

**Exploring the experience of a personal bereavement for nurses working in a palliative care setting, and the experience of returning to work.**

**A Surrey/Sussex Hospice Collaboration**

Working in palliative care involves healthcare professionals being constantly exposed to death and dying and witnessing the distress this can cause both patients and families (Ablett et al, 2007). Experiencing a rapid succession of patient deaths can be a source of stress to hospice nurses compounded by making and severing attachments to many different people (Hawkins et al, 2006). When a nurse or health care assistant (HCA) experiences a personal bereavement, the ability to work within the palliative care environment may be more challenging and have immediate or long term consequence on their personal and professional life.

We became aware of a number of palliative care nurses who had cared for a significant relative or friend at the end of life and returned to working in a palliative care setting afterwards. Some returned to work after a period of leave but found the emotional burden too much and left their role, others coped with temporary redeployment. Some returned to work within days and continued in their roles. Others felt no option but to return to their jobs due to financial commitments. This led 4 hospices in Surrey and Sussex to consider a small qualitative study to explore the experience of bereaved nurses working in palliative care and what measures hospices could take to support and retain bereaved staff. The four hospices (St Catherine's Hospice, Princess Alice Hospice, Phyllis Tuckwell Hospice

and Woking and Sam Beare Hospice joined together to undertake a small qualitative study.

**Aim:** to explore the experience of a personal bereavement for nurses working in a palliative care setting before and after the death of a significant relative or friend.

**Secondary aim:** to make recommendations on how best to provide support pre-and post-bereavement, to retain valuable nursing staff when they experience a personal bereavement.

**Outcome**

To inform and develop initiatives to support nurses working in palliative and end of life care before and after the death of a significant relative or friend.

The four hospices will report the findings to their management teams, Hospice UK and will publish in a relevant journal.

Ablett, J.R. Jones, R.S.P. Resilience and well-being in palliative care staff: A qualitative study of hospice nurses' experience of work. *Psycho-Oncology* 16: 733-740 (2007) 2007

Hawkins, A.C. Howard, R.A. Oyeboode, J.R. Stress and coping in hospice nursing staff: the impact of attachment styles. *PsychoOncology* 16: 563-572 (2007)

We are grateful to Hospice UK for the Small Grant Award they gave us towards the study.

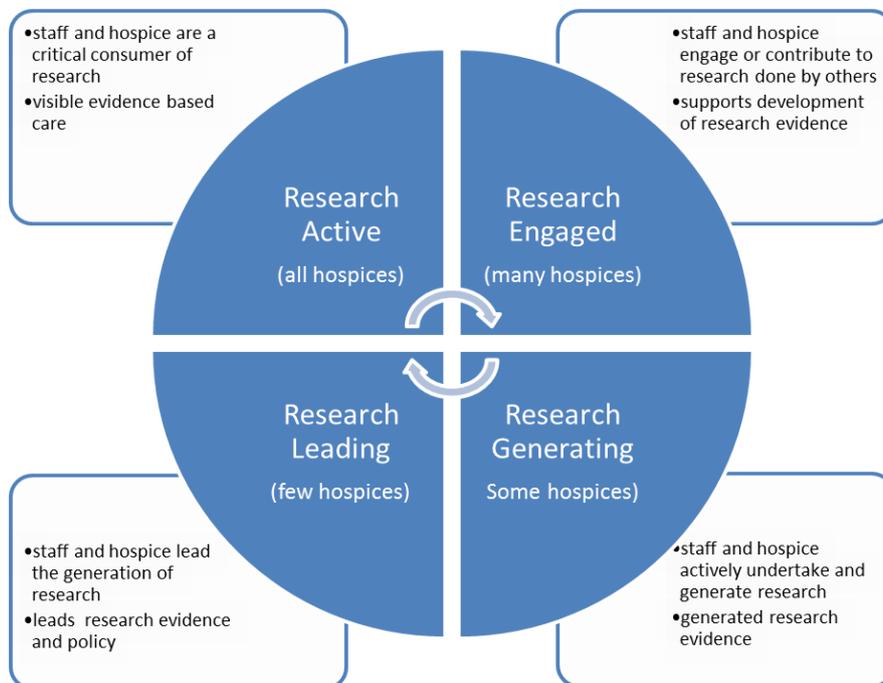
Liz Reed, Research Lead, Princess Alice Hospice

# Promoting research engagement in a UK Hospice

Liz Reed, Research Lead, Princess Alice Hospice

Over the last 4 years, research activity has grown at Princess Alice Hospice (PAH) and has become more diverse through collaboration, in addition to generating some of our own research projects. Based on the Hospice UK research model (figure 1) we have moved from being a simple research active hospice to becoming research engaged, and also started to move into some areas of research generation and leading research within a collaboration. In light of this, and a new organisational strategy, the research team felt there was a need for more robust internal research governance and successfully recruited experts by experience and external academics to attend our quarterly research committee meeting.

Figure 1: Hospice UK model for research active hospices 2017



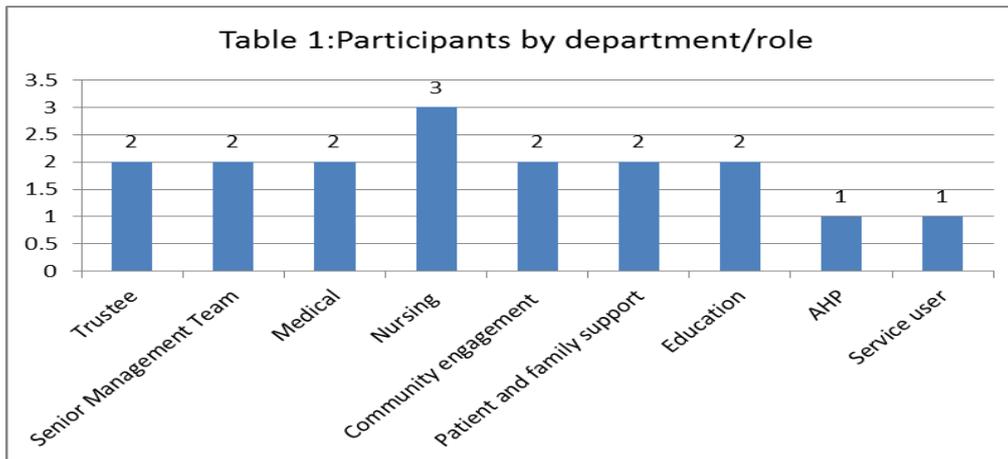
A research strategy workshop was held in September 2017, with good representation from around the organisation and a total of 17 Hospice staff participated (Table 1).

Workshop participants worked in multi-professional groups to consider the organisational strategy in the context of the national picture and to share their perspectives on the way forward for research within the Hospice.

There was agreement that all research activity undertaken at PAH, both internal and external should be aligned with the organisational strategy and the national picture as it evolves. This aims to ensure we are developing relevant knowledge and evidence based practice to support our work.

# Promoting research engagement in a UK Hospice

The importance of how we 'Use- Generate-Use' research within PAH was highlighted. Use the current research literature effectively and competently, *generate* new evidence effectively, and *use and share* new research effectively, to ensure it is presented and disseminated in an accessible way and translated into service development and delivery.



Going forward over the next year we will focus on internal engagement with research through a number of different approaches:

- ◆ 'Why do we do it that way?' sessions for clinical staff on evidence in everyday care
- ◆ Support service development by undertaking literature reviews as a part of the planning process
- ◆ Monthly Research Seminars
- ◆ Work closely and engage with clinical team to support them in research development and involvement in the research process with patients and their families.
- ◆ Support staff to promote their own work through publication/posters at conferences and in journals.
- ◆ Work with our librarian to develop an inclusive 'Reflective Reading group' as a move away from the clinically focused Journal Clubs.

## Next steps.....

Over the next 3 years, the research team will initially re-focus on promoting and developing an internal culture of enquiry to further embed research as part of core business. The Hospice will build the organisation's research capacity and continue to developing existing and new collaborations and maintain a high level of awareness for new internal or externally generated projects.

**"Research is not a luxury; it is a standard for care. It is about being constantly curious and disciplined to discover and implement evidence that informs us about the best models of care, gaps in knowledge and practice, and different ways of working"**

Dr Sarah Russell, Hospice UKs Head of Research and Clinical Innovation.

## Key messages from APC Conference 2018

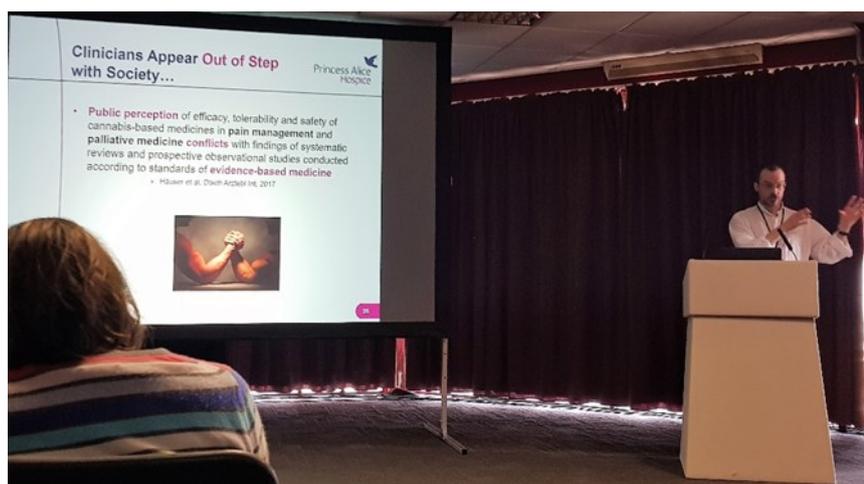
Jenny Palfrey, Darzi Fellow

Two jam-packed days of talks, posters and debate at the Bournemouth International Centre highlighted new research and challenges in palliative medicine.

The title of the conference was *Towards evidence based compassionate care* and there were some really interesting sessions from leading academics including Professor the Baroness Ilora Finlay of Llandaff and Professor David Currow all the way from Australia. This, in combination with a heartfelt and honest talk about compassionate care by Chris Pointon, the widower of the late Kate Granger truly did live up to the brief.

It was also fantastic to have a range of other specialties presenting their work including an excellent closing plenary from Dr Jacinta Tan, a research psychiatrist and medical ethicist, who challenged us to think about mental capacity in the context of eating disorders and when, if ever, it is appropriate to classify anorexia nervosa as a terminal illness.

Ethical debates created lots of conversations and our very own Medical Director Craig Gannon got people thinking in his talk *From cannabis to mistletoe – the evolving ethics in integrated palliative care*. This talk looked at the changing nature of complementary therapies, weighing up how we should approach therapies which may have little evidence of benefit but have the potential for harm – is it for the individual patients to decide? Where does the legal status of drugs like cannabis fit in? and where do clinicians stand morally, ethically and legally?



I'm not sure I came away from the conference with many answers, apart from maybe when to use the direct acting oral anticoagulants (DOACs), but I certainly have more questions and feel that by having open conversations we are better at living and working with uncertainty.

# Research activity at Princess Alice Hospice

## **The Prognosis in Palliative care Study II (PiPS2)**

Professor Paddy Stone, Marie Curie Palliative Care Research Department, University College London

## **OPEL: Optimum Hospice at Home Services for End of Life Care**

Dr Claire Butler, University of Kent

## **Holistic Study**

Dr Ros Taylor, Hospice UK

## **What services influence the care of people with dementia in the last year of life?**

Dr Jennifer Todd, Princess Alice Hospice

## **Development of an educative intervention for nurses working in palliative care to enhance their confidence and competence in communicating with parents and children when a parent nears end of life.**

Professor Emma Ream (doctoral study of Penny Franklin), a partnership between University of Surrey and Princess Alice Hospice

## **LEGACY (Rapid Medical Donation Programme for Breast Cancer)**

Peter Barry, The Royal Marsden NHS Foundation Trust

## **DONATE-GI (Development of OrganoIDs from lethal metastases- Gastrointestinal Tract)**

Peter Barry - The Royal Marsden NHS Foundation Trust

## **The influence of Intercultural Communication in discussion of Advance Care Planning: The case of nurses and care home residents in the UK**

Jane Berg (doctoral study), Deputy Director— Skills, Knowledge and Research, Princess Alice Hospice

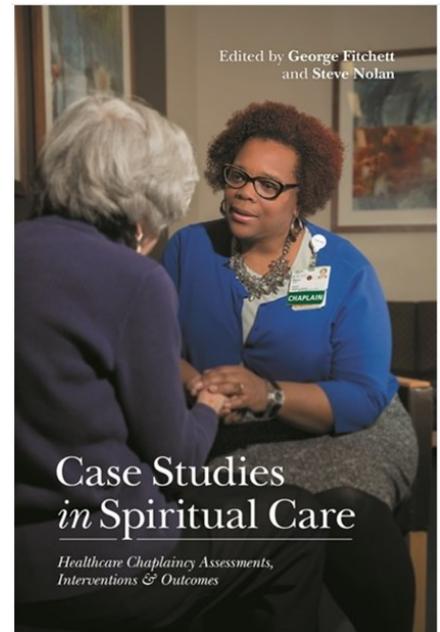
## **Exploring the experience of a personal bereavement for nurses working in a palliative care setting, and the experience of returning to work.**

Dr Jennifer Todd, Princess Alice Hospice (in collaboration with St Catherine's, Crawley, Woking and Same Beare, Woking and Phyllis Tuckwell Hospice, Farnham).

## Princess Alice Hospice publications Spring/Summer 2018

### Steve Nolan, Chaplain, Princess Alice Hospice

In 2012, following a meeting at an international chaplaincy conference in Glasgow, I began working with Professor George Fitchett of Rush University Medical Center, Chicago. George had discovered that no chaplain had ever published a case study. He set up a supportive writing group, with three oncology chaplains, aiming at publishing addressing this deficit. Each case gave background on the patient (respecting the confidentiality safeguards), the chaplain and the clinical context and gave a detailed history of the chaplain's work before discussing the chaplain's assessment of spiritual needs, their interventions and the patient outcomes.



The value of case study research is in clarifying what goes on in spiritual care interventions and making those insights available to colleagues. They also offer a basis for developing further research projects.

Following our meeting, George and I recruited and rigorously selected an international group of chaplain-researchers to document their work to be disseminated in a book-length collection. *Spiritual Care in Practice: Case Studies in Healthcare Chaplaincy*, was published in 2015. It features nine cases in three sections (paediatric, psychiatric and palliative), with each section critiqued by an experienced chaplain and a professional from a related healthcare discipline. We've since co-edited a special issue of *Health and Social Care Chaplaincy* (2018) and this second book-length collection will be published in July this year. In total 28 cases have now been published, inspiring a related project with Dutch chaplains.

The new book will be launched at the Association of Professional Chaplains and the National Association of Catholic Chaplains Joint-Conference in Los Angeles, California. It includes a methodological chapter describing how auto ethnography is a valuable research method for chaplain case study and features one of my own cases.

You can pre-order the book on amazon.

### Conference posters

Gannon, C. The Support of Care Cycle: Integrating Ethics into Healthcare Professional Support and Development in Hospices. Association of Palliative Medicine conference 2018. [LINK](#)