
Briefing from Pat Carragher

Chair of APPM

In November 2012, the APPM held its third annual educational day, and feedback has been very positive, once more...and with this positive feel, it is clear that the APPM is coming strongly through the initial period which followed the amalgamation of the British Society of Palliative Medicine with the Association of Children's Hospice Doctors. Much of this has been in no small part the result of the leadership and guidance from Dr Lynda Brook, which is resulting in this successful amalgamation, an increase in membership, repeated and successful national study days, much representative work at local and national levels, and much more.



And so, at the Annual General Meeting that day, Lynda stood down as Chair, but she is staying on the APPM Executive as its secretary, as Mike Miller moved aside following excellent support of Lynda during these times...we are also hugely indebted to Mike, as well, but both he and Lynda are now threatening to step down from the Executive team later in 2013, so, if this is the case, please

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Anna-Karenia Anderson

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Pat Carragher (Chair)

Yifan Liang (CSAC Chair)

Emily Harrop

Sat Jassal (formulary)

Michelle Koh (vice-chair)

Susie Lapwood
(revalidation)

Victoria Lidstone

Heather McCluggage
(editor)

Katrina McNamara (TfSL)

Mike Miller

Dermot Murphy

consider, even now if you can continue the momentum they have given us, by standing for election!

At that meeting, also, I took over as Chair of APPM, and with it, it is clearly very obvious, already, just how much behind the scenes work Lynda did. Additionally, I can see that there many strands of work to continue to actively support and develop, including the

- Support and education of clinicians working with children and young people with life shortening conditions, whether they work within a hospital, a children's hospice or a community setting
- Support and advice through appraisal and revalidation for doctors working in this field
- Very close working relationship with Barbara Gelb and her team at "Together for Short Lives", itself also just coming through the amalgamation of Children's Hospice UK and ACT, and already there are joint work streams with APPM, and additionally we are indebted to TfSL for all the administrative work for this Association
- APPM Master Formulary – launched in Cardiff last year, available free online, and already being translated into different languages across the world
- Appropriate workforce development, coupled with standards and training in paediatric palliative medicine, referenced so well with the Combined Curriculum in Paediatric Palliative Medicine
- Research considerations across children's and young people's palliative care
- National meetings with the 4th Annual Study Day on Friday 29 November 2013, and earlier the Royal College of Paediatrics and Child Health Annual Scientific Conference in Glasgow, between 5 and 7 June 2013.

All in all, it promises to be another good year, but also significant work for us to be part of, if we are to ensure that children's and young people's palliative care is to continue to find the recognition it deserves across the five countries of the British Isles and beyond!

Pat Carragher February 2013



CAF Plus: Enhancing the Common Assessment Framework



for children with complex healthcare needs

End of Phase – 1 Report

What is CAF Plus?

CAF Plus is an enhanced version of the Common Assessment Framework (CAF) designed to support multiagency assessment, planning and co-ordination of care for all children with complex healthcare needs, disabilities, or palliative care needs. CAF Plus supports consent for inclusion of the child's details on the local disability and/or palliative care register. Data collected through CAF Plus also informs commissioning and service provision. CAF Plus is implemented through supplementary training materials, including video clips and case studies, incorporated into standard CAF e-learning and multiprofessional training programmes.

The CAF Plus Project

The CAF Plus Project was established in 2011, funded by NHS Northwest Innovate Now and facilitated through a steering group lead by Health, working in partnership with the Northwest CAF Co-ordinators Group.

CAF Plus aims to:

- Enhance CAF with a Plus approach to join up assessment and planning for children with complex health needs and their families.
- Further develop multi-agency working by implementing the CAF Plus approach through strategic sign up and operational support, linking local authorities, acute, community and voluntary sector providers
- Strengthen partnership work with parents and increase the number of children with complex healthcare needs that receive coordinated support through CAF Plus and an identified Lead Professional.
- Support professionals working with children with complex healthcare needs in implementing CAF Plus through training, guidance, advice and mentoring.
- Improve understanding ensure consistent application of definitions in order to facilitate collection of data on numbers and needs of children with disability and/or palliative care needs.

The benefits of CAF Plus:

- High **quality** and reduced duplication of assessment of all children with disability, complex long-term conditions and palliative care needs.

- **Innovative** development and enhancement of an established CAF approach building a strong foundation to link specialist assessments and coordinate multiagency planning.
- Improved **productivity** through reduced duplication of multiple health, social care and education assessments; greater focus on services delivered and designed around identified needs of children; coordinated and fully integrated service delivery across statutory and voluntary sector; effective, multi-agency and focused training, releasing time to care.



- Intelligent commissioning enabling **prevention** through ensuring high quality initial assessment process in partnership with parents, enabling early identification of needs and the most appropriate interventions to be delivered in a timely manner to meet children's needs and reducing inappropriate referrals to specialist services.

What have we achieved so far?

- Promoted the **CAF Plus approach** through a range of networks
- Produced a series of CAF Plus materials, which include information for parents, strategic and operational briefs and child and family-centred **CAF Plus standards**.
- Developed supplementary **CAF Plus training materials**, including video clips and case studies, that can be incorporated into standard CAF and multiprofessional training programmes. The interactive learning design has less focus on procedure and forms, using video clips to enable practitioners to enhance and refresh their interactional and relationship-building skills.
- Created a **web based platform** from which services and organisations can find information about CAF Plus, download an extensive library of video clips and other materials, and communicate for mentorship and support.
- Developed a **one day CAF Plus Training programme**. The programme includes child and family-centered assessment, definitions of disability and palliative care, and communication skills for seeking consent for information sharing and for inclusion on disability and/or palliative care register.
- **Delivered CAF Plus training** for over 60 professionals in the Northwest across health, social care and education.
- Initiated a **CAF Plus Pilot in Halton**, involving strategic sign up and operational support in the delivery of multi-agency training.
- **Engaged with and supported various organisations and services** working with children with complex health needs including acute trusts, special schools, hospices and community children's nursing teams to explore potential of CAF Plus.

Key recommendations:

- **Strategic sign up** of executive leadership to the CAF Plus initiative is vital to create momentum in the local system and support and empower front line staff to adopt work effectively across agencies and and unblock barriers to the CAF lead professional role.
 - Discrete education and training sessions are only a small initial focus. Much more is required in terms of preparing expectations and providing **ongoing**

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support for professionals in 'real life' in the form of coaching and supporting from a more experienced CAF Plus professional.

Participants from the day:

"Having the parent video clips makes it feel like there are parents in the room – they say it as it is and it is important to take note"

"The focus today is much more interactive than our local CAF training has been – I'm really enjoying the discussion and opportunity to work in twos and threes – its much more meaningful"



From parents:

"It was a great help because they arranged the CAF meeting, all the professionals are there face to face. I can tell them what I am feeling about the situation, how they can help or this way can help for my family or my child, and they could say what they have done, what is the ongoing process, and how we are going to achieve these things, what we have to do and which professionals have to be involved in this meeting next"

Next steps...

CAF Plus is being supported by Merseyside & Cheshire Health Innovation & Education Cluster (MCHIEC), to support the spread and adoption of innovation locally and strengthen professional education and training in healthcare. The objectives of this second phase are to:

- Deliver CAF Plus training programme for professionals in paediatric medicine, community children's nursing, children's palliative care, special education, paediatric community therapies and social work.
- To provide an ongoing mentorship and support for professionals who have completed the CAF Plus training.
- To evaluate the effect of the CAF Plus programme on professionals insight, knowledge, confidence and abilities to take on the role of lead professional and lead or participate in multiprofessional assessment and care planning.
- To evaluate the impact of the CAF Plus on the experience of multiagency assessment care planning, co-ordination and continuity of care for children and their families.
- To disseminate the findings and encourage further rollout of CAF Plus.

Get Involved!

To find out more or to get involved please contact the project team directly

Lynda.Brook@alderhey.nhs.uk

Revalidation is an opportunity to celebrate good practice, support professional development and flag up what needs to change (GMC 2010)

Since the update I wrote for the September APPM Newsletter, Revalidation has begun! This is ‘Year 0’ and the first doctors (mainly medical leaders) have now revalidated. Most doctors are expected to revalidate in the next 3 years (ie by April 2016). I hope most doctors and Designated Bodies are now aware of the processes and are engaging with development of systems in your organisations to support revalidation.

I was pleased to facilitate discussions at a ‘Leaders of Care’ day hosted by Together for Short Lives recently, raising awareness of the opportunity we have to work together with our non-medical colleagues to inform collection of relevant doctor-specific supporting information, and provision of formative appraisal and professional development opportunities, particularly in children’s hospices. We have a continuing opportunity to influence this positively, in order to ensure that we don’t just ‘tick the box’ but the potential added value in formative appraisal is realised, to support professional development and improve practice in paediatric palliative medicine. It is likely that local and national processes will continue to be developed and refined in the light of early experience with revalidation.

The appraisal process, hopefully now familiar, is outlined in figure 1. Just a few highlights to note:

1. **New APPM revalidation weblink:** I continue to upload more detailed guidance and resources specific to our specialty on the APPM revalidation page (note new link: www.bit.ly/appmrevalidation).
2. **Whole practice appraisal:** This is just a reminder. Revalidation will be based on whole practice appraisal covering all a doctor’s professional roles. We need to provide supporting information from each role (and/ or evidence from other appraisals) to discuss in the ‘whole practice’ appraisal.
3. **Supporting information:** The GMC guidance ‘How can doctors meet the GMC’s requirements for revalidation in the first cycle?’ (April 2012) is extremely helpful and is the bottom line all doctors *must* adhere to regarding supporting information (our Colleges may have additional specialty-specific recommendations). http://www.gmc-uk.org/static/documents/content/Meeting_our_requirements_in_the_first_cycle.pdf
The emphasis throughout is on the doctor reflecting on what the supporting information (even if not personalised) means for their individual practice.
4. **Do you want an appraisal in Paediatric Palliative Medicine?** APPM now holds a small list of ‘revalidation-ready’ trained medical appraisers, who have agreed in principle to offer appraisal to colleagues working in paediatric palliative medicine, availability-permitting. Plan early for the next appraisal year and contact me or Together for Short Lives if you would like to be put in touch with an appraiser in this subspecialty. Any agreement to appraise would be between the appraiser and the Designated Body. Doctors have very different ways of working and portfolio careers, but it would be good practice to aim for doctors working in this field to have an appraiser with experience of the subspecialty (or a closely related field) at least once or twice in the 5 year revalidation cycle.

How can you help ensure that appraisal for revalidation is as useful as possible for all of us working in paediatric palliative medicine

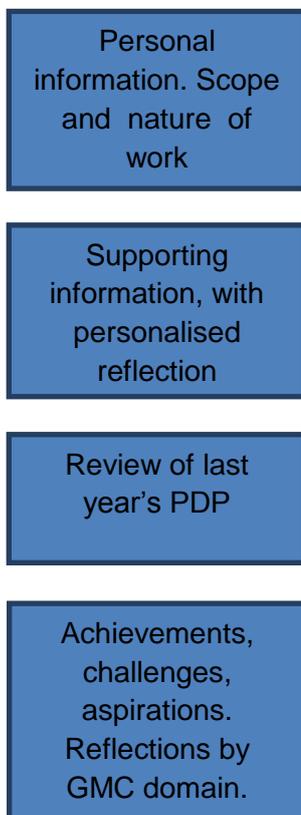
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- a) Are you a *revalidation-ready trained appraiser* who would be willing to appraise your colleagues in this field? If so, please let me know. (Any service agreement and remuneration to be agreed between you and the appraisee's Designated Body).
- b) What systems does your hospice or hospital have to collect *doctor-specific supporting information* for your doctors? If you have systems that are working, please share them and we can pass on examples of good practice.
- c) What experience does your organisation have of organising *patient / carer feedback questionnaires* for individual doctors? What is working? What have you learnt from the process?
- d) What provision does your employing organisation make to provide for their *doctors' professional development in paediatric palliative medicine*? (Time to attend learning events, in house education, signposting to relevant learning opportunities).

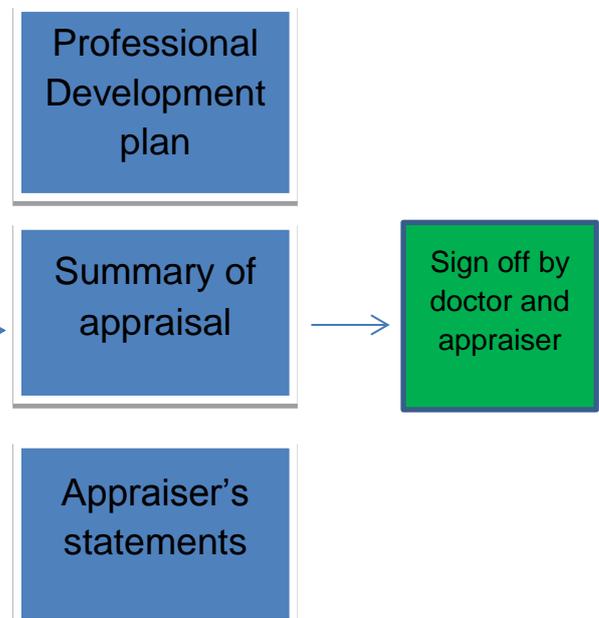
If you have suggestions, examples of good practice, or comments about these areas, please let me know. Equally, if you have questions or concerns I will be pleased to help if I can. Hopefully together we can help ensure that this opportunity is realised, to use appraisal and revalidation to support best practice in paediatric palliative medicine.

Dr Susie Lapwood, Helen and Douglas House Hospices
APPM Revalidation lead
Member, South of England Revalidation Delivery Board
slapwood@helenanddouglas.org.uk

INPUTS



OUTPUTS



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.

Rolling programme of Transition study days: Dates released for 2013

Getting training in Transition is a tricky business. One group of researchers in South Wales have spent the last 2 years looking at what palliative care professionals should learn about transition & the care of young adults and now they are launching a rolling programme of education to improve the knowledge gap.

The study days will be aimed at professionals working with young people, 16yrs and up with palliative care needs - it's not just for doctors and nurses, the project team have specific remit to design education that will be relevant to therapists and social workers too. They will take place in Cardiff and will look specifically at the issues around caring for young adults with life-limiting conditions and palliative care needs.

Dr Lidstone, Project lead and Consultant in Palliative care for 16-25yr olds in Wales said

"Medical advances have led to a great many more children with life limiting conditions surviving into adulthood, and adult services need to provide the right care for this growing population"
"These young adults are a very diverse group of people, and adult palliative teams need the information in order to build the necessary skills"

Research has shown that teams are willing yet uncertain about caring for young adults, because the medical conditions are unfamiliar and the clinical issues are different. "We want to up-skill teams, and give them the confidence to take on the care of these young people with enthusiasm" said Dr Lidstone.

The study days are welcomed by staff at the Marie Curie Hospice Cardiff and the Vale in Penarth, South Wales. Dr Jo Hayes, Medical Director said: "This is just what we need. We are receiving more referrals now for this age-group and we want to make sure we are as ready as possible."

The study days will be open to therapists, social workers, doctors and nurses, and will be run on a first come first served basis, with priority given to those working in Wales. The costs will be kept as low as possible.

Dates are June 12th, Sept 24th, Nov 13th 2013.

Further information is available from Victoria.Lidstone@wales.nhs.uk

Case Report – Subcutaneous clindine infusion for dystonia in end of life care

Dr Emily HARROP, Consultant in Paediatric Palliative Care,

Helen & Douglas House Hospices, Oxford.

EG was a little girl with a mitochondrial disease, presenting with regression of skills and severe dystonia. She attended Helen House children's hospice for respite and family support for the last two years of her life, she died at the age of 4 years. Her dystonia always posed a challenge, and she had a number of hospital admissions with status dystonicus, sometimes triggered by intercurrent illness. In the last year of her life, she developed a rapid, fulminant, unexplained episode of hepatic failure. This eventually resolved, after a long period of intensive care. Unfortunately this was soon followed by catastrophic bowel failure, associated with intra-mural air on an abdominal x-ray, necessitating further intensive care.

At this stage E was not able to tolerate enteral feeding or medication. On weaning from intensive care sedation, she experienced withdrawal associated with a worsening of her dystonia. She was started on a continuous infusion of clonidine intra-venously to manage her withdrawal. This also had a very beneficial effect on her dystonia, as her midazolam continued to be weaned.

Several attempts were made to re-grade E's feeds, with no success. Her absorption was so limited that there was grave concern about converting her to enteral clonidine. Over time it became clear that E was not a good candidate for long term total parenteral nutrition, as she had a progressive neurological condition and also a degree of liver failure.

Discussions were had in order to inform an advance care plan. E's parents accepted that she was now very life limited, in view of there being no reliable means to feed her. They made a plan centred entirely on quality of life for the time remaining. At this stage E was alert, and able to interact, but was 'tied' to intensive care due to her intra-venous infusion. She was becoming bored and her parents were under increasing strain. It became clear that it was in her interest to be discharged from hospital for end of life care, if possible.

Case Report Problems with oral clonidine. Learn from others mistakes.

Editor.

AC is a 14year old boy with calcifying leucodystrophy. Dystonias have become more of a problem in the past year. Oral clonidine helped. When he was stabilised on his dose his pharmacist decided to make the solution up himself rather than pay for the expensive commercially available formulation. Within 24 hours A was noted to have major dystonias causing a lot of pain and distress. As it was thought that it might be a bioavailability issue with the new formulation the dose was escalated over the next few days but to no avail. Arrangements were made for him to return to the original formulation.

It subsequently turned out when the bottle was inspected that the suspension had settled and although his mum was inverting the bottle a couple of times before administering the medication she was not shaking it rigorously as would be required to ensure the suspension was evenly distributed.

He remains on the more stable more expensive product!

Despite there being considerable experience of the use of clonidine by subcutaneous or intra-theal infusion, in the management of adult chronic pain, no published record of its use in paediatric dystonia was found. In discussion with adult anaesthetic colleagues within our acute hospital, we put together a plan to wean E from her IV infusion to a continuous subcutaneous infusion within a children's hospice setting.

This was done on a conversion ratio of 1:1 from intravenous to subcut. E tolerated the switch, but required an increase of around 10% compared to her previous stable intravenous dose, in the first few days. There were no local reactions at the site of the infusion, and the desired pharmacological effect appeared to be observed.

Breakthrough dystonia was managed effectively with buccal midazolam, which was only needed 1-3 times daily for most of her stay. Although E could not be fed, we were able to give her dioralyte via her jejunal tube at a rate approximately equal to one third maintenance. This maintained a urine output, and she appeared comfortable.

E remained stable and able to engage in hospice activities for a further 2 weeks before developing pneumonia. At this stage she became breathless. This was initially managed with buccal morphine, but a longer term solution would be needed. Further enquiry among colleagues in adult palliative care / anaesthetics lead to experience of combinations of clonidine with morphine and midazolam being discussed. The experience published dealt with intra-theal infusions, but as the consequences of precipitation by this route are even less desirable, it proved to be a good starting point. It also became clear that the concentrations of the drugs, were much higher in the intra-theal combination, due to the constraints on volumes.

With all of this in mind, morphine was added to the clonidine subcutaneous infusion. Once again, the infusion fluid remained free of visible precipitation, the line site was not inflamed and the desired effect (reduced breathlessness) was observed.

As her infection progressed, E had some increase in her dystonia requiring a further 10% increase in her clonidine. In the last 48 hours of her life, there was some agitation associated with the dystonia, and a decision was made to add midazolam to her infusion, as the buccal doses were effective but needed more frequently. This further addition still produced a solution free from visible cloudiness, her infusion site remained unaffected, and the agitation / dystonia improved

Although this is only an individual case report, our experience appeared to show:

1. Continuous subcutaneous infusion of clonidine may be a viable option for the management of dystonia in palliative care
2. In our case, it appears that this can be combined in a stable infusion with morphine and midazolam

As the need for end of life symptom management for children with complex neurological diseases increases, this may contribute to the armamentarium. It is also interesting to note that transdermal clonidine patches also exist in the US.

EH.

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Dates for your diary

The 10th Palliative Care Congress



**The 10th Palliative Care Congress will be held at the Harrogate International Centre
from 12 – 14 March 2014**

Bursary applications for the 10th Palliative Care Congress will only be considered from applicants who have submitted an abstract as part of the bursary call for papers.

Anyone wishing to apply for a bursary can submit their paper between
Monday 11 March and Wednesday 8 May 2013

All submitted abstracts with a bursary application will be reviewed by the Scientific Committee and will be notified of the outcome of their application week commencing Monday 10 June 2013. Further information for bursary applications is available in our [Bursary Guidelines](#).
This call is for bursary applicants only. If you do not wish to apply for a bursary please do not submit your abstract before Friday 24 May 2013.

Call for Papers

The call for papers for the 10th Palliative Care Congress will open on **Friday 24 May 2013**

The website for the 10th Palliative Care Congress is now live.

For further information please visit

www.pccongress.org.uk

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Annual Scientific Conference 5-7 June 2013 Glasgow



Save the Date

*The 4th APPM Study day will be held on
Friday 29th November 2013.*

It will be held for the second year running in Friend's House, London.

Last year we had excellent feedback on location of the venue; situated across the road from Euston Station. Once again we hope to have a mix of lectures and workshops as always a focus on the clinical issues. A draft programme will be put on the website in due course and closer to the time.

The APPM AGM will be held during the study day and this year a specialist nurse forum will be introduced to support networking across the sector. This will be held at the same time as the AGM.

*Always happy to hear from you about your ideas for talks/workshop, please don't hesitate to email me.
Look forward to seeing you all there.*

AK (annkarenia.anderson@nhs.net)

PAEDPALCARE FORUM

Together for Short Lives hosts an international email based forum designed to support clinicians to share, exchange and debate approaches to children's palliative care.

The care forum, called *PaedPalCare*, is the go to place if you want to seek expert advice from the world's most prominent children's palliative care clinicians and join in the discussion about new innovations and approaches to caring for babies, children and young people with life-threatening and life-limiting conditions.

The Care Forum is free and fully moderated and the mailing goes out to about 1000 members and stakeholders worldwide.

The forum offers support for practitioners, especially those working on their own, or in countries where children's palliative care is a new specialty. Members of the forum are committed and quick to respond to questions and dilemmas.

Topics and discussions are wide-ranging, and include pain and symptom management; treatment approaches; drug doses and routes; and ethical issues such as withdrawing life-sustaining treatment.

Any professional with an interest in children's palliative care can join.

It is simple to join and start posting messages.

All you need to do is follow the link below, sign up and start posting away!

http://www.togetherforshortlives.org.uk/professionals/care_provision/care_forum

If you have anything that you would like to be included in the newsletter please contact me directly. heather.mccluggage@westerntrust.hscni.net . Editor.

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