

**Identifying when people with
neurological conditions
requires palliative or end of life
care**

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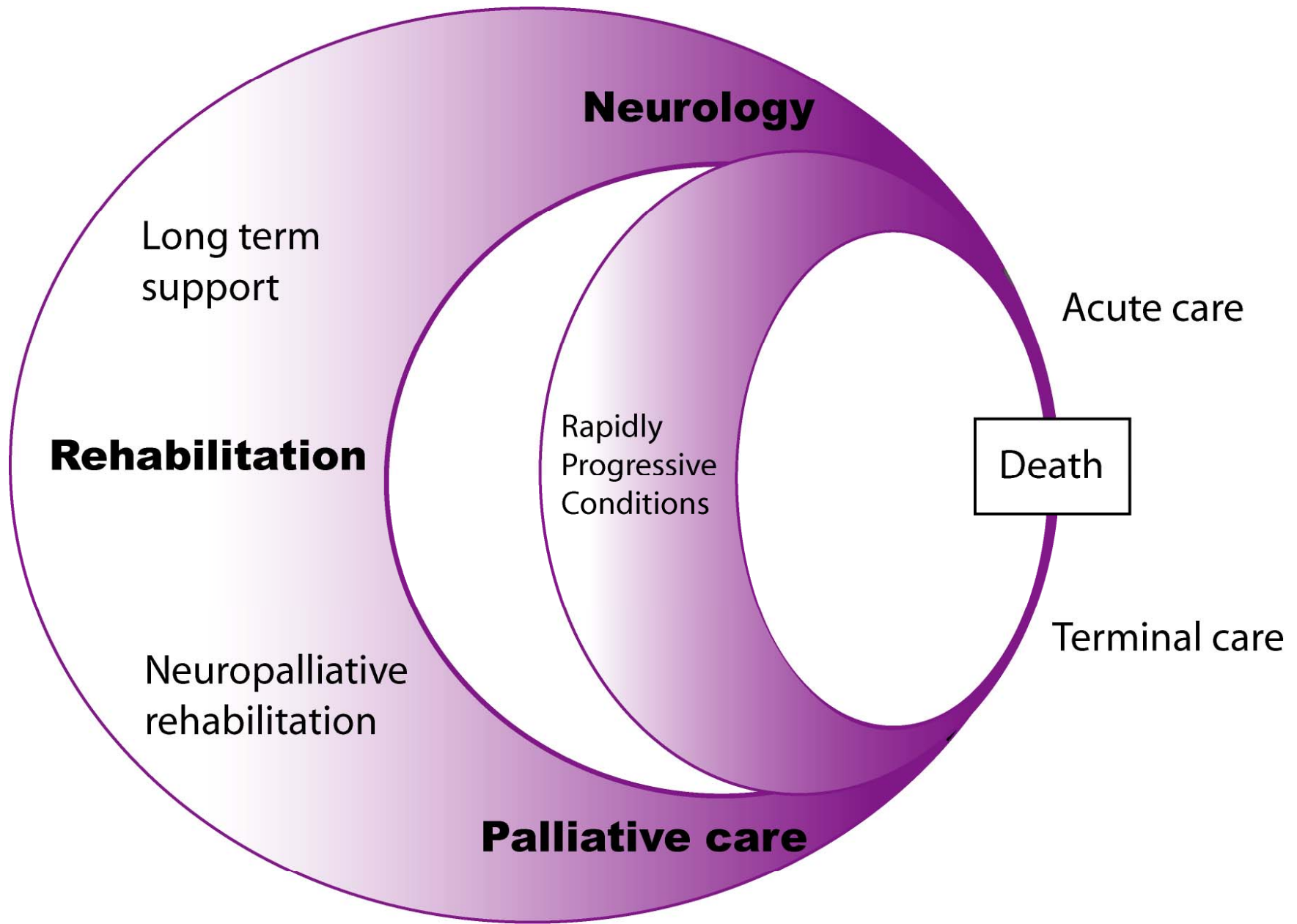
Structure

- Trajectories
- Identifying those nearing the end of their lives
- End of life issues
- The role of Specialist Palliative Care
- The Sunderland experience



Natural history

- MND 2-4 years
- PSP 5-7 years
- MSA 6-9 years
- IPD 10-30 years
- MS - overall only 7-10 years less than population. Significantly worse in severely disabled patients.



Palliative care

Palliative care is defined as:

“**an approach** that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”
(WHO 2002)

So...

- Palliative care is a core medical skill (aka general PC/ supportive care)
- Palliative care is what you do everyday when dealing with neurological patients
- Specialist PC may not be required by all patients

How do we identify those who may be nearing the end of their lives?

Prognostic indicator guidance (GSF)

3 triggers to help IDENTIFY, ASSESS, AND PLAN

- **The surprise question:** “*Would you be surprised if this patient were to die in the next 6-12 months?*” – an intuitive question integrating many factors
- **Choice/need:** They make a choice for *comfort* care or is in *need* of PC
- **Clinical indicators:**
 - General indicators: wt loss; co-morbidities; general decline; decreased albumin; increasing dependence.

MND - GSF

Indicators of rapid deterioration:

- Evidence of disturbed sleep related to respiratory muscle weakness in addition to signs of dyspnoea at rest
- Barely intelligible speech
- Difficulty swallowing
- Poor nutritional status
- Needing assistance with ADLs
- Medical complications (eg pneumonia/ sepsis)
- A short interval between onset of symptoms and diagnosis
- A low vital capacity (eg below 70% of predicted)

IPD - GSF

The presence of 2 or more of the criteria should trigger inclusion on the PC register

- Drug treatment is no longer effective/ an increasingly complex range of drug treatments
- Reduced independence, need for help with daily living
- Recognition that the disease has become less controlled with less predictable “off” periods
- Dyskinesias, mobility problems and falls
- Swallowing problems
- Psychiatric signs (depression, anxiety, hallucinations, psychosis)

MS - GSF

Indications of deterioration and inclusion on the register are:

- Significant complex symptoms (eg pain)
- Communication difficulties (eg dysarthria +/- fatigue)
- Cognitive difficulties
- Swallowing difficulties/ poor nutritional status
- Breathlessness +/- aspiration
- Medical complications (recurrent infections)

Common ground regarding prognosis in neurological conditions

- Swallowing issues
- Breathlessness – aspiration pneumonia
- Communication issues
 - Cognitive impairment
 - Speech
- Complex symptoms
- Reducing therapeutic options

What are the end of life issues?

- Symptom control
- Communication
 - Speech
 - Cognitive impairment
- MCA
 - Advanced statements
 - Advanced decisions
- Advanced care planning (ASAP)
 - GSF/ PPC/ LCP

What is the role of Specialist
Palliative Care in IPD?

NCPC neurology working group guidance

Consider Specialist Palliative Care Referral (after MDT discussion) and when:

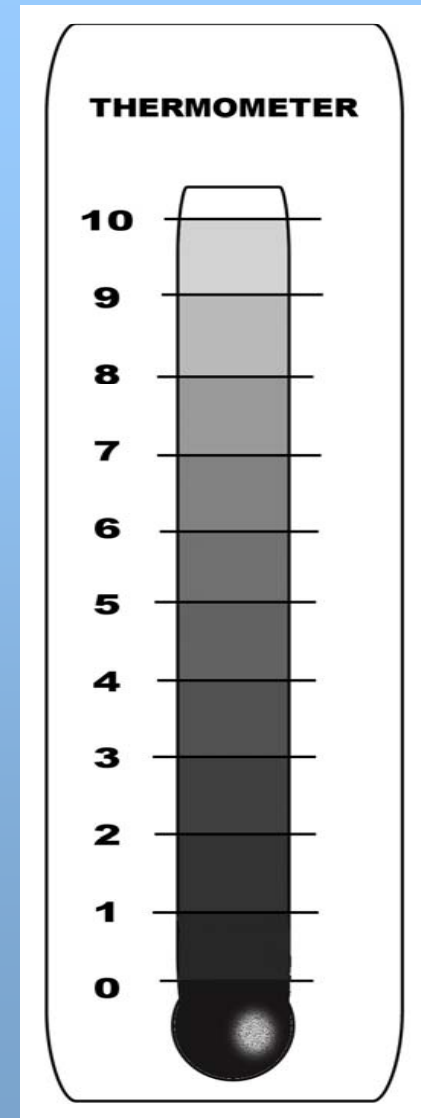
- There are intractable symptoms causing suffering, especially pain but also nausea or breathlessness.
- Difficulties with care coordination / management of complex needs.
- Lifespan is likely to be limited.
- Issues of communication and competence.
- There is a need for care planning, advanced decisions.

The Sunderland experience

- Education
 - Journal club
 - Communication skills (MDT)
- Referral of PSP/MSA/ and advanced PD to Specialist PC for assessment
 - OP
 - Day unit
 - Advanced Care Planning
 - Capacity
- Patient Journey Meeting
 - MDT discussion re: implementation of NSF
- MDT

Management

- Symptom control
- Distress tool
- ACP
 - Preferred Place of Care
 - DNAR
 - PEG



RE - IPD

- **Referral:** distraction therapy for pain; get out of house; respite; ACP
- **Distress Tool (4/10)**
 - Depression/ fears/ nervous/ future issues
 - Loss of faith/ relating to God/ lack of purpose
- **PPC** (faxed to primary care team + NH)
 - “the illness is slowing me down”
 - “I think I’ll get worse”
 - “I would like to be cared for in SBH at the end of my life”
 - Would like to talk about funeral arrangements

JW: PSP

- **Referral:** physio; respite for wife; housebound; ACP
- **Symptoms**
 - Drooling – titrating glycopyrronium 200mcg tds oral
- **Distress Tool (6/10)**
 - Fatigue
 - Nervousness/ anger/ loss of interest
 - transport
 - Loss of faith/ difficulty relating to God
- **PPC/ future issues**
 - “Getting worse day by day”
 - Knows he is dying
 - He would like to be comfortable and at home

JW: IPD

- **PPC**

- “I want to die in the hospice, my mum and dad died here. My husband is aware. My second choice would be at home with support, I don't want to go into the Royal”

“Palliative care professionals do not have a monopoly on caring, and we and our colleagues in other disciplines have much to learn from each other as we focus together on enabling and facilitating the changes which will lead to better palliative care for all”

Derek Doyle