

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

### NEWSLETTER April 2013

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

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#### Update

- Ruth Parry, Jane Seymour and other research group members have submitted a commissioned review of the research evidence about care pathways for the dying. The review forms part of the evidence examined by **The Liverpool Care Pathway Independent Review** which will be reporting to the Department of Health, Ministers, and the NHS Commissioning Board in Summer this year. A summary of findings from the [Caring for Frail Older People](#) project led by Kristian Pollock and Glenys Caswell has also been submitted as contributory evidence. The Independent Review was launched in the context of adverse media reports about the Liverpool Care Pathway. More information about the Review can be found here <http://www.dh.gov.uk/health/2013/01/review-lcp/>. To request a copy of the review when it is made public, please contact Ruth Parry via email: [ruth.parry@nottingham.ac.uk](mailto:ruth.parry@nottingham.ac.uk).
- Kathryn Almack is a speaker at this year's **Marie Curie Annual Palliative Care Research Conference**, 'Palliative and end of life care for all - is everybody equal?' on Friday 22 March.
- In October, Jane Seymour delivered a plenary lecture to the **Scottish Partnership for Palliative Care** annual conference in Edinburgh: 'People like us will become old and very frail'.
- Jane also facilitated a workshop on qualitative research in palliative care at the invitation of Professor Bregje Onwuteaka-Philipsen from the **EMGO Institute for Health and Care Research Expertise Center of Palliative Care, Amsterdam** and gave a lecture to the 2nd Amsterdam Symposium on Palliative Care.
- **Professor Tony Walter**, Director of the Centre for Death Studies (CDAS) at Bath University (<http://www.bath.ac.uk/sps/staff/tony-walter/>) will be giving the next **annual lecture on May 8<sup>th</sup>, 2013**: 'Natural Support Networks and the Ideal of Holistic Care'. Venue: A05 Pharmacy Department, University of Nottingham. 18.00 – 20.00. All welcome.
- **Departure.** **Dimitris Vonofakis**, who has been working on the [Care and Communication](#) study will be leaving the Centre in April to take up new opportunities in Argentina: we wish him well.



## Recent awards

- Linda East and Edward Appiah Boateng (PhD student) were awarded £3600 from the **Wellcome Trust's Ethics and Humanities Small Grant Fund** for a project entitled '*Decision-making in end stage kidney disease (ESKD) in Ghana: exploring the ethical and practical context*'. The award funded a trip to Ghana where Linda and Edward visited three dialysis units to understand more about the ESKD patient's journey. In Ghana, each dialysis session costs patients \$70, and it is estimated that there are fewer than 250 ESKD patients receiving renal replacement therapy in the country. The visit will provide vital background knowledge in the development of Edward's PhD project.
- Jane Seymour is involved in an **NIHR Programme grant** led by Dr Fliss Murtagh at the Cicely Saunders Institute, King's College, London: '*C Change: Delivering high quality and cost effective palliative care for patients in their last year of life and their families*'. The study seeks to develop and validate a patient centred, nationally applicable casemix classification for adult palliative care provision, which reflects needs and captures complexity across different conditions and settings. For more information, please contact Dr Fliss Murtagh [fliss.murtagh@kcl.ac.uk](mailto:fliss.murtagh@kcl.ac.uk).
- Kathryn Almack has been awarded funding for an **ESRC Seminar Series** with colleagues from the Universities of Surrey, Oxford, Keele and the Chinese University of Hong Kong. The seminars aim to identify gaps in knowledge about LGBT ageing in six key areas: older bisexual people's lives; older trans people's experiences; race, ethnicity and religion; economics, resources and social networks; intergenerational issues; and health and social care. Six seminars will be held across the UK. The first is at the University of Nottingham on 24<sup>th</sup> April. For more information, go to: <http://www.nottingham.ac.uk/nmp/events/srcc-esrc-seminar-24-apr-2013.aspx>.

## New research

### ***Care planning and decision making for frail older people who lack decision-making capacity***

This new study is led by Karen Cox and Jane Seymour and is funded by NHS Nottingham City. It examines how the Mental Capacity Act is being used in day to day care practice. We hope it will inform a much larger study of these issues. The Act provides a regulatory framework for decision-making in cases of uncertain mental capacity and aims to uphold the individual's right to autonomy with the right to protection from harm and thereby uphold dignity when capacity is diminished or lacking. The implications of the Act for the care of frail older people are important but little is known about how it is currently being used to inform practice or what role 'systems' factors have in influencing practice. The study involves a systematic review of the relevant literature and focus groups with formal and informal carers. We are pleased to be working on this project in collaboration with Tom Denning, newly appointed Professor of Dementia Care in Nottingham, Jo Cooper, Head of Nursing & Midwifery Research, Nottingham Universities Hospital NHS Trust, Sarah Kirkwood, Nottingham City Care Partnership and Hugh Porter, GP lead for the frail elderly, Nottingham City Clinical Commissioning Group. For further information, contact Professor Karen Cox [karen.cox@nottingham.ac.uk](mailto:karen.cox@nottingham.ac.uk) or Professor Jane Seymour [jane.seymour@nottingham.ac.uk](mailto:jane.seymour@nottingham.ac.uk).

## Research focus

*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](#):

**Lung cancer diagnosed following an emergency admission: improving patient experiences and outcomes.** This study began in December 2012 and runs until May 2014 and is led by Dr Andrew Wilcock of the University of Nottingham with Jane Seymour and Glenys Caswell. It focuses upon lung cancer patients who are diagnosed following emergency admission to hospital (DFA). About 40% of people with lung cancer present in this way, the

highest of any cancer. Most have advanced disease and survival is poor. However, relatively little is known about their needs and experiences. This research will help provide a clear understanding of the characteristics, needs, experiences and outcomes of patients who are DFEA, in order to identify areas where the care offered to patients may be improved. The study consists of three work packages: The first gathers basic information from hospital notes of all patients who are diagnosed with lung cancer. This will allow comparison between patients DFEA and those through other routes. The second work package invites patients DFEA to complete questionnaires to assess their health status, holistic needs and experiences. If the patient is too unwell to take part, a suitable carer can act as a proxy. The final work package involves qualitative interviews with up to 15 patients and 15 carers, to obtain in depth details about their experiences, particularly in relation to symptoms, help-seeking behaviours and the overall care provided to the patient. Recruitment is, as anticipated, somewhat challenging with these patients who are often very ill at the point of recruitment to the study. Nonetheless, participants are gradually joining the project and helping us to build a better understanding of this group's needs, experiences and outcomes. For further information about this project, please contact Dr Andrew Wilcock, email: [Andrew.wilcock@nottingham.ac.uk](mailto:Andrew.wilcock@nottingham.ac.uk).

**The Last Outing study** exploring end of life experiences and care needs in the lives of older Lesbian, Gay, Bisexual and Trans (LGBT) people is now in the first phase of data collection. The project began in September 2012, and is led by Kathryn Almack with two Research Fellows, Anne Patterson and Meiko Makita. The researchers are busy advertising to LGBT-specific organisations interested in ageing and end of life issues. At the time of going to press, the project has recruited 92 survey respondents and over 50 of those have expressed interest in being interviewed in the next phases of the project. Participants are being sought who: currently live in the UK; identify as LGBT; are aged 60 or over (or are under 60 but have a LGBT partner or carer who is 60 or over). Please get in touch if you are interested in publicising or taking part in the study. Further details about the project and access to the survey can be found on the [project website](#)

**A delicate equilibrium: living with HD.** Eleanor Wilson has recently completed this longitudinal PhD study which explored the care needs of those with Huntington's disease (HD), a neurodegenerative disorder with slow progression. The research followed 15 people diagnosed with HD, their family carers, and the health and social care professionals involved in their care for a period of three years. Findings show that living with HD requires continued readjustment to maintain balance between increasing disability, diminishing cognition and living well at home. Multidisciplinary working and coordination by a key worker are central to quality care. These health professionals need to have specialist knowledge of the condition and a built knowledge of the patient and their family in order to provide holistic care. The study identified a number of daily challenges related to decision making and autonomy for both family and professional carers when changes in capacity occurred slowly over time and are couple with behavioural changes. The study has also highlighted some of the wider implications of the genetic nature of the condition by exploring families' decisions to share (or not) genetic information. By incorporating multiple perspectives over time this study adds to what little is known about living with HD. For further information please contact [Eleanor.wilson@nottingham.ac.uk](mailto:Eleanor.wilson@nottingham.ac.uk).

## Education News

- **Postgraduate Research conference.** The third biennial SRCC Postgraduate conference was held in October 2012. The conference was well attended with delegates from across the UK and visitors from Sweden. Feedback was very positive, and the informal atmosphere created by this small, student led conference allowed participants to engage in discussion and share experiences about the challenges of undertaking a PhD.
- **Lifecycle studentships.** Three students supported by the Lifecycle studentships awarded by the Centre are midway through their first year of study. Louise Bramley is investigating the scope for the acute hospital to offer opportunities for Advance Care Planning and the nurse's role in improving end of life care for patients and their carers in this environment. Nayheni Bassah's study will evaluate the impact of palliative and end of life care nursing course on preregistration nursing students' competencies and confidence in the care of the dying in Cameroon. Nicola Turner is exploring young people's experiences of living with and caring for, a parent who is approaching the end of life, the practices of care and interrelationships within such families, and their perspectives and evaluation of outcomes of care.

- **BSc Healthcare Studies (palliative and end of life care) and MSc health and Social care (palliative and end of life care).** The above pathways have a new 30 credit module structure starting Autumn semester 2013. The BSc award comprises three 30 credit modules and the MSc award four 30 credit modules and a 60 credit dissertation. The MSc award will be available as a full time option over 12 months from September 2013. The 2 new core modules for the above pathways:
  - *Critical perspectives in end of life care* explores contemporary debates including ethics, decision making, withdrawing treatment and advance care planning
  - *End of life Care Management* focuses on the delivery and management of care including generic symptom management of complex symptoms, application of end of life care principles and using best practice tools to manage last days of life.

Modules can also be taken as standalone pieces of academic study. For more information or registration for modules/awards go to the [Learning Beyond Registration](#) website.

For more details please contact Becky Whittaker: [becky.whittaker@nottingham.ac.uk](mailto:becky.whittaker@nottingham.ac.uk)

## Practitioner Research Network Open Meetings

*We convene and host regular seminars that are open to practitioners, educators, researchers and other interested parties.* Over the past few months, Practitioner Research Network Seminars have included talks about: end of life planning in relation to severe brain injury and chronic disorders of consciousness, the experiences of people caring for people with motor neurone disease, decision making at the end of life for people with dementia, encouraging people to talk about their illness progression and end of life, and sedation in end of life care for cancer patients. PowerPoint presentations for all these talks and video recordings of some of them can be found here: <http://www.nottingham.ac.uk/nmp/research/groups/srcc/seminars.aspx>

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. See update above, and <http://www.nottingham.ac.uk/nmp/documents/srcc/seminar-fliers-agendas/srcc-8-may-13-annual-lecture-flyer.pdf> for further details.

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)

