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Sue Ryder Care Centre @Nottingham

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



Understanding and improving palliative and end of life care

Summer 2016

Photo credit Dr Natalia Hudson

10th Anniversary Public Lecture
SRCC Anniversary Public Lecture -
29 June 2016.

New staff
Welcome to Dr Wendy Archer, Research
Fellow.

Research news
10 years of research in palliative and end of
life care.

Looking back and looking forward - 10 years of research in palliative and end of life care

This year marks 10 years of research undertaken within the Sue Ryder Care Centre for the study of Supportive, Palliative and End of Life Care.

It has been a fantastic decade of successful research, collaborations, education developments and PhD completions. We have undertaken work on communication at the end of life, advance care planning and choice and decision making, worked with hard to reach groups, examined equality and diversity issues and contributed to national end of life care policy discussions and reviews.

All of this work has been ably led by Professor Jane Seymour and more recently Professor Bridget Johnson, wonderful colleagues who brought distinctive leadership to the group and raised its profile nationally and internationally. Jane has recently moved back to Sheffield

University on a two day a week basis and Bridget now holds a clinical chair at Glasgow University. Both are missed but the centre continues with its next generation of researchers and practitioners continuing to undertake excellent work.

Which brings me to our latest news. As many of you will know, the centre was established following a generous philanthropic donation over 10 years ago. This donation allowed us to establish the centre, recruit Jane Seymour and a number of Research Fellows along with setting up a number of PhD studentships and secure external grant funding from the likes of NIHR, ESRC, CRUK and Marie Curie.

The core funding has now come to an end and so we have taken the opportunity to review our work and will be re-launching in the summer as NCARE – Nottingham Centre for the Advancement of Research into Supportive,

Palliative and End of life care. The aim of the centre is to improve the quality and equity of supportive, palliative and end of life care for individuals and those important to them through the conduct of world leading, interdisciplinary research. We aim to do this through capitalising on our collaborative networks of researchers and practitioners both within and external to the University.

For more information about the centre, its aims and activities please visit www.nottingham.ac.uk/research/groups/srcc

Professor Karen Cox
Deputy Vice Chancellor and Professor of Cancer and Palliative Care, The University of Nottingham

10th anniversary public lecture

Over the past 40 years median survival for people diagnosed with cancer has more than doubled and around half will survive 10 years or longer. This success story follows the combined efforts of science, the development of combinations of more effective treatments and better organisation of services particularly in relation to screening, multidisciplinary teamwork, tackling waiting times and earlier diagnosis.

Success has however highlighted the lack of understanding on life after cancer treatment and what might be done to optimise health for individuals who are now likely to live a long time.

It was not until 2007 that surviving cancer as a health outcome became part of the agenda for health policy in England, when a National Cancer Survivorship Initiative was established. This recent call to fill in the gap of data and evidence relating to long term health outcomes for individuals treated for cancer remains only partially addressed, but is becoming acknowledged as an important emerging field. Studies are providing insights into the wellbeing of cancer survivors and beginning to characterise the kinds of problems people experience as a result of cancer treatment and who might be most at risk.

Opening up is the opportunity of an important new era whereby long-term wellbeing becomes a new target for cancer therapy alongside managing the disease itself. But what would this look like and where should such efforts be directed? This lecture, presented by Professor Dame Jessica Corner, Pro-Vice Chancellor for Research and Knowledge Exchange, will suggest some potential answers and avenues for future research and innovation. There will also be a welcoming introduction by Professor Karen Cox, Deputy Vice Chancellor and Professor of Cancer and Palliative Care.

Join us Wednesday 29 June 2016, 5.30pm in Lecture Theatre 1, Medical School, Queen's Medical Centre.

There will be light refreshments from 5.30pm, with the lecture running 6-7.15pm.

Collaborative study day

As co-convenor of the British Sociological Association's Families and Relationships Group, Kathryn Almack recently organised a study day in collaboration with the Morgan Centre at the University of Manchester.

The Morgan Centre's Artist in Residence joined in and was busy all day sketching! Here is Kathryn in action writing up feedback from the audience:



Practitioner Research Network open meetings

We are pleased to announce dates for the research seminars for the remainder of 2016. These seminars are open to practitioners, educators, researchers and other interested parties.

All seminars begin at 12.30pm with lunch and the presentation commences at 1pm. There will be time after the talks for discussion and networking.

Details about the seminar series are on the centre's website and also advertised via email – if you would like to be added to the email list please contact ann.gibbons@nottingham.ac.uk

Education

The School of Health Sciences provides the opportunity for students to study palliative and end of life care at both degree and masters level.

The BSc Healthcare Studies includes options to complete two 30 credit modules in the speciality in addition to a third optional module and a core module in Evidence Based Practice. For more details on cost, dates and registration, see www.nottingham.ac.uk/healthsciences/lbr

The MSc Health and Social Care (palliative and end of life care) is made up of four 30 credit modules in addition to a 60 credit dissertation. The MSc award is available as a full-time option over 12 months or part-time over 2-4 years. For more details on cost, dates and registration, see www.nottingham.ac.uk/pgstudy/courses/healthandsocialcare

News

Kathryn Almack has been an invited member of an external advisory group established by the Care Quality Commission (CQC), to provide expert input and critical comment into CQC's 'Inequalities and Variations in Provision of End of Life Care' themed programme.

Kathryn's involvement was critical in providing evidence and expertise related to the specific needs of lesbian, gay, bisexual and trans people. The CQC report: A different ending – *addressing inequalities in end of life care* was published in early May and it has already attracted significant media coverage, picking up on the need to improve end of life care for those groups that are so often overlooked and marginalised.

Congratulations to: Louise Bramley and Nahyeni Bassah who were both awarded their PhDs.

Seminar	Seminar speakers
21 July 2016	<p>Gunn Grande – Professor of Palliative Care at the University of Manchester.</p> <p>Title: Supporting family carers during care giving towards the end of life.</p> <p>This presentation will consider the importance of family carers, the impact of care giving on carers and how we may support them, both during care at home and upon discharge home from inpatient care.</p>
15 September 2016	<p>Ethics seminar – A short presentation by PhD student Donna Barnes, followed by discussion groups focused on the practical ethical issues we encounter while doing research.</p>

The two specialist 30 credit modules for the above awards are:

- **Critical perspectives in palliative and end of life care**, which explores contemporary debates including ethics, decision making, withdrawing treatment and advance care planning
- **Palliative and end of life care management**, which 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

These modules can also be completed on a stand-alone basis.

Please contact Becky Whittaker, Assistant Professor Palliative and End of Life Care, for further information: becky.whittaker@nottingham.ac.uk

New staff - Dr Wendy Archer



Wendy recently joined the Centre as Research Fellow working on the VERDIS-AHP project exploring communication between allied health professionals (OTs and PTs) and patients in palliative care environments.

An Applied Sociolinguist, Wendy has worked as a HE lecturer in the UK and overseas (Italy, Germany, Oman) and has supervised dissertation students working on a variety of linguistics and applied linguistics topics, both theoretically-oriented and practice-based. She has also worked as a teacher trainer, is a keen materials developer and an experienced academic writer, most recently contributing to and teaching on an advanced support class for native and non-native PhD Thesis writers. She speaks fluent Italian, French and German.

With her background in applied linguistics, Wendy is particularly interested in understanding how language is used in institutional settings and how this knowledge can be applied in developing specialist communication skills training materials in social and medical settings.

Having previously conducted research using audio- and video-recording techniques in both healthcare and educational contexts (such as antenatal clinics and classroom settings), Wendy's research is primarily qualitative and utilizes the methodology of Conversation Analysis to understand how speakers make sense of one another's verbal and visual contributions in interaction. She also has interests in the use of quantitative methods (e.g. Corpus Linguistics) to explore the construction of social identities and concepts in public and mediated discourse contexts, such as computer-mediated communication (CMC) and media/broadcast talk.

Introducing the VERDIS-AHP project

The new Video-Based Communication Research with Allied Health Professionals (VERDIS-AHP) project aims to develop knowledge about how specialist physiotherapists and occupational therapists communicate with hospice patients and their significant others through speech, touch and gesture to talk about sensitive issues and to make decisions together. This knowledge, alongside clips from video-recordings, will be used to enhance training resources used in communication skills training.

Funded by the NIHR, Dr Ruth Parry and Dr Wendy Archer are working on the project which will collect and analyse, using Conversation Analysis, up to 45 video recordings of consultations and therapy sessions between specialist physiotherapists and occupational therapists with patients (and their accompanying relatives or friends) using inpatient and outpatient hospice and hospital services.

We are now working on developing the protocol and associated ethics documentation in preparation for the start of data collection in the late summer/early autumn.

You can read more about the project by visiting www.nottingham.ac.uk/research/srcc/verdis-ahp

Feature study - PrAISED: Promoting Activity Independence and Stability in Early Dementia

People with dementia can struggle with everyday activities, may stop doing things they need to do, are more prone to accidents and have a higher risk of falling. Physiotherapists can teach exercises which increase activity and improve balance, and occupational therapists can advise on how to do daily activities more easily and safely. However there is little research on how to make these interventions work for people with dementia.

Dr Sarah Goldberg and Dr Kristian Pollock are part of a team of researchers who have been awarded £2.8 million by the NIHR for a six-year programme of research to develop and

evaluate an intervention which aims to keep people with dementia active and independent. The programme is a collaboration between The University of Nottingham, Nottingham University Hospitals, Nottinghamshire Healthcare Trust, City Care Partnership and Bangor University with Professor Rowan Harwood (NUH) as Chief Investigator.

This programme of work involves the development and evaluation of an intensive activity and exercise programme over a year. Part of the programme, led by Dr Sarah Goldberg and Prof Rowan Harwood, will test the feasibility of two interventions (one involving 50 hours of supervised activity over a 12 month period, the

other 11 hours of supervised activity over a 3 month period) compared to standard care of falls prevention advice. We will be using the learning from this to tailor the intervention to the individual participant for the main trial, in which the effects of the intervention are compared with standard care.

A process evaluation, with Dr Kristian Pollock as joint lead, then aims to understand how the intervention is implemented in practice. One of the workstreams will be dedicated to how to motivate people with dementia to adhere to the programme.

Publications

Recent publications

Almack, K (2016) Death, Dying and Bereavement. In Goldberg, A (2016) The SAGE Encyclopaedia of LGBTQ Studies. Sage Publications.

Caswell, G (2016). 'We can do nothing for the dead': The Free Presbyterian Church of Scotland's approach to death and the funeral', in Buckham, S., Jupp, P.C. & Rugg, J. (eds) Death in modern Scotland, 1855-1955: beliefs, attitudes and practices. Oxford: Peter Lang. pp. 301-318.

Caswell, G and O'Connor, M (2015) 'Agency in the context of social death: Dying alone at home', Contemporary Social Science, 10(3), 249-261 DOI:10.1080/21582041.2015.1114663

Pollock, K Is home always the best and preferred place of death? British Medical Journal, 351: h4855, doi: 10.1136/bmj.h4855.

Rietjens, J, Korff, I, Dunleavy L, Preston NJ, Jabbarian LL, Arnfeldt Christensen, C, de Brito M, Bulli F, Caswell G, Cery, Branka, van Delden, Johannes, Deliens L, Gorini G, Groenvold M, Houttekier D, Ingravallio F, Kars M, Lunder U, Miccinesi G, Mimic A, Paci E, Payne S, Polinder S, Pollock K, Seymour J, Simoncic A, Johnsen A, Thit V, Mariette N, de Vries E, Wilcock A, Zwakman M and van der Heide A, 2016. Advance care planning – a multi-centre cluster randomised clinical trial: the research protocol of the ACTION study, BMC Cancer. 16 (264).

Stacey, G, Pollock, K, Crawford, P. The rules of the game in graduate entry nursing: A longitudinal case study. Nurse Education Today, 36: 184–189. DOI: 10.1016/j.nedt.2015.09.016.

Wilcock, A, Crosby, V, Hussain, A, McKeever, TM, Manderson, C, Farnan, S, Freer, S, Freemantle, A, Littlewood, F, Caswell, G and Seymour, J (2016). 'Lung cancer diagnosed following an emergency admission: Mixed methods study of the management, outcomes and needs and experiences of patients and carers'. Respiratory Medicine, 114, 38-45. doi:10.1016/j.rmed.2016.03.006

This publication is available in alternative formats:
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