

Association for
Paediatric
Palliative
Medicine

APPM

www.APPM.org.uk

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From the Chairman

September 2018

Dear colleagues

I trust that you have had busy clinical summers but also some restorative holiday time – I have had both of these in Scotland and as I write this, I prepare to return to another busy spell working in Children's Hospices Across Scotland (CHAS) from my late summer break.

Writing this allows me to reflect on the last 9 years as an executive member of the then newly formed Association of Paediatric Palliative Medicine, which amalgamated the British Society for Paediatric Palliative Medicine (BSPPM) and the Association of Children's Hospice Doctors.

I served first as its first treasurer and I well remember our concerns as we approached the first APPM Conference with very limited background funds, and with insufficient numbers registering early, there might well have been a deficit which could have had financial implications to those had been elected as office bearers! However, you came through, and have each year, so that the 9th APPM Conference is now well within sight, and as with each year, my

thanks especially to the organising committee, and to the important help from the Together for Short Lives team which underpins everything we do. As ever, the conference programme looks both interesting and challenging, so do consider registering for the Hilton in Birmingham in November, if you have not done so already.

This Bulletin also marks my last time that I will write to you all as APPM Chair, as my second term of three years closes at the AGM in November. Altogether, over the last decade or so, I have witnessed and been part of some ongoing but significant changes in children's palliative care – as we work with increasing knowledge of what can be done to support babies, children and young people with palliative care needs we need to be mindful in terms of “just because we can.....”, and always to provide support on an individual basis.

In Scotland, I have been impressed by Dr Catherine Calderwood's (Chief Medical Officer) last two annual reports, entitled, “Realistic Medicine”, and then “Realising Realistic Medicine”, and that this whole area currently asks more questions than there are answers.

In the last year or so, we have seen three high profile cases of children approaching the potential end of their lives, in terms considering when or if there is a right time to re-orientate care to that of principally a palliative intent.....or not. As Chair of APPM, I have recently been involved in work with the Royal College of Paediatrics and Child Health (RCPCH) in terms of supporting both parents and professionals when agreement is not achieved. This will soon be available and I am sure that this will be helpful, but there are still likely to be other high profile cases, so this is something which we should all be preparing for both as individuals, and with the organisations with which we work.

In my view, the APPM is in a relatively strong place to help advise on such areas with increasing:

- * Audit, data collection, and research involving many in our membership
- * Educational opportunities
- * Standard-setting (the latter in collaboration with the College Specific Advisory Committee (CSAC) of the RCPCH, as chaired by Dr Renee McCulloch) and an increasing evidence-base

I am pleased to be able to hand over to the new executive of AK (Anderson), Anton (Mayer) and Emily (Harrop) as office bearers of the APPM, and in the knowledge that the hard work of the last 9 years as an Association is already being built upon.

However, very probably, the greatest achievement during this time has been the publications of the APPM Master Formulary, and much of this has been down to Sat Jassal’s persistence to “help” so many of us to complete promised contributions!

Susie Lapwood has guided us on Annual Appraisal, Tracy Blount has re-stimulated fresh interest from General Practitioner colleagues working in children’s hospices, as well as currently input on the development of a new website for the APPM, and Heather McCluggage has continued to ensure that we get out quarterly Newsletters and bulletins to update us all on developments.

So, I cannot thank everyone for their input over my time of working with you in the APPM, but special thanks to Lynda Brook and Mike Miller in the early years of the new Association, without whom we would not be where we are today. With this comes the absolute need for “new blood”, and so over the next month or so, I will approach some of you to consider standing for election for the next APPM Executive Committee, not least as we may well have 3 or more vacancies – such a commitment is sometimes challenging to fit around our clinical commitments, but I have always found I have learnt more than I could ever put in, and so I thoroughly recommend you consider standing for election.

Many thanks, again, for all your input in the past and going forward,

Pat Carragher

Chair of APPM

APPM Executive

[until November 2018]

Chairman	Pat Carragher
Vice-Chair	A K Anderson
Secretary	Anton Mayer
Treasurers	Anton & AK
Formulary	Sat Jassal
Revalidation	Susie Lapwood
CSAC	Renee McCulloch
Trainee Reps	Jonny Downie Kate Renton
NICE	Emily Harrop Richard Hain Sarah Mitchell
Study Day/website	Tracy Blount Bindu Koodiyedath
Editors	Heather McCluggage Kate Renton
TfSL	Katrina McNamara

9th APPM Paediatric Palliative Care Study Day

Have you booked your place yet?

With just two months to go, we're really looking forward to catching up with lots of you at our annual study day in Birmingham on 23rd November. As usual, the study day will feature specialist lectures, expert panels, seminars, networking, Q&A time and discussions on up to date, relevant paediatric palliative medicine topics.

Highlights at the study day will include:

- Trials, not tribulations: A collaborative model of early phase trials and palliative care (Dr Lynley Marshall, Consultant in Paediatric and Adolescent Oncology Drug Development, The Royal Marsden Hospital NHS Foundation Trust & The Institute of Cancer Research)
- Enhanced supportive care (Dr Richard Berman, Honorary Senior Lecturer in Cancer Science, Consultant Palliative Medicine, The Christie Cancer Centre, Manchester)
- The genie in a bottle: Medics in the wild world of social media (Mark Taubert, Clinical Director & Consultant in Palliative Medicine, Velindre Trust Cardiff)
- The APPM Master Formulary (Dr Sat Jassal, GP & Medical Director Rainbows Hospice Loughborough)
- An Expert Panel Discussion with parental perspective and case studies

Delegates will also have the opportunity to take part in:

- Focus groups for:
 - hospice Doctors/GPs;
 - hospital Doctors/Trainees; or
 - specialist Nurses and Allied Health Professionals.
- Seminars on:
 - parents' and professionals' contrasting perspectives of difficult conversations;
 - the challenge of pain assessments in children with profound cognitive impairment; and
 - developing and sustaining robust relationships within neonatal palliative care specialities.

If you haven't already booked your place, do so soon, as our early bird discount runs out at the end of this month!

View the full programme and book your place: <http://appm.org.uk/15.html>

OTHER EDUCATIONAL OPPORTUNITIES...

4TH GLOBAL GATHERING MARUZZA CONGRESS ON PAEDIATRIC PALLIATIVE CARE,
ROME, 24-27TH OCTOBER.

SEE WEBSITE FOR FURTHER DETAILS:

[HTTP://WWW.CHILDRENPAELLIATIVECARECONGRESS.ORG/CONGRESS-2018/](http://www.childrenpalliativecarecongress.org/congress-2018/)

Tonight I'm thinking of.....

Earlier in the year we all watched appalled as a family's grief and despair was played out in front of the world through the media. Nurses and doctors had abuse thrown at them but were unable to respond publicly.

From Stephanie Nimmo's blog: www.wasthisintheplan.co.uk

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Tonight I'm thinking of the mum of the 18 year old first year nursing student who answered the ward phone during a night shift to have the word "murderer" screamed at her down the line.

Tonight I'm thinking of the little girl who is lying in a hospital bed desperately ill as her family gather around her bedside listening to the sound of protesters outside.

Tonight I am thinking of that girl's aunt who had to have a security guard escort her to the ward to visit her niece.

I'm thinking about the children who were scared when they arrived for medical appointments at the hospital they trusted to be faced with banners emblazoned with the word "murderers".

I'm thinking about the peace and quiet on the intensive care unit as we sat with Daisy for our final hours.

I'm thinking about the staff who held my hand because there was no-one else to hold my hand.

I'm thinking about the nurses who lovingly and carefully washed Daisy's body with me and laid her out under her favourite blanket after her ventilator was switched off.

I'm thinking about the Doctors who came to pay their respects to Daisy after she died, tears in their eyes when they told me how much she meant to them.

I'm thinking about the staff who came to Daisy's memorial service at the hospital that had cared for her for twelve wonderful years, the staff who sobbed openly as they gave up their lunch break to say a last good bye to the little girl who they had loved almost as much as I had.

Tonight I think about a mum in Liverpool

All of the mums, and dads, and parents and grandparents who love their children.

I'm thinking of those of us who made that final, selfless decision to let our child go.

I'm thinking of those of us who know that we did absolutely everything we possibly could for our child.....

The bereaved parents. The ones on the other side.

My friend posted on twitter today that she was scared as she sat next to her daughter's hospital bed. The daughter she was so worried about, the daughter who has already spent 3 long months in hospital, so very poorly. She's scared because the staff who are caring for her daughter are

worried about what is going on outside. The braying mob who are accusing them of keeping a another child in the hospital hostage, of being murderers.

What have we come to when mob rule is taking the place of collaboration? When social media becomes the judge and jury, when people take matters into their own hands?

When you are pregnant, whether it is with your first or your fourth, you dream about what your child will do, the life they will lead, who they will be. In Andy's mind his boys would be fighter pilots and strikers for Arsenal. When you are told that the child you dreamed of is disabled, will not walk, will not talk, will not live to see adulthood, you grieve. You grieve for your lost child, the child you thought you had, you grieve for the loss to come, their early death. Grief makes you sad, it makes you angry, it makes you hate the world. But as a parent the grief is yours alone, it is not there to be hijacked by others for their political or moral gain.

I am not Charlie's mum, I am not Alfie's mum. I am Daisy's mum. As Daisy's mum I knew that my grief was all consuming, I needed people to help me make decisions, I needed to work with my team who were able to be objective but compassionate.

I tried to do the right thing, I tried to be objective, although I knew that Daisy was really poorly, it's not until I look back at the pictures that I realise how poorly. How we had reached the point of no return? I am so grateful that I had a team of trusted professionals around me to support me and guide me, because at the centre of it all was a little girl. I knew that I had to do the right thing for her.

I did not want to prolong her suffering, the inevitable. I wanted to let her go peacefully, with dignity.

The end was calm.

The end did not come with frantic last minute interventions, to strange countries, where they did not speak my language, with more surgery, with more tests. With the same inevitable outcome delayed, but inevitable

On a recent visit to my GP I laughed at the mug he had on his desk "do not confuse my medical degree with your ability to use google". What has happened to the world when we no longer trust and respect our medical teams? When vigilante mobs accuse nurses and doctors of murder?

What are we saying to children when they are dragged along to these demonstrations to scream abuse at nurses entering the hospital for a shift?

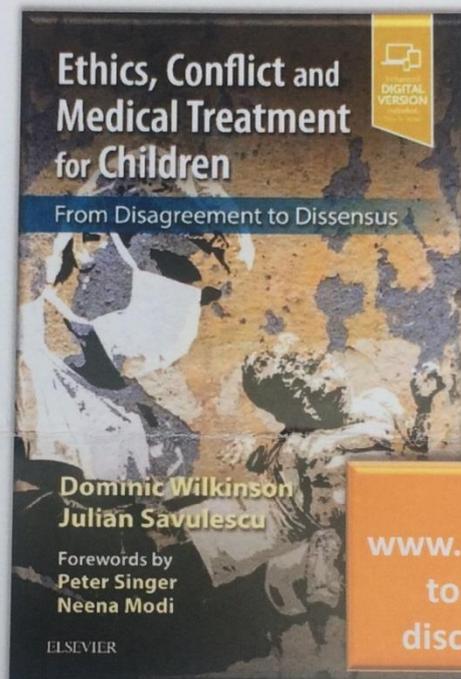
Doctors and nurses who are themselves parents, who fight to keep children alive, who not want to see children suffer needlessly, who are human beings.

At the centre of it all is a child. The child is the most important person in all of this. Medical science is incredible but sometimes it cannot work miracles. Sometimes children die. Sometimes we have to let go of our dreams of our child being a fighter pilot or a striker for Arsenal, sometimes we have to let go.

My thoughts are with Alfie and his family tonight. My thoughts are with the staff who care for the sickest children and support parents through the hardest decisions they will ever have to make. My thoughts are with all the parents trying to do the best for their child.

My thoughts are once again with all of us bereaved parents who are forced to relive our decision and know that when it came to it we did the right thing for our child.

Ethics, Conflict and Medical Treatment for Children



Go to
www.elsevierhealth.co.uk
to save 20%* using
discount code SAVE20

Dominic Wilkinson, Julian Savulescu

£34.99 \$44.99 €39.99

ISBN: 978-0-7020-7781-4

What should happen when doctors and parents disagree about what would be best for a child? When should courts become involved? Should life support be stopped against parents' wishes?

The case of Charlie Gard, reached global attention in 2017. It led to widespread debate about the ethics of disagreements between doctors and parents, about the place of the law in such disputes, and about the variation in approach between different parts of the world.

In this book, medical ethicists Dominic Wilkinson and Julian Savulescu critically examine the ethical questions at the heart of disputes about medical treatment for children. They use the Gard case as a springboard to a wider discussion about the rights of parents, the harms of treatment, and the vital issue of limited resources. They discuss other prominent UK and international cases of disagreement and conflict.

From opposite sides of the debate Wilkinson and Savulescu provocatively outline the strongest arguments in favour of and against treatment. They analyse some of the distinctive and challenging features of treatment disputes in the 21st century and argue that disagreement about controversial ethical questions is both inevitable and desirable. They outline a series of lessons from the Gard case and propose a radical new 'dissensus' framework for future cases of disagreement.

* Expires 31/12/2018

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From the networks...

We asked regional network leads across the UK for updates on their progress and plans for the future. Please see below for details....

East Midlands Network: *Focus on two areas:*

1. *Working with the regional neonatal network we have developed and launched the Regional Care Pathway for the Unborn Child, Neonate or Infant diagnosed with a Potentially Life –Limiting Condition. There was extensive engagement from foetal medicine teams and neonatal services. Embedding and audit to the quality standards in the pathway is ongoing.*
2. *We have also been successful in a bid to NHSE for funding for a 12 month project to improve children's end of life care and provide a retrospective case note audit using NICE quality standards. This has given us some short term funding to develop a team of paediatricians with expertise in children's palliative care.*

Northern Ireland Network: *The paediatric palliative care strategy which was passed in 2016 is now at last starting to fall into place with medical leads in the health trusts being appointed. One major piece of work which has now been completed by the network is the regional documentation for both advanced and emergency Care planning. This regional documentation with its attendant guidance document is due to be launched in November. An e learning module will also be available to help clinicians put these advance plans together. The hope is that with regional documentation all grades of staff will know quickly and easily what has been discussed and where to find it.*

Scottish Children and Young People's Palliative Care Network: *The Scottish Children and Young People's Palliative Care Network (SCYPPCN) has continued to work closely this year with the National Services Division of the Scottish Government in the proposal of a National Managed Clinical Network for the 2200 babies, children and young people that are entering into*

the unstable, deteriorating and dying phase of their palliative condition. The proposal is currently at the second stage of submission and SCYPPCN will be represented at the next phase meeting in November this year by Neil Healy and Caroline Porter the current SCYPPCN Co-Chairs.

SCYPPCN VC meetings continue quarterly with attendance from multiple NHS and Hospice sites across Scotland. Each meeting has two educational speakers and a round up from across the Scottish sites of current practice, recent developments and issues for discussion.

SCYPPCN is about to review the Collaborative Guidance for Staff when a parent wishes to take their child home from hospital after death as this has now been used in practice since October 2017.

The next year requires continued, detailed collaborative working with the NMCN Steering group in its proposed development.

The Thames Valley Palliative Care Network: *The network has been focusing on two key work streams:*

Promoting the implementation of NICE within services across the network

- *Each service has been encouraged to engage in the baseline assessment*
- *Compiling an overall evaluation of evidence gaps*
- *Identifying areas of development that the network can take forward.*

Long term ventilation

- *We are about to launch the Thames Valley Long Term Ventilation Pathway and Standards of Care . This has been a significant piece of work over the last year and we look forward to sharing this more widely next year.*

West Midlands Paediatric Palliative Care Network: *Our priorities in the West Midlands have been to continue work to raise the profile of paediatric palliative care with our local commissioners, and to maintain the network as a supportive forum for the brilliant and committed frontline staff working across the region in this area of practice. Network members have been members of steering groups for a number of national projects with Together for Short Lives and NHS England. Our annual conference (free to attend) will take place on 18th October at Marie Curie Hospice in Solihull.*

We are excited to announce that there are new medical and co-chairs for the network, Dr Sarah Thompson and Marie Clancy. Another key development in the region has been the arrival of Dr Yifan Liang as the first consultant in paediatric palliative medicine at Birmingham Children's Hospital. We are looking forward to the opportunities that this new leadership will bring.

Yorkshire and Humber Children's Palliative Care Network: *The Yorkshire and Humber Children's Palliative Care Network has recently developed a strategy document setting out our ambitions for the Region for the next 5 years 'Closing the Gap in Children's Palliative and End of Life Care'. We have created a website www.yhcpcn.org.uk and twitter account @YoHCPCN and we have developed a regional module for practitioners entitled 'understanding and delivering interdisciplinary children's palliative care'. This is a nine day module with the option to add 5 advanced clinical assessment sessions on with the University of Huddersfield which is starting in November 2018. We are currently working on a journal article 'Where children die, a regional analysis of Child Death Overview Panel (CDOP) data' which we will be presenting at the Martin House Research Centre Conference, The 4th Congress on Paediatric Palliative Care: a Global Gathering 2018 and the Hospice UK conference.*

The 1st Biennial Martin House Research Centre Conference

With thanks to Lorna Fraser for writing this very up-to-date piece about the first Martin House Research Centre conference. It sounds like a great success.

On Friday the 21st September, the University of York hosted the 1st Martin House Research Centre (MHRC) conference. Much to the relief the MHRC team, Hurricane Ali and Storm Bronagh did not prevent (most of) the delegates and all the speakers making the trip to York. More than 90 delegates filled the auditorium.

The Centre Director, Dr Lorna Fraser, gave a short introduction to the MHRC, highlighting the importance of high quality research, the input of parents and young people and the need for collaboration. Then the current APPM Chair, Dr Pat Carragher, gave an excellent plenary highlighting the value of research in influencing policy makers and demonstrating how the ChiSP study¹ has helped CHAS to have conversations and get children's palliative care into key national policy documents.

A varied selection of oral presentations from the submitted abstracts were up next with great questions from the audience.

Before lunch, Helen Weatherly from the world-renowned Centre of Health Economics², gave the audience an excellent introduction into the methods of economic evaluation and highlighted some of the challenges of these studies in palliative care.

A noisy and busy lunch for the delegates whilst they viewed the posters on display before returning to the auditorium for a great overview of outcome measures in palliative care by world expert Professor Fliss Murtagh from the Wolfson Centre for Palliative Care³ in the Hull York Medical School. The CEO of Martin House, Martin Warhurst, then responded highlighting the importance to the organisations, such as Martin House, of having outcome measures and being able to quantify the difference that they make to the lives of children and families.

Another session of submitted oral presentations was next up, a special mention to Dr Sarah Mitchell who managed to present her whole PhD in 10 minutes through the medium of cartoons!

The final plenary session started with a thought provoking presentation by Professor David Abbot (University of Bristol) presenting the very rich data from his study on discussing end of life with young men with Duchenne Muscular Dystrophy⁴. These data highlighted the real need from these men for someone who cared about their lives, and understood their condition, to discuss death and dying with them.

Dr Anne-Marie Childs (Consultant Paediatric Neuromuscular) and Sue Manning (NMD care advisor) then responded discussing the challenges of these conversations in

the clinic environment and highlighting the new guidelines on the care for children and adults with neuromuscular diseases.

It was nice to see, after 4 pm on a Friday afternoon, that the conversations continued beyond the end of the programme. Once the MHRC team have recovered we look forward to planning the 2020 conference.

For more information about the MHRC and their current research studies see:
www.york.ac.uk/mhrc lorna.fraser@york.ac.uk



@UoYMHRC



@lornafraser10

¹ <https://www.york.ac.uk/inst/spru/research/pdf/chisp.pdf>

² <https://www.york.ac.uk/che/>

³ <https://www.hyms.ac.uk/research/research-centres-and-groups/Wolfson>

⁴ Abbott D, Prescott H, Forbes K, Fraser J, Majumdar A. Men with Duchenne muscular dystrophy and end of life planning. *Neuromuscular Disorders*
<https://doi.org/10.106/j.nmd.2017.06.147>

For more educational opportunities don't miss your chance....it's not too late to register for the APPM annual study day (details on page 4)

9th APPM Paediatric Palliative Care Study Day

Date: 23 November 2018, 8:45am - 5:00pm

Organisation: The Association for Paediatric Palliative Medicine

Location: Birmingham

Address:

Hilton Birmingham Metropole, National Exhibition Centre, Birmingham, West Midlands B40 1PP

Price: £150 - £180

[Book event](#)

Join the Association for Paediatric Palliative Medicine (APPM) for their annual study day featuring specialist lectures, expert panels, seminars, networking, Q&A time and discussions on up to date, relevant paediatric palliative medicine topics.