

Caring Communities Program - Project Overview

Organisation: University of Western Sydney, Wentworth Area Health Service Stream of Chronic and Complex Care and Blue Mountains Division of General Practice
Name of Project: Palliative Care Dementia Interface: Enhancing Community Capacity
Length of Project: 3 years

Project Summary

Dementia is recognised as a progressive terminal illness for which there is currently no cure” (Lloyd-Williams, Payne 2002). There are many issues in the care of patients with dementia that parallel those in palliative cancer care (Lloyd-Williams& Payne, 2002). The issue of a perceived deficit in the knowledge and practice of key providers of care about the palliative needs of end stage dementia clients is a major contributing factor to the under-utilisation of mainstream palliative care principles in these clients. This highlights the need for key providers of care to become responsive and orientated to the specific palliative care requirements of individuals experiencing end stage dementia. The proposed project will enhance the capacity of key providers of care in the delivery of direct service provision to be responsive in this area. This is necessary to the establishment of best practice and improved outcomes for clients, family and key providers of care.

Aims

Develop strong partnerships between community based palliative care service providers, specialist aged care and dementia services and residential care facilities to facilitate optimal and sustainable palliative care service delivery for people with end stage dementia.

Facilitate and foster the cultural learning necessary within palliative care and aged and dementia health care professionals to appropriately address the needs of this client cohort, in a sustainable fashion within the broad community.

Objectives

Identify the needs and deficits in health care service delivery and key providers of care (palliative care speciality staff, designated aged/dementia care specialist staff, general practitioners, residential care staff and family members) to individuals experiencing end stage dementia

Engage the relevant key providers of care of this target population and the broader community through the appropriate community based organisations and associations by sharing the information gained from the results of Stage 1 of the project and fostering dialogue and strengthening partnerships. This will facilitate Stage 2 & 3 of the project.

Improve the knowledge and practice of key providers of care, by designing and implementing informal and formal education programs to meet the needs of the target population.

Develop and implement an appropriate model of palliative care delivery to the target population through best practice (reflected in the development of policies and guidelines that drive best clinical practice)

Evaluate the model of care in order to determine efficacy-surrounding outcomes of care, model sustainability and identify redesign potential, if appropriate or necessary.

Project Activities

Stage 1: Aims to identify the needs and deficits in palliative health care delivery, as perceived by key providers of care, inclusive of family members. This will be undertaken by conducting focus groups and interviews in separate groups that make up a multidisciplinary team (palliative care specialty staff,

designated aged/dementia care specialist staff, general practitioners, residential care staff and family members).

Stage 2: The first phase of Stage 2 involves fostering collaboration between these professionals by sharing the findings of Stage 1 in a group discussion context. Using Participatory Action Research (PAR), this group will assist the research team to develop a model of service delivery of care for people with end stage dementia that encompasses guidelines, policies and educational programs designed for key providers of care. This model will be developed and evaluated based upon the findings from Stage 1 and the education program.

Stage 3: Will evaluate the model for its efficacy and sustainability.

Main Message

What we did

The project investigated the needs of people with dementia in the final stages of the disease (the severe and end stages, which can last from one to three years), and their key providers of care. The information learnt was used to develop a model of care for this population.

What has been learned?

- Many people with dementia have never been diagnosed with the condition, or have an incorrect diagnosis.
- There is very little research evidence to guide practice in dementia palliative care.
- Most people in the final stages of dementia are cared for in residential aged care facilities.
- Residential aged care facilities are severely under-resourced, with a low staff: resident ratio; inadequate skill mix of nurses; insufficient professional development opportunities and inadequate amounts of clinical support and governance for the acuity and complexity of the people in their care.
- Family members are not given enough information about dementia right throughout the course of the disease.
- Family members do not receive enough support, including not receiving systematic bereavement support.
- If Area Health Service specialist palliative care staff are to provide a consultation service to people in residential aged care facilities with dementia then they will need additional resources to do so.

What is useful to other projects/communities?

- The resources this project developed such as the Family Information Booklet will be useful for family members with a loved one in the final stages of dementia, and to provide newly diagnosed people with an overview of the course of dementia.
- An intensive model of palliative care education implemented in a residential aged care facility improves the skills and confidence of nurses to manage pain, and improves the outcomes for the resident.

What have been the benefits of disseminating information about your project?

- There is a widespread interest in learning how to improve care to people dying of dementia. Dissemination of the information has encouraged other key providers of care to start addressing the needs of this population.

What needs to happen in order to sustain the key achievements of your project?

- Intensive education and clinical support and governance have to become standard in residential aged care facilities to improve palliation for dementia clients.

- Residential aged care facilities need additional skilled staff, and a higher nurse: resident ratio.
- Area Health Service specialist staff such as palliative care nurses need funding enhanced if they are to become the lead service in providing consultation and support for dementia palliative care to residential aged care facility nurses.