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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**

Autumn 2015

Photo credit Dr Natalia Hudson

Study opportunities

Degree and masters level programmes in palliative and end of life care

Training

Four new training programmes and tools for end of life care

Research news

A round-up of current projects and events

PhD/MD student conference in December

The Palliative Care Research Society in conjunction with the Sue Ryder Care Centre for the Study of Supportive, Palliative and End of Life Care at The University of Nottingham, are hosting a day conference for PhD/MD students in December 2015. There will be opportunities to present your work either orally or in a poster, to network and to attend keynote sessions on 'Preparing for your Viva' and 'First steps post-PhD'.

Research in the field of supportive/palliative and end of life care: developing the next generation of researchers

Date: Tuesday 8 December 2015

Time: 11.00 to 16:00

Venue: University Park, University Of Nottingham

The conference is free of charge to University of Nottingham students. For further information contact:

- Dr Kathryn Almack: k.almack@nottingham.ac.uk
- Dr Glenys Caswell: glenys.caswell@nottingham.ac.uk

Practitioner Research Network Open Meetings

We are pleased to announce dates for the Research Seminars for the remainder of 2015 and the beginning of 2016. These seminars are open to practitioners, educators, researchers and other interested parties.

Seminar	Speaker
26 November 2015	Caroline Nicholson, King's College London
21 January 2016	Annette Furley

All seminars begin at 12.30 with lunch and the presentation commences at 1pm. There will be time after the talks for discussion and networking. The current schedule of speakers is shown above and titles will follow in due course. Details about the seminar series are also advertised via email – if you would like to be included on the email list for such events please contact ann.gibbons@nottingham.ac.uk.

Education and training

Study opportunities in the School of Health Sciences

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

BSc Healthcare Studies

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 cost, dates and registration, see

www.nottingham.ac.uk/healthsciences/learning-beyond-registration

MSc Health and Social Care (palliative and end of life care)

The MSc Health and Social Care (palliative and end of life care) comprises 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 of cost, dates and registration, please visit www.nottingham.ac.uk/pgstudy/courses/nursing-midwifery-and-physiotherapy/health-and-social-care-msc.aspx

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. For further information please contact Becky Whittaker, Assistant Professor Palliative and End of Life Care at becky.whittaker@nottingham.ac.uk.

Launch of programme supporting carers in end of life care

In our last newsletter we reported on a dissemination event for a training programme developed by researchers at the SRCC in collaboration with stakeholders.

This training programme is now published and is freely available online. It will improve the skills of staff and volunteers who provide support to people providing end of life care for a relative or friend at home. The programme has been developed by Professor Jane Seymour, Dr Beth Hardy and Dr Glenys Caswell together with the Carers Federation in Nottingham and colleagues from the Universities of Cambridge, Manchester and Sheffield.

The project was jointly funded by Marie Curie and Dimpleby Cancer Care. It will provide participants with insight into the practical and emotional needs of carers and confidence to deliver support and mentorship. The core training is designed to be delivered over one day and includes discussion guides, group exercises and film clips of carers talking about their experiences.

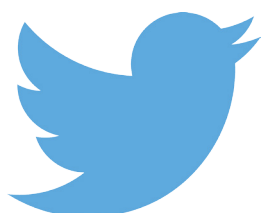
Bill Noble, Medical Director at Marie Curie said: "Informal carers of patients approaching the end of life assume great responsibility in ensuring that their friend or relative has appropriate care and research by UCL found that unpaid carers of people with terminal cancer alone provide health and social care worth £219million each year.

Yet there is often limited support available to them. We need to recognise the contribution carers make and support them in their role. This programme will better enable those that work with carers to ensure they get the right help, advice and support."

Several health and social care organisations have already been involved in piloting the training including Marie Curie who has been using it to train its Support Line advisers, and volunteers for the charity's recently launched Helper service.

Any enquiries please contact Glenys Caswell at glenys.caswell@nottingham.ac.uk. The training programme can be accessed here: www.nottingham.ac.uk/helm/dev/end_of_life/

A new Twitter community of end of life care knowledge and learning



Professor Bridget Johnston (@BridgetJohnst) is co-hosting a new social media venture with Sarah Russell (@learnhospice) and Laura Middleton Green (@heblau).

The vision is for **@WeEOLC #WeEOLC** to become a Twitter community of end of life care learning and practice. It will provide a space for sharing evidence and resources (through #WeEOLC #EBP),

generating interaction and debate. We actively encourage involvement and discussion about a range of topics related to end of life care, from all roles and in all settings.

We will be developing the community over the next few months to include different ways of engaging and learning, and welcome ideas and suggestions along the way.

Find out more at <http://wecomunities.org/blogs/127>, in this short cartoon <https://www.youtube.com/watch?v=FbV6oRWE8c4&rel=0> and in this ehospice article <http://www.ehospice.com/ArticleView/tabid/10686/ArticleId/16835/language/en-GB/View.aspx>

Professor Johnston has been appointed as one of two Macmillan Alumni Patrons. You can find more information about the Macmillan Alumni at <http://www.macmillan.org.uk/Aboutus/Healthandsocialcareprofessionals/Networking/Alumni.aspx>.

Family Troubles: Care and change in diverse contexts

Kathryn Almack and Nicola Turner attended a symposium on Family Troubles: Care and Change in Diverse Contexts, University of Reading, 16 September 2015. Parallel paper sessions included the themes:

- Meanings of 'family' and (troubling) changes in family lives
- Life-limiting illness, dying bodies and family caring practices

Nicola presented findings from her doctoral research - exploring the meaning and practice of 'family' for young people when a parent is at the end of life. Kathryn presented an auto-ethnographic paper using her family's experiences of her father's death at the age of 89 as a 'critical case' to explore the mismatch between personal experience and the policy landscape around end of life care and ways in which this can be troubling to families and also the ways in which it can lead to questions about - or trouble - notions of 'family'.

This event builds on earlier work on the theme of Family Troubles sponsored by the Centre for Citizenship, Identities and Governance at the Open University. For related events and links, see <http://www.open.ac.uk/ccig/research/families-relationships-and-communities/family-troubles>, and watch this podcast for a presentation of the associated book: 'Family Troubles: Exploring Changes and Challenges in the Family Lives of Children and Young People' edited by Jane Ribbens McCarthy, Carol-Ann Hooper and Val Gillies, 2013, Policy Press.

Real Talk – A DVD for communication training

Becky Whittaker, who usually teaches pre and post registration nurses about palliative and end of life care at Nottingham is currently working as a researcher in the group. She is evaluating a new DVD designed for use in training courses that focus on palliative and supportive care communication. The DVD includes clips from real life consultations recorded as part of the VERDIS research project on hospice communication (www.nottingham.ac.uk/verdis).



Approximately 40 professionals up and down the country are using the DVD in their training courses. Becky will be gathering feedback from the trainers and trainees about whether and how they found the materials useful. Results will be out in 2016.

Research on communication used in professional guide

A new guide from Canada called 'Just ask: A conversation guide for goals of care discussions' draws considerably on a publication by group members Ruth Parry, Victoria Land and Jane Seymour (<http://spcare.bmj.com/content/early/2014/10/24/bmjspcare-2014-000649.full.pdf+html>). The 'Just ask' guide is designed to give professionals practical advice on conversations with seriously ill people about medical treatment decisions. It can be downloaded, for free via http://www.virtualhospice.ca/Assets/Just%20Ask%20Booklet-rev-May8_FINAL-web_20150626123629.pdf and http://www.advancereplanning.ca/media/134529/acp_just_ask_booklet-rev-may8_final-print.pdf

International conference on Advance Care Planning

Jane Seymour, Kristian Pollock and Louise Bramley attended the 5th International Conference on Advance Care Planning and End of Life Care, 9-12 September 2015 at the Ludwig-Maximilians-University Munich, Germany, presenting their research on advance care planning in frail older people, as well as participating in international project planning meetings for the EU 'ACTION' trial of advance care planning for cancer patients and networking with 300 conference participants from all over the world.

For further information about the conference, please visit the website at <http://www.acpel2015.org/>

Initiating Advance Care Planning discussions in community settings

The Care and Communication study about how patients and health care professionals initiate discussion of Advance Care Planning has been published and is available at http://www.journalslibrary.nihr.ac.uk/__data/assets/pdf_file/0010/149662/FullReport-hsdr03310.pdf.

This qualitative study looked at how patients and health care professionals initiate discussions about Advance Care Planning (ACP) in community settings. It included interviews with 37 professionals (general practitioners, specialist nurses and community nurses) and 21 patient case studies involving serial interviews with patients, family carers and health care professionals with up to six month follow up.

The study reported that ACP was uncommon and challenging for health professionals who found it difficult to initiate ACP and often postponed discussion until a crisis occurred or death was

clearly imminent. Most discussions focused on specific documented decisions, such as preferred place of death and cardiopulmonary resuscitation, rather than general beliefs and values in the event of future incapacity.

The study highlighted the provisional, uncertain, shifting nature of patients' preferences for future care and the complexity and challenges of advance care planning in community settings.

For further information about the project and its findings please contact kristian.pollock@nottingham.ac.uk.

BOUGH: Broadening our Understanding of Good Home Care

A two-year study to investigate the work of home care workers in supporting people with dementia to live at home is getting underway.

BOUGH: Broadening Our Understanding of Good Home Care will employ a combination of qualitative interviews, participant observation, job analysis and diary keeping. It will explore how home care workers and their clients experience giving and receiving care, so that its function in community support can be described fully, with a view to service development and effective commissioning.

For further information about the study, please contact justine.schneider@nottingham.ac.uk or kristian.pollock@nottingham.ac.uk.

For further information about the study, please visit <http://www.nottingham.ac.uk/go/BOUGH>.

Publications

Recent publications

Gladman, J. R. F., R. Harwood, Conroy, S., Logan, P., Elliott, R., Jones, R., Lewis, S., Dyas, J., Schneider, J., Porock, D., Pollock, K., Goldberg, S. et al. (2015). "Medical Crises in Older People" Programme Grants for Applied Research 3(4)

Parry, R. (2015). Patient-focused practice and communication: Use of communication in the clinical setting Grieve's Modern Musculoskeletal Physiotherapy 4th Edition G. Jull, A. Moore, A. Falla et al. Elsevier.

Pollock, K. and E. Wilson (2015). "Care and communication between health professionals and patients affected by severe or chronic illness in community care settings: A qualitative study of care at the end of life." Health Services and Delivery Research 3(31).

Pollock, K. and J. Seymour (2015). Communication and Advance Care Planning in Older People Palliative care for older people: A public health perspective. L. Van den Block, G. Albers, S. Pereira et al. Oxford, Oxford University Press.



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The University of Nottingham has made every effort to ensure that the information in this newsletter was accurate when published. Please note, however, that the nature of the content means that it is subject to change from time to time and you should therefore consider the information to be guiding rather than definitive.

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