

Meeting the Palliative and End of Life Care Needs of People with Neurological Conditions

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Outline

- How do neurologists work?
- Which neurological conditions may require palliative care?
- Neurological nursing
- What can specialist palliative care provide? MS as model

What do neurologists do?

- Neurological problems are common
 - 20% of GP consultations
- Most are managed by non-neurologists
 - Pharmacy / GP
 - General Medics / Geriatricians (Stroke / Parkinson's)
- Despite seeing a minority of patients we have an important role
 - Difficult / complicated cases
 - Teaching

Neuro ward

Admitted to hospital

See a neurologist

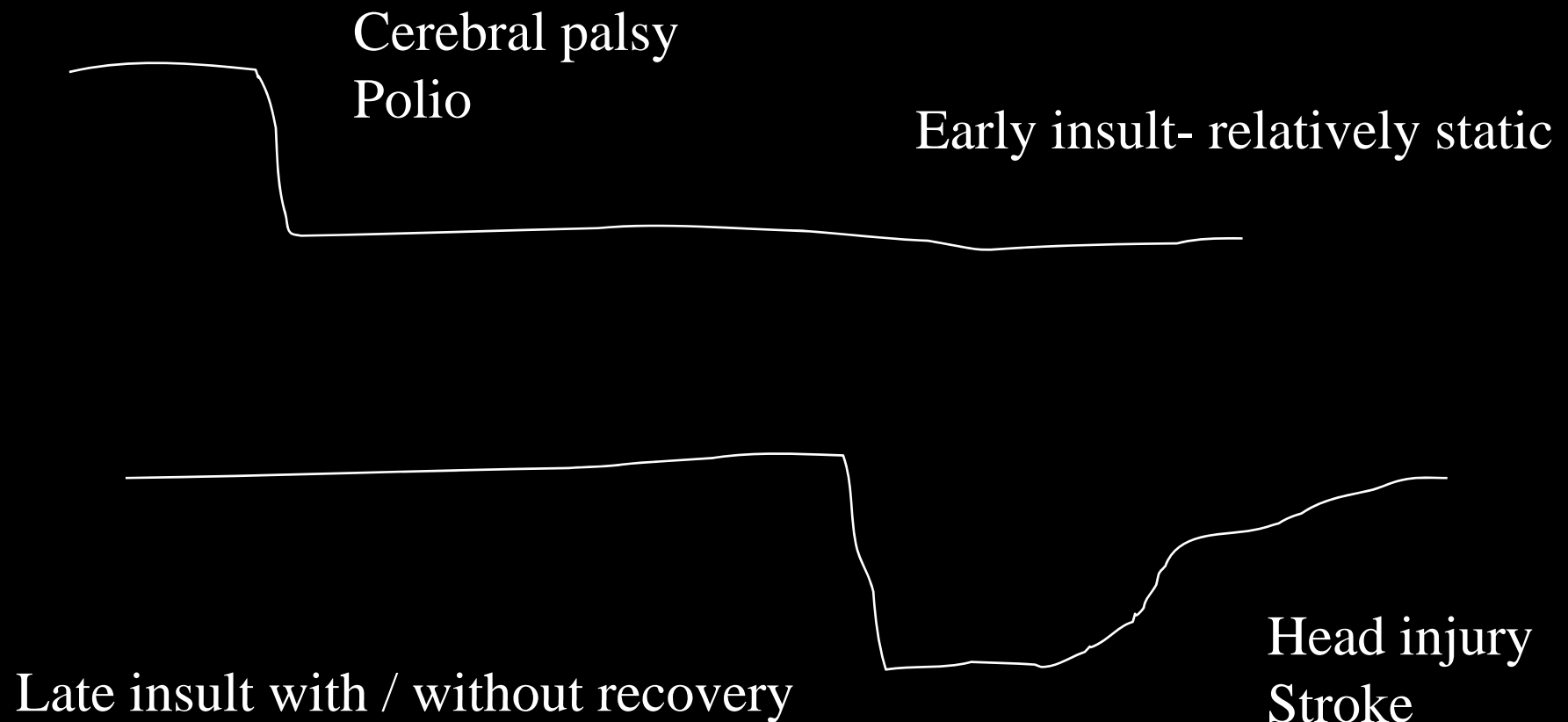
See a doctor

Neurological problems

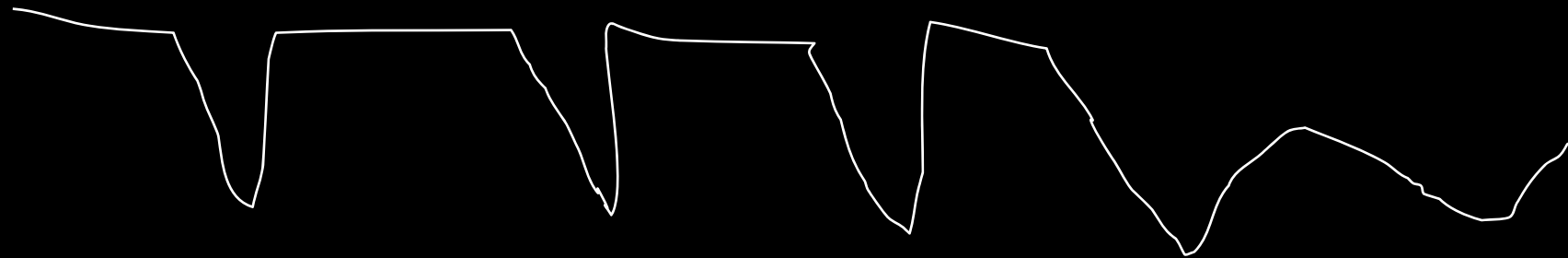
Mental health and neurology

- Chicken or egg
- Is the problem a result of the disease or the disability
- Freud started off as a Neurologist!
- Medically unexplained symptoms vs. mental health problems as a component of the disease.

Patterns of neurological conditions 1



Patterns of neurological conditions 2



Relapsing with / without later progression

Epilepsy

MS

Psychiatric conditions

Progressive

Progressive MS

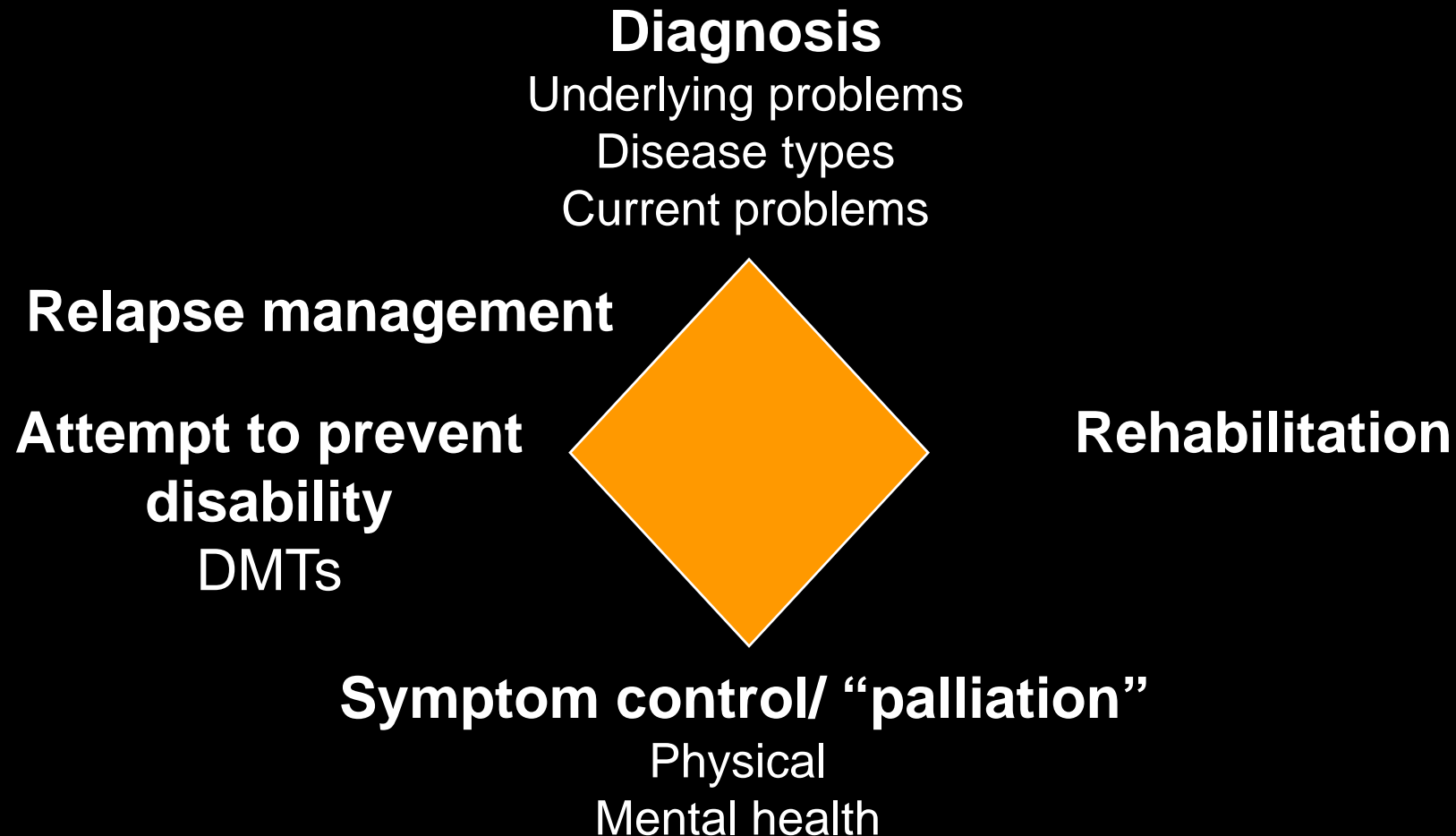
MND

Parkinson's

MSA / PSP

Alzheimer's

Our roles: Where do we fit in?



What does my clinical job consist of?

Outpatient neurology

"Kissing frogs" - the worried well
Many unpleasant but not dangerous
"In the head" thus anxious
18 weeks

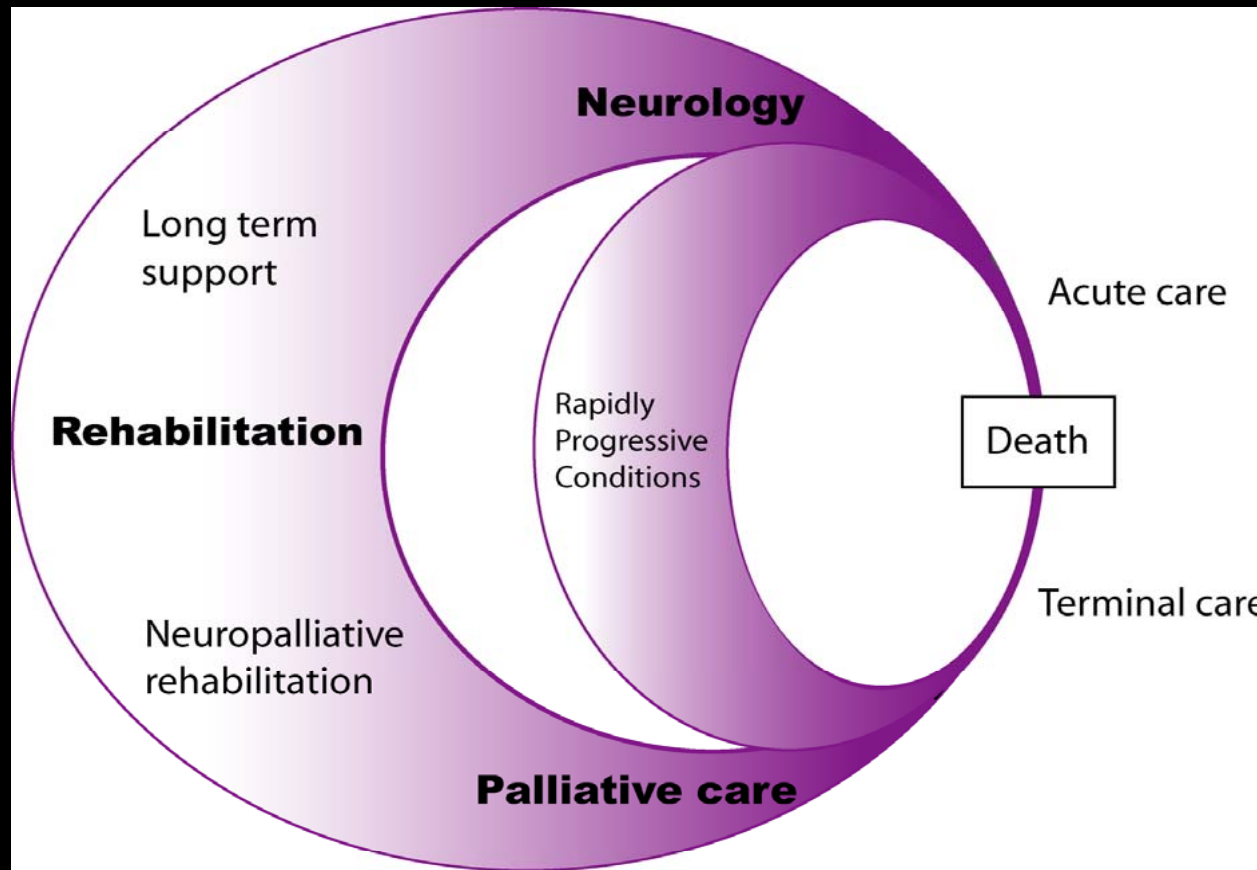
Inpatient neurology

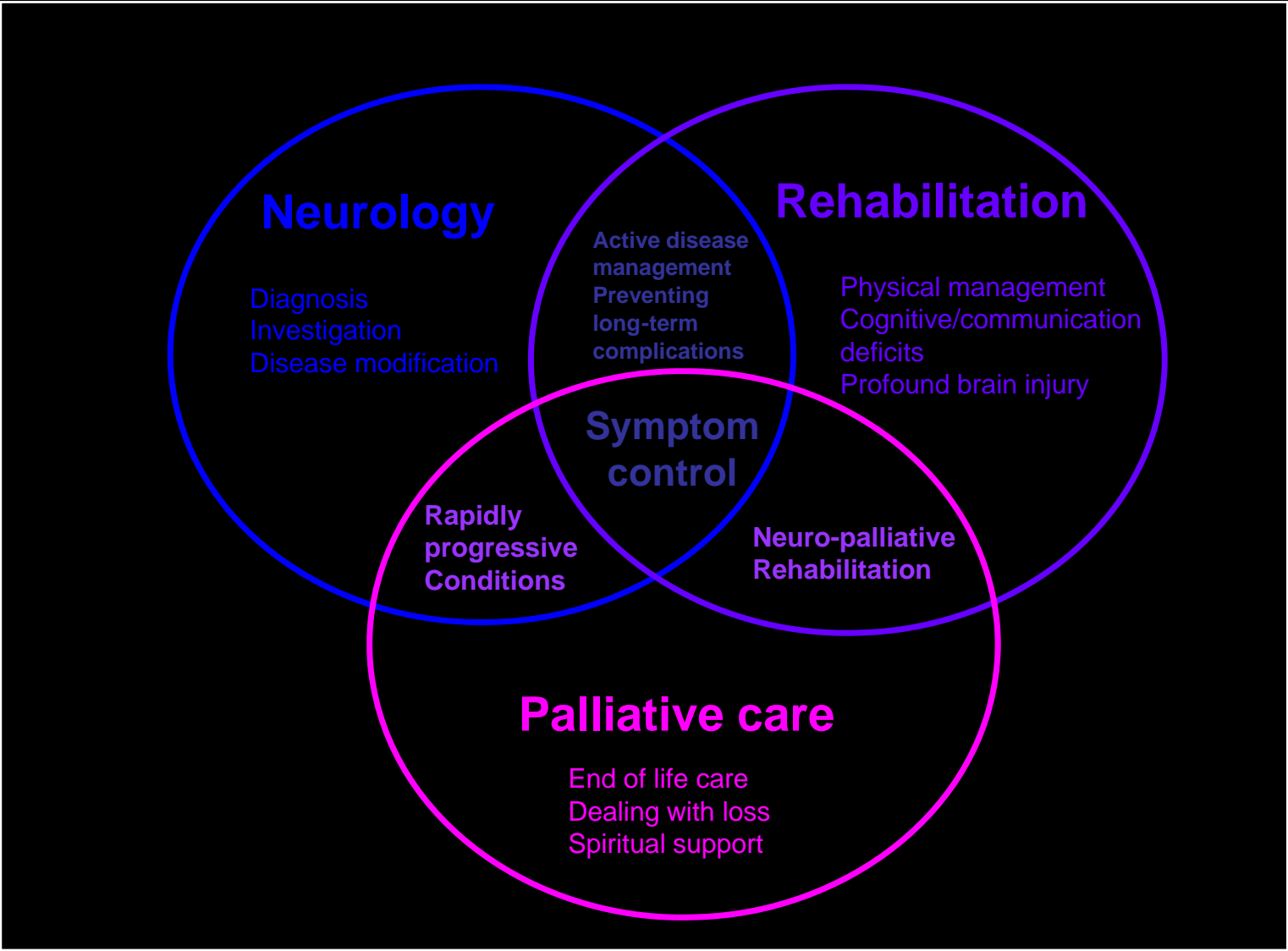
Complicated diagnosis
Some treatable
Consultation service

Chronic disease management

Prevent disability
Manage complications
Team

"Life circles": the relationship of neurology, rehabilitation and palliative care for people with long term neurological conditions





The environment has changed to a brave new world

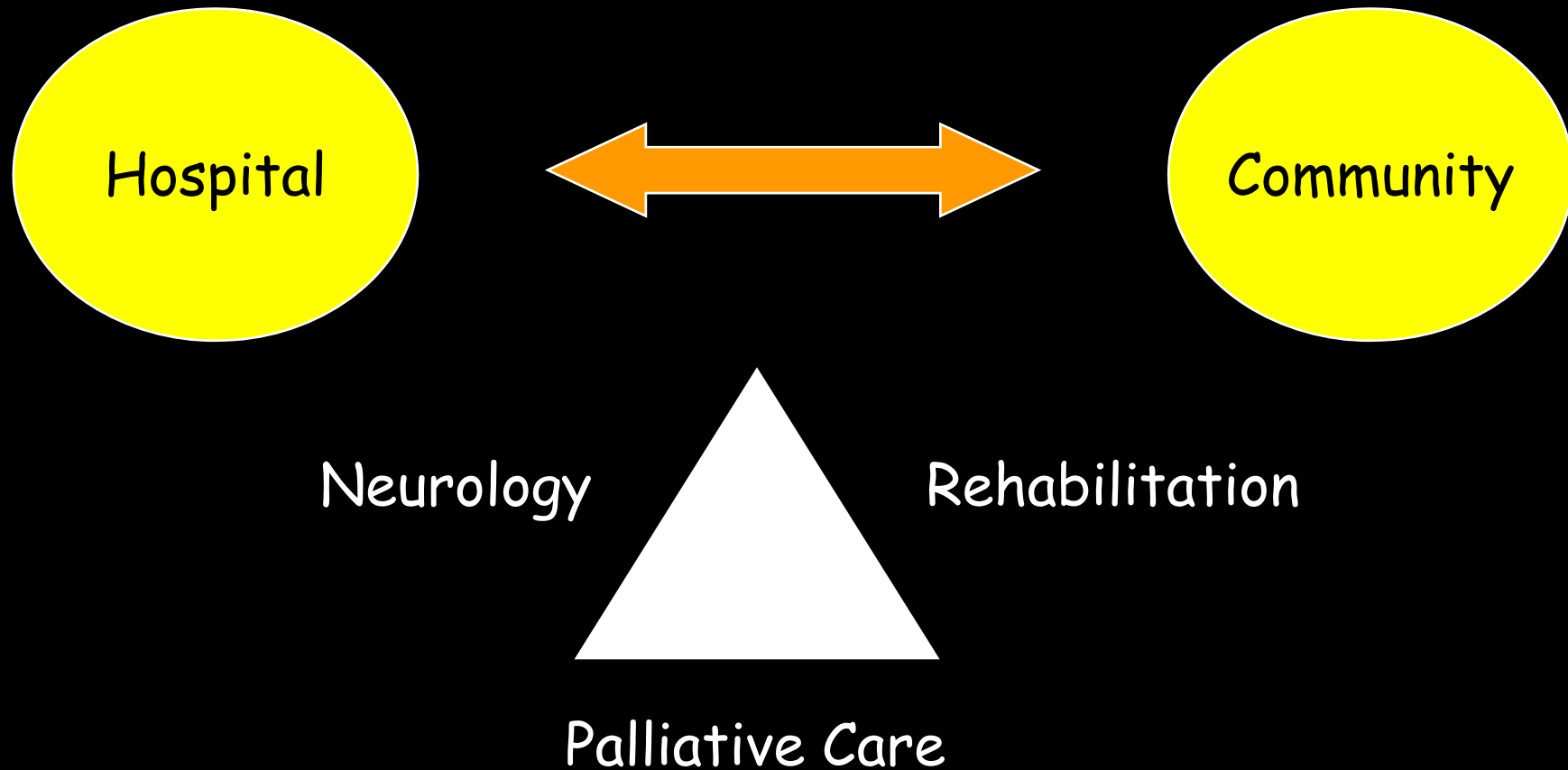
"OLD"

- NSF long term conditions
- NICE guidance
- Team

"New"

- 18 weeks- completing new episodes
- "Choice"- Fragmentation
- Competition between trusts / PCT and trust

Caring for people with advanced disease



What is good about nurses?

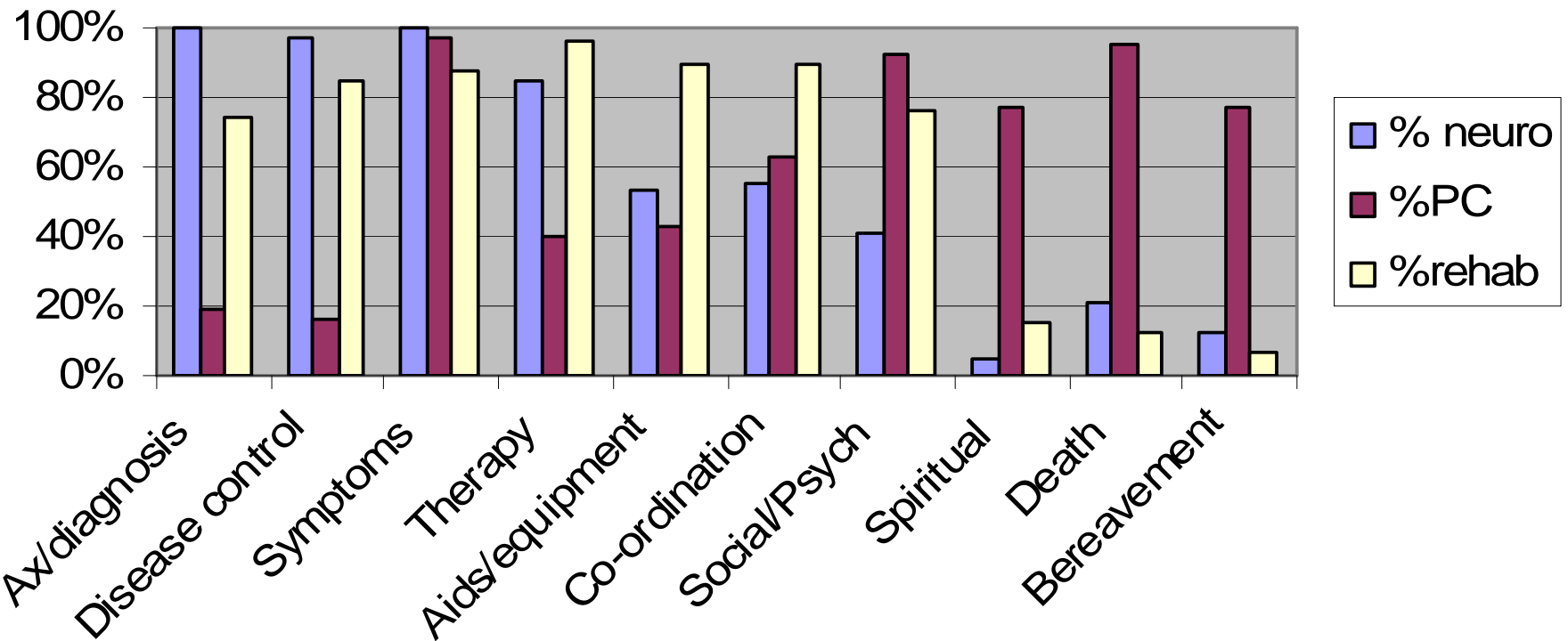
- **Numbers**
 - Lots! Widespread
- **Skills**
 - Can learn anything
 - Breadth or depth
- **Flexibility**
 - Work patterns
 - Hospital and community
 - Skill sets

Which nurses?

- **Specialist neurology nurses**
 - Hospital or community based
 - Wealth of experience
 - 300-500 case load
 - Link to consultant / specialist services
- **Other specialities**
 - e.g. continence
- **Community matron**
 - Community based / link to community teams / GPs
 - Smaller case load "complex cases"
- **Hospital nurses**

Who does what?

Core elements of your service



The MS Team

Doctors

GP

Neurologist

Rehab

Psychiatrist

Nurses

Ward / MS

Continence

District

Therapy

Physio, OT

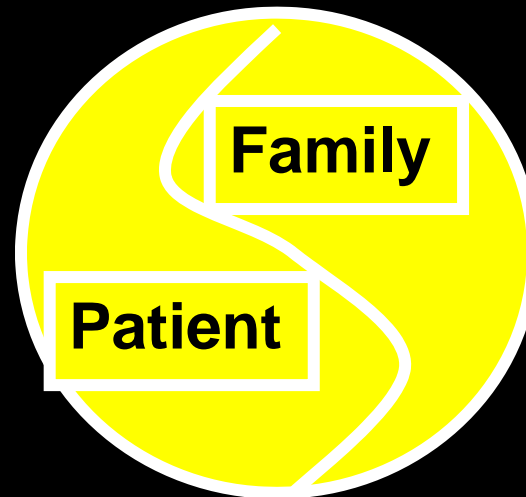
Speech / wheelchair

Extended family
/ friends

Support
organisations

Work

Social services/
professional carers



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%

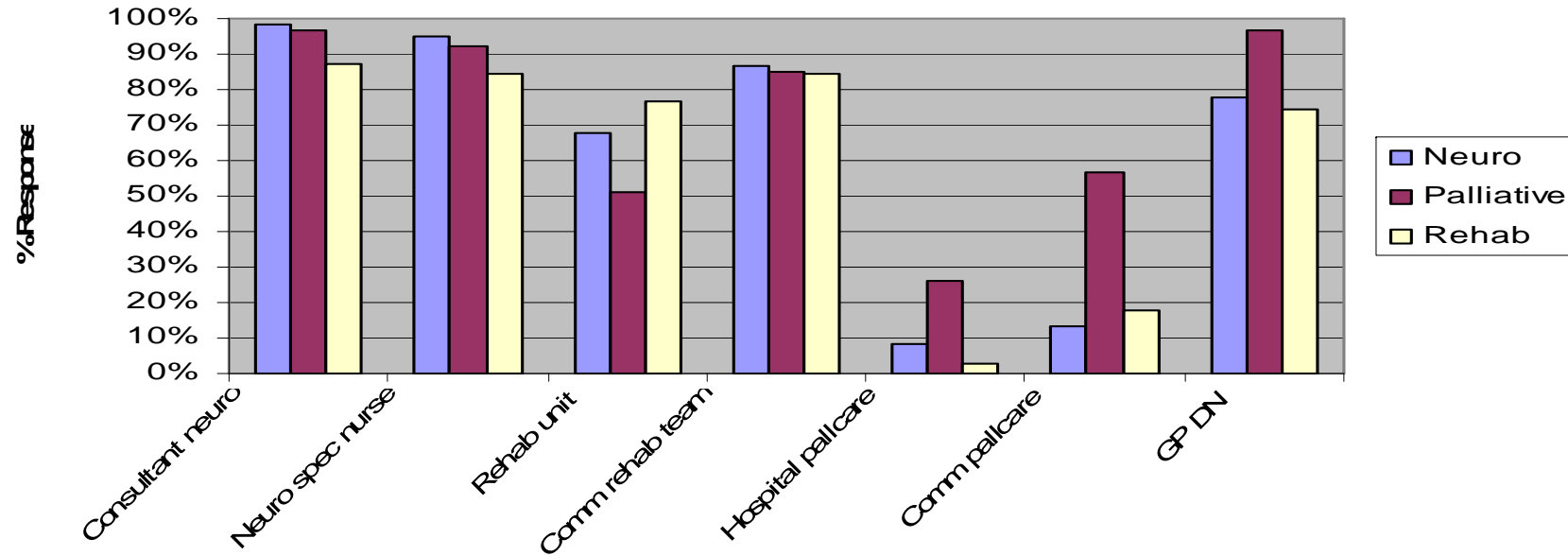
¹ King's study - % with symptom

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

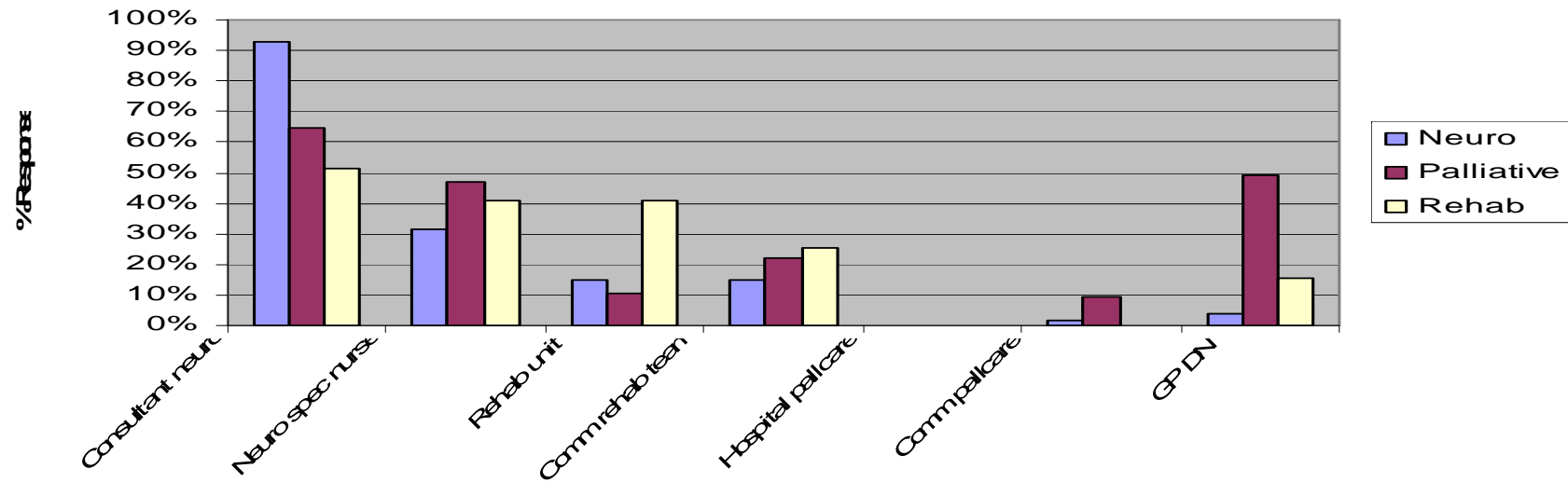
Multiple Sclerosis Scenario

A 25 year old nurse was diagnosed with relapsing remitting multiple sclerosis 18 months ago. She has had three severe relapses and is currently requiring a wheelchair indoors. She is depressed, has severe neuropathic pain and has a urethral catheter for incontinence.

Which Professional Should Be Involved in Care



Which Professional Should Take the Lead



Research Question:

Can the needs of people severely affected by MS be met by a Palliative Care Service?

3 year research project funded by MS Society:

- Service modelling study
- Development of a new clinical service
- Evaluation of the service

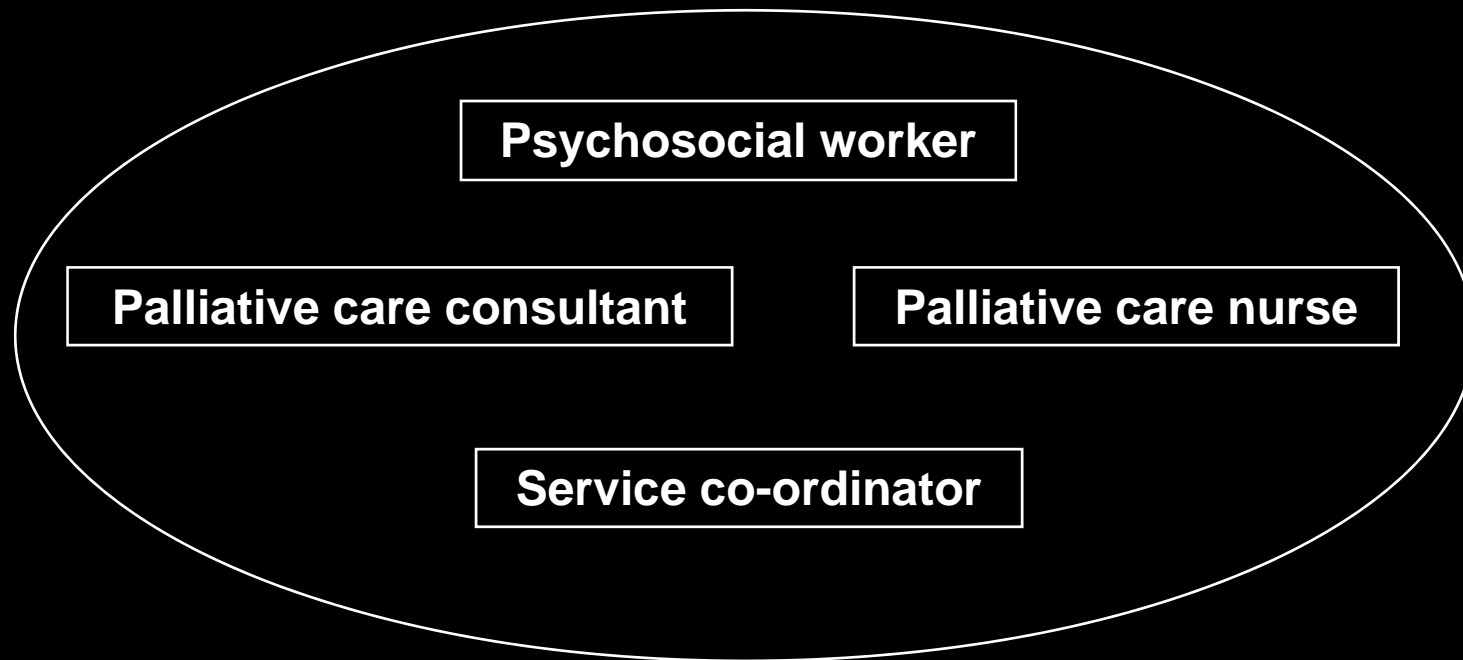
Key Issues Arising From Patient Interviews

- Loss and change
- Support needs: emotional and practical
- Information needs: services, aids and adaptations, benefits, end-of-life planning
- Symptom control
- Care issues: co-ordination, continuity, inpatient care

Key Issues for Service Development

- **Clinical Service**
 - Improving gaps in continuity of care & communication
 - Symptom control
 - Complex psychosocial support
 - End of life care planning
- **Information**
 - Mapping existing services
- **Education**
 - Information exchange between professional groups

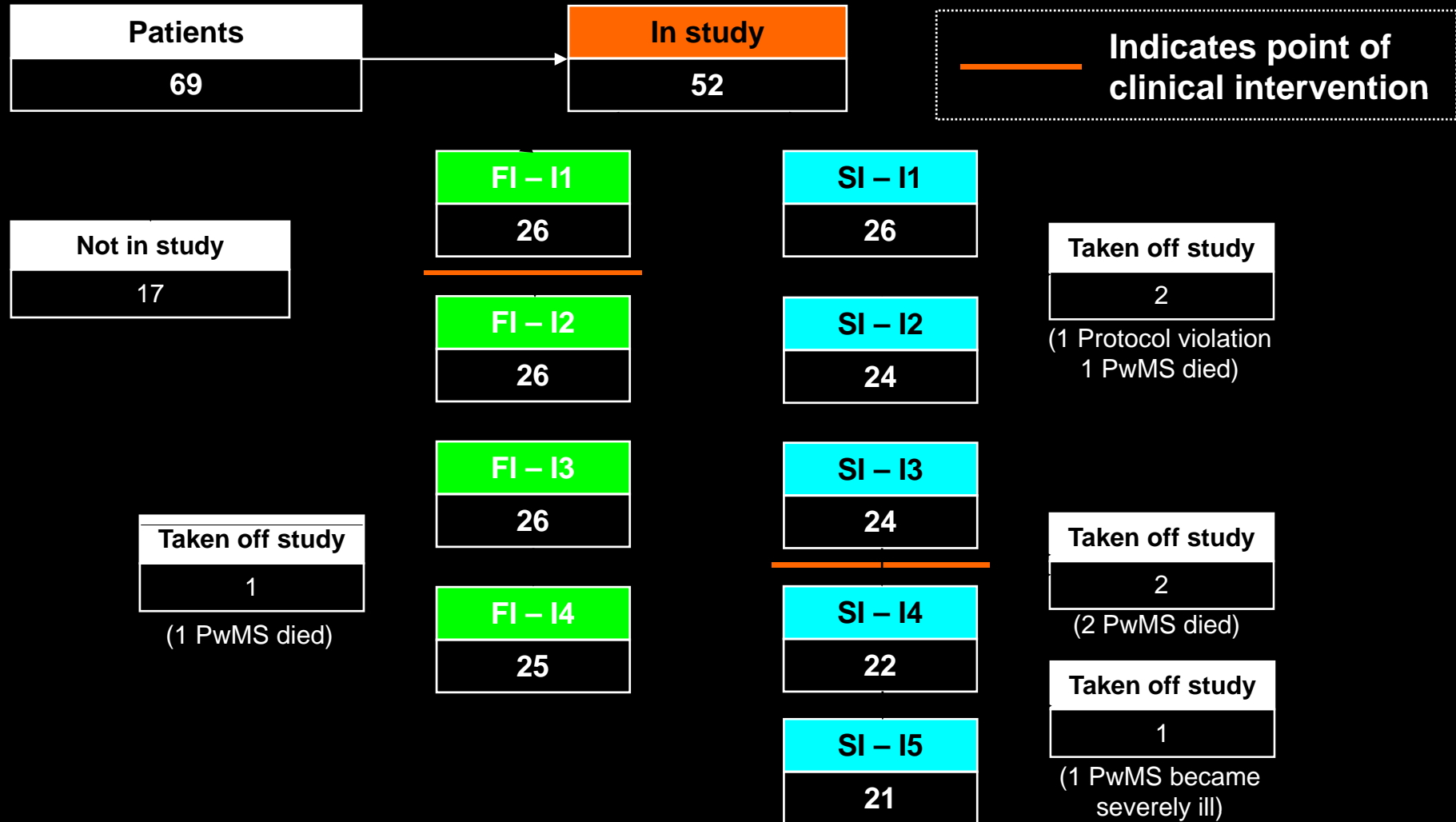
Palliative Care Service for PwMS



Reasons for referral

- Symptom management
- Psychosocial needs
- Competence and consent
- Hydration and nutrition
- Advance directives/ end of life decisions

PwMS included



25 pre study as well!

Differences at 4-6 weeks

- PwMS in FI group had small but significant improvement in nausea compared to SI group ($p=0.039$)
- PwMS in FI group more likely to have seen a paid carer more recently than in SI group ($p=0.018$)

What does palliative care do well?

- Sees someone more quickly
- Cover hospital, home, community
- Nursing teams, hospices
- Not limited by waiting lists, huge clinics...i.e. can devote more time to specific patients
- Not scared of death, families, distress...
- Experience with opioids, end of life issues

How did my patients benefit?

⇒ We identified a neglected group with specific and complicated needs

⇒ Symptom control. There are areas we can do better:

- Pain, nausea, constipation

⇒ Care coordination

⇒ Holistic care

- Death and dying (we are scared of this)
- Autonomy / Existential issues
- Family carer needs

If palliative care takes on neurology patients we may need new models of working

- With existing teams
- One off and intermittent care rather than ongoing care
- More knowledge and experience in neurology

Palliative Care Service: Lessons

- Need to integrate with local services (Neurology and rehabilitation)
- Short term interventions by specialist palliative care may help with specific issues but does not replace key role of team
- Need for more integration and liaison between pall care and neurology services to promote appropriate care for those that are severely affected
 - Only a minority of patients seen by palliative care service identified as having ongoing specialist palliative care needs

"Life circles": the relationship of neurology, rehabilitation and palliative care for people with long term neurological conditions

