

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



The University of  
**Nottingham**

UNITED KINGDOM • CHINA • MALAYSIA

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

NEWSLETTER  
October 2011

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

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## Update

- **Centre director Jane Seymour appeared on BBC Radio 4's Woman's Hour** as part of a discussion about making plans for end of life care. More information at: <http://www.bbc.co.uk/programmes/b012ww6k>
- **What influences care for frail or seriously ill older people with dementia on acute hospital wards?** Having received ethical and governance approvals, [this project](#) is underway.
- **Care pathways of people affected by Huntington's disease:** Centre researcher Eleanor Wilson recently completed data collection for a [project](#) tracking 3 years in the health and social care pathways of 15 families affected by Huntington's disease.
- **End of life care experiences and concerns of older lesbian, gay, bisexual and trans (LGBT) people:** Centre researcher Kathryn Almack is working with the National End of Life Care Programme and the National Council of Palliative Care to host a series of discussion workshops across the country for older LGBT people this autumn, with the aim of developing guidance to address end of life care for this population
- **How people raise and discuss difficult futures:** Centre researcher Ruth Parry is collating evidence from linguistics and sociology research in order to provide clinicians and trainers with insights about raising and discussing sensitive issues, particularly death and dying
- **Does end of life care training work?** Centre educator Becky Chady, working alongside LOROS hospice and NHS East Midlands has led the design of a free, downloadable [toolkit](#) for assessing outcomes of training in end of life care.

## Focus: Centre is focus of fund raising campaign

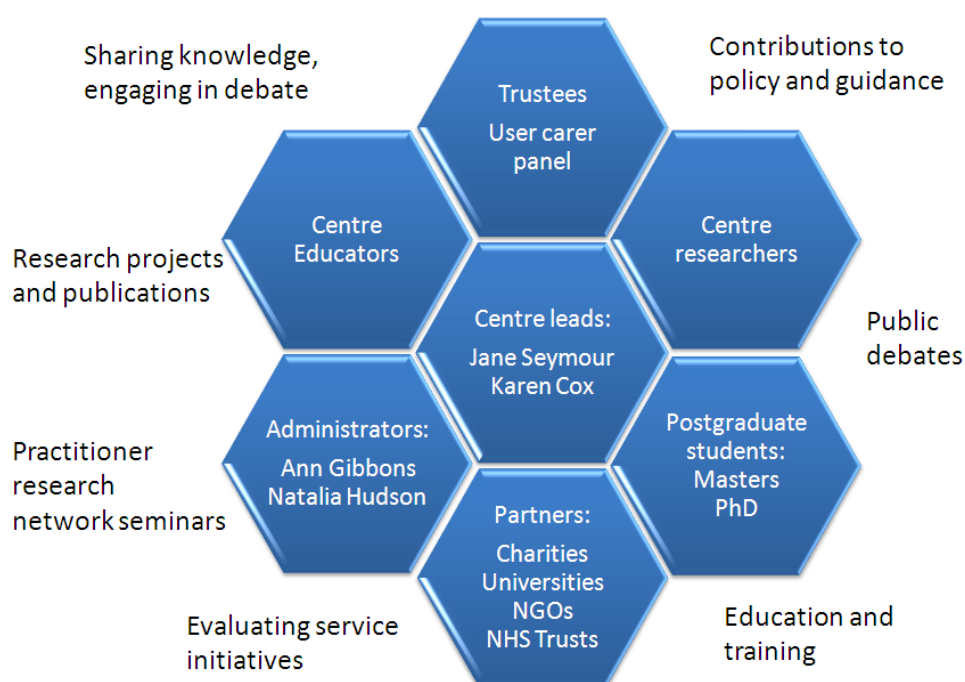


The University's Vice-Chancellor, Professor David Greenaway, led a team of colleagues cycling more than 1,000 gruelling miles from John O'Groats to Land's End over 14 days to raise money for the Sue Ryder Care Centre. Centre researchers joined them for one leg of the journey...

Funds raised from the Life Cycle will allow the Centre to expand its professional education and PhD scholarship programme with a special focus on 'resource poor' groups, including those working in long term care in this country, and those coming from countries where palliative care expertise and capacity is absent or negligible. In the recent past, the Centre has seen graduates from its PhD programme from Jordan, Kenya, India, Thailand and Saudi Arabia: all places where palliative care leadership, especially in nursing, is desperately needed.

## SRCC structure and activities

...understanding and improving palliative and end of life care



## Research news

*Our projects span four key areas: Decision-making and communication; Policy and service evaluation; Experiences of giving and receiving care; and Evaluation of healthcare interventions.* Information on all current and completed projects can be found on our website: [www.nottingham.ac.uk/nmp/srcc](http://www.nottingham.ac.uk/nmp/srcc). Here, we highlight just two of our completed projects:

### ***Exploring the palliative care needs of service users with neurological conditions – informing practice recommendations***

Centre researchers Jane Seymour, Eleanor Wilson and Aimee Aubeeluck worked on this study which used multiple methods to develop understanding about the challenges of delivering palliative and end of life care to people with progressive long-term neurological conditions. The research highlighted how much staff and family members valued the development of long-term relationships with service users in order to recognise their wishes and care needs. This knowledge was particularly important in informing end of life care. The research highlighted particular challenges for staff in delivering palliative and end of life care, including: variable support from specialist community health and social care professionals; organisational constraints; and limitations in funding and access to wider services. For both service users and their families, moving to residential care was a significant and difficult adjustment, although the safety and security of long-term care was valued.

Family carers found that, although difficult, learning about their relatives' wishes for future care was important since it provided a guide to decision-making once the service user could no longer participate. Both staff and relatives recognised it was not always possible to have a planned death and held similar views about what made a 'good death'. An audit of care in the last four weeks of life found that advance discussions about care or expressed wishes for care were rarely documented. This level of recording did not reflect the actual level or extent of discussions taking place with service users and their families. The study is closely related to further projects, particularly with people affected by Huntington's Disease. A final report is available here: [here](#). For more information, contact [Eleanor.Wilson@nottingham.ac.uk](mailto:Eleanor.Wilson@nottingham.ac.uk)

### ***Environments for Care at End of Life: Evaluating the King's Fund Enhancing the Healing Environment Programme***

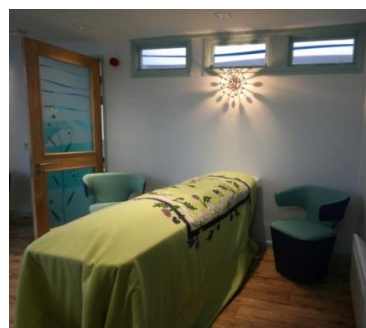
Centre researchers Tony Arthur, Eleanor Wilson, and Jane Seymour worked on this project alongside architect Jonathan Hale and psychologist Alex Forsythe. The evaluation examined NHS based projects set up to enhance mortuary viewing facilities, centralised bereavement services, and end of life care services in prison settings.

Evaluation entailed analysis of documents, focus group and individual interviews, architectural analysis, and ratings of the impact, function, and quality of the build designs. Findings highlighted the need for staff training in the importance of the physical environment and greater channels of communication between estates staff and those delivering care. The evaluation recommended that end of life care environments be culturally and religiously neutral and not overtly or unnecessarily clinical, and that greater attention should be paid to the pivotal role of mortuaries. The evaluation has been [reported](#) in detail and the team is currently working on further analysis and reporting about the important but often overlooked status of NHS mortuaries.

***Example of the results of a NHS hospital mortuary redesign:***



***Before***



***After***

## Education news

### ***National and International PHD student successes***

Our PhD students have conducted studies examining UK, Chinese, Ugandan, Israeli, Thai, Saudi Arabian, Jordanian populations. Recently completed doctorates include Kumar Ramasamy's exploration of end of life care issues among older South Asians in East London, Wesley Too's longitudinal study of palliative care for people living with HIV/AIDS in Uganda, and Gill Horne's study of advance care planning for people affected by lung cancer. New home and international students begin each year, this year we welcomed Issa Almansour, Hamilton Inbadas, and Tes Smith.

### ***Taught courses for NHS and Social Care staff: Improving the End of Life Care Experience***

Fully funded three day courses aimed at any staff working across health and social care and will be running between September 2011 and June 2012. Previous students on this well established course have reported it to be very useful. Dates and application details can be found [here](#).

### ***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. More details the on [Learning Beyond Registration website](#).

### ***Comments from past students:***

- "I found the module thought-provoking, relevant to practice"
- "[tutors] have an excellent, inclusive way of teaching which encouraged us to openly discuss and debate palliative care in practice through a policy, ethical and psychological perspective"
- "having worked within the field of specialist palliative care for many years I found it helpful to revisit subjects, the teaching challenged (rightly) previously held views, e.g. looking at concept of specialist/palliative care and the realisation of how poorly understood it is"

## Publications, presentations, media and public appearances

*Researchers and educators within our group address a wide range of audiences, via both written and spoken word. Here's a small selection:*

***'Let's start the conversation'***. Jane Seymour and Karen Cox were recently panel members at a public discussion meeting entitled 'Let's start the conversation – Advance Care Planning', held in Nottingham, and organised by the University and the Nottingham City and Nottinghamshire County NHS Trust.

**‘Death and emotions’** In November this year, Ruth Parry will speak at an international symposium in Helsinki, Finland which examines ‘Death and Emotions’. Ruth will talk about what is known about how people talk about future death and dying, focusing on how the communication practices that people influence, and are influenced by the emotional aspects of these topics.

**‘Peer education for advance care planning’** Seymour J, Almack K, Kennedy S, Froggatt K (2011) Peer education for advance care planning: volunteers’ perspectives on training and community engagement activities. Health Expectations doi: 10.1111/j.1369-7625.2011.00688.x

**‘Consent when mental capacity can be an issue’** Wilson E, Pollock K, Aubeeluck A (2010) Gaining and maintaining consent when capacity can be an issue: a research study with people with Huntington’s Disease. Clinical Ethics, 5(3), 142-147. Available [here](#)

**‘Improving support for older people looking after someone with advanced cancer’** (2011) Kennedy, S, Bird L, Clarke A, Cox K and Seymour J. Available [here](#)

## 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 decision-making for people who lack capacity; women’s role in funerals; palliative care in Uganda; getting research into practice; NHS mortuary viewing rooms; and communication in late-stage motor neurone disease. Details of past and forthcoming seminars can be found [here](#). To be added to our seminar mailing list, use the contact point at the end of this newsletter. Forthcoming meetings include:

- **‘The Nottinghamshire End of Life Care Pathway – from Concept to Care’** Thursday November 17<sup>th</sup> 2011: 12.30-15.00. Stephanie Pindor and Elise Adam, End of Life Care Trainers NHS Nottinghamshire County
- **‘End of Life Care in Care Homes’ and ‘Do nursing homes for older people have the support they need to provide end of life care?’** Thursday January 19<sup>th</sup> 2012: 12.30-15.00. Adam Gordon, Consultant Geriatrician and Special Lecturer in Medicine of Older People, University of Nottingham; Jane Seymour, Sue Ryder Care Professor in Palliative and End of Life Studies
- **‘The role and work of Help the Hospices’** Tuesday March 27<sup>th</sup> 2012: 12.00-14.30. David Prail Chief Executive Officer, Help the Hospices
- **‘Maintaining dignity in later life: Older people’s experiences of supportive care’** Thursday May 10<sup>th</sup> 18:00. Liz Lloyd, Senior Lecturer in Social Gerontology, University of Bristol

## Contacts

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

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