

# APPM NEWSLETTER

September 2022

“We all need to get the balance right between action and reflection. With so many distractions, it is easy to forget to pause and take stock.” -  
*Queen Elizabeth II*



Tweet us @theAPPMuk

In the space of 48 hours, we witnessed a seismic shift with the end of the second Elizabethan era and a change in prime minister. How these changes will come to affect us, both personally and across society are not yet fully realized. The loss of a strong steadfast committed woman will be keenly felt by many. It has given us all a moment to reflect, for me, the concept of public and private grief, how our families must manage their grief in public forums like work and interacting with health care professionals and their private grief, alone, with family and friends.

On a separate note, joining the overnight 12.5 hour queue after a full day APPM executive committee meeting made me reminisce about my house officer days when we did those Friday morning to Monday morning weekend oncalls and how I do not miss them... at ...all.

We have been successful in two NHSE funding applications to support our work. The first is to support the ongoing work of the APPM formulary (next edition due out Autumn 2023) and the clinical Guidelines (supported by Cochrane Response). The Clinical guidelines topics on seizures, agitation and GI dystonia will be out for review in a few weeks. We hope to have them finalized by the end of the year. We will be then looking to start our next two topics: pain and dystonia. Pain will be broken up into smaller manageable chunks.

If you are interested in being involved then, please email ([chair@appm.org.uk](mailto:chair@appm.org.uk)). Those involved have gained new skills and we all certainly learnt a lot clinically!

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The second successful application was to develop a virtual education program on opiates in paediatric palliative care for prescribers and non-prescribers. We hope to have the program available by March 2023. If you want to support with content then please get in touch.

The APPM has been busy establishing several subgroups in the past year or so, including a neonatal group who are working with BAPM (British Association of Perinatal Medicine) on updating perinatal palliative care guidance. I also want to acknowledge the excellent work of the specialist nursing group who have a wonderful monthly education program that is very well attended. The trainee education program has now completed its first year of a two-year program. Its reputation and numbers have grown but we are ensuring it maintains its primary purpose on supporting GRID and SPIN paediatric palliative care trainees.

Feedback from the 2022 APPM study, was fantastic and our study day group are already hard at work on November 2023 study day. There will be an afternoon on education, followed by our usual full day of clinical topics. The team are looking at an evening networking opportunity between the two days.

There was some discussion at our recent executive committee meeting regarding the APPM AGM being at the lunchtime of the study day. We are going to trial a different approach with a virtual AGM in March/April time. We will update on our activities and give members an opportunity to ask questions and share ideas. Details to follow.

Recently we had to change our APPM bank account, and this has given us an opportunity to pause and reflect on our membership fees. We have spent some time looking at comparable associations and found ourselves rather good value for money! Albeit we want to reflect the change in our membership and encourage our future workforce, so we have introduced a tiered membership. We will be sending information on this to you separately soon.

Finally, I can't finish this piece without thanking, Dr Kate Renton, who is stepping down from the executive and her role as the Newsletter editor. Kate has been a stalwart in ensuring the APPM newsletter has been delivered in a timely manner. She has lovingly curated each edition to ensure you receive relevant up to date information on current topics and events affecting us working in the field of paediatric palliative medicine. Thank you, Kate, we will miss you!

*Anna-Karenia (AK)  
Anderson*

Chair of APPM  
[chair@appm.org.uk](mailto:chair@appm.org.uk)



## Changes to DS1500 process

In simple summary, now if we expect someone will die in 1 year (rather than 6 months) they will be able to have a SR1 completed (replacing a DS1500) and this impacts Universal credit, PIP, Employment and Support Allowance, Child DLA and Attendance Allowance. Child DLA is very relevant to our patients as it is for children under 16.

We know that in paediatrics prognosis is sometimes tricky and certainly 6m and 1 yr can be a bit arbitrary. However, there are no negative consequences to this. If we as paediatricians think there is likelihood of death in 1 year the paperwork can be completed and awards are given for 3 years and then reassessed. This may also speed up blue badges etc.

It is unclear at the moment if the UK will be saturated with forms everywhere or if we will have to apply for them or if it will digital but it is important doctors know what their patients may be entitled to and the process (once it is agreed).

The Bill went through the House of Commons in September and they now plan to implement it ASAP but will need a programme of comms.

Together for Short Lives and NHSE are key to this so keep your eyes peeled for further information.

Written by Michelle Hills

## Talking Transition update from Jo Elverson

### Transition and young adult palliative care subgroup

For the last few years, I have chaired the (Adult) APM special interest group for transition and young adult palliative care. We formed a small peer support group and meet online 3-4 times a year for case-based discussion and networking. The group acts as a hub for information sharing about educational events, new research and ways to promote the needs of young adults within our own specialty. I am keen to know if a group like this would be helpful to APPM members as well. If you are interested and want to know more please contact me through [admin@appm.org.uk](mailto:admin@appm.org.uk).

#### Adult Palliative medicine training

You may be aware that specialty training for adult palliative medicine has recently changed significantly. Palliative medicine trainees will dual-qualify as specialists in palliative and internal medicine and a new curriculum has been developed.

I'm particularly pleased to see the new curriculum has increased emphasis on the specific needs of teenagers and young adults (see box). Huge thanks to Amelia Stockley for her work with the curriculum team to ensure this was included.

#### **Life-limiting illnesses in Teenagers and Young Adults (TYA)**

- Awareness of the range of life-limiting illnesses in teenagers and young adults, such as Duchenne Muscular Dystrophy, Cystic Fibrosis, malignancies affecting the teenage and young adult population, neuro-disability; including the needs of young people moving from paediatric to adult palliative care services
- Awareness of services offered and models of care delivered by paediatric palliative care services across all settings
- Awareness of specific needs of TYA group and ability to access specialist help and support
- Awareness of the complexity of prognostication in these patients
- Awareness of ethical and legal frameworks for decision-making in this population, supporting the navigation of patients and those close to them through the spectrum of childhood, Gillick competence and the application of mental capacity legislation in adults, taking into account the family unit and often well-established patterns of communication and behaviour

See <https://www.jrcptb.org.uk/specialties/palliative-medicine> for more information

Other aspects of the curriculum could also be enriched by learning from paediatric palliative care. The curriculum states that training should include "Exposure to paediatric palliative care and TYA services to support the care of patients transitioning from paediatric to adult services." This is a great opportunity to share experience and strengthen relationships between local paediatric and adult teams and even gives an opportunity to build continuity in care if a trainee is able to continue to support some young people following their transfer to adult services. We would love to hear any examples of ways this could work or has already worked in your local area.

#### Palliative Care Congress 16-17<sup>th</sup> March 2023

The Call for Abstracts for the APM Palliative Care Congress is open until October 21<sup>st</sup> and we are keen to get a good range of submissions for the Transition theme. Please consider submitting any research or quality improvement projects you have been working on. <https://pccongress.org.uk/>

## Trainee Update

Since the last newsletter, the trainees have managed a face-to-face day in London around bereavement, grief and care of the body after death. We enjoyed a picnic in glorious sunshine.

The rolling education programme continues to flourish and is attended by a variety of trainees, and wider MDT members. If you are interested in joining the sessions, please contact [trainee@appm.org.uk](mailto:trainee@appm.org.uk) for log on details.

### Next sessions:

September 30<sup>th</sup> 2022 11:00-13:00- Antenatal and perinatal palliative care. Christine Mott and Emily Harrop

October 11<sup>th</sup> 2022 10:30-12:00- Gut failure and nutrition and hydration at the end of life. Tim Warlow and Richard Hain

November 10<sup>th</sup> 2022 14:00-16:00- Neuropathic pain. Dilini Rajapakse

November 30<sup>th</sup> 2022 14:00-16:00- Prescribing in renal and hepatic failure. Finella Craig and Bhumik Patel

December 7<sup>th</sup> 2022 14:00-16:00- PCAS and opiate rotation. Renee McCulloch

January TBC

February 7<sup>th</sup> 2023 14:00-16:00 Anaesthetic adjuncts. Helen Laycock

March 14<sup>th</sup> 2023 10:00-16:00 Multimodal approaches to analgesia- Face to face interactive day at the Royal Marsden

We are also looking for new trainee representatives as both Laura and Sophie will finish/have finished training in the next 6 months. If you are interested in applying, please contact [trainee@appm.org.uk](mailto:trainee@appm.org.uk). We welcome applications from all trainees with an interest.

## Placement in palliative care for community paediatric trainees – Dr Jess Hudson

### Application

- Community paediatric grid training is a 3-year programme. 24 months of this must be in community paediatrics. The remaining 12 months can be in any 'relevant speciality'.
- Paediatric palliative medicine is one of the 5 specialities listed by RCPCH that can automatically count towards community paediatric training without further CSAC approval needed.
- Funding is likely to be different for different departments and placement (and may well be the more challenging aspect of organising a placement). I continued to sit in a community paediatric post, so my pay came from community paediatrics. To enable this to work I continued to be on the child protection rota for community paediatrics as well as the acute hospital on call rota.
- Practically the placement had to be agreed by the clinical lead at Helen House hospice, my head of department in community paediatrics, my educational supervisor and the head of school for paediatrics.

### What the placement involved

During my time at Helen House Hospice, I was involved in the following activities. Needless to say, all of these were with appropriate senior support and discussion with seniors. Although new to paediatric palliative medicine I never felt at all that I was working outside of my knowledge or skills.

- Clerking children who came to stay at Helen House hospice. Discussing their current symptom control and planning changes to their medication.
- Seeing families on their initial visit to Helen house and getting to know their needs, discussing the role of palliative care with families, and suggesting ways in which the hospice could support them.
- Giving phone call advice to families regarding symptom management.
- Attending home visits to children with difficult to manage symptoms
- Observing, participating in and then leading ACP discussions with families and writing ACPs
- Writing symptom management plans and discussing these with families.
- Attending weekly interdisciplinary team meetings in which all patients with active needs were discussed.
- Observing in ethics panel meetings
- Attending child death review meetings and CDOP meetings
- Joining ward round of children on PICU with palliative care needs.
- Attending MDT meetings for complex cases
- Attending regular teaching
- Leading teaching on safeguarding to the care team

### What were the benefits for a community paediatrician:

- While in community paediatrics we see a snapshot of children during clinics. Seeing families over multiple days as they stayed at the hospice gave me a far greater appreciation of what day-to-day life looks like for families of children with complex needs, enabling me to better provide holistic care for these families and have greater empathy for the complexities they manage at home.
- Working in paediatric palliative medicine increased my confidence in pharmacological management of symptoms in children with complex disability. For example managing tone, drooling, reflux and sleep. I gained experience in writing symptom management plans which is a skill that can carry through to community paediatrics.
- I gained confidence in discussing family's wishes including around end-of-life care and formalising this in an ACP. As community paediatricians get to know families well over a long period of time and are therefore well placed to discuss their wishes and write ACPs.
- Like in community paediatrics, most children under palliative care have support from multiple professionals. Working in palliative care demonstrated to me many great examples of joined up care and brilliant MDT working.
- Some of the children seen in community paediatrics could be supported by palliative care teams. Working in palliative care increased my knowledge of which families to refer into palliative care and gave me confidence to discuss a referral to palliative care with families. I gained an appreciation for how community paediatricians can work together with palliative care to provide very effective care for children with life limiting disabilities.

# Feedback from the 2022 APPM Conference

88% said it was an 'excellent' study day  
98% said they would return

I really enjoyed the whole two days. It was well organised and varied. I loved the food too and the sweets on the table kept people going! Thankyou

Rapid fire Journal Club presented by trainees was a good opportunity to see all together.

Excellent days. Face to face is really beneficial for networking and communication Really well organised

**excellent conference**



Liked the Birmingham Venue - very accessible

It was really good to have the opportunity to come together as a group of nurses. Looking forward to being able to work together as a group/have a phone a friend opportunity if this can be established as discussed in our group

First time I've been to APPM conference and I loved it- one of the best conference formats and great as someone new to working in paediatric palliative care to understand more and see how APPM works.



# RCPCH Conference

## Liverpool

28-30 June 2022



The APPM session at this year's **RCPCH Conference** in Liverpool (June 29<sup>th</sup>) was a joint venture with the British Paediatric Respiratory Society (BPRS) entitled '**First Breaths, Supported Breaths and Last Breaths**'. I was delighted to co-Chair this well attended and lively event with Dr Beccy Thursfield, Respiratory Consultant from Alder Hey.

We opened with an invited lecture from the London Long Term Ventilation (LTV) team, who introduced an Ethical Framework for LTV initiation, and facilitated some discussion about its development. This was followed by a thought-provoking talk on the use of high flow humidified oxygen in community palliative care, by Dr Christopher Edwards from Leeds, describing some positive experiences but also some real challenges for families and professionals.

The APPM session received an impressive selection of research abstracts this year, and the two highest scoring were given oral presentations. Professor Lorna Fraser updated us on the ENHANCE study, looking at Consultant-led specialist paediatric palliative care provision in the UK, highlighting workforce issues. Dr Yifan Liang from Birmingham Children's Hospital followed with a description of the new non-invasive ventilation decision-making tool used within their service, to support difficult decisions.

After coffee Dr Neil Gibson, Consultant in Paediatric Respiratory Medicine from Glasgow, gave a lecture entitled '*The Rights and Wrongs of Long-Term Ventilation*', reflecting on how the practice has evolved during his career and speculating on what the future may hold. The chosen abstracts from the BPRS included work on dysfunctional breathing in young people, which had real parallels with non-pharmacological management of breathlessness in PPC, and immunological differences between infants and adults in response to RSV.

The APPM had a further ten impressive abstracts accepted as posters on display during the conference. It's always a pleasure to support the APPM input to the RCPCH Conference, as it provides a chance to network with PPC colleagues as well as spreading the message to a wider audience of paediatricians from other disciplines. Next year the Conference will be in Glasgow, 23<sup>rd</sup> to 25<sup>th</sup> May 2023, and we have just secured a joint session with BSPGHAN (British Society of Paediatric Gastroenterology, Hepatology and Nutrition). This is timely, as we look to launch the APPM evidence-based guidelines (supported by Cochrane), one of which deals with the management of gut failure.

**Dr Emily Harrop**  
**APPM Research Lead and RCPCH Conference Convener**



## An update on the Children's Palliative care Outcome Scale (C-POS) project

### **What is C-POS?**

Outcome measures used in healthcare meet the needs of multiple audiences. They enable service users to better identify their priorities and outcomes of care for clinicians, who can then conduct more thorough assessments and monitor the outcomes of care planning. Additionally, outcome measures help commissioners ensure that commissioning is patient-centred and outcome-based, and help researchers evaluate care.

However, currently no ideal outcome measure exists for use in paediatric palliative care.

The Children's Palliative care Outcome Scale (C-POS) project is working to develop and validate a child- and family-centred outcome measure to be used by and with children and young people (CYP) and their families affected by life-limiting or life-threatening conditions (LLTTC), and to implement it into routine paediatric palliative care.

### **Progress so far**

The C-POS project is a six-year study funded by the European Research Council. We have worked with our many partners across the UK to complete initial development of C-POS, including our valued Patient and Public Involvement members. Important symptoms and concerns were identified through interviews with CYP with LLTTC, their parents/carers and siblings, health care professionals, and commissioners. The identified symptoms and concerns were then ranked in an online survey by parents/carers and health and social care professionals based on importance to include on an outcome measure for CYP with LLTTC. Additionally, a systematic review of evidence on recall period, response format, and administration mode needed to enable CYP to self-report their health outcomes informed the design of the C-POS.

This evidence was taken forwards into an item generation meeting with the C-POS steering group, consisting of academics, health and social care professionals, and patient and public involvement representatives, and initial versions of C-POS were developed. These initial versions of C-POS have been tested and refined through cognitive interviews and are now ready for final validation.

### **Next steps**

The next step for C-POS is a large-scale validation study to evaluate if C-POS measures what it is intended to measure, if it measures outcomes accurately and consistently, and if it can detect change in CYP's health status over time. To achieve this, we have partnered with UK NHS Trusts, children's hospices, and primary care settings to recruit CYP with LLTTC and/or their parents/carers to complete the C-POS. We are working with numerous sites across the UK, but if you are interested on becoming part of the C-POS project or learning more please do get in touch by email [hannah.m.scott@kcl.ac.uk](mailto:hannah.m.scott@kcl.ac.uk) or follow us on twitter [@CYP\\_CSI](https://twitter.com/CYP_CSI) Following the validation study, finalised and validated versions of the English language C-POS will be ready for implementation into routine care.



## 2022/3 COMPETITION TIME

### **1) Photography:**

We are looking to improve and expand the photos on the APPM website, and so are inviting entries for a photography competition.

Please send us your entries on a theme of:

***"What Paediatric Palliative Care Means to Me".***

The entries will be viewed and scored by members of the APPM executive committee. We will run an annual competition, with all suitable entries being displayed at the annual APPM study day.

The winning entry each year will be announced at the annual study day, and in the newsletter, with the winner receiving a certificate and prize (either book voucher or a book, to be confirmed each year). Runner-up photographs will also be considered for use on the website. Please email [chair@appm.org.uk](mailto:chair@appm.org.uk) with any entries (and to request a copy of our consent form for use of the photographs in the APPM display and website).

**Please also adhere to your local consent policy if taking or sharing photographs of patients or families.**

### **2) Medical students:**

This is open to all medical undergraduate students each academic year (annual competition).

Please write a 500 word essay entitled:

***"What Paediatric Palliative Care Means to Me".***

Please send your entry to [chair@appm.org.uk](mailto:chair@appm.org.uk) by 31st August each year. The essays will be reviewed and scored by members of the APPM executive committee, and the winner will be contacted by email by end of the following September.

The winning entry will have their essay printed in the APPM autumn newsletter that year, as well as a free place at the next APPM study day (excluding travel and accommodation), where they will receive a certificate and their prize (these can be posted if the winner is unable to attend). The essays judged to be in second and third place will also receive a certificate and prize. Prizes to be determined on an annual basis, but likely to be a free textbook or book voucher.

### **3) Audit:**

Open to all postgraduate doctors who are in foundation or paediatric training posts (or doctors in non-training posts who have not reached the level of Consultant). This is an annual competition.

Please complete an audit, on a topic of your choosing, that is relevant to Paediatric Palliative Medicine. Please send a powerpoint presentation of your audit (maximum of 20 slides) to [chair@appm.org.uk](mailto:chair@appm.org.uk) by 31st August each year. The audits will be reviewed and scored by members of the APPM executive committee, and the winner and runner-up will be contacted by email by end of the following September.

The winning entry will receive a free place at the following APPM study day (excluding travel and accommodation), where they will receive a certificate and will have the opportunity to do an oral presentation of their audit. The audits judged to be in first, second and third place will all receive certificates, along with a prize (to be confirmed on an annual basis, but likely to be a book voucher or free Paediatric Palliative Care textbook).

**SAVE THE DATE**

**APPM Face to Face Conference:  
16<sup>th</sup> and 17<sup>th</sup> November 2023**

Venue: Hilton Birmingham Metropole

16<sup>th</sup> November 2022 Education themed sessions

17<sup>th</sup> November 2022 Full day APPM Conference



**Other Educational Opportunities**



5th All Island  
Children's Palliative  
Care Conference

**Communication:  
Compassion and Common Ground**

Titanic Hotel, Belfast, N.Ireland  
17 & 18 November 2022



Royal College of  
Paediatrics and Child Health

*Leading the way in Children's Health*

**'Child Health in a Changing World'**

**23<sup>rd</sup>-25<sup>th</sup> May 2023  
Glasgow**

**Abstract deadline TBD**  
*Specialty symposia joint with  
BSPGHAN (British Society of  
Paediatric Gastroenterology,  
Hepatology and Nutrition).*

## Education and training programs for APPM members

### Annual APPM conference

**16<sup>th</sup> and 17<sup>th</sup> November 2023 in Birmingham**

*One current clinical issues*

*Half day on education (2023) and research (2024)*

Contact: [admin@appm.org.uk](mailto:admin@appm.org.uk)

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### APPM Trainees program

**24month rolling program**

*Combination of virtual and face to face sessions*

*For GRID and SPIN in paediatric palliative care trainees*

Contact: [trainee@appm.org.uk](mailto:trainee@appm.org.uk)

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### Specialist nursing education program

**Monthly program**

*Monthly virtual sessions with additional face to face meetings through the year.*

*Organised by specialist nurses in the field*

Contact: [admin@appm.org.uk](mailto:admin@appm.org.uk)

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### Opiate education program

**From March 2023**

*Virtual education program for prescribers and non-prescribers on opiates in paediatric palliative care*

*Further information 2023*

Contact: [admin@appm.org.uk](mailto:admin@appm.org.uk)

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