

## Abstracts

a high standard. Options for extending the service to nursing home settings are being explored.

### P124 IMPROVING END OF LIFE CARE FOR PATIENTS WITH DEMENTIA

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**Introduction** Dementia is predominantly a disease of later life but there are at least 15 000 people under 65yrs who have the illness. Symptom relief is often missed as these patients are unable to communicate effectively.

#### Aims of the Project

- Improve the quality of End of life Care for people who are diagnosed with dementia admitted to hospital
- Increase the awareness of staff caring for these patients
- Promote advance care planning for people with dementia
- Support families of people suffering from dementia with decision making

**Methods** A flow chart was designed and coloured to reflect the local End of Life Care Model. There was close liaison with trust staff about developments in dementia care within the acute setting and teaching materials were developed to train staff on caring for patients with dementia in their last days of life.

**Results** The Trust collated results from the dementia screening tool used to assess every patient over 75yrs; it demonstrated an increase in knowledge for staff in trust to recognise dementia as a terminal disease.

**Discussion** The project aimed to support patients with dementia from diagnosis to bereavement. The work was a collaboration between the Acute Trust and local hospice services. Work streams were formed to develop care pathways, integrated working and shared learning. The trust adopted the butterfly scheme which the CNS team promoted when visiting patients with dementia and raise awareness of importance of advanced care planning for these patients.

**Conclusion** Improving the knowledge of staff around caring for patients that are dying who have dementia improves their ability to effectively observe and manage symptoms, improves the quality of care and job satisfaction whilst improving outcomes and relieving distress for patients and families.

### P125 PILOTING THE DESIGN AND DELIVERY OF A FIVE-DAY COURSE ON END OF LIFE CARE FOR PEOPLE WITH DEMENTIA. A JOINT VENTURE

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The drivers for this project included National guidance and policy, such as the Prime Minister's Challenge (Department of Health (DH) 2012) and "Living Well with Dementia (DH, 2009) and the National end of life care strategy (DH, 2008). Regional influences were Dementia Local Implementation Groups (DLIG) and "Dementia-friendly communities". The development of the course was funded through the Regional Innovation Fund (RIF). The hospice is revising the organisational strategy, with a view

to reaching more people who are dying and their families, through enhanced joint working.

The aim was to bring professionals together, sharing their specialist expertise to develop and deliver a five-day course to a wide variety of health and social care providers.

Initial work centred on accessing appropriate health and social care providers to help to design and deliver the course.. The group met regularly (over a period of six months), initially to establish the framework of the course and, subsequently, to design and agree the course content, intending to use facilitators from a range of disciplines.

A pilot five-day course was delivered in the Spring of 2013, attended by a diverse group of participants, including staff from mental health, learning disability, hospices, care homes, and community settings as well as a care commissioner. The course was facilitated by specialists from mental health, social care training, Alzheimer's society, specialist palliative care, care home setting, palliative medicine and hospice education, as well as a person with dementia. An assortment of teaching and learning techniques were used to encourage shared learning. Electronic evaluation has provided evidence of participants' learning.

This course has the potential to enable care providers to learn more about end of life care for people with dementia, reaching more people in all settings, in line with National, regional and organisational strategy.

### P126 RESPITE CARE REFRAMED - A PALLIATIVE CARE SERVICE FOR THE FUTURE

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Respite care is currently disregarded as an essential component of palliative care despite interest on the part of Government and others to support home based end of life care and to increase access for people with chronic degenerative conditions.

During the last 2 years an East London hospice has delivered an updated model of respite care that recognises and responds to new emerging groups of users and seeks to enable more people to remain at home during their illness.

A new, nurse led service, headed by a nurse consultant, has been established which delivers planned respite care. The service proactively seeks to support people with non malignant conditions including young adults undergoing transition from children to adult services.

This shift results in time being given to a multi professional review of the patient and carer's needs as a basis for establishing an updated care plan, designed to enrich the patient's life and maintain their function and wellbeing. Access to other hospice services is also made available. It is particularly effective when the patient is admitted in a relatively stable state and can consider / negotiate different approaches to care in a safe environment. Seven beds are now open to provide this care. Development of this new model has required a different culture of care, development of staff skills and new working relationships within and outwith the hospice.

The service has been well used (average occupancy 80%). Review of activity data reveals a higher than average use of these beds by people with non cancer conditions (47%) and increasing utilization of young people undergoing transition (12 episodes). User satisfaction is high and the impact of care, measured through SKIPP is positive. Carer feedback, via focus groups

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indicates that the service is a vital one & suggestions about improvements will help inform service development plans.

### P127 HOSPICE RESPITE: MOVING FORWARDS NOT BACKWARDS

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Anecdotal evidence suggested that respite provision at an independent hospice was dominated by patients with neurological or non cancer diagnoses and that a small number of patients had a disproportionately large amount of respite admissions compared to those with a cancer diagnosis. A service review was undertaken to investigate whether the provision of respite was equitable across all patient groups. A retrospective review of notes identified patients referred for a respite admission within a 12 month period. The individual patient files were scrutinised to obtain relevant data for analysis, including the level of specialist palliative care received prior to admission. Respite provision appeared to attract a fairly equal number of referrals across cancer and non-cancer groups, although the latter were more likely to access multiple episodes of respite. Of the non-cancer groups, those with a neurological condition represented the highest proportion of patients accessing respite. It is likely that these results are due to the longer term, unpredictable nature of non-cancer conditions resulting in increased carer burden and subsequent need for respite care. The care needs of non-cancer patients suggest that a specialist palliative care centre is not necessarily required for respite. It is recommended that: alternative models of respite care are explored for these patients such as nursing home or an increase in home-care packages; the hospice continues to support local nursing home providers in order to facilitate the provision of high quality respite care within our community; during a patient's first respite admission, an assessment is undertaken to determine the most suitable place for ongoing respite care; respite guidelines to be adjusted to reflect a specified number of admissions per year.

### P128 DOES RESPITE CARE ADDRESS THE NEEDS OF PALLIATIVE CARE SERVICE USERS AND CARERS?

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**Research aims** To explore the perspectives and experience of respite care of married or bereaved palliative care service users and carers and to establish in what ways respite care addresses their needs. The research is located in a professional doctorate study.

**Background** There are clear indications that over the coming years, as more people live longer into old age and die as a consequence of chronic disease, an increasing amount of support for carers of patients with palliative care needs will be required. In UK policy and guidance, respite care is frequently mentioned as a key factor in supporting carers. However, little is known about respite care for people in this group and the study addresses this gap in knowledge.

**Methods** The approach was qualitative, the methodology was interpretive and the method used was constructivist Grounded

Theory. Data collection was carried out by unstructured informal interview with couples who had experienced hospice respite care. Social network circle activity was undertaken as part of theoretical sampling.

**Results** Respite care is valued by palliative care service users and carers although there are some fundamental tensions in service models which limit its potential. A theory of vulnerability and resilience was developed which accommodated issues of needs and acceptance, choice and risk, loss and gains.

**Conclusions** The articulation of respite care needs and the insights gained in this study have the potential to influence hospice practice and provide a platform for innovative service development and improvement which is sensitive to the needs and capacity of local communities.

**Application to hospice practice** A reframing of respite care as an empathic response within a new palliative care approach is proposed. Within this the centrality of the relationship is reinforced and the need for support over a potentially long and more uncertain trajectory is acknowledged.

### P129 EQUITABLE ALLOCATION IN NEEDS-LED CARE: DEVELOPING AN ASSESSMENT TOOL FOR RESPITE ALLOCATION IN A HOSPICE FOR YOUNG ADULTS

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**Background** The hospice provides support for young people with life-limiting illnesses, central to which is respite care. It is recognised that decisions about respite care provision are of fundamental importance to patients and their families. The referrals team invests time, clinical judgment and combined knowledge to assess each case and agree an allocation of respite care.

A project was undertaken to develop a tool for allocation of respite care. This tool would structure the allocation of respite according to a matrix, allowing the team to provide evidence of equitable allocations, allow direct comparisons between cases and potentially improve time efficiency.

**Aims** The aim was to develop and validate a simple scoring matrix which could be used to assess each patient's need for respite and ensure an appropriate allocation of nights.

**Approach** The tool was developed through a grounded theory approach, refining and developing the tool through testing until an accurate version was created.

**Outcomes** This project has successfully captured, and defined, the collective knowledge and experience of the referrals panel. This collaborative decision-making process, that has historically relied heavily on personal and professional knowledge, combined with a holistic understanding of the complex lives and needs of patients and their families, has been explored. These tacit aspects have been articulated, defined and quantified in the assessment tool produced.

**Application** This project represents a step forward, in response to current national agendas that call for hospices to demonstrate quality and equity ahead of GP Commissioning.

Adopting the tool will ensure that allocation continues to be a transparent and equitable process, which is able to be articulated and justified to patients, families and wider colleagues, allowing the organisation to demonstrate accountability and good governance.