

2D End of Life Care

Living and dying with dementia in care homes: the Evidem end of life study

Approximately, a third of all people with dementia live in a care home (Knapp et al 2007). This study aims to explore the support needs and end of life care for people with dementia in care homes, and develop and test a dementia specific approach to palliative care for NHS and care home staff. The study is in two phases. Phase one involves case note review and interviews to track prospectively for two years the care needs and service use of up to 150 older people with dementia living in care homes.

By September 2009 preliminary findings will be available. We will present data on the changes in the participant's health and function and what the study reveals about how care home staff, and NHS practitioners define, assess and provide end of life care for this population. In particular, we will consider how different care home cultures and models of care influence care delivery and the older persons experience of living and dying in a care home. Discussion will focus on how the findings inform the use of existing end of life care resources and the development of dementia specific frameworks for use in care homes by care home as well as visiting NHS staff and palliative care specialists.

Knapp M, Prince M Albanese, E Banerjee, S Dhanasiri, S Fernandez, J L Ferri, C McCrone, P Snell, T and Stewart, R. (2007)
Dementia UK: a report into the prevalence and cost of dementia prepared by the Personal social Services Research Unit (PCSSRU) at the London School of Economics and Institute of Psychiatry at King's College London for the Alzheimer's Society: Alzheimer's Society London

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Living With Loss

Although community resources have been expanded to keep pace with legislation, carers are often still find themselves on duty 24 hours per day. In this situation the carer (husband/wife) may have little time to reflect on and deal with his/her emotions, but their sadness as they slowly lose a loved one can be overwhelming at times. Such sadness, if not addressed, does not simply disappear but may take the form of depression, guilt, anger or anxiety. Cognitive Behavioural Therapy (CBT) is a form of psychotherapy that allows that carer to become aware of the interaction between his/her thoughts, behaviour, physiology and emotions. By collaboratively challenging possible thinking errors e.g. I didn't do enough, by re-instating previously pleasurable behaviours e.g. hobbies, and by developing skills e.g. relaxation, the carer can be much better equipped to manage the many losses that are resultant from dementia.

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Assessment of the palliative care needs of patients with advanced dementia in Haringey

Background

Assessment of the needs and constraints for accessing end of life care has been made for a number of key patients groups e.g. cancer patients, heart failure patients. However there has been no structured assessment undertaken by the charity for patients suffering from dementia.

Aim

- Identify the major barriers for dementia patients and their carers in accessing good quality end of life care
- Suggest cost effective ways of enabling improvements based on review findings

Method

- Case note study for 10 patients who have recently deceased
- Recruitment of cases via local stakeholder group
- Individual semi structured interviews with carers
- Focus group with key stakeholders in the patient care pathway e.g. DNs, social workers, homecare staff, residential care staff, Admiral Nurses, etc

Conclusion - full results expected by time of event

- Identification of key issues of importance and concern to patients, carers and service providers
- Scoping of existing services in Haringey for this patient group
- Improved care pathways and outcomes for people with advanced dementia.
- Dissemination of learning via local event, publications and conference presentations

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