

09:45-10:00
Official Opening of Congress by
Professor Ian Gilmore
President, Royal College of Physicians

Professor Ian Gilmore is the President of the Royal College of Physicians. He is a Consultant Physician and Gastroenterologist at the Royal Liverpool University Hospitals and Honorary Professor at the Department of Medicine, University of Liverpool. His specialty interest is liver disease.

Professor Gilmore was previously Registrar of the College and a member of Council. He chaired a Working Party in 2001, producing the report *Alcohol – can the NHS afford it? A blueprint for a coherent alcohol strategy*. Professor Gilmore continues to chair the Alcohol Committee and now also chairs the Alcohol Health Alliance in which relevant agencies work together in a coherent and focussed framework. He is Chair of the European Alcohol and Health Forum Science Group and is a member of the Climate and Health Council.

He is currently a Commissioner for Sir Michael Marmot's review of the social determinants of health in this country and a member of the National Quality Board. He has lectured extensively overseas and has had particularly fruitful clinical and research collaborations with American colleagues. He continues to undertake some clinical work.

Professor Gilmore is married with three children.

11:30-12:20

International initiatives: learning from developing countries

Rosemary Kiwanuka

Palliative Care Association of Uganda

Professional training: BSN, Aga Khan University Kampala; Dip Palliative Care, Makerere University Kampala; DBA, London Executive Business College UK; Certificate in Palliative care, Hospice Africa Uganda; URN, Uganda Nursing Council.

The first Ugandan Palliative care Nurse – Has 14 years of experience in Palliative care. Worked with Hospice Africa Uganda from 1994 – 2005. Participated in developing curriculum for Health care and non Health care Professionals, Medical and Nursing Schools. Supported Malawi and Tanzania to develop a training curriculum for health care workers. Provides technical assistance in educational and advocacy to other African countries ie Uganda, Tanzania, Malawi, Botswana, Ivory Coast. She also provides technical assistance to local organisations providing palliative care.

Authored the Sexuality chapters in A Clinical guide to Supportive and Palliative Care for HIV/AIDS in Sub Saharan Africa, 2006 Edition.

Currently she is National Coordinator Palliative Care Association of Uganda a post she has held for three years (January 2006 to date).

Title: The Role of the National Association: Experiences of the Palliative Care Association of Uganda

Introduction: Palliative Care Association of Uganda (PCAU) supports and promotes the development of palliative care throughout Uganda. It is a membership association that brings together organizations and individuals involved in palliative care. PCAU plays a national coordination role for palliative care in partnership with the Ministry of Health of Uganda. This has enhanced the scale up of palliative care, in regard to training and education, standards and service delivery including accessibility to pain medications.

Issues: As member organizations continue to train health, allied and non-health professionals to deliver palliative care, PCAU faces the challenge of ensuring that trained service providers are mentored supported and access on-going education. PCAU ensures that health facilities are able to access pain medications including opioids. Advocacy with health administrators to support palliative care provision, following the training of their health workers is another responsibility. Fledging palliative care services have to obtain organizational development support from PCAU, including structure and systems set up.

Description

With limited resources, PCAU is using creative approaches to support all above functions, with technical and logistical support from MoH and member organizations. MoH volunteers transport for support supervision to district services and member organizations provide technical support. However, without constrained resources PCAU is unable to all the support required. Demand for practical support from trained health workers is overwhelming, while opiophobia among health workers remains an issue. Services across the country expect financial support from the national association, yet its also financially struggling.

Lessons and recommendations: Working with MoH as a key partner has enhanced national scale-up. Support from health administrators must be ensured for trained health workers to deliver services. It is essential to establish countrywide communication networks. Taking palliative care to the local level through district facilities facilitates scale-up.

Dr Mhoira Leng

Palliative care is a global philosophy and a health care right. However many parts of the developing world do not have access to the most basic support and care. Most of the world's oral morphine is consumed in a small number of developed countries with many millions without access to strong analgesia. The needs are overwhelming especially when measured alongside poor economic growth and development. Different models of care exist with many skilled, committed and enthusiastic colleagues giving leadership. What is the overall picture of global palliative care? What are the key challenges in developing world palliative care? What lessons can UK palliative care glean? How can we improve our mutual learning? How can we work in partnership to ensure palliative care for all? These questions will be addressed with an overview and specific lessons from India and Africa.

11:30-12:20

Paediatric palliative care in the primary care setting: How Specialist Palliative Care can help.

Dr Lynda Brook

Macmillan Consultant in Paediatric Palliative Care

Alder Hey Children's Hospital

Dr Satbir Singh Jassal

Medical Director

Rainbows Children's Hospital

The average a GP will provide end of life care to a child dying at home only two or three times in his or her entire career. It is therefore not surprising that the possibility of having to provide direct support paediatric palliative care at home is viewed by many as difficult and anxiety provoking.

This presentation will review the three tools developed for the End of Life Programme for adults: The Liverpool Care Pathway for the Dying, the Gold Standards Framework and the Preferred Priorities for Care Document. We consider the relevance of each of these tools to paediatric palliative care. We then present examples of how these tools have been adapted for use in paediatric palliative care emphasising the similarities and important differences between their application in paediatric versus adult end of life care.

Providing end of life care to a child dying at home is an unusual challenge for most General Practitioners. However remembering the basic principles of good palliative care and adapting familiar end of life care tools can do much to alleviate this anxiety and ensure that every child dying at home receives the best possible end of life care: getting it right first time, every time.

I am a full time senior partner general practitioner and medical director of Rainbows Children's Hospice in Loughborough, Leicestershire and have worked in children's palliative care for 16 years. I have written and edited the Rainbows Children's Hospice Symptom Control, am an editor of PaedPalLit an abstract journal and have written the chapter on team working in the Oxford Textbook of Paediatric Palliative Care for Children. I am Have just finished co-writing the Oxford Handbook of Paediatric Palliative Medicine. I am co-chairing the education and training subgroup of the BSSPM and ACHDoc. I have a very tolerant wife and two even more tolerant children

Dr Lynda Brook

MBChB, FRCPCH, MSc, Dip Pall Med, Dip Ethics
Macmillan Consultant in Paediatric Palliative Care
Alder Hey Children's Hospital
Liverpool

Lynda.Brook@RLC.NHS.UK

Lynda was appointed as Macmillan Consultant in Paediatric Palliative Care at Alder Hey Children's Hospital Liverpool in June 2003. She is Chair of the Merseyside and Cheshire Children and Young People's Palliative Care Clinical Network Group and Chair of the Northwest Region Children's Palliative Care Network. Lynda is also Chair of the British Society for Paediatric Palliative Medicine (the Royal College of Paediatrics and Child Health Paediatric Palliative Medicine Special Interest Group) and has been a trustee of Claire House Children's Hospice since 1999.

Lynda was one of the working party involved in the development of the ACT (Association for Children with life limiting conditions and their families) Framework for the Development of Integrated Multi-Agency Care Pathways for Children with Life-threatening and Life Limiting Conditions. She has also contributed a chapter for the Oxford textbook of Paediatric Palliative Care.

Lynda is currently leading on the development and implementation of the Liverpool Care Pathway for the dying Child with Professor John Ellershaw and his team. She has also been involved in local work developing advance care planning for paediatric palliative care. She is working with Dr Kerri Thomas, and the Pan Birmingham Paediatric Palliative Care Network undertaking exploratory work prior to the development and implementation of the Gold Standards Framework for Children.

14:00-15:00

Cogito, ergo ouch: meditations on the psychology of pain
Professor Mick Sullivan, Professor of Psychology and Medicine
Mc Gill University, Montreal, Quebec

Dr. Michael Sullivan is currently Professor of Psychology and Medicine at McGill University, and Scientific Director of the University Centre for Research on Pain and Disability. He has lectured nationally and internationally on the social and behavioral determinants of pain-related disability. He is known primarily for his research on the relation between catastrophic thinking and pain experience, and for the development of community-based approaches to the management of pain-related disability. Dr. Sullivan has published over 100 scientific papers, 12 chapters, and 4 books. He currently holds a Canada Research Chair in Behavioral Health. Dr. Sullivan obtained his undergraduate training at McGill University and his graduate training at Concordia University in Montreal.

Over the past two decades, pain catastrophizing has emerged as the most powerful psychological predictor of pain outcomes. Individuals who obtain high scores on measures of pain catastrophizing experience more intense pain, are more likely to develop mental health difficulties and show more pronounced pain-related disability. Recent research also shows that pain catastrophizing is a prognostic indicator for poor surgical outcomes and poor response to analgesic medication. This presentation will provide a brief summary of what is currently known about the negative impact of pain catastrophizing, and the mechanisms by which pain catastrophizing influences pain outcomes. The presentation will also describe novel interventions designed specifically to target pain catastrophizing in order to improve the health and mental health outcomes of individuals suffering from persistent pain.

15:30-1630

How to involve users in service development and research

Dr Marilyn Kendall, Research Fellow, University of Edinburgh

Marilyn Kendall is a Research Fellow in the General Practice Section of the University of Edinburgh. Having completed a Ph.D. concerned with service users' experience of severe mental illness, she has since worked with patients, and their carers, in the last year of life on a number of community based palliative care studies. She has a particular interest in narrative inquiry and service user involvement in research.

Mr David Ardron

Chair NCRI Consumer Liaison Group

David has worked widely in consumer affairs in lung cancer research now for five years. Both of his parents were cancer patients, his father with lung cancer and his mother with breast cancer. He is chair of the North Trent Cancer Research Network Consumer Research Panel and acting vice chair of the North Trent CN Patient Partnership Group. He is also a member of NCRI Lung Cancer Clinical Studies Group, and Chair of the NCRI Consumer Liaison Group. He was a member of the NCRI PET Scanning Research Strategic Planning Group. He sits on the trial management group for the MRC QUARTZ trial in Lung Cancer. He is interested in the practical role that local consumer research panels have to play in health research, and has been invited to describe the work of the North Trent Panel at many meetings and conferences. He engages in peer review, both for network cancer services, and national research applications. His background is in science teaching and computer literacy. He sits as a member of other National Cancer Initiatives including, NICE, NCIN, and the National Lung Data Audit.

Thursday 11th March 2010

08:00-08:50

Getting going with research

Dr Bee Wee

Senior Clinical Lecturer in Palliative Medicine

Sir Michael Sobell House, Oxford

Dr Marilyn Kendall

Research Fellow

University of Edinburgh

Dr Bee Wee is Consultant and Senior Lecturer in Palliative Medicine at Sir Michael Sobell House, Fellow of Harris Manchester College and Associate Director of Clinical Studies at Oxford University, and Head of the Oxford WHO Collaborating Centre for Palliative Care. Originally from Malaysia, she trained in Ireland and worked in Hong Kong before being appointed Consultant/Senior Lecturer in Palliative Medicine and, later, Deputy Director of the Medical School, Southampton University. Whilst working as a full-time consultant, she undertook her PhD on death rattle (awarded 2003) so she has experienced first-hand the struggles of juggling the conflicting demands of clinical, teaching and research commitments.

Her research interests continue in the area of living with disability in end of life care. She co-edited, with Nic Hughes, an OUP publication "Education in Palliative Care: Building a Culture of Learning" (2007).

In 2009, she was appointed the national Clinical Lead for e-learning in end of life care for the Department of Health (www.e-elca.org.uk). She takes up the two-year Presidency of the Association for Palliative Medicine of Great Britain and Ireland in March 2010.

In her spare time, she walks, punts, cooks and enjoys the many pleasures of Oxford!

Marilyn Kendall is a Research Fellow in the General Practice Section of the University of Edinburgh. Having completed a Ph.D. concerned with service users' experience of severe mental illness, she has since worked with patients, and their carers, in the last year of life on a number of community based palliative care studies. She has a particular interest in narrative inquiry and service user involvement in research.

Thursday 11 March 2010

08:00-08:50

Challenges and opportunities for palliative care in the community

Professor Scott A Murray

Columba's Chair of Primary Palliative Care, University of Edinburgh

Five key challenges that face palliative care in the next decade will be outlined, and ways of meeting these challenges effectively in the community will be illustrated.

These challenges are

- 1) palliative care for all, extending beyond cancer to all diagnoses
- 2) palliative care from diagnosis of a life-threatening illness, not just in the terminal stage,
- 3) concern for all dimensions of need, not prioritizing the physical,
- 4) palliative care in all settings, especially in generalist settings such as home, homes and hospitals
- 5) palliative care for all, including resource-poor settings.

The masterclass will examine practical ways that palliative care specialist nurses and doctors, and general practitioners and community nurses might take these opportunities forward through clinical care, quality improvement and research.

Scott is a practising general practitioner and also leads the Primary Palliative Care Research Group which is a multi-disciplinary team based at the University of Edinburgh. This group seeks to understand the experiences of patients with life limiting illnesses and their carers, and to develop, test and advocate for best models of holistic care throughout the last year of life. Their strategic focus is on people with organ failure (such as heart failure and COPD) and the frail elderly, as well as on cancer; and on interventions which can deal with multiple dimensions of need, including spiritual or existential issues.

Scott is a clinical research advisor to the BMJ where he is currently leading a "Making a difference campaign" for all people at the end of life. Together with Dr Stephen Barclay from Cambridge he chairs the International Primary Palliative Care Research Group, and regularly visits African countries, where he used to work, to conduct training, service evaluation and research there.

Thursday 11 March 2010

09:00-10:00

The Abe Guz Lecture – Deconstructing dyspnoea to improve everyday practice

Professor David Currow

Professor of Palliative and Supportive Services

Flinders University,

Breathlessness remains one of the most feared symptoms in clinical practice. The sense of overwhelming doom generated by severe breathlessness needs to be actively and effectively addressed.

Unlike most other symptoms, it continues to worsen as death approaches. It has a major impact on patients, their carers and their health professionals.

The burden of breathlessness across the community is significant and most clinical services other than palliative care fail to address the symptom while simultaneously addressing any potentially reversible causes. As such, other clinical services have a great deal to learn from hospice and palliative care services.

Breathlessness is a complex somato-psychic experience. As such, anything that can influence the generation, transmission, meaning or response to the stimuli that caused the perception of breathlessness can theoretically help to relieve breathlessness. Understanding the underlying pathophysiology is crucial in addressing breathlessness at the bedside.

Underlying causes for breathlessness include cardio-respiratory disease, neurological disease and cachexia. Understanding the burden of breathlessness in the palliative population, and in the population more broadly across the community is crucial for good palliative care.

Non pharmacological interventions are being rigorously evaluated in their ability to generate and maintain reduced breathlessness at rest or on minimal exertion. Pharmacological interventions (including oxygen) are being rigorously evaluated. There is level 1 evidence for the use of opioids in this setting.

Professor David Currow is currently the foundation Chief Executive Officer of Cancer Australia, the Australian government's national cancer control agency. He continues to hold the appointment of Professor of Palliative and Supportive Services at Flinders University, Adelaide, Australia.

David initially trained as a physician in internal medicine with sub-speciality training in palliative medicine. At the same time, he completed a Master of Public Health exploring changes in the reported incidence of cancer unknown primary in New South Wales over a 25 year time period. Former roles include foundation Director of the Nepean Cancer Care Centre, Sydney and Area Director of Palliative Services Wentworth Area Health Service, Sydney. Since 2000 he has had the Chair of Palliative and Supportive Services at Flinders University where there are more than 200 distance students studying at a post-graduate level around the world from a variety of discipline backgrounds. He has published widely in palliative care journals and the general medical literature. Among other projects, he is co-chief investigator on an anthology of evidence for palliative care practice and service delivery – www.caresearch.com.au Other research interests include the symptomatic management of dyspnoea, improving population based planning for people with life limiting illnesses and improving the evidence base around which clinical decisions are made in palliative care.

David holds grants from the National Health and Medical Research Council and the National Institutes of Health (USA). He continues on the Board of the International Association of Hospice and Palliative Care and has been on the American Society of Clinical Oncology (ASCO) taskforce on palliative care education. He is a former president of the Clinical Oncological Society of Australia and a former president of Palliative Care Australia, the peak body for palliative care in the country. He is a senior associate editor of the Journal of Palliative Medicine.

Thursday 11 March 2010

10:45-11:45

Dying with diabetes

Professor David Kerr

Consultant Physician and Visiting Professor

Bournemouth Diabetes and Endocrine Centre

Dr David Kerr MD FRCPE is Consultant Physician and Diabetologist at the Bournemouth Diabetes and Endocrine Centre (www.b-dec.co.uk). He is also Honorary Senior Lecturer at the University of Southampton and Visiting Professor at Bournemouth University. As part of this latter position he is the lead member for clinical research at the newly established Post Graduate Medical Research and Education Centre.

As well as providing clinical service in Internal medicine and Diabetes, Dr Kerr runs one of the largest insulin and glucose sensor programmes in the UK. His research interests include the use of technologies in diabetes care, the problem of hypoglycaemia and the prevention of obesity in children and young adults. As a Scotsman seeking to educate his English neighbours on the important things in life, Dr Kerr also has a long-term research interest in the physiology of pleasurable pastimes including the use of alcohol and caffeine.

Dr Kerr is Editor of Diabetes Digest, Co-Chair of the Insulin Pump Association and Co-Founder of the UK Diabetes National In-patient Network (DINN). Outside of work his main aim in life is to improve his embarrassingly bad golf handicap and stay in his current squash league, the standard of which is well-above his own.

Thursday 11 March 2010

10:45-11:45

Children: Different – but the same species. The evidence base for paediatric palliative care

Dr Richard Hain

LATCH Senior Lecturer and Honorary Consultant in Paediatric Palliative Medicine

University Hospital Wales

Mr Nigel Ballantine

Lead Cancer Pharmacist, Birmingham Children's Hospital

Two equal and opposite errors can be made in relation to specialist palliative medicine in children. The first is that children are so similar to adults that a thorough understanding of paediatrics is unnecessary. The second is that children are so different that what we already know about palliative medicine in adults is of no value.

In reality, though the practice of palliative medicine in children is unquestionably a paediatric specialty, the evidence-base on which it is built still comes largely from adults. A good practical knowledge of this therapeutics base is an essential grounding in paediatric palliative medicine.

This workshop will consider how much truth there is in the fundamental assertion and article of faith among paediatricians that 'children are not small adults', looking in particular at the development of pharmacokinetics over the course of childhood and using opioids as an example.

Richard Hain is Senior Lecturer in Paediatric Palliative Medicine at Cardiff University School of Medicine. His clinical training was in adult palliative medicine, paediatrics and paediatric oncology. His academic background was in pharmacology, particularly of opioids in children. His current research interests include opioids in children and epidemiology of paediatric palliative care. He has written a number of research and review articles, is an editor of the Oxford Textbook of Palliative Care in Children and Co-author of other chapters and textbooks including the Oxford Handbook of Palliative Medicine in Children.

Thursday 11 March 2010

14:00-15:00

Public health and Palliative care: International developments

Professor Allan, Kellehear

Professor of Sociology and Head of the Department of Social & Policy Sciences

Public health approaches to end of life care are new to many of us in palliative care. Employing health promotion and community development strategies in the context of a clinical service devoted to end of life care has seemed to some people as complicated at best and counter-intuitive at worst. Nevertheless, these approaches are proving increasingly popular and are rapidly being adopted here in the UK as well as in many countries world-wide. This partly reflects a major shift towards an interest user and community involvement at the end of life that effectively addresses the twin issues of increasing access to palliative care and continuity of care at the end of life. This presentation will describe international developments in the public health approaches to palliative care as these have emerged from the relevant health services in India, Japan, Australia, and the USA. Some observations and comparisons with developments in the UK will also be made.

Allan Kellehear is Professor of Sociology and Head of the Department of Social & Policy Sciences at the University of Bath. From 1998 to 2006 he was Professor of Palliative Care and Director of Australia's first public health palliative care unit at La Trobe University in Australia. He has held visiting professorships in Australia, Britain, Japan and Hong Kong and in 2009 was William J Clinton Distinguished Lecturer at the William J Clinton Presidential Center and Clinton School of Public Service at the University of Arkansas in Little Rock, USA.

His most recent books include 'Compassionate Cities: Public health and end of life care' (Routledge 2005); 'A Social History of Dying' (Cambridge University Press 2007) and the edited volume 'The Study of Dying: From autonomy to transformation' (Cambridge University Press 2009). He is co-editor (with Glennys Howarth) of 'Mortality', the international journal of interdisciplinary studies of death, dying and bereavement published by Taylor & Francis.

Thursday 11 March 2010

16:30-17:30

Stroke: Is it the end? – Living with uncertainty

Dr Michelle Kidd

Associate Specialist in Stroke Medicine

North Cheshire Hospitals NHS foundation Trust

Stroke: Is it the end? – Living with uncertainty

Stroke is a life-limiting illness. It may either present as a terminal event in the form of a massive stroke or repeated strokes may be part of a patient's decline over several years.

Using real-life interactive case histories the session will explore the palliative issues and ethical decision making that surrounds the care of patients dying from stroke. Topics covered will include stroke as a terminal event in vascular dementia, symptom management following massive stroke and caring for stroke victims at the end of their life in the community

Dr Michelle Kidd

I qualified from Liverpool Medical School in 1997. I was a junior doctor in the Mersey region in general medicine during which time I spent six months at the Walton Neurosciences Centre. I obtained MRCP (UK) in 2001 shortly before the birth of my first daughter. I joined the department of Medicine at Warrington Hospital, initially as a staff grade but I have subsequently been appointed as an Associate Specialist in stroke in 2007. Although at times I have covered most of the medical specialities I have always had a passion for stroke medicine and neurology. This has led to my current role on Warrington's Stroke unit. End of life care is an inevitable part of Stroke medicine and palliative medicine is a major part of my working life. I have become the lead for palliative medicine on the unit and I am engaged in a wider role within my trust looking at end of life strategy for all patients.

I work three days a week and the rest of the time I am mother of two girls and a jazz singing sensation.

Thursday 11 March 2010

16:30-17:30

Innovative Research Methods: using observation in a palliative care context

Dr Catherine Walshe, University of Manchester

Dr Jane Griffiths, University of Manchester

Dr Gail Ewing, University of Cambridge

Qualitative research using observation as a data collection method is rarely used in palliative care research. However observational work has particular strengths as it enables privileged insights into situations under study, facilitates gaining trust and cooperation of participants and permits a more direct method of data collection compared to interviews. Observation can be a very powerful tool in providing evidence that has a direct influence on clinical practice.

In this workshop we will explore reasons for using observational methods in palliative care research, give examples of when observational methods would be appropriate, and discuss roles in observational research. We will enable the translation of this theoretical work into practice through a discussion of the practical issues of using observational work in palliative care research. This is based on our recent and ongoing experiences of using observations to understand the work of district nurses in palliative care across two separate studies.

Issues that we will debate in this workshop include:

- Presenting observational work for research ethics committee approval, gate-keeping, and negotiating access to observational sites.
- Obtaining and maintaining consent from different participants, and addressing this in longitudinal observational research.
- Accessing observational opportunities and issues of availability and flexibility.
- Recording observational data.
- Practical issues such as positioning yourself as an observer in the setting, and responding to issues that arise during the observation.
- Discussing enacting different observational roles in practice, and how our professional backgrounds affect these roles.
- Integrating observational data with other study data such as interviews.
- Analytical issues such as approach to analysis, triangulation, rigour and the interpretation of observations.

By the conclusion of the workshop participants should have a greater understanding of when and how to use observational methods, and an appreciation of the practical issues in conducting such research.

Catherine Walshe is a RCUK Research Fellow/Lecturer at School of Nursing, Midwifery and Social Work at the University of Manchester. She has a clinical background in nursing, particularly community nursing.

Catherine's research interests reflect this clinical background, and her studies explore issues of primary palliative care. She is currently engaged in a series of studies funded by a 5 year RCUK post-doctoral fellowship exploring the role of district nurses in providing palliative care to patients at home.

Catherine contributes to the work of the Cancer Experiences Collaborative, is on the executive committee of the Palliative Care Research Society and the editorial board of the journal 'Palliative Medicine'.

Gail Ewing is a Senior Research Associate at the Centre for Family Research, University of Cambridge. In the last twelve years she has worked on research in palliative care. These include studies on symptoms and needs of palliative patients in primary care, circumstances surrounding death at home and the effects on family caregivers in bereavement, early support visits provided by district nurses to palliative patients at home and perspectives of palliative care in an acute hospital setting.

In the last two years Gail has been working with Dr Gunn Grande, Professor Sheila Payne and the National Forum for Hospice at Home on a follow up of their earlier work with family carers to identify key components of carer support and to develop and test a carers' support needs assessment tool for use in practice.

Gail was a member of the Help the Hospices Working Group on Carer Assessment. She is also a member the EAPC Task Force on Family Carers.

Friday 12 March 2010

08:00-08:50

Palliative Care Research – challenges, pitfalls and rewards

Dr Bridget Johnston, Senior Research Fellow, University of Stirling

Dr Marilyn Kendall, Research Fellow, University of Edinburgh

This session will look at the particular challenges, pitfalls and rewards of conducting research with people who are very ill, and their families. It will consider practical, ethical and methodological issues, including possibilities for service user involvement, at all stages of the research process. There will be opportunities for participants to share their own experiences and to discuss ways of addressing any problems and celebrating achievements

Dr Bridget Johnston BN (Hons), PGCE(FE) RGN PhD

Bridget trained as a nurse at St Bartholomew's Hospital in London. She worked at Barts as a Staff nurse in Medical Oncology before doing a full time degree in Nursing at Cardiff University. She completed her adult teaching qualification alongside the final year of her degree. Bridget was then a clinical teacher in Edgware and Barnet before taking a Macmillan Lecturers post in Cambridge. From 1995-2006 Bridget worked at Strathcarron Hospice in Stirlingshire as a Lecturer, helping set up the first Post Graduate Diploma in Palliative Nursing in Scotland at the University of Glasgow. She completed a PhD at Glasgow University in 2002. In 2006 Bridget joined the team at the Cancer Care Research Centre at University of Stirling on a 2 year post doctoral fellowship to explore the experience of patients and carers regarding end of life care through the promotion of self care as a Senior Research Fellow. She is now programme lead for the Symptom Improvement Programme.

Marilyn Kendall is a Research Fellow in the General Practice Section of the University of Edinburgh. Having completed a Ph.D. concerned with service users' experience of severe mental illness, she has since worked with patients, and their carers, in the last year of life on a number of community based palliative care studies. She has a particular interest in narrative inquiry and service user involvement in research.

Friday 12 March 2010

08:00-08:50

VTE in advanced disease

Dr Miriam Johnson

Senior Lecturer in Palliative Medicine and Honorary Consultant Hull and York Medical School, St Catherine's Hospice and Acute Trust

Dr Simon Noble

Clinical Senior Lecturer in Palliative Medicine, Cardiff University

The association between cancer and venous thromboembolism (VTE) has been recognised for over 140 years and its management of in the advanced cancer population pose several unique challenges to palliative care teams. Anticoagulation with conventional oral agents is associated with increased bleeding rates and recurrent thromboses. Newer agents such as low molecular weight heparins offer improved efficacy and safety but require a daily injection.

Whilst VTE is common in cancer, its true impact in the palliative care population is still unclear. In a specialty devoted to patient centred care, it is important at all times to use informed patient choice to guide treatment options in the palliative care setting. The role of thromboprophylaxis in a heterogeneous palliative care population is still unclear and the use of prophylaxis in the hospice setting remains controversial.

This session will aim to review the evidence for the treatment and prevention of VTE in palliative care as well as identify areas of uncertainty that require further investigation.

Dr Simon Noble is a Clinical Senior Lecturer in Palliative Medicine at Cardiff University and Honorary Consultant at the Royal Gwent Hospital in Newport. His research interests include the management of venous thromboembolism (VTE) in cancer, quality of life effects of VTE and their therapies, clinical decision making in VTE management and the patient journey. He is co investigator on the FRAGMENTIC study which is an RCT of 2200 lung cancer patients investigating the impact of dalteparin on survival in lung cancer patients and is co director of the Thrombosis Research in Advanced Disease Alliance.

He is on the faculty for the 1000 Lives Campaign in Wales acting as medical director for the thromboprophylaxis intervention. He also chairs the All Wales Thromboprophylaxis Group and the All Wales Thrombosis Campaign for Lifeblood, in his capacity as Lifeblood Medical Director for Wales. He is treasurer of the UK Thromboprophylaxis Forum and is on the NICE guideline development group for thromboprophylaxis in hospitalised patients.

He has published 5 books, 20 chapters and over 50 original papers and abstracts. His most recent book "Venous thromboembolism in Advanced Disease" edited with Miriam Johnson and Agnes Lee is ranked 966,603 in the Amazon best seller list

Dr Miriam Johnson is a Senior Lecturer in Palliative Medicine at Hull-York Medical School. Her research interests include symptom management in advanced heart failure and venous thromboembolism (VTE) in advanced cancer patients (MD thesis 1999). She is Honorary Consultant to St. Catherine's Hospice and the Acute NHS Trust hospital, Scarborough, and has developed one of the first UK joint cardiology-palliative care services. She is a member of the Science Committee of the UK Association of Palliative Medicine, the National Council for Palliative Care Heart Failure Policy Group, the National Cancer Research Institute Clinical Studies Group in Palliative Care and is co-director of the Thrombosis Research in Advanced Disease Alliance.

She is a grant holder of 3 NIHR grants one of which is a study of clinical decision making regarding VTE in advanced cancer. She is a reviewer for NIHR grant applications and a manuscript reviewer for a number of major journals. Recent VTE publications (co-author; Simon Noble) include a systematic review and meta-analysis of management of VTE in patients with advanced cancer (Lancet Oncology 2008) and "Venous thromboembolism in Advanced Disease; a Clinical Guide" (co-editors: Simon Noble and Agnes Lee) is the first book to address this difficult management issue.

Friday 12 March 2010

09:00-10:00

Advance Care Planning: for good or ill?

Dr Fiona Randall

Consultant in Palliative Medicine, Christchurch Hospital, Dorset

Mr David Ardron

Chair National Cancer Research Institute Consumer Liaison Group

Advance Care Planning (ACP) is a voluntary process of discussion about future care between a patient and a health care professional in advance of anticipated future loss of capacity, so that the patient's preferences may be known when capacity is later lost. The outcome of the discussion is recorded, if the patient so wishes, in an advance statement/advance care plan which informs best interests judgements about treatment and care (including location of care) when capacity is later lost. ACP is thus different from ordinary care planning.

But in ACP the patient has to contemplate much information (often unpleasant) about future illness scenarios - yet many of those scenarios will not actually occur. Regarding future treatment preferences, patients will need similar information as they would need to give or withhold consent. Emotional distress or trauma may result from contemplation of future illness scenarios, treatment possibilities, and ways of dying.

Patient and family may disagree about future preferences leading to conflict, but it is the patient's wishes which are sought and which will count in best interests judgements.

There is currently much political emphasis on the importance of patients dying in the place of their advance choice. But the questions on ACP documents refer to place of care (not death), and preferences change, so these documents may not accurately reflect a patient's last stated preference for place of death. The ACP process may lead to unrealistic expectations in terms of achieving place of death.

Patients' preferences change – if such changes are not recorded, the statement/plan will give misleading information.

Patients and professionals may not adequately understand the purpose and process of ACP and the important role that the advance statement/advance care plan will play in decision making once they lose capacity.

Dr Fiona Randall has been a Consultant in Palliative Medicine in an NHS Specialist Palliative Care Service since 1982. She has a special interest in health care ethics and in 2000 completed a philosophy PhD on the philosophy of palliative care.

Publications include "Palliative Care Ethics" 2nd Edition 1996, "The Philosophy of Palliative Care: critique and reconstruction" published in February 2006, both by Oxford University Press. A book on ethics in end of life care is in press.

She has been a member of the BMA and APM Ethics Committees. She was the APM's representative in discussions on the Mental Capacity Act and its Code of Practice. She has served on a research ethics committee.

She has been involved in compiling both The End of Life Care Programme and the RCP evidence-based guidance on Advance Care Planning, as well as the guidance on Advance Decisions to Refuse Treatment. She has clinical experience in these areas. Within her own acute hospital setting she is a member of the clinical ethics committee.

Mr David Ardron has worked widely in consumer affairs in lung cancer research now for five years. Both of his parents were cancer patients, his father with lung cancer and his mother with breast cancer. He is chair of the North Trent Cancer Research Network Consumer Research Panel and acting vice chair of the North Trent CN Patient Partnership Group. He is also a member of NCRI Lung Cancer Clinical Studies Group, and Chair of the NCRI Consumer Liaison Group. He was a member of the NCRI PET Scanning Research Strategic Planning Group. He sits on the trial management group for the MRC QUARTZ trial in Lung Cancer. He is interested in the practical role that local consumer research panels have to play in health research, and has been invited to describe the work of the North Trent Panel at many meetings and conferences. He engages in peer review, both for network cancer services, and national research applications. His background is in science teaching and computer literacy. He sits as a member of other National Cancer Initiatives including, NICE, NCIN, and the National Lung Data Audit.

Friday 12 March 2010

10:30-11:30

Developing and working in a community generalist palliative care team

Dr Paul Barker

Miss Pauline Cartmell. Community Matron, Generalist Palliative Care Team, Bournemouth

Dr Simon Pennell

GP, Southbourne Surgery

The End of Life strategy has now offered a stimulus to develop and improve palliative care services.

In 2005 a Community Generalist Palliative Care team was launched across the Bournemouth area with the support and vision of the PCT. Our motive grew from the observation that there is a 'Paradox in Death' – that is;

Most dying people would prefer to remain at home, but most of them die in institutions.

Most of the final year of life is spent at home, but most people are admitted to hospital to die.

Our aim has been to provide a service that has the intention of providing care for patients in the community for as long as possible, and whenever possible allow the patient's choice to die at home to become a reality with the support of a multidisciplinary team in the community.

We would like to share and discuss with you in an interactive workshop how the service has developed, and just how it works. We shall share clinical cases and scenarios with you to demonstrate not only the strengths and successes of the service but also to identify some of the difficulties and limitations we have identified on the way.

Dr Simon Pennell

Dr Simon Pennell has been a local GP for 20 years during which time his passion and recognition of the value of quality End of Life care has grown. He has been a Macmillan GP Facilitator for several years supporting the organisation of palliative care in primary care. He is a GPwSI in palliative care with the community palliative care team in Bournemouth. Between 2005 and 2007 he completed the Diploma in Palliative Care in Cardiff University passing with Distinction. He has worked closely with the local Out of Hours Service to support work aiming to provide a high standard of care out of hours.

Pauline Cartmell

Pauline Cartmell Community Matron for the Generalist Palliative Care Team
Bournemouth and Poole Community Health Service

Joined NHS in 1970 and worked as an Enrolled Nurse till 1989 following further training became a Registered Nurse in 1990.

Predominantly worked mainly Medical Wards until 1999 when she became a Lung Cancer Nurse Specialist for the Royal Bournemouth Hospital, working within the community and hospital environment.

2003 joined the Bournemouth Primary Care Trust as a Coordinator for Intermediate care, piloted the "Evercare Project" for the PCT which later established the first Community Matrons within the Bournemouth area.

Within the same PCT changed roles to monitor standards of care within local Nursing Homes, following on from the monitoring role, commenced work within the Continuing Health Care Team. Missing the patient contact and palliative care nursing began the role of Community Matron in Palliative Care in 2008.

Friday 12 March 2010

11:40-12:40

Rehabilitation – living with disability

Dr Gail Eva, Research Fellow, University of Oxford

Dr Diane Playford, Senior Lecturer/Honorary Consultant Neurologist

UCL Institute of Neurology

Rehabilitation is widely accepted as a useful response to the decline in physical function experienced by patients at the end of life. Patients value being able to maintain some level of independence, to participate in family and social life, and to have choice and control over their everyday affairs – all of which can be enhanced by rehabilitation approaches.

However, providing rehabilitation in palliative care can be challenging, for a number of reasons. Patients with life-threatening illnesses do not fit traditional models of rehabilitation service delivery. There are some interesting and significant differences between patients' adjustment to disability in longer-term conditions compared with life-threatening illness. There is also controversy over whether 'rehabilitation' is even a useful concept in this area: to what extent, for example, can mainstream rehabilitation strategies be imported into a palliative care context?

Goal-setting is a rehabilitation strategy which is widely used in longer-term conditions such as stroke, multiple sclerosis and spinal cord injury. It has been applied with varying levels of success in palliative care. Generally speaking, there is enthusiasm for using goal-setting with palliative care patients, but very little consensus on whether and how it works.

In this session, we will examine the applicability of mainstream models of rehabilitation and goal-setting to palliative care. We will draw on the latest research on goal setting in order to highlight some of the issues and controversies, encouraging the palliative care community to pay attention to the debates and discussions taking place in the mainstream rehabilitation field.

Dr Gail Eva

I graduated from the University of Cape Town in 1985 with a degree in Occupational Therapy. I spent the next five or so years working in and around Cape Town, setting up service-user led community projects with people with disabilities, particularly spinal injuries. In 1990, I moved to London and worked at the Royal Marsden Hospital where I became interested in rehabilitation in cancer and palliative care. I have worked in Oxford since 1997, initially developing an occupational therapy service on the oncology in-patient units, and then moving into specialist palliative care. Between 2002 and 2007 I managed the Hospital and Community Macmillan Nurse Teams at Sir Michael Sobell House hospice in Oxford. Throughout my career, I have had a strong interest in research, and I have now moved into teaching and research full-time.

My PhD centered on disability and rehabilitation in metastatic spinal cord compression. My current research focuses on the evaluation of a rehabilitation intervention for cancer-related fatigue towards the end of life.

Dr Diane Playford is Senior Lecturer at the Institute of Neurology and Honorary Consultant Neurologist at the National Hospital for Neurology and Neurosurgery. At the NHNN she leads the neurological rehabilitation service which has 28 in-patient beds for people with neurological disability including stroke, non traumatic spinal cord injury and progressive neurological disorders such as multiple sclerosis, as well as providing out-patient services.

Her research interests include the evaluation of rehabilitation processes and interventions including goal setting and vocational rehabilitation. She has recently been appointed Director of Institute of Neuropalliative Rehabilitation at the Royal Hospital for Neurodisability, Putney.

Friday 12 March 2010

Debate

If Assisted Suicide were legalized: how should health care professionals be involved?

Witnesses: Professor Ilora Finlay Professor Sheila McLean and Mr John Paley

Panellists tbc

Professor Sheila A.M. McLean LL.B., M.Litt., Ph.D., LL.D. (Edin), LL.D. (Abertay, Dundee), F.R.S.E., F.R.C.G.P., F.Med.Sci, FIBiol, F.R.C.P.E. (Edin), F.R.S.A.

International Bar Association Professor of Law and Ethics in Medicine
Glasgow University

Professor McLean is the first holder of the International Bar Association Chair of Law and Ethics in Medicine at Glasgow University and is Director of the Institute of Law and Ethics in Medicine at Glasgow University and co-director of the Centre for Applied Ethics and Legal Philosophy. She has acted as a consultant to the World Health Organisation, the Council of Europe, and a number of individual states. She has acted as an expert reviewer for many of the major grant awarding bodies and similar organisations outwith the United Kingdom. She has published extensively in the area of medical law, is on the Editorial Board of a number of national and international Journals and is regularly consulted by the media on matters of medical law and ethics. In 2005 she was awarded the first ever Lifetime Achievement Award at the Scottish Legal Awards. Her most recent book, *Assisted Dying: Reflections on the Need for Law Reform* was awarded the Minty Prize of the Royal Society of Authors and the Royal Society of Medicine in 2008.

John Paley has a degree in philosophy from Cambridge, but pursued a career as a jobbing researcher until the 1990s, when he reverted to being a philosopher. Since then he has written on a number of philosophical topics in health care, especially nursing, His current interests include clinical cognition, complexity theory, philosophy of qualitative research methods, narrative, spirituality in health care, and nursing ethics. However, in real life he plays bass in an old codgers' rock band.