

Shared decision making in advanced MS and palliative care

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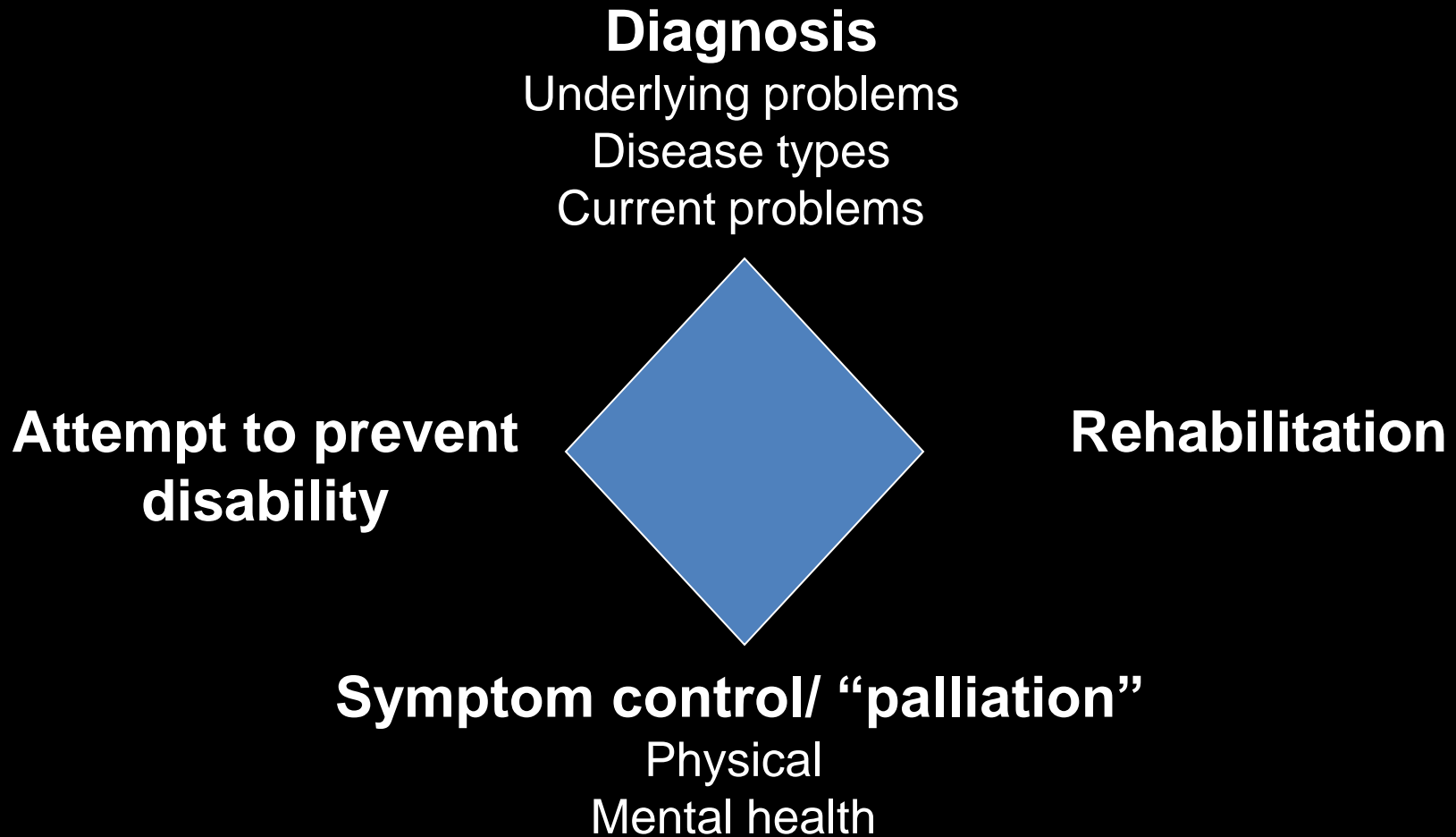
1. Role of PC (palliative care) in MS care : Prognosis in MS

- Balancing hope and despair
- Progression happens early
- Causes of death
 - Suicide (euthanasia)
 - Complications of chronic disability: infections, pressure sores, nutrition problems, respiratory problems (aspiration)

"The silent face of MS"

- Emphasis on early diagnosis and therapy
- Difficulty accessing specialist services
(varies between countries/ areas)
- Physical access
- Cognition and communication
- Family support
- Care homes / community care limited skills
- As out patients survive to older ages they develop other diseases e.g. cancer

Our roles: Where do we fit in?



Comparison of advanced MS 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.

In general

- MS is incurable from diagnosis : no clear cut-off between curative – palliative phase. Danger = waiting (too long) for terminal phase to discuss palliative and end-of-life issues.
PC experts can help doctors and teams to address these issues in time.
- MS can be progressive = continued experience of loss/mourning process : care for existential problems should be addressed as soon as they emerge.
PC is expert in this matter and can be involved in existential crisis situations (even in early phases).



Similarities

Conventional PC

- Disease progression
 - Discomfort
 - Experience of loss
- Threatened QoL
- Terminal care
- Bereavement support

MS PC

- Disease progression
 - Discomfort
 - Experience of loss
- Threatened QoL
- Terminal care
- Bereavement support



Differences

Conventional PC

➤ Existential problems:
different perspective:

- restricted life span
- more predictable disease course

MS PC

➤ Existential problems:
different perspective:

- almost intact life span
- unpredictable disease course
challenging for continuous
mental adaptation



Differences

Conventional PC

- Clear cut-off curative - palliative phase (in most cases)
- Certain shortened life span
- Barrier for PC is becomes lower in time nowadays



MS PC

- No clear cut-off curative - palliative phase
- Occasional (uncertain) shortened life span
- Barrier to referral to PC in MS is higher then in cancer!



Differences

Conventional PC

▶ Shorter time span of care:

- *Advantage :*

- Quality and intensity of care input and support is needed for a shorter time.
- Perspective of family: unbearable situation but for a short time. ...

- *Disadvantage:* less time for building a relationship of trust, ...

MS PC

✓ Longer time span of care:

- ✓ *Advantage:* knowing pt and families well = more time for building a relationship of trust, ...

✓ *Disadvantage:*

- ✓ Keeping teams creative and motivated in continuously looking for better comfort and support options
- ✓ Families can also burn out.
- ✓ ...



Differences

Conventional PC

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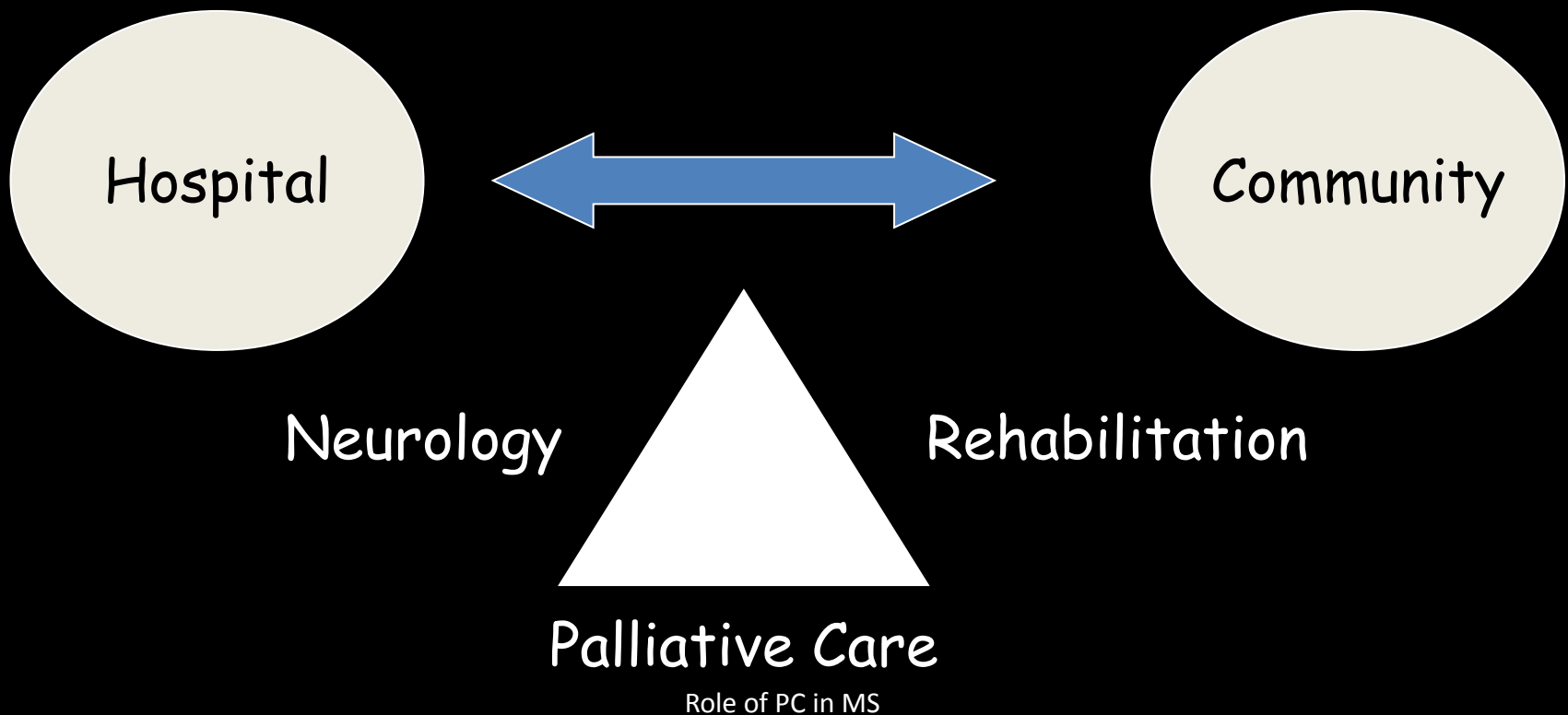
- ▶ Last days and weeks in a *nice environment* with special attention to create a home atmosphere
- ▶ Higher quota for staff – more resources.

MS PC

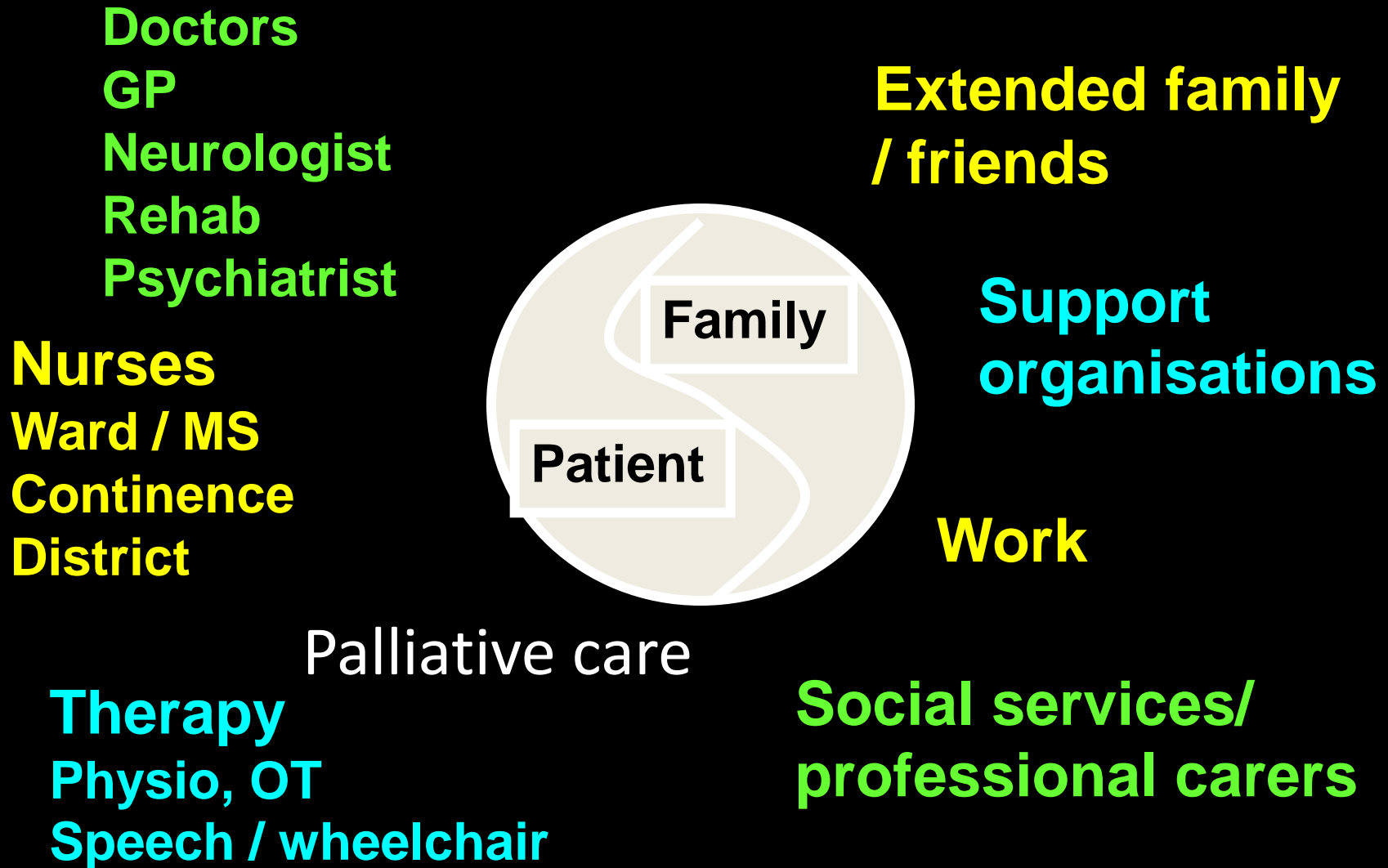
- ▶ Cognitive problems creating changes in relationships with family, carers, team + specific problems in assessing pain, anxiety, QoL.
- ▶ *Standard* hospital or MS center *setting* – living longer in a less nice environment!
- ▶ Standard quota for staff
- ▶ Resources!!



Creating partnerships: Caring for people with advanced disease involves a balance



The MS Team



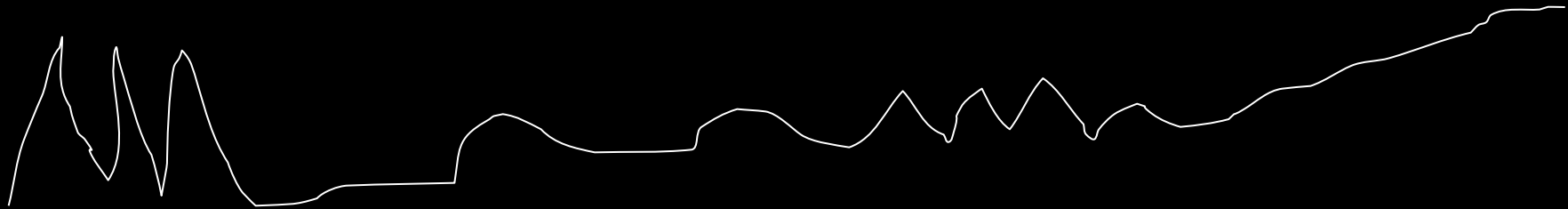
What is good about nurses?

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

Which nurses?

- Specialist MS neurology nurses
 - Hospital or community based
 - Wealth of experience
 - 300-500 case load
 - Link to consultant / specialist services
- Community matron
 - Community based / link to community teams / GPs
 - Smaller case load “complex cases”
- Hospital nurses
- Palliative nurses
- Other specialist nurses: Mental health, continence

Different models of working



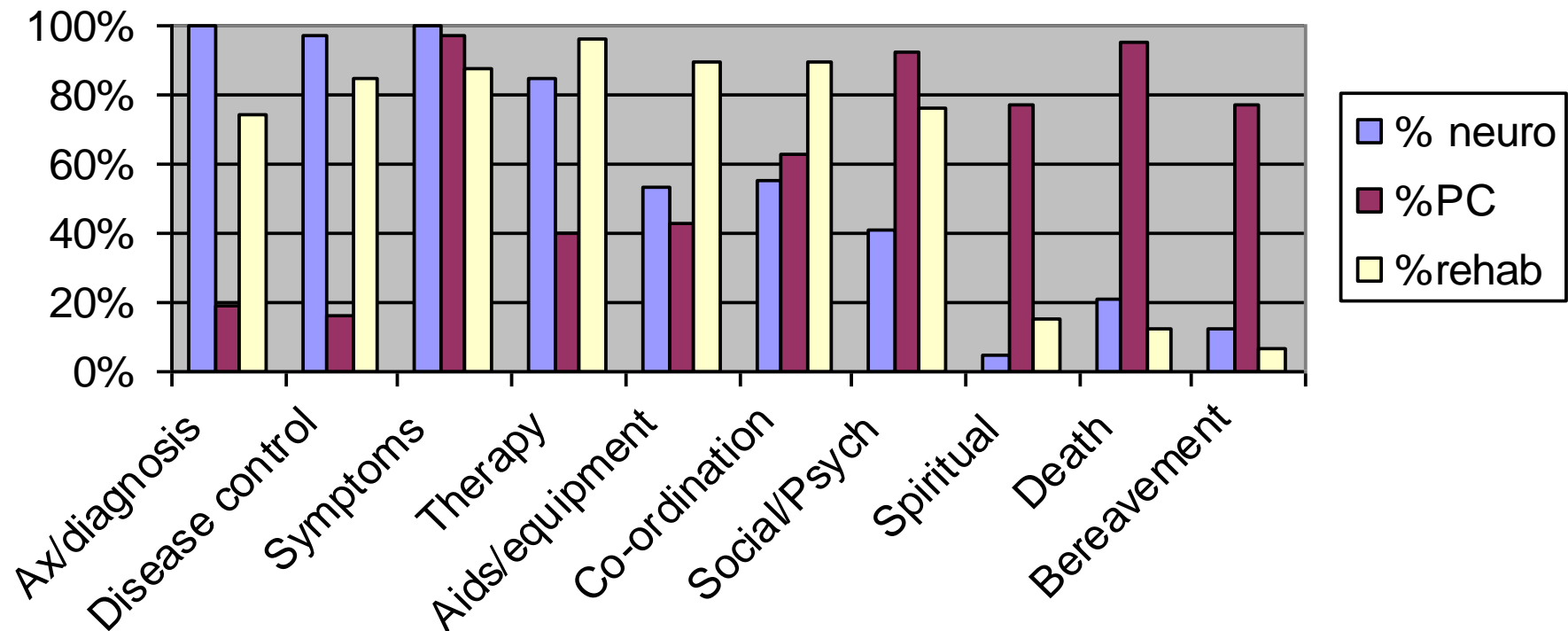
Neurology : Diagnosis, review, crisis management, progression



Palliative care: intense over shorter time with bereavement

We asked neurologists, rehabilitation specialists and palliative care consultants about core elements of their service.

Core elements of your service



End of life support

- Provided by:
 - 100% palliative physicians
 - 73% neurologists
 - 53% occasionally, 20% often.
 - 60% of rehabilitation physicians
 - 47% occasionally, 13% often.

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

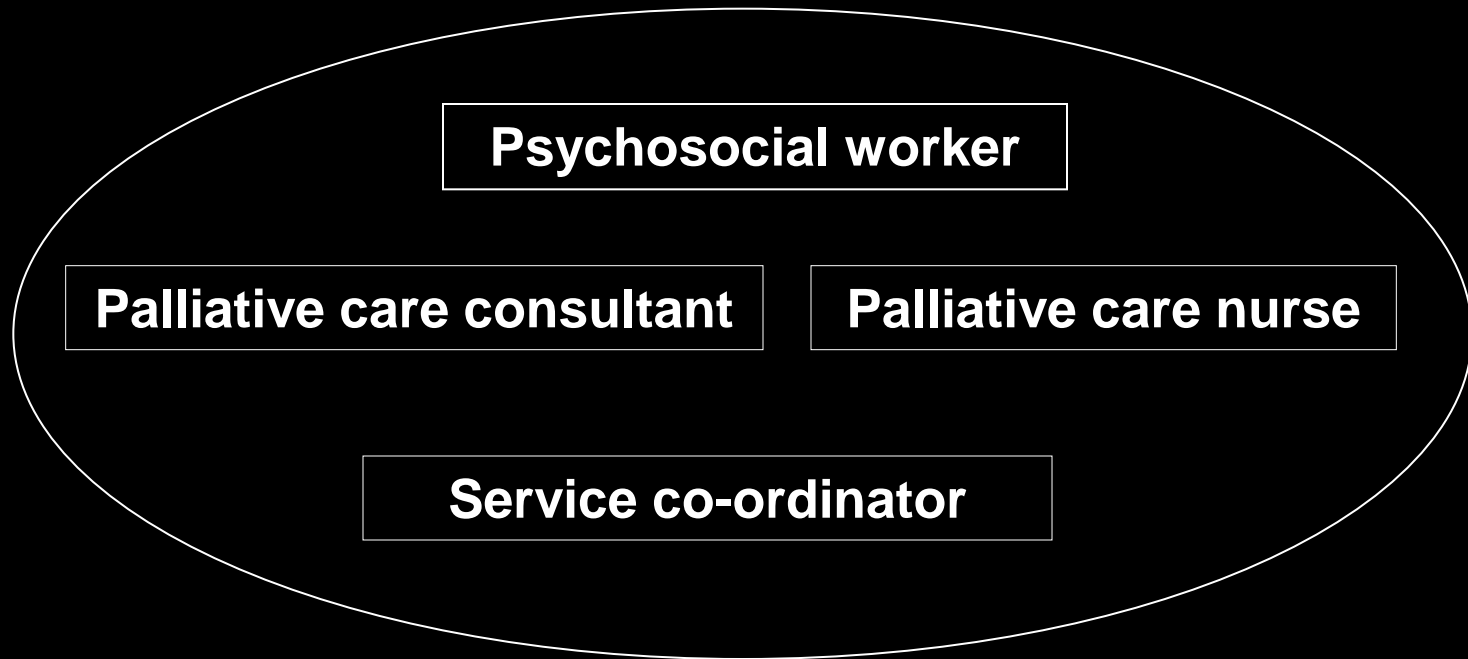
Key Issues Arising From Patient Interviews

- 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

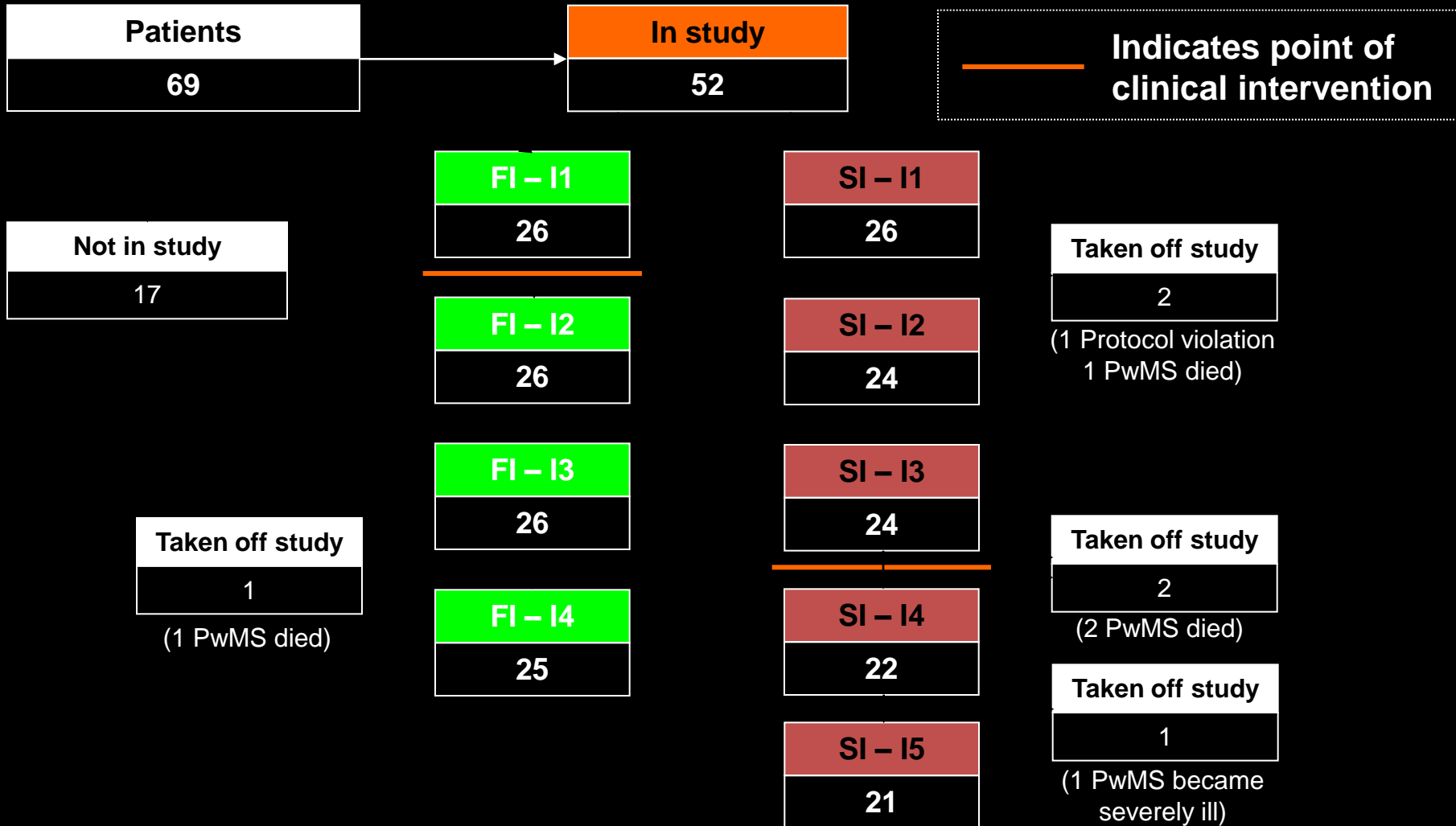
This led to Service Development

- **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



PwMS included



25 pre study as well!

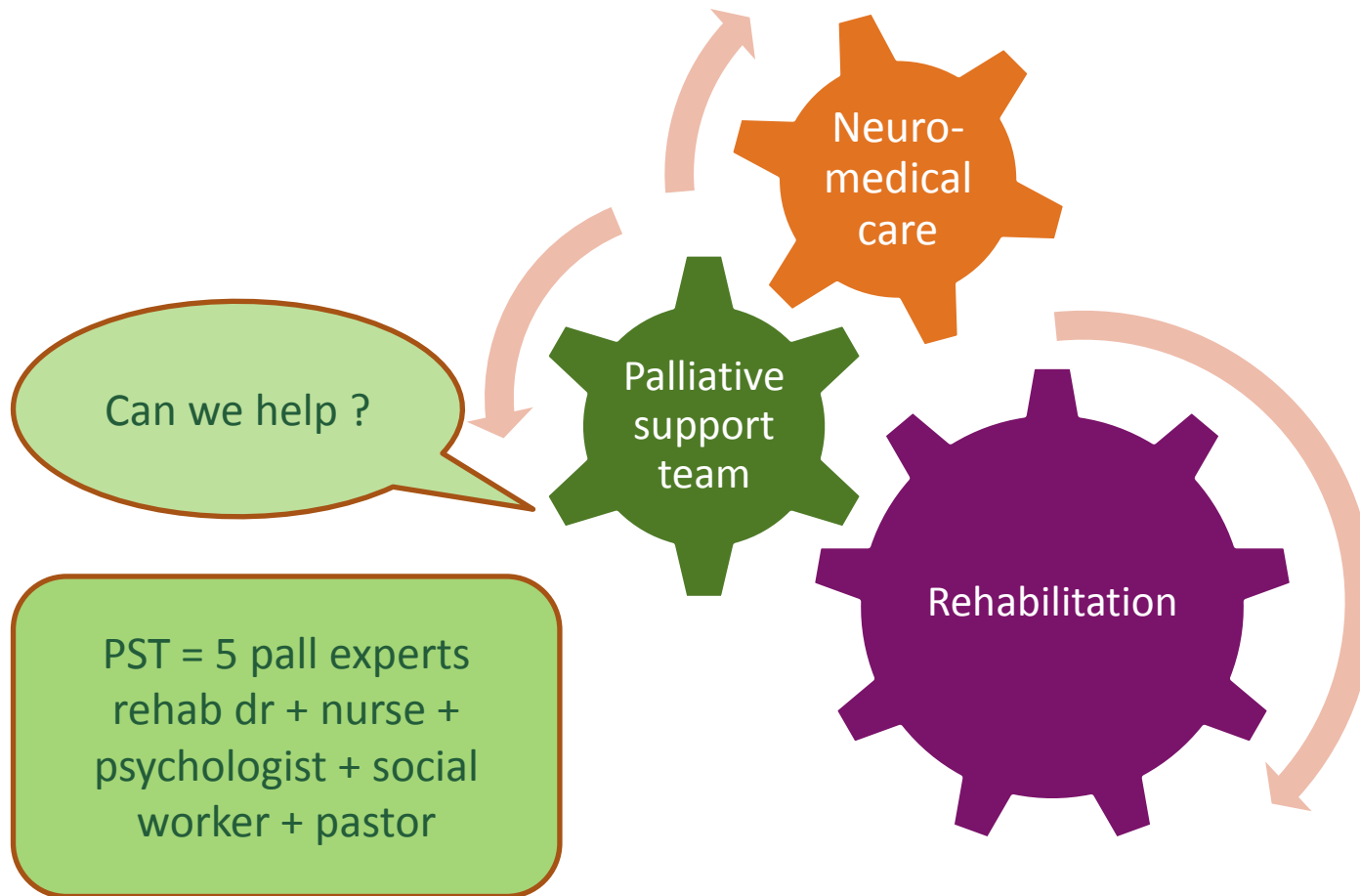
Triggers for referral to MS PC

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 ($p=0.018$)
- Lower costs

How to realize this in Nat. MS Center Melsbroek?

PST = palliative support team!



Palliative support team in National MS Centre Melsbroek

- = input of palliative expertise in our integrated MS-care
- Advice in advanced pain and symptom control management (f.e. switch to step 3 on pain ladder, starting up morphine pump, treating dyspnea and anxiety,...)
- Information bank : counseling pts, relatives, teams on palliative care, end-of-life decisions, making a will, euthanasia, ...
- Teaching, coaching and advising teams in terminal fase challenges like
 - prioritizing in care (f.e. being able to stop regular care rituals if not helpful or wanted by patient, making team goals on this new (last) goals)
 - communication with/between pts and relatives
 - ...



Palliative support team in National MS Centre Melsbroek

- = input of palliative expertise in our integrated MS-care
- Complex psychological and social needs : existential issues, end-of-life decisions,...
- Bereavement support
- Euthanasia: ± 5 cases last years (1-2 in the center)
 - Information- bank for pts, relatives and team
 - Euthanasia-procedure in NMSC : 'palliative filter' = can PST add care options to relieve the suffering of patients asking for euthanasia
 - Counseling and supporting patient and relatives in the whole process
 - Team coaching and support (before, during, after): how to care for pt in the last days, how to deal with special requests of a patient, how to say goodbye,...



2. Triggers for input of palliative care in MS

- Not all patients with advanced MS need the expertise of PC-specialist!

1. Triggers coming from PATIENTS:

1. Expressing **dyscomfort**: advanced symptoms with insufficient response of conventional care (pain, anxiety,...)
2. Expressing **existential pain**, suffering and **disease fatigue**: e.g. only being able to receive care and not giving to others/contributing to the lives of others anymore.
3. Patient expressing **questions and wishes about advanced care planning**, palliative and/or **end-of-life issues** (incl. euthanasia).



Triggers for input of palliative care in MS

2 Triggers coming from RELATIVES:

1. Expressing **existential pain**, suffering and **disease fatigue**
2. Expressing **questions** on and bringing in ideas about **advanced care planning, palliative and/or end-of-life issues**



Triggers for input of palliative care in MS

3 Triggers coming from CARE TEAM:

1. Advanced symptoms with insufficient response of conventional care (pain, anxiety, ...)
2. Need for clear instructions about medical interventions in life-threatening situations with need for care decisions (artificial nutrition, referral to acute hospital, ventilatory support, ...)
3. Detecting signals of existential questions in a patient or relative
4. Suffering of the team: dealing with progressive loss and suffering, lack of contact with some patients (cognition and communication pbs), handling conduct disorders, ...



3. Symptoms needing palliative care input (1)

- ▶ Complex pain syndromes
- ▶ Dehydration and malnutrition in a severely disabled person
(esp. cognitively frail person) needing decisions on tube feeding
- ▶ Mouth hygiene problems (esp. in non-cooperative person)
- ▶ Severe respiratory problems (limited respiratory volume and weak cough strength) needing ventilatory support
- ▶ Anxiety and fear of dying (alone)
- ▶ Existential pain and fatigue: not being able to contribute anymore, only being able to be a receiver of care, feelings of meaninglessness,...



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

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
- Is palliative care willing, interested and capable of taking on neurology?

Symptom management- Concise Guidance

<http://www.rcplondon.ac.uk/pubs/content>

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CONCISE GUIDANCE TO GOOD PRACTICE

A series of evidence-based guidelines for clinical management

NUMBER 10

**Long-term neurological conditions:
management at the interface between
neurology, rehabilitation and palliative care**

NATIONAL GUIDELINES

March 2008



THE
NATIONAL
COUNCIL FOR
PALLIATIVE
CARE



Acute care:

"Swing your legs over the bed"



What happens
when our
patients are
admitted to
acute general
wards?

Chronic conditions in hospital: Checklist 1

- Prior to admission
 - Is it necessary? Can it be planned?
- On admission
 - Inform caring team
 - Check medication / equipment
 - Check competence

Chronic conditions in hospital: Checklist 2

- Review in hospital
 - Posture / spasticity / pressure sores
 - Anticoagulation
 - Bladder / bowels
 - Swallow / nutrition / Respiration
 - Cognition / depression
 - Pain
- If considering a procedure
 - ? Appropriate/ competent
- Prior to discharge
 - Appropriate for patient / family
 - Inform team/ arrange follow up

Chronic conditions in hospital: Checklist 2

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MENTAL CAPACITY ACT 2005

- In force since 2007
- Broad objectives:
 - To support adults with impaired capacity so that they can make decisions for themselves wherever possible
 - Where they cannot take decisions, to provide a protective framework for decision-making
 - To provide a framework for those who have to take and implement decisions
- Much attention has focussed on implementation and compliance
- Intended by government to deliver cultural change

MENTAL CAPACITY ACT

Principles

- Capacity
- Autonomy (including the opportunity to make decisions which health professionals disagree with)
- Voluntary process
- Best interest for the individual
- Future planning
- The role of proxy in supporting decisions
 - Lasting power of attorney
 - Court appointed

MCA: FIVE UNDERLYING PRINCIPLES

1. Presumption of capacity
2. Individuals should be supported where possible so that they can make their own decisions
3. People have the right to make decisions that may seem eccentric
4. Decisions should be in a person's best interests
5. Decisions should be as unrestrictive as possible

A QUICK SUMMARY

ASK YOURSELF THE FOLLOWING

1. What decision has to be made?
2. Does the person have capacity to make it?
 - What support is required to help them make it?
3. If no capacity:
 - Is there a proxy -lasting power of attorney or a Deputy - to make the decision?
 - If it involves treatment, is there an advance decision refusing it?
4. In all cases where the person doesn't have capacity & there is no valid & applicable advance decision refusing treatment, ask:
5. WHAT ARE THE PERSON'S BEST INTERESTS?

BUT REMEMBER FUTURE PLANNING IS VOLUNTARY

- People should be offered chance but NOT required to make advance care plans, or advance decisions refusing treatment, or appoint LPAs
- Risks:
 - asking at inappropriate times or in an inappropriate way
 - forcing people to have discussions they do not want to have - increasing rather than reducing distress
 - painting by numbers (closed not open discussions)
 - quality of care will be judged by numbers of advance care plans. They are a tool not an outcome

ACP and end-of-life decisions (1)

- **When?** Goal = in advance ('Being prepared brings mental rest.')
- **As soon as possible:** looking at individual in his specific situation (initiative comes from patient, relative, doctor or care team)
 - The question 'Should we discuss end of life decisions you think?' **can be taken as an opportunity or dropped by patient** (when not ready)
- **As late as needed:** if professional observes triggers for PC (see above).



ACP and end-of-life decisions (2)

► How?

- Conversation patient ∞ medical doctor (if wanted + team member s.a. nurse or psychologist)
- Patient decides whether presence of relative is wanted.
Professional can make suggestions on this (esp. in cognitive pbs + to care for the relationship) but does not impose his opinion.
- Professional invests sufficient time and mental space for exploration and reflection.
- Inviting patient to come back on this issue. Never closing the conversation : leaving it open for evolution.
- If patient unable to give informed consent: conversation doctor ∞ relative.



ACP and end-of-life decisions (3)

► Euthanasia: a special case (in B, NL, Lux)

- Conversation patient ∞ medical doctor should start on initiative of the patient (if wanted + team member s.a. nurse or psychologist)
- Patient decides whether presence of relative is wanted.
- Professional invests sufficient time and mental space for exploration and reflection.
- Inviting patient to come back on this issue. Never close the conversation : leaving it always open for evolution.
- Personal opinion: medical doctor can suggest himself the option of euthanasia in one specific situation: if palliative care is failing in relieving the suffering of a patient in a (pre)terminal stage e.g. MND, MS + cancer,...



Legislation in Belgium

- 3 relevant laws supporting patients' roles in medical decision making– all published in 2002

Law on Patient Rights

s.a.: Right on agreement or refusal of medical examinations and treatment.

- Making a negative will (I express what I do not wish)

Law on Palliative Care

- “Every patient has the right to receive palliative care at the end of his life.”
- Legislation organising existing PC in Belgium (criteria for different PC-settings in Belgium, starting point for financing and evaluation of PC)

Law on Euthanasia



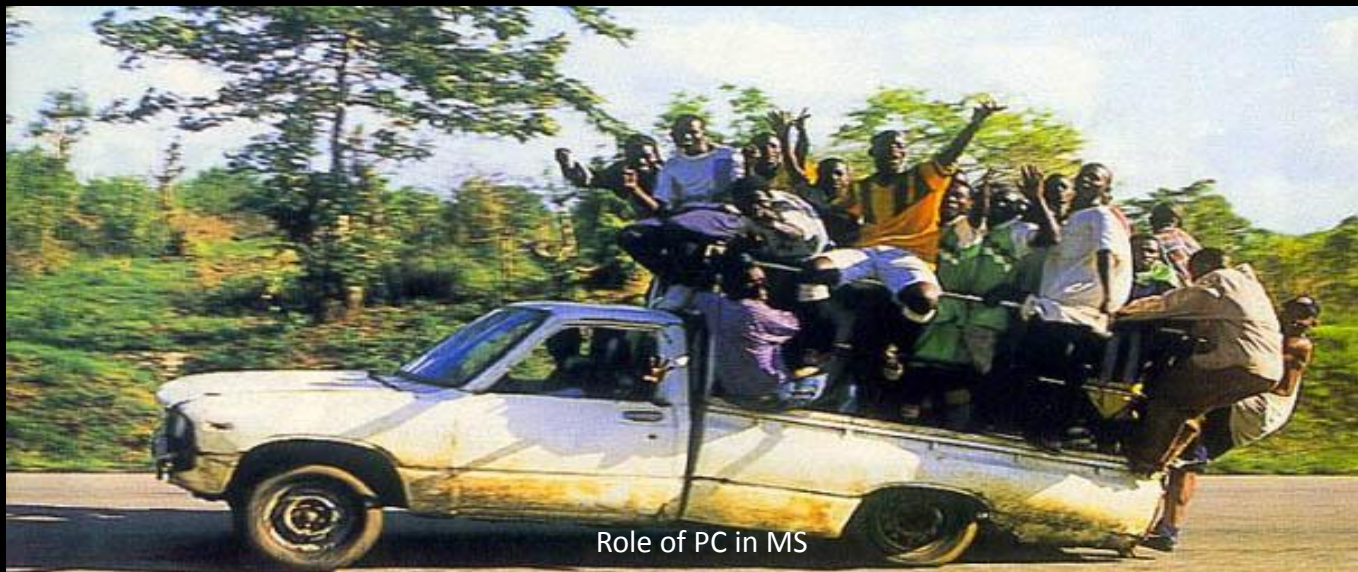
Law on Euthanasia (May 2002)

- ▶ Ending life of a person on his own request is legal if:
 - The patient
 - = adult ($\geq 18y$)
 - = legal capable (has performant capacity to think and to act)
 - Experiences unbearable physical and/or psychic suffering
 - In the context of incurable medical condition (due to a disease or accident) with no perspective of improvement :
 - Request (written) = voluntarily (without pressure of others), sustainable and lasting request.
 - It is performed by a medical doctor + respecting a strict procedure

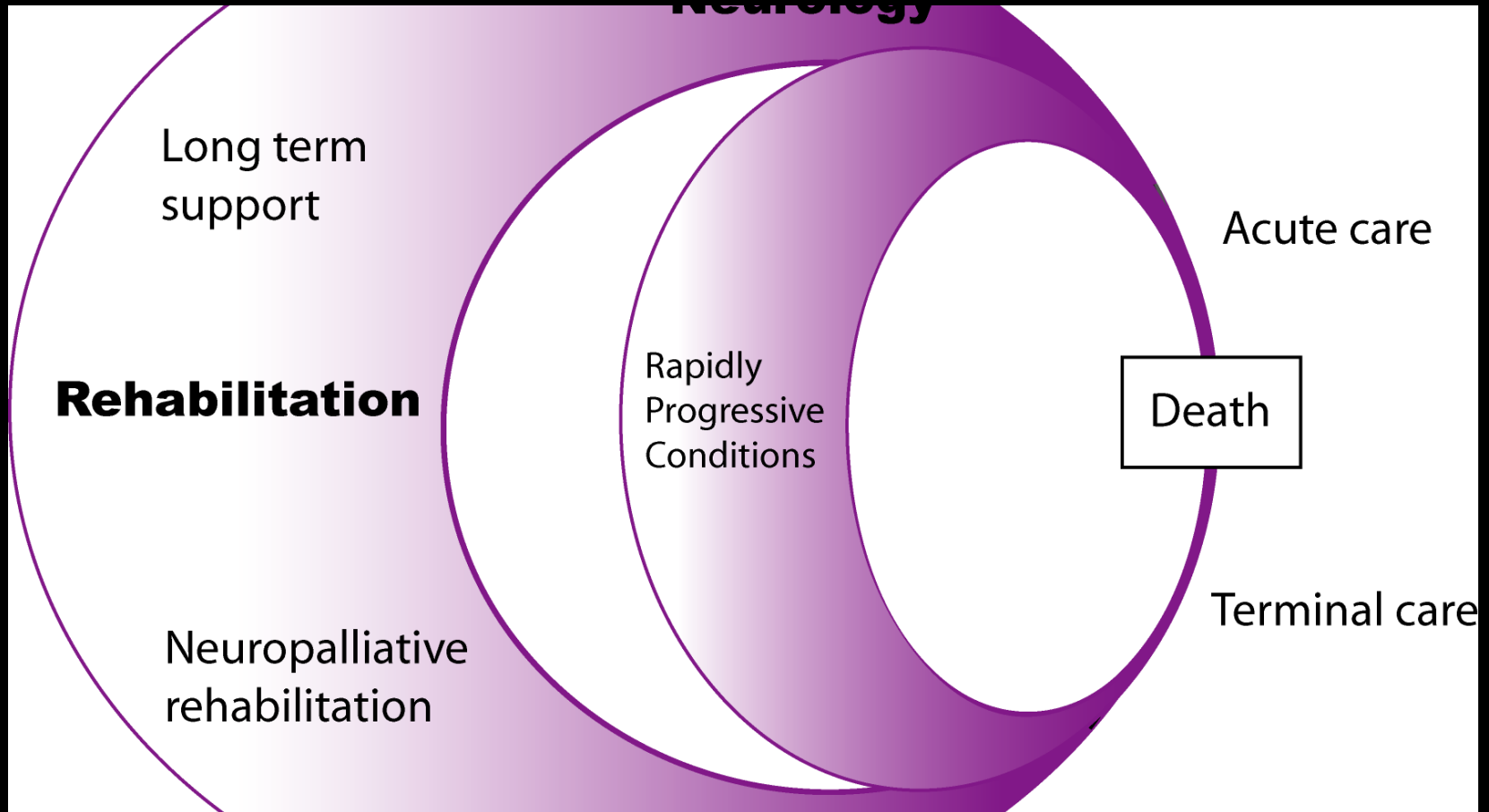


Working together requires

- Willing partners
- Realistic understanding and expectations of the other service
- Resources



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



Thanks for your attention

