

Association for  
Paediatric  
Palliative  
Medicine

# APPM

[www.APPM.org.uk](http://www.APPM.org.uk)

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## From the Chairman

Dear Colleagues  
Easter 2018



It has been a long winter for most, if not all of us, with weather conditions adding to already busy clinical work-loads, but it is April next week, so we can hope for better soon. Nonetheless, there has been building on what was discussed at the APPM conference and AGM in

November, and the APPM executive has met and things are moving on with:

- Development of a new website
- Colleagues are beavering away with the latest version of the APPM Master Formulary
- New developments within research, not least with work between APPM and Together for Short Lives, and with the Martin House Research Centre
- Progress with work at the College Specific Advisory Committee (CSAC) in terms of a new curriculum which is closely allied to other subspecialty groups at the Royal College of Paediatrics and Child Health.

We still rely heavily for administrative support from Together for Short Lives, but there are significant changes in personnel there with both Katrina McNamara now just retired, and Barbara Gelb indicating this is her intention by the early summer.

## Executive Committee

**Pat Carragher** [Chairman]

**A K Anderson** [vice-chair]

**Anton Mayer** [sec/treasurer]

**Sat Jassal** [formulary]

**Suzie Lapwood**

[revalidation]

**Emily Harrop** [NICE]

**Tracy Blount** [GP]

Involvement, study day organisation]

**Jonathan Downie** [trainee rep]

**Renee McCulloch** [CSAC]

**Bindu Koodiyedath**

**Richard Hain**

**Katrina McNamara**

[Together for Short Lives]

**Heather McCluggage**

[editor]

Both have been great friends of the APPM, with Katrina working tirelessly with us over many years and in many different pieces of work. Similarly, Barbara has offered both formal and informal support, and so I would like to take the chance to thank them both for all their hard work in the development of paediatric palliative care, and to wish them every success in the future.

I also wish to thank Tracy Blount, in particular, for her hard work in setting up what will be another great conference in November 2018 in Birmingham, and for giving us far more than the “bare bones” for the next one beyond this in London in 2019. She has also worked very hard in terms of seeking support and representation for GP colleagues working within children’s hospices, and I am now looking to see if there is someone out there who can take this on further as Tracy will increase her commitment to her GP practice and so will stand down from the executive in November. So thank you very much Tracy, and I will now be approaching other colleagues to see if they have capacity to develop this further; I would be very happy to assist with this.

Similarly, we now have an increasingly active trainee group with two meetings per year and some really interesting developments, including the inclusion of “simulation” at the last meeting. At present Jonny Downie is leading on this, but we need two more trainees to join him, and while we have at least one interested party to work with Jonny, is there anyone else with some

capacity? It is really interesting work and also looks great on a curriculum vitae!

So, this is a direct appeal to this readership, members and non-members for that matter – we could well have four vacancies in the executive this autumn as terms of office start to come to their maximum times. I will stand down as Chair and step off the committee but would still be keen to support in any way, but there are other gaps coming too. We are looking for colleagues to join and further shape the APPM through the work of its ‘exec’ and in particular I am interested to hear from any of you who have specific skills with websites and/or production of the APPM newsletter and other updates.

Beyond this I will approach several more of the APPM membership over the next 4 weeks to see if any of you are interested in the ongoing development of paediatric palliative medicine across the UK and Eire, and also to see how this links with the international movement through ICPCN ([www.icpcn](http://www.icpcn)), these are both very exciting and interesting times.

By all means email or phone me if you would like to talk about joining the executive team.

Best wishes to you and to the APPM as it continues to develop.

Pat Carragher

[pat.carragher@chas.org.uk](mailto:pat.carragher@chas.org.uk) (07900926858)

## NICE Update - Shared Learning Examples

Emily Harrop

Over the last year, it has been interesting to see work carried out on baseline assessment of services against the recent NICE Guidance for Infants, Children and Young People (NG61). Some of the learning from this process has now been reviewed by NICE and is available in their library of Shared Learning Examples. These documents aim to show how NICE guidance and standards have been put into practice by a range of health, local government and social care organisations.

The key objective of these examples of good practice are to:

- **highlight learning that could be useful to others**
- **have clear objectives, including an explanation of what was happening before the project, why it was needed and how it was implemented**
- **outline any barriers the organisation faced when implementing the project and the methods used to overcome these**
- **outline the effect the change had on service performance and outcomes through an evaluation process**

The links below will lead you to the two examples relating to NG61:

1. **Helen & Douglas House working within Thames Valley Network**

<https://www.nice.org.uk/sharedlearning/networked-approach-to-implementing-ng61-end-of-life-care-for-infants-children-young-people>



## 2. Together for Short Lives, a national perspective

<https://www.nice.org.uk/sharedlearning/supporting-the-children-s-palliative-care-sector-to-implement-the-nice-end-of-life-guideline-for-children-and-young-people>

It would be good to hear how other services have used the process of baseline assessment, and whether the issues encountered are similar to those reflected in the documents above.

**Dr Emily Harrop**

Consultant in Paediatric Palliative Care

Deputy Chair of the Guideline Development Committee for NG61

***Are you currently pursuing doctoral studies (PhD, Professional Doctorate or similar) in an area relevant to children's and/or young people's palliative care? Or are you considering this as part of your future career development? Do you supervise doctoral candidates in this field? If so, we would like to hear from you.***



**Research in Children's Palliative care  
Doctoral Student's task force**

Since 2012 the Association of Paediatric Palliative Medicine and Together for Short Lives have worked together to foster a research culture through the **Joint APPM/TfSL National Research Group**.

One strand of this work was to establish the Doctoral Students' Task force, whose remit has focussed on supporting the development of trained researchers to pursue rigorous enquiry and generate robust evidence, in order to support the delivery of the highest standards of care for children, young people and families.

The Doctoral Students' Task force aims to

- create opportunities for **peer support**,

- to foster links between academic institutions and service providers,
- and to develop a network of potential external examiners.

We encourage the dissemination of recent publications and share opportunities for presentations and debate on key research areas. **Several group members actively contribute to [Synopsis](#), a database of research abstracts relevant to this field.**

For current or prospective PhD students, we are producing a “Top Tips” guide with signposts for challenging areas such as

- gaining ethical approval,
- literature searching,
- and writing for publication.

We are developing a list of current and recent doctoral students and their projects, and a database of potential examiners too. We have established a dedicated private Facebook group for networking (eCPC PhD News). If these would be useful to you, please get in touch so that we can include your details on our mailing list/contact groups.

**To develop a research capacity in a small specialty, spread across the country, we need to collaborate and share our experiences.** If you'd like to be involved in shaping and supporting the development of a research culture for children's palliative care, please contact Lizzie Chambers at [lizzie.chambers@togetherforshortlives.org.uk](mailto:lizzie.chambers@togetherforshortlives.org.uk).

**Nicky Harris, on behalf of the TfSL/APPM Doctoral Students' Taskforce**

**Save the date** for the 9th APPM Paediatric Palliative Care study day! **23 November 2018** in Birmingham, UK

## Use of blended "table food" diets via gastrostomy. Questions and answers

The number of people receiving home enteral tube feeding continues to increase, particularly amongst children with neurodisability and an unsafe swallow. Many of these are gastrostomy fed.

The accepted standard feed for patients is still liquid, nutritionally complete, pre-prepared commercial feed which is sterile, standardised and easy to prepare and administer.

However, there is currently increasing interest in the use of liquidised food (Blended/ pureed, 'table food'), both in addition to and as a replacement for commercial feeds. There are anecdotal reports of benefit, and little evidence of harm.

However, there is at present little robust research evidence to support this practice, so as yet it cannot be formally recommended.

A collaborative research project is being planned to help clarify the likely benefits and harms of such practice.

***In order to support practice pending an improved evidence base, various resources have recently been developed:***

1. We are frequently asked questions by health care professionals who are being asked to support families and carers practically with the use of liquidised food / blended diet. We therefore convened a small working party with interdisciplinary representation from British Dietetic Association, Children's Hospice Southwest, Helen and Douglas House Oxford,



and including dietician representation from 2 NHS Hospital Trusts. Our aim was to draw together some questions and suggested answers, and to complement and signpost to some of the guidance, evidence base and resources already available. The resulting document is now available here:

[http://www.togetherforshortlives.org.uk/assets/0002/2083/20171016\\_Use\\_of\\_blended\\_or\\_liquidised\\_table\\_food\\_diets\\_via\\_gastrostomy\\_-\\_Q\\_and\\_A\\_-\\_Lapwood\\_et\\_al\\_16.10.17\\_3\\_.pdf](http://www.togetherforshortlives.org.uk/assets/0002/2083/20171016_Use_of_blended_or_liquidised_table_food_diets_via_gastrostomy_-_Q_and_A_-_Lapwood_et_al_16.10.17_3_.pdf)

2. The British Dietetic Association had also produced an excellent 'Practice Toolkit', available here <http://www.healthynation.org.uk/toolkit/>

This also includes evidence tables, an example risk assessment, and monitoring pro forma

3. Some children's hospices and NHS trusts have also now produced their own interim practical guidance for their settings, to help support parents, carers and families as well as health care professionals, where a decision has already been made for liquidised feed to be used. Further areas have guidance and policy currently being developed. Contact individual centres for further information, but examples of such guidance are listed here:
  - Children's Hospice Southwest (2016): Staff guidance and risk management for administering blended food via gastrostomy. Parent guidance: Your child's blended diet whilst staying at the hospice (available on request from [Suzanne.brown@chsw.org.uk](mailto:Suzanne.brown@chsw.org.uk))
  - Helen and Douglas House (2017): Staff guidance and risk management for administering blended food via gastrostomy (available on request from [slapwood@helenanddouglas.org.uk](mailto:slapwood@helenanddouglas.org.uk))
  - Leicestershire Partnership NHS Trust (2017): Administration of liquidised diet via gastrostomy buttons <http://www.leicspart.nhs.uk/Library/AdministrationofLiquidisedBlendedDietviaGastrostomyButtonsFYPCexpNov197363.pdf>

Please be in touch if I can help with further queries support practice in this developing area.

Dr Susie Lapwood,  
[slapwood@helenanddouglas.org.uk](mailto:slapwood@helenanddouglas.org.uk)  
Helen and Douglas House, Oxford  
February 2018



to



Extension of community Healthcare Outcomes .

<https://www.hospiceuk.org/what-we-offer/clinical-and-care-support/project-echo>

Having had a year of an ECHO project in paediatrics in Northern Ireland we decided to set up a two year echo project in paediatric palliative care.

ECHO is a tool for healthcare education, it is a hub and spoke model.

The “experts” are at the hub, the rest of the contributors are at the “spokes”

People connect in through their computers, tablets or phones via a network called zoom.

Sessions are set at a time and frequency that suits it’s participants. We learnt that twice a month was too often to get a consistent buy in from busy clinicians , so we are trailing a monthly session . Each session lasts 90 mins.

A typical session has an expert at the hub give a 25-30min informal talk on a specialist subject. followed by another clinician giving a case history presentation. All the people at the spokes as well as those at the hub may make constructive comments about the case. No-one is criticised but everyone learns from each other.

In stead of having a cascade of information from top to bottom everyone can take part and give their experience of what does and doesn’t work.

The format has been used in adult palliative care for a while and has recently been adopted by Hospice UK as one of their preferred methods of education and staff support. It allows those working at a distance from a “centre of excellence” to avail of the knowledge and experience of the staff there without having to travel miles to formal teaching days.

In our Paediatric palliative care programme we plan to have sessions on a variety of issues from staff stress and resilience to symptom management at end of life. On 12th April Katrina McNamara is going to present on “If Carlsburg did Children’s Palliative Care.....”

Watch out for an ECHO project near you, zoom in and become a spoke in a very effective wheel of learning and support.

Dr Heather McCluggage; Medical Lead for Paed Pall Care Western HSCTrust NI.

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**APM Neurological Palliative Care Special Interest Forum**  
In collaboration with Arthur Rank Hospice Charity

**AN UPDATE ON PROGRESSIVE  
NEUROLOGICAL DISEASE**

**Monday 6th November 2017  
9am -5pm**

**VENUE: Education Centre, Arthur Rank Hospice  
Cherry Hinton Rd, Shelford Bottom. Cambridge CB22 3FB**

**Topics include**

- **Prolonged disorders of consciousness**
- **Management of muscle spasm**
- **Artificial nutrition in neurological conditions , including feeding issues MDT and use of nasal endoscopy in MND**
- **Management of Duchenne Muscular Dystrophy**

**Cost £110**

**Register online via Eventbrite**

**<http://www.arch.org.uk/pro-education.asp>  
further information available from the Education team  
[education@arch.org.uk](mailto:education@arch.org.uk) tel 01223657780**



I would like to remind members of this charity. React supports children with potentially terminal illnesses and their families with equipment both medical and domestic. Also there are holiday homes around the UK and, on occasion, financial help for accommodation costs when a child is being treated out of area. Applications are checked and a means test is applied. This service neatly dovetails with the care provided by the organisations we work within.

When dealing with your patients please think of React. We might be able to help!

[www.reactcharity.org](http://www.reactcharity.org) Dr Mike Miller

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**We would like to do an article on “blended diets” in the next issue, If you have any experience of using it we would love to hear from you**

[heather.mccluggage@westerntrust.hscni.net](mailto:heather.mccluggage@westerntrust.hscni.net)

