



The Sue Ryder Care Centre for  
Palliative and End of Life Studies  
Annual Report 2008/2009



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## Foreword from Professor Mark Avis

It is pleasing to note the growing international reputation of the Sue Ryder Care Centre for Palliative and End of Life Studies and its recognition as a centre of excellence in end of life care research and education. The importance of high quality end of life care is a prominent feature of current health policy, and our School recognises the value of hosting the Sue Ryder Care Centre in providing the education, research and leadership that support this key health aim.

The School of Nursing, Midwifery and Physiotherapy achieved an excellent result in the recent Research Assessment Exercise (RAE); it is now recognised as one of the leading research-led nursing and midwifery Schools in the UK. It is important to acknowledge the contribution that the Sue Ryder Care Centre has made in strengthening the School's research environment, and to recognise the individual and collective efforts of Centre staff in building the School's overall research profile. In addition, the School has been successful in gaining funding from the National Institute for Health Research to support the development of a clinical academic training pathway. The School is able to offer an integrated approach to career development for clinicians in palliative and end of life care that combines specialist practice with Masters, Doctoral and post-Doctoral education programmes. This approach provides a welcome opportunity to break down the career distinctions between researcher and practitioner in health care.

I look forward to developing these opportunities further with colleagues in the Sue Ryder Care Centre.



**Professor Mark Avis**

Head of the School of Nursing, Midwifery and Physiotherapy, University of Nottingham

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## Introduction

I am pleased to be able to share with you the fourth annual report from the Sue Ryder Care Centre for Palliative and End of Life Studies. Our goal is to contribute to the wider mission of improving end of life care for all, and to change the cultures of care and of public opinion so that better end of life care is a matter of critical discussion, open concern and concerted action. The Centre is funded by a visionary and generous private donation to the University of Nottingham for ten years, between 2005 and 2015.

The Centre now enters its fifth year, with an exciting portfolio of research and educational initiatives and a strong and growing team of talented staff and students. We have had success in obtaining research grants from the Economic and Social Research Council, from the National Institute for Health Research (through collaboration with the UK Cancer Experiences Collaborative) and continue to conduct work by commission for leading charities and policy makers in the field of palliative and end of life care, working with them to promote best practice and develop policy in line with the priorities identified in the *End of Life Strategy* of 2008. We have supported the widening of palliative and end of life care education in the School of Nursing, Midwifery and Physiotherapy through the rationalisation of Masters and 'Learning Beyond Registration' provision, worked to support a successful bid for external funds to enable the development of short courses with funded places for practitioners, and gained two full time funded PhD scholarships. We have a growing international dimension to our work, with collaborative research ongoing last year with colleagues from Austria, Belgium and Holland and visiting scholars from Spain and the USA.

We continue to have the invaluable assistance of colleagues within the wider School of Nursing, Midwifery and Physiotherapy and the University of Nottingham, as well as the support of colleagues at Sue Ryder Care, our partnership group and within the Cancer Experiences Collaborative. We thank them all for their collegiality, support and guidance and look forward to working with them during 2010.



**Professor Jane Seymour**

Sue Ryder Care Professor in Palliative & End of Life Studies



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## A word from some of our partners

### Ann Macfarlane OBE

Being a partner with the Sue Ryder Care Centre for Palliative and End of Life Studies offers the opportunity to meet other professional academics and practitioners within the private and voluntary sectors. Such a partnership is a great way to learn and to share information in an area of work that remains under-developed. Much research and work undertaken at national and international level is now centred on palliative and end of life care but there remains a gap between what academics and practitioners have learnt and still need to learn, as well as what people who may require palliative and end of life support actually want to know in terms of information and the support available to them. These gaps are evidenced at local level as health and local authorities grapple with improving their knowledge as they work to deliver appropriate services within their local communities.

As an independent Rights and Independent Living Consultant I am privileged to have access to the research being undertaken by Jane Seymour and her colleagues. In return I can offer input from the work I am contracted to do with a variety of organisations that involve the views of people who may require services and those who already receive them. My work mainly focuses on people whose voices are seldom heard and who have little or no choice and control in their lives.

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### Jane Connell, MND Association

The Motor Neurone Disease Association's mission is to fund and promote research to bring about an end to MND. Until then we will do all that we can to enable everyone with MND to receive the best care, achieve the highest quality of life possible, and die with dignity. We will also do all that we can to support the families and carers of people with MND.

A high standard of palliative and end-of-life care is vital to ensure our aims are met and we campaign nationally and locally for better care for all those who are living with MND. We were delighted that Professor Jane Seymour spoke about clinical research into MND at our East Midlands conference and that two MSc students have chosen to do their dissertation on MND. This is a most exciting academic unit to be involved with and we believe the centre's excellent research and teaching will ensure improved palliative and end of life care in the future. We look forward to using its findings to make a real difference to the quality of life of all families living with MND.





## George Bell, Head of Education, Help the Hospices

Help the Hospices is the leading charity supporting hospice care throughout the UK. We are here to represent and support our members, and we work with them and other organisations as they strive to grow and improve hospice and palliative care throughout the UK and across the world. We recognise and value the opportunities that working in partnership with Professor Jane Seymour and the Sue Ryder Care Centre for Palliative and End of Life Studies at Nottingham University and the Sue Ryder Care Partnership Board present in helping us to deliver our goals.

We acknowledge the importance of engaging with the diverse membership represented on the Partnership Board and aim to be full and active members by helping to promote the work of the Board, especially the fields of research and practice development in hospice and palliative care. The opportunity relates well to our existing partnership with the End of Life Observatory and Lancaster Management School at Lancaster University as well as hospices throughout the country and support of the delivery of the MA in Hospice Leadership.




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## Visiting researcher - Inés Barrio-Cantalego

### Lecturer in Bioethics, University of Granada, Spain

**10th November - 12th December 2008**

During my time at the Sue Ryder Care Centre for Palliative and End of Life Studies I was able to attend a number of teaching sessions to increase my understanding of the modules offered within the Centre. I also took the opportunity to attend the Social Aspects of Death, Dying and Bereavement conference in Sheffield as well as a number of research presentations within the School. During these sessions it was particularly interesting to meet people from different countries and discuss different aspects of end of life care delivery. In order to see how some of these research findings and such theoretical knowledge can affect patient care I also visited St. Joseph's Hospice in London. I am grateful to Professor Jane Seymour and Dr Kristian Pollock for arranging access to such a range of learning opportunities, and to Mark Avis, Head of School for the kind welcome.

## Completed projects

Project title	Duration	Project team
Advance care planning and the mental capacity act in specialist neurological and palliative care centres	May2008-2009	J. Seymour <sup>1</sup> , E. Wilson <sup>1</sup> , P. Perkins <sup>2</sup> , J. Appleton <sup>2</sup> <sup>1</sup> University of Nottingham, <sup>2</sup> Sue Ryder Care
Advocacy for End of Life Issues	June 2007 - November 2008	J. Seymour <sup>1</sup> , A. Clarke <sup>2</sup> , K. Froggatt <sup>3</sup> , G. Bellamy <sup>4</sup> <sup>1</sup> University of Nottingham; <sup>2</sup> Aberdeen University; <sup>3</sup> Lancaster University; <sup>4</sup> University of Sheffield
A peer education programme for end of life education among older people	April 2007 - May 2009	J. Seymour <sup>1</sup> , S. Kennedy <sup>1</sup> , K. Almack <sup>1</sup> , B. Crosbie <sup>1</sup> , A. Clarke <sup>2</sup> , C. Sanders <sup>3</sup> , K. Froggatt <sup>4</sup> , M. Gott <sup>5</sup> , M. Welton <sup>6</sup> (representing the Peer Education Project Group) <sup>1</sup> University of Nottingham; <sup>2</sup> Aberdeen University; <sup>3</sup> University of Manchester; <sup>4</sup> Lancaster University; <sup>5</sup> University of Sheffield; <sup>6</sup> Sheffield Teaching Hospitals NHS Trust; <sup>7</sup> Including Margaret Cock, Carmen Franklin, Muriel Richards, Ivy Sharpe & Don Thompson
Choice and decision making in palliative care: a study of patients', carers' and health professionals' experiences	Oct 2006 - Oct 2008	K. Cox <sup>1</sup> , J. Seymour <sup>1</sup> , D. Porock <sup>1</sup> , K. Almack <sup>1</sup> , N. Moghaddam <sup>1</sup> <sup>1</sup> University of Nottingham
End of life care in nursing homes: Understanding and mapping solutions	October 2007 - September 2008	J. Seymour <sup>1</sup> , K. Froggatt <sup>2</sup> , A Kumar <sup>1</sup> <sup>1</sup> University of Nottingham <sup>2</sup> Lancaster University
Independent Evaluation of the Marie Curie Cancer Care 'Delivering Choice' Programme	April 2005 - December 2009	S. Payne <sup>1</sup> , J. Seymour <sup>2</sup> , C. Ingleton <sup>3</sup> A. Sargeant <sup>1</sup> , J. Chatwin <sup>1</sup> <sup>1</sup> Lancaster University; <sup>2</sup> University of Nottingham; <sup>3</sup> University of Sheffield
Perspectives of older people on end of life care	May 2008 - May 2009	J. Seymour <sup>1</sup> , J. Brown <sup>2</sup> , R. Deschepper <sup>3</sup> , B.D. Onwuteaka-Philipsen <sup>4</sup> , S. Payne <sup>5</sup> , S. Pleschberger <sup>6</sup> <sup>1</sup> University of Nottingham; <sup>2</sup> University of Southampton; <sup>3</sup> Vrije Universiteit, Brussels; <sup>4</sup> VU University, Amsterdam; <sup>5</sup> Lancaster University; <sup>6</sup> University of Klagenfurt, Austria
Predicting weight loss in people with cancer: Development and validation of a screening tool	January 2007 - December 2008	V. Halliday <sup>1</sup> , J. Addington-Hall <sup>2</sup> , D. Porock <sup>1</sup> , A. Wilcock <sup>1</sup> , S. Langley-Evans <sup>1</sup> , J. Hopkinson <sup>2</sup> , A. Arthur <sup>1</sup> <sup>1</sup> University of Nottingham, <sup>2</sup> University of Southampton

Further details on all these studies can be found on the website [www.nottingham.ac.uk/nmp/research/cancer/index.php](http://www.nottingham.ac.uk/nmp/research/cancer/index.php) along with contact details for access to final reports.

## New research projects

<b>Title</b>	Environments for Care at End of Life: Evaluation of the King's Fund 'Enhancing the Healing Environment' Programme.
<b>Funder</b>	King's Fund
<b>Funding</b>	£50,684
<b>Start/Finish date</b>	October 2008 - April 2010
<b>Project staff</b>	Jane Seymour, <sup>1</sup> Antony Arthur, <sup>1</sup> Eleanor Wilson, <sup>1</sup> Alex Forsythe, <sup>2</sup> Jonathan Hale, <sup>1</sup> <hr/> <sup>1</sup> University of Nottingham; <sup>2</sup> University of Aberystwyth

This study evaluates the King's Fund Enhancing the Healing Environment Programme by assessing the process of change undertaken by 20 project teams across the country involved in renovating a key physical space used in the delivery of end of life care. The multi-method design explores the impact the renovation projects have on the delivery of end of life care and on those using the physical environment, both staff and patients and families. The study aims to examine what has been learnt about the way attitudes to death and dying are influenced and changed by the physical environment.

<b>Title</b>	Older adults with advanced cancer living alone: an exploratory study.
<b>Funder</b>	Dimbleby Cancer Care
<b>Funding</b>	£70,205
<b>Start/Finish date</b>	April 2009 - October 2010
<b>Project staff</b>	Barbara Hanratty, <sup>1</sup> Julia Addington-Hall, <sup>2</sup> Antony Arthur, <sup>3</sup> Gunn Grande, <sup>4</sup> Sheila Payne, <sup>5</sup> Jane Seymour, <sup>3</sup> Lucy Cooper, <sup>1</sup> <hr/> <sup>1</sup> Liverpool University; <sup>2</sup> University of Southampton; <sup>3</sup> University of Nottingham; <sup>4</sup> Lancaster University; <sup>5</sup> University of Sheffield

This project is part of the *Cancer Experiences Collaborative* portfolio. Its aims are to provide an in-depth understanding of how living arrangements influence experiences of living with advanced cancer for older adults and to examine the feasibility of tools to be applied in a future longitudinal cohort study. The study employs qualitative interviews and measurement of health related quality of life and service use among older people who have advanced cancer and are living alone at home. Telephone interviews with carers are also being undertaken. This study is in its first year, however ethical approval has been gained and data collection is underway.

<b>Title</b>	<b>Transitions between services at the end of life for older people: patient and provider perspectives</b>
<b>Funder</b>	National Institute for Health Research Service Delivery and Organisation Programme
<b>Funding</b>	£486,254
<b>Start/Finish date</b>	January 2009 - December 2011
<b>Project staff</b>	Barbara Hanratty, <sup>1</sup> Julia Addington-Hall, <sup>2</sup> Michael Goldacre, <sup>3</sup> Gunn Grande, <sup>4</sup> Sheila Payne, <sup>5</sup> Jane Seymour, <sup>6</sup> <hr/> <sup>1</sup> Liverpool University; <sup>2</sup> University of Southampton; <sup>3</sup> University of Oxford; <sup>4</sup> University of Manchester; <sup>5</sup> Lancaster University; <sup>6</sup> University of Nottingham.

This project is part of the *Cancer Experiences Collaborative* portfolio. A quantitative analysis of routine data; interviews with patients who have heart failure, lung cancer and stroke, a survey of bereaved carers; and an interview study with providers and commissioners of care are combined to better understand the patterns and causes of health service transitions and their association with older people's experiences at the end of life. This study is in its first year and interviews with patients are underway.

<b>Title</b>	<b>Transitions to palliative care for older people in acute hospitals</b>
<b>Funder</b>	National Institute for Health Research Service Delivery and Organisation Programme
<b>Funding</b>	£470,000
<b>Start/Finish date</b>	January 2009 - December 2011
<b>Project staff</b>	Merryn Gott, <sup>1</sup> Christine Ingleton, <sup>1</sup> Claire Gardner, <sup>1</sup> Jane Seymour, <sup>2</sup> Michael Bennett, <sup>3</sup> Mark Cobb, <sup>4</sup> Bill Noble, <sup>1</sup> Tony Ryan, <sup>1</sup> Sue Ward, <sup>1</sup> Chris Parker, <sup>1</sup> <hr/> <sup>1</sup> University of Sheffield; <sup>2</sup> University of Nottingham; <sup>3</sup> Lancaster University; <sup>4</sup> Sheffield University Hospitals NHS Foundation Trust.

This project is part of the *Cancer Experiences Collaborative* portfolio. It aims to examine how transitions to a palliative care approach are managed and experienced in acute hospitals as well as to identify best practice from the perspective of older patients and key service providers and commissioners. A mixed methods design is being used, including focus groups with health care professionals, a census of hospital inpatients to ascertain palliative care needs; questionnaire completion by GPs of patients with palliative care needs and interviews with patients who have palliative care needs or their representatives. Although in its first year, the focus groups for this study are complete.

<b>Title</b>	<b>Managing suffering at the end of life: A study of continuous sedation</b>
<b>Funder</b>	The Economic and Social Research Council
<b>Funding</b>	£267,000
<b>Start/Finish date</b>	November 2009 - May 2012
<b>Project staff</b>	Jane Seymour, <sup>1</sup> Sheila Payne, <sup>2</sup> Julia Addington-Hall, <sup>3</sup> Clive Seale, <sup>4</sup> Nigel Mathers, <sup>5</sup> Henry Smithson, <sup>5</sup> <hr/> <sup>1</sup> University of Nottingham; <sup>2</sup> Lancaster University; <sup>3</sup> University of Southampton; <sup>4</sup> Queen Mary College; University of London; <sup>5</sup> University of Sheffield

This study focuses on the issue of continuous deep sedation until death in order to shed light on some important aspects of care of the dying about which little is currently known. The study has two parts. Part 1 includes firstly, a review of two bodies of literature: i) clinical research and practice; ii) ethical, social science and philosophical, and secondly, a secondary analysis of an existing data set comprising surveys completed by 3,733 UK medical practitioners about their end of life practices. Part 2 will involve a series of 30 case studies using qualitative methods to interview staff and relatives most closely involved in the care of decedents who received continuous sedation until death at home, in hospital or in hospices.

Completion of this project will enable a sociologically informed understanding of some important but little studied practices associated with end of life care and contribute to efforts to develop research methods in end of life care where complex ethical and technological factors feature. The findings will inform debate and the development of practice and policy in end of life care via collaboration with the ethics collaborative of the National Council for Palliative Care in England, The National End of Life Care Programme, the European Association of Palliative Care and other key stakeholders.

<b>Title</b>	<b>Public attitudes to death, dying and bereavement: a review</b>
<b>Funder</b>	The National Council for Palliative Care/ The National End of Life Care Programme
<b>Funding</b>	£35,224
<b>Start/Finish date</b>	April 2009 - October 2009
<b>Project staff</b>	Jane Seymour, <sup>1</sup> Antony Arthur, <sup>1</sup> Karen Cox, <sup>1</sup> Kristian Pollock, <sup>1</sup> Wendy Stanton, <sup>1</sup> Sheila Kennedy, <sup>1</sup> Arun Kumar. <sup>1</sup> <hr/> <sup>1</sup> University of Nottingham

This project is a systematic review of the literature describing research and public awareness campaigns relating to death, dying and bereavement. It aims to review published qualitative and quantitative studies and 'grey' literature both in the UK and internationally which relates to public attitudes to death, dying and bereavement. There will also be a consultation with a network of national and international colleagues to relate our work with the emergent thinking around raising public awareness in this field.

# Educational activities

## A report from Becky Chady, lecturer in palliative and end of life care

I joined the University in September 2008 as a full time lecturer and have responsibility for the palliative and end of life care education at Masters level, working with Dr Tony Arthur, and the 'Learning Beyond Registration' (LBR) programme. Both of these are hosted by the School of Nursing, Midwifery and Physiotherapy. Since I came into post, I have been charged with synthesising the provision of education at these levels and of seeking funds to widen our provision to practitioners across the region, who may not otherwise access education in palliative and end of life care.

We currently offer degree and Masters' level modules in both Lincoln and Nottingham offering flexibility for practitioners across the region. In the last year we have provided education to 68 practitioners at degree level, most of whom are registered on the BSc Healthcare Studies (palliative care pathway). In response to demand, one of the modules is solely distance learning since some practitioners find it difficult to attend the University on a regular basis.

Over the last year, I have worked with staff from the Sue Ryder Care Centre and the wider School of Nursing, Midwifery and Physiotherapy to review and synthesise the provision of LBR and Master's education. As a result, we have changed the way that we deliver master's level palliative and end of life care education. This is now a pathway within the postgraduate certificate/diploma/MSc Programme for Health and Social Care. We currently have 8 practitioners registered on this pathway.

We aim to ensure all the modules delivered reflect the new core competencies as identified in the *End of Life Care Strategy of 2008*, and have visiting clinical lecturers involved in the delivery of education. We currently employ a Practitioner Health Lecturer (PHL) on a secondment from specialist clinical practice.

In September 2009 we were successful in being awarded £48,500 by the Workforce Confederation for the delivery of a specialised three day short course for 100 non-traditional LBR staff working in health and social care staff, to be delivered at all our centres across the region.

A new palliative care advisory group, launched in September 2009, aims to meet three times a year and actively engage with users, practitioners and commissioners across the region to advise and guide the ongoing developments of high quality palliative and end of life care education offered by the University.

# Doctoral student progress

## Graduating Students

Special congratulations go to our graduating student this year who has undertaken her viva voce examination and successfully completed her PhD.

**Lamya Gazzaz:** *Saudi nurses' perceptions of nursing as an occupational choice: a qualitative study*

Supervisors: Antony Arthur, Mark Avis

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## New students

Welcome to our new students who have joined the PhD/MPhil programme this year to undertake work with a focus on palliative and end of life care. We have been successful in gaining full time scholarships for the Faculty of Medicine and Health Sciences and from the Economic and Social Research Council to support two of our students in their studies.

**Emma Blows:** *Living with cancer and the reconstruction of self after diagnosis of, and treatment for, life threatening disease.* Supervisors: Karen Cox, Jane Seymour

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**Yupawadee Kantabanlang:** *Views and experiences of carers of people with palliative care need.*

Supervisors: Karen Cox, Kathy Almack

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**Tikva Meron:** *'Advanced directives' contribution to palliative care management for people with long term conditions in Israel'.* Supervisors: Jane Seymour, Kathy Almack

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## Ongoing students

**Janice Barratt:** *Identifying lay carer interventions that are effective in helping people with dementia overcome difficulties with eating and drinking.* Supervisors: Antony Arthur, Jeanette Lilley

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**Steve Brummell:** *Clinical decision-making in action: the use of cardiopulmonary resuscitation in the Accident and Emergency Department.* Supervisors: Jane Seymour, Gina Higginbottom

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**Gill Horne:** *The views and perceptions of patients with lung cancer: discussions about preferences for end of life care and treatment.* Supervisors: Jane Seymour, Sheila Payne

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**Munikumar Ramasamy:** *Tailoring end of life care? perspectives' of older South Asians living in East London*  
Supervisors: Jane Seymour, Antony Arthur.

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**Julie Skillbeck:** *Understanding frailty in adults with complex problems receiving social care: An Ethnographic Study.* Supervisors: Jane Seymour, Antony Arthur.

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**Wesley Too:** *Palliative care for people living with HIV/AIDS in Uganda.* Supervisors: Jane Seymour, Michael Watson

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**Eleanor Wilson:** *Exploring the care needs of those affected by Huntington's Disease.*  
Supervisors: Kristian Pollock, Aimee Aubeeluck.

## Seminars

### Co-hosted by the Sue Ryder Care Centre for Palliative and End of Life Studies with the Supportive and Palliative Care Research Group

We have a programme of meetings for the forthcoming year to which everyone is welcome. They include:

#### Research seminars

- 90 minute mid-day sessions
- Presentation and discussions related to research
- Demonstration and discussion of research tools e.g. SPSS, EndNote
- Round up of news

#### Research seminar dates for 2010 to be held at the Queen's Medical Centre: 12.30 to 2.00pm

Date	Speaker/methodological issue	Venue
Thurs Jan 14th	<ul style="list-style-type: none"> <li>• Lynn Furber: 'Breaking bad news to patients whose treatment is to be discontinued</li> <li>• Using EndNote (Librarian)</li> </ul>	B73
Thurs March 18th	<ul style="list-style-type: none"> <li>• TBC</li> <li>• Researcher ID (Jacqueline Collier) TBC</li> </ul>	B73
Weds July 14th	<ul style="list-style-type: none"> <li>• TBC</li> <li>• Using SPSS (Antony Arthur) TBC</li> </ul>	D104
Thurs Nov 25th	<ul style="list-style-type: none"> <li>• TBC</li> <li>• Using NVivo (Kristian Pollock/Kathryn Almack)</li> </ul>	TBC

#### Practitioner Research Network meetings

- 2.5 hour sessions with lunch provided
- Mixture of presentations from group members and practitioners and an update on research that has been published
- Scope for networking and discussion



## Practitioner Research Network meeting dates for 2010 to be held at the Queen's Medical Centre: 12.30 to 3.00pm with lunch

Date	Speaker/literature update	Venue
Wed Feb 24th	<ul style="list-style-type: none"> <li>• Phil Mayor - East Midlands Local Cancer Network</li> <li>• Matthew Maddocks – role of therapeutic exercise in incurable cancer</li> <li>• Literature update – Kathryn Almack</li> </ul>	B73
Wed June 9th	<ul style="list-style-type: none"> <li>• Andy Kutarski – St Barnabas Hospice TBC</li> <li>• Collette Manning – a nurse manager of the neurological disability unit (special interest in palliative care) TBC</li> <li>• Literature update – Arun Kumar</li> </ul>	D104
Weds Sept 8th	<ul style="list-style-type: none"> <li>• John Bains – Education Officer for the East Midlands Region of the Parkinson's Disease Society</li> <li>• Iain Nash – nursing pain team (issues relating to pain management) TBC</li> <li>• Literature update – Elli Wilson</li> </ul>	D104

### Annual Lecture

- To be held in the autumn, lecture followed by drinks reception, 5.30 – 7.30pm.
- This years' lecture Thursday 22nd October 2009:  
 "The Chicken Talk to the Duck": The Experiences of Older Chinese People of Cancer and Palliative Care Services in the United Kingdom - Professor Sheila Payne  
 Help the Hospices Professor of Hospice Studies & Director of the International Observatory on End of Life Care, Lancaster University

### Our next Annual Lecture

Thurs 21st October 2010, 5.30 to 7.30pm

### PhD day

- An annual event to invite PhD students researching topics under the remit of supportive and palliative care to present their work
- Wed 19th May 2010, 10.00 to 3.00pm

All meetings are open for anyone to attend although the Research seminars will have a more academic focus and the Practitioner Research Network a practitioner focus.

Dates, venues and speakers will be put on the web-site  
[www.nottingham.ac.uk/nmp/research/cancer/seminars.php](http://www.nottingham.ac.uk/nmp/research/cancer/seminars.php)

Details will also be circulated via our email lists. If you would like to be added to the list please email Kathy Almack: [K.Almack@nottingham.ac.uk](mailto:K.Almack@nottingham.ac.uk)

## Dissemination

### 'End of Life Decision Making' conference. Birmingham, 27th January 2009

In January 2009, the Centre took a key role in organising a conference hosted jointly by the Palliative Care Research Society and the Cancer Experiences Collaborative on 'End of Life Decision Making'. This is one PhD student's account of the day:

*The conference hosted over seventy delegates, focusing on aspects relating to the conversations, and their contexts, that do, could or should take place at the end of life. Speakers took complementary approaches; clinical, philosophical, ethical and legal, and were drawn from many areas of professional practice; medicine, nursing, palliative care organisation and research. Twelve posters presented widely varying methodologies for examining end of life situations and attracted much interest. The conference brought together early and experienced researchers from UK-based and international institutions. The experience was excellent for placing my own PhD study within the wider current research field. It was gratifying to have my work commented on by experienced researchers and even more so to receive a second place commendation for my first ever poster.*

Dr Philomena Swarbrick (PhD student)

### Papers in peer reviewed journals

Almack K, Clegg J and Murphy E, (2009). Parental negotiations of the moral terrain of risk in relation to young people with intellectual disabilities. *Journal of Community & Applied Social Psychology*, 19(4):286-299

Bird L, Arthur A, Niblock T, Stone R, Watson L, Cox K (2009) Rehabilitation programme after stem cell transplantation: randomised controlled trial. *Journal of Advanced Nursing* (in press)

Clarke A, Sanders C, Seymour JE, Gott M and Welton M (2009) Evaluating a peer education programme for advance end-of-life care planning for older adults: The peer educators' perspective. *International Journal of Disabilities and Human Development*, 8(1):33-41 Sp. Iss

Gott M, Ingleton C, Gardiner C, Ryan T, Noble B, Seymour J, Bennett M, and Cobb M. (in press) How can we improve end of life care for older people in acute hospitals? *Nursing Older People*

Horne G, Seymour JE, and Payne S (2009) Advance care planning: evidence and implications for practice. *End of Life Care*, 3(1):58-65

Ingleton C, Payne S, Sargeant A and Seymour J. (2009) Barriers to achieving care at home at the end of life: transferring patients between care settings using patient transport services. *Palliative Medicine*, available at: *Palliative Medicine OnlineFirst*, published on July 30, 2009 as doi:10.1177/0269216309106893

Kennedy S, Seymour JE, Almack K and Cox K (2009) Key stakeholders' experiences and views of the NHS End of Life Care Programme: findings from a National Evaluation. *Palliative Medicine*, 23:283-294

Lee LL, Arthur A, Avis M (2008) Using self-efficacy theory to develop interventions that help older people overcome psychological barriers to physical activity: a discussion paper. *International Journal of Nursing Studies*, 45(11):1690-1699

Lee LL, Perng S, Ho CC, Hsu HM, Lau SC, Arthur A (2009) A preliminary reliability and validity study of the Chinese version of the self-efficacy for exercise scale for older adults *International Journal of Nursing Studies* 46(2):230-238

Wilson, E (2009) Care at the end of life for people affected by Huntington 's disease. *Clinical Genetics: Abstracts for the World Congress on Huntington's Disease, Vancouver, 12-14th September* vol76:S1

## Other published outputs

Byrne J, McNamara P, Seymour J, and McClinton P (eds) (2009) *Palliative Care in Neurological Disease: A team approach* Radcliffe, Oxford pp158

Seymour J (2009) 'The principles and practice of palliative care' in Byrne J, McNamara P, Seymour J, and McClinton P (eds) *Palliative Care in Neurological Disease: A team approach*, Radcliffe, Oxford 15-26

Seymour J, and McNamara P, (2009) 'Supportive and palliative care needs in progressive long-term neurological conditions: an overview' in Byrne J, McNamara P, Seymour J, and McClinton P (eds) *Palliative Care in Neurological Disease: A team approach*, Radcliffe, Oxford p27-46

Seymour JE (2009) End of Life Care. In: Mallik, M., Hall C., and Howard D (eds) *Nursing Knowledge and Practice*. 2nd Edition. Elsevier Press

Seymour JE (in press) Advance care planning: an overview. In: Thomas K and Lobo B (eds) *Advance Care Planning in End of Life Care*. Oxford, Oxford University Press

Wilson E (2009) 'Patients and families' in Byrne J, McNamara P, Seymour J, and McClinton P (eds) *Palliative Care in Neurological Disease: A team approach*, Radcliffe, Oxford pp85-98

## Reports

Cox K, Seymour J, Moghaddam N, Almack K, Porock D and Pollock K. (2008) *Choice and decision-making in palliative care: a study of patients', carers' and health care professionals' experiences*. Final report to the Mid Trent Cancer Network. University of Nottingham

Kumar A and Allcock N. (2008) *Pain in older people, reflections and experiences from an older person's experience*. University of Nottingham, Help the Aged and the Pain Society

Payne S, Seymour J, Ingleton C and Chatwin J (2009) *Independent evaluation of the Marie Curie Cancer Care 'Delivering Choice Programme'. CHESS and CAPCCS workstreams (Leeds)*. Final report to Marie Curie Cancer Care

Seymour JE, Almack K, Bellamy G, Clarke A, Crosbie B, Froggatt K, Gott M, Kennedy S, Sanders C, Welton M (2009) *A peer education programme for end of life care education among older people and their carers*. Final report submitted to the Burdett Trust for Nursing and Help the Aged

Seymour JE, Froggatt K and Kumar A (2009) *End of life care in care homes: Understanding and mapping solutions*. Final report to the National End of Life Care Programme

Wilson E, Seymour J, Perkins P, and Appleton J *Advance care planning and the mental capacity act in specialist neurological and palliative care centres*. Part one–Audit (June 2008) and Part Two–Staff views (June 2009), University of Nottingham

## Presentations

Almack K, Seymour J, and Kennedy S. (2009). The views, experiences and needs of older lesbian, gay and bisexual people in relation to end of life care. *Cancer Experiences Annual Scientific Meeting*, Manchester (April 2009) and the *11th Congress of the European Association for Palliative Care*, Vienna (May 2009). (Poster presentation)

Almack K. (2009) Sexual orientation and end of life care. *Help the Aged event* for older lesbians, gay men and bisexuals 'Over the Rainbow but not over the hill' (March 2009). (Presentation)

Aubeeluck A, Wilson E, Seymour J, and Taylor R. (2009) Investigating Quality Of Life in Family Caregivers Of Huntington's Disease Patients. *World Congress on Huntington's Disease, Vancouver*, 12-14th September (poster presentation)

Aubeeluck A, and Wilson E. (2009) Psychological Distress and Self-efficacy in HD spousal caregivers – are there gender differences? *World Congress on Huntington's Disease, Vancouver*, 12-14th September (poster presentation)

Aubeeluck A, and Wilson E. (2009) The HD family caregivers' quality of life (QoL) – findings from focus group studies. *World Congress on Huntington's Disease, Vancouver*, 12-14th September (poster presentation)

Chady B (2009) Becoming a nurse teacher, transience, identity and role adaptation: a new model in action. *Nurse Education Tomorrow*, Cambridge, September 10th (presentation)

Chatwin J, Payne S, Seymour J, Ingleton C. (2009) Improving end of life care in care homes in the United Kingdom: An evaluation of the Care Homes End of Life Supportive Services programme (CHESS). *11th Congress of the European Association of Palliative Care* (Poster presentation)

Gardiner C, Gott M, Ingleton M, Ryan T, Seymour J, Bennett M, Noble B, and Cobb M. (2009) Transitions to palliative care for older people in acute hospitals *Palliative Care Research Society Meeting* 12th November (presentation)

Gott M, Ingleton MC, Ryan T, Seymour J, Bennett M, Noble B, Cobb M. (2009) Transitions to palliative care for older people in acute hospitals in the UK. *11th Congress of the European Association of Palliative Care* (Poster presentation)

Kennedy SM, Seymour J, Almack K (2009) The views, experiences and needs of older people in relation to end of life care. *11th Congress of the European Association of Palliative Care* (Poster presentation)

Kennedy SM, and Seymour J. (2009) Facilitating success: A review of literature about the contribution of 'champions' to service improvement programmes. *11th Congress of the European Association of Palliative Care* (Poster presentation)

Kumar A, Seymour J, Froggatt K. (2009) Supporting end of life care in care homes: A survey. *11th Congress of the European Association of Palliative Care* (Poster presentation)

## Presentations

Payne SA, Rurup ML, Onwuteaka-Philipsen BD, Deschepper R, Pleschberger S, Seymour JE. (2009) Interviewing older people about end of life issues: Experiences of qualitative research in four countries. *11th Congress of the European Association of Palliative Care* (Poster presentation)

Seymour JE (2009) Opening the black box: The contribution of ethnography to palliative and end of life care research. *Qualitative Research in the NHS: Annual Meeting*, Papworth NHS Foundation Trust, Cambridge

Seymour JE (2009) End of life decision making. *East Midlands Cancer Network, Evening Meeting*, Derby

Seymour JE (2009) End of life decision making. *Primary Palliative Care Conference*, Liverpool. (Plenary)

Seymour JE (2008) Advance care planning. *Leicestershire Hospice Evening Seminar*

Seymour JE (2008) Prognostication in palliative care. *Regional Link Nurse Annual Conference*, Nottingham. (Plenary)

Seymour JE, Pleschberger S, Brown J, Deschepper R, Onwuteaka-Philipsen B, Payne S, Rurup M (2009) Interviewing older people about end of life issues: Engaging with ethical frameworks in four countries. *11th Congress of the European Association of Palliative Care* (Oral presentation)

Seymour JE, Kennedy S, Almack K, Crosbie B, Welton M (2009) Views, experiences and educational needs of community nurses about advance care planning. *11th Congress of the European Association of Palliative Care* (Poster presentation)

Seymour JE, Crosbie B, Froggatt K (2009) The voices of older people living in supported 'extra care' housing about end of life care. *11th Congress of the European Association of Palliative Care* (Poster presentation)

Wilson, E (2009) Living with HD –care at the end of life. *World Congress on Huntington's Disease, Vancouver*, 12-14th September (invited presentation)



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