

Annual conference 2011: Thinking ahead in palliative care

This year's conference took place at the Royal College of Physicians of Edinburgh on Thursday 6 October 2011. Around 220 people attended and preliminary evaluations indicate that the programme was very well received. A summary of conference presentations and workshops is provided below.

Advance care planning in dementia – will it make a difference and how?

Professor Julian Hughes, Honorary Professor of Philosophy of Ageing and Consultant in Old Age Psychiatry

Julian Hughes explored different models of care and how these relate to dementia care and advance care planning, highlighting some of the difficulties associated with advance care planning in dementia. He then considered some of the literature, which indicates that though dementia is seen as a barrier to advance care planning, people with dementia are more likely to receive palliative care if they have been able to participate in advance care planning. He finished by exploring 'personhood' in dementia, and the ethical and practical implications this has for palliative care including advance care planning.

COPD: planning for the end in a lifelong condition

Dr Hilary Pinnock, Senior Clinical Research Fellow, University of Edinburgh

Hilary Pinnock highlighted a study which contrasted the experiences of living with a diagnosis of COPD with living with a diagnosis of lung disease. Though health studies indicate that that people with COPD have on average worse health than people with lung cancer, people with COPD generally have less to say about their illness and access fewer services. It was suggested that, having had no defined diagnosis or 'starting' point, COPD is generally experienced as a 'way of life' rather than an illness. This, alongside the clinical features of COPD, has implications for advance care planning, since it is difficult to define a point when one should start to think about/plan for death, and people with COPD have a 90% chance of returning home after an emergency hospital admission due to an exacerbation.

Advance Care Planning: How is it for you?

Dr David Oxenham, Medical Director, Marie Curie Hospice Edinburgh

David Oxenham led an interactive session using digital polling technology to explore delegates' views on, and experiences of, advance care planning.

The nature of hope during palliative care

Dr Jeremy Keen, Consultant in Palliative Medicine, Highland Hospice

Jeremy Keen explored attitudes to hope and the role of hope in medicine over the ages and in the personal lives of clinicians and patients. In times and places when advanced medicines have been unavailable, or where a person is becoming more sick despite medicines, engendering hope can be a main role of the clinician, and can have concrete effects on a person's physical or emotional wellbeing. However, preserving false hope may make for more pain in the future. It was suggested that people can shift their hopes depending on their circumstances, and that it is important that clinicians recognise the importance of hope in their own lives and in the lives of patients.

Supporting each other in the age of austerity and social media

Dr Alex Jadad, Rose Family Chair in Supportive Care, Chief Innovator and Founder, Centre for Global eHealth Innovation, University of Toronto

Alex Jadad discussed the potential benefits that social innovations such as Facebook, Skype, and mobile phones can have for healthcare, and the need for the palliative care community to be aware of and make use of these innovations for the benefit of patients. He gave examples of how he uses social media within his own clinical practice internationally. He mentioned the need to be aware of and integrate into practice other relevant changes, highlighting for example a proposal that the WHO definition of health should be altered to emphasise the importance of adapting and self managing in the face of social, physical and emotional challenges. He also highlighted the internet as an information tool, the opportunities it provides for 'prescribing of information', and the importance of Wikipedia as many people's first port of call for information.

20 takes on death, dying and bereavement

Delegates viewed an exclusive preview of a short film which presented members of the Scottish public talking about death, dying and bereavement. The film was commissioned by *Good Life, Good Death, Good Grief*, the new Scottish alliance to promote more openness about death dying and bereavement.

Breakout Session A: Google, and Facebook, and Twitter... Oh my! What skills do we need in the second decade of the 21st Century?

Dr Alex Jadad, Rose Family Chair in Supportive Care, Chief Innovator and Founder, Centre for Global eHealth Innovation, University of Toronto

Alex Jadad reflected on the skills we need to be comfortable operating in the 21st century. In a highly interactive session he gave delegates an overview of internet innovations such as: Alexa, Google, Facebook, Twitter and Zotero. The power of social media is that you can build on the collective knowledge of other people. He suggested that not only can taking full advantage of freely available online functions save time and money, but that the advancement of social media is unavoidable so we need to understand it and attempt to harness its benefits.

Breakout Session B: So What about us?

Ros Scott, Director of Organisational Development, Children's Hospice Association Scotland

Alison Blair, Activities Co-ordinator, Children's Hospice Association Scotland

Ros Scott and Alison Blair explained the work of Children's Hospice Association Scotland (CHAS), and the need to find ways of adapting services to accommodate the needs of young people as they grow older and become adults. They explained that CHAS is working to form partnerships with other organisations in order to fulfil the needs of young people. Delegates were encouraged to think of ways in which their organisation might be able to help in meeting the needs of young people, how their service might be able to adapt to meet these needs, and what barriers there may currently be to young people accessing their services.

Breakout Session C: It's not just about medicines!

Janet Trundle, Macmillan Specialist Pharmacist in Palliative Care together with other members of the NHS Greater Glasgow and Clyde Macmillan Pharmacist Facilitator Team

Janet Trundle shared developments from the 3-year Pharmacist Facilitator Project currently underway in NHS Greater Glasgow and Clyde, where Macmillan Pharmacist Facilitators have been established to help further develop community pharmacy capacity and improve service provision/co-ordination through the enhanced support of Community Pharmacy Palliative Care Networks. She gave delegates real-life scenarios illustrating examples of gaps in, and issues relating to, current service provision. Participants were then asked how these scenarios could be improved/avoided by considering communication, information, carer support and anticipatory care.

Breakout Session D: A vision for the future of Palliative and End of Life Care

Adrienne Betteley, Palliative and End of Life Care Programme Manager, Macmillan Cancer Support

Diana Hekerem, Head of Partnership, Commissioning and Development, Marie Curie Cancer Care

Adrienne Betteley described some of the past, present and future work of Macmillan Cancer Support. Diana Hekerem spoke about Marie Curie Cancer Care, focusing particularly on the work they are undertaking in partnership with other organisations. Both speakers emphasised the importance of different organisations working together towards common aims, and delegates were encouraged to consider questions relating to partnership working with the voluntary sector.

Having the last laugh – Clowning and Dementia

Magdalena Schamberger, Artistic Director and Chief Executive, Hearts and Minds

Magdalena Schamberger gave a presentation about the work of the Elderflowers, who use the performing arts to overcome challenges in communication with elderly people affected by dementia. She explained that the Elderflowers concentrate on the present not the past, and are able to connect with the essence of a person with dementia. She showed a film illustrating the evident enjoyment of people with dementia interacting with the Elderflowers. The presentation was followed by an entertaining interactive performance by the Elderflowers themselves.

Social attitudes and palliative care – prospects for transformational change?

Professor Phil Hanlon, Professor of Public Health, University of Glasgow and Vice Chair, Accord Hospice

Phil Hanlon discussed the gradual separation of the once ingrained cultural notion of “the good, the true, the beautiful”, and the resulting modern world where superficial financial aspects are considered first and foremost with insufficient balancing regard to other factors. The hospice movement provides an ‘oasis in modernity’, where ‘the good, the true and the beautiful’ are still intact in theory and in practice. He suggested that the rest of the society needs to re-discover this balance if we are to create a health service where health professionals aren’t ‘frazzled’ and that is fit for purpose for the changing economic, social and environmental circumstances that are inevitably on their way.