

Why the current focus on palliative and end of life care for people with neurological conditions?

**Lucy Sutton
Director of Policy Development**

What is NCPC?

- **The umbrella body for palliative care**
- **Promotes palliative care for all**
- **Provides guidance on best practice
Influences government policy**
- **Supports all sectors involved in
providing, commissioning and using
palliative and end of life care services**

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Why the focus on Palliative and End of Life Care?

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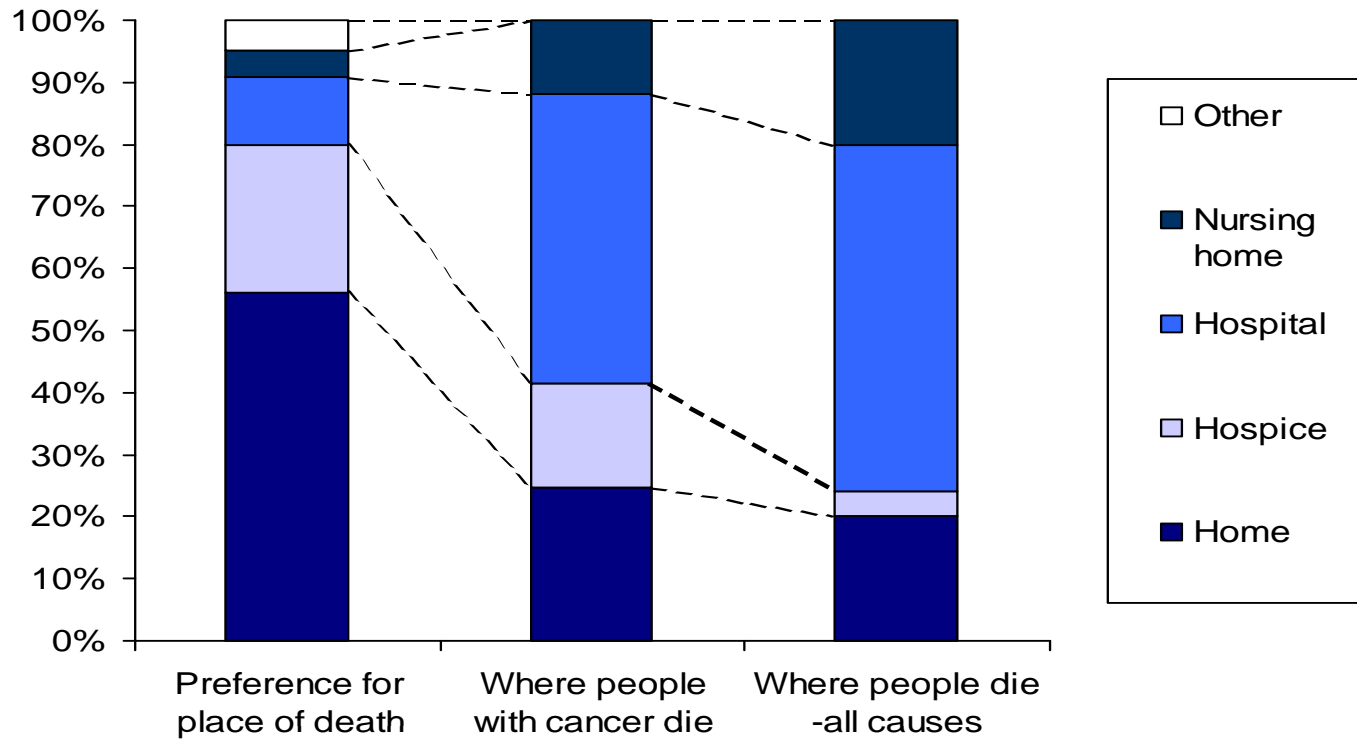
Background

- **Around 500,000 people die in England each year**
- **DH has never had a comprehensive strategy on end of life care**
- **Some patients receive excellent care, others do not**
 - 54% of complaints in acute hospitals relate to care of the dying / bereavement care (Healthcare Commission 2007)
- **95% of access to PC services cancer**
- **Ageing population, baby boomers**
- **Emergency admissions**
- **Choice, personalisation and control**

- **Life expectancy is increasing. However, healthy life expectancy whilst rising, is not keeping track with that increase: life expectancy and healthy life expectancy both increased between 1981 and 2001, with life expectancy increasing at a faster rate than healthy life expectancy.**



Choice - preferred and actual place of death



Living Alone

- **1/4 European households live alone – greatest in elderly with over 50% of 75+ women living alone**
- **Being older and female –ve association with death at home**
- **Co-morbidity increases risk of dying in hospital**
- **People do not want to die alone**
- **Carer burden increases with age – family living within 10-15 miles decreasing**

End of Life Care

- **New Minister**
- **White Paper**
- **PCT Baseline Reviews**
- **End of Life Care Strategy**
- **NAO Review of End of Life Care**
- **Lord Darzi NHS Review**
- **NSF for LTNC**
- **NICE PD, MS, Dementia**

END OF LIFE CARE pathway. Key

steps

Strategic Coordination (PCTs and LAs)

- Public awareness and discussion
 - Discussion with patient as end of life approaches + assessment + care plan
- ↓
- Coordination +/- register
- ↓
- Integrated service delivery (community, hospitals, care homes, hospices etc.)
- ↓
- Review
- ↓
- Last days of life
- ↓
- Death
- ↓
- Care after death

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Strategic coordination

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Why for People with Neurological Conditions?

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Comparison with other advanced diseases

Symptom	MS ¹	Cancer ²	Heart disease ²	Respiratory disease ²
Pain	68%	35-96%	41-77%	34-77%
Fatigue	80%	32-90%	69-82%	68-80%
Nausea	26%	6-68%	17-48%	?
Constipation	47%	23-65%	38-42%	27-44%
Breathlessness	26%	10-70%	60-88%	90-95%

¹ King's study - % with symptom

² Solano, Gomes, Higginson. Journal of Pain and Symptom Management, 2006: 31:58-69.

‘Palliative care type’ symptoms

Symptoms (Cancer) Ellershaw et al	Frequency Ellershaw et al (n = 125)	Frequency Lee et al (n = 123)
Pain	74%	85%
Immobility	66%	58.5%
Anorexia	~50%	13%
Insomnia	~40%	49.6%
Constipation	~30%	23.6%
Nausea	~26%	9.8%
Dyspnoea/ SOBOE	~20%	35.8%
Vomiting	~15%	4.1%

Symptoms

	MND	Cancer
Pain	94%	35-96%
Depression	44-75%	3-77%
Dyspnoea	85%	10-70%
Dysphagia	56%	35%
Constipation	53%	23-65%

Long Term Conditions NSF Quality Requirement 9

- **People in the later stages of long-term neurological conditions are to receive a comprehensive range of palliative care services when they need them to control symptoms; offer pain relief and meet their needs for personal, social, psychological and spiritual support, in line with the principles of palliative care.**

**“PROFESSIONALS WORKING IN
NEUROLOGY, REHABILITATION AND
PALLIATIVE CARE NEED TO WORK
CLOSELY TOGETHER AND WITH PRIMARY
CARE STAFF.....COMBINING THEIR
EXPERTISE TO SUPPORT PEOPLE IN THE
ADVANCED STAGES OF LONG-TERM
NEUROLOGICAL CONDITIONS”**

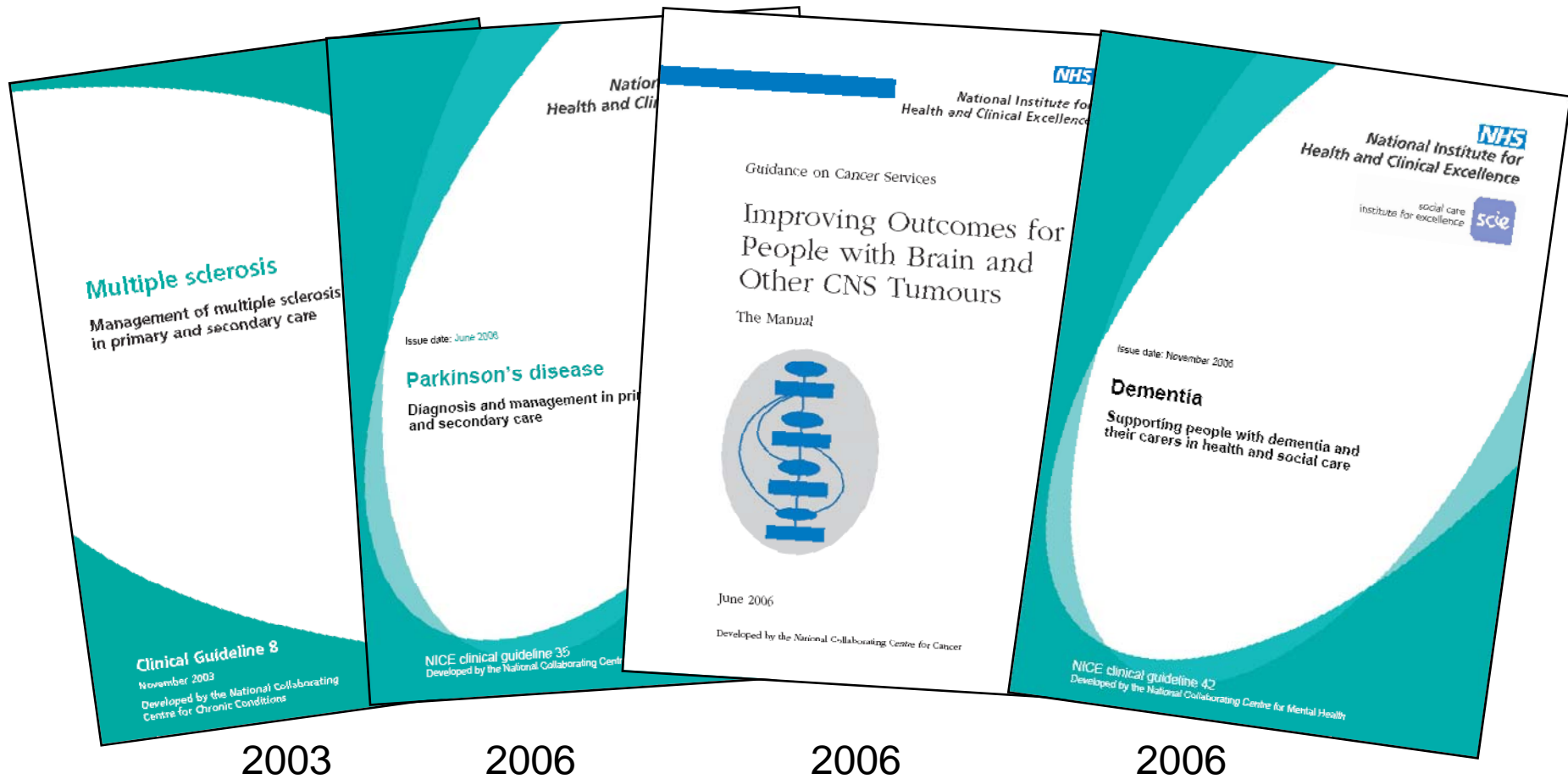
SOME WAYS IN WHICH THE NSF SUGGESTS THIS COULD BE ACHIEVED INCLUDE:

- SPECIALIST PALLIATIVE CARE TEAMS WORKING ALONGSIDE SPECIALIST NEUROLOGY AND NEURO-REHABILITATION TEAMS IN ORDER TO PROMOTE CONSISTENT, SHARED PRACTICE
- PALLIATIVE CARE SKILLS TRAINING BEING GIVEN TO NEUROLOGISTS AND NEUROLOGY SPECIALIST NURSES ETC
- TRAINING IN RELEVANT ASPECTS OF NEUROLOGY AND NEURO-REHABILITATION FOR SPECIALIST PALLIATIVE CARE TEAMS

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NICE Neurology Guidelines

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



2003

2006

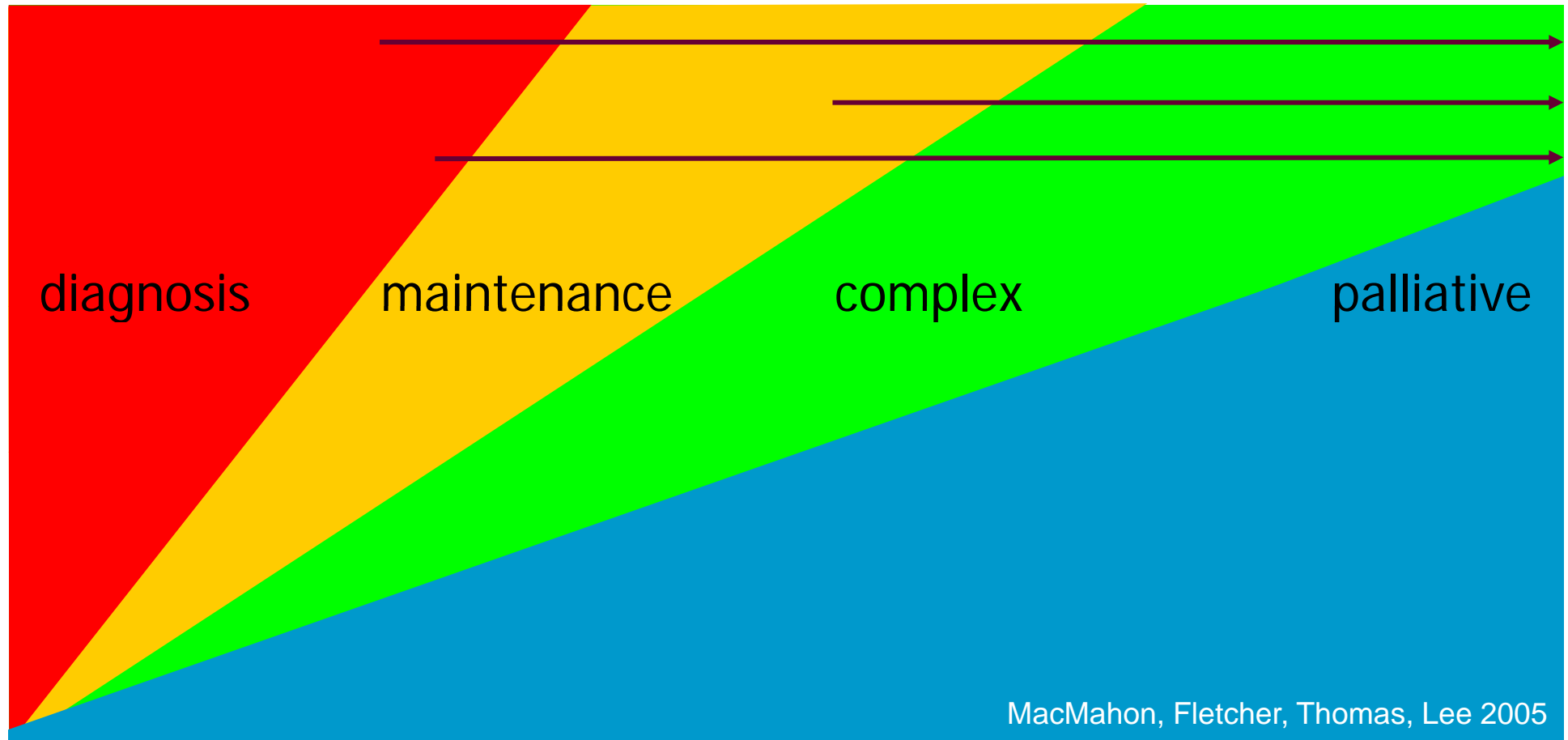
2006

2006

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All recognise the importance of Palliative Care

time course of the disease



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

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- NEUROLOGY CAN DEVELOP AN UNDERSTANDING OF THE PRINCIPLES OF PALLIATIVE CARE AND INCORPORATE THESE INTO PRACTICE.....
- PALLIATIVE CARE CAN DEVELOP AN UNDERSTANDING OF THE NEUROLOGICAL DISEASES AND THEIR TREATMENTS.....
- AND TOGETHER WITH REHABILITATION THEY CAN WORK TOWARDS THE BETTER MANAGEMENT OF SYMPTOMS (PHYSICAL AND PSYCHOSOCIAL) FOR PEOPLE WITH NEUROLOGICAL CONDITIONS AND THEIR LOVED ONES/CAREGIVERS

Sharing the learning to date

- **Focus on Neurology October 2007.**
 - Survey of current services.
 - Pathway for meeting palliative care needs.
 - Working to ensure coordination of services.
 - Tools for enabling good practice
- **RCP Concise Guidance**
- **Working with Neurology nurse specialists**
- **Comorbidity**

CONCEPTS OF 'NPR'

Disease

Impairment

Disability/Activity/Capacity

Handicap/Participation/Performance

Satisfaction

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