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

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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