

Palliative care for patients with progressive neurological disease: A consensus paper based on available evidence

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EFNS / EFNS Taskforce

- **Joint working group**
 - **European Association for Palliative Care**
 - **European Federation of Neurological Societies**

Taskforce

- **Dr David Oliver Chair** UK EAPC
- **Professor Raymond Voltz** Germany EFNS
- **Professor Gian Borasio** Switzerland
- **Dr Rachel Burman** UK
- **Dr Augusto Caraceni** Italy
- **Professor Marianne De Visser** Netherlands
- **Dr Wolfgang Grisold** Austria
- **Dr Stefan Lorenzl** Germany
- **Dr Simone Veronese** Italy
- **Dr Virginio Bonito** Italy

Methods

- **Literature search**
- **837 references considered**
- **Two investigators looked at literature**
- **Draft**
 - **Taskforce**
 - **Larger group of interested professionals**
- **Final draft**
 - **Taskforce**
 - **Larger group**

EFNS / EAPC Guideline – 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**

- ***Research question***
 - **Assessment of effectiveness of early palliative care involvement**

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**

- ***Research question***
 - **Effectiveness of Multidisciplinary team**

Communication

- **Communication should be**
 - **Open**
 - **Set goals and therapy options**
 - **Use structured models, SPIKES**

- ***Research question***
 - **Effectiveness and methods of communication of diagnosis**

Communication

- **Early advance care planning encouraged**
 - **Especially if expectation of**
 - **Impaired communication**
 - **Cognitive deterioration**
- ***Research question***
 - **Use and Effectiveness of ACP**

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**

Symptom management

- *Research questions*
 - **Best methods of symptoms management**
 - **Breathlessness**
 - **Pain**
 - **Secretions**

Carer support

- Needs of carers assessed regularly
- Support of carers – before and after death

- *Research question*
 - Best methods of carer support

Professional carer support

- **Professionals should reduce emotional exhaustion and burnout by**
 - **Education**
 - **Support**
 - **Supervision**

- ***Research questions***
 - **Methods of staff support /supervision**

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**

End of life care

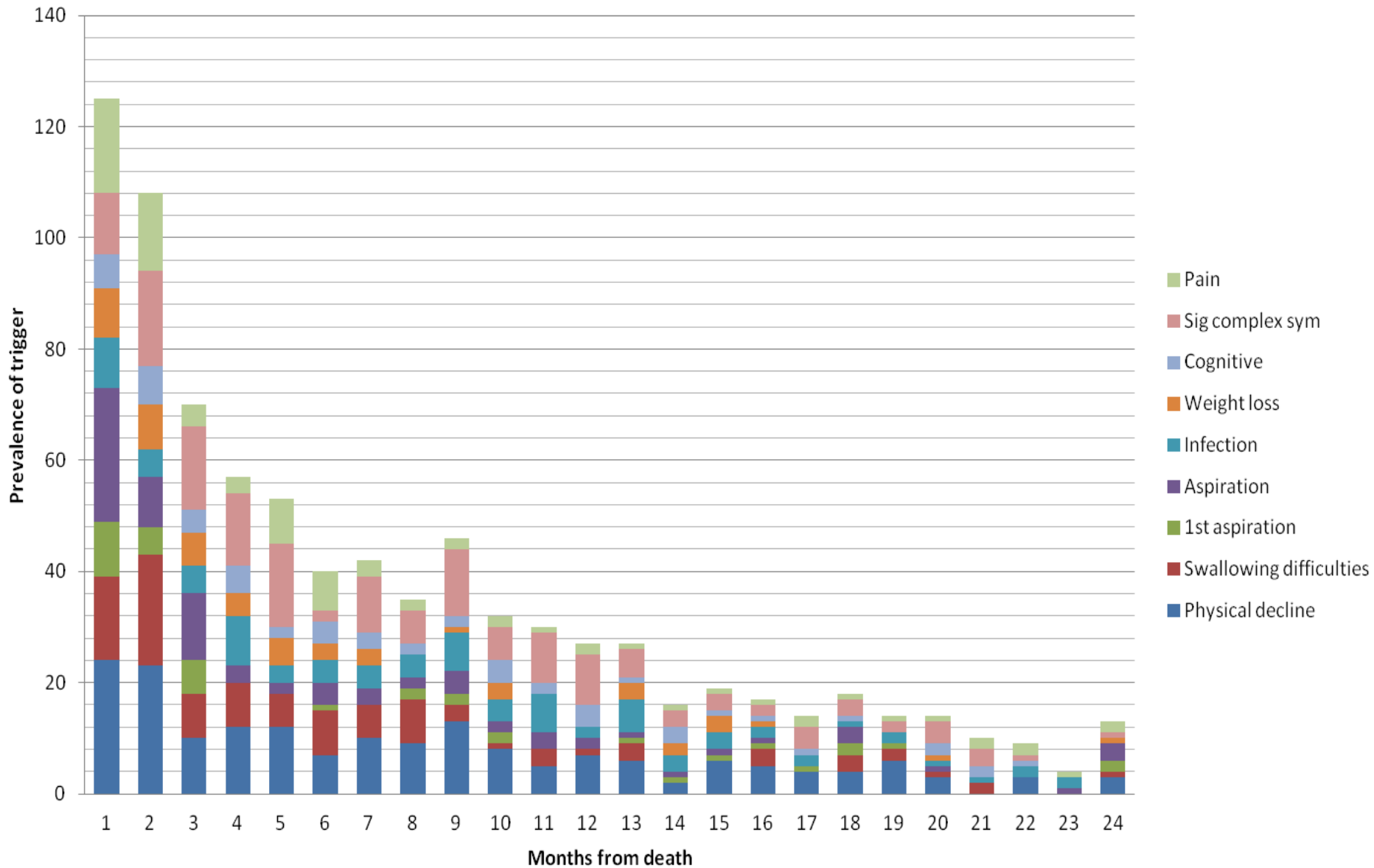
- **Recognition of deterioration over last months and weeks important**
- **Diagnosis of the start of the dying phase allows appropriate management**
 - **Interventions**
 - **Medication**
 - **Carer and family support**
- ***Research question***
 - **Use of triggers in recognition of end of life**

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: a framework for implementation. National End of Life Care Programme 2010

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**
- ***Research question***
 - **Effective methods of education**

Future plans

- **Publication of the consensus paper**
 - **European Journal of Neurology**
 - **European Journal of Palliative Care**
- **Palliative care to be included in other guidelines**
- **Development of the collaborative approach**