

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
Spring 2012

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

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Update

- **A new study focusing on Advance Care Planning** and funded by the National Institute for Health Research has recently begun at the Centre. Centre researcher Kristian Pollock is leading the study. We welcome new Research Fellow Dimitris Vonofakos to the Centre: he will be working on this study. See Research News section.

- **Centre Director Jane Seymour is taking part in the Help the Hospices Commission into the Future of Hospice Care.** More details below.

- **Jayne Brown, Senior Research Fellow at SRCC is moving to become Professor of Palliative Care at the [Centre for the Promotion of Excellence in Palliative Care](#)** – a collaboration between De Montfort University and The



Leicestershire and Rutland Hospice (LOROS). We're sorry to see her go, but delighted she will continue working closely with us.

- **One of the Centre's PhD graduates wins a Royal College of Nursing Award for his thesis:** Dr Kumar Ramasamy's work examines how older South Asians make efforts to adhere to important social and cultural values relating to death and dying, while rebuilding and adapting those values to the challenges of living in an emigrant community. More information on his work [here](#).
- **Life Cycle PhD studentships awarded for end of life care research in marginalised groups and resource poor contexts.** More below.
- **Jane Seymour participated in a panel evaluating the quality of care sciences research in Sweden** earlier this year at the invitation of the Swedish Research Council. Valuable lessons were learnt for the development of international quality research of relevance to palliative and end of life care.

Focus: Service User Involvement group publishes briefing

Briefing paper published by public involvement group

The Palliative Care Studies Advisory Group is a service user involvement group which supports studies based at Nottingham and Sheffield Universities. The group was set up in 2009, and recently published a briefing paper about its work, and highlighting the benefits of this kind of involvement.

As the briefing paper says:

“Involving patients, carers, and advocates in research is about doing research with the public rather than to or about the public. It is a way of allowing lay representatives to influence the research agenda. If research reflects the needs and views of the end user, it is more likely to produce results that can be used to improve practice in health and social care. Public involvement means not only monitoring what is done during the life of the research project, but the way in which it is done.”

The briefing paper can be downloaded [here](#). Paper copies can be obtained from Kate Chadwick: K.Chadwick@sheffield.ac.uk.



Research News

There's plenty going on at the Centre. Our projects span four areas: Decision-making and communication; Policy and service evaluation; Experiences of giving and receiving care; and Evaluation of healthcare interventions. For full details, see the [Research Projects section](#) on our website. Here is news of some of our current studies:

A new study focusing on Advance Care Planning, entitled 'Care and communication between health professionals and patients affected by severe or chronic illness in community care settings' has recently begun at the Centre. It is funded by the National Institute for Health Research's Health Services and Delivery Research Programme, and led by Dr Kristian Pollock (Kristian.Pollock@Nottingham.ac.uk). Advance Care Planning is a process whereby a patient, in consultation with health care providers, family members and important others, makes (and periodically reviews) decisions about future health care should he or she subsequently become incapable of participating in treatment decisions. The study will investigate two important aspects of Advance Care Planning (1) how patients, informal carers and health professionals start off the process, and (2) the long term results of the process in terms of how closely expressed preferences for end of life care are actually met. The study will be based in 10 General practices throughout Nottinghamshire and Bassetlaw, and will entail qualitative interviews and individual patient case studies. More information can be found [here](#).

Transferring knowledge about end of life care experiences and concerns of older lesbian, gay, bisexual and trans (LGBT) people. Following on from a series of discussion workshops across the country for older LGBT people in September and October 2011, Centre researcher Kathryn Almack has continued to work with the National End of Life Care Programme (NEOLCP) and the National Council of Palliative Care to address issues arising out of the workshops. As part of that work, there will be a national LGBT and EoLC conference on June 21st in London. This is aimed at a mixed audience of health and social care staff working around end of life care, LGBT people and those who work with them. The purpose is to showcase ongoing work and good practice in the field; to raise awareness as to why this is an important issue for everyone to address; and to facilitate each participant to identify action points that they can take from the conference to put into action in their own workplace or community. For further information on the conference and the project, please contact Kathryn: K.Almack@nottingham.ac.uk tel. 0115 8231204.

Older adults' experiences of end of life care. Centre staff have been involved in research examining older adults' experiences of end of life care, which has involved patients with lung cancer, heart failure and stroke. The study has been led by Dr Barbara Hanratty from the University of Liverpool and is funded by the National Institute for Health Research Service Delivery and Organisation Programme. Study outcomes include a paper in the Journal of the Royal Society of Medicine: 'Funding health and social services for older people – a qualitative study of care recipients in the last year of life' which draws attention to the gap that exists between the health and social care system that older adults living towards the end of life expect and what may be provided by a reformed welfare state. More information can be obtained from Professor Seymour: Jane.Seymour@nottingham.ac.uk.

Cancer Experiences Collaborative Scholar works on the Distress Thermometer. Psychologist Kirsten Stewart-Knight recently undertook some research at the Centre as a Cancer Experiences Collaborative Scholar. These scholarships aim to enable clinicians to work with experienced researchers to develop their knowledge and interest in research through a short term project. Kirsten undertook a systematic literature review on the 'Distress Thermometer' a rapid screening tool which aims to assess patients' wellbeing and enhance clinicians' understanding of patients' needs supervised by Jane Seymour and Ruth Parry. She found that there is evidence that the tool is used in many supportive and palliative care settings, but that more knowledge and research is needed about the validity of the tool and whether it accurately detects and uncovers patients' distress and concerns. A poster reporting the work was recently presented at the Palliative Care Congress Conference 2012, an abstract can be found [here](#).

Education news

Life Cycle PhD Scholarships

Thanks to the generous donation to the Centre from the 'Life Cycle' undertaken by a team led by the Vice Chancellor, Professor David Greenaway in 2011, the Centre has been able to offer three 'Life Cycle' PhD studentships in palliative and end of life care.

Students from the UK, Cameroon and the USA will be undertaking research on marginalised groups and resource poor contexts. Another PhD studentship about research into the role young carers play in end of life care, which is part funded by the School of Sociology and Social Policy, has been advertised [here](#).

For further information about the advertised scholarship, please contact Dr Kathryn Almack, email: k.almack@nottingham.ac.uk tel: 00 44 (0)115 82 31202, or Prof Saul Becker, email: Saul.Becker@nottingham.ac.uk tel: 0044 (0)115 95 15403.

More information about the Life Cycle can be found [here](#).



Postgraduate courses on end of life care *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 until June 2012. Previous students on this well established course have reported it to be very useful. Dates and application details can be found at: <http://moodle.mylearningspace.me.uk/>

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: <http://tinyurl.com/6kps9cj>

For details, please contact Becky Chady: becky.chady@nottingham.ac.uk

Other news

Commission on the Future of Hospice Care

Following the publication of the Demos report 'Dying for Change' The Help the Hospices Commission into the Future of Hospice Care was set up to provide strategic direction for hospices for the next 10 to 20 years. The Commission is chaired by Dame Clare Tickell, chief executive of Action for Children. Its vice chair is Dame Barbara Monroe, chief executive of St Christopher's Hospice. Professor Jane Seymour has been invited to take part in the Commission, and will contribute to a report which will have wide-ranging implications for the development of hospice and palliative care that will be published in mid 2013. For further information go to the [Help the Hospices website](#).

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. Details of past and forthcoming seminars can be found at: <http://tinyurl.com/5tgxarw>.

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

Forthcoming meetings include:

- **'Maintaining dignity in later life: older people's experiences of supportive care'** Thursday May 10th 18.00-19.30. Dr Liz Lloyd, Senior Lecturer in Social Gerontology, University of Bristol
- **'Controlled drugs and Harold Shipman: what he did, why he did it, and impact on practice today'** Thursday 28th June 2012 12.30-15.00. Dr Jerry Seymour, Consultant in Old Age Psychiatry, Doncaster and South Humber NHS Foundation Trust
- Thursday 13th September 2012 12.30-15.00. **'Decision making towards the end of life'** (title tbc). Rowan Harwood, Professor of Geriatric Medicine, Nottingham University Hospitals NHS Trust

Contacts

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