Association for Palliative Medicine
Neurological Palliative Care Special Interest Forum
NEWSLETTER 3, MARCH 2018

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Welcome to the third 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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Report from the APM Neurological Palliative Care Special Interest Forum Study Day held on 6th November 2017

A big thank you to Dr Sarah Grove for arranging the APM NeuroSIF study day held at Arthur Rank Hospice last November. For those who were unable to attend, Sarah has kindly summarised the key learning points from the day.

Assessment and Management of Prolonged disorders of Consciousness (PDOC)

Assessment of people with PDOC is difficult due to fatigue, variability through the day and posture (usually standing improves conscious level). It is important to be aware that patients with a PDOC need very careful assessment by an experienced neurologist, on more than one occasion, and that there may well be a spectrum of injury from permanent vegetative state to minimally conscious state, rather than two separate conditions.

It is also difficult to prognosticate for these patients - although age <39 years, traumatic (rather than hypoxic) brain injury and the presence of auditory evoked potentials and blink to visual threat are good prognostic indicators, their absence doesn't rule out the possibility of recovery.

Management of spasm

Increased tone can be helpful (eg for walking, transferring, reducing risk of DVT) but treat if painful or reducing function:

1. Remove noxious stimuli eg pressure sores, faecal impaction.
2. Rehabilitation – standing frames can be really helpful – stretch all muscle groups, don't need to be able to weight bear to use them. Good posture vital.
3. Oral medication – baclofen, diazepam, dantrolene (only one that acts directly on muscle, but can elevate LFTs), tizanidine (check baseline LFTs and 12 weekly thereafter, can cause fulminant hepatitis), gabapentin, clonazepam, sativex (only licensed for spams due to MS and in combination with another agent).
4. Botulinum toxin or phenol nerve or muscle point blocks – he mainly uses phenol, which is cheaper than botulinum toxin and effect usually lasts at least a year.

Neuromuscular conditions

Life expectancy for DMD is now 23 in England, having been improved by steroid use to maintain

mobility, scoliosis surgery to maintain posture, NIV and cough assist devices for respiratory compromise, artificial feeding and proactive management of cardiomyopathy. Dystrophin is also present in the CNS, so psychiatric and behavioural problems are common, mainly ASD, ADHD and anxiety. These boys and young men can live in a persistently vulnerable state for years, but indications that they are approaching end of life include decreasing function, no further medical management options, increasing weight loss and increasing frequency of respiratory illnesses. Pain is a common problem as they get older, usually musculoskeletal in origin and they are highly likely to be osteoporotic from immobility and long-term steroid use. Another late problem is volvulus, so it is important to make sure they are having their bowels open regularly.

Artificial nutrition for those with progressive neurological conditions

NCEPOD 2004 and NPSA alert 2011 advised that decisions about artificial feeding (AN) should be taken by a MDT. Recent ProGas study showed that it wasn't clear that AN improved quality of life, nutritional status or survival in MND, but certainly increased the burden on carers. Patients with MND are hypermetabolic, and malnutrition is a risk factor for death. One study has shown a survival benefit with a high calorie diet. Preferred means of providing AN is via PEG (long term NG tube placement carries side effects, including risk of displacement, sinusitis, reduced ventilator capacity and oropharyngeal colonisation, thus increasing pneumonia risk).

Addenbrookes Hospital practice:

1. Feeding issues MDT which is comprised of gastroenterologists, palliative care, Elderly Medicine consultants, endoscopy staff, SALT and dietician and which discusses all TPN, PEG insertions and home NG feeding. Audit has shown that 62% of patients discussed at the MDT died within one year. The meeting has significantly reduced mortality, almost certainly through better patient selection.
2. Insertion of gastrostomies via nasal endoscopy – unsedated and patient can be sitting up. Much better tolerated, though not always technically possible.

Suicidal ideation in patients with life-limiting illness

Completed suicide is rare – 8/100,000/ year in UK. Self-harm is common in the young, but only 1-2% of those who self-harm go on to complete suicide, and the risk is greater in the elderly. Having a current medical disorder increases the risk of suicide by almost the same amount as having a previous history of deliberate self-harm. A significant minority of patients with a life-limiting illness express a persistent wish for hastened death (though may not be contemplating acting on this). This is most associated with depression and treating the depression changes this wish for hastened death in a majority, but not all people. Common concerns linked to this wish for hastened death are fear of future suffering, loss of autonomy and perception of being a burden.

Cochrane review (http://www.cochrane.org/CD007503/DEPRESSN_antidepressants-for-depression-in-physically-ill-people) indicates that antidepressants do work and are worth trying, even in those with a short prognosis.
Another useful paper:
http://journals.plos.org/plosone/article?id=10.1371/journal.pone.0037117https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4700969

e-ELCA module on non-invasive ventilation in MND

There is now an e-ELCA module on NIV in MND, written by Christina Faull and colleagues. It is number 10_06, in the Specialist Content section. The session outlines the evidence base and practicalities of this important treatment option.

Recent articles of interest

Palliative care triggers in progressive neurodegenerative conditions: An evaluation using a multi-centre retrospective case record review and principal component analysis – Hussain, Algar and Oliver, Palliative Medicine Online first, February 2018
Results from this study have been presented at previous APM NeuroSIF study days, so it is great to see the results published now. A total of 12 specialist palliative care units across the UK provided data from 300 patients: mean patient age 70 years, 50% male, diagnoses included motor neurone disease 58%, Parkinson's disease 17% and Parkinson's Plus syndromes 12%. There was a high burden of palliative care triggers, with the most frequent being deteriorating physical function, complex symptoms and dysphagia. The conclusion is that prospective studies assessing which triggers are useful for different conditions are now required.

Enteral feeding in motor neurone disease: Patients' perspectives and impact on quality of life – Chhetri et al, Palliative Medicine 2017 31(7):676-677
This was a questionnaire-based prospective study of 21 patients with MND receiving enteral feeding. 17 patients were followed up for 6 months and 10 for 12 months. The majority reported "little" or "no problem at all" with the tube, and generally the tube was associated with improved quality of life. However, clinical complications including leakage, pain, redness/ irritation, bleeding and infection occurred in up to 70% of participants, and up to 40% had difficulty in maintaining gastrostomy site hygiene. The authors advise that the decision to offer enteral feeding requires careful individualisation based on patients' needs, expectations and wishes.

The burden of multiple sclerosis and patients' coping strategies – Lorefice et al, BMJ SPC 2018 8:38-40
This Italian study aimed to evaluate the differences between patients with MS and healthy controls in coping styles. 135 patients with MS and 94 healthy controls were recruited. The study found that patients with MS were less likely to use coping strategies that involve seeking social support and problem solving than the healthy controls. There was greater impairment of social support in patients with a longer duration of disease, and there was an association between the use of avoidance strategies and levels of depression and disability. They suggest that "invisible" symptoms such as fatigue, dysphagia, pain, sphincter dysfunction, cognitive impairment and mood disorders are as important as the more visible problems, and recommend use of psychosocial interventions to increase patients' adaptive coping mechanisms to manage the burden of MS.

The views of adults with Huntington's disease on assisted dying: a qualitative exploration – Regan et al, Palliative Medicine Online First, November 2017
Seven participants who were gene positive for Huntington's disease were interviewed to explore their views on assisted dying. All were either pre-symptomatic or at an early stage of their disease trajectory, but their views were influenced by the experience of having had family members who had died from the condition. Some of the themes expressed were similar to those found in studies of members of the wider community, namely right to personal autonomy and compassion. However, they also spoke about the threat to self and potential loss of role and personality from the disease. Decision-making in assisted dying was described as a difficult and complex process, with family as important stakeholders. However, discussing the issues with family was difficult, and equally the opportunity for open discussion with medical professionals was lacking. The authors recommend that clinicians have honest discussions with such people, including around issues relating to perceived loss of self, which was seen as of greater concern than symptom management, and options such as advance care planning. They suggest that further research with people with Huntington's disease who are in the later stages of their illness, and on family member's conceptualisations of assisted dying, would be valuable.

Cochrane review of symptomatic treatments for amyotrophic lateral sclerosis/ motor neuron disease – Ng et al, 2017
This reviews the evidence from Cochrane Systematic Reviews of all symptomatic treatments for MND, including cramps, spasticity and sialorrhoea. It provides a useful summary, though the evidence base for managing many of the symptoms is limited.

Resources to support people with MND who are considering placement of a feeding tube and their carers

There is a helpful website with resources to support people living with MND who are considering placement of a feeding tube and their carers. It is at https://mytube.mymnd.org.uk/. There are short films about making the decision to have a feeding tube, experience of having a tube fitted and caring for the tube.

Forthcoming study days

There are several study days on MND over the next few months:

10th April 2018 – Advances in Care in MND, Oxford

8th June 2018 – MND: How far can and should we go, Kings College Hospital

20th June 2018 – MND and Palliative Care, Royal Glamorgan Hospital

Further information about all of these study days is available on the MNDA website https://www.mndassociation.org/forprofessionals/professional-education-and-development/study-days/

Looking further ahead, there is a PSPA European Study Day on 25th October 2018 at the Royal College Of Physicians, London, which is free to attend. There is also an International Research Symposium the following day, 26th October, at the same venue. There is further information at https://www.pspassociation.org.uk/for-professionals/study-days/ , though the programme details aren't out yet.

If you have any information which you would like to be included in the next newsletter, please send it to arunahodgson@doctors.org.uk