

# Palliative care and neurology – a consensus developing for the work of the EAN and EAPC

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# Disclosures

- **There are no disclosures**

# Learning objectives

- **To be able to define palliative care and analyse its impact in the care of neurological disease**
- **To acquire knowledge and understanding and evaluate of the of the role of multidisciplinary team in palliative care**
- **To be able to identify the triggers which indicate end of life in progressive neurological disease**

# Key message

- **Palliative care, addressing physical, psychosocial and spiritual aspects of care, is helpful in the care of patients with progressive neurological disease**

# Neurological disease

- **Progressive disease**
- **Disabling**
- **No curative treatment**
- **Treatments may slow progression**

# **Palliative care**

**An approach that improves the quality of life of patients and their families facing problems associated with life-threatening illness, through the prevention and relief of suffering, early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual**

**WHO 2002**

# Palliative care aims

- Provides relief from pain and other distressing symptoms
- Affirms life and regards dying as a normal process
- Intends neither to hasten or postpone death
- Integrates the psychological and spiritual aspects of patient care

# **EAN / EAPC Consensus – overall aims**

- **Aim**
  - **Ensure palliative care approach included**
  - **Advance care planning**
  - **Family support**
  - **Carer support**
  - **Bereavement care**
  - **Triggers for palliative care**
  - **End of life care**



# Early integration of care

- **Palliative care should be considered early in the disease trajectory, depending on the underlying diagnosis**

**Temel JS, Greer JA, Muzikansky et al N Eng J Med 2010; 19: 733-742.**

# Multidisciplinary team

- **Assessment and care should be provided by multidisciplinary approach**
  - **At least three professions**
    - **Physician**
    - **Nurse**
    - **Social Worker**
    - **Psychologist / counsellor**

# Multidisciplinary team

- **Patients should have**
  - **Multidisciplinary palliative care assessment**
  - **Access to specialist palliative care**

**Aridegbe T, Kandler R, Walters SJ et al. Amytroph Lat Scler 2013; 14:13-19**

**Rooney J, Byrne S, Heverin M et al. J Neurol Neurosurg Psychaitry 2015; 86: 496-503.**

# Communication

- **Communication should be**
  - **Open**
  - **Set goals and therapy options**
  - **Use structured models, SPIKES**
  
- **Early advance care planning encouraged**
  - **Especially if expectation of**
    - **Impaired communication**
    - **Cognitive deterioration**

# Symptom management

- **Physical symptoms**
  - **Diagnosis**
  - **Pharmacological and non-pharmacological management**
  - **Regular review**
- **Proactive assessment of**
  - **Physical issues**
  - **Psychosocial issues**
- **Principles of symptom management should be used**

# Carer support

- **Needs of carers assessed regularly**
- **Support of carers – before and after death**
- **Professionals should reduce emotional exhaustion and burnout by**
  - **Education**
  - **Support**
  - **Supervision**

**Gelfman LP et al J Pain Symptom Manage 2008; 36: 22-8.**

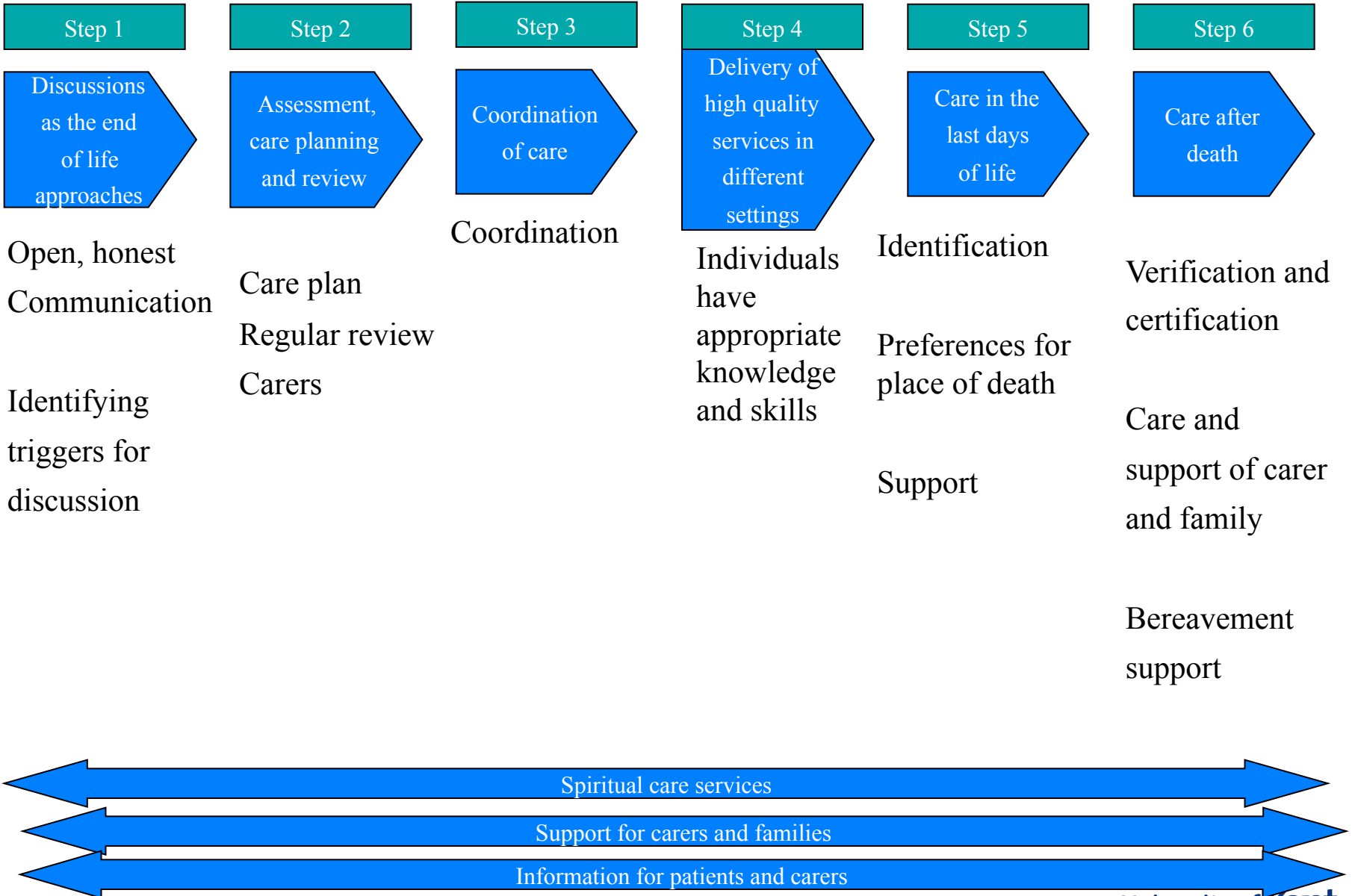
**Caap-Ahlgren, M. and O. Dehlin, Aging Clin ExpRes,2002.  
14(5): p. 371-7.**

# End of life care

- **Continued and repeated discussion**
  - **As continual changes**
    - **Physical**
    - **Cognitive**
    - **Preferences**
- **Encouragement of open discussion about dying process**
- **Encourage open discussion about the wish for hastened death**

Neudert C, Wasner M, Borasio GD. J Neurol Sci. 2001; 191: 103-109.

# The End of Life Care Pathway





# End of life care

- **Recognition of deterioration over last months and weeks important**
- **Diagnosis of the start of the dying phase allows appropriate management**
  - **Interventions**
  - **Medication**
  - **Carer and family support**
- **Use of care pathways helpful**

Di Leo S, Beccaro M, Finelli S et al. Palliat Med 2011; 25: 293-303

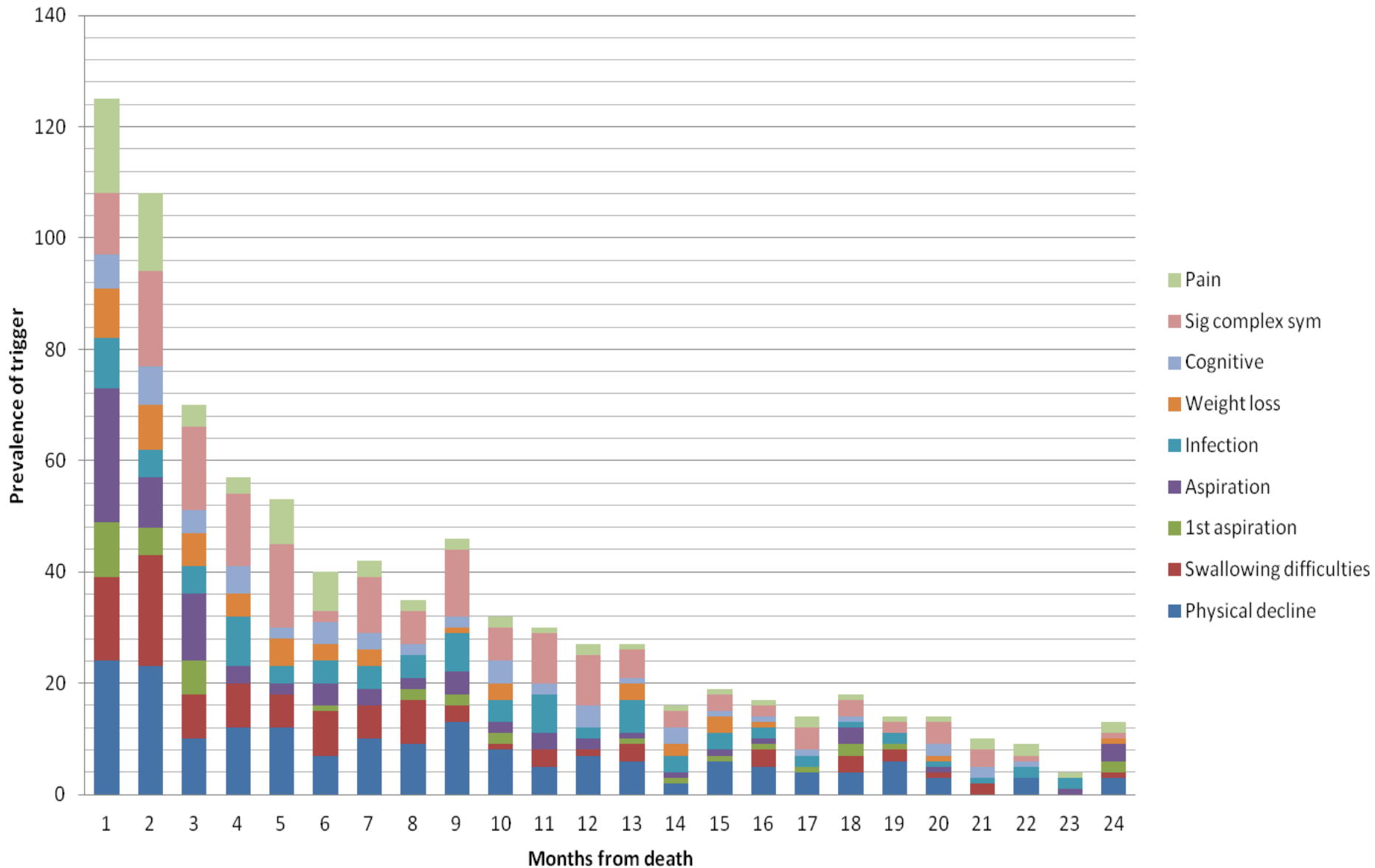
# Triggers for end of life care

- **Generic for neurological care**
  - **Patient request**
  - **Family request**
  - **Dysphagia**
  - **Cognitive decline**
  - **Dyspnoea**
  - **Repeated infections**
  - **Weight loss**
  - **Marked decline in condition**

**End of life care in long term neurological conditions. 2010**

**Hussain J, Adams D, Allgar V, Campbell C. BMJ Supp Pall Care 2014; 4: 30-37**

# Triggers in months prior to death



# Training and education

- **Palliative care principles in the training and continuing education of neurologists**
- **Understanding of neurological symptoms in training and continued education of specialist palliative care professionals**

**Szmulowicz E et al J Palliat Med 2010; 13; 439-452.**

**McConigley R et al Palliat Med. 2012 Dec;26:994-1000.**

# Curriculum

- **All neurologists should have experience and awareness of the multidisciplinary palliative care assessment and know when to refer for specialist palliative care**
- **Professionals involved in the care of progressive disease should receive education, support and supervision to reduce the risks of emotional exhaustion and burnout**

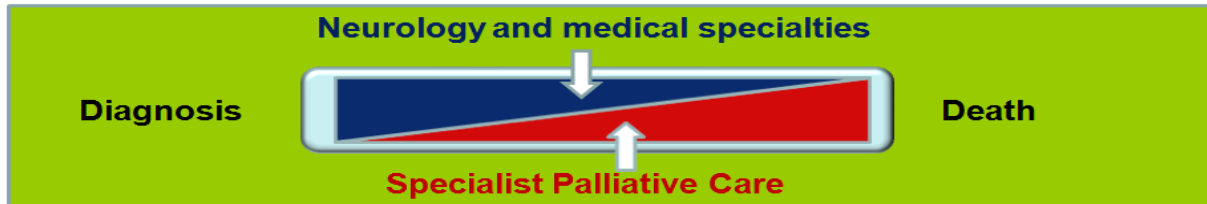
Pereira SM et al Nurs Ethics 2011;18: 317-26.

Gouveia Melo C, Oliver DJ. J Palliat Care 2011. 27: 287-95.

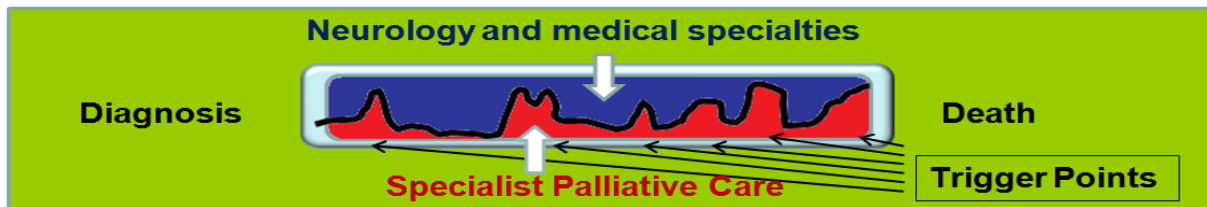
A, The traditional model of late involvement of specialist palliative services



B, The model of early and increasing involvement of specialist palliative services



C, The model of *dynamic* involvement of palliative services based on trigger points



Bede P et al 2009

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  - R Voltz                      GD Borasio                      A Caraceni
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  - S Veronese
- **EAPC and EAN**
- **Wider group who have commented on draft proposals**

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# Care in neurological disease

- **A challenge**
- **Recognition of need**
  - **Patients and families**
  - **Carers**
  - **Services**
- **Collaboration**
  - **Neurology**
  - **Rehabilitation medicine**
  - **General medical care**
  - **Primary care**
  - **Specialist palliative care**



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