

Association for Paediatric Palliative Medicine (APPM) Newsletter – Spring/Summer 2023



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From the Chair

It has been a busy first few months of the year. Our first set of clinical guidelines are now online, our opiate education programme is being finalised and our first APPM face to face nursing day should have been held on 9 March but sadly, had to be cancelled due to snow – it will be re-scheduled. The opiate education programme was borne out of concerns for changes in drug formulation availability (MST granules and diamorphine). Our education lead, Laura, is currently finalising the programme outline which will be available on a digital platform later in the year.

From our nursing exec members, their monthly virtual education meetings have continued to be highly successful with an average of 50-70 attendees per session. Our pharmacy group has formally agreed to support this on a regular basis. The pharmacy group are very proactive in supporting several APPM projects and are looking to regularly contribute to the APPM newsletter (see introduction on page 8)

Planning for our annual conference in November is underway. The conference will be held in Birmingham and will feature an initial half day which will focus on education in paediatric palliative care and the following day will be the usual feast of information overload with a focus on transition. Talking of transition, Dr Jo Elverson is setting up an APM/APPM transition group- if you are interested in joining, please contact our administrator (admin@appm.org.uk) who will put you in touch with Jo.

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<https://www.appm.org.uk>

Dr John Allen has joined the Executive as the representative for Ireland and Dr Marian Williams from Northern Ireland remains on the Executive to offer an All Ireland perspective to the APPM. There are some early thoughts about an All Ireland sub-committee but for the moment John and Marian will be looking at the APPM work-streams and considering the best approach of engaging in and disseminating the work of the APPM to All Ireland.

With this new development of APPM expanding beyond the UK, alongside the enormously positive impact that our nursing and allied health professionals have had on the APPM, we will be spending the next 6-9 months thinking about our current strategy and branding. As always, we welcome your thoughts and comments on the direction of travel of the APPM and what more we could be doing to support our members.

We have established a new Executive role, Hospice Medical Lead, with Dr Christine Mott having taken on this role. She is currently gathering information and contacts on the medical leads across the children's hospice sector. Please contact our administrator for further information or if you want to be included. Dr Lizzie Bendle is looking to expand the remit of our post-graduate competition to a quality improvement project (previously audit), we welcome submissions from any professional working in the field. Further details on our website. Please see the winning essay on page 15 of this newsletter.

The remainder of the year will be busy for the APPM with our digital opiate education programme, conference in November, webinar series in April, starting the next clinical guidelines series in September and the next edition of the APPM formulary due out later this year. In the meantime, have a lovely Easter break. Not sure I am looking forward to it myself with my last set of GCSE revision...roll on June (and then onto A levels... empty nest syndrome...spending time with my husband...so much to look forward too!)



Anna-Karenia (AK) Anderson

Chair of APPM chair@appm.org.uk



APPM CONFERENCE 2023

Thursday 16 November – half day of education themed sessions

Friday 17 November - full study day on the theme of transition

The Hilton Conference Centre, Birmingham

See pages 6 and 7 for more details



Clinical guidelines

AT LAST.....

We successfully launched our first three clinical guidelines on Seizures, Agitation and GI Dystonia in January 2023. They are now available for use on the APPM website. Each guideline has a similar layout: an introduction on the purpose of the guidelines, a topic scope, definitions, general principles, communication, assessment, initial considerations, non-pharmacological management, pharmacological management, end of life care and a summary. The topics each have a colour theme for online viewing (and printing, though I suspect that is irrelevant if your organisation is anything like mine where it is greyscale only and colour cartridges are sold or exchanged like contraband). For each clinical guideline, there is a colourful algorithm which is downloadable separately...and looks great in greyscale too.

Under each of the guidelines there is also an evidence section. If you click on the evidence section arrow, you will be taken to the 'Evidence to Decision Table' for each topic. The table (which is a euphemism for a multi-page document) describes the decisions made for each piece of evidence within the guideline.

There will be a Webinar series running from Monday 24 April to Friday 28 April 2023. To book Mon-Thurs click on the link below

[APPM Clinical Guidelines Webinar Series](#)

The webinar series consists of 4 bookable one hour sessions from 1.00-2.00 pm - £5.00 each + booking fee:

Monday 24 April - Developing evidence for clinical guidelines

Tuesday 25 April - GI Dystonia

Wednesday 26 April - Seizures

Thursday 27 April - Agitation

Friday 28 April will be a **free** session which will be an introduction to the clinical guideline process to provide some information about how the guidelines are developed and the work involved. It is relevant to anyone interested in understanding the work behind the guidelines better or those who may be interested in joining the next planned series. The session will provide some insights into the work involved and provide an opportunity to ask questions. **Contact admin@appm.org.uk for a link to join.**

It uses a 3-step process of (1) judgement, (2) research evidence and (3) additional considerations to answer a series of questions to assess the guidelines in various domains (eg desirable effects, values, certainty of evidence, equity and feasibility). Towards the end of the document there is a judgement summary to give a sense of the level of evidence overall and a recommendation. Additionally in the evidence section on the website, there is a methodology report which describes the process for each guideline from PICO formation to systematic review to consensus development. Each topic had a systematic review and a report prepared by Cochrane. This included the summary of results from observational non-comparative studies and, on the rare occasion, when there is a relevant comparative study with a GRADE (evidence level) rating and a Forest plot included.

The guidelines were published onto the APPM website in January 2023. Once again **THANK YOU** to our wonderful dedicated Clinical Guidelines Group. Special shout out to the topic leads, our patient representative and parent representatives. They navigated us beautifully to the finish line. Also, to Gemma, our systematic reviewer from Cochrane Response. Her patience during the systematic review when I kept putting 'interesting papers but not relevant' into the keep pile was masterful - she created a separate pile for me and anyone else who was starting to go down interesting but not relevant rabbit holes.



We have already received some wonderful feedback!

- *'Can I extend a wholehearted congratulations to everyone involved in the guidelines, we are already finding them so useful. It was mammoth work from many, with superb results. Sitting on the peripheries, I have been in awe of how they have come together. Thank you and well done'*
- *'These guidelines are FANTASTIC! They will make such a difference...'*
- *'Being part of the wider group was an amazing learning curve for me.'*
- *'When I was approached about joining this group to support the work of APPM, I was shall we say, just a little reticent. Well, it has been an emotional journey, but it has been a real privilege to be involved with such a talented and passionate group of healthcare professionals, striving to achieve the very best for children and young people in the most challenging situations.'* (parent representative)
- *'So glad I did this, learned so much and would highly recommend to other trainees.'*
- *'Wow, wow, wow'*
- *'Seeing these 'live' is just amazing. What a journey. It was clearly worth the pain of going through all those abstracts!'*
- *'What a great resource to have.'*

Now we are on to the promoting stage! One of our Exec members, Jill Yates, along with Tim Warlow, are presenting the GI Dystonia topic to various specialty groups, meetings and conferences including the All Ireland Palliative Care Conference. NHS England is also promoting them through their networks and systems as well as their communication bulletins.

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The Clinical Guidelines 2nd Series will formally kick off with an initial meeting on Friday 29 September (1200-1300).

Please email me if you are keen to join the session
chair@appm.org.uk

This Gastrointestinal Dystonia poster has been part of an oral presentation at the SACCH Meeting and the oral Ireland Meeting as well as a poster at the BPNA ASN created by members of the GID Clinical Guidelines Group.

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Gastrointestinal Dystonia (GID) in Children with Severe Neurological Impairment

Background
GID consensus statements were developed in 2022 by the British Society of Paediatric Gastroenterology Hepatology and Nutrition (BSPGHN). These provided a foundation for further evidence based guidelines for children with GID who would benefit from a palliative care approach.

These new guidelines were needed due to an increasing number of complex children with evolving GI symptoms and pain associated with feeds: presenting with significant distress; impacting on quality of life; leading to multiple investigations, medications, and hospital admissions.

GID Definition
Clinical manifestations of distress (pain behaviour, hypertonicity, retching, vomiting, vagal phenomenon, abdominal distension) attributable to the gastro-intestinal tract, directly and indirectly related to feeding and bowel habit, where confounding systems distress have been addressed or excluded

Must include
Severe neurological impairment (SNI)-GMFSC 4-5
Temporal relationship with feeding and symptoms must be present
Feed intolerance that has reached threshold for GID would include malnutrition, or GI symptom being the greatest burden on quality of life

Objective
To develop the first evidence based guideline for assessment and management of children with GID who could benefit from a palliative care approach



Method
A systematic review was performed with Cochrane support. It was not possible to use GRADE approach due to no studies identified. The group identified additional supporting indirect evidence that was considered useful to guide discussion around recommendations. The group also developed guidelines into the assessment and management for GID from the direct/indirect evidence and consensus opinion.

Results
1399 unique abstracts were screened. Of these, 53 full texts were reviewed and 52 excluded; 1 case report was identified.

Conclusion
Clear definitions of what GID is and what it isn't
Discussion of how these children present: Pain predominate, Upper GI predominate, Lower GI predominate
Recommendation of non pharmacological and pharmacological management
End of life guidance
To be published early 2023 on APPM website (open access)



Dr T Warlow, [lead author] University Hospital and Wessex Children's Hospital, Dr J Yates, St John's Hospital, NHS Lothian, Dr N Taylor, Paediatric Palliative Care GRID Trainee for Yorkshire Deansy, Martini's House Hospice, West Yorkshire, Dr B Koodiyedath, Northampton General Hospital, Ms G Villaverde, Cochrane Response Support, Ms L Griffiths, Parent Representative, Dr P Sertor, Retired Paediatric Palliative Care Consultant, Dr S Holt, Alder Hey Children's Hospital, Dr F. McEllogg, Temple Street Children's University Hospital, Dublin, Editor Dr A.K. Anderson, The Royal Marsden NHS Foundation

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**Association for
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**Association for Paediatric Palliative
Medicine Conference
16 and 17 November 2023
Hilton Conference Centre, Birmingham**

The APPM Conference, taking place on 16 and 17 of November 2023 attracts speakers and delegates from across the UK to discuss the latest issues and updates in paediatric palliative medicine. The focus for 2023 is supporting children and young people to transition from paediatric to adult services.

We are delighted to be able to announce two of our keynote speakers:

Ilora Finlay, Baroness Finlay of Llandaff, who has worked tirelessly both in practice and parliament to guarantee palliative care for all since the 1970s. A former President of the Royal College of Medicine, from Cardiff, she is a professor of palliative medicine at Cardiff University School of Medicine and is Consultant at the Velindre Cancer Centre in Cardiff. On 28 June 2001, she was made a life peer as Baroness Finlay of Llandaff in the county of South Glamorgan.

Alex Ruck-Keene KC (Hon) is an experienced barrister, writer and educator. His practice is focused on mental capacity, mental health and healthcare law. He also writes extensively, editing and contributing to leading textbooks and (amongst many other publications) the 39 Essex Chambers Mental Capacity Law Report, the 'bible' for solicitors (and others) working in the area. He is the creator of the website [Mental Capacity Law and Policy](#), providing resources and expert commentary on some of the most difficult mental capacity issues.

Early bird tickets will be available from 5 April at [APPM Conference 2023](#)
Additional discount for APPM members



Call for abstracts

CALL FOR ABSTRACTS



APPM Annual Conference, Birmingham

16 and 17 November 2023

The Association for Paediatric Palliative Medicine invites colleagues working with life limited children and families to submit abstracts for our Annual Conference.

The APPM Conference, taking place on 16 and 17 of November 2023 attracts speakers and delegates from across the UK to discuss the latest issues and updates in paediatric palliative medicine. The focus for 2023 is supporting children and young people to transition from paediatric to adult services.

This year's meeting will feature a poster session on the second day at which attendees can present their audits, research, or quality improvement projects. We welcome abstracts related to all aspects of care. This is an excellent opportunity to showcase your work in the area of palliative care and to share best practice with interested professionals from around the country.

To submit an abstract, please [click here to download an abstract template](#) then fill it in and submit it to admin@appm.org.uk

Please submit your abstracts to us by **1 August**. Members of the APPM Executive Committee will review your abstract and you will be notified of acceptance during the week commencing **18 September**.

We look forward to receiving your abstracts and to welcoming you to our Conference in November!

Welcome to our Pharmacy members who are growing in number

APPM Pharmacy Group Newsletter Corner

Hello and welcome to the APPM Pharmacy Group newsletter corner! My name is Nirusha Govender (Associate Director for Medicines Governance & Pharmacy Education, NHS Kent and Medway ICB) Chair of the APPM Pharmacy Group. Yes, I am trying to distract you with Marley my cavapoo in this picture, who is also known to make regular appearances on virtual events. 🐾 We plan to feature regular pharmacy updates here, so do watch this space! 📺



Who we are?
We are a dynamic and diverse group of approximately 15 pharmacists working in/with specialities/interests in paediatric palliative pharmacy from across the United Kingdom.

Our Aims:
Our primary aim is to support the APPM with clinical and professional expertise in medicines optimisation for paediatric palliative care in line with the recommendations made by the "Royal Pharmaceutical Society Palliative & End of Life Care Pharmacy's contribution to improved patient care".



01 CLINICAL ROLE
Day-to-day clinical screening of Symptom Management Plans (SMPs), supporting discharges, medication related enquiries, counselling parents and potentially prescribing medications too!

02 GOVERNANCE AND SAFETY
Medicines optimisation especially when a patient transitions into primary care, reducing the risk of errors that directly or indirectly impact a patient and/or reporting errors, audits & research

03 SERVICE IMPROVEMENT
Assist in the development of clinical Pharmacy services in line with local and national objectives, continually review processes to improve patient care, such as transition from secondary to primary care

The Growing Role of a Paediatric Palliative Care Pharmacist
An brief overview of where we can support a palliative care patient

EDUCATION & TRAINING 04
Identify the training needs of staff within and outside pharmacy (GPs, hospice staff, nurses for example), develop strategies to meet their learning needs and regularly support their development

FORMULARY & GUIDELINES 05
To develop and implement guidelines locally and nationally, regular evidence based review of existing medicines and support the addition of new medicines to the formulary too

COST IMPROVEMENT 06
Improve the cost-effective use of medicines across the interface, encourage prescribers to follow formulary recommendations and ensure unlicensed specials are prescribed only where clinically appropriate



NURSING

We would like to apologise once again for the short notice cancelling the Nurses' study day at Birmingham Children's Hospital. We hadn't quite anticipated the amount of snow falling and our main priority was to ensure the safety of all delegates. We were really disappointed as there was so much enthusiasm for the day with some great speakers, face to face networking and the sharing of innovative delivery models of 24/7 end of life care.

We are delighted to announce that we have a new date for our Nurses' Networking and Education Study Day at Birmingham Children's Hospital.

Networking eMpowering Profiling

NEW DATE
19 June 2023
10.00-15.30 hrs
Birmingham Children's
Hospital

An education/networking opportunity for nurses working in paediatric palliative care

Keynote Speakers:

National context for children's palliative care
Gareth Jones, CYP PEoLC, NHS England

Children's Palliative Service Specification and its impact on practice and commissioning
Jan Sutherland-Oakes, Director of Care, Claire House

Discussion and information sharing

Models of care to facilitate 24/7 end of life care in a setting of family's choice from neonates to young adults

For registration go to the link or click on the QR code below:

Study day organised and supported by the
Association for Paediatric Palliative Medicine

MONDAY 19 JUNE 2023

Click on the link below to buy a ticket unless you previously purchased one for 9 March which is transferrable – please inform admin@appm.org.uk

[APPM Nurses' Networking & Education Event](#)

Free education sessions for nurses – see what's on offer below

Nurse Education Sessions

Short education sessions via Teams are offered several times a year. We have a mailing list of nurses and AHPs to whom we send a link inviting them to join the hour long session. These are free and you just need to email admin@appm.org.uk to register your name to receive links and updates. Our next two sessions are:

Wednesday 19 April – Clonidine and its uses – Dr Emily Harrop, Consultant in Paediatric Palliative Care and Medical Director, Helen & Douglas House

Wednesday 17 May – Secretions management – Dr Kate Renton, Consultant in Specialist Paediatric Palliative Care, Southampton General Hospital/Naomi House Hospice. The sessions are from 8.30 am to 9.30 am. More dates will be sent out for later in the year.

LEARNING

Education Update

We are continuing to develop our education resources and work is currently underway to develop an education package around opiates. We are hoping the first package will run later in this year- details to follow soon.

We are hoping to host a bi-monthly virtual journal club. It would be really great to have input from the whole MDT, so if you would be interested in presenting or attending a virtual journal club, please email: education@appm.org.uk to be added to the mailing list.

If you would like to highlight interesting educational opportunities happening in your area, please email: education@appm.org.uk and we can add them to the next newsletter.

Dr Laura Nohavicka
Education Lead

Are you a Paediatric Palliative Care educator in the South-East?

(Kent, Surrey, Sussex, Berkshire, Oxfordshire, Buckinghamshire, Hampshire, Isle of Wight)

Come join our multidisciplinary education network and digital platform for creation and sharing of resources. Quarterly meetings to agree priorities and share news, optional sign-up to workstreams to create blended/fully digital/F2F learning opportunities across the region.

For more info/to join, please email admin@appm.org.uk with your name, job title and where you work.



TRAINEES



Trainee Update

We held our first face-to-face day of the year at Shooting Star House this month; Multi-modal Approaches to Analgesia, it was great to see so many attendees - thanks to AK and team for a great day! In February, we also had an excellent session on Anaesthetic Adjuncts from Dr Helen Laycock looking at the use of interventions such as nerve blocks and epidurals. In addition, this year we have introduced online peer-facilitated sessions alongside the education programme, looking at sharing trainee experiences across the UK and offering peer support particularly for those working in solo training posts. In line with this, we provided support sessions for those trainees interviewing for GRID posts in January and hope to provide further networking events later on in the year.

Dates for the diary:

13 April 13:00 - Peer-led session on the DEN.

14 June – Wellbeing and Resilience; Looking after ourselves in PPM, with Dr Charlotte Mellor and Dr Sadie Thomas-Unsworth, on the DEN

May - Virtual Ethics and Law series, including sessions on ethics in practice, decision-making, conflict and mediation and a facilitated ethics case-based peer support session. Details to follow shortly.

Please do continue to spread the word about the education programme to all interested trainees, access to these sessions is via email at trainee@appm.org.uk

[Dr Anna Chadwick/Dr Genevieve Southgate](#)

[APPM Trainee Representatives](#)

APPM Competition time 2023

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 any entries (and to request a copy of our consent form for use of the photographs in the APPM display and website) by 31 August 2023. The winner will be contacted by email in October 2023.

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



2. Essay: What Paediatric Palliative Care Means to Me



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 by 31 August 2023. The essays will be reviewed and scored by members of the APPM executive committee, and the winner will be contacted by email in October 2023.

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. 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 31 August 2023. 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).

Here are the results/names of the winners for the 2022 APPM competitions:

Undergraduate Essay:

- 1st prize Hadeel Tabaqchali
- 2nd prize – Lavanya Chandel
- 3rd prize – Ananya Arora

Photo

- 1st prize Hadeel Tabaqchali
- 2nd Justine Soh
- 3rd Haroon Khokher

Audit:

- 1st prize Anne Hadwick



All winners have been notified and received certificates and book vouchers.

Winning photo entries 2022



1st place
Hadeel Tabaqchali



2nd place
Justine Soe



3rd place
Haroon Khokher



Winning essay in 2022 by Hadeel Tabaqchali



What Paediatric Palliative Care Means to Me

A founding principle of the NHS is putting patients at the heart of healthcare, but to truly achieve this each patient must be considered as an individual⁽¹⁾. Paediatric palliative care is a holistic approach to the care of an infant, child or young person who has a life-limiting or life-threatening illness that transcends the biomedical model concerned solely with treating physical symptoms^(2,3). It recognises that an individual and their family will have unique physical, emotional and social needs and attempts to address these to ensure the best possible quality of life is retained throughout a patient's illness trajectory⁽³⁾.

Paediatric palliative care involves the input from primary, secondary and specialised healthcare professionals alongside the wider multidisciplinary team⁽³⁾. In conjunction with managing physical symptoms and providing psychological support, these professionals can help address an individual's social needs⁽³⁾. While attending a paediatric oncology clinic, I was able to experience this first-hand as the occupational therapist assessed the patient's mobility issues, discussed environmental adjustments to help the patient retain independence and organised a home visit with the family. I was also exposed to the impact of ill health on the wider family unit as the parents described the physical and emotional toll of having to care for a child with complex needs. However, as part of the palliative care process they were able to have short respite breaks and the patient's brother had engaged in activities as part of a sibling support programme, both of which helped relieve some of the daily pressures they faced.

Prior to entering the medical field, I thought palliative care was for patients approaching the end of their life or who were no longer receiving curative treatment, a common misconception⁽⁴⁾. However, palliative care can be provided from diagnosis, with the degree of engagement tailored depending on the needs of the patient at different points in their journey⁽³⁾. It allows preparation for different eventualities including the development of Advance Care Plans to outline goals of care, consider risks and benefits of future care options and enable patients and their families to input their preferences⁽⁵⁾. By engaging early, healthcare professionals can build rapport and trust from the onset. It enables Advance Care Planning to be a carefully deliberated process rather than a single discussion, whereby preferences can be continually updated to meet evolving needs as a patient matures or circumstances change⁽⁶⁾. If end of life care is required, paediatric palliative care teams have difficult discussions about death and dying with children of different ages and their families, and aim to support their wishes for instance, around the location of death⁽⁷⁾.

To me paediatric palliative care is an active process that enables the changing needs, beliefs and wishes of a patient and their family to be considered in healthcare decisions. It requires a multidisciplinary approach to provide holistic care that is personalised to the wider biopsychosocial needs of the family unit. After all no two families are the same, so why should they be treated this way in clinical practice?

References

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6. Nice. End of life care for infants, children and young people with life-limiting conditions: planning and management. 2019 [cited 26/08/2022]; Available from: <https://www.nice.org.uk/guidance/ng61/chapter/recommendations>
7. Harrop E, Edwards C. How and when to refer a child for specialist paediatric palliative care. *ACE Education and Practice Edition*. 2013;98:202-8.



**Congratulations to all
our winners**

Problem Solving in Paediatric Palliative Care

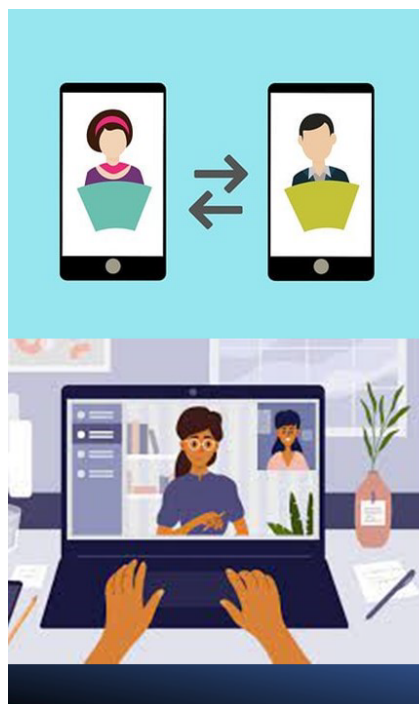
A Masters level short course in paediatric palliative care. This course is organised by Cardiff University in collaboration with Ty Hafan Children's Hospice and the All Wales Managed Clinical Network for Children's Palliative Care. The course will run face to face on 24 April, 22 May and 3 July supported by independent study in between the live taught days, which is designed for you complete at a time to suit your schedule.

[Link For further information and to book](#)

Dr Jo Griffiths

Consultant in Paediatric Palliative Medicine & community child health

All Wales Managed Clinical Network & Swansea Bay University Health Board



Take Part in an Interview about Staff Wellbeing and Retention in Children's Hospices

Thank you to those who have completed our online survey on wellbeing and retention among children's hospice staff.

We would now like to invite **current** and **former** children's hospice staff to take part in an online interview between April and June.

If you are:

- A member of clinical staff at a children's hospice OR
- Have left a clinical post at a children's hospice in the last 5 years

We would love to hear from you.

The interview will take place over Microsoft Teams, at a time to suit you, and we expect it to take around an hour. Your answers will be anonymised.

Please email csprinz@helenanddouglas.org.uk if you would like to volunteer or find out more.

Wednesday 24 May 2023 1430-1730

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

British Society for Paediatric Gastroenterology, Hepatology & Nutrition and Association of Paediatric Palliative Medicine

The session will focus on gastroenterological symptoms and nutrition in infants, children and young people with palliative care needs. We have invited guest speakers with expertise in the evidence-based management of gastrointestinal symptoms, blended diets, surgical feeding interfaces, as well as a parental perspective. I am excited to be able to confirm our final programme below:

- 14:30-14:35 Introduction and welcome, Dr Emily Harrop
- 14:35-15:00 The APPM Evidence Based Guideline on Gastrointestinal Dystonia, Dr Tim Warlow
- 15:00-15:25 Developing and evaluating Wilbo's Blends, Gareth Birkett
- 15:25-15:35 'YourTube' the role of different diets in children who are gastrostomy fed
- 15:35-15:45 Definition, description and classification of breakthrough pain by patients, caregivers, clinicians and expert groups: a rapid systematic review
- 15:45-16:15 Comfort break and e-Poster viewing
- 16:15-16:40 The roll of surgical gastro-jejunal Tube feeding for children in palliative care, Mr Alex Lee
- 16:40-16:50 A tertiary centre review of outcomes of paediatric patients with gastrointestinal associated with neuro-disability
- 16:50-17:00 Joining forces in GI dystonia – A one year review of an innovative MDT approach
- 17:00-17:25 Blended diet as treatment for feed intolerance, Serena Burgin
- 17:25-17:30 Close and Summary, Dr Lucy Howarth



DWP Special Rules for End of Life

From 3 April 2023, the final stage of extending the eligibility criteria will go live for three disability benefits (PIP, DLA and AA), following similar changes made last year (to UC and ESA). This means that from 3 April, any individual who is likely to have 12 months or less to live will be able to make a claim for fast-tracked financial support via the Special Rules.

Clinicians play a key role in supporting their patients to claim under the Special Rules and those clinicians caring for patients need to be aware of this change.

The Special Rules provide people nearing the end of life with faster and easier access to some benefits

- On 3 April 2023, improvements to the Special Rules criteria have brought PIP, DLA and AA in line with previous changes made to UC and ESA in April 2022.
- **Therefore, individuals who are likely to have less than 12 months to live can now claim PIP, DLA, AA, UC and ESA via the Special Rules.**
- Clinicians, such as a GP, consultant, hospice doctor or senior specialist nurse, can be asked to provide medical evidence on an SR1 form to support benefit claims made via the Special Rules process (the SR1 form has replaced the DS1500, please destroy all copies of the DS1500).
- For more information about the Special Rules, obtaining an SR1 form and for guidance about providing medical evidence, please go to www.gov.uk/dwp/special-rules
- **Please also disseminate this information into your clinical community to encourage clinicians to talk about financial support as part of wider conversations about what matters most to their patients.**



Children's Palliative care Outcome Scale (C-POS) Study



The Children's Palliative care Outcome Scale (C-POS) team are working to implement a new outcome measure to help understand what is important to children with serious illness and their families.



Using outcome measures can help:

- Children and families identify what is important to them
- Clinicians conduct thorough assessments and monitor outcomes
- Commissioners ensure that commissioning is patient-centred and outcome-based



How can you get involved?

We are looking for parents and carers (including siblings with caring responsibilities) of children with serious illness, and health and social care professionals that care for children with serious illness to take part in a workshop to help us understand how best to implement the new C-POS measures into routine NHS care.

If you are interested in taking part, contact Hannah Scott (PhD Candidate) at hannah.2.scott@kcl.ac.uk for more information.

Workshops will take place at the end of March/beginning of April

ASSOCIATION OF PAEDIATRIC PALLIATIVE MEDICINE

We are always keen to welcome new members to the APPM and in the last year have offered a tiered membership scheme which includes group membership for nurses and other allied health professionals for up to 5 named colleagues at £100.

Your 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 for Palliative Care, and you may sign up as a member

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

Please tell your colleagues about us

Finally, a big thank you to Kate Renton who has stepped down from being editor of this newsletter.

Lizzie Bendle
Newsletter Editor
Sue Lakie
Newsletter Administrator

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