology and Neurosurgery, Queen Square. She has a particular interest in neuro-degenerative disorders and regularly lectures nationally to Speech and Language Therapists and to a wider audience. She is the Chair of a Specific Interest Group in Neurology for Speech and Language Therapists in the South East.

Tricia is married with two grown up children.

Liz Garrod



Liz qualified as a nurse in 1985 and has held a number of positions over the years but mainly within the field of palliative care and in the last decade more specifically neuro-palliative service provision, working as a Community Clinical Nurse Specialist in both Buckinghamshire and Hertfordshire. She was the end of life care lead for West Herts for two years before taking up her current role as Coordinator and Project Lead for Rare and Rapidly Progressing Neurological

Conditions, a unique post, instigated following an award for innovation from the East of England Transformation Board. This has involved the development and implementation of a comprehensive, integrated community care pathway for people living with identified rare and/or, rapidly progressing neurological conditions in Hertfordshire, from the point of diagnosis and PSP is amongst the five identified conditions for the project.



The PSP Association

PSP House, 167 Watling Street West,
Towcester, Northamptonshire NN12 6BX

T: 01327 322410 F: 01327 322412
www.pspassociation.org.uk

Registered charity numbers: England & Wales 1037087 / Scotland SC041199

