



POST

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

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New Committee Members



Anna Bradley

I am a ST3 trainee in North East / North Central London, currently based at St Joseph's Hospice. I am very much

looking forward to representing Palliative Medicine trainees on the Specialty Advisory Committee in England.



Isobel Jackson

I am a LTFT ST4 trainee and I am looking forward to joining the Trainees Committee as the Northern Ireland and Wales SAC

representative. After undergraduate training at University of Oxford I completed the Graduate Entry Medicine programme in Swansea and have remained in South Wales for my medical training to date. When not in work I can be found on our local beach with my family!

Thursday 30 March 2017
16:30 – 17:30



Annual General Meeting

“Come and have your say”



Hall 1A
Belfast Waterfront
2 Lanyon Place
Belfast
BT1 3WH

The APM Supportive and Palliative Care Conference (ASP Conference)

30 and 31 March 2017 ● Belfast Waterfront
CPD: 12 credits

Visit the [ASP Conference page](#) for more information



President's Report

You will see I have written quite enough alongside Mark in this edition, so I am going to mention only one thing apart from encouraging latecomers to the ASP conference in Belfast and reminding you all that key issues like Shape of Training will be discussed there. Currently I have no fresh news at the time of writing, although I imagine the next Post will reflect on the meeting.

Right now, I wish to highlight the local Sustainability and Transformation Plans (STPs) <https://www.england.nhs.uk/stps/>. Once again, we see an opportunity to get palliative and end of life care on the local agenda/priority lists for each STP as it is forming. However, reports to date are mixed as to our success. We are therefore asking those of you who have been successful in engaging commissioners to make your experiences known to us so that we can share good ideas and ways to avoid pitfalls.

We all know that STPs' priorities will be the holy grail of saving money whilst improving quality. We know also that some of the things that we offer in palliative care can do both - the most obvious of which is to support avoidance of unnecessary hospital admission especially when the patient would prefer to be at home. However, there are plenty of others.

In order to support as many of our members as possible, we would like to hear

- from those of you who have engaged with your STPs to know the do's and don'ts
- where your local STPs have included palliative care and/or EOL care in their work plans, how you managed to achieve that
- As many experience and examples of success as you can bring to us.

We plan to share your experiences of how you achieved what you did and any other advice to other members via the website.

Please responses either to Dr Sarah Cox or Becki at the secretariat. We will then disseminate the key advice and post it on our site.

Finally this will be my last Post contribution as your President. Thank you for tolerating and supporting me and the Exec, it has been my privilege to serve you all.

Rob George
President

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

Evidence still insufficient that advance care documentation leads to engagement of healthcare professionals in end-of-life discussions: A systematic review.

Ebony Lewis, Magnolia Cardona-Morrell, Kok Y Ong et al

Palliative Medicine 2016, Vol 30(9), 807-824

In a systematic review of advance care documentation, the effectiveness of enhanced clinician's involvement in initiating end of life discussions was assessed. Twenty four, mostly qualitative, studies involving over 23,000 participants were included. Most studies reported that staff had a positive attitude to the use of advance care documentation to improve communication. There was one well designed cohort study that provided high level evidence indicating that the advance care documentation prompted an end of life discussion, but more evidence is needed.

Impact of Different Exercise Programs on Severe Fatigue in Patients Undergoing Anticancer Treatment. A Randomized Controlled Trial.

Markus K. Schuler, Leopold Hentschel, Wadim Kisel, et al

Journal of Pain and Symptom Management January 2017; Vol. 53; No. 1; 57-66

In this RCT the impact of a structured individual exercise program on fatigue in patients with advanced cancer undergoing curative and palliative treatments over 24 weeks was assessed. There was a reduction in mental fatigue for the groups taught the exercise program and worsening of fatigue in the control group.

Prepared by the APM science committee

To Tweet or Not to Tweet

Mark Taubert and Rob George discuss the Pros and Cons of Twitter

Mark: Twitter has changed the way I learn, receive information and news and how I communicate professionally. I follow a number of Palliative Care researchers, journals, the EAPC and institutions like ESMO, together with a number of news outlets like Guardian Healthcare. Oh, and of course Dr Ollie Minton, who's tweets are informative and funny. He is a compulsory follow if you're in palliative care and new to Twitter! I get a lot of new information from Twitter, and will try to learn something new each week by clicking on a suggested link. It can also help you virtually attend a conference that perhaps you did not have the time or cash to go to in person; conferences now have hashtags and by typing in the designated hashtag into the Twitter search engine, you can see comments, presentation links and posters that people have posted.

I also use it to find out the prevailing mood regarding certain topics. For example, there is a lot written about the Liverpool Care Pathway and #LCP on Twitter. Many comments appear misinformed, and I had a Twitter conversation with one individual who was initially very disparaging about LCP, but had in fact never read the LCP document. I posted her a link and I think her views perhaps softened somewhat regarding this emotive topic.

The TalkCPR website which was featured in the recent APM Post has an associated hashtag called #TalkCPR. Through social media promotion, we were able to attract more than 100K people to <http://talkcpr.wales> in the first 7 months of our campaign. If you type #TalkCPR into Twitter, you will see a lot of comments, including some from patient/carer representatives, which are actually very positive about this form of information dissemination. It is a different approach to merely churning out a patient information leaflet.

There is a lot of negativity on Twitter and some things have upset me. I suppose you need to decide how much you wish to communicate. You can remain 'silent' on Twitter and just pull in new information, or you may wish to post a few Tweets about professional aspects you are interested in and want to share with others. I have been trolled once or twice but it has affected me very little, having said that the Tweets were not personal. I have seen how Trolls, like bullies, try to gang up on individuals and try to discredit and humiliate them. It can be very anarchic, and so it is not for everyone.

I've also used it for teaching purposes. My Tuesday medical students now regularly hear my twitter handle, and I tell them that I'll post a link to the NICE Guideline on malignant spinal cord compression, for example. They love it, and it saves me time.

Rob: For me, the 'social media', and in this case Twitter, is and remains the quintessential two edged sword of our time: the realisation at once of an almost open access to our world, the best of its ideas and the opportunity as a single voice to have impact and even to make a difference.

Continued on page 4

Palliative Adult and Paediatric Guidelines (PANG 4)

The fourth edition of the Palliative Adult and Paediatric Network Guidelines (PANG) were published in November 2016. Since the first edition of PANG was published in 2002 more than 300,000 have been printed and distributed across the UK and beyond. The fourth edition includes extensive updates since the 2011 publication of PANG 3. These Adult and Paediatric Guideline updates have been completed by an authorship team of more than eighty health care professionals from nine regions across the UK.

PANG is a not for profit venture based on collaboration between the different regions who have shared the responsibilities of updating the guidelines and ensuring that they remain an evidence based and **practical** form of clear advice and support for those involved in the care of patients approaching the end of life.

With the retirement of Caroline Lucas and Andrew Hoy the Editorial team for PANG 4 includes, Max Watson, from Northern Ireland, Peter Armstrong a Palliative Care Pharmacist, Ian Back from Wales, Craig Gannon from Surrey and Nigel Sykes, formerly of St. Christopher's hospice.

The Guidelines have been produced in three formats to improve accessibility for the population of generalist health care professionals for which that they have been created.

Printed version: The 500 page 18cm X10 cm handbook has been stitch bound to ensure longevity even at the depths of the most crammed GP bag or clinicians pocket.



Printed version

The handbooks have been bought by the PANG partners at a subsidised rate for distribution across their areas. For those not part of the partner areas copies can be purchased from Amazon, or from www.simplyorderit.com/pal or telephone: 0344 824 3430

Web version: The guidelines are also available on the web and can be accessed through links on the websites of the nine PANG partners. The PANG Guidelines are hosted on the Palliative Care Matters website where additional resources created by PANG editor Dr. Ian Back are also available.

Hand Held version: For the first time PANG is now also available as a Kindle version from the Amazon website. For

PANG version 3 we created an app, the PalliApp but it proved difficult to manage because of the need to constantly renew the app whenever operating system software was updated. By using Kindle we are confident that the Guidelines will now be available consistently and through using the KINDLE search tools the Guidelines should be really easy to navigate using phones and handheld devices.

“Armed with these guidelines let us raise the bar even further with respect to the quality of clinical care we give to patients at the end of life, while we lower the bar so that more patients and carers with various illnesses may benefit earlier rather than later. Palliative care for all by all!”

Professor Scott A Murray MBE

Web version



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To Tweet or Not to Tweet... continued from page 2

... But freedom when fused with unaccountability and anonymity ipso facto will have a dark side: general and targeted bile, invective, un-evidenced opinion and 'false news'. Nevertheless, we are all grown-ups who can judge for ourselves and freedom is worth the risk of personal humiliations, knocks and home truths and most any other sling or arrow for that matter since the advantages to which Mark points outweigh the harms. Problem is, though, the high moral ground and grand political theory disperses like morning mist when things get 'up close and personal' and one get tangled in a world of polar opinions, especially if one expresses an objective and verifiable opinion against an apparent prevailing tide. Then Twitter is a bully's paradise and hunting ground for such dogs of war.

For me the experience was the recent failed round of claims for assisted suicide following the defeat of Marris' Bill in the Commons and leading up to the BMA debates of this last summer when the profession ejected the proposition from medical practice. As a part of the profession that should have a known view, I posted on our website that the arguments and data hadn't changed, and neither had our opinion. No big deal one would have thought since both statements were verifiably true and well known. However, over the next 3 days or so I had well over 15,000 tweets / retweets, orchestrated by the gloved fist of opposition deploying its constituency to protest that I had stifled debate.

One may respond objectively that it was probably no more than a puff or ripple in the flow of information and forgotten within days – the modern version of yesterday's news being today's chip paper, or even proof positive that I was speaking the truth if the remarks merited such a coordinated yet anodyne attack.

It didn't feel that way – I began to feel irrationally paranoid and my confidence across the board ebbed away; I found myself questioning the most mundane of my judgments and intellectually paralysed, but most telling, I switched off my Twitter feed and have not ventured there for many months. Call me a coward and you may well be right, but my voice was silenced – and I have to say that there were very few voices in support, so others were too.

For me the moral of this tale is that unrestrained freedoms when there is no brake of proportionality carries not just a personal cost, but may well become the highway to a new face of tyranny in the fold of liberal tolerance – after all look who now uses it as their principal vehicle of communication. That said, it is where the engaged congregate, and there still remains on balance more good than ill, although the odds may be shortening.

e-ELCA

Writing an advance decision to refuse treatment

This new session (01_06b) compliments sessions 01-05 Advance Decisions to Refuse Treatment: Principles and 01_06a Advance Decisions to Refuse Treatment in Practice. It uses four cases studies to help professionals think about how to support patients in the process of creating an advance decision to refuse treatment for different circumstances:

- A current life limiting condition
- Planning for cognitive decline in dementia
- A well patient

Examples of potential wording are taken from the work of the charity My Living Will. This was quite a challenging session to write and I hope you find you it useful.

Access – OpenAthens & Hospice codes

Health Education England e-Learning for Healthcare has added the thousands of e-learning sessions, including those of e-ELCA, to OpenAthens resources. The OpenAthens eligibility criteria, which are managed by NICE, cover anyone working directly with NHS patients. Anyone working directly on the development and/or delivery of training materials for either NHS staff or NHS patients within an organisation that

provides NHS-commissioned care or commissions care for NHS patients in England is also covered. This includes charities, voluntary organisations, local authorities and healthcare students.

For more detailed information on the eligibility criteria, and to register visit: www.nice.org.uk/about/what-we-do/evidence-services/journals-and-databases/openathens/openathens-eligibility

For more information about accessing e-LFH resources via OpenAthens visit: <http://support.e-lfh.org.uk/get-started/openathens/>

Additionally, each hospice and care home has its own registration code which staff can use to register for free access. Hospice codes are available from me, Becki at the APM, Hospice UK and from e-LFH support.

Are you interested in being the next clinical lead for e-ELCA?

I shall be stepping down from the role in July 2017 after three-years. Do get in touch if you might be interested in taking on the role which will be advertised in the spring.

Christina Faulf

APM e-ELCA Lead

mail to: Christinafaulf@loros.co.uk

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