

# APM Neurological SIF Update

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Association for  
Palliative Medicine  
Of Great Britain and Ireland

# Aims of the session

- Overview of the SIF
- Reflections from Joint Study Day with Transition SIF
- Triggers for palliative care in progressive neurological conditions study

# Overview of the SIF

- Established 5 years ago
- Over 100 members from around the UK
- Aims to share ideas & good practice around palliative care in progressive neurological diseases
- Emails & newsletters to disseminate relevant information

# Reflections from Joint Study Day with APM Transition SIF

- Held in Birmingham in June 2016
- Presentations available on APM website



## Topics covered

Transition from children's to adult palliative care services

Challenges & pitfalls of Duchenne Muscular Dystrophy

Challenging behaviour

Physiotherapy for young people with life-limiting conditions

Seizures, spasticity & dystonia

Whizz-Kidz (mobility provision for children & adults)

Gut failure in neurodisability

# Duchenne Muscular Dystrophy (1)

- Session led by Dr Derek Willis, Consultant in Palliative Medicine & Dr Tracey Willis, Paediatric Neurologist
- Trajectory of DMD transformed by proactive management
  - Steroids started age 4-5 years
  - Delays loss of ambulation to age 11-15 years, reduces likelihood of spinal surgery & delays respiratory problems
  - Regular monitoring & treatment of cardiac & respiratory problems – ACEI,  $\beta$ -blockers, NIV
  - New therapies in development



# Duchenne Muscular Dystrophy (2)

- Some children's hospices no longer take DMD patients due to improved survival
- Pain a major issue in late stages
- Derek runs a joint palliative clinic at Oswestry for adult patients with neuromuscular diseases
- He is part of the national Northstar group developing guidelines for care for adult patients with neuromuscular disorders
- He is keen for input from anyone else working with these patients

# Triggers for Palliative Care Study - background



- End of life care in Long Term Neurological Conditions, published 2010
- Highlighted challenges in end of life care in this group
  - Long duration of illness
  - Unpredictable time course
  - Complex MDT care

# Potential triggers for palliative care input & advance care planning

- Swallowing problems
- Recurring infection
- Marked decline in physical status
- First episode of aspiration pneumonia
- Cognitive difficulties
- Weight loss
- Significant complex symptoms



# Triggers in advanced neurological conditions – preliminary study

- Retrospective study of 62 patients under the care of a specialist palliative neurology service, who had died
- Frequency of triggers increased as each patient approached death
- Four symptom components explained 76% of the variance:
  - rapid physical decline
  - significant complex symptoms, including pain
  - infection in combination with cognitive impairment
  - risk of aspiration.
- Referral criteria based on the triggers can facilitate appropriate & timely patient access to palliative care.
- Larger studies prospectively validating the triggers are required.

Hussain J, et al. BMJ Supportive & Palliative Care 2014;4:30–37

# Triggers in advanced neurological conditions study

- 12 Specialist palliative care providers
- 300 patients
  - Mean age 70 years
  - 58% MND 17% PD 12% PD Plus 9%MS
- Assessed triggers in last 24 months of life

# Triggers in advanced neurological conditions study

- Final paper submitted to Palliative Medicine
  - Jamilla Hussain – Hull York Medical School
  - Victoria Allgar – HYMS/ Health Sciences
  - David Oliver – University of Kent
- Thank you to Dr David Oliver for providing the slides for the Triggers study results & to all the centres involved in the project

# An invitation

- The value of the APM Neuro SIF depends on the contributions of its members
- New members are always welcome
- Coordinator Dr Aruna Hodgson [a.hodgson@wlh.org.uk](mailto:a.hodgson@wlh.org.uk)

