

The Experiences of Working as a Palliative Care Registrar in Uganda

"Allahu Akbar" the call to prayer awakens me. I look out of my window to see people collecting grass hoppers. These had arrived in abundance, raining down like biblical locusts; and in the evening I taste this local delicacy!

These experiences and the joy of learning about a culture through living within it are part of why I chose to work as a registrar with the Mulago Palliative Care Unit (MPCU) in Uganda's national referral hospital. This is one of few African hospital palliative care services linked with an active research and teaching programme.

The size of Mulago Hospital amazes me. The bed capacity of 1,600 is always exceeded. Wards are full and beds, often hosting a patient on top and their carer underneath, spill out into the corridors. An MPCU research study demonstrated that greater than 40% of these patients have palliative care needs.

Mornings begin with palliative care team meetings unlike any I have previously experienced. Doctors, nurses, visiting healthcare students and SHOs on training placements, squeeze into the palliative care office to partake of sweet milky tea, chapattis, homemade cakes and discussion about patients.

Patients are mostly referred by Doctors or Link Nurses. Link Nurses, are on many wards and have been given extra training by MPCU to provide basic palliative care now handling 80% of problems at ward level. MPCU also provides training to all medical students, interns and many specialty doctors in Mulago. This teaching, vital to the advancement of palliative care, is challenging for a small team with many demands on its members.

From the meeting, we head out into the busy bustling wards. Patients have a huge variety of pathology as well as physical, social, and spiritual needs. Poverty and belief in traditional healers

mean that many patients present late. Complications of HIV, advanced cancers and spinal cord compression are common along with rising numbers of non-communicable diseases. Whilst radiotherapy is available and the radiologist helpful, the only machine is old and breaks down often!

The challenges of poverty cause me sorrow and frustration, but the benefit of palliative care is apparent everyday. MPCU works hard to provide holistic care with Ugandan volunteers forming an invaluable part of this team. Their tasks range from washing and praying with patients to collecting medications, planning education for a now orphaned child, or sourcing a local language bible for a patient.

After a busy day's work we all disperse home, joining the throng of commuters, packed into buses, perched on motorbikes and stuck in traffic jams! And, if it is the weekend, we head off to explore the amazing landscapes and wildlife that is abundant in Uganda.

My experiences in Uganda have more than met my expectations. Undoubtedly, there are daily stresses of time, resources and daily living that make palliative care and team work challenging. However, I have had unique opportunities to gain skills and experience in teaching, service development and management that I will be able to take home and apply. I have also learnt much about the local culture and made great friends who have enriched my life.

Gursaran Purewal and Anna Cleminson

Gurs and Anna were supported by Cairdeas international palliative care which provides assistance for volunteers working in Uganda and other resource-limited settings to facilitate the growth of palliative care through education, training and mentoring. For further information – Website: www.cairdeas.org.uk, visit the Cairdeas page on Facebook or email: operations@cairdeas.org.uk

New APM Committee Members



Leila Platt, APM Juniors Chair (joining the Junior and Executive Committee) - Edinburgh Medical School graduate, working as an FY1 doctor in Geriatric and Acute Medicine at Raigmore Hospital, Inverness. Inspiring teaching via St. Columba's Hospice, Edinburgh and an elective at St. Joseph's Hospice, Hackney ignited my passion for Palliative Medicine. Having been involved with the APM's Junior Members

Working Group since its inception, I look forward to building on the work of outgoing Chair, Dan Knights and the previous committee.



Aruna Hodgson, Education Committee

I am a Consultant in Palliative Medicine, and have worked at Wigan and Leigh Hospice for the past 9 years. I have extensive experience of organising and delivering education over many years and am delighted to have the opportunity to serve the APM membership as part of the Education Committee.

President's Report

"Christmas is coming and the goose is getting fat, please to put your data in the workforce survey's hat." Yes it's that time of year again when I get down on my knees and plead with you to fill in the workforce survey.

We all know that our work is expanding year on year. You will also be aware of the national drive to take posts out of specialty training and into general practice. I am sure you all know there are still places in the country with unfilled Palliative Medicine consultant posts or inadequate consultant numbers. If our trainee numbers are decreased it will result in all of us being more stretched and quality of care suffering.

In our recent negotiations with HEE we fought the case hard for maintaining trainee numbers and put a case for expansion. As many of you know the data that they rely on for workforce planning from the Centre for Workforce Intelligence is deficient for Palliative Medicine with so many doctors working in the voluntary sector. This is why the data you provide through the annual workforce survey is of such key importance. We have no firm commitment so far but due to the strength of the data we presented from previous surveys we are optimistic that our case has been heard.

Thank you to the 582 (54%) of you who have filled out the survey. Some of you are doing better than others. Sixty-four percent of Republic of Ireland members have completed it. Only thirty-eight



percent of those in the North West have! Please, please complete it. It is all our futures at stake.

On a different note those of you who read the e-bulletin will have seen that our website was hacked in mid November. This was swiftly identified and action was taken to prevent future hacks. We believe the hacker was looking for bank details. We do not keep bank details on the website. However they were able to get a list of email addresses and strongly encrypted passwords. We are advised that the passwords should not be identifiable. I am very sorry if this leads to any SPAM or Phishing messages. Those of you who have not seen the ebulletin please check your SPAM folders and mark as not SPAM or whitelist the APM messages so that we can keep you informed.

Sheila Richards, who was our first administrator and who has supported us part time in retirement, has decided it is time to retire for good. I am sure all of you will wish to join me in thanking Sheila for all she has done for the Association through almost thirty years and wish her well in her retirement.

Finally my best wishes for a Merry Christmas and a Happy New Year.

David Brooks
President



Palliative care for young adults: Are we making a difference?

One thing I love about palliative care as a specialty is the willingness to be genuinely patient-centred – addressing the individual's needs in a flexible, empowering and "can do" way. As a consultant working at Douglas House (a hospice for teenagers and young adults), I have witnessed the impact such an approach can have in tailoring appropriate care for this group of people.

We know that with improved survival for many childhood conditions, the numbers of young adults with non-malignant conditions and palliative needs are growing¹. In addition, there is increasing recognition that teenage and young adult cancer (TYAC) patients have particular needs and face particular challenges that are not always sufficiently addressed².

Many young people with life-limiting conditions face multiple and complex trials, including difficult symptom management, physical and learning disability, and developmental and psychosocial issues. In addition to other palliative care services, they may benefit from a greater focus on respite provision, on goal-setting and enablement and on support for parents and siblings.

The growing population of young adults with life-limiting illnesses presents a new challenge to existing adult palliative care services, but this challenge is by no means insurmountable and there are many fantastic examples of service developments across the UK that aim to meet the needs of this population.

Examples of innovative practice include tailored day hospice sessions, transition clubs, young adult units attached to an existing adult or paediatric hospice and hospice at home, as well as dedicated young adult hospices. Close collaboration with other specialties can be hugely valuable in identifying people who may benefit from palliative care, facilitating early discussions about

advance care planning, and building trusting relationships with young adults and their families.

At Douglas House, we have built up significant experience in caring for young adults with palliative care needs in the 10 years since we opened. We have a multidisciplinary team who are able to support young adults in a wide range of areas: from attending music festivals to managing complex seizures and spasms; from discussing sex and dating to providing end of life care following withdrawal of ventilation.

We are constantly learning more and aim to keep developing our service to meet the needs of this expanding population. In recognition of the difference that can be made in the lives and deaths of young adults, we are putting on a conference in January 2015. This conference is an opportunity to bring together people who are already 'doing it' as well as, those keen to get involved, in order to share our experiences, learn from each other and think creatively about the future. We hope you will join us.

For further details of the work of Helen and Douglas House and the conference visit: www.helenanddouglas.org.uk/conference2015/

Jo Elverson
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Helen and Douglas house

1. Fraser L, Miller M, Hain R, et al. (2012) Rising national prevalence of life-limiting conditions in children in England. *Pediatrics* 2012;129:e923-9
2. Grinyer A and Barbarachild Z. (2011) Teenage and young adult palliative and end of life care service evaluation. School of Health and Medicine Lancaster University 2011.

A Brief History of the APM 'through the years'

We continue with 1993 - 1996

When I became Chairman of the APM at the end of 1992, I was succeeding two very experienced consultants, Derek Doyle and Graham Thorpe. I had come from an oncology background to a single-handed palliative medicine post in 1985, and was relatively inexperienced in the specialty. I was at times rightfully accused of being reactive rather than pro-active – though in my defence, I have to point out there was a lot to react to at that time!

The main issue throughout my period as chairman was the development of palliative medicine into a recognised medical specialty, equivalent to any other. There were two strands in this process. One was persuading the relevant bodies, primarily the Royal College of Physicians, to recognise and accept us. The other was to develop a training programme which was appropriately rigorous, while meeting both the needs of trainees and the needs of future employers, particularly hospices.

Dr Gillian Ford had done a lot of skilful political manoeuvring behind the scenes, and this culminated in 1993 in the formation of a Specialty Committee for Palliative Medicine. This was initially joint between the RCP and the RCGP, the chairmanship rotating between representatives of the two colleges. However, as Palliative Medicine became increasingly recognised as a sub-specialty of Medicine and its training programmes came under the aegis of the RCP, interest from the RCGP diminished and finally the committee became a Medical Specialty Committee of the RCP.

During my chairmanship, medical training was still divided into Registrar and Senior Registrar appointments. The number of Senior Registrar appointments in the country was strictly regulated, and the Specialist Advisory Committee of the College determined in which Region each new post should be placed. We had to advise

the SAC on the distribution of new posts, trying to balance the need to develop the specialty, particularly where there were very few existing consultants, with the fact that SRs needed consultants as trainers and therefore could not themselves be the advance guard for the specialty. The high number of women training in palliative medicine meant a substantial demand for part-time posts, and training in these, often individually tailored, posts had to be of equivalent quality. We also tried to apply pressure to ensure that there was a consultant in palliative medicine on the appointment committee for consultant posts – not always easy when the RCP insisted their representative had MRCP at the very least, and was preferably a Fellow!

It had been clear from the beginning that for effective specialty training we needed a Core Curriculum, and this work was completed before I took up the chair. During my tenure we distributed the Core Curriculum as widely as we could and tried to ensure that palliative management was included in the curricula of other relevant specialties. It was especially gratifying for the members of the APM who had written the curriculum to see it taken up by the EAPC as the basis for a European curriculum.

Within the APM itself, the major development was the formation of the Ethics Committee. Ilora Finlay, Fiona Hicks and Fiona Randall were among those leading the debates, particularly on voluntary euthanasia, just as live a topic then as now. We developed good working relationships with other specialty associations whose work overlapped, particularly the British Pain Society. It was a continuing pleasure to see with each AGM the continued growth of the APM, from the inaugural meeting (which I attended) to a membership of over 600 by the time I handed over to Ilora Finlay.

Contributed by **Anne Naysmith**

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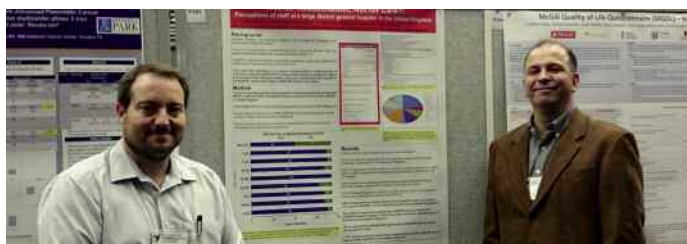
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International Congress on Palliative Care (ICPC): Live Long and Prosper



*So give a little bit
Give a little bit of your time to me
See the man with the lonely eyes
Oh, take his hand, you'll be surprised
Roger Hodgson, Give a Little Bit*

The final reflection of the ICPC, set to the sounds of Supertramp, showed images of inspired delegates. We had been dazzled by some of the best talent that palliative care has to offer. It was time to plan for our return to England, but not before sharing some lessons learned and insights gained.

The ICPC is held biennially in the city of Montreal, where the term 'palliative care' itself was coined by Professor Balfour Mount. Although spread over four days the volume of content makes it impossible for one to attend even a reasonable proportion of the sessions on offer. This year's iteration featured four whole-day Masterclasses, eight plenary speakers, 98 workshops, 289 poster presentations, two film screenings, and over 1,000 delegates representing some 60 countries. Our contribution to this juggernaut was a poster showing the results of a study where we questioned health professionals' understanding of "Do Not Attempt Cardio-Pulmonary Resuscitation" orders, particularly 'permissible' interventions when one is in place.

Whilst a thorough discussion of the ICPC is beyond the scope of this article, we nevertheless feel inclined to share with you some of the speakers who appeared to seek, to paraphrase David Tasma as he said to Dame Cicely in 1948, only what was in our minds and in our hearts:

Professor Stephen Lewis. Charismatic global politician and tireless champion of victims of HIV/AIDS. He reminded delegates of the successful United Nations (UN) Millennium Goals and the omission to-date of any reference to hospice palliative care in the UN

Sustainable Development Goals. His call to arms was so profound that the Montreal Declaration of Hospice Palliative Care was drafted during the night following his address and signatories are increasing daily.

Professor Mary Lynn McPherson. Pharmacist at the University of Maryland, USA. Her "Therapeutic Misadventures in Pharmacopalliation" session showcased her ability to share expert knowledge and experience through a wry lens. Although we still have reservations about 'adding methadone to the drinking water' we have no doubt about the authenticity of her numerous teaching awards.

Professor Irene Higginson. A beacon of palliative care who continues to inspire people around the world. Her report on the past, present, and future of the Cicely Saunders Institute was a shining example of the power of collaboration and of United Kingdom leadership in palliative care.

Professor Sheldon Solomon. Social psychologist at Skidmore College, USA. He co-developed Terror Management Theory which posits that culture itself and self-esteem serve to buffer the potential for death anxiety. Subsequent experiments have shown behaviour towards others can be significantly altered by mortality salience at a completely subconscious level.

Professor Bernard Lapointe. In his closing plenary address the director of Palliative Care McGill left no doubt as to the state of the palliative care union across the globe. He took the audience on a fascinating journey of how our specialty got to where it is today. He also reminded us that there is more work to do now than ever, not least because of Quebec Bill C-52, passed in June 2014, set to decriminalise euthanasia in Canada. This may be a cautionary tale for the UK.

As we left the Palais des Congres for the final time we felt secure leaving the building in the capable hands of Jedi Knights, the Avengers, and Doctor Who. Montreal's Comiccon had started an hour before the ICPC finished.

Live long and prosper.

Jon Tomas Registrar Palliative Medicine, West Midlands.

Charlie Davis Consultant Palliative Medicine, Somerset Partnership NHS Foundation Trust

The Editorial Board would like to thank you for your contributions to APM Post throughout 2014 and encourage everyone to send in articles of interest to your colleagues.

If you would like to contribute, please contact:

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With all good wishes for 2015

David, Jason, Dylan, Simon, Mark, Joy,
Becki and Heather

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