

Association for  
Paediatric  
Palliative  
Medicine



## INVITATIONS

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MAKING DECISIONS  
TO LIMIT TREATMENT  
IN LIFE-LIMITING AND  
LIFE-THREATENING  
CONDITIONS: A  
FRAMEWORK FOR  
PRACTICE.

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## STUDY DAY

November 27th

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# NEWSLETTER

## From the Chairman

Dear colleagues

Year on year, we appear to be working in increasingly complex situations, whether these are in a children's hospital unit, a children's hospice or in the community. Children's palliative medicine does appear to becoming more established as a mini-speciality, and I see a real growing interest in palliative care for those babies, children and young people (BCYP) who need this care. Publication of Lorna Fraser's work in 2011 challenged all of us to identify greater numbers who may need palliative care from the following broad groups:

- \* Neonates
- \* BCYP living in areas of deprivation, whether in inner city or rural areas
- \* BCYP from ethnic minorities.

Judging from conversations, emails and letters in my in



Pat at last year's  
APPM Study day

trays we are beginning to address these areas, while acknowledging that we have along way to go.

These areas will be further explored at our annual education day and AGM in London on 27 November. I am very grateful to the organising committee, the speakers and to colleagues in Together for Short Lives who so brilliantly take care of the pre-event and on-the-day administration. My thanks, also, to all those who have attended this meeting over the last few years and to those who are considering attending this year. Booking numbers for this year's event are already up compared with this time last year. Please note the "early bird" booking rate will soon close but also consider cascading information about the conference to other colleagues who have perhaps not yet seen it.

This year we have seen two paediatric palliative conferences in the UK, one in Birmingham (Together for Short Lives: 'Living Matters for Dying Children') and another in Cardiff (International Paediatric Palliative Care Network (ICPPCN): 'Medicine and Compassion: Tool for the Trade or a Dangerous Distraction'). At the RCPCH annual conference, in Birmingham in the spring, APPM colleagues joined with those from PICU and Respiratory Paediatric sub-specialities, and debated, "Just because we can....." Inevitably, we ended up with more questions than answers, But we are beginning to see wider public debate about palliative care (as well as death, and assisted dying and suicide) across the UK and Ireland in recent months.

With this there are increasing calls for improved general and specialised palliative care, and we must work to ensure that these considerations include discussions and subsequently policies and monies which can help the care for babies, children and young people with palliative care needs, as well as their families. My belief is that good general palliative care is an integral part of good medical care, but I recognise that paediatric palliative care is improved by specialised input, not least because many

## *Executive Committee*

*2015.*

Pat Carragher (Chair)

Lynda Brook (secretary)

Dermot Murphy  
(treasurer)

Anna-Karenia Anderson

Yifan Liang

Sat Jassal (formulary)

Susie Lapwood  
(revalidation)

Emily Harrop

Tracy Blount

Michelle Hills

Anton Mayer

Heather McCluggage  
(editor)

Katrina McNamara  
(TfSL)



generalists do not regularly undertake the care of children with palliative or end of life care needs. Together for Short Lives is increasingly working with APPM to ensure that this message is more widely heard both within Paediatrics but also with many of our stakeholders. I am keen to support this, as for most of us direct clinical work is still occupying much of our professional lives, and so the links between the two organisations should continue to strengthen, and one of these areas is with a combined research group.

Alongside this the APPM is:

- \* Developing increasing links with doctors and other care professionals working in the care of children and young people with palliative care needs, who have not previously been aware of the work of the APPM.
- \* Looking at workforce development, as well as competencies for doctors working in children's palliative care, as laid out in the 'Combined Curriculum', and the CSAC is now exploring how to offer more SPIN (Specialist Interest) posts in paediatric palliative medicine (PPM).
- \* Improving educational opportunities in PPM across the UK, as well as continuing our annual educational conference, in strengthening the Diploma in Palliative Medicine (Paediatric Option) from the University of Cardiff, and piloting twice yearly PPM trainee events.
- \* Continuing the dissemination of the 2015 APPM Master Formulary, and to consider a neonatal section for its 4th edition, currently planned for 2017.
- \* Looking to strengthen international links with EPAC and ICPCN, by attendances at conferences in Buenos Aires, Montreal and Rome next year, and also by direct clinical input and teaching in many countries.

I am keen that the APPM coordinates this wide variety of workstreams, and it is my intention to contact many of you in the coming months to see how we can involve more of the wider membership within specific projects.

Lastly, I look forward to seeing many of you in London in November.

Best wishes

Pat Carragher

## Invitation to join the International Paediatric Palliative Care forum (iPDF)

On behalf of the Paediatric Palliative Care Special Interest Group (PPC SIG) of the Asia Pacific Hospice Palliative Care Network (APHN), we will like to invite you and your colleagues to join us as we launch our very own discussion forum focusing on children's palliative care.

We hope that you can lend us your support by participating in this forum

To join the forum, all you have to do is

1. Sign up for a Google account (if you do not have one)
2. Click on this link [https://groups.google.com/forum/?hl=en#!forum/aphn\\_ipdf!](https://groups.google.com/forum/?hl=en#!forum/aphn_ipdf!)

Our forum is moderated by an international multidisciplinary group of experts. You can certainly look forward to many fruitful discussions with equally passionate colleagues around the globe.

We look forward to your active participation in the discussion!

Joyce Chee  
APHN Executive

## Calling all GPs working in Paediatric Palliative Care!

*The APPM is working to create better links and support for GPs involved in PPC including hospices. We can advise regarding appraisal, PDP learning and provide a clinical network. We would also like to develop a national picture of GP roles within the speciality.*

*Please contact me through TSL (<mailto:appm@togetherforshortlives.org.uk>.)*

*There will be a GP networking session at the conference on 27th November. See you there!*

*Dr Tracy Blount*

## A Must Read,

*Arch Dis Child* 2015;**100**:s1-s23 doi:10.1136/archdischild-2014-306666

# Making decisions to limit treatment in life-limiting and life-threatening conditions: a framework for practice.

It's ten years since the RCPCH published the last guidance on withholding and withdrawing treatment.

This new look at the subject is up to date and challenging.

We all want to do our best for our patients, but do we always act with the “best interests of the baby child or young person” really at the heart of what we do. Go back to Pat's question of “just because we can.....”should we??

We have the ability to keep babies and children alive longer than we use to but are we just prolonging their dying process at times rather than giving them quality life?

Making these decisions can be very difficult for families and professionals alike so it is really good to see some concrete advice in the form of this guidance document.

The document is seen as a legal and ethical framework to work through rather than a protocol to be strictly adhered to. It is to be used in conjunction with careful, sensitive, respectful and compassionate conversations with our young patients if competent and their families

Deciding that not to treat is the right option can be very difficult indeed. The document highlights the points that

treatment can be

A. withheld, i.e. never commenced,

B. withdrawn, i.e. stopped or

C. limited, meaning a line is drawn where treatment will not be escalated further

There are several differences from the 10 year old document,

it recognises the importance of good palliative care for these BCYP.

It highlights shared decision making between professionals and parents and the CYP.

With the current increased demand for organ and tissue donation the role of this is highlighted

It puts the decisions into 3 categories

1. when life is limited in quantity
2. when life is limited in quality
3. when a competent CYP makes the decision for themselves and needs the family and professionals to support them

As Larcher, Snaith and Brierley say in the editorial in **Infant** VOLUME 11 ISSUE 4 2015

RCPCH hopes its framework will be of use to doctors and nurses looking after the sickest infants and their families and encourages healthcare professionals to describe their work and undertake research in this area.

I would encourage any of you who have not yet read the publication to do so.

Editor



## **Global Palliative Care – working towards sustainability**

**A two-day conference and workshop  
for practitioners, funders, trainers and  
supporters**

**26<sup>th</sup> and 27<sup>th</sup> September 2015 at  
Hornton Grange, University of Birmingham**

**Chaired by  
Mike Wooldridge, Journalist and Broadcaster**

### **Themes to be explored include:**

- the context in which palliative care services are being developed and delivered in resource poor settings;
- education and training initiatives;
- the challenge of funding and sustaining these services

### **Keynote Speakers:**

Julia Downing	Angela Kaiza
Tulip Mazumdar	Fiona Rawlinson
Kaly Snell	Liz Grant

### **Conference fees:**

<b>Full programme, including accommodation and all meals,</b>	<b>£165.00</b>
<b>Two Day attendance, including lunches: Saturday and Sunday (not evening dinner)</b>	<b>£90.00</b>
<b>One Day attendance, including lunch: Saturday or Sunday</b>	<b>£45.00</b>

**To register, please visit our website:  
[www.palliativecareworks.org](http://www.palliativecareworks.org)**

**and click on the **Eventbrite** link in the News section *Palliative Care Works is a non-profit Charitable Incorporated Organisation , reg. no. 11619196th***



# Don't forget the 6th APPM Study Day 27th November

**Park Crescent Conference Centre, 229 Great Portland St, London, W1W 5PN**

## **Programme**

0900-0930 Registration, coffee and networking

Chair: Dr Pat Carragher

0930-1015 Dystonia Dr JP Lyn, Paediatric Neurologist, Evelina Hospital London

1015-1100 Challenging management of Dystonia Evelina team: Dr JP Lyn, M Paed. Neurologist;

Case based discussions- expert panel Dr Charlie Fairhurst, Cons Paed. Neurodisability; Dr Joanna Laddie, Cons PPM

1100-1120 Coffee

Chair: Dr Susie Lapwood

1120-1200 Neuroenteric failure Dr Camilla Salvestrini, Paediatric Gastroenterologist, Addenbrookes Hospital

1200-1230 Case discussions GI failure- panel based (discussions around ethics/ Panel TBC

who gets PN/management of complex pts with PN/ GIT failure) Dr Camilla Salvestrini

1230-1330 Lunch

1310-1410 APPM Annual General Meeting (AGM) Pat Carragher, Chair APPM Including Paediatric Palliative care training Dr Yifan Liang, Chair PPM, RCPCH CSAC

1310-1410 Nurses forum Julie Bayliss, Nurse Consultant, GOSH

Concurrent sessions:

1410-1450 Workshop 1:

a) Organ donation

b) Pitfalls of Prescribing in PPC

c) Death certification- new rules and regulations

a) Neil Healy, CNS organ donation

b) Dr Sat Jassal, Editor APPM formulary/Anita Aidow, APPM Specialist Pharmacist

c) Dr Alan Fletcher, Medical Examiner

1450-1520 Coffee GP networking session (location tbc) Dr Tracy Blount

1520-1600 Workshop 2:

a) Organ donation

b) Pitfalls of Prescribing in PPC

c) Death certification- new rules and regulations

a) Mr Neil Healy

b) Dr Sat Jassal Editor APPM formulary / Anita Aidow, APPM Specialist Pharmacist



c) Dr Alan Fletcher, Medical Examiner

1600-1700 Chair: Dr Anton Mayer

1600-1700 Long term ventilation and palliative care                      Dr Colin Wallis, Consultant  
Paediatric, Getting it right? Getting it wrong?                      Respiratory Medicine;  
Dr Renée McCulloch, Consultant PPM, Great Ormond Street Hospital

1700-1710 Feedback and close of day

***We do really want to see you there.***

*contact Together for short lives or download an application form from  
[www.APPM.org.uk](http://www.APPM.org.uk)*

*There are many more short courses listed at the together for short lives  
website, professionals, events  
[www.togetherforshortlives.org.uk](http://www.togetherforshortlives.org.uk)*

*If you have any comments or feedback on anything covered in this  
newsletter please contact the Editor at  
[heather.mccluggage@gmail.com](mailto:heather.mccluggage@gmail.com)*