

## What services influence the care of people in the last 12 months of life?

Princess Alice Hospice is excited to be undertaking a research study exploring the last year of life of 20 people who died with dementia in partnership with Kingston NHS Foundation Trust and Epsom and St Helier NHS Trust.

Dementia is being described as one of the most important health and care issues the world faces. In England, there are approximately 670,000 people living with dementia, which is now one of the top five underlying causes of death (Department of Health, 2013).

While significant research has explored the role of palliative care in dementia care, there is still little understanding of which services influence care at the end of life. In view of the growing need of this population requiring good end of life care, this study aims to explore in detail what happens to patients with dementia in the last year of life and understand what health and social care services actually influence their care. In particular, we are interested in the potential role and significance of specialist palliative care services for this population.

Princess Alice Hospice has seen a year on year increase in the number of people with dementia referred to the service for Specialist Palliative Care (SPC). In one year the Hospice received 223 referrals for people with primary dementia and had 161 deaths. Referral patterns suggest that patients with dementia are referred to the Hospice late in the illness trajectory; the average length of time from referral to death is short (average only 22 days) irrespective of place of care or place of death.

### Research question:

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

### Research aims:

1. To retrospectively map the illness trajectory in detail (health and social events ) over the last 12 months of life for patients who died with dementia (where dementia was the primary cause of death or a significant contributor to the death).
2. To understand the triggers resulting in a change of healthcare setting, in particular the admission and discharge process from an acute setting.
3. To identify symptom burden and potential barriers to adequate symptom control.
4. To identify referral source, timing and triggers for referral to health and social care services and SPC services and the outcome of referral to different services.
5. To identify what services influence the care of people with dementia in the last year of life.
6. To assess the feasibility of developing further research in this area (obtaining data, participant identification and recruitment).

### Study design:

This is a retrospective exploratory study using a mixed methods approach: a review of medical documentation of twenty patients who died 3-6 months previously where dementia was the primary cause of death or a significant contributing factor in their death who have an informal carer. Ten of the patients selected will have been referred to and accessed SPC services (hospital or hospice) at some time point in the last year of life. We will also interview their bereaved carers to understand the experience of the last 12 months of life.

We aim to report our findings in 2016/2017.

## Hospice UK 2015 Conference: Key messages to take home

Six members of our staff attended the 2015 Hospice UK conference. They report the key messages below. A central theme is that the nature of palliative care is changing and how professionals need to seek ways to meet the needs of the changing population.

### **Sustaining the workforce- responsibilities and resilience:**

Jessica Pryce-Jones of the I-Opener Institute demonstrated how to manage our energy most effectively: highlighted some new thinking on burnout and balancing life not work-life balance.

### **New thinking in hospice care:**

James Norris of Dead Social (deadsocial.org) raised interesting and challenging issues on death, dying and bereavement. The website offers practical advice for people on how to manage social media accounts such as Facebook, Instagram, LinkedIn, mobiles and PC's when a person has died. Heather was reminded of a friend whose partner died suddenly and she was unable to access his mobile phone which caused her great distress at the time. Digital legacies require planning.

### **Learning from the Use of Outcome Measures:**

Fliiss Murtagh talked about using the Palliative Care Outcome Scale (POS) to focus multidisciplinary discussions on patient's problems and symptoms, to make plans and systematically identify areas of symptom difficulty. This tool can be used to describe the complexity of needs and to help us identify those with greatest need. The main disadvantage is time and resources to collect results.

Overall this was a well attended conference with many interesting posters on display (see our posters on page 4).

One negative aspect of the conference was that 'Art' was very much on the outer edge of the conference, which was disappointing. There were no Arts based plenary sessions to share the influence and celebrate the arts and arts therapies with the main conference for consideration and learning.

**Health Allen, Senior Staff Nurse, Team Leader, In-Patient Unit**

**Gill Thomas, Art Therapist/Practice Educator**

**Eleni Tsiompanou, Associate Specialist in Palliative Medicine,**

**Nicola Owen, Community Clinical Nurse Specialist**



## National Association for Hospice at Home conference 2015

The annual conference this year took place in Leeds. Myself & Emma Collard presented a poster on the Hospice at Home, Enhanced Support Service (LINK).

Some of the presentations were of recent research studies, for example Professor Sheila Payne presented the strengths of Integrated care although they were yet to make final recommendations.

Key messages included that an increasing workforce is needed to support patients in their homes at the end of life and the need to utilise volunteers in many different roles. The importance of being able to respond rapidly, which our poster on our Enhance Support Service fitted with well 'The right place, the right time & right skills.'

Jane Cummings delivered a keynote speech on 'A Vision for End of Life Care' and the message was asking patients "what matters to you?" rather than what's the matter? She spoke of the 6 ambitions to realising the vision: Helping people to stay independent, maximising well-being and improving health outcomes:

Working with people to provide a positive experience of care, delivering high quality care and measuring impact, building and strengthening leadership, ensuring we have the right staff with the right skills in the right place and supporting positive staff experience.

**Ann Smith, Community Team Manager**

## Developing and presenting a conference poster for the first time

I finished my Masters degree in 2013 and put many hundreds of hours into writing my dissertation. Now it was finished, what next? Unfortunately the Hospice UK Conference is only every two years, so I had a little wait but this year I had the chance to put forward my findings in the form of a poster at the Conference in Liverpool.

Before my poster was accepted I had to send them an abstract and was delighted to get the thumbs up.

So how to go about developing a poster?

Luckily, I had the support of both our Education and Communications teams to guide me through the process.

Firstly, I looked through some poster examples, which made it clear that 'less is more'. The posters that attract attention are not too wordy and have illustrations that grab your attention. They need to flow vertically, horizontally or in a circle but be clear.

My first job was to write a few bullet points on the background to my study including relevant referencing and the conclusions and implications for practice then to design the central part of the poster.

My research was qualitative and therefore the findings were based on the quotes from the participants which needed to take the main stage. The three main findings were set out in three columns. In each column I wanted to use one striking illustration. This proved to be a little tricky. I had forgotten you cannot just take an illustration from the internet as there is the small issue of copyright! Thanks to the Hospice's Communications Team, I ended up with pictures to illustrate carer burden

for the first column, an image of a donkey laden with goods for the second and used my most striking quote in a speech bubble for the last.

The conference exhibited many posters and the posters that attracted my attention used the strategies I was advised to use for mine. I had never presented a conference poster before. It was an interesting process; I learned lots and enjoyed contributing to the Hospice UK conference.

**Charlotte Penn,  
Community Clinical Nurse Specialist**



## New publications

### **Development of a Hospice Research Strategy through organisational consensus**

Liz Reed, Research Lead  
Jennifer Todd, Consultant in Palliative Medicine,  
Princess Alice Hospice

European Journal of Palliative Care, 2016,23:2

## Hospice UK conference posters

### **A phenomenological study to explore the experience of family caregivers living with patients with symptoms of advanced cancer**

Charlotte Penn

[Click here](#)

### **A study exploring the lived experience of adults with xerostomia within a community/day hospice setting**

Nicola Owen

[Click here](#)

### **Enhancing a sense of community: evaluation of a hospice based choir**

Gill Thomas

[Click here](#)

### **Open Art Studio**

Gill Thomas

[Click here](#)

### **2014 National UK food and nutrition hospice survey: Implications for practice and recommendations**

Eleni Tsiompanou

[Click here](#)

## A practical guide to End of Life Care

Edited by Clair Sadler

Senior Lecturer, Princess Alice Hospice

This book is an accessible guide for all those working in health or social care and caring for people at the end of their lives. This will include people in such roles as healthcare assistants, hospice workers, volunteers, nurses and other carers.

The writing of the book was a collaborative process coordinated by the editor (senior nurse lecturer based at the hospice) and the project was greatly enhanced by a steering group that met regularly. Each member of the steering group led on one or more chapters. They worked with clinical colleagues from a range of disciplines – inpatient and community nursing, social work, occupational therapy and medicine. Some colleagues chose to write, others preferred to discuss their thoughts and have them written up by someone else – both approaches worked and enhanced the content. This was a hospice wide endeavour.

