

APPM NEWSLETTER

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From the Chair



Anna-Karenia (AK) Anderson

I hope this newsletter finds you all safe and well. During these strange times, it seems like the new norm is change! I hope you are riding these waves and finding some of these changes positive and professionally rewarding. For me, video-linked professional meetings across care settings are the way forward. They seem far better attended and more time efficient than face to face meetings. It would be wonderful to hear your experiences about positive changes during this pandemic. I welcome your emails (chair@appm.org.uk) around your experiences and perhaps we can pull these together to share more widely.

The APPM has been engaged nationally with the COVID end of life care agenda and working closely with adult colleagues on various published national NHS guidance. Guidance on community and hospice paediatric palliative care, written many weeks ago, has still not been published and now a little redundant I think. However more importantly, I want to thank Drs Jonathan Downie, Lizzie Bendle, Marian Williams and Jo Griffiths for their excellent work on producing COVID guidance in paediatric palliative care which has been adapted for

Inside This Issue

Guideline development	2
Yvonne Carter Award – hear from the recipient	3
Changes to World Health Organization Guidance	4
Update from the trainees	5
Educational opportunities	6-8
New APPM Executive members	9-11
Competition time	12
Can you help with a research study?	13

each of the four nations. Their work is on our website [here](#) (or copy and paste this address <https://www.appm.org.uk/guidelines-resources/covid-19-clinical-guidance/>). The national focus now shifts to considering the approach to the longer term issues that this pandemic is throwing at us.

In view of the uncertainty around COVID and social distancing measures, the executive committee took the decision to postpone the annual APPM study day due to take place later this year in Birmingham. We will update you when we have a new date. In the meantime, the APPM is continuing to work hard for you. Our new nurses and pharmacist are now on the executive and we are all very excited to hear their views and ideas.

The clinical guidelines group met in May and we have now identified our first three topics. The APPM members will be a key part of developing each clinical guideline, both in guideline draft reviews and recommending stakeholders in specific topics. Furthermore, it is also anticipated that with some topics there may be very limited published evidence, in these cases the members will be asked to participate in Delphi surveys as part of the process. We will keep you updated.

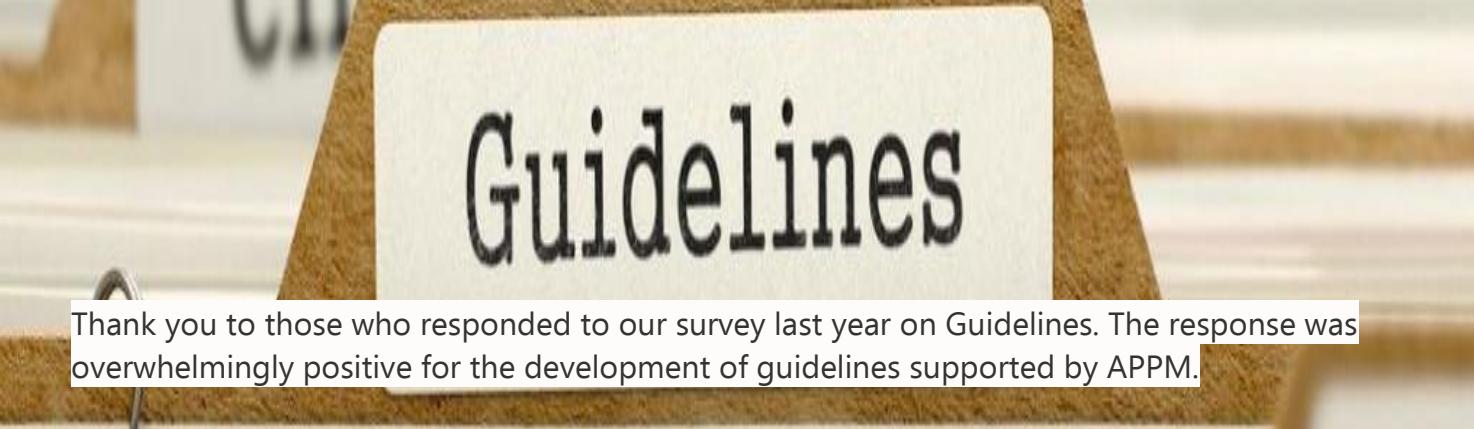
Finally, I want to congratulate Dr Sarah Mitchell on her award, ‘Yvonne Carter Award for outstanding early career researcher 2020’. Sarah is our GP committee member representative. We are thrilled for her personally but also grateful that she has shone a spotlight on paediatric palliative care within the GP medical landscape. [Read more about this on page 3]. We hope she can present her work at the postponed APPM study day next year.

As always, if you have any thoughts or comments on the work of the APPM, please get in touch, I always love to hear from you.

For now: *Kia kaha, kia maia, kia manawanui* (Be strong, be brave, be steadfast)

Anna-Karenia (AK) Anderson

Chair of APPM



Guidelines

Thank you to those who responded to our survey last year on Guidelines. The response was overwhelmingly positive for the development of guidelines supported by APPM.

We have collated the feedback from the survey and have decided to focus initially on three topics: **Agitation, Terminal seizures, and Gut failure/Neurogenic gut**. As part of the ongoing process we will be asking our lovely APPM members for review and input into the guidance developed.

Moving forward we will look to expand the topic list and consider the next priorities. We will also be looking at existing national guidelines not seeking to replicate robust work already undertaken. We may also in some cases consider endorsing some guidance.

As part of the survey, we asked if you would like to be involved in guidance development. We have now established a clinical guidelines committee that will aim to meet face to face twice a year and teleconferences in between. If you are interested in being involved please email: chair@appm.org.uk

We are also looking for a **parent/patient representative** to join the team: The parent/patient would be involved in developing the topic questions, considering the evidence and support the writing of the guidance. The involvement will include 1-2 face to face meeting per year and several video-conference meetings per year. Any travel or subsidiary costs for travelling to meetings will be paid for. Please let me know if you may have an interested parent/patient who would like to be involved: chair@appm.org.uk

The Yvonne Carter Award

Professor Yvonne Carter CBE was an outstanding and inspirational GP leader and advocate for palliative care in primary care who is remembered for her remarkable impact on academic general practice. Each year, the Royal College of General Practitioners Scientific Foundation Board, and the Society for Academic Primary Care jointly present the Yvonne Carter Award for Outstanding New Researcher, and I am amazed to have won it this year. The award recognises the contributions of early career researchers in advancing the discipline of academic primary care through research.

I have been motivated to do research through my clinical experience as a GP, and recognising that we need to improve palliative care delivery in primary care for patients of all ages, with all life-limiting conditions, and their families. My research aims to understand patient and family experiences of healthcare, and produce policy-relevant recommendations. My PhD was a realist investigation of palliative care delivery for children, and included children with life-limiting conditions and their family members as participants. In my new research fellowship, I am working on multi-disciplinary, mixed-methods research to investigate the healthcare experiences of patients with cancer and multi-morbidity, particularly at moments of crisis. Patient and public involvement is an integral part of my research, and I have been privileged to work with groups of young people who have provided advice on research design and methods, as well as taking part in dissemination activities including conference presentations and workshops.

When travel is possible again, I will use the award funds to travel to Canada to develop a collaboration with colleagues at the Universities of Calgary and MacMaster. I would really encourage anyone with an interest in research to pursue it – while you do need resilience to deal with the (apparently inevitable!) academic rejections, occasionally there are amazing moments like winning this award, and seeing your research having a positive impact on the care that patients receive.

Editorial note: Do check out Sarah's publications which are really insightful and offer valuable advice directly applicable to clinical practice. These are the references for a couple of her most recent applications. She's also well worth following on twitter (if that's your thing):  @MacGPSarah

Mitchell, Sarah J., Bennett, Karina, Morris, Andrew J., Slowther, Anne-Marie, Coad, Jane, Dale, Jeremy, 2019. Achieving beneficial outcomes for children with life-limiting and life-threatening conditions receiving palliative care and their families : a realist review. *Palliative Medicine*

Mitchell, Sarah J., Spry, Jenna L, Hill, Emma, Coad, Jane, Dale, Jeremy, Plunkett, Adrian, 2019. Parental experiences of end of life care decision-making for children with life-limiting conditions in the paediatric intensive care unit : a qualitative interview study. *BMJ Open*, 9 (5)



*Dr Sarah Mitchell:
Proud recipient of the
Yvonne Carter Award for Outstanding
Early Career Researcher 2020*



Changes in the WHO Guidance on Chronic Pain Management for Children and Access to Controlled Medicines

The World Health Organization withdrew the 2012 '*WHO guidelines on the pharmacological treatment of persisting pain in children with medical illnesses*' in June 2019, following concerns about their interpretation and in light of new scientific evidence that had come to light since their publication. At the same time their 2011 document '*Ensuring balance in national policies on controlled substances*' was also discontinued for similar reasons. WHO made a clear web statement affirming their commitment to ensuring that people suffering severe pain should have evidence based access to effective pain relief medication including opioids: https://www.who.int/medicines/areas/quality_safety/guide_on_pain/en/

As part of this process, adult / adolescent cancer pain guidance was published in 2019; '*WHO Guidelines for the pharmacological and radiotherapeutic management of cancer pain in adults and adolescents*': <https://www.who.int/ncds/management/palliative-care/cancer-pain-guidelines/en/>

In addition, two new international guideline development groups (GDGs) were formed in late 2019 / early 2020 to create updated guidelines entitled:

1. '*WHO Guideline for the management of chronic pain in children*'
2. '*Ensuring balanced national policies for access and safe use of controlled medicines*'

Progress reports:

WHO Guideline for the management of chronic pain in children

A public consultation was held for stakeholders in January this year, with feedback submitted on behalf of APPM by AK Anderson (Chair). Following this an initial meeting of the committee was held by Webex to discuss the scope further. The committee includes a service user, who is an adolescent chronic pain patient, as well as a wide international representation of diverse professionals. The committee were then asked to finalise the scope via an on-line prioritisation exercise and the final version is now available on the link below: https://www.who.int/maternal_child_adolescent/SCOPE-Guideline-pain-in-children.pdf

The APPM is represented on this committee by Sat Jassal (our Formulary Editor) and myself. The scope will now be used by the Cochrane PaPas group, who are undertaking the reviews for WHO, to provide the evidence for a face to face meeting of the GDG in Geneva in September 2020.

Ensuring balanced national policies for access and safe use of controlled medicines

The public meeting for stakeholders for the scope of this guideline was on 19th February, I fed back on behalf of the APPM. The GDG again has a wide representation including Julia Downing, Chief Executive of the International Children's Palliative Care Network (ICPCN). The GDG will finalise the scope in March / April 2020, the draft scope can be viewed below:

https://www.who.int/medicines/SCOPE_Ensuring_balance_v5_Jan_2020.pdf?ua=1

It is hoped that both the new guidelines will be completed by the end of 2020.

Dr Emily Harrop, Secretary of APPM Exec.

An update from the trainee contingent

The trainee group of the APPM is made up of a diverse collection of general paediatric trainees, oncology and community trainees, as well as those who are undertaking GRID training in paediatric palliative care. Our study day in December focused on respiratory support, ethics of long term ventilation and some additional teaching on cannabis and opiates, and was well attended and well received. A number of the trainees' group will be involved in the APPM guidelines group. We are hoping to run a simulation training day for trainees in September, but this will be dependent on the coronavirus situation.

If you, or anyone you know or teach would be interested in joining the trainees' group, please let us know.

Sophie and Laura (trainee@appm.org.uk)



EDUCATIONAL OPPORTUNITIES

Please do let us know of anything you would like to contribute to future newsletter - we are always keen to share knowledge/opportunities. Email: newsletter@appm.org.uk

The current global situation has meant that many conferences have been rearranged. See below for latest updates (correct as of 4th June 2020)...



RCPCH Conference and exhibition 2020

Since the necessary cancellation of the face-to-face RCPCH Conference 2020, we are pleased to update you on opportunities to get involved online.

Was due to be held in Liverpool in April 2020 – now going online for 25th September 2020 <https://www.rcpch.ac.uk/news-events/rcpch-conference-exhibition/cancellation>



**11th World Research Congress Online
European Association for Palliative Care**
One Voice, One Vision in Palliative Care

Interactive online sessions 7- 9 October 2020

Was due to be held in Palermo in May 2020 – now going online for October 2020: <https://eapcresearchcongress2020.eu/>



Was due to be held in Manchester in March 2020 – now planned for Autumn 2020 – watch this space: <https://www.togetherforshortlives.org.uk/changing-lives/sharing-learning-networking/conference-2020/>



The
Martin House
RESEARCH CENTRE

In partnership with



The Martin House Research Centre 2nd Biennial Research Conference 16th April 2021

Was due to be held in September 2020 – now rearranged for April 2021

EAPC 2021

17th World Congress of the European Association for Palliative Care

Exploring new dimensions

20 – 22 May 2021 | Helsinki, Finland



#EAPC2021

Was due to be held in September 2020 – now rearranged for September 2021

Association for
Paediatric
Palliative
Medicine

11th APPM Paediatric Palliative Care Study Day

Was due to be held in November 2020 – now rearranged for
17th/18th June 2021 in Birmingham
SAVE THE DATE



European Congress on
Paediatric Palliative Care
08.-10. Sept. 2021, Kristiansand, Norway



European Congress on Paediatric Palliative Care

08. - 10. September 2021
Kristiansand, Norway

#PPC2021

Share Tweet

Early bird until 15/05/2021



**5TH MARUZZA
INTERNATIONAL
CONGRESS**
ON PAEDIATRIC PALLIATIVE CARE

Rome, 25th-28th October 2021

Was due to be held in October 2020 – now rearranged for October 2021

We are really pleased to welcome new members to the APPM executive committee – please see below for their biographies:

LESLEY FELLOWS – Nurse Member

Lesley Fellows qualified as a RN (child) in 1998 from the University of Chester and has since completed a BSc in professional Practice and MSc in palliative and end of life care. Her career started on a children's ward in North Wales which then progressed into the community, supporting children with life limiting conditions. Lesley joined Claire House children's Hospice in 2003 and set up the Hospice to Home Service in 2007. Such service has significantly grown and now the 24/7 Rapid Response services is commissioned to provide end of life care across Wirral, Cheshire and Merseyside. As a Nurse Consultant Lesley is passionate about nurse led palliative care; promoting choice in place of care and palliative care in the critical care environment.



The reason for joining the APPM executive is to advocate for the amazing work that specialist nurses are providing across the country within paediatric palliative care and to support safe NMP prescribing within complex symptom management.

NIRUSHA GOVENDER – Pharmacy Member



I am a Senior Pharmacist for Children, Young People and Dental Services at Kent Community Health NHS Foundation Trust (KCHFT). My career as a pharmacist over the past 20 years has provided me with opportunities to develop extensive knowledge, skills and vast experience in both my clinical and senior management roles supporting community services including specialist community children's nursing, school and immunisation nurses, health visitors, community paediatricians and dental services to name a few. Originally from South Africa, I moved to the UK in 2001 and have been in my current role for the past 10 years. In 2018, I qualified as a Pharmacist Independent Prescriber and I am currently progressing with an MSc in Medicines Optimisation. I have a keen interest in Paediatric Palliative Care especially with a focus on supporting medication safety when delivering clinical services to children and families in their own homes. Children's palliative care is provided through a complex range of services including healthcare, social services, education and voluntary services such as hospices.

In 2012, as a member of the Kent and Medway CYP Palliative Care Network multi-disciplinary clinical group; I successfully facilitated and supported the development and design of a Community Paediatric Palliative Drug chart with an aim to:

- Support the safe and effective prescribing and administration of medicines to palliative children and young people by minimising the risk of administration, transcribing and prescribing errors.
- Facilitate seamless transfer of care between different care settings and promote multi-agency collaborative working.
- Promote good clinical record keeping and compliance with legislative requirements for controlled drugs.

As a new member of the APPM I am looking forward to continuing to promote medication safety and raising the profile of the pharmacy profession, through working with the APPM Executive Committee and members on a national scale supporting further clinical developments in paediatric palliative care.

HELEN QUEEN - Nurse Member

I have had an overarching specialist interest in palliative care and parallel care planning for both children and young people with malignant and non-malignant diagnoses during the last 25 years. My roles have been varied but include the delivery of excellent clinical care, championing parallel care planning and promoting advanced care planning to ensure the best quality of life and outcomes are achieved throughout the disease trajectory and into end of life care.

My clinical skills and broad experience in the specialist fields of oncology, haematology, oncology research and haemophilia have been gained from working in various Regions both in the acute sector and in the community. This has led to a greater depth of clinical knowledge and an increased awareness of the challenges in delivering quality care to children and families, encompassing their needs and choices and those of statutory agencies. I have worked in a variety of leadership and managerial roles including establishing a children's Macmillan Service within the demographic region of North Staffordshire. A service audit I completed resulted in funding from Macmillan to further develop and expand the service including palliative and bereavement care, an on-call service and clinical supervision of staff.

My experience has shown me that it is important to provide appropriate, timely and individual and unique symptom control to patients and care to the wider family whilst also providing ongoing support, education and teaching to the wider health care teams. My current role is pivotal in meeting the service needs to enhance the patient experience and to continue to develop services with a shared vision to provide a service which cares for families from the start of their journey when the future is uncertain or from the time of diagnosis through treatment and into palliative care and end of life care planning and into their journey of bereavement.

I am the team leader for both the palliative and bereavement team and the specialist oncology nursing team. In both teams we have been creating a more united team approach and developing a more generic approach to our care pathway to provide a dove-tailed service that is effective and meets the needs of all palliative patients and their families. This has been an opportunity enabling



collaborative working across sites and improving care provision to improve the patient journey and improving the patient experience in addition to improving patient flow, capacity, sustainability and learning opportunities.

Alongside my clinical knowledge base I have completed a BSc (Hons) in palliative care and an MSc in clinical oncology with a specialist interest in palliative care and parallel planning at the University of Birmingham. I therefore have a good, working knowledge of research practice and challenges. I continue to teach at the University on the pre- and post-graduate nursing programmes and the Masters programme. I have presented work at several international Conferences and national conferences including SIOP, EAPS, CCPC and nationally including TYAC and the RCN.

I have been working towards building resilience in the teams and creating a more united team approach in providing a service that is effective and meets the needs of the patients and the families in both teams and now incorporates a joint post with the local hospice to enable collaborative working across sites and care provision without boundaries and improving patient flow, capacity and sustainability. This has been a challenging time for both teams with new ways of working as a result of service changes and required a great deal of support and guidance and investment in the teams to enhance communication and co-operation and reduce conflict, through regular one to one's, team meetings, huddles and PDR's. Through this investment in the expertise and recognition of the strengths within the team we have been able to bridge gaps, enable new strategic development of services and grow, learn and enhance both the care, the team and the service. I am passionate about children's palliative care and in opportunities to work in unison through sharing our experiences, expertise, challenges and celebrations as well as our difficulties and open the forum of discussion and sharing more widely through the APPM. As nursing professionals we have more opportunities to share practice, learn and communicate across the network nationally and internationally as we continue to enhance knowledge and expertise and share our voice and our expertise.

JILL YATES - Doctor Member

I am very excited at being involved with the APPM. I am a Consultant Paediatric Consultant based in West Lothian Scotland. My interest is in neurodisability. I love working with the children, families and the extended team of professionals for all agencies that work with these children. I am passionate about making sure the children have the best possible life with their families, within school and their communities and not minimise the amount of time they spend in hospital.

I did all my medical and paediatric training around London and the South East of England. I was very fortunate to work at the National centre for young people with Epilepsy, Chailey Clinical Services and spent a lot of time at the Evelina Children Hospital. My interests include my dogs (currently 4 Gordon Setters!), walking, yoga and trying to be as self-sufficient as possible on our small holding. I look forward to meeting and working with you all.

Competition time

We are pleased to announce three new, exciting, annual APPM competitions (open to members and non-members). Exact deadline for all competitions to be confirmed (COVID19 has slowed us all down).

Firstly, a **photography** competition. 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” by Spring 2021 (date TBA). The entries will be viewed and scored by members of the APPM executive committee. All suitable entries will be displayed at the APPM 2021 study day. The winning entry will be given a prize of £50 of Oxford University Press vouchers, and the photograph will be used on the APPM website. The winner will be announced at the study day. Runner-up photographs will also be considered for use on the website. Please email 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.



Secondly, an **undergraduate essay writing** competition. Open to all medical undergraduate students in the 2019-2021 academic years. Please write a 500 word essay entitled “What Paediatric Palliative Care Means to Me”. Please send your entry to chair@appm.org.uk by Spring 2021 (date TBA). 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 May 2021. The winning entry will receive £50 of Oxford University Press Vouchers and will have their essay printed in the APPM summer 2021 newsletter, as well as a free place at the APPM 2021 study day (excluding travel and accommodation), where they will receive a certificate and the voucher prize (these can be posted if the winner is unable to attend). The prize for the essay judged to be in 2nd place is £25 of Oxford University Press vouchers.

Finally, a **postgraduate audit** prize. 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) in the 2019-2020 training year. 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 by Spring 2021 (date TBA). The audits will be reviewed and scored by members of the APPM executive committee, and the winner and runner-up shortly after the deadline in Spring 2021. The winning entry will receive £50 of Oxford University Press vouchers and will receive a free place at the APPM 2021 study day (excluding travel and accommodation), where they will receive a certificate and the voucher prize, and will have the opportunity to do an oral presentation of their audit. The prize for the audit judged to be in 2nd place is £25 of Oxford University Press vouchers.

Please let us know what you think about the newsletter, and send any suggestions/requests for content by email: newsletter@appm.org.uk or tweet: @theAPPMuK

Dear APPM Members:

My name is Eiman Nabag, and I am a PhD student at the Swansea University. The research I am conducting for my Doctoral thesis involves exploring the role of Islamic religion and culture in end-of-life decision making for children with life-threatening conditions, their families, and healthcare practitioners. This project will be conducted under the supervision of Dr Tracey Maegusuku-Hewett and Professor Fiona Verity.



The purpose of this study is to explore Islamic culture and religion as one of the factors in improving the quality of life for children with life-threatening illnesses and their families throughout the illness period, and especially at end-of-life stage.

The research aims to look at health professionals perspective on the importance of culture in delivering care for children and their families at end-of-life; as well as the perspective of parents on the ways culture and religion shape their understanding of palliative care, parental responsibilities and decision making at end-of-life.

I am hereby inviting you to take part of a 15-30 minutes phone interview to capture your thought and perspective on decision making in paediatric palliative care as a health care practitioner caring for children in a multicultural society.

Your responses to the questions will be kept confidential. Each interview will be assigned a number code to help ensure that personal identifiers are not revealed during the analysis and write up of findings. There is no compensation for participating in this study. However, your participation will be a valuable addition the research and findings could lead to greater public understanding of cultural importance in paediatric palliative care.

This study has been reviewed and given favourable opinion by an NHS Research Ethics Committee.

If you are willing to participate please e-mail me at 748993@swansea.ac.uk and suggest a day and time that most suitable for you. If you also require any further information, please do not hesitate to contact me via the e-mail address mentioned above.

Thank you for your time and consideration.

Yours sincerely,

Eiman Nabag
College of Human and Health Sciences, Swansea University
Swansea, SA28PP
Wales, UK