HOW IMPLEMENTING DECIDING RIGHT IN CUMBRIA SUPPORTS GOOD PRACTICE IN ADVANCED CARE PLANNING (ACP): A CASE STUDY

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Introduction Deciding Right (DR) is an integrated approach to making decisions about future care. It draws together statute and good practice for ACP with children, young people and adults across all sectors of health and social care, and embeds this through shared documentation. It starts with a conversation between the professional and patient about their right to make care decisions in advance. The project is jointly hosted by three of the independent hospices in Cumbria, and is strategically linked with the 1% GP palliative care registers campaign.

Case Study We will present a case study of Betty, 76yrs, with end stage COPD and multiple co-morbidities. This is a complex case featuring repeated hospital admissions and fluctuating capacity around end of life care. Through exploring this case history we will show how DR made a real difference to choice, control and sense of self for Betty, and to the health and social care management of her care. We will demonstrate how DR was important in facilitating multi-disciplinary working and critically, cross agency information sharing at end of life.

Discussion Establishing DR shared documentation across the whole of health and social care has been crucial in rolling out ACP conversations and this approach is effecting change in organisational culture. Training and education for professionals builds capacity within the existing workforce to change current practice, and engagement with students helps to future-proof the principles of DR in Cumbria.

Learning points 1. Making ACP conversations the responsibility of all professionals is key to ensuring that conversations happen early enough in people's journey for them to be well thought through and meaningful.

2. Agreeing and adopting shared documentation for Health, Social Care and 3rd Sector organizations is fundamental to ensuring that ACP conversations held are recorded appropriately and in a meaningful format for all concerned.

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DEATH, DYING AND DEMENTIA: DIMINISHING **DILEMMAS AND DISTRESS**

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Background/context There are currently 750,000 patients living with dementia in United Kingdom (Alzheimer's Society, 2011) with evidence of inappropriate hospital admission of patients with advanced dementia (Pace, et al, 2011). NICE, (2013) suggest a palliative care approach from diagnosis till death. Following a critical reflection relating to the end-of-life care of patient with dementia, the local hospice collaborated with local advanced dementia unit to hold bi-monthly meetings to improve

Aim As a result of this collaboration patients are supported to receive their end-of-life care in familiar surroundings resulting in equality of care to those who are cognitively intact.

Approach used Bi-monthly meetings assess newly admitted patients and identify patients approaching end-of-life. Discussions are documented in case notes with particular significance to DNACPR, preferred place of care/death and communication with relatives.

Outcomes As a result of this collaboration the outcomes are fourfold

- · Patients can expect an agreed care plan at end of life, with coordination of specialist dementia and palliative care services.
- Carers can expect increased support, are involved in advanced care planning, have access to newly formed carers group and access to bereavement care.
- · Dementia unit staff have increased expertise, improved their uptake of education on end of life issues, have received bespoke communication training and have rapid access to specialist palliative care advice.
- Hospice staff have improved recognition of needs of advanced dementia patients and allows them an opportunity to seek advice on control of symptoms of other dementia patients

Application to hospice practice This collaboration allows both units to transfer their skills to benefit an increasingly ageing population. It allows the hospice to plan ahead for the increase in future referrals of dementia patients in line with predictions.

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IMPROVING END OF LIFE CARE ON INPATIENT **DEMENTIA WARDS**

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Introduction This audit and service review looks at a collaborative approach to improving the end of life care for people with dementia on inpatient wards in Cornwall. It has prevented many inpatients resident on the inpatient dementia ward being transferred to the acute hospital for symptom control or terminal

Background People with dementia over 65 years of age are using up to one quarter of hospital beds at any one time and it is estimated that that the majority of the 100,000 people who die with dementia are in hospital. Multiple initiatives have set out to improve the end of life care of these patients. Despite this, there is evidence that suggests that end of life care for people with dementia is significantly poorer than for people without dementia.

Methods An inreach service to the dementia wards was provided by the hospice nursing and medical staff. The three key aspects were:

- Guidance specific end of life care guidelines were written collaboratively, taking into account the complexities of setting, staffing and patient group.
- · Confidence buliding Dementia unit staff were educated in palliative care principles & skills, with hospice nursing staff & doctors providing peer education and support.
- Support the dementia units were given 24/7 access to the hospice advice line with availability of consultant review withing 24 hours when needed.

Results Transfers of patients to the acute trust were reduced and end of life transfers eliminated in patients with contact with the inreach service. Staff confidence and expertise was developed to

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Abstracts

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

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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 asses 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.

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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.

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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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