

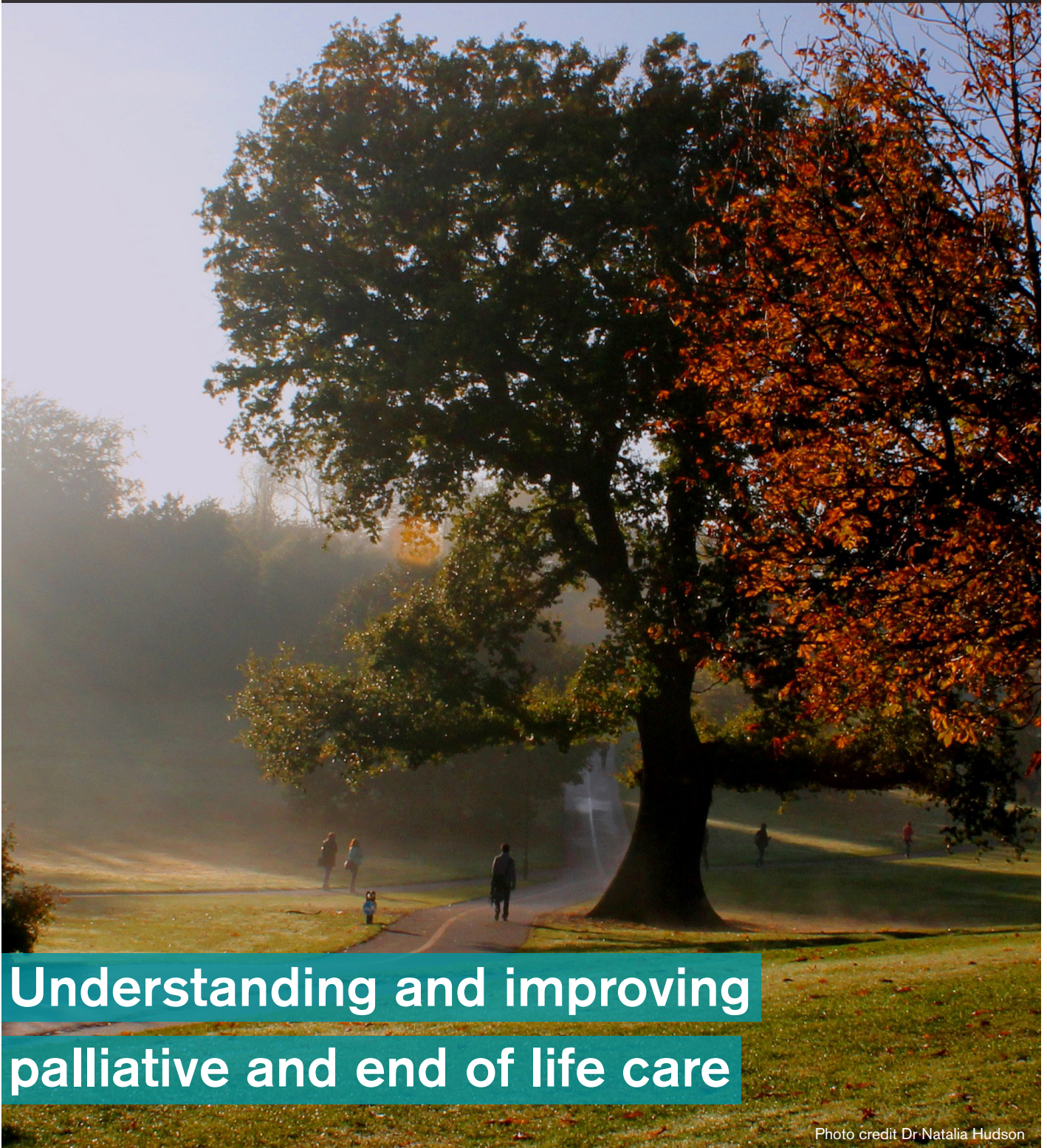


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# Sue Ryder Care Centre @Nottingham

Sue Ryder Care Centre for the Study of Supportive, Palliative and End of Life Care Newsletter Spring 2015



## Understanding and improving palliative and end of life care

Photo credit Dr Natalia Hudson

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### Annual lecture

SRCC Annual Public Lecture -  
6 May 2015.

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### New staff and PhD students

Welcome to Dr Sarah Goldberg, Hana  
Agustina, Dalhat Khalid and Claire Smith.

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### Research news

A round-up of current projects and events.



## Annual public lecture 2015 New research grants

**The 2015 Sue Ryder Care Centre annual public lecture will take place on Wednesday 6 May 2015 from 6.15-7.15pm in Lecture Theatre A30, Lakeside Arts Centre on University Park Campus.**

The speaker is Dr Richard Harding of the Cicely Saunders Institute, Kings College London, who will be speaking on: "Palliative and end of life care: an essential component of the global health agenda" Light refreshments will be served at 5.30pm followed by the lecture at 6.15pm.

All are welcome but please endeavour to email [ann.gibbons@nottingham.ac.uk](mailto:ann.gibbons@nottingham.ac.uk) if you are planning to attend.

Funding for further development of the Dignity Care intervention (DCI) for use by Community Nurses (CNs) with older patients nearing the end of life. NIHR Programme Grant for Applied Research (PGfAR)

Development Funding Nottingham City Clinical Commissioning group May 2015-April 2016. Evaluation of Nottingham City Clinical Commissioning Group End of Life Long term Conditions Pilot July 2015-Jan 2016

Additional Funding for Evaluation of Macmillan Specialist Care at Home Project to incorporate the Pictor technique as a data collection tool. Macmillan Cancer Support Jan 2015-March 2016

### Overseas visits

## Prestigious travel award for Nicola

In January of this year, Nicola Turner, a PhD student in the SRCC, travelled to California to deliver a presentation at the Fourth International Conference on the Geographies of Children, Young People and Families at the University of San Diego. She was able to do so due to her successful application for a prestigious Graduate School Travel Prize. Her paper, 'Caring to the End: young people living with a parent at the end of life', was included in a session on 'Families, care and relationality'. This was a valuable opportunity for Nicola to discuss some of the initial findings from her PhD study with a diverse audience and to learn from colleagues who are also studying family care in a variety of contexts. The trip thus enabled Nicola to build positive links with family care researchers from around the world.

## Jane visits SRCC PhD student in Malawi

Jane Seymour has recently returned from a trip to Malawi, where she was able to visit Kennedy Nkhoma, one of the Centre's PhD students. Kennedy has had the key findings from his study published in the Journal of Pain and Symptom Management 'An educational intervention to reduce pain and improve pain management for Malawian people living with HIV/AIDS and their family carers: a randomised controlled trial' <http://www.ncbi.nlm.nih.gov/pubmed/25666517>



Jane Seymour with Kennedy Nkhoma at Msuzu Hospital.

## Presenting research in Philadelphia

On 26 February 2015, Jane Seymour and her colleague Dr Brian Cassel from Virginia Commonwealth University presented a paper reporting their comparison of palliative care in England and the USA at the Annual

Assembly of the American Association of Hospice and Palliative Medicine at the Pennsylvania Convention Center, Philadelphia. One of the plenary speakers at the conference was Dr Atul Gwande, author of the acclaimed book 'Being Mortal'.

You can see a film of Dr Gwande in conversation with the ehospice Chair, David Prall by following: <http://www.ehospice.com/uk/ArticleView/tabid/10697/ArticleId/13103/language/en-GB/Default.aspx>

### Education

## Education

**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 four 30 credit modules and the MSc award four 30 credit modules in addition to a 60 credit dissertation. The MSc award is now available as a full-time option over 12 months from September 2013.

The two core 30 credit modules for the above pathways are:

- Critical perspectives in end of life care, which explores contemporary

debates including ethics, decision making, withdrawing treatment and advance care planning

- 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

Please contact Becky Whittaker for further information at: [becky.whittaker@nottingham.ac.uk](mailto:becky.whittaker@nottingham.ac.uk)

## Supporting carers

On 18 February 2015 a research sharing workshop was held at the East Midlands Conference Centre which reported on the development of a training programme that has been developed by SRCC researchers in collaboration with a range of stakeholders.

The group, including Carers Federation, Age UK (Nottingham), specialist palliative care providers, bereaved carers and academic experts in this field met to discuss progress on the project. 34 people attended the workshop, representing 18 different organisations. Lively discussion was held about how this training could be used in different areas and the utility it may have for different organisations. The training programme is currently being finalised and will be available for use from Summer 2015. This research has been funded by Marie Curie and Dimpleby Cancer Care.

Any enquiries please contact Glenys Caswell: [glenyscaswell@nottingham.ac.uk](mailto:glenyscaswell@nottingham.ac.uk)



Discussion underway at the supporting carers workshop.

## VERDIS at conferences

Ruth Parry has recently visited several venues to talk about findings from the 'VERDIS' project - which entails video-based research on communication in palliative care.

These have included Keele University, the Medical School at the University of East Anglia, LOROS Hospice in Leicestershire,

and St Christopher's Hospice. Over the coming months, Ruth, and colleague Marco Pino will be talking at several conferences about their research on how patients, their relatives, and experienced doctors broach the difficult topic of the patient's impending death. These conferences will take them to Loughborough in the UK and then further afield to Antwerp in Belgium.

## Public involvement, engagement and co-production

Sue Ryder Group member Ruth Parry, and one of her research advisors Jeanne Rae recently attended a workshop led by Derek Stewart OBE – who has wide experience of both working on, and teaching about improving research

with the help of the public.

Newsletter readers may want to look at Derek's blog 'Make a Difference' at [www.derek-online.blogspot.co.uk](http://www.derek-online.blogspot.co.uk)

### Staff

## New staff and PhD students

### Dr Sarah Goldberg

Sarah has recently joined the SRCC as Associate Professor in Older Persons Care. Prior to joining the SRCC she worked as a senior research fellow in the Division of Rehabilitation and Ageing at the University of Nottingham, where she was involved in the evaluation of a specialist medical and mental health unit (MMHU) at Queens Medical Centre. Sarah continues this important work through funding from the Alzheimer's Society, developing a series of re-useable learning objectives (RLOs) on the hospital care of patients with dementia. Sarah's other research interests include development of the role of Advanced Nurse Practitioner for frail older patients; patients with dementia who are verbally agitated and how healthcare professionals communicate with patients with dementia.

### Hana Agustina

Hana is a first year PhD student from Indonesia who joined the Sue Ryder Care Centre in January 2015. Her proposed study is 'Developing a learning model for improving compassionate care among undergraduate nursing students when they are caring for people during an end-of-life period: a study in an Indonesian context'.

### Dalhat Khalid

Dalhat is the most recent PhD student to join the SRCC. His research topic concerns "The meaning of dying with dignity in End of Life Care among patients with cancer in the Oncology Unit, Ahmadu Bello University Teaching Hospital (ABUTH), Zaria, Nigeria".

### Events

## Practitioner Research Network – Open Meetings

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

Seminar	Speaker
16 July 2015	Hannah Rumble, University of Exeter
24 September 2015	Christopher Saunders
26 November 2015	Caroline Nicholson, King's College London

All seminars begin at 12.30pm with lunch and presentations commencing 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](mailto:ann.gibbons@nottingham.ac.uk)

### Claire Smith

Claire, a Staff Nurse on the Oncology Ward at the City Hospital Nottingham, has joined the SRCC on a part-time basis, for 6 months from January 2015. Claire has been awarded a scholarship; an NHS England and Health Education England National Care Maker Clinical Scholar Bronze Award, and is being mentored by Professor Bridget Johnston. Claire is undertaking a study about compassionate care at the end of life.

### Visiting academic - Susanne de Kort

The SRCC is currently hosting a visiting colleague from Leiden in the Netherlands. Susanne is an elderly care physician and ethicist whose main interests are in palliative care and moral reflections upon what constitutes good care.

## VERDIS: project

The VERDIS project aims to capture communication within hospice consultations between experienced doctors and patients and their relatives.

The purpose is to better understand a number of specific areas of communication, and to translate those understandings into staff guidance and training. Several Sue Ryder group members are working on the project: Ruth Parry, Marco Pino, Victoria Land, and shortly – Laura Jenkins. A total of 37 consultations were video-recorded with five doctors, 37 patients using inpatient and outpatient hospice services, and 17 relatives or friends who accompanied the patients. We are now working on both analysing the verbal and non-verbal communication captured in the video-recordings and preparing training resources for use in staff communication skills training. We are focusing on several topics: empathy, pain, how experienced clinicians help patients to talk about their impending death in a sensitive manner, how shared decisions can be facilitated, and how advance care plans get talked about and made during consultations. You can read more about the project by searching 'VERDIS @ nottingham' or here [www.nottingham.ac.uk/verdis](http://www.nottingham.ac.uk/verdis)

## The Last Outing: project findings

Dr Kathryn Almack has been working together with the renowned gerontologist Gloria Gutman from Simon Fraser University to co-convene a Symposium at the International Association of Gerontology and Geriatrics European Region Congress in April 2015 in which findings from the The Last Outing project will be presented.

Kathryn has coordinated a panel of five speakers from Canada, UK, Sweden, Ireland and Spain. Two other conference presentations will disseminate findings from the project and will take place at the Royal College of Nursing Education Forum conference - April 2015: "I have no wish to be at the tender mercies of a homophobic carer/service": exploring end of life experiences and care needs in the lives of older lesbian, gay, bisexual or trans (LGBT) people. Queer Kinship and Relationships International Conference, Poland - June 2015: Friends, families and kinship: proximity and intimacy in the support networks of LGBT elders.

## Therapy research project

Are you interested in physiotherapy and occupational therapy in supportive, palliative and end of life care?

Following on from video-based research on experienced palliative doctors' communication with patients, Ruth Parry will shortly begin similar video-based research with physiotherapists and occupational therapists who are palliative specialists. She is keen to hear from professionals and from lay people who are interested in this area and who might be interested in getting involved in the project.

Contact Ruth by email: [ruth.parry@nottingham.ac.uk](mailto:ruth.parry@nottingham.ac.uk)

### Publications

## Recent publications

Almack, K, Moss, B. and Smith, T (2015) Research and policy about end of life care for LGBT people: identifying implications for social work services. Chapter 10, 173-186. Published in J. Fish. and K. Karban, (eds.), Social Work and Lesbian, Gay, Bisexual and Trans Health Inequalities: International Perspectives. Bristol: Policy Press.

Brooks, J., Bravington, A., Hardy, B., Melvin, J and King, N, (2015) 'It's not just about the patient, it's about the families too': end-of-life care in the home environment. *BMJ supportive & palliative care*. 5(1), 114-115

Cameron D and Johnston B (2015) The Development and Initial Validation of a Questionnaire to Measure the Key Attributes of the Community Palliative Care Specialist Nurse Role *IJPN* 2014 vol 21 no 2 p.87-95

Gysels, Marjolein, Johnston, Bridget, Bausewein, Claudia, Petkova, Hristina and Murtagh, Fliss E. M., (2015) What influences the place of care and death in people with advanced dementia? *European Journal of Palliative Care*, 2015; 22(2)

Hardy, Beth, King, Nigel and Rodriguez, Alison, (2014). The experiences of patients and carers in the daily management of care at the end of life. *International journal of palliative nursing*. 20(12), 591-8

Johnston B M, Rogerson E, Ma Macijauskiene J Blaževiciene A Cholewka, P (2014) Self-management in the context of palliative nursing a modified concept analysis. *BMC Nursing* 2014, 13:21 doi:10.1186/1472-6955-13-21

Johnston, B. (2014) Is effective, person-centred, home-based palliative care truly achievable?. *Palliative medicine*, 28(5), 373-374.

Johnston B M (2014) Palliative home based technology from a practitioners' perspective

benefits and disadvantages" "Smart Homecare Technology and TeleHealth 2 (2014). (open access)

Johnston BM, McIlpatrick S Connolly M, Barry C Östlund U, Narayanasamy M, (2015) Dignity conserving care in palliative care settings: An integrative review *Journal of Clinical Nursing* doi 10.1111/jocn.12791

Johnston BM Confidentiality and qualitative research (2015) (Editorial) Vol 21, No 1 p.3

Johnston, B Gaffney M, Pringle J and Buchanan, D (2015) 'The Person Behind the Patient: A Feasibility Study Using the Patient Dignity Question for Patients with Palliative Care Needs in Hospital', *International Journal of Palliative Nursing*. *IJPN* 2014 vol 21 no 2 p.71-77

Johnston, B M Pringle J, Gaffney M, Narayanasamy M J, McGuire M and Buchanan D (2015) The dignified approach to care: using the Patient Dignity Question as an intervention to enhance dignity and person-centred care for people with palliative care needs in the acute hospital setting. *BMC Palliative Care* (open access)

Pringle J Johnston B Gaffney M Buchanan D (2015) Dignity and person-centred care for people with palliative care needs in the acute hospital setting: a literature review. *Palliative Medicine* doi DOI: 10.1177/0269216315575681

Westwood, S, King, A, Almack, K, Yui-Suen, T and Bailey, L, (2015). Good Practice in Health and Social Care Provision for Older LGBT people. Chapter 8, 145-158 Published in J. Fish. and K. Karban, (eds.), Social Work and Lesbian, Gay, Bisexual and Trans Health Inequalities: International Perspectives. Bristol: Policy Press.

### For further information please contact:

Dr Ruth Parry, Principal Research Fellow  
Sue Ryder Care Centre  
School of Health Sciences  
The University of Nottingham  
Queen's Medical Centre  
B Floor, South Block Link Corridor  
Nottingham, NG7 2HA

e: [srcc@nottingham.ac.uk](mailto:srcc@nottingham.ac.uk)

w: [www.nottingham.ac.uk/research/groups/srcc](http://www.nottingham.ac.uk/research/groups/srcc)

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