

# APPM NEWSLETTER



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## From the Chair

The APPM is 10 years young this year and with that in mind we are looking at how APPM can further support its members in providing increasingly complex care to life limited children. This year, beside our annual study day, indeed the day before, we are running a research focused day on Thursday 14<sup>th</sup> November with leading UK researchers in paediatric palliative medicine across various disciplines. I am grateful for the support of Cicely Saunders Institute in providing the venue.

Aside from the new research day, we are currently in the process of gaining an online membership subscription to Palliative Medicine as part of your unchanged membership fee. As soon as this is sorted we will let you know!

The APPM executive committee has had an influx of fresh faces, bringing new ideas and energy. Each executive member now has a defined role which will enable various strands of work to be taken forward. Dr Sarah Mitchell is looking at how we support hospice doctors and GP working in the field more. Dr Lizzie Bendle along with Dr Marian Williams is reviewing how best our website can support our members and we are taking our first steps into the development of guidelines. This will require a lot collaborative working and is in the calm and capable hands of Dr Jo Laddie.

The new edition of the APPM formulary will, with a good wind, be available by the study day in November. For the first time we will have international reviewers on the formulary. We will continue to provide the APPM formulary free to access online but are thinking about printing and

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selling hard copies for those of you like me who are bit old school (I write all over mine). As always one hard copy formulary is given out as part of the study day price in the year of its completion and release.

We have an executive meeting in June time and as always I welcome comments or thoughts from the APPM membership about how the APPM can best support its members. Please email me before our meeting so I can discuss your comments or ideas.

And yes, as part of our 10<sup>th</sup> anniversary celebrations I am thinking about a birthday cake at the APPM study day in November! Just need to decide on the flavour....and who will cut it!

AK Anderson, APPM Chair



# The Exec Committee

**CHAIR: Dr AK (Anna-Karenia) Anderson** - Consultant in PPM at Royal Marsden Hospital and Shooting star children's hospices. Also works as volunteer supervisor for the child death helpline for over 12years. *Also responsible for co-ordinating APPM research meetings*

**VICE-CHAIR/TREASURER: Dr Anton Mayer** – Consultant in Paediatric Intensive Care and PPM at Sheffield Children’s Hospital.

**SECRETARY: Dr Emily Harrop** - Consultant in PPC & Interim Medical Director, Helen & Douglas House. Honorary Consultant in PPC, Oxford University Hospitals NHS Trust. *Also responsible for co-ordinating APPM research meetings and representing PPM at RCPCH annual conference*

## OTHER MEMBERS AND THEIR RESPONSIBILITIES:

**Dr Lizzie Bendle** – Consultant in PPM, Evelina London Children’s Hospital. *Website*

### Co-opted Links:

*Together for Short Lives:  
RCPCH CSAC*

**Lizzie Chambers  
Renee McCulloch**

**Dr Sophie Bertaud** – ST7 PPM GRID trainee at Great Ormond Street Hospital. *Joint trainee representative*

**Dr Jonathan Downie** – ST8 PPM GRID trainee at Great Ormond Street Hospital. *Outgoing trainee representative*

**Dr Richard Hain** Consultant and Lead Clinician in PPC, Children’s Hospital Cardiff. Visiting Professor, University of South Wales. *Sponsorship/APM representative*

**Dr Sat Jassal** – MBE, Medical Director at Rainbows Hospice for Children and Young Adults and GP. *Formulary*

**Dr Natalie Kemp** - Clinical Lead for Children & Young People at Jersey Hospice care developing a new service on island. Paediatric SAS grade doctor with Honorary contracts at Jersey General Hospital and University Hospital Southampton *Hospice doctors representative and Study day organising*

**Dr Joanna Laddie** – Consultant in PPM, Evelina London Children’s Hospital. *Guidelines*

**Dr Abigail Macleod** – Associate Specialist Paediatrician with special interest in Paediatric Palliative Medicine. *Study day organising*

**Dr Sarah Mitchell** – GP and NIHR Doctoral Research Fellow. *GP representative and jointly responsible for Twitter feed*

**Dr Laura Nohavicka** – ST5 trainee due to start sub-speciality training in London in September. *Joint trainee representative*

**Dr Kate Renton** – Recently completed PPM GRID training in Yorkshire and Humber, currently on maternity leave (from clinical work at least!). *Editor newsletter and jointly responsible for Twitter feed*

**Dr Marian Williams** – Consultant Paediatrician (and medical lead for PPC) at the Southern trust in Northern Ireland. *Resources*

If you want to really familiarise yourself with us...check out our ‘mugshots’ on the APPM website: [www.appm.org.uk](http://www.appm.org.uk)

## Changes to CDOP

by Karen Brombley, Deputy Designated Nurse for Safeguarding, Oxfordshire CCG and Vicky Sleaf, National Child Mortality Database Project Manager, University of Bristol



The recent publication of the revised version of Working Together to Safeguard Children, 2018 (chapter 5) and the new Child Death Review Statutory and Operational Guidance (2018) have introduced significant changes to the child death review process. The purpose of these changes is to reduce some of the variability of practice that had developed between CDOPs over the years and to enable a more consistent approach to the review of child deaths and the collection of data by the National Child Mortality Database (NCMD). Updates were also made to the statutory CDOP forms, new versions of which were published in September 2018.

The aim of the program remains the same: that the process of systematically reviewing the deaths of children is grounded in respect for the rights of children and their families, with the intention of learning what happened and why, preventing future child deaths and improving services for children and their families.

### Key changes:

- Transfer of governance of the process from DfE to DHSC. This recognises that the majority of child deaths in England arise from medical causes.
- Responsibility for Child Death Reviews is now held jointly between Local Authorities and Clinical Commissioning Groups who must commission a CDOP process in their area, ensuring that their CDOP reviews at least 60 deaths per year. This is to ensure enough data is collected to identify significant learning.
- All families should be offered a key worker who will provide a single point of contact for them, supporting and signposting as necessary.
- Every child death has an individual local review by the multiagency team who were involved in the care of the child before discussion by CDOP. This meeting already happens in many places and is also known as the M&M meeting, the local case review meeting or the final case discussion meeting.
- Introduction of the National Child Mortality Database to collate Data collected by CDOPs at a national level. National experts have been involved in contributing to the development of this database, including representatives from APPM.

**NCMD**  
National Child Mortality Database

How these changes are implemented is subject to local interpretation. Agencies are required to publish plans for their new arrangements by the 29/06/19 and have implemented the plans by 29/09/19.

For more information on the requirements of the new guidance, go to

<https://www.gov.uk/government/publications/child-death-review-statutory-and-operational-guidance-england>

### The NCMD has now gone live!

For more information on the National Child Mortality Database, go to

<https://ncmd.blogs.bristol.ac.uk/>

**SAVE THE DATES...****The APPM 10<sup>th</sup> Anniversary Study Days:****14<sup>th</sup> November 2019 – Cicely Saunders Institute****15<sup>th</sup> November 2019 – 30 Euston Square**

A sneak preview of what you can expect:

Esteemed speakers ... Challenges and rewards in research ... Neuroimaging to understand pain ... Ongoing research studies... Latest research findings ... Communicating with children about death ... Managing disagreements and limits of Parental Autonomy ... Advance care planning ... Symptom management: itch/skin conditions; dystonia

Registration now available with discounts for attending both days, and also for booking early: <https://www.appm.org.uk/events/>

Please do let us know of anything you would like to contribute to future newsletters...we are always keen to share knowledge/opportunities

**OTHER EDUCATIONAL OPPORTUNITIES to consider...**

Please also check Together for Short Lives website  
and do let us know about any you wish us to advertise on the APPM website

**RCPCH Conference 2019:****Paediatrics: Pathways to a Brighter Future**ICC, Birmingham, 13-15<sup>th</sup> May 2019<https://www.rcpch.ac.uk/news-events/rcpch-conference>**16<sup>th</sup> World Congress of the European Association for Palliative Care:**

Global palliative care – shaping the future

Berlin, Germany. 23-25<sup>th</sup> May 2019<http://www.eapc-2019.org/home.html>

## The Medical Examiner System: "A brief update"

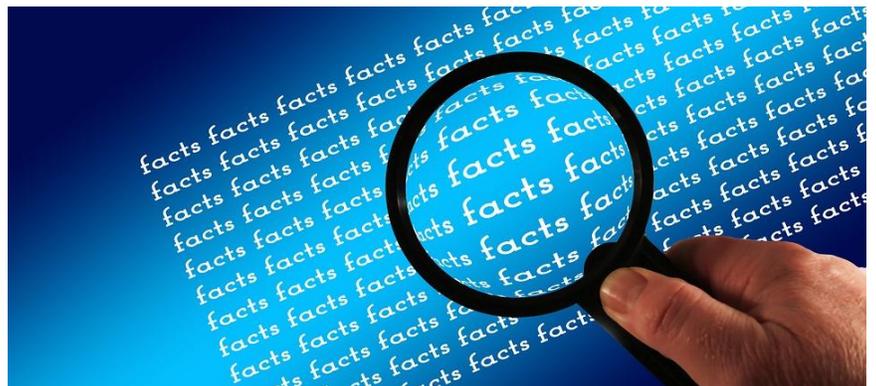
written by Dr Anton Mayer



The idea of having a medical examiners system has been on the cards for a number of years. The concept is that there should be oversight of all deaths, specifically those not referred to the coroner, thus including all expected and unexpected deaths. Despite pilot medical examiner systems having been successfully running in two areas of the country (including Sheffield) since 2008 – there has been no formal introduction of the system. A consultation document from the UK government in June 2018 proposed; a non-statutory medical examiner system initially with medical examiners to be appointed from within the NHS and a national Medical Examiner to provide guidance to those undertaking the role. Funding for this would be covered by the current system of cremation fees as well as central government funding. An anticipated roll out date has been set for April 2019 although widespread implementation will take longer.

Medical examiners are senior medical doctors, who are trained in the legal and clinical elements of death certification processes. A National Medical Examiner is to be appointed to NHS Improvement to provide leadership and guidance to medical examiners. The later in turn will probably be employed by NHS acute Trusts. They will have an independent professional line of accountability to a regional structure outside their employing organisation, to a regional lead medical examiner. However they will still remain accountable to their employing NHS acute Trusts Board. Medical examiner officers, who may have a nursing or other clinical background, will provide support to medical examiners, including being a point of contact and source of advice for relatives of deceased patients, healthcare professionals and coroner services. A digital system is being developed to support roll-out, to ensure a joined-up process and consistency of approach to scrutiny by medical examiners. An e-learning training package for medical examiners is now available via the Health Education England website, plus face-to-face training is in the process of being created. It is unclear what categories of death recruited medical examiners will investigate; ideally it would be Hospital and community deaths alike.

The idea is that all medical certificates of cause of death completed by doctors will be reviewed by a medical examiner, with the aim of improving the quality and accuracy of cause of death certification as well as giving bereaved families more opportunity to raise concerns, ensuring referrals to coroners are made appropriately and promoting learning and good practice by feeding into a given clinical governance processes. There are a number of benefits from the implementation of such a system which have been highlighted by the pilot sights. These include: improvement in the accuracy of death certification, reduction in medical certificates of cause of death being rejected by the registrar, a reduction in direct complaints following discussion of the cause of death with someone independent of the primary care provider.



Following the death of a young adult, initial contact would be made to the responsible medical examiner by the doctor treating the patient on their final illness. The role of the medical examiner

is then to: review the medical records and diagnostic information so agreeing the cause of death and the overall accuracy of the proposed medical certificate cause of death. He or she would then discuss the cause of death with the next of kin or informant and establishing if they have any concerns with care that could have impacted or led to death. Other roles include: acting as a medical advice resource for the local coroner, informing clinical governance systems to highlight deceased patients who require a mortality case record review so any formal learning can be gained for the provider organisation, ensuring that patterns and or concerns with care and associated clinicians and or providers are raised appropriately.

References and useful sites for further information:

<https://www.rcpath.org/profession/medical-examiners.html>

<https://www.bma.org.uk/advice/employment/ethics/implementation-of-the-medical-examiner-system>

<https://www.gov.uk/government/consultations/death-certification-reforms>



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The DIPPER study, led by Professor Ian Wong, aims to explore the feasibility of a randomised clinical trial of transmucosal diamorphine vs oral morphine for breakthrough pain in children and young people with life limiting conditions.

**We would like to talk to healthcare professionals involved in the care of children with life-limiting illnesses receiving palliative care in primary and secondary care to explore their perspectives on the prescribing and administration of transmucosal diamorphine and oral morphine for breakthrough pain. Would you be interested in attending one of these focus groups?**

**Payment will be made in respect of locum cover and travel.**

<b>Date and time:</b>	Friday, 17 May 2019: 11 – 1 pm
<b>Venue:</b>	Rainbows Hospice, Loughborough
<b>Date and time:</b>	Friday, 07 June 2019:
<b>Venue:</b>	London (venue tbc but near Euston)
<b>Date and time:</b>	Friday 14 June, 2019: 11 – 1 pm
<b>Venue:</b>	Helen & Douglas House Hospice, Oxford

Please contact Liz Jamieson for further information:  
[e.jamieson@ucl.ac.uk](mailto:e.jamieson@ucl.ac.uk)





## The latest update from GP and hospice doctors representatives...

By Dr Sarah Mitchell

One of the key strengths of service delivery in children's palliative care is the diversity of the workforce. Alongside the nursing staff, psychologists and therapists who comprise the multi-disciplinary teams caring for children with palliative care needs, medical staff come from many different clinical backgrounds, bringing a wide range of experience and expertise.

The APPM is committed to supporting all doctors working in the field of paediatric palliative medicine. The future development of education and training, and peer support for doctors working in children's hospices and GPs who are involved in children's palliative care, is a priority.

We are gathering evidence that highlights the challenges for doctors working in children's hospices. At APPM study day in November 2018, Dr Jo Frost presented her PhD work, which focusses on different aspects of models of care in children's hospices, including the provision of medical cover. Data from Jo's research suggests that as many as 2/3 of doctors working in children's hospices are GPs. An APPM survey study carried out by Dr Tracy Blount provided insights into the high level of medical complexity that doctors in children's hospices are dealing with, and that not all doctors working in children's hospices have access to paediatric palliative medicine specialist support.



As well as doctors in children's hospices, the APPM is aware of the need to promote and support the role of GPs caring for families where a child has a life-limiting or life-threatening condition in the wider community, particularly for those approaching transition.

The APPM workstream looking at education, training and support for GPs and children's hospice doctors will be led by Sarah Mitchell (GP in Sheffield and PhD fellow at the University of Warwick, [S.Mitchell6@nhs.net](mailto:S.Mitchell6@nhs.net)), and Natalie Kemp (Clinical lead for Children and Young People, Jersey Hospice [nataliekemp@jerseyhospicecare.com](mailto:nataliekemp@jerseyhospicecare.com)). We already have an email list of 69 interested GPs and children's hospice doctors, and we would like to develop this list into a virtual network for collaboration and support. We aim to engage the RCPC and RCGP in this important agenda, bring together a directory of existing educational resources for GPs and children's hospice doctors, to develop the relevant section of the APPM website, and to propose the development of new resources. If you are interested in any elements of this work please get in touch.

## And from the new trainee representatives...

Hi, we are the new trainee representatives on the APPM executive.

**Laura Kemp:** I am an ST5 trainee, due to start sub-speciality training in London in September. I am currently seconded to Helen and Douglas House hospice as part of my community paediatric placement. I completed my MSc in paediatric palliative care in 2018.

**Sophie Bertaud:** I am an ST7 GRID trainee at Great Ormond Street Hospital. I have a MA in Bioethics and a strong interest in PPM research.

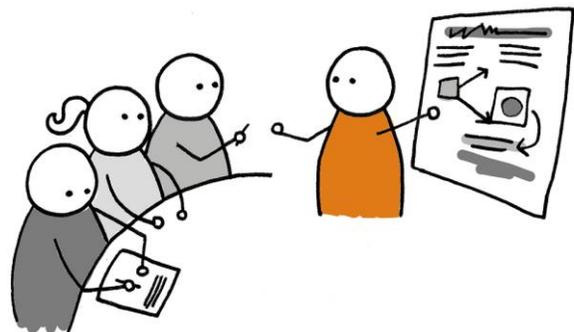
We are aware that by following on from Jonny and Kate as trainee reps we have very big shoes to fill! But we are both very pleased to be joining the team and excited about the challenge.

As our first mission we are organising the next trainee study day, which will take place on 14<sup>th</sup> May 2019 at the RCPCH In London. This day will be aimed at GRID trainees and those working within the speciality. We are planning an exciting programme that will be linked directly to the curriculum competencies. The morning session will be focused around Advance Care Planning and we will spend the afternoon looking at bereavement.

We will have a second study day later in the year that we hope to extend out to paediatric trainees with an interest in palliative care with the aim of raising the profile of PPM amongst general trainees.

As well as developing the study days, we hope to use our time in the role to improve networking amongst trainees across the country, with the hope of identifying trainee needs and collaborating on future quality improvement and research projects.

We look forward to meeting as many of you as possible in our new role.





**Yorkshire and Humber**  
Children's Palliative  
Care Network

## Annual Study Day March 2019

### **With thanks to Dr Michelle Hills for writing this review. Something to aspire to....**

On the 13th March 2019, the Yorkshire and Humber Children's Palliative Care Network held its annual conference attended by 150 people in the region (and a few sneaked in from further afield!). The huge number of people present demonstrated the importance of having a local study day, giving professionals who often share patients the opportunity to network and learn from each other. The theme of ethical dilemmas in children's palliative care seemed a topical and well received one in the current times.

Finding a programme to suit a wide audience including experienced and junior professionals is a challenge and the day was a testament to the work that goes into collaboration and shared learning across a region. The attendees came from a huge cross section of different environments including hospices and community teams, district general hospitals & multiple specialties from tertiary hospitals. The individuals included a wide cross section of professionals from nurses, social workers, consultants, psychologists, doctors and even a hospice CEO.

Adam Nicholls opened the day with an overview of ethical principles and education about the role of a clinical ethics committee, which has recently been set up in Leeds. We were delighted to welcome external speakers Joe Brierley and Bhumik Patel from Great Ormond Street who shared their wisdom about the ethics of long term ventilation and cannabis. Jan Aldridge gave a fascinating talk about the impact of ethical challenges on children, their families and the staff and in an ironic way the impact on staff was left until last reflecting the way many professionals also feel their needs are sadly left until last. Veronica Neefjes provided a talk about conflicts between families and medical teams, something the audience felt passionate about and which led to much discussion over lunch. Michelle Hills and Anton Mayer led a workshop allowing everyone to participate in ethical decision making regarding cases concerning the use of TPN and long term ventilation (both when parents beg for interventions and when parents are asking for them to stop). Judging by how few people voted definitively one way or the other the audience recognised the challenges that clinicians, ethics committees and lawyers face. We were very fortunate to have a barrister Katharine Scott share the legal perspective and discuss high profile cases as well as a bereaved parent Steph Nimmo give a passionate personal perspective about her daughter Daisy.

In addition the day provided an opportunity for Sue Picton, our network chair, to share the news that the three STPs/ICS for the region have agreed to fund a network coordinator for a managed clinical network, something originally pump-primed by the local hospices. The region has also been selected as a site to pilot the new NHS England Commissioning model and it was wonderful to have so many stakeholders in a room to discuss such news.

Networks can provide huge challenges but working together can also help to create strength and fairness for children across a region. A large well attended and well received study day is one small part of the Network but a valuable one. Now to start the preparations for next year...



### **With thanks to Dr Lizzie Bendle for writing this review. Something to inspire us...**

I had the pleasure of attending the 7<sup>th</sup> European Academy of Paediatric Societies five day congress in Paris; it was a fascinating week in a truly beautiful city. The EAPS Congress is organised by the three societies of the European Academy of Paediatrics (EAP), the European Society for Paediatric Research (ESPR) and the European Society of Paediatric and Neonatal Intensive Care (ESPNIC). In 2018 the organisers also invited ten other important European paediatric societies, one of which was the European Association of Palliative Care (EAPC).

The Congress is a huge event, attended by a large global audience; it had a full and varied programme with a mix of plenary sessions, education symposia, invited speakers, short oral presentations and poster presentations, as well as plenty of networking opportunities and social events over the course of the week. The over-riding theme was of "Tomorrow's World" and finding a voice for children as we strive to work through the challenges and developments of the modern world. There were talks from world leaders (for example from the UN and WHO) about Global child health, climate change and resource crisis, and the future of healthcare.

The EAPC organised some specific palliative medicine sessions throughout the week, which were really fascinating and informative. We had four main sessions. The first was on "Advanced care planning for children with life-limiting conditions and life-threatening illnesses", during which we had talks covering clinicians approaches to advance care planning, parents approaches to advance care planning, and three short oral presentations of shared research experiences in this area. The second session was concerning "Ethics and Organ Donation" and included presentations and discussions surrounding controversies in neonatal organ donation, donation after circulatory determination of death, and supporting the family (and caring for the child) awaiting organ donation. The third session was concerning "Redirecting Neonatal care", with talks covering the counselling and decision making around treatment withdrawal for newborn infants and the development of a national framework for prenatal counselling in extreme prematurity. The final session was "Younger and older: ethical issues at the start and end of life", and this session had presentations concerning decision making, when to start and when to stop neonatal resuscitation and ethical issues around palliative care.

It was wonderful to see Paediatric Palliative Medicine having such good representation at the Congress, giving us the opportunity to hear from speakers from across Europe, share experiences and ideas, and discuss how to improve our specialty and the care that we offer to the children and young people we see. The full programme is available online and is well worth a look:

<https://eaps.kenes.com/2018#.XKIEFphKjIU>

## Hospice Africa Uganda – By Dr Heather McCluggage



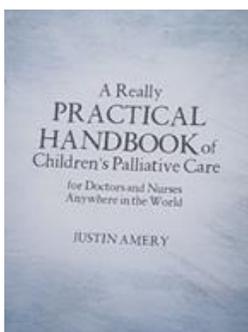
In October 2018 I had the privilege of attending some of the celebrations for the 25th Anniversary of Hospice Africa Uganda. It was founded in 1993 by Dr Anne Merriman, Prof Julia Downing continuing that work in Africa for about the last 15 years.

Hospice Africa Uganda has as their mission statement:

*“To bring Peace to the suffering in Africa, through providing and facilitating affordable and accessible palliative care in Uganda and other African countries.”*

Over the past 25 years it has influenced Makerere university to introduce palliative medicine into its undergraduate medical teaching as well as postgraduate degrees for health care professionals. It is now the centre for morphine production for all of Uganda.

At present they have about 2000 patients in their care programmes which is a small part of the number of people in Uganda who could benefit from palliative care services. They work in three centres across the country, staffed by nurses, social workers and many volunteers both local and international. They welcome volunteers from all areas of health care for short or long periods and look after adults and children.



I go to Uganda once a year to teach whole person medicine to clinical officer students as part of a team of doctors from the UK. We are always received very well. The palliative care needs of both adults and children is always highlighted to us.

Dr Justin Amery previously of Helen House spent many years developing children's palliative Care in Uganda and it was a joy to see his book on sale in the hospice on the day of the celebrations.

It was my pleasure to represent both APPM and PRIME international [Partnerships in International Medical Education] at the celebrations.



Heather and Dr Eddie Mwebesa,  
Medical Director of HAU