

Palliative Care & Neurological Conditions: Neuro-Palliative-Rehabilitation - The Neurology Perspective

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What is Neurology?

- Neurology is the branch of medicine that deals with disorders of the nervous system, including the brain, spinal cord, peripheral nerves and muscle
- These can be conditions which are managed almost entirely in the community (such as epilepsy & migraine), acute neurological emergencies (such as stroke & meningitis) and chronic disabling conditions (such as dementia, multiple sclerosis & Parkinson's disease)

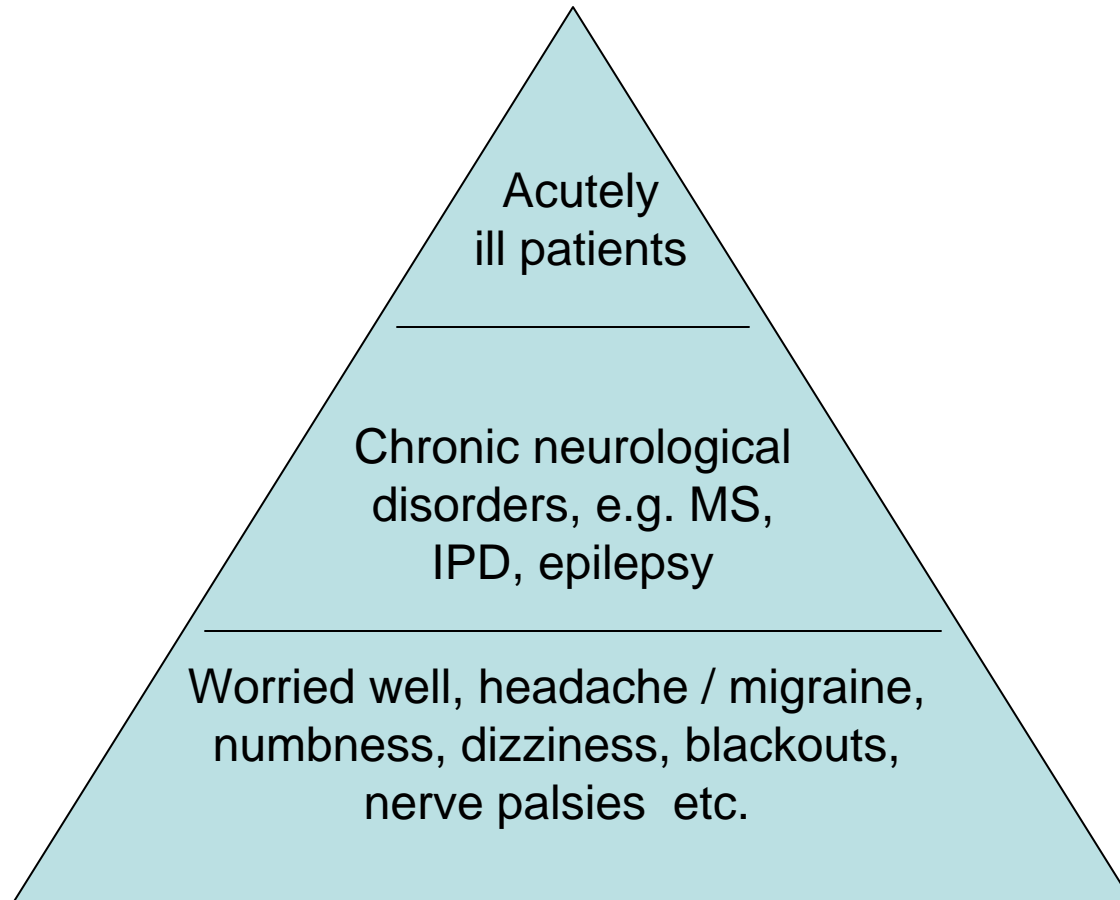
How common are neurological conditions?

- One in eight consultations with a GP is for a neurological symptom, commonly headaches, blackouts, dizziness, tingling or weakness
- 20% of acute admissions to hospital have a significant neurological problem (half of them stroke)
- 2% of the population have a disability, often severe and progressive, as a result of a neurological condition

The Neurologist

- In the UK there is considerable **geographic variation** in access to neurological services
- Relatively **small number** of neurologist in the UK
 - 352 whole time equivalent neurologists in 2003 (1 per 170 000 population)
 - 250 in 1995
- Neurologists in the UK largely work in a “**hub & spoke**” model – working together in regional neuroscience centres with attachments to DGHs
- **Specialist Nurses**
 - In some regions, disease-specific clinical nurse specialists work with neurologists to manage chronic diseases

Who do Neurologists see?



Limitations of the Neurologist

- **Insufficient Neurologists** to see the large volume of referrals received within the required time-frame AND provide on-going care for chronic conditions (15 minutes follow-up appointments often insufficient to address complex problems)
- Neurologists are largely **hospital-based** whereas focus of the management of long-term neurological disease is in the community

What can Palliative Care Offer?

- Holistic approach (physical, psychosocial, cultural, spiritual)
- Experience in symptom control
- End of life decisions
- Community centred
- In-patient facilities for terminal care / respite
- Day hospice facilities
- Complementary therapies
- Bereavement counselling

Neurology & Palliative Care

Neurology

- Large volumes of patients – many well
- Infrequent follow-up over long period
- DGH / tertiary centre-based
- Diagnosis, Treatment & symptom control

Palliative Care

- Comparatively fewer patients – all unwell
- Frequent follow-up over short period
- Hospital / hospice / community based
- Holistic care, symptom control & end-of-life planning

Which patients may benefit from Palliative Care input?

- Rapidly progressive fatal neurological conditions, e.g. CNS tumours, motor neurone disease
- Life shortening, progressive neurological diseases in advanced stages, e.g. Multiple Sclerosis, Parkinson's disease
- Acute neurological illness with poor prognosis

NSF LTC

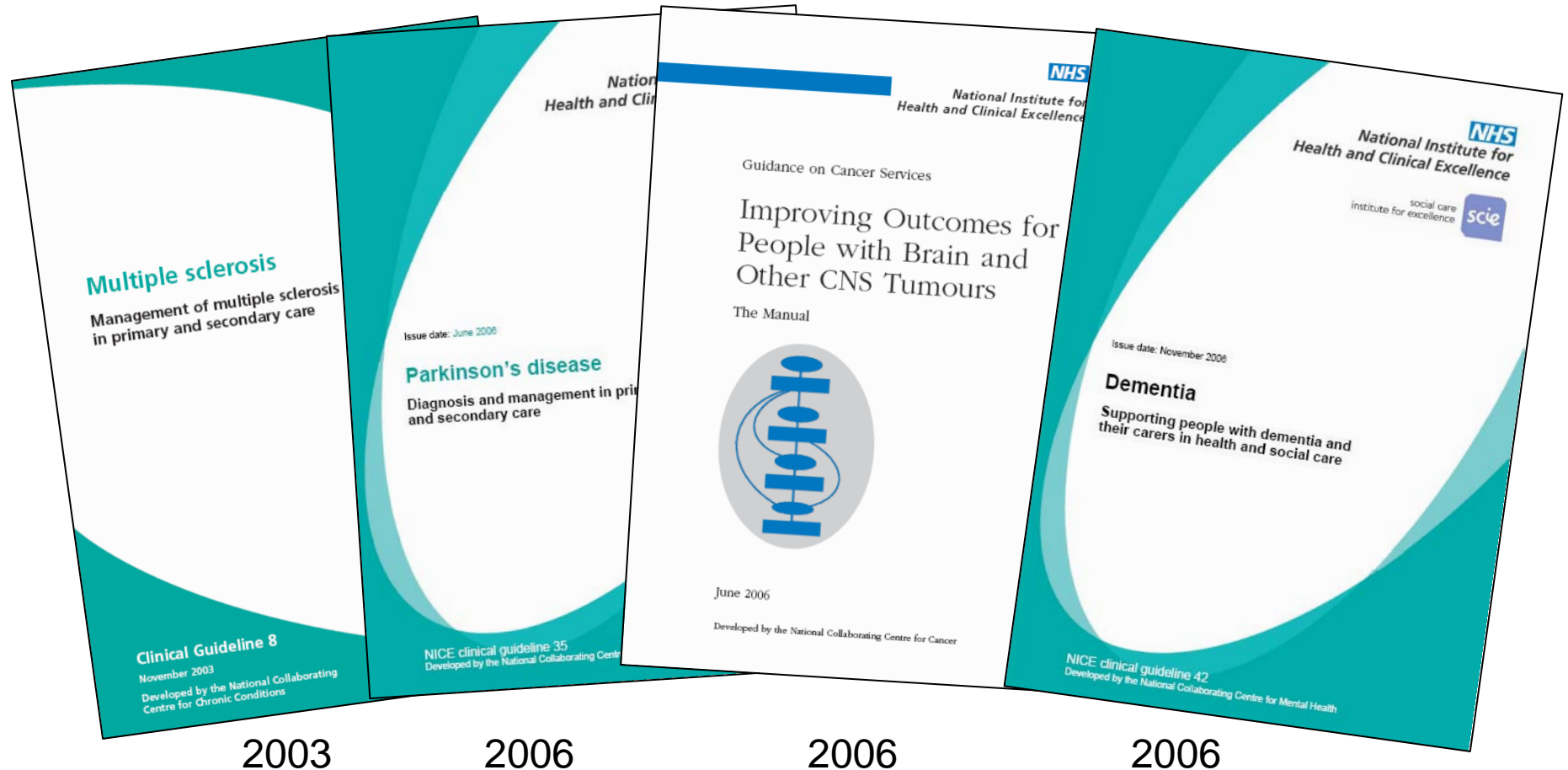


National Service Framework for Long- Term (Neurological) Conditions (2005)

Quality Requirement 9:
Palliative Care

NICE Neurology Guidelines

Multiple Sclerosis, Parkinson's Disease, CNS Tumours, Dementia



All recognise the importance of Palliative Care

Challenges

Neurology

- Need to be more accessible to patients with LTC
- Need to deal better with end-of-life issues
- Closer links with Palliative Care

Palliative Care

- Need to be more flexible in the model of care they provide
- Improved familiarity with long-term conditions
- Closer links with other specialties

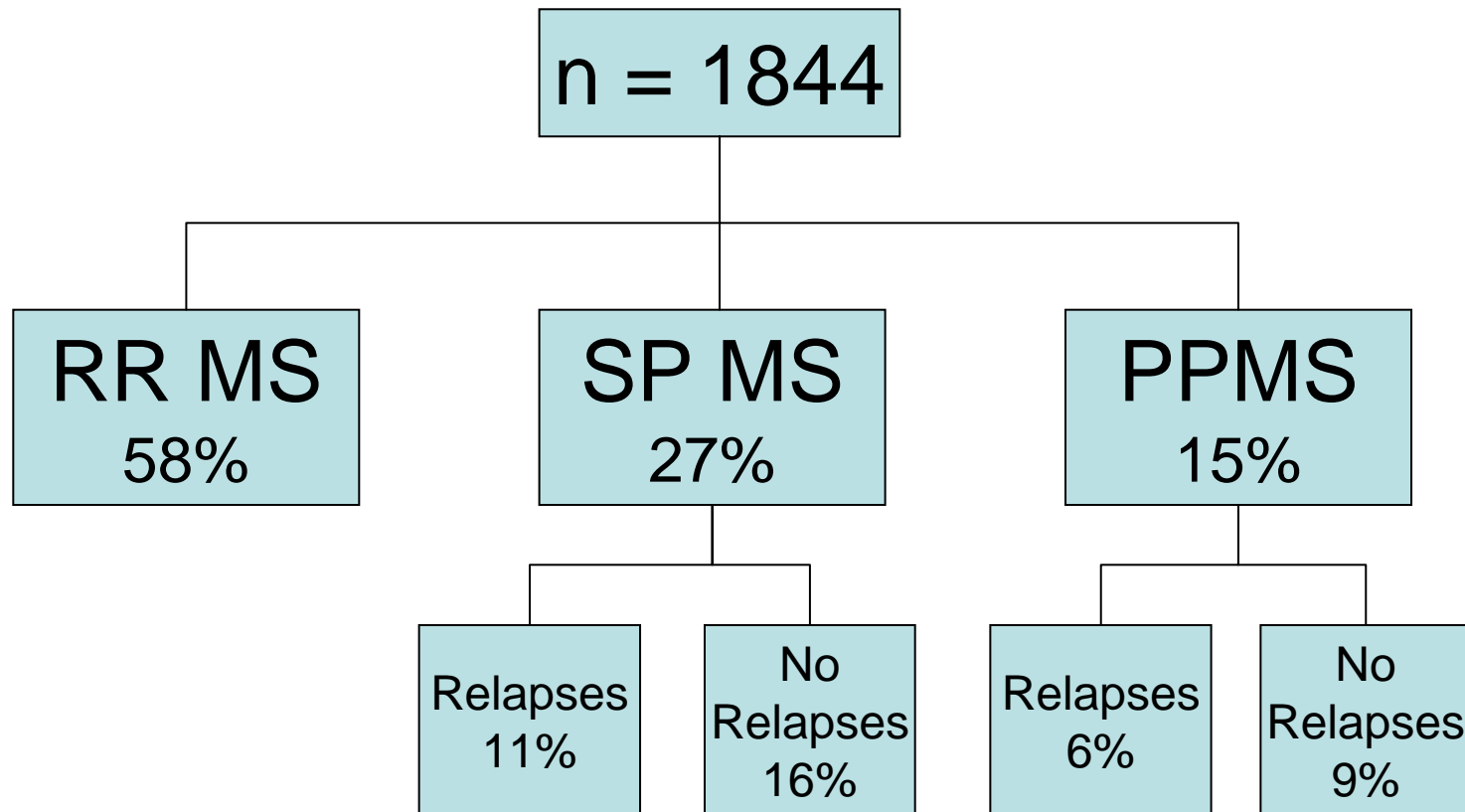
Multiple Sclerosis

- Chronic, life-shortening disease (average life-expectancy 30 years from diagnosis)
- Usually presents during working life (20 – 50 years of age)
- More common in women (increasing)
- Incidence 3 – 6 / 100 000, Prevalence 1 in 800
- Initially relapsing-remitting (RR MS) course (with or without residual disability) followed in the majority by a progressive neurodegenerative condition (SP MS) leading to significant disability
- 10 – 15% present with progressive disability without preceding relapses (PP MS)
- Partially effective treatments available for relapses but no current therapy available to modify neurodegenerative stage

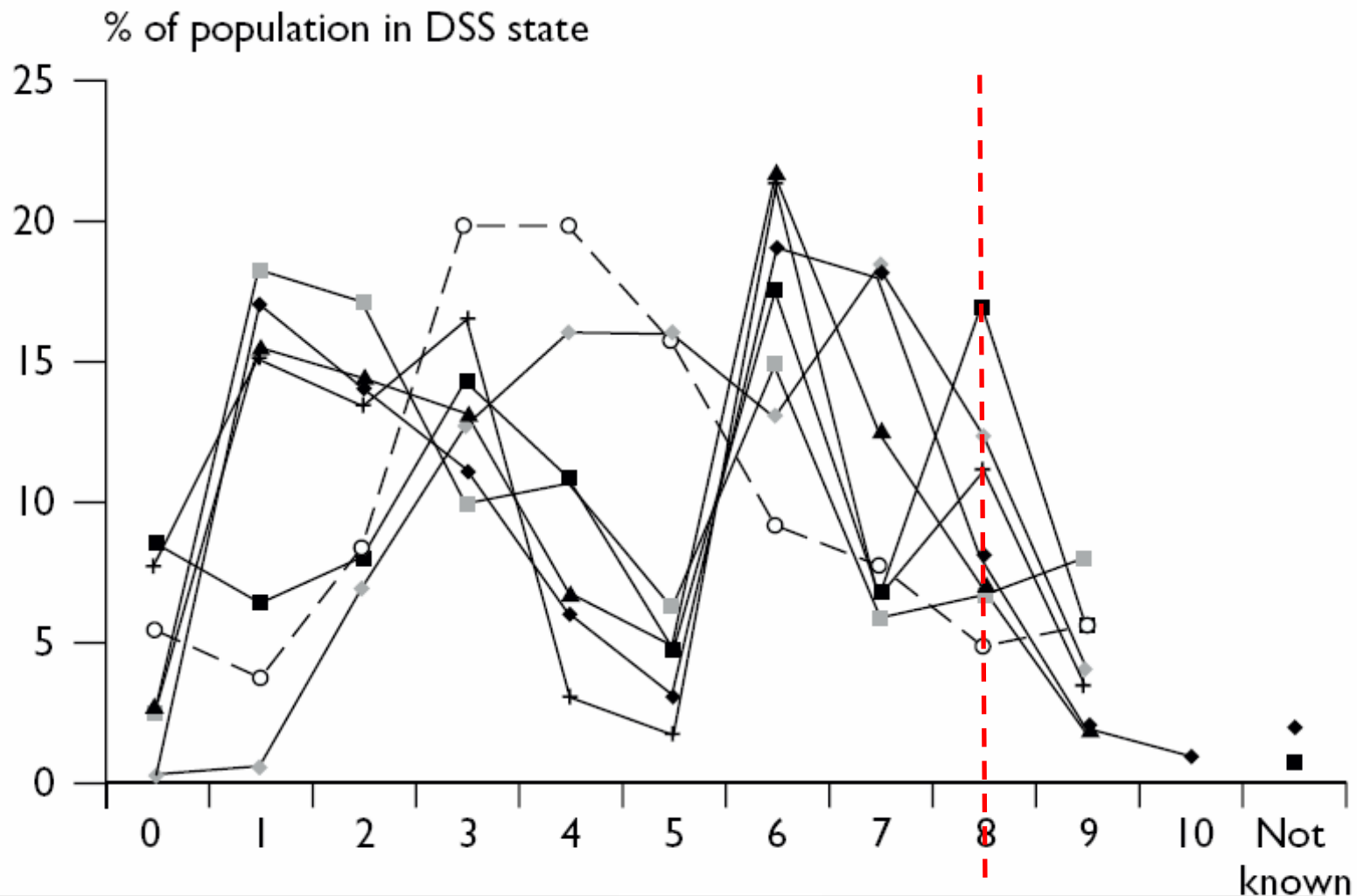
Multiple Sclerosis

Clinical Disease Course: Cross-sectional

Lyon MS Cohort



Disability in Multiple Sclerosis



Disability: significant stick chair bed-bound grave



The King's Centre for Palliative Care in Neurology

King's College London & King's College Hospital

Palliative Care Project for People with MS

3 year research project funded by MS Society launched in 2003
Collaboration Palliative Care & Neurology

Guidelines and referral pathway for PwMS developed

Patient information leaflet published by MS Society (2006)

Has led to an improved relationship between the Neurologist & Palliative Care Physicians involved

Complex Needs Clinic

- Multidisciplinary Clinic
- Held monthly at King's College Hospital
- MS nurse, Neurology consultant, Palliative Care consultant, Consultant in Neuro-rehabilitation, neuro-physiotherapist plus community health care workers
- Single one hour consultation leading to care plan

Complex Needs Clinic Case

- Ms JC (50 years old)
- MS diagnosed in her 20s – progressive for many years (SP MS)
- Past history of seizures – well controlled

- Bed-bound – no use of legs or right arm, some useful function of left arm
- Severe pain and spasticity (left leg worst at present)
- Right hip dislocation due to spasticity 5 years ago. Attempts at replacing joint resulted in chronic infection. Hip removed but discharging sinus and chronic fracture of right femur following surgery persist

Complex Needs Clinic Case

- Pressure sores
- Suprapubic catheter
- PEG feeding tube
- Significant cognitive impairment

Current medication

- Baclofen 10mg nocte, tizanidine 2mg bd, trimethoprim, glycerol suppositories, movicol, phenytoin 90mg, fentanyl patch, fentanyl lozenges PRN
- Previous attempts at nerve blocks in past

Complex Needs Clinic

Case

- Lives with partner and 5 year old son
- Sexually active until recently – previously reluctant to have treatments that may lessen perineal sensation
- Had been in nursing home prior to conceiving child and had returned home to have family life
- Carers 2/day – partner main carer but working full-time
- Since birth of son she wishes to be actively managed to prolong the time she has with her son

Complex Needs Clinic

Case

Recommendations

- Botox injected into hamstrings and adductors on left
- Not suitable for baclofen pump due to chronic sepsis therefore plans to liaise with pain consultant re admission for intrathecal phenol followed by respite admission to St Christopher's Hospice
- Community physiotherapy arranged
- Encourage to sit out of bed
- Liase with local wheelchair service
- Patient put in touch with (recently appointed) local MS nurse

Conclusions

- A small, but significant, proportion of people with neurological conditions would benefit from the extra dimension that palliative care can provide – palliative care is unlikely to be flooded with referrals
- Palliative care is becoming a requirement in the recommendations for the optimal management of many long term neurological conditions

Conclusions

- Palliative care professional may need to rethink the model of care they provide when managing conditions with a more chronic course than cancer
- Neurology & Palliative Care teams need to work together (clinical & educational) to provide optimum care to this patient group