Palliative care for neurological patients

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What happens in neurological disease?
- Progressive disease
  - MND, PD, MSA, PSP, CBS
  - Dementias
  - Disease progression
  - Disabling
  - No curative treatment
  - Treatments may slow progression / help with symptoms
  - Patients deteriorate and die

Neurological disease – variable prognosis
- Multiple sclerosis
  - Disease modifying treatments
  - Variable progression / prognosis
- Stroke
  - Sudden death
  - Progressive disability
  - Uncertainty
- Brain injury

Specific issues
- Huntington’s Disease
  - Genetics
- Parkinson’s Disease
  - Movement problems
- Multiple Sclerosis
  - Incontinence / cognitive change
- Stroke
  - Uncertainty

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

EAN/EAPC Consensus on palliative care
Oliver DJ et al, Eur J Neurol 2016;23: 30-38.

Assessment
- Physical
  - Symptoms
  - Positioning / mobility
  - Communication
- Psychological / emotional
- Social
- Spiritual
**Symptoms**
- Pain
- Dyspnoea
- Dysphagia
- Incontinence
- Constipation
- Speech problems
- Delirium
- Anxiety / Depression

**Psychosocial care - patient**
- Multiple losses
  - Physical
    - mobility, speech
  - Cognitive changes
  - Emotional
    - expression problem
- Fear of disease
- Fear of death and dying

**Psychosocial care - family**
- Role changes
- Losses
  - Patient
  - within partnership
- Fears of the disease
- Finances
- Emotional changes
- Death and dying

**Spiritual / existential aspects**
- Not necessarily religious
- Spiritual distress
  - Loss of function
  - Loss of communication / cognition
  - Autonomy
  - Death
- Fears of dying and death

**Team assessment**
- Multidisciplinary
- Multiagency
- Increased need to ensure
  - co-ordinated approach
  - not overwhelming patients
  - carers supported

**Multidisciplinary team care**
- NICE Guidance recommends MDT approach
  - including palliative care expertise
- Evidence of effectiveness
  - Sheffield
    - Median survival
      - MDT 19 months
      - Standard care 11 months
  - Ireland
    - Survival benefit
      - MDT 1.22 years
      - General clinic 0.88 years

Goftron et al 2018

Gofton et al 2018

NICE 2016

Aridegbe et al 2013

Rooney et al 2015
End of life care

- Anticipation
- Symptom management
- Communication
  - Patient
  - Family
  - Carers
  - Team
- Support of all involved
- Complex ethical decisions
  - Withdrawal of ventilation

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

Oliver DJ et al, Eur J Neurol 2016;23: 30-38.

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 Programme 2010
Hussain et al 2013

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

Oliver DJ et al, Eur J Neurol 2016;23: 30-38.

Assessment and palliative care involvement
Effectiveness of palliative care

- Increasing evidence of effectiveness for neurological patients
  - Quality of life
  - Symptom improvement
    - Pain
    - Breathlessness
    - Sleep
    - Bowel problems
  - Emotional issues
  - Social issues
  - Spiritual area (non-religious)
  - Carer support
  - Similar death rate in participants and control group
  - Cost effective

Solari et al 2017; Edmonds et al 2010; Higginson et al 2010; Veronese et al 2017; Buzgova et al 2020; Wei Gao et al 2020

Role of palliative care

- May be from diagnosis
  - ALS
  - Severe stroke
- May be at times throughout the disease progression
  - Parkinson’s disease
  - MSA / PSP / CBD
  - MS
- At the end of life
  - Any disease

Collaboration

- Increased understanding of roles
- Increased contact
  - according to need
- From early in the diagnosis
- Particularly towards the end of life
- Increased education of all involved
- Aim to improve quality of life / quality of dying of patients and families

Oliver et al 2020

Palliative care and neurology – the future

- Specialist palliative care
  - Complex situations
    - Physical / psychosocial / spiritual
  - Ethical issues
  - Advance care planning
  - Multidisciplinary team approach
    - Physician
    - Specialist nurse
    - Psychosocial carer

References

- Oliver D et al. BMJ Support Palliat Care 2020; doi 10.1136/bmjspcare-2020-002322
- Veronese S et al BMJ Supp and Pall Care 2017; 7:164-172