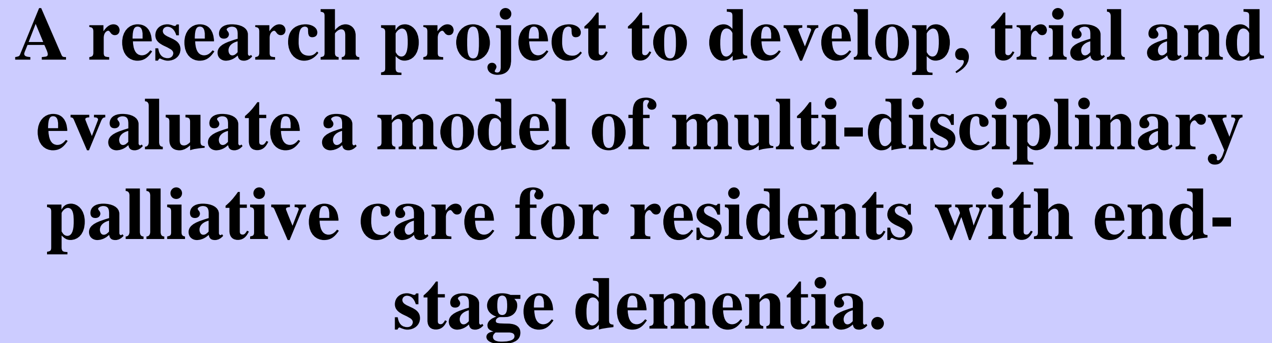

Investigators:
Prof Jenny Abbey
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Prof Helen Edwards
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Funded by The Prince Charles Hospital Foundation

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- To develop, trial and evaluate a structured model of multi-disciplinary palliative care for residents with end-stage dementia
- To evaluate the quality of dying and death before and after the introduction of the model of care
- To evaluate the palliative care knowledge and attitudes of residential aged care staff before and after the introduction of the model of care

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Methodology

- July 2004 – Dec 2005
- Multi-method approach
- Three phase project
  - Phase 1 – Complete
  - Phase 2 – Complete
  - Phase 3 – Currently in progress

Phase 1

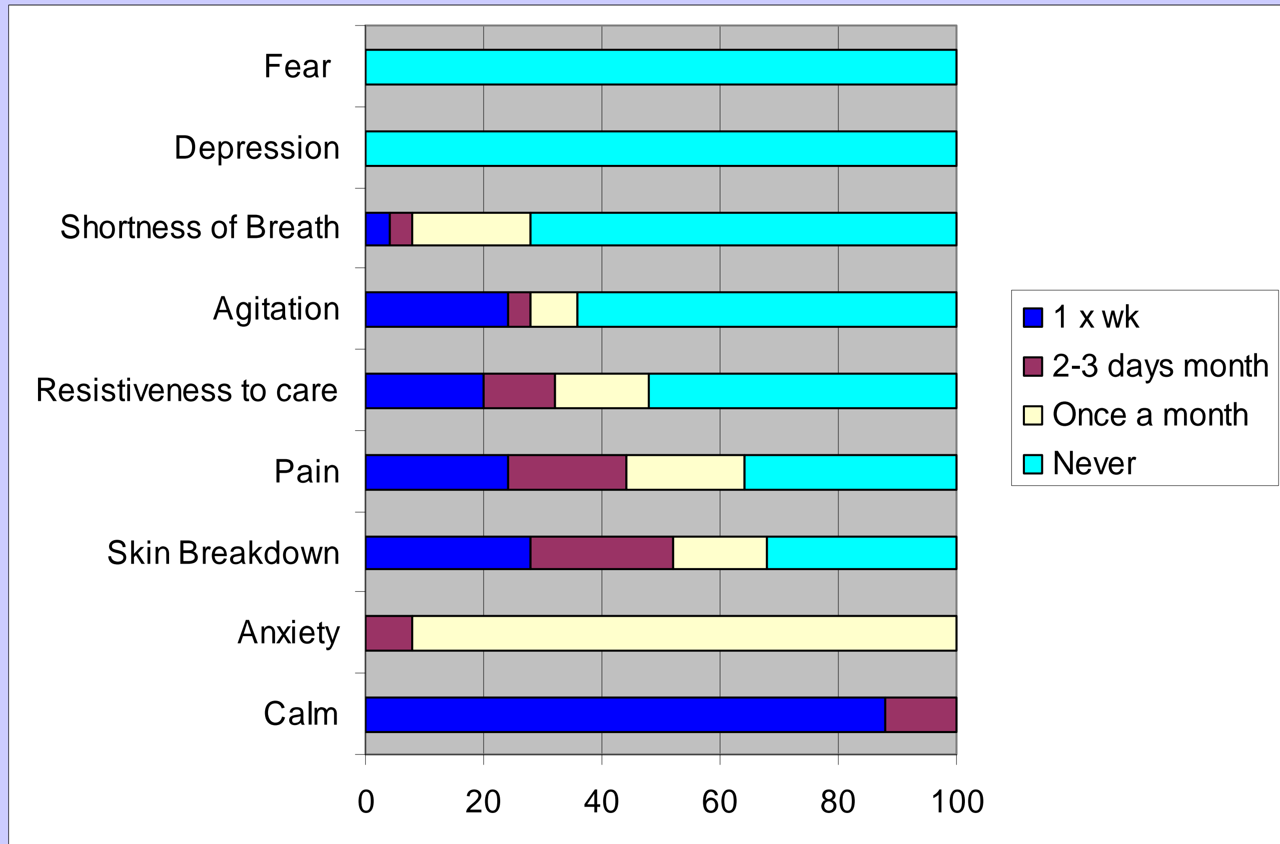
- Retrospective audit of 25 resident deaths from two facilities.
  - Symptom management at the end of life in dementia scale – SM- EOLD

    (Volicer and Blasi 2001)

- Interviews with bereaved relatives
  - Open ended questions
  - Satisfaction with care at the end of life in dementia – SWC – EOLD

    (Volicer and Blasi 2001)

SM-EOLD – 90 days prior to death



Strongly Disagree	*Disagree*	*Agree*	*Strongly agree*
1	*2*	*3*	*4*

Item	Mean
I feel that my care recipient got all necessary nursing assistance	3.60
My care recipient received all treatments or interventions that he or she could have benefited from.	3.52
All measures were taken to keep my care recipient comfortable	3.44
The health care team was sensitive to my needs and feelings	3.36
I felt fully involved in all decision making	3.16
I did not really understand my care recipient's condition	**2.84**
I would probably have made different decisions if I had had more information	**2.76**
I always knew which doctor or nurse was in charge of my care recipient.	**2.72**
I felt that all medication issues were clearly explained to me.	**2.72**
I felt my care recipient needed better medical care at the end of life	**2.72**

Bereaved carer interviews

- Tape recorded and transcribed
- Preliminary findings
  - Limited interaction with the GPs
  - Rehearsal for death
  - Unaware of impending death until very late
  - Movement to another section prior to death was unsettling for resident, carers and staff

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Phase 2

- Four education sessions for residential aged care facility staff to introduce the model of care
- Provision of a CD- ROM for staff unable to attend education sessions
- Provision of multiple copies of Guidelines for a Palliative Approach in Residential Aged Care

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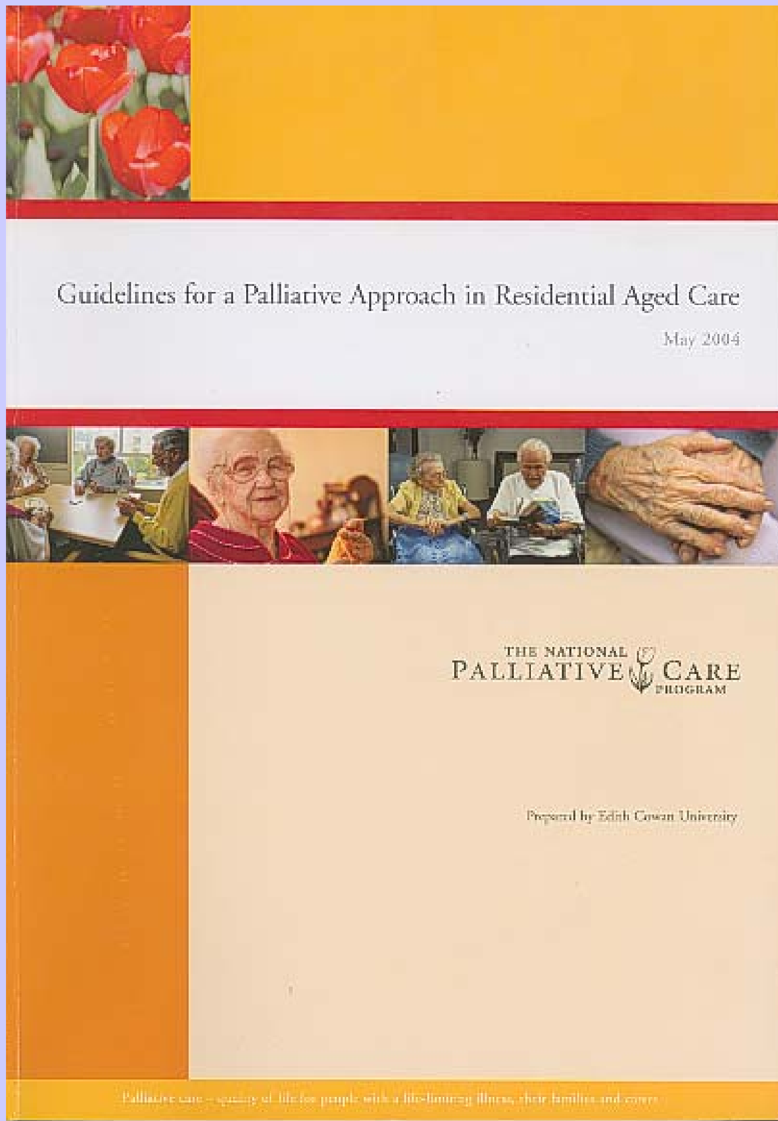
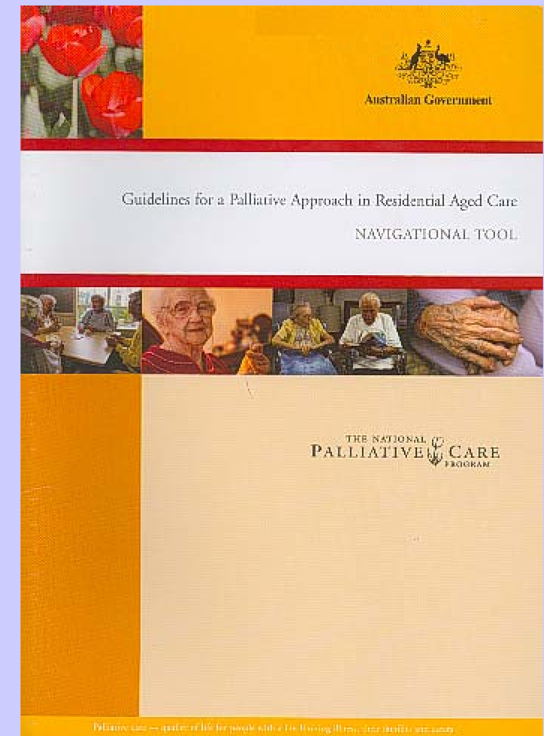
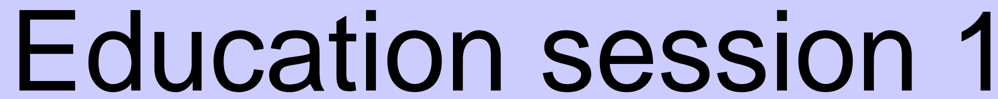




- Australian Government Department of Health and Ageing 2004, Guidelines for a Palliative Approach in Residential Aged Care, Rural Health and Palliative Care Branch, Australian Government Department of Health and Ageing Canberra



Education session 1

- The palliative approach
- End-of-life (terminal care)
- Denying death
- Attitude, knowledge, skills and process in relation to dignity and quality of life

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Education session 2

- Physical symptom assessment and management
  - Dysphagia
  - Nutrition and hydration
  - Weight loss
  - Bowel care
  - Skin integrity
  - Fatigue
  - Pain

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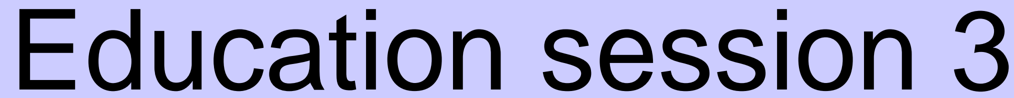

Education session 3

- End-of-life (terminal) care
  - I don’t know what to say – awkward questions
  - Medication management
  - Death rattle
  - Nausea and vomiting
  - Suction
  - Signs of death
  - Bereavement support for the family

Education session 4

- A structured approach – how do we put it together
- Documenting observations
- Documenting residents needs
- Documenting relative’s needs
- Writing care plans
- Case conferencing

Staff knowledge and attitudes

- Pre-test quiz for residential care staff
- Palliative Care Quiz for Nurses
  - - True/False (Ross et al 1996)
- 25 additional questions
  - - Yes/No/Sometimes (Maddocks et al 1999)

- Facility 1 – 76% response rate
- Facility 2 – 54% response rate

Sample of questions with low positive responses

Question	Facility 1	Facility 2
Pain is well managed in our organisation	**29.2%**	**45.8%**
Morphine is the standard used to compare analgesic effect of other opioids	**22.7%**	**30.5%**
Drugs that cause respiratory depression are appropriate to treat severe dyspnoea	**31%**	**33%**
I believe staff are supported following a resident's death	**27.1%**	**43.1%**

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Sample of questions with low positive responses from Registered Nurses

Question	Facility 1	Facility 2
I am confident converting one analgesic drug to another	**17.9%**	**18.8%**
Morphine is the standard used to compare analgesic effect of other opioids	**22.7%**	**30.5%**
I am competent setting up a Graseby pump	**22.5**	**22.8**
Drugs that cause respiratory depression are appropriate to treat severe dyspnoea	**31%**	**33%**

Phase 3

- Prospective study of 25 residents with end stage dementia
  - Fortnightly assessments
  - Interviews with carers
  - Interviews with residential care staff
  - Observations and field notes
  - Photography
  - Case conference
  - Follow up interview with carers 3 months post death – SWC – EOLD
  - Chart audit – SM - EOLD

Phase 3 – Inclusion criteria

- Diagnosis of dementia in medical file
- Are incontinent
- Are either mute or making noises that may appear to show distress
- Show a reduced interest in, or opposition to, taking food and fluids
- Have experienced weight loss
- Experience pain
- Have poor skin integrity
- Have poor peripheral circulation
- Expected to die within the next 12 months

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Phase 3 – Case Conferencing

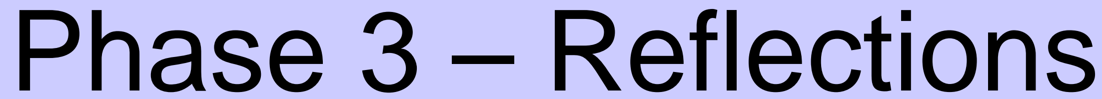
- Face to face case conference with multidisciplinary team including family members
  - Organised by nursing staff
  - GP can bill using EPC numbers
  - Conducted in the facilities – usually hold two case conferences back to back if same GP
  - Length approximately 20-30mins each
  - Staff asked to prepare using pro-forma

Aims of the case conference

- Discuss a residents history
- Identify the resident’s multidisciplinary care needs
- Identify outcomes to be achieved by members of the case conference team
- Identify tasks that need to be undertaken to achieve these outcomes
- Allocate those tasks to members of the case conference team

Phase 3 – Data collection

- Commenced February 2005
- Facility 1 – 4 residents consented
  - 3 died prior to case conference but had at least 2 assessments
  - 1 current – case conference completed
  - 3 new residents – consent currently being sought
- Facility 2 – 9 residents consented
  - 2 died prior to case conference but had at least 2 assessments
  - 7 current – 5 case conferences completed



Phase 3 – Reflections

- Positive comments by staff regarding education and involvement in research
- GP cooperation – variable
- Positive feedback from carers regarding case conference
- Need for training for staff to conduct palliative care case conferences

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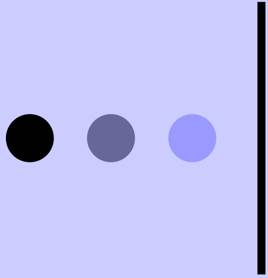

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