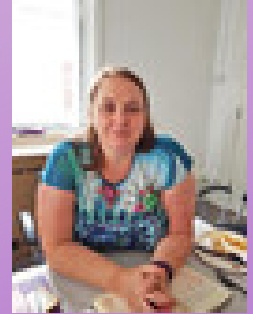


Contents	Page
From the Chair	1
Conference Reports: APPM 2023	3
RCPCH - May 2023	5
EAPC - June 2023	8
Nursing	9
Pharmacy: A Day in the Life of a PPC Pharmacist	10
APPM Formulary Version 6	12
Training/Education	15
CYPACP update	17
APPM Competitions	18
“What Paediatric Palliative Care Means to Me” - winning essay	19
APPM Sub-Group requests	21
Membership	22

## From the Chair

Still recovering from the two-day APPM conference in Birmingham- it was bigger, with posters, loads of learning and some challenging discussions. For those of you who missed the fireworks, Baroness Finlay after her talk has arranged an All-Party Parliamentary Group meeting to ‘Finding solutions to complex issues’ for healthcare professionals. Senior healthcare professionals working with children and young people with life limiting conditions have been in touch and we have arranged a vocal and articulate expert representative group to attend. We will share the outputs from that meeting which is due to be held in late January 2024. Suffice to say healthcare professionals’ voices and experiences need to be heard as part of the discussion regarding complex care decision-making.



For your diaries, next year’s conference will be held in London on 21-22 November 2024. I can’t promise more fireworks, but I am sure the study day team will ensure the conference puts on a great show!

The work for the next set of clinical guidelines (pain and dystonia) started in late September (never too late to join in - just email [chair@appm.org.uk](mailto:chair@appm.org.uk)). We have a feedback questionnaire <https://forms.gle/qu8Uj8AAZgpv3K5k6> on the clinical guidelines which you are invited to complete. In due course we will be collecting anonymised data on the practical use of the guidelines. This will be available on the APPM website in due course. All information and feedback we receive helps us in the development of our second set of clinical guidelines and when we come to review our topics in 3 years! It does not feel that far away.

Thanks to our new APPM formulary editor, Lynda Brook, the new edition has now been released and paper versions can be bought via the APPM website. We are looking at ways to ensure the sustainability of the formulary balanced with

accessibility for our UK and Ireland colleagues but also those in developing countries. The formulary is now translated into at least 5 different languages and used in various countries including, Greece, Malaysia, Japan, Ukraine and Russia. Naturally, we will be looking to update these translations with the new formulary.

For those members who want to be more involved, there are several sub-committee groups you can join: APPM/APM transition, trainee, perinatal or research groups (please email [admin@appm.org.uk](mailto:admin@appm.org.uk)). Our excellent nursing leads run a highly successful regular education event. If you have a topic recommendation or know a great speaker- please let us know.

We are continuing to forge links with speciality groups and thanks to Jill Yates on our Executive Team have recently established, a link with BACCH (British Association for Community Child Health). Jill and Lizzie Bendle ran a highly successful workshop at their conference in early September. We are hoping we can be a regular fixture at their conference and in their newsletters. We have also made links with our adult counterparts at APM and are looking at ways to share our resources and communicating with our members.

As always, if you have any ideas or thoughts then please get in touch - always love hearing from you - see the link below to a survey in which we would like your views on the APPM.

Have a lovely festive season! Look forward to a New Year with lots more exciting APPM projects planned.

**A-K Anderson**  
**Chair, APPM**

**Association for  
Paediatric  
Palliative  
Medicine**

## The next five years for the APPM



**We invite members of the APPM to take part in a survey to inform the APPM Executive Committee as they start to write a strategy for the next five years**



**The APPM is your organisation. Please take part to help make it what you would like it to be using this link**

**<https://forms.gle/j1g8g8WjvePh6qgH8>**



# Conference Reports



## APPM Conference 2023

### **APPM Education Day - Thursday 16 November**

The 2023 APPM Conference started with a half day focussed on education, organised by Dr Laura Nohavicka. We were honoured to have the day opened by Dr Ann Goldman, who shared some of her challenges and experiences as the pioneer of paediatric palliative medicine, having established Great Ormond Street's multi-disciplinary Symptom Care Team in 1986.

Opportunities for postgraduate studies in palliative medicine were presented by the teams at King's College, including their Hyflex option for attendance, (<https://www.kcl.ac.uk/study/postgraduate-taught/courses/palliative-care-msc-pg-dip-pg-cert>), and Cardiff, offering both a Master's programme as well as other short courses (<https://www.cardiff.ac.uk/professional-development/available-training/short-courses/view/palliative-care>).

Georgina Brightley reflected on her experiences of postgraduate study whilst working as a Clinical Nurse Specialist, sharing challenges and successes provided. There was a focus on simulation work, with presentations on simulation teaching at two different hospices; a course on talking to families when death is a possible outcome, and how this worked in an online format, and a multi-disciplinary approach to learning about end of life care. Following this, presentations on online learning highlighted a breadth of resources to support our learning - a national module on Opioids in Children which has just launched, online programmes through the APPM including one programme for nurses, and another for doctors undertaking specialist GRID and SPIN training. The successes of the Palliative Care Foundation Programme, and the EPEC Paediatrics programme were also presented, and rounded off a selection of fantastic resources available to the paediatric palliative care community.

The day was closed by Dr Rachel Clarke, who spoke of her experiences as an adult palliative care consultant during Covid, her observations of high-profile paediatric cases and how these are presented in the media. She reflected on the challenges of ensuring clear messaging and how we can support understanding and accurate reporting of medical details in these challenging cases.

***Dr Genevieve Southgate, APPM Trainee Rep***

## APPM Conference - Friday 17 November

Day 2 focussed on supporting children and young people to transition between paediatric and adult palliative care services. The day opened with a keynote speech from Baroness Ilora Finlay entitled 'Palliative care across the life course'. The audience



were invited to consider perspectives on some of the most complex and emotive areas of our work that appeared at odds to the practices and support we know we offer and deliver. It was certainly thought-provoking and highlighted the need for ongoing discussion in wider circles.

Marisa Mason CEO of NCEPOD delivered an engaging talk describing the outcomes of 'The Inbetweeners' report published in June 2023. Without diminishing the efforts of projects highlighted throughout the conference, the study conclusions reflected the need for clarity and accountability in delivering transition services that are fit for purpose. The report and recommendation checklist can be found here [NCEPOD - Transition: \(2023\)](#).

Breakout sessions followed, touching on collaborative models of working when caring for young adults at end of life, management of chronic pain in adolescents, maximising the opportunities create through inter-specialty working and the work of the Medicines for Children Project. The morning closed with focus groups looking at workforce and resilience in specialist nurse and allied health professional roles, and the annual trainee rapid fire Journal Club – shared with our adult palliative care trainees.

The afternoon kicked off with a panel discussion exploring the work in transition between paediatric and adult palliative care professionals of the Cardiff and Vale University Health Board and Ty Hafan Children's Hospice. We were privileged to hear from Donna Kitson, the parent of Mollie, who had benefitted directly from this collaborative approach. Delegates could then attend another of the breakout sessions before coming together for the final talk about the updated APPM formulary – copies remain available to order in hardcopy or to download <https://www.appm.org.uk/formulary/>

Thank you for joining us at the APPM conference 2023; to all our organisers and contributors – congratulations on a fantastic effort across the 2 days. We look forward to seeing you all next year!

***Dr Anna Chadwick APPM Trainee rep***



**British Society for Paediatric Gastroenterology, Hepatology and Nutrition (BSPGHAN)  
and Association for Paediatric Palliative Medicine (APPM)**

**Joint session 24 May 2023**

**Nutritional support in life-limiting conditions: Working together to support safe & comfortable feeding**

I was delighted to co-chair this well-attended, energising and thought-provoking session with Dr Lucy Howarth, Consultant Paediatric Gastroenterologist. We started with an invited lecture from Dr Tim Warlow, Consultant in Paediatric Palliative Care, University Hospital Southampton NHS Foundation & Naomi House & Jacksplace. Tim chaired the APPM / Cochrane guideline on gastrointestinal dystonia and his talk illustrated the process of producing guidance in an evidence sparse area, where even the definition of the symptom had to be agreed by committee. He spoke eloquently about the benefits of joint working with BSPGHAN and talked us through the output of the process. The need for the guideline was clearly illustrated by questions and points for discussion raised by the audience, who came from a wide range of paediatric specialties.



Our second invited speaker was Gareth Birkett, founder and CEO of Wilbo's Blends and father of William (known as Wilbo), who benefits from a blended diet. Wilbo's blends have now sold to over 10,000 customers internationally and feedback has been extremely positive. The team have secured a grant for further research, which they hope will contribute to making the product more easily available and able to support more families in the future. Watch this space!

Prof Lorna Fraser gave a research abstract presentation updating us on the results of the 'Your Tube' study examining the role of different diets in children who are gastrostomy fed. Data from her study of children fed blended diets, compared to those on a sterile milk feed, appears to show symptomatic benefits for children receiving blended diets.



Professor Christina Lioffi presented the first stage of the BEACON study, which will aim to clarify the way that breakthrough pain, for all children with palliative care needs is measured and reported, so as to improve their care.

Mr Alex Lee, Consultant Paediatric Gastrointestinal Surgeon gave the first of the invited lectures from BAPGHAN. He spoke about the role of surgical interventions (post-pyloric feeding, fundoplication) in children with palliative care needs and feeding difficulties. His talk was a practical and insightful pulling together of the pros and cons of surgical interventions, dovetailed with the role of dietary treatments and / or medical symptom management. Alex has helped co-produce a series of educational videos with families and colleagues. These short films allow them to refresh their skills and troubleshoot feeding-related problem.

The oral abstract presentations for BAPGHAN both came from Birmingham Children's Hospital. Dr Khaled Elesnawy presented a tertiary centre review of outcomes of paediatric patients with gastrointestinal dystonia associated with neurodisability. Dr Laura Kelly (ST7 Paediatric Gastroenterology trainee) then further described the multidisciplinary approach needed, by describing a local clinic where gastroenterology, dietetics and palliative care are joining forces for GI dystonia, presenting a one-year review of this innovative MDT approach.

Finally, Dr Chris Bakewell (ST6 Paediatric Gastroenterology, Southampton Children's Hospital) rounded off the afternoon with BAPGHAN's second invited lecture entitled 'Blended diet as treatment for feed intolerance'. This was a perfect summary to the whole session, bringing together many of the themes already identified by others.

For me, the key learning points of the afternoon were that:

- We now have a tight definition for gastrointestinal dystonia
- We also have evidence-based guidance co-created by BAPGHAN and APPM
- Blended diets are a very promising intervention and more user-friendly products are in development
- 'Permissive feeding' is an important concept, allowing families to feed children with feed intolerance / gastrointestinal dystonia in manner led by quality of life and comfort, rather than purely weight gain / calories – this is also in line with NICE Guidance (NG61)
- Parents of children with feeding difficulties need to be recognized as experts in their child's care and they form a crucial member of any treatment team.

I am grateful to the speakers who provided such excellent presentations, to the engaged and interactive audience and (of course) to my co-chair, Lucy.

**Dr Emily Harrop, Helen & Douglas House and Oxford University Hospitals  
Consultant in Paediatric Palliative Care & APPM Convener for  
RCPCH Conference 2023**



Home | News and events

## RCPCH Conference 2024

We look forward to seeing you at next year's RCPCH Conference as our big event returns to Birmingham from 25 to 27 March 2024. The theme for RCPCH Conference 2024 is 'Building a bright future together'.



Association for Paediatric Palliative Medicine



British Association of Perinatal Medicine

Join us next year for an exciting joint session with the British Association of Perinatal Medicine.

Invited lectures will include data to support the delivery of perinatal palliative care, understanding the edge of viability, perinatal advance care planning, and long term ventilation. We also have a talk from someone with lived experience of complex neonatal care.

*Session date and time:*

*Tuesday 26 March 13:30-16:30*



6<sup>th</sup> All Island  
Children's Palliative  
Care Conference

6th All Island Palliative Care Conference  
Challenging the Boundaries: Ante-natal to Adulthood  
25 and 26 April 2024

Early bird tickets on sale until 22 February 2024  
Midlands Park Hotel, Portlaoise, Co Laoise, Ireland  
Abstract submissions close 20 December 2023





# Report from the EAPC Conference - June 2023

Back in June it was good to see so many members of the APPM at the EAPC 18th World Congress in Rotterdam. The theme for the Congress this year was equity and diversity with the middle of three days having dedicated paediatric palliative medicine sessions. It was fantastic to see members of the APPM showcasing their expertise and work in both oral and poster presentations throughout the congress. Sessions were rich and varied in their content and included wide-ranging and eye-opening international content. Stark contrasts in accessibility to palliative care across the world were highlighted with topics ranging from the use of robots and artificial intelligence in palliative medicine to the Kerala model for palliative care in India and learning about sky burials in Nepal.

Shocking statistics in a plenary presentation emphasised homelessness as being a life-limiting diagnosis and other sessions highlighted heart-breaking inequities in death and dying: “my home is not a nice place to live let alone a nice place to die”. Paediatric specific sessions included a chance to reflect on the challenges as clinicians of responding to suffering and being ‘vulnerable enough’; considering frameworks for practice and supporting displaced children.

Opportunities for shared learning within generic sessions were extensive with sessions on all expected aspects of clinical and non-clinical palliative care topics. Consideration was given to palliative care in the context of emergency services and reaching groups including minority ethnic populations and those with intellectual disabilities. There were international views on ‘a wish to hasten death’; Kathryn Mannix discussing increasing public understanding of death by ‘narrating death-beds’ and an eye-opening yet entertaining workshop on ‘miscommunication with the media’ enjoyed by several APPM members.

The endless learning opportunities are too numerous to list but above all the conference and European sunshine provided an excellent opportunity to network with peers and friends old and new.

***Dr Naomi Taylor***  
***Consultant in Paediatric Palliative Medicine***  
***Martin House Hospice***

# Nursing

## **Education and Training**

We were delighted to see so many nurses at the APPM conference in Birmingham. During the nurses' networking session, we provided some updates and some APPM opportunities for 2024.

We will continue to deliver the regular virtual teaching sessions throughout 2024 and we are planning a nurses' conference in Birmingham Children's Hospital on Thursday 9 May: please hold the date. A big thank you to all of the speakers of the education sessions throughout 2023, we really appreciate your time, expertise and knowledge.

## **Opportunities**

We are keen to engage a group of nurses with a particular interest in education and training and will be recruiting several nurses in the New Year to join the Nurses APPM Faculty of Education to help plan and coordinate both virtual and face to face training/education opportunities.

## **Supervision and Peer support**

Beth Ward, Claire House Clinical Psychologist presented "Compassion Focused Staff Support" at the conference as what we are hearing nationally is that there are significant challenges with workforce recruitment, retention, and resilience. We have suggested setting up virtual peer support/supervision groups so that nurses can reflect difficult clinical cases, discuss operational challenges, creative and innovative ideas, share policies/SOP, benchmark etc.

We will be launching this initiative in the New Year and we will be looking for volunteers to become supervisors of groups – approximately 10 members. Becoming a supervisor will include arranging dates, managing the sessions including group dynamics, and taking some notes of themes discussed. Please look out for more information in the New Year on how to apply for such opportunities.

We also would like to encourage nurses to join the APPM. Annual subscriptions are very reasonable (£35 for an individual or £100 for a group of up to 5 nurses). With membership you will get reduced conference fees, a bi-annual newsletter and hear about topics of importance that arise within the paediatric palliative care world. To join just go to the website <https://www.appm.org.uk/about-appm/join-the-appm/>

Finally, we wish you all a Merry Christmas and hope you and your teams get some well-deserved family time off over the festive period whilst balancing the needs of the children and families in your specialist care.

**Lesley Fellows and Helen Queen**



Image by Freepik

## **A Day in the Life of a Paediatric Palliative Care Pharmacist by Patrick To, Demelza Pharmacist**

Paediatric palliative care pharmacists play a vital role in the care of paediatric patients with life-limiting illnesses. We work closely with other healthcare professionals to provide comprehensive symptom management, education, and support to patients and their families.

A typical day for myself at Demelza includes:

### **Attending clinical meetings:**

Palliative care pharmacists regularly attend clinical meetings to discuss patient care plans and make recommendations. These meetings may involve other healthcare professionals, such as doctors, nurses, social workers, and chaplains.

### **Conducting medication reviews:**

Paediatric palliative care pharmacists conduct medication reviews to ensure that patients are taking the right medications at the right doses. We also make recommendations for changes to medication regimens to improve symptom management and reduce side effects.

### **Providing education to patients and families:**

Providing education to children and families about their medications, their illnesses, and their care options is a vital part of our role. We deliver this support by answering questions about pain management, symptom management and end-of-life care.

### **Meeting with patients:**

Paediatric palliative care pharmacists often meet with patients and their families to discuss their symptoms, concerns, and goals of care. They may also provide counselling and support to patients and their families.

### **Participating in clinical governance:**

A key role is participation in clinical governance activities to ensure that the quality of care provided to patients is high. This may involve developing and implementing medication related policies and procedures, conducting audits, and educating other healthcare professionals.



### Here is an example of what I do on a typical day at Demelza:

**9AM - 10AM:** Check emails and answer any clinical or technical queries that have been sent to me over the past week. As I only work one day a week for Demelza, these can build up quite quickly. Some recent queries have included: how to prescribe insulin safely for a patient whilst in respite care, and using Maxitrol™ topically on a PEG site for the treatment of granulomas.

**10 AM - 11AM:** Meet with clinical governance team for our weekly catch up. The clinical governance team consists of senior nurses, physiotherapists, occupational therapists, administrators, and myself. In these meetings, we cover the goals for the week, and discuss any upcoming deadlines and that need to be completed to ensure that the hospice is operating safely and effectively.

I love this part of my role, as the diversity of healthcare professionals in this team reflects the overall goals of ensuring great care for service users in all aspects of their care.

**11AM - 12PM:** If I have the opportunity, I'll provide ad-hoc medicines teaching for nurses and talk about medicines that aren't frequently seen in palliative care medicine. Medication like insulin, creams, and vitamins have been hot topics recently.

**12PM - 1PM:** Lunch break, I often use this time to catch up socially with the team, and because the Demelza Kent site is situated in some lovely grounds, I go for a bit of a walk!

**1:00 PM - 2:00 PM:** Review medication incidents that have happened over the past week on Vantage, the incident reporting system. I will often track and see if there are any trends in the incidents reported. If any incidents involve an external party (such as community pharmacists, GPs, or hospital colleagues), I contact them and ensure that learning and ways to prevent it from happening again are passed on to their team. Every quarter, I write a report on medication incidents which then gets fed back to the quarterly clinical governance assurance meeting.

**2:00 PM - 3:00 PM:** Attend a meeting with the clinical lead nurses about safe use of medication. Recently we have been discussing the safety of administering paracetamol to our service users without needing a prescription.

**3:00 PM - 5:00 PM:** Document patient care activities and complete paperwork, sometimes I'll use this time to catch up with my line manager and see if there are any long term projects that need thinking about.

This is just an example of my day, and the specific duties of a palliative care pharmacist in a hospice will vary depending on their workplace and patient population. However, all paediatric palliative care pharmacists share the common goal of providing compassionate and high-quality care to children with life-limiting illnesses, and supporting their families.

# APPM Formulary

## 2024

### Version 6



The new edition of the APPM Formulary is now available to purchase or download for free from the website [www.appm.org.uk](http://www.appm.org.uk). This latest edition represents a substantive revision from the previous version. The entire formulary has been reviewed and updated incorporating recent published literature, specialist advice and feedback from formulary users. Many of the monographs have been extensively rewritten and references have been brought up to date. The formulary has also been completely reformatted, including greater use of tables and with the aim of improving clarity and navigability.

Important changes include:

- Substantially revised or reformatted opioid equivalence tables including new recommended approximate equi-analgesic ratios for morphine, diamorphine and oxycodone
- Use of a QR code to link the printed formulary directly to the APPM Website for updates and supplementary information

The APPM formulary was first published in 2012 with the objective of providing a single overarching paediatric palliative care formulary from which other formularies are derived. The primary audience is professionals working in paediatric palliative care in the UK. The 6th Edition of the formulary consolidates previous work, making dose recommendations that are as safe, sensible and simple as possible. The new formulary takes into account available evidence, including new evidence together with expert opinion and experience.

For this edition we have particularly concentrated on drugs that are used differently in paediatric palliative care. We more frequently administer drugs by alternative routes including greater use of subcutaneous infusions, buccal, intranasal or sublingual, and drugs are often converted to different routes during a course of treatment. We use drugs for different indications compared with other areas of medicine including using opioids for palliation of dyspnoea and antipsychotics for their anti-emetic properties. The paediatric palliative care patient population is also different. Our patients are often sicker and with multiple co-morbidities. Our patients are frequently atypical in terms of body weight and/or composition for age. Polypharmacy is common. Our patients are more frequently being treated in non-hospital settings.

Morphine and diamorphine are important drugs that are frequently used differently in paediatric palliative care. However the primary research evidence to support dosing recommendations is sparse. The greatest experience and evidence is with oral morphine in palliative care, intravenous morphine in the post-operative and intensive care settings and with older children and adults.

The BNFC 2023-24 dose recommendations for morphine and diamorphine include a number of important inconsistencies when viewed from the perspective of how these drugs are used in paediatric palliative care. These include subcutaneous morphine bolus doses up to twice the oral dose in the 6 – 11 month age range and different dosing frequencies for oral versus intravenous/subcutaneous bolus morphine in the 3 – 5 month age range. An editorial decision was therefore taken to not to adopt the BNFC dose recommendations for the 6th APPM formulary reverting instead to a “back to basics” approach.

Established evidence suggests that oral absorption of morphine is more variable and may be higher in neonates. Volume of distribution is also higher in preterm babies and neonates particularly during days 2 – 5 of life. Morphine is converted to active metabolites in the liver and then excreted by the kidneys with maturation to adult pharmacokinetics by approximately 6 months. Clearance of morphine may be higher in some younger children. Diamorphine is a pro-drug which is converted to morphine by serum esterases (1).

The new edition of the APPM formulary also takes into account important new evidence derived from two independent systematic reviews and a pharmacodynamic modelling study (1–3). This evidence is outlined in the new approximate equianalgesic ratios for morphine and diamorphine in the table.

<b>From</b>	<b>To</b>	<b>Ratio</b>
Oral morphine (1-3)	IV morphine	3:1
IV morphine 2, 3	IV diamorphine	2:1
IV morphine 2, 3	Intranasal morphine	1:1

APPM dosing recommendations for morphine and diamorphine are informed by the established and new evidence. Dose recommendations for oral and bolus dosing in younger children have been extrapolated from infusions because these recommendations have remained relatively static and can be traced back to primary research, providing the strongest evidence base. We recognise that equianalgesic data is derived largely from single doses and is therefore likely to underestimate potency relative to infusions. For older children, greater emphasis has been placed on oral dosing evidence as the research base is stronger.

There is some unpublished evidence that bioavailability in adults may be slightly lower for subcutaneous versus intravenous administration of morphine. However for the purposes of the APPM formulary we assumed 100% bioavailability for both



intravenous and subcutaneous routes, recognising that this is likely to be safer and subsequent doses will be titrated according to response. The available evidence means that slightly different equi-analgesic ratios for oral: intravenous/ subcutaneous morphine have been used to derive dose recommendations for opioid naïve patients. However, once patients are established on morphine, an oral - intravenous subcutaneous ratio of 3:1 - should be used in all patients.

Midazolam dosing in paediatric palliative care is another area where there has been much debate and discussion through successive formularies. A number of pieces of work have informed dosing recommendations in the new formulary including a structured literature review and a survey of professional practice. The results of the midazolam prospective data collection were not published in time for formulary deadlines. The work so far confirms that the research evidence is currently insufficient to make firm recommendations for midazolam dosing in paediatric palliative care for anxiety, agitation at end of life, cerebral irritation or dystonia rescue. Instead the APPM formulary team has taken a back to basics approach. Dose recommendations in the new APPM formulary are therefore extrapolated from adult palliative care, paediatric conscious sedation and paediatric epilepsy including consideration of bioavailability data.

Now that the new edition of the formulary is published, the formulary editorial team is beginning to consider next steps. Further work may include an international version of the formulary in English but with recommendations for essential and core drugs and possible alternatives for settings where particular formulations are not available. There are plans for the formulary to be translated into German and Japanese and it is likely that other languages will follow. Finally there are a number of questions and issues that have arisen from the formulary work which may in turn lead to further research projects.

As ever the formulary editorial team welcomes feedback, comments, suggestions, and recommendations from healthcare professionals in the UK and across the world. Please email [Lynda.Brook@alderhey.nhs.uk](mailto:Lynda.Brook@alderhey.nhs.uk)

Formulary orders: [www.appm.org.uk](http://www.appm.org.uk)

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3. Gastine S, Morse JD, Leung MT, Wong ICK, Howard RF, Harrop E, et al. Diamorphine pharmacokinetics and conversion factor estimates for intranasal diamorphine in paediatric breakthrough pain: systematic review. *BMJ Support Palliat Care.* 2022 Feb 19;bmjspcare-2021-003461.

**Dr Lynda Brook**  
**Editor - APPM Formulary**

# Training/Education

## Training dates in early 2024 for Medical Trainees

### Friday 19 January

7.00-8.30 pm  
Interview support  
evening for GRID  
applicants

### Friday 9 February

Half day study  
morning via the DEN  
Leadership and  
Research in  
Paediatric Palliative  
Medicine

### Monday 18 March

End of Life Care  
Study Day  
London  
Venue TBC

Queries about training  
to  
[trainee@appm.org.uk](mailto:trainee@appm.org.uk)

# Problem Paediatric Palliative Care



A course organised by Cardiff University in collaboration with Ty Hafan Children's Hospice and the All Wales Managed Clinical Network for Children's Palliative Care.

A blended learning programme, comprising four face to face teaching sessions In South Wales, supplementary online learning resources and project based work

- 12 February 2024: Principles and philosophy of paediatric palliative care
- 11 March 2024: Period of stability/need for parallel planning - including symptom control
- 8 April 2024: End-of-life phase including Advance Care planning
- 13 May 2024: Bereavement and staff support / project presentations.

Delegates will be supported to undertake a project in paediatric palliative care relevant to their work place in order to take theoretical skills into practice.

For more information or to enrol go to:

<https://www.cardiff.ac.uk/professional-development/available-training/short-courses/view/problem-solving-in-paediatric-palliative-care>



## OPIOIDS IN CHILDREN

a blended learning module

### Why? What? Who? and How!

**Why?** Children who are palliative may have complex pain requiring an individualised approach to management. NHS England commissioned the development of this module to support professional learning in a post-MST granules world.

**What?** Designed to run over three months, learners can access interactive e-learning components at their own pace and attend live virtually delivered face-to-face sessions to complement.

Content covers:

1. Assessment of pain
2. Pain management in children with palliative care needs
3. Simple opioids
4. Complex opioids, opioid conversions

**Who?** National application, suitable for all healthcare professionals who are managing children in pain, particularly those who may need to prescribe opioids. This may include registrars, consultants, nurses, general practitioners, pharmacists and allied healthcare professionals, across hospital, hospice and community.

OPIOIDS in CHILDREN  
with palliative care needs



Association for Paediatric Palliative Medicine



**How? Register interest by scanning the QR code or emailing [admin@appm.org.uk](mailto:admin@appm.org.uk). Applicants will be entered into the next available course.**





Child and  
Young Person's  
Advance Care Plan

We are delighted to have made so much progress on the CYPACP in the last year or so, with the main highlights being:

- A new version of the CYPACP launched in June 2023.
  - The Webinar launching, a copy of which can be accessed from the website: <http://cypacp.uk/document-downloads/care-plan/>
- Guidance for the new version of the CYPACP (produced in collaboration with professionals, patients and public – funded by Marie Curie)
  - Including 'at a glance' documents for easy access <http://cypacp.uk/document-downloads/guidance/>

In addition to this there are many other exciting projects / activities ongoing. These include:

- Working with Resus UK to produce a 'Modified Resus' Help sheet – specifically recognising that this is appropriate for young people with palliative care needs and helping to advocate for these patients, in particular within adult services.
- Continued discussions and requests for a national database / digital system
- Supporting local regions in adopting the CYPACP
- Various educational events across the country.

The work to date is a combined effort from many of you in the APPM for which we are very grateful. This has proved so powerful due to the wide range of professions, expertise and the geographical spread of you all and we would like to continue this wide collaborative working.

## **NEXT STEPS**

We are now planning to update our contact list and revise our structure as follows.

- Helen and I will continue as Co-Chairs
- A core Steering Group – aiming to have regular email communication and online meetings (perhaps quarterly, and maybe more frequently as needed)
- A wider Collaborative Stakeholder Group – to utilise when needing a wider consult for important issues, and for feedback into new versions, etc

We really want to ensure wide representation from different professions, specialties and geographical spread. If you would be interested in joining us either

1. in contributing to a core Steering Group (we may need to be selective to ensure a balanced mix of expertise), or
2. as part of a wider Collaborative Stakeholder Group (you can say 'yes' to both!) - please email [admin@appm.org.uk](mailto:admin@appm.org.uk) with
  - a. Your profession / role
  - b. Specialist area / background relevant to CYPACP [eg transition, ante-natal, etc]
  - c. Geographical region

***Dr Ross Smith, Consultant in Paediatric Palliative Medicine***

***Leeds Teaching Hospital NHS Trust / Martin House Children's Hospice***

***Dr Helen Bennett, Director of Care***

***Alexander Devine Children's Hospice Service***

# APPM Competitions 2024

## Photography competition:

We are always looking to improve and expand the photos on the APPM website, and so are inviting entries for a photography competition. Please send your entries on a theme of: "What Paediatric Palliative Care Means to Me" to [chair@appm.org.uk](mailto:chair@appm.org.uk) by 31 August 2024. 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 Conference. The winning entry each year will be 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.



## Essay competition:

This is open to all medical undergraduate students each academic year. Please write a 500 word essay entitled: "What Paediatric Palliative Care Means to Me". Send your entry to [chair@appm.org.uk](mailto:chair@appm.org.uk) by 31 August. The essays will be reviewed and scored by members of the APPM Executive Committee, and the winner will be contacted by email by the end of the following September. The winning entry will have their essay printed in the APPM autumn newsletter that year and will receive a certificate and prize. 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.

## Quality Improvement Project:

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. Have you initiated or developed a quality improvement project that is relevant to Paediatric Palliative Medicine? If so, you can send a PowerPoint presentation of your work (maximum of 20 slides) to [chair@appm.org.uk](mailto:chair@appm.org.uk) by 31 August 2024. The projects will be reviewed and scored by members of the APPM Executive Committee, and the winner and runner-up will be contacted by email in October 2023. The winning entry will receive a free place at the APPM study day (excluding travel and accommodation), where they will receive a certificate and will have the opportunity to give 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).



The results of the 2023 Essay competition are:

First place: Harriet Sharp and her winning essay is below

Second place: Annie Smithson

Third place: Emily Mander



Congratulations to the prize-winners who have been contacted with their certificates and prizes. Thank you to all who sent in entries.



Prize-winning essay by Harriet Sharp, Brighton & Sussex Medical School

## *What Paediatric Palliative Care Means to Me*

The World Health Organisation defines paediatric palliative care as “the active total care of the child’s body, mind, and spirit, and also involves giving support to the family”[1]. However, there is still a stigma around what palliative services actually provide[2,3].

During my 4-week elective at Hope House and Tŷ Gobaith children’s hospices, I witnessed the palliative support available for children with life-limiting illnesses. It was quickly evident that hospices are not a place of sadness, but a place (as the name suggests) of hope.

The Snowflake Suite[4] is a bedroom dedicated for families to say goodbye to children who have died; allowing families to sensitively process their grief in ways tailored to their wishes and needs. The name “Snowflake” encompasses what palliative care means to me.

Snowflakes, like families using palliative services, are unique. It is important that palliative care mirrors an individual approach whilst working cohesively with families to sensitively discuss a child’s journey. Speaking to a mother of a child residing in the hospice, I learnt how she felt alone when her child was first diagnosed with neonatal hypoxic-ischaemic encephalopathy in hospital. It was not until she reached the hospice that someone actually asked, “How are you?.” “Giving support to the family”[1] is as important as caring for a child. Families help their children’s development[5], but equally require practical and emotional support themselves. Working with families to understand their individual situation helps to optimise paediatric plans to best suit both children’s and their network’s needs. Paediatric palliative care is, therefore, the active collaboration between health professionals, families, and children[6]. Signposting to the various multidisciplinary counselling, sibling support, social work, and financial support services allows both the child and family to be cohesively cared for together, optimising outcomes and supporting individuals’ rights to choose the care that is best for them.

I attended an All Wales Paediatric Palliative Care Team meeting, discussing Advanced Care Plans. One child the multidisciplinary team discussed had plexiform neurofibromatosis and was at risk of airway obstruction from nerve impingement. The Advanced Care Plan was important to help alleviate anxiety for the family, as well as allowing the care team to outline a sensible plan should a



time-sensitive situation arise. I appreciated that the first step of the plan was to "ensure that [the child] feels safe and loved". Like snowflakes, palliative treatment can be complex, but can also provide a sense of tranquillity amongst whirlwinds of uncertainty and sadness. Palliative paediatric care encompasses the protection of a child's right to be a child and be cared for[3], remembering their basic needs first and foremost. By adopting a holistic, biopsychosocial model, the varied needs of children and their families can be addressed.

To me, paediatric palliative care reflects the beauty amongst the harsh reality of child mortality or them living with debilitating conditions. By identifying and supporting families through the precious moments, cherished memories can be created to allow a family to feel warmth, love, and hope when faced with the fragility of life.

**Harriet Sharp**  
**Brighton & Sussex Medical School**

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### **Calling all Speciality Doctors!**

If you are a Speciality Doctor in PPC we'd like you to join the new APPM Speciality Doctor Group. We will be putting together an email list, and will then be asking what you would like from the group.

If you are interested, or have any questions, please email [csprinz@helenanddouglas.org.uk](mailto:csprinz@helenanddouglas.org.uk).

Paula-Ann Bailey has also set up a Speciality Doctors WhatsApp Group, which you can join via this QR code:

Thank you!

Caroline Sprinz (Helen House) and  
Paula-Ann Bailey (Keech)



### **Calling all Hospice Medical Leads**

APPM has formed a collegial group of children's hospice medical leads, recognising that many work as the only or one of a small team of doctors. We meet and discuss issues relevant to care in hospices, promote integration of medical services in Hospices, disseminate resources, pathways, education and research opportunities and provide a collaborative space to discuss challenging cases. Meetings will be held on a quarterly basis.

Please consider providing us your email address to be added to the mailing list and invited to our next meeting

<mailto:admin@appm.org.uk>

## Association for Paediatric Palliative Medicine

We are always keen to welcome new members to the APPM and the offer of a tiered membership scheme which includes group membership for nurses and other allied health professionals for up to five named colleagues at £100 per annum has been very popular and has led to a more multi-disciplinary membership.

Membership includes:

- Peer support for all health professionals in paediatric palliative care
- Reduced rates for members at APPM events
- Education and networking sessions in paediatric palliative care
- Bi-annual newsletters
- Online access to the leading journal in our field: **Palliative Medicine**
- The APPM is affiliated with the European Association of Palliative Care and you may sign up as a member

The APPM is also affiliated with other organisations such as the Association of Palliative Medicine, the International Children's Palliative Care Network and the British Association for Community Child Health.

Membership type	Cost per year
Senior doctor including medical consultant, associate specialist, general practitioner	£60
Researcher (main role)	£45
Junior doctor including any doctor in training	£45
Allied Health Professional including pharmacist	£35
Nurse (individual)	£35
Nursing and/or allied health professional team membership up to 5 named members	£100
Undergraduate in healthcare including medical nursing allied health professionals	Free of charge

## Please tell your colleagues about us

Lizzie Bendle, Newsletter Editor  
Sue Lakie, Newsletter Administrator

To contact the APPM:  
Email: [admin@appm.org.uk](mailto:admin@appm.org.uk)  
Website: [www.appm.org.uk](http://www.appm.org.uk)