Role of the Specialist Nurse in Parkinson’s

Clare Keeley PDNS Sheffield Teaching Hospital
• First PDNS was appointed in 1989 in response to the need for better support and care for people with Parkinson's.
• Shift from the consultant being the main source of knowledge to the nurse who could provide ongoing, expert care which was easily accessible to patient and carer
Sheffield Service

- 3 Nurses based at RHH working alongside Neurologist and Neurosurgeons involved in DBS
- Run Nurse led clinics, Outreach clinics, Telephone clinics, Ward visits, Home visits
- Cover Sheffield, Barnsley, Rotherham, Doncaster, Derbyshire, Chesterfield, Worksop
Debbie Bolam at NGH working with Care of the Elderly Physicians

Covers NGH but is employed by Primary care and does Home visits and some clinics
What do we do!

- Specialist Nurse plays a vital role in providing expert knowledge and advice to PWP and their families
- Give ongoing support through different stages of the condition to improve quality of life
- Work closely with other professionals
- Source of education to all involved in care
Stages of Parkinson’s

• Diagnosis
• Maintenance stage
• Complex stage
• Advanced/Palliative stage

Parkinson's awareness in Primary care
Diagnosis Phase - Aims

• Difficult time for PWP and their family. Hope to help them achieve acceptance of diagnosis
• Provide information about PD and it’s treatment and support that’s available
• Discuss medication and options to treat
• Referral to MDT
• Encourage to contact us as needed
Maintenance stage

- Condition can be stable and will be on a relatively simple regime of medication.
- Encourage exercise and keeping active
- Advice on management of NMS
- Titrate medication if necessary
- Generally reviewed 6 monthly but encouraged to contact PDNS as needed
Complex stage

- Drugs which may have been effective in the past begin to lose their effect
- Develop motor complications—Wearing off, on/off fluctuations, dyskinesia’s
- Reduced mobility, severe tremor, freezing, speech difficulties etc.
- Leads to complicated drug regimes
- May be referred for DBS
Non motor aspects of the complex phase

- Psychiatric manifestations - depression, anxiety, hallucinations, cognitive problems
- Sleep dysfunction
- Secondary pain due to complications in PD e.g. dystonia, rigidity, restless leg syndrome
- Autonomic dysfunction
Role of MDT in complex phase

• As medication becomes less effective and predictable the MDT play an important role in maintaining function and independence.

• PDNS and MDT can work together to work out what is best for patient and carer and hopefully avoid hospital admissions.
Palliative Phase

- Problems with long term use of dopaminergic drug therapy
- Problems with immobility, falls, chest infections, UTI’s
- Dysphagia and aspiration
- Neuropsychiatric complications and dementia often lead to residential care
- Many symptoms of PD not relieved by drugs
Role of PDNS in Palliative care for PD

- Medication advice to other HCP – palliative care team, nursing homes, community care staff etc.
- Carer and family support
- Help with CHC assessment
- Preferred Place of care – avoid hospital admissions
- Useful to have case reviews with all involved in care
Role of the PDNS

- Coordinator of care
- Assessment
- Advice
- Support
- Education
- Multi-disciplinary team support/liaison
- Link between Primary and Secondary care
- PwP and family advocate
Thank you for attending this study day as by developing your knowledge around the care of people with Parkinson’s you will really make a difference to the care they receive and their quality of life.