Association for Paediatric Palliative Medicine

Newsletter Autumn 2013

In this issue:

Greetings from Dr Pat Carragher Chair APPM

Summer days are moving to more autumnal ones all over the British Isles, which means that the fourth annual APPM educational day is nearing! The programme is packed full with a mixture of lectures and workshops staring with registration at 0900 at the Friends' Meeting House in London at 29 November 2013. Bookings are being made earlier that last year, so if you or a colleague is interested in attending, see the contact details within this Newsletter, and act soon! See page 13.

Joe Brierley, PICU Consultant at Great Ormond Street starts the day off with a review of the ethical interface between PICU and Palliative Care and no doubt he will tackle, "Because we can, should we?" The morning looks at complex neuro-disability, the palliative care funding review, and commissioning of paediatric palliative care moving to a panel discussion before lunch, with the APPM AGM before we break into workshops, and then later all join together to tackle respiratory tract management and muscle spasm before the 'close of play'. The meeting aims to tackle many of the issues which challenge our everyday practice, and therefore should improve practice across the UK and Ireland. At the same time the First All-Ireland Children's Palliative Care Conference will look at similarly broad range of subjects related to our mini-speciality, as yet more evidence of the increasing interest in Paediatric Palliative Medicine across the world. (See www.icpcn.org)

The recent APPM Executive Meeting highlighted the volume and variety of the different work going on within Paediatric Palliative Medicine across the UK and beyond. There is an exciting revision of the APPM Formulary going on, with the last edition now translated in different languages, including Russian. I encourage you to follow what's happening next 'after' the Liverpool Care Pathway, and especially for children – we have APPM members working in this field, in close association with Together for Short Lives. More when there is more to report.

In July 2013, Together for Short Lives, working in close collaboration with the Commission into the Future of Hospice Care, hosted an event for children's hospices and stakeholders from the wider children's palliative care sector to begin to address the emerging findings from the Commission and to begin to enable discussion and debate about its implications for children's palliative care. It is definitely worth a read, and this can be done by viewing **http://www.togetherforshortlives.org.uk/professionals/resources/3682_the_future_of_hospice_care_2013_free_download_available**

This is organised around six themes, which includes what the core service could look like, what sort of workforce needs to be developed, and how to develop an evidence base, all not far from the essential objectives of the APPM – see our website. 'Together' hosts another very relevant development of this at its next conference in Birmingham on 18 March 2014 – look out for this or keep it a diary note for yourself!

I hope to meet many of you again at the APPM conference on 29 November.

Pat Carragher, Chair of APPM

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Recognition of a Special Interest in Paediatric Palliative Medicine

Are you or do you have a trainee who is interested in paediatric palliative care?

There are more trainee paediatricians with an interest in children's Palliative medicine than there are places available for grid training. Also many of those with an interest do not wish to work full time in the sub-specialty. The CSAC (Central specialist advisory committee) for the RCPCH in children's palliative medicine have now established a SPIN (Special Interest) Module.

Such training is relatively straightforward where there is grid training (London, Wales and Yorkshire) but it is less obvious elsewhere. However, with some fore thought and planning this can easily be built into the last three to four years of training. The trainee will have to establish links with local paediatricians who practice palliative medicine. The CSAC can help to make these links and advise on training. The usual Work Based Assessments should have aspects of palliative medicine in them and assessments shared with the local paediatrician with expertise in palliative medicine.

The trainee will be expected to have some useful contact with a Children's Hospice and clear recognition of the difference with adult hospices. Attendance at study days in palliative medicine is also probably necessary.

There are some paediatricians who may wish to undertake the University of Wales (Cardiff) Diploma in Paediatric Palliative Medicine. If they have not already done so, they should be encouraged to make links with the CSAC and local paediatric palliative medicine and work towards formal recognition of their special interest. It would be a shame not to complete this process.

There is some guidance on Special Interest Modules on the RCPCH website but the CSAC (Dr Yifan Liang yifan.liang@stees.nhs.uk and Dr Mike Miller mmiller@martinhouse.org.uk) would be happy to hear from paediatric trainees or importantly paediatricians spending a significant amount of time in palliative who would like to encourage their trainees to develop a recognised interest in palliative medicine.

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Revalidation Update

Since the last APPM newsletter, revalidation has got under way and at least some of us have now successfully and (hopefully) painlessly been revalidated. There are no major changes to report, but systems are still being developed and the likely requirements may well continue to change.

From my perspective, the main things to note are:

1. Appraisal does now need to reflect the **whole of practice**. So if you have more than one medical role, all roles must be brought to the appraisal. This will mean including supporting information and appraisal summaries (where available) from all roles, and discussing all your medical roles in your 'main' appraisal meeting (the one in your Designated Body). There may still be work to be done in ensuring that organisations (particularly independent hospices) have systems that support doctors in collecting appropriate supporting information.

2. Systems and standards for **patient and colleague feedback** are continuing to be developed. Patient and carer feedback is probably the area where we may need to do most work in the children's palliative care sector. It is quite possible to obtain meaningful parent / carer and sometimes patient feedback in our sector. We have an opportunity to develop, pilot and report on systems in our own settings, and to share our learning with others in children and young adult palliative care. Please let us know about what works (and what doesn't) in your setting, and share any tips to help us all obtain useful and objective feedback from carers (and patients where possible), without overloading families.

3. Systems and policy for **'Responding to Concerns'** about doctors are still being developed nationally. Given the small number of doctors working in paediatric palliative care, we won't expect to gain great experience 'in house' in dealing with concerns. However, we will need to know how to respond in such cases, and will need to review our individual organisational policies as national guidance emerges in the coming months.

4. Many doctors have little experience or understanding of paediatric palliative care. Specialty-specific input to appraisal would therefore be helpful, at least some years in each revalidation cycle. To this end, APPM has developed a list of a few of our members who are trained medical appraisers and are willing (diaries-permitting) to offer appraisal including a focus on paediatric palliative medicine. This willingness does not imply availability for any particular appraisal year. We welcome expressions of interest in joining this list, as well as requests to be appraised: please contact me or APPM (appm@together for short lives.org.uk) for further information.

   The Revalidation page on the APPM website has further information and links
   www.bit.ly/appmrevalidation
   and I endeavour to keep these updated. If you have outstanding queries about revalidation, or tips for good practice, please do be in touch:

Dr Susie Lapwood
APPM Revalidation Lead
South of England Revalidation Advisory Board
slapwood@helenanddouglas.org.uk

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Central Neurogenic Hyperventilation in a child with progressive brainstem astrocytoma.

Central neurogenic hyperventilation (CNH) was reported by Plum and Swanson in 1959 in a group of comatose patients with pontine infarcts[1]. They described that the hyperventilation persists during sleep, the patient has a low arterial PaCO2, high arterial PaO2 and high arterial pH in the absence of drug or metabolic causes. Cardiac and pulmonary causes for hyperventilation should also be excluded.

Case Report

A previously fit and well boy presented at the age of 8 with a 4 week history of headaches and vomiting and 2 day history of intermittent shaking of his right arm. His neurological examination was normal but an initial CT scan of his head revealed left sided thalamic space occupying lesion with triventricular hydrocephalus. This was later confirmed to be a localised left thalamic anaplastic astrocytoma (WHO Grade III).

He underwent an endoscopic third ventriculostomy and biopsy, then partial surgical resection a month later, followed by proton beam radiotherapy in the USA. He had a residual right hemiparesis post surgery but otherwise made a good recovery.

His post radiotherapy scan showed a reduction in size of the residual thalamic tumour compared to the pre-operative imaging 3 months prior. A focus of high signal in the right medulla oblongata was noted and was thought to possibly represent a second focus of tumour.

Unfortunately, the patient subsequently presented to hospital with a 2 day history of headache and early morning vomiting and developed hyperventilation and agitation soon after admission. He was sedated with propofol but he remained tachypnoeic. His initial arterial blood gas was: pH 7.57, pCO_2 1.65, pO2 15.0.

He was also noted to have a leak from his ventriculostomy wound on presentation. CT scan of his brain showed hydrocephalus and a CSF leak via his wound. He was started on IV antibiotics and dexamethasone and also had an external ventricular drain inserted.

Whilst intubated during his post-operative period, he had a CT scan of his chest which demonstrated no pulmonary pathology that could account for the hyperventilation.

He was extubated after 24 hours, remaining on a morphine infusion (20mcg/kg/hr) and dexamethasone. His respiratory rate had normalised to 12-21 post-extubation. His morphine infusion and dexamethasone were gradually weaned over the following week without recurrence of the hyperventilation.

Central Neurogenic Hyperventilation in a child with progressive brainstem astrocytoma.

A repeat MRI during this admission demonstrated progression of the thalamic tumour in the resection cavity with extension into the pons and cerebellum. He was then transferred to another oncological centre for family to explore treatment options on a research trial.

Central Neurogenic Hyperventilation

CNH in conscious patients is rare. Following Plum and Swanson's report, there have been approximately 30 described cases, 9 of whom are children[2,3].

The most commonly reported cause of CNH is pontine tumours: primary brain tumours, infiltrative lymphoma or leukaemia[2]. It has also been described in a patient with brainstem encephalitis[4] and a child with a mitochondrial encephalopathy[5].

The pathophysiology of how a brainstem lesion causes CNH is not completely understood. Plum and Swanson proposed that CNH "results from the uninhibited stimulation of both the inspiratory and expiratory centres in the medulla by the lateral pontine reticular formation and by laterally located descending neural pathways"[1]. However, there are multiple modulatory pathways between the pontine and medullary respiratory centres and it is unlikely that only specific inhibitory pathways are disrupted. Activation of stimulatory respiratory pathways and reduction in intra-cerebral or brainstem pH have also been proposed[2].

Treatment of CNH is poorly described. In 3 patients with brainstem neoplasms, steroids were administered with good clinical response although none reported how long the effect was sustained[2,6,7]. There is one case report of the use of an IV bolus of Midazolam with an immediate but transient effect[7]. The use of morphine bolus was effective in 1 of 2 reported cases and in the patient who responded, oral methadone was then used for ongoing treatment[2,8]. One patient was successful managed with an intravenous fentanyl infusion, and this was sustained when changed to a transdermal fentanyl patch[9].

***In summary*,**

CNH is a rare clinical syndrome, most commonly related to a brainstem malignancy. There is very little literature on its management; there have been reports in using steroids and opiates to alleviate the symptom.

Dr Michelle Koh

References

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Book Review

Complete Tubefeeding

Everything you need to know about tubefeeding, tube nutrition and blended diets

Eric Aadhaar O'Gorman (2012)

(ISBN 9781470190224)

The author of this helpful and unusual book was himself a happy 'tubie' (owner of an enteral feeding tube). He described this book as a definitive guide for anyone living with or preparing to receive a feeding tube, and those who care for them. The book is informed by personal experience, experience of other 'tubies', research, common sense, wit and humanity, in order to ease the paths and transitions experienced by those living with and managing tube feeding. The book thus offers sound practical advice in addition to well-researched background information. This book does not set out to help with the decision as to whether to embark on tube feeding, although does help explain the processes involved. Once that decision has been made, it will be very useful in supporting a patient, family and professional carers in the practical implications of living with an enteral feeding tube.

The first half of the book includes sections on the different types of feeding tubes, their placement, use and care, with helpful tips to make living with a feeding tube as easy as possible. This also includes advice on practicalities around feeding (position, rate, venting etc) as well as care of the feeding tube site. Given the significance of feeding to both patients and their families, the inclusion of a thoughtful and constructive chapter on 'heart and mind: psychology, family and mealtimes' adds further value to a book that is otherwise focussed much more on physical practicalities.

The second half of the book is devoted to 'tube nutrition', including advice on commercially available formula feeds as well as a substantial section on issues around blended 'real food' diets (including tips on blending, and some suggested recipes). There is growing interest in the use of blended diets and this book will support families in this: it would of course be important to consider this section in the context of current dietetic advice for an individual patient, as well as impending guidance from the Parenteral Nutrition Group of the British Dietetic Association. Reassuringly the author acknowledges that he is not a medical professional and encourages readers to consult with their own health care professionals.

'**Complete Tubefeeding**' is written in a straightforward, empathic and readable style, suitable for a wide range of readers. A high proportion of children and young adults with life limiting illnesses do require tube feeding at some stage in the course of their lives. This is therefore a useful book to consider for our

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hospice and hospital libraries as well as to put into the hands of our older patients and particularly their immediate family and carers.

Dr Susie Lapwood

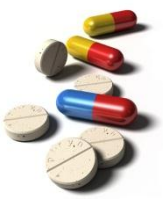
Paediatric Palliative Care Prescribing update

After the successful publication of the second edition of the APPM Master Formulary in July 2012 the Master Formulary Group are now beavering away in preparation for the next edition of the APPM Master Formulary which is scheduled for July 2014. The APPM Master Formulary Group is grateful to Together for Short Lives who have agreed to take on funding for maintaining the Master Formulary as part of their portfolio. The new edition is likely to include a number of new mongraphs together with more detailed guidance on using the buccal route for medication and dosing of midazolam as an infusion at end of life. There is also the second APPM Master Formulary Survey which we hope will be available online and in paper format at the APPM study day on 29th November. In the meantime there are a couple of important changes to bring to your attention.

MHRA Recommendations on Codeine

The majority of you should be aware on the back of recommendations from the World Health Organisation and A European review of the safety **of codeine-containing medicines** licensed for pain relief in children **the MHRA concluded that c**odeine should only be used to relieve acute moderate pain in children older than 12 years and only if it cannot be relieved by other painkillers such as paracetamol or ibuprofen alone.
Furthermore, a significant risk of serious and life-threatening adverse reactions has been identified in children with obstructive sleep apnoea who received codeine after tonsillectomy or adenoidectomy (or both). Codeine is now contraindicated in all children younger than 18 years who undergo these procedures for obstructive sleep apnoea.

From a personal perspective I have had two children under my care who had significant adverse reactions to codeine whilst it is difficult to recall any children who have had significant adverse reactions to other drugs used in palliative car and I had already moved away from prescribing codeine for my patients before the WHO analgesic ladder was formally revised. However this always led to the question of what to use instead…There are a number of options but somehow none of them seem entirely satisfactory. Moving to dihydrocodeine may appear to solve the problem but the side effect profile of both drugs is similar although dihydocodeine is an active drug and therefore not subject to the intra-individual variation in metabolism seen with codeine. Locally our experience with tramadol in children is growing and there is a soluble preparation that can be used for those unable to take tablets or requiring a smaller dose. However this not licensed for children under 12 and little dosing information for children under 5 years. My preferred option in terms of medicines safety is to use 1/10 of the strong opiate dose of morphine. This has the advantage of a range of preparations including the slow release granules as well as injection. There is a wealth of experience in children and at least some morphine preparations are licensed in children as young as 1 year.



However the challenge with using low dose morphine is the understanding not just of patients and their families but also of professionals. Colleagues not experienced in palliative care and not familiar with usual strong opiate morphine doses have misinterpreted the fact that a child is on morphine as being indicative of the child being nearer to end of life and having a greater need for palliative care than is necessarily the case. I find I have to emphasize this very carefully with parents, professionals and the child's GP. Locally at Alder Hey Children's Hospital our medicines safety team has been considering options carefully both for palliative care patients but also importantly for the wider group of patients that the Trust supports. The likely outcome is that we will recommend low dose morphine for all our patients requiring the "second step" of the WHO analgesic ladder. It will be interesting to hear what other centres are doing.

Revised morphine equivalent doses for fentanyl transdermal patches

Astute members of the APPM will have noted that the Palliative Care Section of the BNF for Children (BNFC) has been recently updated. This has highlighted a couple of important issues. Firstly the BNF has changed their recommended oral morphine equivalent doses used when converting to or from a fentanyl transdermal patch. This is now in line with recommendations of Palliative Care Formulary 4 and the UK Medicines Information Service where a 25 microgram fentanyl patch is considered to be equivalent to 60mg oral morphine not 90mg. This has implications in that children converting from morphine to fentanyl will receive a larger dose of fentanyl particularly if the dose of morphine they are rotating from is at the bottom of the new ranges. It seems sensible to be cautious and start low. Of course the converse is true when switching from transdermal fentanyl to morphine or calculating morphine breakthrough doses.

Finally you may notice that the updated Palliative Care Section of the BNFC is very similar to the adult BNF and consequently some of the subtleties of paediatric palliative care are missing. The APPM Master Formulary Group is aware of the need to engage with the BNFC Editorial Board to highlight the differences between prescribing for children's palliative care and prescribing for adults palliative care. This new edition has provided the impetus to refresh this initiative.

Lynda Brook September 2013

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A BALANCING ACT

A 13 year old boy with a mucopolysaccharidosis was admitted to the PICU in his metabolic centre from his local hospital with a progressive chest infection. Unfortunately there were the usual complications of intensive care that included persistent diarrhoea and abdominal pain. He also had an obstructed thoracic inlet and had to have a tracheostomy. Although he was sustained on parenteral nutrition it was felt that this was not a viable long term solution.

A plan was developed to introduce octreotide 50 micrograms subcutaneously three times daily as well as mebeverine 135mg three times daily. He had a two week course of metronidazole. It was then possible to very gradually increase the volume of dioralyte through his gastrostomy and once 60ml/hr was tolerated a gradually increasing strength of an elemental feed was introduced.

There was slow improvement, but also times when his gastrostomy had to be aspirated to reduce severe distress and the feeding regimen had to go back a few steps. There was the usual difficult balance between pushing calorie intake managing his and his parent's distress.

After four months on PICU it was possible to transfer him to the hospice close to his home for step down care. He was discharged home on mebeverine and octreotide as above with his parents or home nurses giving sc injections through a subcutaneous port. He was also on lansoprazole 30mg twice daily, gaviscon advance 5ml one hour after the evening feed and as need, a fentanyl 75mcg patch, gabapentin 200mg three times daily, diazepam 1mg morning and lunch, diazepam 3mg at lunch time, chloral hydrate 400mg at night and he was being weaned off clonidine. His feed was Perative (1.3kcal/ml) and seemed to be tolerated.

At home he made good progress although his bowels were upset by a course of ciprofloxacin given for a pseudomonas ear infection and he had a further course of metronidazole. He was started on nebulised colomycin.

It was possible to reduce the fentanyl patch and wean off the gabapentin. Erythromycin at prokinetic doses was introduced but not thought to be essential.

Weight gain tended to be elusive, but he was managed at home until a worsening episode of abdominal pain and increased gastric aspirates led to admission to hospital and IV fluids.

He was discharged home after a few days but then relapsed. With a lot of support from the local paediatrician and children's nursing team. It was possible to support him at home with intravenous fluid and slowly

increasing volumes of dioralyte and then introduction of feed. Rifaximin was then introduced and was so successful in stopping the diarrhoea that one dose of methylnaltrexone was given to help constipation. He continued with intermittent abdominal pain that was managed by aspirating his stomach and stopping of reducing the rate of feed rather than by giving an opiate. Diazepam or chloral hydrate was used if he was very unsettled.

His bowel slowly resumed normal working but he continued to be more on Rifaximin than off it. When well he enjoyed those around him and his favourite place was home. He would have favourite carers.

Management of these children is often fraught with concerns about weight loss so there is urgency to get calories in, but then distress about the intense discomfort that giving calories too quickly can cause. By concentrating on hydration, aspirating the stomach to relieve distress and increasing volumes slowly before adding calories it is possible to build up feed volumes without causing too much distress. Carers need to have guidance so they can respond quickly and yet ensure that minimal fluids are absorbed. Urine concentration should be monitored as a guide to hydration. The pH of gastric aspirate should be monitored to ensure that pain is not due to persistent acidity.

In retrospect it is likely that the only medication that had any direct influence on the outcome was the use of antibiotics directed at bacterial overgrowth. Although metronidazole is cheap and easily available neurological side effects are likely to develop with long term use and non-absorbed antibiotics such as vancomycin or rifaximin are better choices.

It is possible to manage these children at home and the consistency of care often makes this easier, although it would be rare to give IV fluids at home.

Sadly **bowel dysmotility** is likely to increase in these degenerative diseases and continue to present significant management problems but the expectation is that death will be due to respiratory rather than gut failure.

Mike Miller

Martin House

Association for Paediatric Palliative Medicine

A wee word from Katrina McNamara, Together of Short lives

Commissioning in England

As the new NHS arrangements in England are starting to settle, more clarity in commissioning arrangements for Children's Palliative Care is starting to emerge, with CCG commissioners now in post and getting to grips with their portfolios of responsibility,

The development of the proposed tariff for palliative care continues, with the Palliative Care Funding Programme team hosting a 'clinical sense check' meeting with clinical leads in the four children's sites and they have been holding meetings with the individual sites to support the analysis of the data which is now underway. The 'clinical sense check' in June brought together practitioners from across the pilot sites who broadly concluded that there was much consistency in the way that the classification system is being used by the pilots to capture both the clinical complexity and palliative care needs of children.

Earlier in the summer Together for Short Lives, the UK children's palliative care organization, launched a concise, five-page document for all CCGs, describing: the population of children who need palliative care; the services and professionals who provide it; and how children's palliative should be commissioned within the context of the five stages of commissioning set out by the NHS Institute for Innovation and Improvement. The document can be downloaded from http://www.togetherforshortlives.org.uk/about/our_policy_work/186_commissioning_children_s_palliative_care_in_the_new_nhs

And finally.....don't forget

Association for Paediatric Palliative Medicine

4th APPM Paediatric Palliative Care Study Day

29th November 2013,
Friends House, 173 Euston rd, NW1 2BJ, London

For further information or a registration form, please contact Tel: 0117 916 6422

or email appm@togetherforshortlives.org.uk

0900-0930	**Registration and coffee**	
	Chair:	TBA
0930-1010	Interfacing between PICU and Palliative care: the ethical issues	Dr Joe Brierly, PICU consultant, Great Ormond St Hospital, London
1010-1050	Update on management of complex neurodisability	Dr Claire Lundy, Consultant in Paediatric Neurology & Neurodisability
1050-1110	Coffee and Networking	
	Chair:	TBA
1110-1130	Palliative care funding review pilot: Experience from Paediatrics	Dr Lynda Brook
1130-1200	Commissioning of Paediatric Palliative care: Commissioner (10mins) GP (10mins) Together for short lives (10mins)	Martin Cunningham, Local Commissioner Dr Sat Jassel Katrina McNamara
1200-1230	Panel of experts: Discussion on commissioning and reviewing services	Katrina MacNamara Lynda Brook Sat Jassal Martin Cunningham
1230-1320	Lunch	
	Chair:	TBA
1320-1340	Concurrent sessions: APPM Annual General Meeting (AGM) Nurses forum	 Pat Carragher, Chair of APPM Julie Bayliss, Nurse Consultant, GOSH
1340-1420	Workshop 1: a) Topical analgesics/wound care OR b) Neonatal care and advance care planning OR c) Buccal medication: the old and the new	 Dr Patricia Grocott Dr Koh Dr Emily Harrop
1420-1500	Workshop 2: a) Topical analgesics/wound care OR b) Neonatal care and advance care planning OR c) Buccal medication: the old and the new	 Dr Patricia Grocott Dr Koh Dr Emily Harrop
1500-1520	Coffee and Networking	
	Chair	TBA
1520-1540	Developing Paediatric Palliative care services in Kuwait: what we can learn for our own practice	Dr Renee Mc Cullouch
1540-1600	The Spectrum of children's palliative care: practical application	Dr Lynda Brook
1610-1650	Respiratory tract management in the palliative care setting	Dr Gary Doherty, Consultant in Paediatric Respiratory Medicine
1650-1700	Feedback and close of day	

Heather McCluggage