

# PCRS

Palliative Care Research Society

## Palliative Care Research Society Newsletter

Issue 22 July 2008

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### End of life decision making conference: dilemmas and directions

The PCRS and the Cancer Experiences Collaborative are pleased to announce their forthcoming conference focusing on end of life decision making.

The conference will be held on Tuesday 27<sup>th</sup> January, 2009, at the Holiday Inn, Birmingham. Speakers include: Professor Luc Deliens, Head of the End of Life Care Research Group, Vrije Universiteit, Brussels, Simon Chapman, Ethics Advisor, National Council for Palliative Care, London, Dr Simon Conroy, Senior Lecturer/Geriatrician, University of Leicester Medical School, Professor David Jones, School of Theology, Philosophy and History, St Mary's University College, London and Professor Clive Seale, School of Social Sciences and Law, Brunel University of West London.

Abstracts by 30<sup>th</sup> October 2008 for workshops and posters are invited in the areas of: ethical dilemmas in clinical care at the end of life; educational aspects; philosophical and cultural studies; research into end of life decision-making.

Please see <http://www.pcrs.org.uk/events.php> to register for the conference and/or submit an abstract. Delegate rate: £85 (£75 for PCRS/CECo members £50 for PG students) or £100 to include PCRS membership. For further information, contact: Prof Jane Seymour, University of Nottingham. Email: jane.seymour@nottingham.ac.uk Tel: 0115 82 31202

### Forthcoming conferences and study days

#### **Delivering the End of Life Care Strategy**

This conference provides an important opportunity to learn about how the End of Life Care Strategy will be delivered.

Delivering the End of Life Care Strategy. It's on the 11<sup>th</sup> September 2008, at 76 Portland Place, London from 10.15 to 17.00. Prices from £290. See [http://www.healthcare-events.co.uk/conf/uploads/brochures/159\\_20080512-162249\\_End\\_of\\_life\\_Sept.pdf](http://www.healthcare-events.co.uk/conf/uploads/brochures/159_20080512-162249_End_of_life_Sept.pdf) for details

### **Prognostication: The Most Frequently Asked Question?**

11 September 2008, St Christopher's Hospice, London

This study day will look at some of the tools that are emerging to provide measures of prognosis across a range of diseases. How successful are they and what can we hope for in the future? Given the current limitations of our ability to forecast prognosis accurately, the day will also consider how we can best help patients and those close to them to cope with uncertainty—and how our services manage it for themselves. For More Information and to Book Online: [www.stchristophers.org.uk/education](http://www.stchristophers.org.uk/education).

### **17<sup>th</sup> International Congress on Palliative Care**

The programme for this event is now available on the congress website at [www.pal2008.com](http://www.pal2008.com). The congress is held from 23<sup>rd</sup> – 26<sup>th</sup> September 2008 in the Palais des Congres in Montreal, Canada. Bringing together over 1500 participants from around the world, the Congress provides an opportunity to review and share the latest developments in research as well as perspectives on end-of-life care from different cultures, spiritual traditions, and professions.

### **Spirituality in Palliative Care**

This LOROS event will be held at Launde Abbey, Leicestershire on the 8<sup>th</sup>, 9<sup>th</sup> and 10<sup>th</sup> October 2008. The conference offers delegates the opportunity to reflect on the meaning of spirituality to them, both personally and professionally. Price from £100 for a day delegate. For more information visit [www.loros.co.uk](http://www.loros.co.uk) or e-mail [education@loros.co.uk](mailto:education@loros.co.uk).

### **Delivering effective end-of-life care: developing partnership working**

This joint Kings Fund/Marie Curie and National Council for Palliative Care conference will highlight key challenges for implementing the End of Life Care Strategy, identify areas for collaborative working across health and social care, and look at how to develop effective service delivery. The conference takes place on the 15<sup>th</sup> October 2008 from 9.30 – 16.15 in London. Price from £200. For more information visit their website at [http://www.kingsfund.org.uk/events/endoflife\\_care.html](http://www.kingsfund.org.uk/events/endoflife_care.html)

### **Palliative Care in 3D: 'diversity, dilemmas, and difficulties'**

A two day conference organized by the Royal Society of Medicine in association with St Catherine's Hospice, Scarborough. from Tuesday 14<sup>th</sup> to Wednesday 15<sup>th</sup> October 2008 at The Spa Complex, South Bay, Scarborough, North Yorkshire YO11 2HD. Costs for places vary depending on profession/status. For further details see email: [joyce.achampong@rsm.ac.uk](mailto:joyce.achampong@rsm.ac.uk) or to book online direct, please visit [www.rsm.ac.uk/palliativescar](http://www.rsm.ac.uk/palliativescar)

### **Reviving the Spirit within palliative care practice**

This multi-professional learning conference takes place from the 29<sup>th</sup> – 30<sup>th</sup> October 2008 at the Airth Castle Hotel, Stirlingshire. For further details see [www.strathcarronhospice.org](http://www.strathcarronhospice.org).

### **ANTEA worldwide palliative care conference**

This will be held in Rome from the 12 – 14<sup>th</sup> November 2008, in collaboration with the EAPC. The main conference goal is to outline, in a consensus conference, the core curricula for health professionals working in palliative care. For further details see [www.anteaconference2008.com](http://www.anteaconference2008.com). Abstract submission deadline 31<sup>st</sup> August 2008.

## End of life decision making

Please see the first article for details of our one day conference on end of life decision making. It will be on the 27<sup>th</sup> January 2009 in Birmingham.

### Report from the EAPC research forum

The fifth EAPC RESEARCH FORUM 2008 was held in Trondheim, Norway from 29<sup>th</sup> – 31<sup>st</sup> May 2008. As with previous EAPC research forums this was a comprehensive programme with over 1000 delegates and approx 400 posters and about 100 oral presentations over the 3 days. The social programme was also very well organised in Trondheim with the highlight for me a concert in Trondheim Cathedral. The programme consisted of both plenary and concurrent papers with themes from translational research (molecular biology to the clinic to family and children. As always it was sometimes difficult to choose which concurrent paper session to choose. The EAPC are good at highlighting poster presentations and to this end the guided poster tours and poster discussion sessions were good. As always the opportunities to network, particularly with people from different backgrounds and countries were excellent. Details of the forum can be found at <http://www.eapcnet.org/research2008/index.html> and the abstracts have been published in *Palliative Medicine* June 2008; 22 (4): pp 399 – 565. *Bridget Johnston*

### Report from the Palliative Care Congress

The 7<sup>th</sup> Palliative Care Congress was held in Glasgow from 29<sup>th</sup> April to 1<sup>st</sup> May 2008 and attracted 590 delegates. Numerous presentations and workshops reflected current issues in palliative care such as Development of Palliative Care beyond the Cancer Diagnosis, Use of Care Pathways in End of Life Care, Palliative Care within the Primary Care, Self Management and Patients' Involvement in Care Delivery, Complementary Therapies, Advanced Symptom Control, Psychosocial Care and Research Issues. Sixty Poster Presentations were displayed under two categories, Research and Clinical Innovation, in spacious halls that offered conference participants a good opportunity for viewing.

The conference offered an excellent opportunity for networking and 'catch up'. As well as being well represented by UK based academics and clinicians, the conference attracted delegates from various countries within Europe such as Norway, Denmark, Sweden, Netherlands and Spain. Delegates had also travelled as far as from Australia, Canada, New Zealand and Japan. Hosted in Scotland, the conference was opened by Elaine Stevens and included some beautiful slides presenting Scotland at its best. An attractive stage and the creative use of light contributed significantly to the atmosphere of the conference.

In the first plenary presentation, Professor Sanchia Aranda challenged the dominance of RCTs and questioned how accurately this research methodology could capture change/improvement in palliative care practice. She highlighted that while RCT is the gold standard of research methodology, its original intention was to measure drug effectiveness that focuses on outcome measures rather than the effectiveness of a process. She argued that the palliative care field must develop an enhanced research agenda. She reminded the conference participants that even Archie Cochrane himself when a prisoner of war discovered that spiritual distress in his dying fellow prisoner could be relieved only by being held physically. This intervention was not scientifically proven but it worked. Not surprisingly, it became evident that the plenary stimulated lots of discussion amongst the delegates.

An example of a well facilitated and informative workshop was Dr Craig White's workshop where he introduced the use of Distress Assessment System implemented within the Ayrshire and Arran Health Board. This approach assesses the distress experienced by patients with palliative care needs. Systematic distress assessment has the potential to enhance practice by giving a structure to significant conversations that otherwise may be hard to initiate.

I am sure all delegates would agree that overall this was a very memorable conference. Well done to all those who organized it so successfully!! Details of the congress can be found on their website at <http://www.pccongress.org.uk/welcome.php> and abstracts from the congress have been published in Palliative Medicine June 2008; 22 (4): pp 567-603. *Erna Haraldsdottir*

## Long-term neurological conditions and palliative care

The National Council for Palliative Care, British Society of Rehabilitation Medicine, and Royal College of Physicians have produced new guidelines for long-term neurological conditions, entitled Long-term neurological conditions: management at the interface between neurology, rehabilitation and palliative care. These guidelines build on the Quality Requirements in the National Service Framework for Long-term (Neurological) Conditions (LTNCs) to explore the interaction between specialist neurology, rehabilitation and palliative care services, and how they may best work together to provide long-term support for people with LTNCs and the family members who care for them. The guidelines also provide practical advice for clinicians when caring for someone with an LTNC, as well as outlining indications for specialist referral. For more details, including how to order, please see <http://www.rcplondon.ac.uk/pubs/brochure.aspx?e=244>

## The Doyle Club and PCRS

The Doyle Club is part of the Association for Palliative Medicine. It is a forum for doctors undertaking specialist training in palliative medicine, for representation, information-gathering and networking. With the new curriculum for specialist training, all registrars are now required to be involved in research, but this can be difficult to achieve in isolation and in relatively short-term training posts.

The Palliative Care Research Society is an excellent forum to support research involvement and can support training doctors in getting involved in research. A representative from the Doyle Club is elected to provide liaison and improve communication between the two organisations – this is a valuable link which has been helpful in both directions in the past. The present Doyle Club representative is specialist registrar Louise Mason, who is a co-opted member of the PCRS committee. If you have networking ideas or would like to make contact about PCRS/Doyle Club issues, Louise can be contacted on [louise@louisemason.com](mailto:louise@louisemason.com)

## Re-launched PCRS website

Please check out our brand new website at [www.pcrs.org.uk](http://www.pcrs.org.uk). We've had a complete redesign to make it easier for you to find all sorts of information about the PCRS including details of our forthcoming events, abstract submission, past newsletters and more. Make sure you've bookmarked it at [www.pcrs.org.uk](http://www.pcrs.org.uk)! If you've any feedback about the website, please contact Catherine Walshe at [catherine.walshe@manchester.ac.uk](mailto:catherine.walshe@manchester.ac.uk).

## Joining the PCRS

The society is easy to join, with full details and an on-line form on the website at [www.pcrs.org.uk](http://www.pcrs.org.uk). Membership costs just £30 per year and benefits include:

- Reduced registration fees for some of the conferences organised, or jointly organised by the PCRS (note: individuals who are considering attending at least one such conference during the year will often find it

economically advantageous to join the PCRS simply in order to benefit from the reduced conference fee).  
Note: this does not apply to every conference.

- Access to a list of members' contact details and research interests to facilitate multi-professional and multi-centre research initiatives.
- PCRS newsletters.

**For general enquiries**

Dr Marilyn Kendall  
Research Fellow  
Primary Palliative Care Research Group  
Division of Community Health Sciences:  
GP Section 20 West Richmond Street  
Edinburgh  
EH8 9DX

[marilyn.kendall@ed.ac.uk](mailto:marilyn.kendall@ed.ac.uk)

**For membership enquiries**

Dr Gail Eva  
Sobell Study Centre  
Churchill Hospital  
Headington  
Oxford  
OX3 7LJ

[gail.eva@ndm.ox.ac.uk](mailto:gail.eva@ndm.ox.ac.uk)

**Items for the newsletter:** Dr Catherine Walshe, [catherine.walshe@manchester.ac.uk](mailto:catherine.walshe@manchester.ac.uk), 0161 306 7649