An End of Life Care Pathway for Palliation in Dementia
Project Title

The implementation of an End of Life Care Pathway for those living with dementia in residential and community care settings
Project Funding

The Department of Health & Ageing - Local Palliative Care Grants Program Round 5
Wesley Mission Brisbane

- 968 Residential Aged Care (RAC) Licences (13 RAC’s)
- Approximately 970 RAC Staff
- 416 Community Aged Care Packages (8 Centres)
- Approximately 150 Community Aged Care staff
Wesley Mission Brisbane

- 50- 75% Community Clients have dementia (or cognitive impairment)
- 80- 90% RAC Residents have dementia (or cognitive impairment)
Project Objectives

• Implement the End of Life Care Pathway (EoLCP) in Residential Aged Care (RAC) and Community Care

• Adapt RAC EoLCP for Community Care
Project Objectives

• Develop and implement EoLCP education modules specific to the care of people living with dementia in RAC and Community Care
Project Objectives

• Evaluate Project
  ➢ Numbers of clients on EoLCP
  ➢ Staff surveys
    ~pre 42% return rate
    ~post
  ➢ Education evaluations

• Adapt education modules for online and/or DVD learning
Translating Research

Wesley Mission Brisbane’s (WMB) Project is based upon outcomes of research conducted by Brisbane South Palliative Care Collaborative (BSPCC) 2007-2009.
Translating Research

Bethesda Caring Centre (WMB) and 5 other Brisbane RAC’s involved in 21 month research for the implementation of the EoLCP in RAC’s.
Translating Research

- Develop an EoLCP tool to guide the care of the dying in RAC’s in Australia

- Explore whether the EoLCP improves clinical outcomes for dying residents
Translating Research

- Dying residents who were commenced on the EoLCP were significantly less likely to be transferred to hospital
Translating Research

- so more able to die in-place in a familiar environment with carers who were known to them
Translating Research

- significant improvements in the quality of palliative care
- access to specialist palliative care services
- improved care coordination, symptom management
Translating Research

➢ improvements in care were supported by family responses
➢ staff felt more confident and competent to deliver palliative care and communicate with family members/loved ones
Translating Research

- The pathway project (299 deaths in 21 months) provided some of the first evidence internationally that the use of palliative care pathways improves resident outcomes of care.
Translating Research

It has been shown that patients with dementia are receiving different end of life care to those who are cognitively intact \(^3\).
Translating Research

If discussions and treatment decisions do not occur with families, decisions may be made by “default”, resulting in unnecessary transfer to acute care settings or other interventions ¹.
Translating Research

The EoLCP increases the confidence and competence of Registered Nurses to assess when an elderly client has entered the terminal phase of their life and plan care with the health care team and family.
# The EoLCP Assessment Tool

## Signs and symptoms associated with the terminal phase

- Experiencing rapid day to day deterioration that is not reversible
- Requiring more frequent interventions
- Becoming semi-conscious, with lapses into unconsciousness
- Increasing loss of ability to swallow
- Refusing or unable to take food, fluids or oral medications
- Irreversible weight loss
- An acute event has occurred, requiring revision of treatment goals
- Profound weakness
- Changes in breathing patterns
WMB Project - Education

• Dementia
  ➢ Types
  ➢ Incidence
  ➢ Trajectory
  ➢ Person centred care
WMB Project - Education

• Pain management in the elderly (± dementia)
• Nutrition and hydration in the elderly (± dementia)
• Spiritual/ cultural considerations
WMB Project- Education

• Palliative Approach
  ➢ Issues surrounding the elderly with life limiting illness/es
  ➢ Advance Health Directives
  ➢ Advance Care Planning
  ➢ Case Conferencing
  ➢ What is Palliative Care
WMB Project- Education

• End of Life Care
  ➢ Symptom management/medications
  ➢ Comfort care
  ➢ **How to use the EoLCP**
  ➢ Grieving/ bereavement
It is vital that we provide education to clinicians who guide day-to-day care and consult with families regarding a cognitively impaired client’s future care.
Leadership

36 staff have completed “Palliation in Dementia Care” course QUT/QLD DSTC

These staff are Palliation Advisors (PA)
Leadership

• All 13 RAC’s
  ~ have at least 1 PA
  ~ larger RAC’s up to 4 PA’s

• 7 out of 8 Community Care Centres have at least 1 PA
Leadership

Palliation Advisors Forums (6):

• Assist with course
• More specialised education on end of life care
• Standardisation of EoLCP documentation and project implementation
Leadership

WMB Palliation Advisors are our Clinical Leaders
WMB Project Achievements

Education/forums in 14 months

Sessions = 82

Total staff = 1027
WMB Project Achievements

• 133 attendees at PA forums

• 242 (98%) RAC and Community RN/EEN’s- 7.5 hours

• 323 (66%) RAC Assistant Nurses/ Personal Carers- 7 hours
WMB Project Achievements

• **111 (97%)** Community Personal Carers - 7 hours

• **113** RAC Hospitality staff - 3 hours
WMB Project Achievements

• **17** Leisure & Lifestyle Coordinators - 3 hours

• **86** “in kind” attendees (Doctor’s Forum x 3 - **29**, Allied Health, Pastoral Care and Admin staff)
WMB RAC EoLCP Implementation

RIP n = 313 in 14 months

Sum of Hospital
Sum of Home No Pathway
Sum of Home Pathway
WMB Project Achievements

• Community (Comm) EoLCP trialled in Bundaberg from September 2010

• Comm EoLCP launched November 2010
WMB Project Achievements

• All palliative care clients in Bundaberg are placed onto the Comm EoLCP

• Other Community Centres (7) are aiming for enhanced at home end of life care for those clients on aged care packages
WMB Project Achievements

• Staff feedback has demonstrated increased knowledge and confidence about a palliative approach and good symptom management at end of life
WMB Project Achievements

Post implementation staff survey

Manager comment: “The majority of our clients are dependent upon their families to make decisions for them by the time they are admitted to this facility. The families are certainly more involved in the decision making around the end of life from the day of admission”.
WMB Project Achievements

Chaplain comment: “I have found since the inclusion of the EoLCP at the places where I work there has been a better evidenced based coordination of care and relatives and staff work very well together providing the care for a resident”
Registered Nurse’s comments: “The extensive training and implementation of the pathway has certainly improved end of life care.” “These new skills/education empower staff to confidently deliver appropriate end of life care to residents and family members”.

WMB Project Achievements
WMB Project Achievements

Assistant Nurse comment: “the project was so successful and everyone who participated gained knowledge and understanding how to deal and care who are end of life and also residents with dementia”.

WMB Project Achievements

• Most RAC’s have improved their physical environments for end of life care and support for families
The Way Forward

• Education to continue until June
  ~Capture new staff particularly
  RN & EN’s

• Final PA forum
The Way Forward

• Palliation Advisors will continue:
  ➢ Facilitate learning/ ensure ongoing EoLCP implementation
  ➢ Educate new staff
  ➢ Promote a palliative approach in their RAC/ Centre
The Way Forward

- Design ongoing learning packages
  ~ annual updates and new staff

- Review Palliation in Dementia Care course participants workplace resources for utilisation across organisation
The Way Forward

• EoLCP Project Officer is part of reference group for National Standards Assessment Program (NSAP)

• Reference group are reviewing existing standards to implement into Residential Aged Care
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References


2. Residential Aged Care End of Life Care Pathways Project, funded by Department of Health and Ageing, Authors: Julie Thomson RN Project Officer; Fiona Israel RN MCounts, Manager; Dr Margaret Charles PhD, Senior Lecturer, Sydney University.