

Association for
Paediatric
Palliative
Medicine

APPM

www.APPM.org.uk

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From the chairman

Dear colleagues

Previously, I have written to you all with the news of the increasing level of interest in children's palliative care, and from all I can see this very much continues.

This was reinforced at the recent APPM annual conference in London where there were many excellent

presentations as well as case discussions. Over 100 people attended, and from the feedback which we received "everyone would recommend the day to a colleague!"

Of course, there were constructive criticisms, but these were mostly about the lunch time food, and all of these are being taken on board by a group of three doctors who are working with Dr 'A K' Anderson to put on the 6th annual event at the same venue as in 2014, but on **Friday 27 November 2015** – please note it in your diary if you haven't already, but there will be more information as soon as more of the speakers confirm their provisional acceptances.



Executive Committee

2015.

Pat Carragher (Chair)

Lynda Brook
(secretary)

Anna-Karenia
Anderson [study day]

Yifan Liang (CSAC
Chair)

Sat Jassal (formulary)

Susie Lapwood
(revalidation)

Emily Harrop

Dermot Murphy

Tracy Blount

Michelle Hills
[trainee rep]

Anton Mayer

Heather McCluggage
(editor)

Katrina McNamara
(TfSL)

There are other national/international conferences planned in the interim (see pages 8 &9) but to highlight three others:

•'Living Matters for Dying Children' - (Together for Short Lives) – Birmingham – 14 & 15 April 2015.

•'Advocating for Children in a Rapidly Changing World' – RCPCH annual conference – Birmingham – 28 to 30 April 2015.

•"Medicine and Compassion: Tool for the Trade, or Dangerous Distraction?" 7th Cardiff International Conference in Paediatric Palliative Care – Cardiff – 8 to 10 July 2015.

It is highly likely by the time this is circulated that the first of these will be fully booked, but there are still places at the other two. The RCPCH conference in April affords the opportunity for the APPM to join with the subspecialties of Paediatric Intensive Care and Respiratory Medicine. There should be a very interesting afternoon session on Wednesday 29 April when specialists from within one region will look at the potential management of babies with SMA I and debate the options, broadening this to, "Just because we can....."

I believe the area of increasing therapeutic options for babies, children and young people who are probably life-shortened continues to challenge us all, and striking the right balance between developing advances and, at the same time, offering excellent palliative care is a skill to be practised on a case by case basis.

Accordingly, there is lots that can be learnt from highlighting good practice and debating optimal outcomes, so it is hoped that the

RCPCH will provide a platform for this for a wider audience than just ourselves.



This is one of the challenges for the APPM – a review of our recently refreshed website shows just this with the recapping of our objectives. At our annual conference in November 2014, we also held our AGM. **We offered our thanks to the three executive members who stood down with Mike Miller demitting with his imminent retirement at Martin House, and Michelle Koh and Victoria Lidstone also stepping down at this stage**, but with all three are very much maintaining their active interest in Paediatric Palliative Medicine.

Into these three vacancies at the Executive Group of the APPM we all welcomed:

- Tracy Blount (Hospice doctor at Rainbows Children's Hospice and General Practitioner at the Jubilee Medical Practice, Leicester).
- Michelle Hills (Trainee representative, but completing her CCT).
- Anton Mayer (PICU consultant in Sheffield and Medical Director of Bluebell Wood).

Since the AGM we have had two meetings and we are becoming more focussed about seeking how best to:

- Communicate with you all – we plan to maintain 6 monthly Newsletters but to have updates (an e-bulletin on one page of A4) sent to all members every 2-3 months.
- Communicate with our key stakeholders, which we plan to do increasingly in conjunction with Together for Short Lives, with whom we now have an agreed business model in terms of our administrative support.
- Increase the number of accredited courses in relation to Paediatric Palliative Medicine within regions across England, and across Wales, Northern Ireland and Scotland, as well as Eire which also formally joined with APPM at the AGM in November 2014.
- Improve links with General Practice and particularly with GPs working in children's hospices – and we are indebted to Tracy Blount joining the APPM executive to help us with this.
- Continue links with training for Paediatricians with a special interest in this – Michelle Hills and Yifan Liang are working on this.
- Disseminate the 2015 Combined Curriculum in Paediatric Palliative Medicine which was developed by the RCPCH and the APPM, through its College Specific Advisory Committee (CSAC), which Yifan Liang chairs
- Help with appraisal and revalidation – Susie Lapwood continues to act as our guru on this, and updates us regularly.

- Advertise the 2015 Master Formulary edited by Sat Jassal, (aided and abetted by Anita Aindow (Principal Pharmacist at Alder Hey Children's Hospital Trust) and many others – Sat and his team are already beginning work on the 2017 version!



- Be represented at the NICE group looking at Paediatric Palliative Care in England – more in due course as this work is essentially just beginning.
- Promote research– APPM is represented on the APPM-Together for Short Lives Group, which Professor Myra Blue-Langner chairs – more of this later in the year.
- Continue International work – so that we can link with Together for Short Lives in further fostering so much excellent work already being done in the International Children's Palliative Care Network (ICPCN), but also the European Association Palliative Care (EAPC).

Clearly there are other emerging areas of interest but the APPM Executive Group is asking each executive member to continue or to develop an interest in at least one of the above, but our intention is to very much **ask all APPM members to actively participate in this joint work**, and to invite individual colleagues to consider working with various of these groups. This can then be reported back to us all through e-bulletins and the Newsletter, and at our annual educational meeting, and also, of course, verbally when we separately meet up throughout the year.

Very clearly the work of our subspecialty is continuing on many fronts, and we are keen the APPM should coordinate this, to the betterment of children and their families, as well as supporting ourselves and other professionals who are working in this field.

Best wishes to all

Pat Carragher

APPM Study Day Nov 2014 Review

Once again the APPM study day was well attended and very well received! 104 delegates enthusiastically descended in London from all backgrounds of paediatric palliative medicine. The 70% response/feedback rate was incredibly useful and thank you to those who gave the APPM committee food for thought for 2015. The venue was positively received although we promise work is already full steam ahead for improved catering! The event was evaluated as good/excellent by 93% respondents and 100% would recommend the day to a colleague. We hope this will mean an even bigger and better 2015 study day.



This year's topics were interesting and varied with engaging speakers including non-palliative specialists and a pharmacist to add more flavour. We covered themes ranging from the neurobiology aspects of pain, cardiology, fatigue and metabolic diseases. In all, something for everyone! There was also a good opportunity for a full update on the APPM formulary (latest edition). All talks and the formulary can be found via the APPM website.

To conclude the day, workshops and case reflections were held. These, once again, provided a useful arena to discuss complex case scenarios.

Future thoughts for further study topics will be used for planning the next event and we are looking at ways to meet the networking needs of some delegates.

The APPM study days are not only good for CPD but are, hopefully, a stimulating arena for networking, generating ideas for research and changes in practice. We look forward to welcoming you in 2015!



How can one train in Paediatric Palliative Medicine (PPM)?

Perhaps you are a trainee reading this because you have an interest in palliative medicine, have stumbled across the APPM but are unsure how to develop your skills, knowledge and experience. Perhaps you have already decided this is the career choice for you but you are unsure whether to work as a specialist or develop an interest. Perhaps you know a trainee who would appreciate advice but you are unsure how to guide them. Hopefully this will unravel the mysteries and explain the process and options of PPM training.

PPM has been a recognised sub-specialty since 2006 and as with other subspecialties, training has become more structured and formalised. The recently updated APPM Curriculum (<http://appm.org.uk/14.html>) outlines what those in the field believe doctors at different levels are expected to know and provides guidance for training and study. The competency levels can obviously be obtained by doctors from any background and supports the development of the broad church of PPM doctors. Postgraduate qualifications such as a Diploma in (paediatric) Palliative Medicine are often undertaken to support learning.



In the Curriculum, level 3 should be attained by a paediatrician (consultant or Staff or Associate Specialist (SAS) doctor) who has developed a special interest (SPIN) in PPM, an established children's hospice doctor or GP with Special Interest (GPWSI) in paediatric palliative care. Level 4 should be achieved by a specialty consultant paediatrician in PPM, or a small number of children's hospice medical leaders (mainly leaders in sub-specialty formation and development, and with roles beyond their local hospice), and who have a substantive role in children's palliative medicine.

Becoming a specialist paediatric palliative medicine consultant

A tertiary specialist in paediatric palliative medicine must complete sub-specialty training through the National Training Number (NTN) Grid Scheme following formal appointment through the Grid matching process. There are currently Grid posts in Cardiff, London and Yorkshire. The training is 2 years and includes 3 months of adult palliative medicine.

Posts are advertised annually in September, to commence the following September. Due to the limited number of places available not all locations will be available each year. When part time trainees are in post this does lengthen the time before a post will become available again. Posts are only available to paediatric trainees in 'run-through' training. At the completion of training, doctors will be on the specialist register for both general paediatrics and PPM.

Becoming a paediatrician with a special interest in palliative medicine

The RCPCH specialty advisory committee (CSAC) recognises that SPIN doctors often deliver a substantial proportion of the clinical care and that an expansion in their numbers will be important in the PPM workforce sustainability in the future. Training and recognition of general paediatricians with special interests has become more structured and standardised. The framework of competences for the SPIN module in PPM, trainee handbook and SPIN application form are available on the RCPCH website. Trainees need to outline their proposed plan and educational supervisor and submit their interest

to the CSAC who can also advise on training opportunities.



There are very few non-grid training posts in PPM and therefore most trainees will need to tailor a personal training plan alongside their existing training posts, making the most of opportunities in other placements, eg. neonatology, neurodisability, oncology.

Their plan should include some hospice

and adult palliative medicine experience. The CSAC are happy to discuss details further with trainees or supervisors.

On completion of SPIN training, trainees meet with the CSAC for portfolio review. CSAC looks for knowledge of the 'level 3' curriculum and fulfilment of the portfolio requirements. A letter of commendation will then be given in recognition of their SPIN training. Specialist registration will be in general paediatrics on completion of training.

The CSAC would like to be able to recognise the commitment, passion and experience of many paediatricians with an interest in PPM. It is liaising with the RCPCH with regards to grid trainees in other sub-specialties, SAS doctors and post-CCT training. PPM is a continually expanding and developing specialty and we need to nurture talent and interest. Training posts are limited but



training opportunities are out there. The CSAC wants to help people get the training they need. Up to date CSAC contact details are on the RCPCH website.

Michelle Hills, Yifan Liang

QUIZ TIME!

Define what makes a paediatric palliative medicine specialist in 200 words (max)

Winning answer will be the leader to our section in the forthcoming multi-dimensional RCPCH curriculum!

Answers to michelle.koh@naomihouse.org.uk

Can you help?

Are you interested in shaping training for the next generation of PPM doctors? Is supporting education important to you?

Here is your opportunity to influence the continued development of specialty training in the UK!

Two posts on the RCPCH Specialty Advisory Committee are available (Training Advisor and Assessment Advisor) and we would love to hear from you!

further details see <http://www.rcpch.ac.uk/what-we-do/nominations/rcpch-nominations>

or contact yifan.liang@stees.nhs.uk (CSAC Chair)
<http://www.rcpch.ac.uk/what-we-do/nominations/rcpch-nominations>

or contact yifan.liang@stees.nhs.uk (CSAC Chair)

What's On?

14 & 15 April 2015. **Together for Short Lives Living Matters for Dying Children** Birmingham

27th April

Supporting Parents through Pregnancy Loss and the Death of a Baby' Advocating for Children in a Rapidly Changing World' [training@childbereavementuk.org]

28th April

Introduction to **Paediatric Cytotoxic Medication** Study Day [nurses]
Royal Marsden

29th April 1.45 pm to 6pm.

“Just because we can”



joint session with British Paediatric Respiratory Society, Paediatric Intensive Care Medicine and APPM.

May 7th 11th 12th 14th and 22nd **Child Bereavement Courses**

June 4th **Multi faith Paediatric Care Conference** Birmingham

June 9th and 10th **Child Bereavement Courses**

29th June. **Children’s and Young People’s Oncology Psychological and Neuropsychological Study Day** The Royal Marsden

July 8th-10th **"Medicine and Compassion: Tool for the Trade, or Dangerous Distraction?"**

Cardiff International Conference in Paediatric Palliative Care

10th September **Exploring Paediatric Spiritual Care Conference** Birmingham

For further courses see Together for short lives website. www.togetherforshortlives.org.uk

Learning by doing



With simulation based education having proved itself as an effective teaching method, we felt this could be used for paediatric palliative care health professionals. Death is the inevitable end-point in hospice care. However, the management of symptoms continues to be the mainstay of hospice management, and deaths are still relatively rare. For example, hospice nursing staff will infrequently manage patients undergoing a compassionate extubation (otherwise known as one-way extubation). These situations require input from highly trained and experienced health professionals. Relating to end of life care, there is only one chance to get it right.

A paediatric palliative care simulation study day was designed, aimed primarily at healthcare professionals (ranging from healthcare assistants to doctors) who manage these patients in the community/hospice. We believe this is the first of its kind in the UK. The aim was to establish whether attendance at the study day improved confidence and/or knowledge in the management of specific common and/or difficult situations in palliative care. The course was held at our local high-fidelity simulation centre, and costs to participants were met by Health Education Yorkshire.

On the day, following introductions, participants completed a basic demographic questionnaire, followed by questions regarding their confidence in different situations, and true-false questions to test their pre-course knowledge. They then were given the

opportunity to take part in at least one of five scenarios based on uncommon or difficult situations that may be encountered in paediatric palliative care. When not participating directly, they were able to watch the scenario play out via video link. The five scenarios varied but involved situations such as end of life care symptom management, basic life support, and compassionate extubation. Prior to each scenario, a basic description of the patient were given and participants were reminded to act in their usual roles. A debrief discussion was held after each simulation episode in order to draw on important learning points and answer any questions raised by the topics encountered.

At the end of the day, participants again completed the same confidence questionnaire and true-false questions. Thus far, 57 healthcare workers have participated in five separate study days. The results of this demonstrated an improvement in confidence and knowledge following attendance at the course. Feedback from the day has also been overwhelmingly positive.

We feel this course has been so successful due to its ability to practice in real-time unfamiliar situations in a safe environment. The involvement of all levels of healthcare workers is also to its credit, and participants relished the opportunity to network and discuss experiences. In order to take this course further, there are plans to involve actors in breaking bad news scenarios. The recruitment of a psychologist may also contribute to the value of debrief. The scenarios used on this course can be further adapted/extended and new scenarios could be designed. We hope that the success of the course could lead to further courses developing across the UK.

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If you have anything you would like to have included in the Newsletter please contact the editor heather.mccluggage@gmail.com