Association for Paediatric Palliative Medicine

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Michelle Koh

Victoria Lidstone

Susie Lapwood (revalidation)

Heather McCluggage (editor)

Mike Miller (Secretary)

Dermot Murphy

Toni Wolff

Dr Lynda Brook Chair APPM writes

The APPM continues to develop the resources and services available for our members. We are excited to be able to announce that we have secured a **one year free trial online subscription for BMJ Supportive and Palliative Care Journal** and you should each individually be receiving information on how you can access this shortly. Over the next few months we are also going to be working on developing the APPM website www.act.org.uk/appm to include a specific **Education and Training Page** and an area for accessing **APPM peer reviewed protocols and guidelines**. If you have anything that you would like to submit for either of these please do not hesitate to get in touch.

APPM Executive At the November 2012 AGM we were delighted to be able to elect Dr Emily Harrop and Dr Lidi (Victoria) Lidstone to the APPM executive team. They are joined by Dr Sat Jassal who, as a GP working in General Practice as well as Palliative Care working to help us identify ways to actively engage with General Practitioners who are working both in General Practice and Children's Palliative Care.

The APPM executive is working closely with the newly formed Together for short lives which brings together Children's Hospices UK and ACT into one organisation. We are particularly keen to ensure that we work collaboratively in areas such as education and training, policy and practice in order to ensure a consistent approach and maximum benefits across the sector.

Other project work The second edition of the **APPM Children's Palliative Care Master Formulary** is scheduled to be launched at the Cardiff International Conference on Paediatric Palliative Care in July 2012 . The APPM Children's Palliative Care Master Formulary provides information on indications, routes and standardised doses for paediatric palliative medicine based on systematic literature review and appraisal of available research evidence together with expert consensus opinion where there is insufficient research evidence. Findings of the APPM online international paediatric prescribing survey will be presented at the Palliative Care Congress in March and an abstract has been submitted for the Cardiff International Conference on Paediatric Palliative Care. Thanks to all who completed the questionnaire.

Research meetings and study days *See page 11 for full details*

(APM) at the 9th Palliative Care Congress, www.pccongress.org.uk There will be a range of paediatric palliative care oral presentations, poster presentations and guest speakers.

The APPM is collaborating with the Clinical Ethics and Law group at the **Royal College of Paediatrics and Child Health Annual Scientific Conference** 22 – 24th May SECC Glasgow www.rcpch.ac.uk. The joint session will have a particular focus on ethical aspects of palliative care including submitted abstracts and panel discussion

- Compassionate extubation
- Refusal of treatment, including the advance refusal of care
- Resource issues related to place of care
- Maintaining the confidentiality of children and young people whilst also meeting our obligations to their parents

Other current APPM activities include:

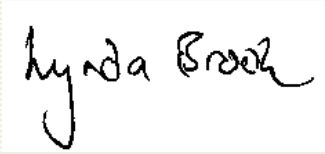
Ongoing work linking in with **the Palliative Care Funding review** http://palliativecarefunding.org.uk . The Palliative Care Funding Review team was tasked with reviewing the current funding mechanism for dedicated palliative care for adults and children in England. The pilot sites for data collection are due to be announced very shortly and we will keep our members informed of progress.

Support for **appraisal and revalidation** particularly for doctors working in paediatric palliative medicine outside the NHS. A further briefing letter will be sent to Hospice CEOs and heads of care in the next few weeks.

Development of **standards for education and training in paediatric palliative medicine** for those not eligible for CCST via RCPCH.

Quality assurance and validation of **Specialist Training in Paediatric Palliative Medicine** via the RCPCH Paediatric Palliative Medicine CSAC. The CSAC sits formally under the RCPCH and is affiliated to the APPM. More information is available via the RCPCH website.

Finally the APPM will be working closely with Together for Short Lives and the Department of Health in the development of the **Children's and Young People's Outcomes Strategy.** This national strategy will identify the health outcomes that matter most for children and young people and consider how well these are supported by the NHS and public health outcomes frameworks [and by other benchmarking information available to HWB partners] and make recommendations. The strategy will consider the spectrum of children and young people's health needs and outcomes, including palliative care, children with long term conditions and children with complex health needs. We are also keen to link children's palliative care outcomes to adult standards for palliative care.



Dr Lynda Brook – Chair Association for Paediatric Palliative Medicine Lynda.Brook@alderhey.nhs.uk

March 2012

Association for Paediatric Palliative Medicine

The second edition of the APPM master formulary

The first edition of the APPM master formulary was released in 2011. The work was very well received both at home and abroad.

Almost immediately after its production a new team was put together to work on the second edition. We were aware from the initial work that there were a number of discrepancies and omissions. Some of these such as deciding whether to give infusions per hour or per 24 hours were quite easy to resolve. Others such as the use of methadone had been very complex and difficult to obtain agreement on. The four drugs that we have had the most difficulties with have been methadone, ketamine, dexamethasone and fentanyl. The literature reviews conducted on these drugs have been sent out to a APPM members as well as being put onto the website. The conclusion from these reviews has been that there is no strong evidence to recommend specific dosages of these drugs in all situations in terms of paediatric palliative care. What we have been able to do is begin to understand where future research into drugs needs to be focused. Some of this research is already being done i.e. Fentanyl research in Australia, other research we hope to direct through joint working with a number of paediatric research groups with whom we have established links.

The second edition of the formulary is now being prepared. Within a few months the work will go out for peer review and we hope to have the formulary ready to present at the Cardiff International PPC meeting in July 2012.

We are currently looking at the sustainability of the formulary by trying to work with Together for Short Lives to obtain funding for the next 3 years. This will then allow us to keep the formulary up to date with new guidance and research in the field.

Dr Sat Jassal

Chair of the APPM sub group

on Master formulary

Good Practice Focus

This project was inspired by the children's community respiratory physiotherapy service of Tower Hamlets.

Feedback from families has been extremely positive:

This is a fantastic service and gives me peace of mind. You are really quick to respond to any of my concerns.'

'Moira is wonderful. I really wish I'd had her for my other little girl'.

'I will be ringing you all the time! I definitely think it will be made permanent because there are lots of children that will need you.'

Rapid Response Respiratory Physio Project

This project was set up by Moira Flanigan children's physiotherapist at Nottingham Children's Hospital with the support of Toni Wolff, community paediatrician and David Thomas, respiratory paediatrician

The service provides out-reach respiratory physiotherapy to children with severe disabilities when they develop chest infections. As well as a rapid response when the child becomes unwell, Moira also trains parents and carers in chest clearance techniques to prevent chest infection in these very fragile children

30 children received the service in the initial 6 month pilot, which was funded from the DH £30 Million. Admissions and emergency department attendances for these children were significantly reduced. The 2 local PCTs, Nottingham City and Nottinghamshire County agreed funding to extend the project and to collect more data

There are now 42 children receiving the service. Data collected by the PCTs indicated an average 90 respiratory related spells per year into secondary care for these children, which was reduced to 30 spells in the 12 months of the project with a cost saving of over £120,000 per year.

The project has been given further funding from the PCTs including a second physio to extend the service across the whole of Nottinghamshire.

Association for Paediatric Palliative Medicine

Newsletter

The APPM and the CSAC: What are they and what's the difference?

It is gratifying to be able to look back over the last ten years and realise the progress made in paediatric palliative care. From individual doctors developing an interest in children's hospice and palliative care in isolation, we evolved first into specialist groups of children's hospice doctors and paediatricians with an interest in palliative medicine, and more recently joined forces to make the Association for Paediatric Palliative Medicine. The joint group brings together the skills of a diverse range of doctors including general paediatricians, community paediatricians, paediatric oncologists and general practitioners as well as specialist paediatricians and children's hospice doctors.

The changes in specialist paediatric palliative medicine have been no less seismic, though they have probably affected rather fewer people. One of the fringe benefits of becoming a recognised subspecialty within the Royal College of Paediatrics and Child Health was that we were provided with the administrative infrastructure for a Specialist Advisory Committee (SAC) in Paediatric Palliative Medicine.

The SAC has two principal functions. Its first is to coordinate specialist training for those paediatricians wishing to specialise in the new field of paediatric palliative medicine. This involves establishing educational goals (which in practice we had already done in partnership with the APPM), approving grid training posts in paediatric palliative medicine by carefully balancing the number of trainees with the expected number of new posts, providing a framework of supervision and teaching for those trainees as they progress through their programme, and finally advising that a trainee has completed the programme required and should be issued with a certificate of specialist training.

The SAC is convened by the RCPCH. Its second function is to act as the link between the Royal College and the rest of paediatrics in relation to paediatric palliative care. In relevant matters relating to the RCPCH, the SAC speaks for palliative medicine.

The SAC has begun to take on roles that flow naturally from these main functions. We anticipate that it will become increasingly possible for a formalised post certification training to be available to clinicians who already hold certificates. For most colleges, these will either be GPs or consultants. We are probably unique in aspiring ultimately to consider the training needs of both. In the meantime, the SAC is also providing structured training sessions for Level 4 and some Level 3 trainees across the country.

The two functions of the SAC, then, are to coordinate specialist training in paediatric palliative medicine, and to act as a conduit between paediatric palliative medicine and the RCPCH.

Since both the SAC and the APPM comprise doctors working in children's palliative care; it is understandable that their functions are often confused. In reality, the role of the APPM is quite distinct; both more diverse and more innovative than its sister organisation in the RCPCH. Where the SAC by its nature represents a narrowly defined group of paediatric palliative medicine physicians, the APPM can offer a much broader array of opinions.

The SAC can usually speak only for paediatrics; the APPM can speak for the whole of paediatric palliative medicine. The SAC has to focus on the training needs of specialist trainees in paediatric palliative medicine, while the APPM can address those of all professionals. The APPM is not a statutory body, with all the strengths and weaknesses this implies. It is not bound by the regulations of the RCPCH, but on the other hand cannot speak with the authority of the RCPCH.

The SAC and the APPM have, in fact, two quite distinct functions. The functions are complementary. The SAC could not possible give a voice to the range of opinions and comment offered by the APPM. Many of the functions of the SAC in advising the College on matters to do with paediatric palliative care can only be done because the SAC can turn to the APPM to solicit the opinion of this wider body of professionals. There is extensive cross representation between the two groups, and it is essential that this should continue if the SAC is to fulfil its fit function as the voice of palliative care to the RCPCH. The APPM constitution states that the APPM Executive must include formal representation from the CSAC and this may be achieved either by an individual being appointed at executive level to both bodies or through co-opting a member of the CSAC. On its part, it has been decided that the SAC should always include a specialist in PPM, a paediatrician working in a children's hospice and a general paediatrician with a special interest in PPM. It is also agreed that the SAC will co-opt others where necessary to make the most of their experience. The APPM is the natural source of such members and co-options.

So it is clear that the APPM and the SAC, despite the overlap in their membership, are both necessary, and that they are complementary. The job of the SAC is to be goal orientated and focused, and this needs be counter balanced by a body such as the APPM that can be creative, and encourages blue sky thinking from a diverse range of members' opinions. On the other hand, if those opinions are to be enacted formally and given the authority of the RCPCH, it is necessary for there to be an SAC to act as conduit.

Richard Hain, Chair SAC in PPM, RCPCH *Lynda Brook, Chair APPM*

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Executive Group of APPM – Working on your behalf

There are increasing numbers of requests coming in to the APPM for our comments as an organisation, or sometimes our endorsement of various national developments, such as guidance documents and care pathways. One recent example was the Emergency Health Care Plans – Core Principles and Guidance for Professionals which is being produced by the Council for Disabled Children in conjunction with the Royal College of Paediatrics and Child Health. We realised that we need a system to enable us to respond as an organisation in a prompt and coordinated way. We have therefore put the following in place. Requests for APPM involvement / comments on work of national importance will be directed to the chair of APPM who will then circulate the document or opportunity to join a specific working group to the members of the APPM executive. One or sometimes two of the executive members will volunteer or be chosen to be involved on our behalf, leading on our response with appropriate consultation with and feedback to the executive group as appropriate. *The wider membership of APPM will be consulted and informed via the newsletter.* ***Your comments on this arrangement are welcome and can be addressed to*** toni.wolff@nuh.nhs.uk

Processes for revalidation of doctors have continued to develop rapidly since the last newsletter. Hospices and their doctors have just been sent a further update letter with a list of resources to support both professional development and revalidation. I will not reiterate here the hospice-specific guidance in that letter, which will also be available on the revalidation section of the APPM website: the key issue is to ensure that each doctor is linked to a Responsible Officer and that if necessary the hospice has recognised its need to be a Designated Body and to complete an Organisational Readiness Self Assessment exercise.

With the first doctors likely to be asked to revalidate from December this year, and every doctor due to have been revalidated by April 2016, we all need to ensure that we have revalidation-ready processes in place. Revalidation presents a positive opportunity for both employing organisations and their doctors to ensure that high quality appraisal and professional development opportunities are resourced and accessed, and systems developed to ensure appropriate supporting information is readily available. Time invested to develop good systems now, will optimise the benefits and reduce the burdens of medical revalidation over the longer term. There will continue to be rapid developments in the next few months. The GMC will shortly be writing again to every doctor to ensure that we all have a Responsible Officer (RO) and are engaging with preparations for revalidation: in paediatric palliative care, this will include planning the collection of appropriate supporting (Specialty-specific guidance is still in draft form at

http://www.aomrc.org.uk/news-a-publications/205-whats-new.html, complementing the broad guidance issued by GMC in April 2011: http://www.gmc-uk.org/doctors/revalidation/supporting_information.asp). The Revalidation Support Team is planning a final version of the 'Medical Appraisal Guide, draft available at: http://www.revalidationsupport.nhs.uk/about_the_rst/rst_projects/mag_projects.php).

It is intended that doctors should undergo **'whole practice' appraisal**, with evidence of their paediatric palliative care work being represented in their revalidation appraisal even if this is a relatively small part of their overall work, and their 'revalidation appraisal' is in a different field such as general practice or hospital paediatrics. This evidence could include a summary from a separate hospice appraisal and/or other supporting information from the paediatric palliative care role.

Patient and colleague feedback questionnaires: These will probably only be required once in a five year revalidation cycle, in the early years, although doctors may do this more often. Various commercial companies are developing questionnaires that meet the GMC Guidance for such tools. RCPCH has now launched a pilot tool for obtaining patient feedback in paediatrics, although patient feedback (e.g. from parents and carers). The RCPCH tool is only validated for hospital outpatient settings, but has been used in other settings, too, and may prove feasible to use in hospice settings. Watch this space.

given our patient population, we may need to rely largely on proxy patient feedback (e.g. from parents and carers). The RCPCH tool is only validated for hospital outpatient settings, but has been used in other settings, too, and may prove feasible to use in hospice settings. Watch this space.

APPM is aware that doctors will need to demonstrate their professional development activity in paediatric palliative care as well as in any other professional roles. We are aiming to circulate a menu of learning opportunities in the field: below are a list of some. There are many new resources available following the DH 30 million projects. To complement the annual APPM study day, we may set up regional Core Crriculum study days. ***Please let us know if you would find this helpful***

The Revalidation Support Team recognises that doctors working in **independent hospices** have particular and unique concerns in relation to revalidation (small specialty, many outside the NHS or combining palliative care with other roles in a portfolio career, difficulty appointing a Responsible Officer): they are keen to offer support. They are therefore considering planning 2 days probably in April / May (one in the south, one in the north) to inform, advise, support, and answer questions as the process evolves. Please let me know if you would be interested to attend one of these days, and what issues you would like to see covered during the day.
For **further information**, the APPM website www.act.org.uk/appm hosts a revalidation section which we endeavour to keep up to date. This includes a PDF of my presentation on the subject for the APPM study day on 25 November 2011. . Please keep me informed with any questions or concerns as the process develops.

Association for Paediatric Palliative Medicine

Professional Development Resources (links checked 17.2.12)

- Children's Palliative Care: A Handbook for GPs : www.act.org.uk/gps
- Basic Symptom Control for children's palliative care: www.act.org.uk/symptomcontrol
- Association for Paediatric Palliative Medicine Master Formulary www.act.org.uk/appmformulary
- www.palliativedrugs.com (Palliative Care Formulary, Bulletinboard, shared guidelines)
- West Midlands paediatric palliative care e-learning (22 modules): http://wmdsafelive.ocbmedia.com/index.php/
- e-ELCA (End of Life Care for All): more than 150 on line learning modules http://www.endoflifecareforadults.nhs.uk/education-and-training/eelca
- EACH Library and Information Service: http://www.each.org.uk/what-we-do/library_info_service
- Mental Capacity Act 2005 training module: http://www.helpthehospices.org.uk/mca/index.htm
- Advance Directives to Refuse Treatment: www.adrt.nhs.uk includes training modules
- Current Learning in Palliative Care (CLIP) at: http://www.helpthehospices.org.uk/clip/index.htm
- BMJ Learning: wide range of modules at: http://learning.bmj.com/learning/home.html
- Contact APPM for further learning opportunities (e.g. at Certificate, Diploma and Masters level)

Useful links to support medical Revalidation (checked and updated 17.2.2012)

GMC: Good Medical Practice framework for appraisal and revalidation (April 2011) http://www.gmc-uk.org/doctors/revalidation/revalidation_gmp_framework.asp

GMC: Supporting information for appraisal and revalidation (revised April 2011)http://www.gmc-uk.org/Supporting_information100212.pdf_47783371.pdf

GMC: Guidance on colleague and patient questionnaires (revised April 2011)http://www.gmc-uk.org/Colleague_and_patient_questionnaires.pdf_44702599.pdf

GMC: 'Good Medical Practice' guidance for doctors (2006)http://www.gmc-uk.org/static/documents/content/GMP_0910.pdf

Responsible Officer guidance (July 2010)

http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_119418.pdf . Page 13 has table ' How do I find out who my responsible officer is?'

Organisational readiness for revalidation self assessment tool and briefing note

http://www.revalidationsupport.nhs.uk/files/ORSA_2010-11_v1.0.pdf

http://www.revalidationsupport.nhs.uk/files/Briefing_for_DBs_on_ORSA_exercise_010211.pdf

http://www.revalidationsupport.nhs.uk/ for more general information about revalidation and appraisal. Hosts the draft 'Medical Appraisal Guide'at http://www.revalidationsupport.nhs.uk/medical_appraisal_guide/

and 'Responsible Officer newsletters' at : http://www.revalidationsupport.nhs.uk/responsible_officer/responsible_officer_newsletter.php

Draft specialty-specific guidance on supporting information (October 2011) is available at

http://www.aomrc.org.uk/revalidation/revalidation-publications-and-documents/item/speciality-frameworks-and-speciality-guidance.html

RCGP Revalidation guide for GPs v 6 (Sept 2011) http://www.rcgp.org.uk/revalidation/revalidation_guide.aspx **https://appraisals.clarity.co.uk/** for an Appraisal toolkit and electronic forms etc. This site includes a proforma 'Structured Reflective Template' (SRT) for each section in the supporting tools. (Note new website address from 21.5.11)

Association for Paediatric Palliative Medicine

Newsletter

Scotland successfully launches nationwide resuscitation plan for children

The Scottish Government has been instrumental in leading policy development for resuscitation planning in both adults and children. As part of "Living and Dying Well", a national consultation exercise on all aspects of Palliative Care, the first national policy for DNA CPR decision making in Europe was launched. Simultaneously the children and young people's acute deterioration management plan (CYPADM) was launched in January 2011.

CYPADM grew out of are recognition that resuscitation planning was poorly done throughout the country. A core group of professionals co-opted individuals from a huge variety of disciplines and sectors and there was a fantastic working relationship between these disparate groups. This degree of consensual working produced a document that aimed to prevent unnecessary, unwarranted or unwanted attempts at resuscitation while clearly delineating which resuscitative measures were appropriate. The policy and document are greatly strengthened by this remarkable example of cohesive working. As it was a Government backed initiative, the whole policy frame work was reviewed by the General Medical Council, leading defence organisations and Scottish Government Legal Offices.

An audit of the first year's use of the form via the Scottish Paediatric Surveillance Unit is almost complete. Returns from the first nine months since implementation have shown a gratifying use of the form. This was achieved through the hard work of professionals in all sectors including children's hospices, schools, respite care facilities and the Scottish Ambulance Service. Each Health Board appointed local champions for the process. They were responsible for trickle down education and training. A training package was devised by the NHS Education for Scotland (NES) and two training packages were produced and distributed on professionally produced DVDs.

The resuscitation plan is seen as the first step in providing a much larger end of life care plan and pathway for all children with life limiting and life threatening disorders within Scotland.

The CYPADM documentation can be viewed and downloaded at the Scottish Government website. The easiest way to do this is to enter CYPADM into a search engine and the policy document, form, fax sheet, Chief Medical Officer's letter and guidance notes will all appear. There is a separate parent's information sheet that will be available on the web shortly. The educational DVDs have proved remarkably popular and are free to any medical professional working in Scotland. It has been used extensively by our colleagues in adult medicine to illustrate advanced communication techniques. **For colleagues working outside Scotland, the DVDs are available via contacting Dr Dermot Murphy at the Royal Hospital for Sick Children, Yorkhill, Glasgow.**

Ongoing audit will be accompanied by in-depth qualitative research looking at the experiences of health professionals, other involved professionals and most importantly families involved in this process. **The combined adult and paediatric policies have been chosen to be presented as a key note lecture at the 9th Palliative Care Congress in Gateshead and the paediatric work stream has been submitted to the Cardiff conference in June**. We hope to publish the results later on this year.

Dr Dermot Murphy.

Association for Paediatric Palliative Medicine

Newsletter

New Special Interest Fora to be launched at the Palliative Care Congress, Gateshead 2012:

A new SIF for Transition will be launched at the Palliative Care Congress this March by the All Wales Clinical Lead for Transition, Dr Victoria Lidstone.

Dr Lidstone says "As we know, the numbers of young people with life-limiting conditions surviving through childhood is increasing year on year, and we need to make sure that services are ready to take on this 'New' population. With good joint working between paediatric and adult services we can really make a difference for these young people. Come and chat through some of the issues and meet other enthusiastic professionals at the inaugural SIF meeting"

The meeting will take place at the Congress on Friday 16th March at lunchtime. Everyone is very welcome, just turn up on the day. Hope to see you there!

Interested in Young Peoples' Palliative Care?

Why not join the Transition UK E-group?
Network with like-minded colleagues
& keep up to date with study days, events and policy.

Email me at Victoria@Lidstone.net to join.

EVENTS 2012

The 9th Palliative Care Congress.
The Sage Gateshead,
14-16 March 2012
www.pccongress.org.uk

RCPCH
Annual Conference 2012
22-24 May 2012 SECC, Glasgow

www.rcpch.ac.uk.

THE 6TH INTERNATIONAL CARDIFF CONFERENCE ON PAEDITARIC PALLIATIVE CARE
11 - 13 JULY 2012

- Science, morality and meaning: the palliative package? –

PPC2012@cardiff.ac.uk

3rd Annual APPM Study Day
16th November 2012

Including AGM

www.act.org.uk/appm.