This is the first edition of an occasional newsletter from Palliative Care Works to our friends, associates and clients.

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We shall welcome contributions, opinions and news items – which should be sent to the Secretary, Stephen Chowns, schowns@aol.com
Editorial

Welcome to the first edition of the PCW newsletter!

We plan to send this publication to all our friends and contacts twice a year.

Contributions are warmly invited – though we make no promises about publishing everything we receive! Our aim is encourage and inform the international palliative care community, with a special emphasis on nations and communities where resources are scarce.

The core team of Palliative Care Works trustees (listed at the end of the newsletter) is enhanced by a group of associates. Both groups are multi-disciplinary; indeed, it is one of the principles we advocate that palliative care has clinical, social and spiritual dimensions.

If you would like to be registered as a Friend of PCW please send the following information to me – and I will ensure that you receive this newsletter and other communications connected with our activities in the UK, Africa and elsewhere.

- Your name, designation and postal address
- Your e-mail address
- Your profession or role in palliative care

I look forward to hearing from you.

Stephen Chowns
Secretary, PCW
Ledbury, England
PCW annual meeting 24 September 2016
from 10.00am – 4.00pm, in the

Lecture Theatre, Study Centre, Sir Michael Sobell House, Churchill Hospital, Oxford, OX3 7LI.

Following the success, last year, of inviting the overseas bursary students on the multidisciplinary PC course at St Christopher’s to our conference in Birmingham, we have again invited the six students on this year’s programme, and asked them to give a short presentation about the developments and challenges of PC in their country.

Also in the programme will be personal reports from teaching/mentoring in Uganda, Rwanda and Cameroon. PCW members will feed back on this year’s APCA conference in Kampala. We hope to have an update on the revised edition of the PC toolkit.

There will be plenty of time for discussion and networking!

Programme:

Sharing Global Palliative Care Experiences
09.30hrs -10.00hrs Coffee on arrival
10.00hrs-10.45hrs PCW Annual General Meeting of Trustees
(Open meeting - all welcome)
10.45hrs-11.00hrs Coffee
11.00hrs-11.45hrs Experiences in Uganda and Rwanda,
Dr Gurssaran Purewal, Locum Consultant in Palliative Medicine, Wirral Foundation Trust
11.45hrs-13.00hrs Feedback from APCA conference 2016 and PCW projects
13.00hrs-14.00hrs Lunch
14.00hrs-15.30hrs Sharing Global Palliative Care Experiences
St. Christopher’s bursary students’ presentations
15.30hrs-16.00hrs Palliative Care Toolkit update
16.00hrs Finish

Michael Minton

For more info: mjminton@doctors.org.uk
Training and mentoring in Ethiopia 2016/2017

Around the time of our last conference, PCW trustees were extremely excited to be approached by a potential donor organisation keen to explore collaborating on delivering a PALLIATIVE CARE TOOLKIT training programme in a resource limited setting. This sort of opportunity does not come along often so we were naturally very keen to explore it. Two particular countries came to mind for similar but contrasting issues and, after due consultation, it was agreed that we approach Dr Nicola Ayers in Ethiopia to see if PCW could help there.

Nicola, a British nurse, has lived and worked in Ethiopia and Yemen for over 20 years and is the palliative care adviser to the Ethiopian Ministry of Health. She had been working on developing a policy and although she had devised a course, and actually delivered training to 24 Doctors and Nurses from the four large hospitals in Addis Ababa, she was looking for support in delivering further training with on-going mentorship over a two-year time scale.

A team of three from PCW - a nurse, a social worker and a doctor, met with Nicola and the donor organisation earlier this year, and it was clear that there was a meeting of minds! The potential donor was satisfied that this project should be supported and has been busy securing funding since then. The PCW team and Nicola met recently at the APCA conference in Kampala and had a very productive time, finally agreeing an outline plan.

Phase One: November 2016: A two week PCW visit to Addis Ababa for a training of multi professional health care workers, working in collaboration with colleagues in Addis. This will also set up mentorship links.

Phase Two: May 2017: A three week training programme. It is anticipated that by the end of the programme in 2017, 120 health care workers in and around Addis will have been trained. This second phase will also include a programme of training of trainers. We hope that a process of cascading knowledge and skills from those trained, supported by mentorship, will follow and lead to further strengthening of palliative care services with integration into local health care systems.

Both PCW and Dr Nicola Ayers wish to pay tribute to the donor organisation for their extraordinary generosity in making this exciting collaborative venture possible.

George Smerdon
Book Review

A Really Practical Handbook of Children’s Palliative Care
For Doctors and Nurses Anywhere in the World
(And including the APPM Master Formulary 2015)
– by Justin Amery

This is a really helpful and useful book for all those working with children needing palliative care. It supports an understanding of children’s palliative care across settings, providing confidence to care for children wherever you are in the world from the UK, USA, and Africa to India.

The structure of the book is based around simple questions that we ask of ourselves in difficult situations when working with children who are dying. The content supports what we already know and develops our knowledge where there are gaps.

Divided into fifteen parts it covers all the practical topics around symptom management to the more difficult subjects of communicating with children and talking about end of life, grief and bereavement. The symptom management section helpfully describes what the symptom is, possible causes, impact, assessment and management.

Where management and treatment refers to medicines the APPM master formulary is a valuable resource as part of the book.

Justin also recognizes the rewards and challenges for health care professionals working within children’s palliative care and explores how we should look after ourselves by understanding what is stressful and how to make ourselves more resilient.

The book is easy to read, is an excellent resource and one that you can dip in and out of as you need to. It is available as a hard copy or downloadable from the ICPCN website

http://www.icpcn.org/a-really-practical-handbook-of-childrens-palliative-care/

Helen Bennett
Snapshots and sound bites from the 
Africa Palliative Care Association Conference 
August 16th – 19th 2016

The fifth APCA international conference was held this year in Kampala, Uganda, with 480 delegates from over 40 countries worldwide, of which 28 were African countries. The theme was Resolution to Action, Differentiated Care for Diverse Communities and there was frequent reference made to the WHA 2014 resolution 67.19 calling for the strengthening of palliative care as a component of comprehensive care throughout the course of life.

The conference was attended by five PCW trustees, who all felt it was a worthwhile experience and raised the profile of PCW.

There were three plenary sessions, with 21 speakers from around the world and plenty of opportunity for discussion and comments.

Some favourite sound bites from the plenaries are:

“In God we trust: all others must bring data” from Faith Mwangi Powell.

“I don’t have a powerpoint but I do have a point” from Dr Stephen Watiti, followed by a riveting life story of being a surgeon and becoming infected with HIV. His near death experiences and personal account of receiving palliative care will be long remembered. We bought his book ‘Conquering HIV and AIDS – my personal
experience of living with HIV’. This is well worth reading. He has also written ‘HIV/AIDS: 100 commonly asked questions’.

And finally “Don’t ask ‘where is the money? You should be asking ‘where are the patients?’.” From Dr Amandua of the Uganda Ministry of Health.

The concurrent sessions had four tracks with 51 papers presented, 15 workshops and eight sessions to meet the experts.

PCW together with Andrew Main from Insightful Meanings led a workshop on Mentoring that was well attended and had some very positive feedback. The interview between Eseenan from Ghana and George was the highlight of the workshop for me.

The three PCW bursary winners all gave very competent and well presented papers. Prospellina Ndhlovu from Zambia gave a very simple but well presented paper showing under-recording and under-treatment of pain in a surgical ward. Eseenam (Dr Anita Agbeko) from Ghana gave an excellent reflective paper describing the necessity for continuing mentoring by herself and the team to other members of staff to boost their confidence to do palliative care. Our final bursary winner was Dr Meshak Liru from Kenya who gave a very illuminating paper on the physical and social problems of children with sickle cell disease. Another of our mentees from Accra, Ghana, Dr Mawuli Gyakobo gave an excellent presentation on ‘Perceived barriers to opioid availability in Ghana’.

Other memorable sound bites from the concurrent sessions were:

Joan Marston from South Africa on paediatric palliative care: “Don’t forget the children” and encouraging us to all do “just one more thing” to close the gap for children in need of palliative care.

Paul Mmbando from Tanzania on paying for palliative care services: “There is a huge difference between being willing to pay and able to pay”

Keri Thomas of Gold Standards Framework asking the question: “Would you be surprised if this patient died in the next year?” in order to give a better standard of care to patients possibly in their last year of life.
Andrew Amata from Trinidad and Tobago, described a perfect mobile health care including palliative care on Tobago. Why don’t we all retire there?

Dr Nahla Gafer from the Sudan gave a superb paper entitled ‘Palliative care, together with active treatment, offers the best chance for patients with metastatic cancer.’ Afterwards she described huge difficulties as the Ministry of Health forbade her to come to the conference at the last moment and she was fearful of what would happen on her return.

Prof Julia Downing gave an evaluation of the Integrate project showing how successful this was in integrating palliative care into the national health systems in the four African countries involved. Liz Grant, almost at the same time but in a different room, presented the emergent frameworks from 12 models of palliative care in the same four countries.

There were 112 posters from 22 countries. Two were from PCW mentees. Edgar (Tanzania) with how palliative care helps the generation born with HIV, and Ishita (Maharashtra, India) with a comparison of palliative care needs in HIV patients on two continents.

For PCW trustees, the meeting of old friends, updating and networking with our mentees from many places, and planning the way ahead for our future projects in Ethiopia, Ghana, Kenya, Rwanda and Tanzania was a very valuable experience. The colourful Gala Dinner with the energetic African dancing and many very colourful national costumes, the launch of the all-important Ann Merriman Foundation to ensure that HAU has continued funding, and just the peaceful and beautiful surroundings of the Speke Resort Hotel made it a memorable experience.

Karilyn and Richard Collins
Bursary awards for the APCA conference

In a new venture for Palliative Care Works we supported a number of people to attend the 5th International African Palliative Care Conference in Kampala in August 2016. Financial support was available to palliative care practitioners in Africa who we had worked with in recent years.

Three bursary winners were identified; Dr Meshack Liru from Kenya presented on the Social Dimensions of Sickle-cell Disease: Unmet Palliative Care Need in Homa Bay, Kenya. Dr Liru, a paediatrician working to develop palliative care in Homa Bay, described how a large proportion of the children he cares for have symptoms of sickle cell disease. His study of 100 children between the ages of 3 and 18 interviewed children and their caregivers to try to understand the psychosocial effect of the disease. The study found that these children require further support and psychosocial palliative care input.

Ms Prospellina Ndhlovu, from Zambia presented a study on the Assessment of Pain in Cancer Patients in the Male Surgical Ward at Ndola Central Hospital. This retrospective study used analysis of patient records; the findings indicated that documenting pain assessment was often incomplete and inadequate. Prospellina called for a more systematic approach to pain assessment in the hospital.

Dr Anita (Essannam) Agbeko, a surgeon from Kumasi, Ghana, presented on Palliative Care Training as a Process Not an Event. In this session she highlighted the importance on on-going mentorship and support for those health and social care practitioners trying to develop their palliative care skills and knowledge. This study involved interviews with six clinicians; the participants felt inadequate and had a tendency to avoid discussing delicate issues with their patients for fear of aggravating the distress of their patients.
Mr Edgar Ngelangela from Tanzania submitted a poster on *How Palliative Care can help a generation born with HIV in Muheza District.*

He just missed the award of a full bursary, though we were able to assist his attendance at the conference.

The PCW Trustees would like to congratulate all the bursary winners on their hard work, excellent presentations and their passion for palliative care in their countries. We look forward to working with you in the future and seeing palliative care services in your countries develop.

*Jane Appleton*
A Brief History of ...Us!

It’s really all Winston Churchill’s fault!

In 2006, I was awarded a Winston Churchill Travelling Fellowship which enabled me to visit six countries in Africa in early 2007 to investigate, among other things, the impact of palliative care training on day to day practice. Spending time with nurses, social workers, doctors and others who were passionate about palliative care, and doing their best to run services with very few resources, was extremely humbling. And it was clear that the need for training and support at all levels was substantial.

I had already been thinking of what I might do once I left teaching palliative care at Oxford Brookes University, and as I travelled around to Botswana, Uganda, Kenya, Tanzania, Malawi and Zimbabwe, the idea of continuing to do some education or training in Africa steadily took root. I soon abandoned the notion of a ‘one-man band’, as it was clear that I needed someone who enjoyed computer work much more than I did – so Stephen came on board. We talked our ideas over with Ruth (Wooldridge) and then with Oxford Brookes colleagues at the APCA conference in Nairobi later in the year; and in February 2008, seated around a kitchen table, some six or seven of us we held our first proper meeting. By the end of the day we had given ourselves a name, set up a website and each put £50 in the kitty. We had lift-off!

Now, in 2016, we are a Charitable Incorporated Organisation, with eleven Trustees and a bank balance of rather more than three figures. We have worked with the Princess Diana Memorial Fund, Tearfund, AfrOx, Cairdeas and the University of Edinburgh, delivering Toolkit workshops, Training of Trainers, and face-to face mentoring, in both East and West Africa. Most recently, we were contracted by WHPCA to review and update the Palliative Care Toolkit (whose authors are all PCW Trustees), and our current plans include a two-to-three year programme in Ethiopia, and pro bono work focusing on children’s palliative care, in Homa Bay, Kenya.

We are small, and probably not perfectly formed, but, like Topsy, we have ‘growed’, and we look forward to continuing to contribute in some small way to advancing palliative care in resource-poor situations.

Gillian Chowns

Palliative Care Works – a Charitable Incorporated Organisation

Trustees: Jane Appleton, Helen Bennett, Charlie Bond, Gillian Chowns, Stephen Chowns, Karilyn Collins, Richard Collins, Vicky Lavy, Michael Minton, George Smerdon, Ruth Wooldridge

Associates: Charles Campion-Smith, David Oliviere, Hannah Parks, Rina Patel, Fiona Rawlinson.