December 2016 Issue No. 17

apm POST

The Newsletter of the Association for Palliative Medicine of Great Britain and Ireland

IN THIS ISSUE

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ASP Conference Updates

Organised by The Association for Palliative Medicine
30-31 March 2017 ● Belfast Waterfront, Northern Ireland

Programme

The organising committee is pleased to announce the programme is now available – ***please click here to view***

Registration

Registration remains open, click ***here*** to see the registration fees and book your place. *Please note the Early Bird Fees will close on Friday 13 January at 5 pm.*

Accommodation

In conjunction with Visit Belfast, we have now opened the accommodation booking service via the APM website. Please ***book*** your hotel early to secure your preferred room, as Belfast is a high occupancy city.

Late Breaking Abstracts

The main call for papers has now closed and submissions are being reviewed. The late breaking call for abstracts will open on 12 December and will close on 31 December.
To submit, you will need the following username and password, then click on the blue 'Abstract Submission' box

Username – **ASP2017** *Password* – **Shamrock**

Submission Guidelines are available
– ***click here to view***

For further information on the conference,
click here

APM Supportive & Palliative Care asp Conference

President's Report

As winter arrives and the cold winds of uncertainty blow across political fields worldwide, it's both sobering and encouraging to read what is going on in our own neck of the woods here and abroad.

• As I head off for Africa myself, I cannot but start with Cassie's account of Uganda and how 'they could make for patients and their families with what they had in their little medical kits and their big hearts. They were frustrated that they didn't have the resources to do more.' We might say the same, although we are talking billions fuelled by our society's denial of human mortality, and for us by the public purse, not a family's worldly wealth. Ageing and dying are not diseases to be fixed they're realities to be engaged, for it is not that we die, but how we live as we die and what that means now in our politicised world. I shall have some things to say about this at ASP in Belfast;

• So to Mark's piece on CPR, which is about so much more than web resource and process. We must thank him for engaging in the public space with the impact of his letter to David Bowie - an observation on living and dying well. Please follow the links to get some inspiration. Any of us has the potential to get out positive messages as Kath Mannix, myself and others are showing in the more traditional platforms if you search on iPlayer etc. Be encouraged: step out and share your vision too;

• Please be booking in now for the conference in Belfast. It is important and a 1 stop shop for your CPD! The programme is now complete thanks to Andrew and the team's hard work and is well worth it. There is something for everyone and a chance to meet and share the good the bad and (maybe) the ugly from your areas;

• Finally, on workforce, training etc.- areas of enormous strategic significance for the next year - we will be sending out briefings over coming weeks, and have substantial sessions on both Shape of Training and 7-Day working in Belfast. It's also becoming apparent that the lack of consultant staff is beginning to have a troubling impact across the hospice sector. We are seeking to find answers and wise ways forward with Hospice UK and will be holding a day with them in February.

Make sure you keep an eye on the website and our bulletin for updating.

Rob George
President

The Science Committee's articles of the month from the APM journals.

A selection of recent articles of the month selected by the science committee. These articles are updated in the bulletin every month which may also be used for journal clubs.

Pharmacovigilance in hospice/palliative care: the net immediate and short-term effects of dexamethasone for anorexia, illustrates the potential value of routinely collected clinical data and shows how clinical services can engage in collaborative service improvement projects even if they do not necessarily have the infrastructure to participate in randomised controlled trials. 69% reported ≥1 reduction anorexia scores by day 7. 32% had harms (insomnia, depression, euphoria and hyperglycaemia), including 10 of 24 patients with no benefit.

How to Deal With Relatives of Patients Dying in the Hospital? Qualitative Content Analysis of Relatives' Experiences, is a secondary qualitative analysis of relatives' responses to 10 open questions on the quality of dying in a Dutch hospital. If bereaved relatives feel acknowledged by the trust staff in their role as caregiver, representative, and close relative, be involved in decision making and be informed in a timely fashion, then they felt they were in a better position to represent the patient.

The bereavement experiences of lesbian, gay, bisexual and/or trans* people who have lost a partner: A systematic review, thematic synthesis and modelling of the literature, reported that loss of the primary relationship is a universal experience, regardless of sexual or gender identity. Additionally experiences around the time of death were often shaped by interactions with healthcare professionals, legal and financial issues, and HIV or AIDS. Social and familial support, and if their relationship was disclosed openly also influenced bereavement

Feasibility of assessing patients' acceptable pain in a randomized controlled trial on a patient pain education program, showed in a secondary analysis (n=72) of a randomized controlled trial, that 97% of patients were able to give a score for what pain score was acceptable to them. 36% scored this as moderate and 13% as severe pain. Patients' ratings of acceptable pain were stable at 8 weeks.

Jason Boland, *on behalf of the APM Science Committee*

TalkCPR Project

In 2015, as part of the Welsh 'Sharing and Involving Do Not Attempt Cardiopulmonary Resuscitation' intiative, we started work on a project to improve communication aids for people with palliative illness. The result was the 'TalkCPR' project, co-designed by patients and carers. It aims to improve communication and dialogue between patients and their healthcare professionals with regard to **Do Not Attempt Cardiopulmonary Resuscitation** (DNACPR) decisions.

The venture represents a collaborative effort between all NHS Wales Healthboards and Trusts, as well as the Dying Matters in Wales charity Byw Nawr and support from the Bevan Commission as a Bevan Exemplar project. Initially, two videos (see them here: http://talkcpr.wales or just google: 'TalkCPR') were produced for patients and carers who wanted to know more about this topic and required a resource to help shared decision making with their clinical team. Two further videos were developed to provide healthcare professionals with tips and approaches to start this difficult conversation. Provisions have also been made for blind, partially sighted and deaf patients.

Continued on page 3

TalkCPR Project ...continued

The impact of these videos on patients, nurses and doctors was measured through pre and post-video surveys and a focus group session. Results showed a significant increase in the confidence of staff with regard to openly discussing DNACPR after watching the videos. The evaluation and IQT methodology used can be viewed here: https://www.nice.org.uk/sharedlearning/talk-cpr-project-talkcpr

These short films have been made available in each health board and trust in Wales. Several English Trusts have come forward and are using the videos in their own settings, and Pulse magazine have written a feature for GPs in the UK, on this novel video and website approach. A media campaign has made the #TalkCPR project very prominent in the public domain, with Benedict Cumberbatch reading out a letter at Hay Festival mentioning this NHS Wales project and a Guardian article on cardiopulmonary resuscitation which went viral. Both NICE and the GMC have published the TalkCPR website resource and the project has won the 2016 NHS Wales award for improving quality.

It is hoped that the use of video and website information for patients around difficult areas such as CPR wishes can inform part of a more sharing approach, allowing patients and their proxy to be involved in key decisions, expressing their views and thoughts in advance of a deterioration and providing good quality information.

Dr Mark Taubert, *Clinical Director for Palliative Medicine, Velindre NHS Trust;*
Twitter: @DrMarkTaubert

Hospice Africa Uganda

Hot and sticky, being thrown about in the back of a Land Rover heading into the bush along an orange dirt track, with a milk crate full of liquid morphine on my lap and a bag of various other medicines under my feet, I was a long way from home. And I was a long way from the palliative care experience I'd had in medical school.

Last November, I spent four weeks on elective with Hospice Africa Uganda. Forty-eight hours after finishing my general medicine placement in an NHS hospital on the South coast of England, I was sat on the floor under the thatched roof of the home of a sixty year old lady with Kaposi's sarcoma. Tears rolled down her drawn, angular cheeks as she told us of her pain. She had sold everything she owned to pay for treatment which had not worked. She was not alone.

I met many more people with advanced cancers who'd taken their children out of school and sold their homes to pay for courses of chemotherapy or radiotherapy that they could not afford to complete. When the money was gone the hospitals sent them home to die. Most were cared for by family or neighbours until the end. But some, often those with fungating and infected tumours, were ostracised and left to suffer their final days alone.

The HAU team did their very best to offer symptom control, spiritual support, financial and practical help and bereavement care to anyone in need. Everyday I was amazed at the difference they could make for patients and their families with what they had in their little medical kits, and their big hearts. They were frustrated that they didn't have the resources to do more.

I saw and learnt a lot in those four short weeks. I was moved by the stories of many, but not more so than when meeting a lady my own age with advanced cervical cancer. She was a single mother of a twelve year old boy who was a child of rape. They were Rwandan refugees and had no other family. The boy had dropped out of school to look after his mother. He cooked for her, fed her, washed her and cleaned her clothes and sheets. He slept under her bed every night and he dutifully emptied colourful plastic buckets of various bodily fluids at regular intervals. The team did everything they could to help them, and they worked tirelessly to find security for him when she died.

A year on I am working on a surgical ward in Edinburgh. The pace of life is very different. Our struggling NHS is a stark contrast to the health systems of Uganda, and most of the rest of the world. But our patients' struggles are the same. When I am caught up in the stresses and strains of junior doctor life in the NHS, I worry that we are losing a sense of what's important. From time to time I pause to remember the peeling paint and faded green printed letters on the well-worn door of the Hospice Africa Uganda clinic: Adding Life to Days, Not Just Days to Life.

Cassie Northcott

e-ELCA

Symptom management for the dying adult
A brand new session in e-ELCA brings together management of symptoms in the last days of life http://portal.e-lfh.org.uk/Component/Details/439889. Jane Wale has worked very hard to make this practically useful with flow charts and downloads of exemplar prescriptions for anticipatory prescribing. In addition to the common symptoms that require thinking about, it also guides the management of diabetes in the last days.

The session is designed for doctors in training and nurses in hospitals and community settings and may also be useful for pharmacists. It is longer than many e-ELCA sessions but we thought, on balance, this was preferable to dividing it into two sessions. Do send us feedback as to how you integrate this into your local training and teaching.

Video tutorials: How to make use of e-ELCA
I recently uploaded a video tutorial about using e-ELCA to support the Priorities for Care of the Dying Person https://www.youtube.com/watch?v=bQ1CMzXku6o. I hope you find it useful to share with your colleagues and local educators. Follow me on Twitter to get notification of further uploads.

GMC end of life care campaign
You may be aware of the work that the GMC is doing and the resources they are making available to support doctors working with patients with advanced illness http://www.gmcuk.org/guidance/28733.asp The e-ELCA session by Andrew Thorns introduces the General Medical Council's Treatment and Care Towards the End of Life Good Practice in Decision Making. It highlights the key principles and good practice standards set out in the guidance, illustrating how they can be applied using examples from practice http://portal.e-lfh.org.uk/Component/Details/308536

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e-ELCA
End of Life Care for All

Research Methodology Workshop

Organised by the APM Science Committee, kindly supported by Marie Curie

Wednesday 29 March 2017
Northern Ireland Hospice, Belfast, Northern Ireland

This one day course will cover the key areas in the curriculum for research methods.

It includes critical appraisal of systematic literature reviews, quantitative and qualitative literature, with 'hands-on' workshops. Research in palliative medicine, including a workshop on developing the research question will be covered.

This course is essential for trainees who do not get research exposure during their training and those wanting to develop their interest or own research further.

Click here to view the programme

Registration is now open!

Register Now

Marie Curie
Care and support through terminal illness

Registration Fees

APM Member Early Bird Rate (until 13.01.17) ***£75***
Non Member Early Bird Rate (until 13.01.17) ***£95***
APM Member Standard Rate (after 13.01.17) ***£100***
Non Member Standard Rate (after 13.01.17) ***£120***

End of Life Care Study Day

To be held in conjunction with the APM's Supportive and Palliative Care Conference Study Day: Organised by the APM, in association with the All Ireland Institute of Hospice and Palliative Care (AIIHPC)

Friday 31 March 2017 Belfast Waterfront, Northern Ireland

Click here to view the programme

Registration is now open!

Register Now

Registration Fees

Early Bird Rate (until 13.01.17) ***£150***
Standard Rate (after 13.01.17) ***£200***

AIIHPC
All Ireland Institute of Hospice and Palliative Care

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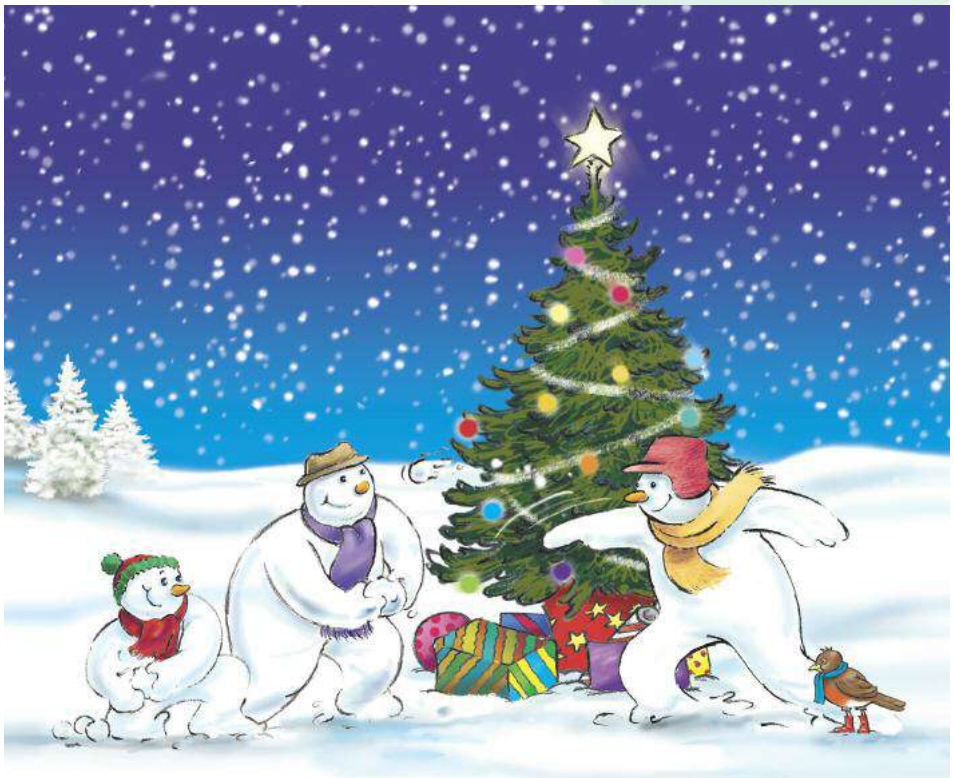
New Committee Members

Laura Gordge
– Mentoring Co-ordinator, APM Juniors Committee
I am a core medical trainee in South London and excited to take up the role of mentoring coordinator for the APM Juniors committee. I completed my foundation years in North London and then took a year out of training after FY2. This allowed me to spend time in a clinic in India which was a fantastic experience. I look forward to engaging with both juniors and more experienced members of the APM to encourage interest in palliative medicine among pre-specialty doctors.

Roberta Jordan
– Education Co-ordinator, APM Juniors Committee
I currently work at the Overgate Hospice in Elland, having completed CMT in London last August. I've really enjoyed the move to Yorkshire. I'm undertaking the RCP educator accreditation, regularly contribute to teaching, have organised a range of educational programmes and work with medical schools in exams and applications. I will be applying for palliative medicine specialist training next year and really look forward to working with the APM Junior committee as the new education coordinator.

Simon Etkind
– Trainee Representative, APM Science Committee
I am an ST4 trainee in the London Deanery and am currently nine months into a PhD at the Cicely Saunders Institute. For my PhD, I'm investigating the care goals and preferences of frail older adults with complex illness. I hope to use my mixed clinical-academic experience to provide a useful link between the science and trainees committees



The Editorial Board would like to thank you for your contributions to APM Post throughout 2016 and encourage everyone to send in articles of interest to your colleagues. If you would like to contribute, please contact: heather@compleatconference.co.uk

With all good wishes for 2017

Rob, Jason, Dylan, Simon, Mark, Becki and Heather