



**Association for Palliative Medicine Neurological
Palliative Care Special Interest Forum
Newsletter 1, March 2016**

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for All Programme

**Welcome to the first newsletter of the APM
Neurological Palliative Care SIF.** I hope you
find it of interest. If anyone comes across any
useful information or articles which you would
like to be included in future newsletters, please
do let me know.

Aruna Hodgson, Consultant in Palliative
Medicine, Wigan & Leigh Hospice
a.hodgson@wlh.org.uk

SAVE THE DATE

The APM Transition & Neurological Palliative Care SIFs Joint Study Day

**Friday 24th June 2016
The Studio, Birmingham**

Topics & speakers will include:

Dr Amelia Stockley, Consultant in Palliative Medicine, Helen and Douglas House, Oxford
Transition from children's to adult services for young people with life-limiting illness

Dr Emily Harrop, Consultant in Paediatric Palliative Medicine, Oxford
**Symptom management in children and young people with non-malignant neurological
disease**

Sarah Clemence - Transition Physiotherapist for all of Wales
Physiotherapy for young people with life-limiting conditions

Professor Rowan Heath, Health Care of Older People, Nottingham
Caring for people with challenging behaviours

Dr Camilla Salvestrini, Paediatric Gastroenterologist, Addenbrookes
Gut failure in neurodisability: a paediatric centre experience

Edwina Perkins, Specialist Neuromuscular Care Advisor, Muscular Dystrophy Research Centre,
Newcastle
Duchenne's Muscular Dystrophy

Further details to follow shortly!

Key Publications

APM Guidance for Professionals on the Withdrawal of Assisted Ventilation at the Request of a patient with MND

Hopefully you may already be aware of this document which was published in November 2015. The Guidance was developed by a multiprofessional and interspecialty group, chaired by Christina Faull. It gives detailed information about the key components for safe and effective withdrawal of ventilation at the request of patients who are ventilator-dependent. It has been endorsed by a number of organisations including the GMC, RCP, MNDA and Hospice UK.

In addition to the guidance document, a list has been compiled of people with experience of withdrawing assisted ventilation who are willing to offer support to professionals facing this situation for the first time. An audit of process and outcomes in regard to withdrawal of ventilation has also been developed, which aims to evaluate the usefulness of the guidance and increase the evidence-base in this area of care. The guidance, audit tool, and information about how to contact those with experience in the area are all on the APM website.

NICE Guideline on Motor Neurone Disease: assessment and management

This was published in February 2016, the Guideline Development Group having been chaired by David Oliver. The guideline describes good practice in care from diagnosis to end of life, and includes helpful recommendations in areas of symptom management such as saliva problems, nutrition and gastrostomy, communication and respiratory problems.

EAPC / European Academy of Neurology Taskforce on Neurological Palliative Care Consensus Review on the development of palliative care for patients with chronic and progressive neurological disease

David Oliver chaired this review, which concluded that there is increasing evidence that palliative care and a multidisciplinary approach to care lead to improved symptoms and quality of life of patients and families. The full publication can be found on the EAPC website.

Other forthcoming study days

Wednesday 4th May 2016

Palliative Care in Neurology, Cicely Saunders Institute, King's College, London

Cost £75 (£55 for students & those with income under £25,000 per annum)

Further details available at

<http://www.kcl.ac.uk/lsm/research/divisions/cicelysaunders/newsevents/eventrecords/2016/may/Palliative-Care-in-Neurology-Conference.aspx>

Friday 10th June 2016

Motor Neurone Disease "NICE to Manage", King's College, London.

Cost £120.

Further details available at <http://www.stchristophers.org.uk/education/course/mnd-conference/>

Recent articles of Interest

Advance care planning in motor neurone disease

Two articles by **Leigh Murray and Phyllis Butow** from the University of Sydney have been published recently on advance care planning in motor neurone disease. The first is a systematic review in *Palliative and Supportive Care*. They aimed to summarize what is known about the prevalence, content, patient/caregiver benefits, healthcare professional (HCP) awareness/support, and healthcare outcomes associated with ACP in the MND setting. Of the 422 studies identified, 16 were included. The research methods generally lacked rigor. Advance directive (AD) prevalence varied considerably across studies, with disease progression the strongest predictor of AD completion. They concluded that important benefits may be associated with ACP in the context of motor neurone disease (e.g. feelings of control/relief and refusal of unwanted treatments). However, further evidence is required to verify findings and identify optimal streamlined approaches (e.g. use of decision aids) consistent with patients' and caregivers' needs over time.

Palliat Support Care. 2015 Oct 14; :1-22. Epub 2015 Oct 14. DOI:
<http://dx.doi.org/10.1017/S1478951515001066>

Their second article is a qualitative study of caregiver preferences, and is in *Palliative Medicine Online First*. They interviewed 18 former caregivers of deceased patients with motor neuron disease. A total of 10 patients had created a disease-specific advanced directive, 'Letter of Future Care', and 8 had not. A total of four global themes emerged: Readiness for death, Empowerment, Connections and Clarifying decisions and choices. Many felt the letter of future care was or would be beneficial, engendering autonomy and respect for patients, easing difficult decision-making and enhancing communication within families. However, individuals' 'readiness' to accept encroaching death would influence uptake. Appropriate timing to commence advance care planning may depend on case-based clinical and personal characteristics. Their conclusion was that advance care planning can assist patients to achieve a sense of control and 'peace of mind' and facilitates important family discussion. However, the timing and style of its introduction needs to be approached sensitively. Tools and strategies for increasing the efficacy of advance care planning for motor neurone disease should be evaluated and implemented.

Palliat Med 0269216315613902, first published on February 4, 2016
<http://pmj.sagepub.com/content/early/2016/02/03/0269216315613902.abstract>

The impact of gastrostomy in motor neurone disease

The most recent edition of *BMJ Supportive and Palliative Care* (March 2016) contains an article by Stavroulakis et al on the challenges and benefits of gastrostomy insertion from a patient and carer perspective. This was a retrospective qualitative exploration using semistructured interviews with patients and their informal carers. 27 patients consented to the study; of these, 23 underwent a successful gastrostomy. 10 patients and 8 carers were interviewed, approximately 3 months following a successful gastrostomy. Participants described clinical complications, practical issues, time restrictions imposed by strict feeding regimens and psychological issues, which adversely impacted on quality of life. However, the establishment of a safe alternative route for feeding and medication, and the reduced worry over difficult meals and weight loss, were described by all as outweighing these negative impacts. Participants also described having received education/training on gastrostomy feeding both in hospital and in the community, which helped them to cope during the transition from oral to gastrostomy feeding.

BMJ Support Palliat Care 2016;6:52-59
<http://spcare.bmj.com/content/6/1/52.abstract>

Irish Hospice Foundation Palliative Care for All Programme

Members working in Ireland may already be aware of the Irish Hospice Foundation's Palliative Care for All Programme, which provides support, direction and guidance to those working to incorporate palliative care principles into care. The Foundation and the Neurological Alliance of Ireland completed a project in 2014 looking at the **palliative care needs of people with advancing neurological conditions**. This revealed that people in Ireland with advancing neurological disease were experiencing difficulties in accessing palliative care and not getting it early enough in their illness. The report emphasises how the palliative care approach is relevant at many different points in a patient's illness and an action plan has been developed to address this issue.

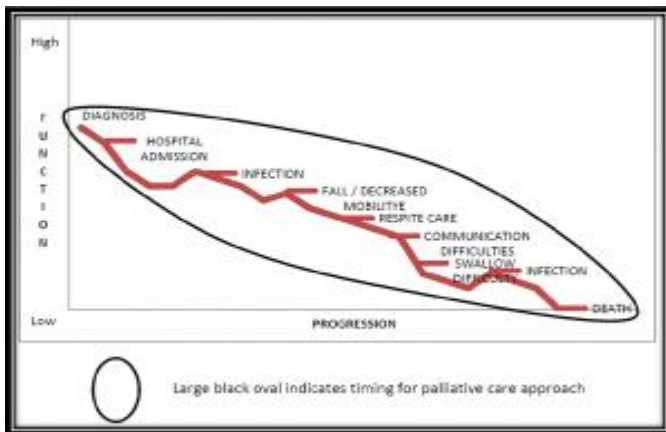


Diagram taken from Irish Hospice Foundation website

The report and action plan are available at <http://hospicefoundation.ie/healthcare-programmes/palliative-care/palliative-care-for-all/advancing-neurological-illness/>

There are a number of resources on the Irish Hospice Foundation website for healthcare professionals looking after patients with advancing neurological conditions. These appear to be aimed at staff working in generalist settings and may be useful to SIF members who provide training to these groups of staff. The website outlines what to consider in the following circumstances:

I'm looking after someone who has just been [diagnosed](#) with an advancing neurological condition:

A person with an advancing neurological condition has just been [admitted](#) to my ward:

I'm looking after a person with an advancing neurological condition who has an [infection](#):

I'm looking after someone with an advancing neurological condition who had a [fall/ their mobility](#) is declining:

A person with an advancing neurological condition has just been admitted to my unit for [respite](#) care:

I'm involved in the care of somebody with an advancing neurological condition and is experiencing [communication](#) difficulties:

I'm involved in the care of somebody with an advancing neurological condition and is experiencing [swallowing](#) difficulties:

I'm looking after somebody with an advancing neurological condition who is [dying](#):

Many thanks to Jamilla Hussain for her contributions to this newsletter.
Please send any information for the next newsletter to a.hodgson@wh.org.uk