



**Association for Palliative Medicine
Neurological Palliative Care Special Interest Forum
NEWSLETTER 4, MAY 2019**

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Welcome to the fourth newsletter of the APM Neurological Palliative Care SIF

I hope you find the newsletter 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.

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Exciting opportunity to be the next coordinator of the APM Neurological Palliative Care SIF

I have now been coordinator of the NeuroSIF for 3½ years, and as the Terms of Reference for the group state that the coordinator term of office is for 3 years, the time is overdue for me to hand the role on to someone who can bring fresh enthusiasm to the group. If you would be interested in taking on this (not very arduous) role, then please contact me as soon as possible. Thank you.

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Forthcoming study day

Untangling the Web: St Christopher's and Kings MND Care and Research Centre Annual conference.

7th June 2019

Topics will include:

- The MND association – a 40 year perspective
- Clinical trials update
- Novel Therapies
- Pain, cramps and fasciculations
- Augmentative and alternative communication
- The ethics of choice and control
- The impact of apathy on quality of life and carer burden.

For further details see:

<https://www.stchristophers.org.uk/course/motor-neurone-disease-annual-conference>

Recent articles of interest

Many thanks to Dr Jamilla Hussain for her suggestions for this section.

Challenges facing palliative neurology practice: A qualitative analysis.

Gofton TE, Chum M et al. *J Neurol Sci.* 2018 Feb 15;385:225-231.

This qualitative study aimed to develop a conceptual understanding of the specific characteristics of palliative care in neurology and the challenges of providing palliative care in the setting of neurological illness.

Specific characteristics of neurological disease that affect palliative care in neurology were identified:

- 1) Timelines of disease progression
- 2) Barriers to communication arising from neurologic disease
- 3) Variability across disease progression
- 4) Threat to personhood arising from functional and cognitive impairments related to neurologic disease.

Moreover, three key challenges that shaped and complicated palliative care in neurology were identified:

- 1) Uncertainty with respect to prognosis, support availability and disease trajectory
- 2) Inconsistency in information, attitudes and skills among care providers, care teams, caregivers and families
- 3) Existential distress specific to neurological disease, including emotional, psychological and spiritual distress resulting from loss of function, autonomy and death.

These challenges were experienced across groups, but manifested themselves in different ways for each group.

The authors conclude that further research regarding prognosis, improved identification of patients with palliative care needs, developing an approach to palliative care delivery within neurology and the creation of more robust educational resources for teaching palliative neurology are expected to improve neurologists' comfort with palliative care, thereby enhancing care delivery in neurology.

<https://www.ncbi.nlm.nih.gov/pubmed/29277430>

Palliative care in neurology: integrating a palliative approach to amyotrophic lateral sclerosis care

Anne Hogden, Samar M. Aoun, Peter L. Silber *EMJ Neurol.* 2018;6[1]:68-76.

This narrative review examines connections between neurology, specialist palliative care, and an integrated palliative approach to care for people living with neurodegenerative conditions, using amyotrophic lateral sclerosis (ALS) as a case study. Challenges to co-ordinated ALS care and smooth care transitions between multiple services and healthcare professionals are discussed, including the timing of palliative care delivery in ALS; the education and training needs of healthcare professionals; and misperceptions of palliative care held by healthcare professionals, patients, and families. The benefits of adopting an integrated palliative approach to care for patients, families, and healthcare professionals are clarified. The review concludes that a palliative approach integrated into the care plan of people with ALS from the time of diagnosis can optimise quality of life by relieving symptoms; providing emotional, psychological, and spiritual support pre-bereavement; minimising barriers to a comfortable end of life; and supporting the family post-bereavement. Recommendations are made for enhancing the training of neurology health professionals within the wider community.

<https://www.emjreviews.com/neurology/article/palliative-care-in-neurology-integrating-a-palliative-approach-to-amyotrophic-lateral-sclerosis-care/>

Symptom dimensions in people affected by long-term neurological conditions (LTNCs): a factor analysis of a patient-centred palliative care outcome symptom scale.

Rebecca Wilson, Nilay Hepgul et al. *Nature Scientific Reports* Vol 9, Article 4972 (2019).

The symptom subscale of the Integrated Palliative Outcome Scale for LTNCs (IPOS Neuro-S24) comprises 24 items measuring symptom severity. Descriptive statistics and psychometric properties of the scale were assessed, with data being analysed from 238 patients. A reliable four-factor structure of symptom experience in LTNC patients was identified (fatigue, motor symptoms, oral problems and non-motor symptoms), with results suggesting that symptom dimensions are common across LTNCs. The authors conclude that the IPOS Neuro S-24 is an appropriate tool to measure symptoms in LTNC patients, which may improve care.

<https://www.nature.com/articles/s41598-019-41370-3.pdf>

Assisted ventilation in motor neurone disease during inpatient palliative care: barriers and utilisation.

Gleeson A, Johnson F. *BMJ Support Palliat Care*. 2019 Feb 2. [Epub ahead of print]

This study aimed to establish the extent to which hospices and specialist palliative care units (SPCUs) in the UK and Ireland currently manage patients with MND using assisted ventilation and to identify any associated barriers.

97.4% of responding units admit patients with MND on non-invasive ventilation (NIV), but only 28.2% admit those using tracheostomy ventilation (TV). 80.8% of units have adequate expertise in the management of NIV, compared with 7.7% for managing TV. 35.9% and 2.6% of units have a policy for managing patients using NIV and TV, respectively. 14.1% respondents had been involved in the care of patients with MND using TV in the specialist palliative care setting in the last 5 years.

The authors conclude that a minority of UK and Irish hospices/SPCUs provide support to TV MND patients and few units currently have management or admission policies for this cohort of patients. Respondents indicated a lack of appropriate expertise and experience. Further exploration of these barriers is required to establish how to optimise care for TV MND patients in this setting.

<https://www.ncbi.nlm.nih.gov/pubmed/30712020>

Assessing the validity of proxy caregiver reporting for potential palliative care outcome measures in Parkinson's disease

Kelly Sebring, Jo Shattuck et al, *Palliative Medicine* July 2018

A cross-sectional study of Parkinson's disease patients and caregivers who completed a battery of outcome measures relevant to palliative care. There was moderate to good agreement between patients and caregivers for many of the measures, but in general caregivers tended to attribute higher symptom severity than patients, particularly where the patient had more advanced disease. The authors conclude that caution is indicated when considering caregiver proxy reporting for most of the outcome measures assessed, particularly in Parkinson's disease patients with advanced disease.

<https://journals.sagepub.com/doi/abs/10.1177/0269216318785830?journalCode=pmja>

Randomized controlled trial of a home-based palliative approach for people with severe multiple sclerosis.

Solari A, Giordano A et al. *Mult Scler*. 2018 Apr;24(5):663-674.

This study found that a home-based palliative approach had a slight impact on symptom burden of patients with severe MS but no impact on patient quality of life.

<https://www.ncbi.nlm.nih.gov/pubmed/28381133>

Neurological symptoms in palliative care patients

Johanna Anneser, Victoria Arenz and Gian Domenico Borasio Front. Neurol., 25 April 2018

This study found that neurological symptoms (excluding pain) were common in palliative care patients with an underlying non-neurological diagnosis, particularly sleeping problems, difficulty concentrating, sensory symptoms and vertigo/ dizziness. As these symptoms may impact severely on quality of life, they conclude that it is essential to implement neurological expertise in palliative care. <https://www.frontiersin.org/articles/10.3389/fneur.2018.00275/full>

The Case for Proactive Neurological Care

This report published by Sue Ryder uses a case study approach to assess the health and social care costs and values of different care pathways for people with MND, Huntington's Disease and also Acute Brain Injury in the UK. For each of the three cases they characterise and cost indicative care pathways. These pathways are grounded in case studies, built through interviews with people living with these conditions and staff and carers who know them well. The results indicate that the proactive approach to care provided by Sue Ryder, which can deliver better quality and longevity of life, can also deliver a saving to the funder of 30-50% on annual care costs. There is greater financial investment in home and residential social care support with the proactive approach, but the costs of the less effective 'reactive' care pathways are driven up substantially by the increased frequency of visits to hospital required.

<https://www.sueryder.org/sites/default/files/2018-09/Sue-Ryder-The-Case-for-Proactive-Care.pdf>