

# Sue Ryder Care Centre for the Study of Supportive, Palliative and End of Life Care



The University of  
**Nottingham**

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*... Understanding and improving palliative and end of life care*

**NEWSLETTER**  
**Autumn 2012**

Welcome to the SRCC Newsletter, one of the ways we share information and updates.  
We welcome your comments.

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## Update

- **In August, Jane Seymour visited colleagues at Sköndal University College, Stockholm, Sweden at the invitation of Professor Joakim Öhlén.** She spent two days with Professor Öhlén and his colleagues, sharing lessons and experiences from the Sue Ryder Care Centre to help them as they establish their new Palliative Care Research Centre. We look forward to continuing collaboration with colleagues in Sweden. For further details about the Ersta Sköndal University College Palliative Care Research Centre, please go [here](#).
- **Postgraduate Research Conference:** The third SRCC conference for PhD students conducting research in areas of supportive & palliative care is taking place on Wednesday 31st October 2012: Research in the field of supportive/palliative and end of life care: developing the next generation of researchers. For further details [visit event page](#).
- **Annual Lecture:** Professor Tony Walter, Director of the [Centre for Death Studies \(CDAS\) at Bath University](#) will be giving the next SRCC annual lecture on May 8th 2013.
- **Two new studies** will soon be under way at the Centre: Cascading knowledge about end of life care at home", and "Lung cancer diagnosed following emergency admission: Improving patient experiences and outcomes". Further details below.
- **Arrivals.** The Centre is delighted to welcome two new researchers and three PhD students, details below.
- **And departure.** Dr Tony Arthur, who has been working at the University of Nottingham since 2001 and joined the Centre in 2006, is moving to become Professor of Nursing Science at the University of East Anglia in January 2013. In his new post he hopes to develop his work in ageing and the care of older people but will retain strong links with Nottingham through the Cognitive Function and Ageing Study and the ongoing supervision of doctoral students based in the Centre.



## Focus: New arrivals

Two research fellows have been appointed to work on a new study funded by Marie Curie Cancer Care and led by Centre researcher Kathryn Almack. The study will explore end of life care experiences and concerns of older lesbian, gay, bisexual and transgender (LGBT) people (see below).



Anne Patterson has a PhD in Social Sciences focussing on adults with learning disabilities. Her research interests include the health and social care experiences and needs of vulnerable and/ or marginalised groups.



Meiko Makita has recently completed her PhD in sociology at the University of Glasgow. Her doctoral thesis explored the ageing experiences of older Mexican women.

Contact details of all our researchers can be found on [SRCC members' page](#).

## Research News

*Our research projects span four areas: Decision making and communication; Policy and service evaluation; Experiences of giving and receiving care and Evaluation of health care interventions. For full details, see the [Research Projects section](#) on our website. Here is news of some of our current studies:*

### **The last outing: exploring end of life experiences and care needs in the lives of older LGBT people. Kathryn Almack**

A study focusing on end of life care experiences and concerns of older lesbian, gay, bisexual and transgender (LGBT) people has recently begun at the Centre.

LGBT people have been found to experience discrimination in relation to quality of end of life care. While LGBT and heterosexual individuals may share end of life care experiences and concerns, there are likely to be separate issues that need to be addressed among LGBT people. The oldest generations of LGBT people grew up at a time when coming out resulted in serious negative social repercussions and various forms of prejudice or intolerance. Despite changes in more recent times, many older LGBT people may still be reluctant to disclose important aspects of their identity. To date little work has investigated access and provision of services for LGBT people at the end of life. This study will be the first of its kind across the UK and will run for two years. It will consist of three phases:

- 1) A survey of LGBT elders' experiences and needs in relation to care in later life and end of life care.
- 2) Interviews with some of the survey respondents to examine in-depth issues highlighted from the survey.
- 3) A public engagement workshop to feed back findings and to collaboratively develop recommendations to contribute to outcomes of the study.

### **Understanding the role of nurses in decisions to use anticipatory prescriptions to manage symptoms and distress in the last days of life. Elli Wilson**

This three- stage study is led by Jane Seymour. The second phase of the study is now complete (83 observations and 72 interviews with professionals involved in prescribing, issuing and using medications at end of life). Analysis of these data is currently underway and reveals some important findings:

Community nurses are more confident and autonomous decision makers than those in nursing homes. Some GPs lacked confidence to prescribe and often relied on prompting by nurses, making good relationships between nurses and GPs essential. Policies vary across regions and access to out of hours pharmacies is highly variable.

Anticipatory prescriptions were perceived to reduce delays and prevent hospital admissions for patients as well as save time and stress for nurses, especially those working out of hours. This allowed patients to die at home or in a nursing home and prevented calls to out of hours teams. We are now designing a questionnaire for a wider cohort of nurses in phase three of the project, based on these findings.

Further information about this study can be found [here](#).

**Facing Death and Rediscovering Spirituality: Exploring Historical Traditions to Inform a Model of Spiritual Care for Palliative Care practice in India: *Hamilton Inbadas (PhD student)***

This study explores cultural and traditional understandings of spiritual care for the dying in Kanyakumari district of Tamil Nadu, India and will examine the resonance of these with the perspectives of palliative care professionals.

Historical traditions are not only carriers of traditional wisdom for the care of the dying, but they also contain deep-rooted meanings that shape the perception of death and caring for the dying in the present. Using oral history methodology, this study aims to establish an understanding of practices in the care of the dying as perceived and practiced in the past and the place and role of spirituality in these practices. The outcome of the study will be the articulation of principles for a model of spiritual care in Indian Palliative Care Practice.

**Managing Suffering at the End of Life: A Study of Continuous Sedation: *Jane Seymour***

Jane Seymour leads this study which is funded by the ESRC and has been run in parallel with similar studies in Belgium and the Netherlands under the UNBIASED (UK Netherlands Belgium International Sedation) Study. It takes the form of a series of qualitative case studies, which seek to understand how the practice of sedation in end of life care for difficult symptoms is managed in different care settings and what challenges this raises for nurses, doctors and bereaved family members. We have completed the data collection and hope to be able to publish the first results in early 2013. For further information about the study see [link](#).

*Two new studies will soon be under way at the Centre*

***“Cascading knowledge about end of life care at home: the development and piloting of a training programme for those who help carers and a carer resource pack”***

This two year project is funded by Dimpleby Cancer Care and Marie Curie Cancer Care. The project is led by Professor Jane Seymour with research input from Dr Glenys Caswell. The aim is to develop and pilot a training programme for volunteers and support workers who help carers providing home based end of life care, as well as to produce a resource pack for carers. The project is being carried out in association with the Carers' Federation, based in Nottingham and will start in December 2012.

***“Lung cancer diagnosed following emergency admission: improving patient experiences and outcomes”***

This project, which is funded by the Roy Castle Lung Cancer Foundation and begins at the start of December 2012, aims to develop an understanding of the characteristics, needs, experiences and outcomes of patients who are diagnosed with lung cancer following an emergency admission to hospital (DFEA), in order to identify areas in which the care provided to them may be improved. The research will be led by Dr Andrew Wilcock, Macmillan Reader in Palliative Medicine and Medical Oncology. Professor Jane Seymour and Dr Glenys Caswell will be working on the qualitative element of the project, which involves interviews with patients and carers.

**Education news**

**Completed PhD**

Postgraduate Centre student Stephen Brummel has completed his doctorate and awaits official award for his research: “Clinical decision-making in action: The use of cardiopulmonary resuscitation in the Accident and Emergency Department”. Further details of this project can be found [here](#).



**New PhD students**

The Centre is delighted to welcome 3 new PhD students starting in September, and supported by the Lifecycle Studentships awarded by the Centre:

Nahyeni Bassah, will be undertaking research into ‘Education that makes a difference to end of life care at the bedside in resource constrained contexts: the situation of Cameroon’; Louise Bramley will be working on a project ‘Improving understanding of end of life decision making in the acute care setting’. Nicola Turner will be carrying out a study of young carers involved in caring for a parent with palliative care needs. This project is jointly funded through the SRCC LifeCycle fund and the department of Sociology and Social Policy.

## Accredited modules for stand-alone study, and for BSc and MSc pathways

These explore contemporary end of life care delivery and management, ethical debates, generic symptom management at end of life, and understanding loss and grief. Modules can be taken singly or as part of a BSc or MSc pathway. The MSc award is available as a full time option over 12 months from September 2012. More details the on [Learning Beyond Registration website](#).

For details, please contact Becky Chady: [becky.chady@nottingham.ac.uk](mailto:becky.chady@nottingham.ac.uk)

## Recent publications

- Almack, K., Cox, K. et al. (2012). [After you: conversations between patients and healthcare professionals in planning for end of life care](#). *BMC Palliative Care* 11(15).
- Coveney, C., Armstrong, S. et al. (2012). [Callers' experiences of calling a national suicide prevention helpline: report of an online survey](#). *Crisis advance online*.
- Freemantle, A. and Seymour, J. (2012) [Why is the Liverpool care pathway used for some dying cancer patients and not others? Healthcare professionals' perspectives](#). *BMC Research Notes*.
- Kenny, R. and Wilson, E. (2012) [Successful multidisciplinary team working: An evaluation of a Huntington's disease service](#). *British Journal of Neuroscience Nursing*, 8(3):137-142.
- Hanratty, B., Lowson, E. et al. (2012) [A comparison of strategies to recruit older patients and carers to end-of-life research in primary care](#). *BMC Health Services Research*, 12:342 doi:10.1186/1472-6963-12-342.
- Pollock, K. (2012). [Procedure versus process: ethical paradigms and the conduct of qualitative research](#). *BMC Medical Ethics* 13(25).

## ehospice - palliative care news online, on mobile and on tablet

ehospice is an exciting new online resource which brings you all the latest hospice, palliative and end of life care news and intelligence from the UK and around the world. Help the Hospices is managing the UK edition, and there are also six other country/region editions as well as international editions for adult and children's care. Visit the site at [www.ehospice.com](http://www.ehospice.com) and look out for the iPad and iPhone apps and mobile website, which will be available soon.



## Practitioner Research Network Open Meetings

*We convene and host regular seminars that are open to practitioners, educators, researchers and other interested parties.* During the last few months, these have included talks and discussions about end of life care in residential homes, the work of healthcare assistants in dementia care, and a new end of life care education initiative for health and social care workers.

Please visit our [meetings page](#) to view the full list and details of past and forthcoming seminars. You will also find video recordings of the talks you missed and might be interested in.

Apart from regular lunchtime seminars we organise an evening Annual Lecture. Professor Tony Walter, Director of the [Centre for Death Studies \(CDAS\) at Bath University](#) has kindly agreed to give our next Annual Lecture. It will be held on May 8<sup>th</sup> 2013. Details will be circulated and available online shortly.

To be added to our seminar mailing list, use the contact point at the end of this newsletter.

## Contacts

Dr Ruth Parry, Senior Research Fellow  
Sue Ryder Care Centre for the Study of Supportive,  
Palliative and End of Life Care  
School of Nursing, Midwifery, and Physiotherapy  
University of Nottingham,  
Queens Medical Centre  
B Floor (S Block Link Corridor)  
Nottingham, NG7 2HA  
UK

Email: [srcc@nottingham.ac.uk](mailto:srcc@nottingham.ac.uk)  
Centre website: [www.nottingham.ac.uk/nmp/srcc](http://www.nottingham.ac.uk/nmp/srcc)

