



## Association for Palliative Medicine Neurological Palliative Care Special Interest Forum NEWSLETTER 2, APRIL 2017

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### Welcome to the second newsletter of the APM Neurological Palliative Care SIF.

A particular welcome to new members of the SIF, as a number of people have joined following the NeuroSIF session at the recent APM Conference (report below).

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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### Report from the Inaugural APM Supportive & Palliative Care Conference

It was fantastic to see so many people at the APM NeuroSIF session at the recent APM Supportive & Palliative Care Conference held in Belfast at the end of March. Apologies to anyone who missed out as the session was so popular that the room we were allocated wasn't really big enough, a few people were standing at the back & I know of at least one person who tried to come in partway through & was unable to do so due to lack of space.

Dr Colette Donaghy, Consultant Neurologist and Director of the Northern Ireland MND Care Centre gave an excellent update on MND, including the results of the regional audit of end of life care in MND and qualitative study of specialist palliative care in MND which she & colleagues had undertaken.

Professor Christina Faull spoke about the APM Guidance on Withdrawal of Assisted Ventilation at the request of a patient with MND, which was published in November 2015. The guidance calls for ongoing collation of a core dataset to help inform practice in this area, & Christina gave a summary of 16 core datasets received to date.

Finally, I gave a short overview of the APM Neurological SIF and the joint study day held in June 2016 with the APM Transition SIF. I also presented a summary of the results from the Triggers in advanced neurological conditions study (courtesy of David Oliver who had provided the slides for this). A paper about the Triggers study has been submitted to Palliative Medicine, so do look out for it in due course.

Thank you to those who tweeted from the session. Some of the posts are included in a summary of the conference by Bernadette Keefe <https://t.co/FYtv4JQMYa>. Click on the "Play" sign & you will get to the slides. The NeuroSIF posts start at slide 23. They are interspersed with slides from concurrent sessions & continue to slide 53.

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

The guidance has now been available for nearly 18 months and both this and the associated audit tool can be found in the "Publications" section on the APM website. As well as making use of the guidance yourself, it would be great if you could promote it to your colleagues & encourage as many as possible to submit audit data for patients with any diagnosis who have had assisted ventilation withdrawn. This will help to increase the evidence base and enable the guidance to be updated if necessary.

Palliatiivedrugs.com undertook a survey of experiences of withdrawal of assisted ventilation at the request of a patient in August-September 2016 & the results can be found on the Palliatiivedrugs.com website.

### Key Publications

#### NICE Quality Standard on Motor Neurone Disease

This was published in June 2016 & outlines 5 quality standards for care of patients with MND.

Statement 1 - Adults diagnosed with MND are given information about the diagnosis, prognosis and management of MND by a consultant neurologist with expertise in treating people with MND.

Statement 2 - Adults with MND who have respiratory impairment are offered non-invasive ventilation (NIV) based on regular assessments of respiratory function and symptoms.

Statement 3 - Adults with MND receive tailored equipment and adaptations without delay, based on regular multidisciplinary team assessments.

Statement 4 - Adults with MND receive personal care and support from a consistent team of workers who are familiar with their needs.

Statement 5 - Adults with MND are given opportunities to discuss their preferences and concerns about end of life care at diagnosis and key stages of disease progression.

The full document is at

<https://www.nice.org.uk/guidance/qs126/resources/motor-neurone-disease-75545361935557>

### Forthcoming study days

#### Friday 23<sup>rd</sup> June 2017

Clinic to Community: a Collaborative Approach, King's College, London.

Cost £120.

Further details available at <http://www.stchristophers.org.uk/course/MND17>

## Calculating medication doses for patients with Parkinson's Disease who develop swallowing problems

Anyone who has had to try and work out what to do with Parkinson's medications when a patient develops swallowing problems or is nil by mouth may like to know that there are a couple of online calculators to help with this situation. One was developed by Northumbria Healthcare NHS Foundation Trust PD service, and can be found at <http://www.pdmedcalc.co.uk/>. The tool simply asks you to enter the patient's usual medications, before calculating the equivalent doses of dispersible madopar for administration via a nasogastric or PEG tube. The tool also provides a suggested rotigotine patch dose, for situations where transdermal delivery of replacement medication may be more appropriate.

The other was developed by a team of Parkinson's specialists and pharmacists with the support of the Southampton/Isle of Wight Excellence Network regional working group and the British Geriatrics Society Movement Disorders Section. This is at <http://www.parkinsonscalculator.com/>.

## Recent articles of interest

### **Palliative care for Parkinson's disease: Patient and carer's perspectives explored through qualitative interview – Fox et al, Palliative Medicine Online First, Sept 2016**

Siobhan Fox and colleagues undertook a qualitative study of people with Parkinson's disease (n = 19) and carers (n = 12), across three Movement Disorder Clinics in the Republic of Ireland. People with Parkinson's disease and their carers were unfamiliar with the term palliative care. When informed of the role of palliative care, most felt that they would benefit from this input. Key times when extra support would be welcomed were at diagnosis and with advancing illness. Their conclusions were that a holistic palliative care approach could address the complex physical and psychosocial symptoms experienced by people with Parkinson's disease and their carers, and people with Parkinson's disease and their carers are open to palliative care. They recommended that further research needs to explore how palliative care can be introduced into the routine care of people with Parkinson's disease.

### **Caregiving in ALS – Galvin et al, BMC Palliative Care Sept 2016**

There is clearly a lot of research going on in Ireland about neurological conditions. Miriam Galvin, based in Dublin, and colleagues used mixed methods of data collection and analysis to assess burden and difficulties associated with informal caregiving in ALS. The quantitative data showed that psychological distress, hours of care provided and lower quality of life, were significant predictors of caregiver burden. From the qualitative data, the caregiving difficulties were thematised around managing the practicalities of the ALS condition, the emotional and psychosocial impact, limitation and restriction, and impact on relationships. They conclude that understanding the components of burden and the difficulties experienced as a result of caring for someone with ALS allows for better support of the caregiver, and assessment of the impact of burden on the care recipient.

### **Enteral feeding in motor neurone disease: Patients' perspectives and impact on quality of life – Chhetri et al, Palliative Medicine Online First Nov 2016**

Just to prove that I haven't just chosen to highlight articles from Ireland, this one is from Preston, Lancashire. Chhetri et al undertook a questionnaire-based prospective study of 21 patients with MND receiving enteral feeding at 3, 6 and 12 months post-gastrostomy. The majority reported 'little' or 'no problem at all' with the tube, problems being more common in the first 3 months post-gastrostomy. Clinical complications including leakage, pain, redness/irritation, bleeding and infection occurred in up to 70% of participants, though less than 20% perceived them to be a significant problem. Up to 40% had difficulty in maintaining gastrostomy site hygiene. More than 70% reported no interference with their family life, intimate relationships or social activities and had no difficulties 'at all' in using the gastrostomy tube. Only 17.7% (n=3) wished for gastrostomy tube removal at 6 months but none of those who were still in the study at 12 months wanted removal.

## Research Studies in Progress

### **ToNiC (Trajectories of Outcome in Neurological Conditions) Study**

This is a national study examining the factors that influence quality of life in patients with neurological conditions, including MS and MND. It is hoped that TONiC will have a significant and positive impact on the lives of all patients living with neurological conditions, regardless of symptoms, stage of illness, age or social status.

Further information is at <https://tonic.thewaltoncentre.nhs.uk/>.

### **OPTCare Neuro**

This study is evaluating a new service for people severely affected by long-term neurological conditions. 7 centres (London, Nottingham, Liverpool, Cardiff, Brighton, Chertsey & Sheffield) are participating in the study. Patients with MS, PD, PSP, MSA or MND who have unresolved symptoms which haven't responded to usual care are offered a short term integrated palliative care intervention. This is delivered by multiprofessional palliative care teams and consists of approximately 3 visits over 6-8 weeks. Further information is at

<http://www.kcl.ac.uk/lsm/research/divisions/cicelysaunders/research/studies/OPTCARE-Neuro/index.aspx>

## Forthcoming Research Studies

Marie Curie and the MNDA announced in March that they would be funding three new research studies that aim to improve the quality of palliative and end of life care received by people with MND. Studies will look at various aspects of palliative care for MND.

One, being conducted at the University of York, aims to identify gaps in existing research and develop a more complete picture of the needs of patients and carers.

Another, at the University of Manchester, recognising the central role that carers play in palliative care, aims to develop a tool that will empower them to better coordinate support for themselves and the patient.

A third study at the University of Sheffield looks at the specific burden of excessive saliva affecting some people with MND - a particularly distressing symptom, which doctors currently consider to be poorly treated.

(Information taken from <https://www.mariecurie.org.uk/media/press-releases/>)

**Many thanks to David Oliver & Christina Faull for their contributions to this newsletter. Please send any information for the next newsletter to [a.hodgson@wlh.org.uk](mailto:a.hodgson@wlh.org.uk)**