

Palliative care for neurological patients

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1

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

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2

Neurological disease – variable prognosis

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

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3

Specific issues

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

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4

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.

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5

Assesment

- Physical
 - Symptoms
 - positioning / mobility
 - communication
- Psychological / emotional
- Social
- Spiritual

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6

Symptoms

Pain
Dyspnoea
Dysphagia
Incontinence
Constipation
Speech problems
Delirium
Anxiety / Depression

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7

Psychosocial care - patient

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

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8

Psychosocial care - family

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

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Spiritual / existential aspects

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

Goffon et al 2018

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10

Team assessment

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

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11

Multidisciplinary team care

- NICE Guidance recommends MDT approach – including palliative care expertise
NICE 2016
- 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

Aridegbe et al 2013

Rooney et al 2015

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12

End of life care

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

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13

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.

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14

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

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

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15

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

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16

Carer support

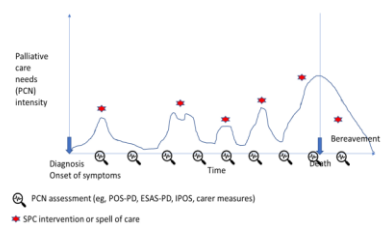
- Needs of carers assessed regularly
- Support of carers – before and after death
- Professionals should reduce emotional exhaustion and burnout by
 - Education
 - Support
 - Supervision

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

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17

Assessment and palliative care involvement



PCN assessment (eg. POS-PD, ESAS-PD, IPOS, carer measures)
SPC intervention or spell of care

General palliative care, neurological and rehabilitation care

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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

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19

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

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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

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21

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

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22

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23