



An Australian Government Initiative



Professor Jenny Abbey
Director; Dementia Collaborative
Research Centre for Consumers,
Carers and Social Research



Reconciliation

In keeping with the spirit of Reconciliation, I acknowledge the traditional owners of the land on which we are meeting today, and acknowledge the important role Indigenous people continue to play within our community



An Australian Government Initiative

DEMENTIA CARE NURSING

PROMOTING WELL-BEING IN PEOPLE
WITH DEMENTIA AND THEIR FAMILIES

EDITED BY TREVOR ADAMS

body

kitwood

personhood

reflection

story

voice

evidence

relationships

systems



Adams, T. (2008). *Dementia Care Nursing: Promoting well-being in people with dementia and their families*. United Kingdom: Palgrave Macmillan



An Australian Government Initiative



Small, N. Froggatt, K. Downs, M.
(2007). *Living & Dying with
Dementia: Dialogues about
palliative care*. Melbourne: Oxford
University Press

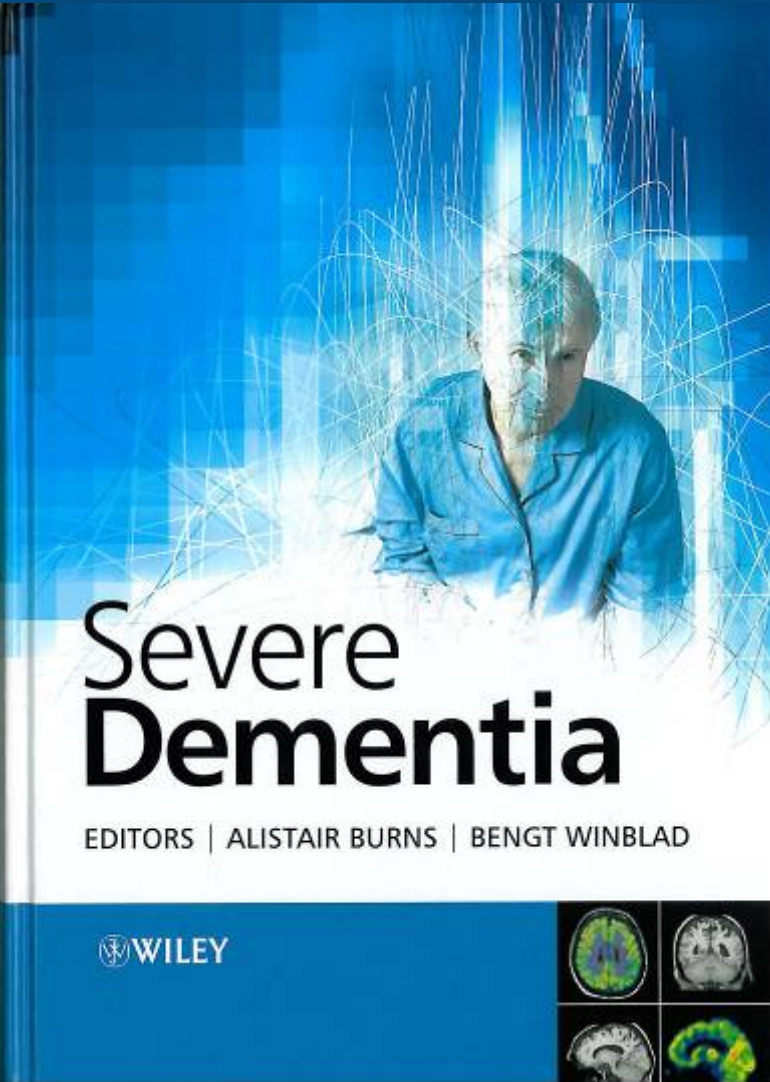
Living and Dying with Dementia

DIALOGUES ABOUT PALLIATIVE CARE

NEIL SMALL | KATHERINE FROGGATT | MURNA DOWNS



An Australian Government Initiative



Burns, A. Winblad, B. (2006).
Severe Dementia. Queensland:
John Wiley & Sons Australia Ltd



An Australian Government Initiative

Palliative Care and Aged Care *A Guide to Practice*



Rosalie Hudson and Margaret O'Connor

ALISMED PUBLICATIONS

Hudson, R. & O'Connor, M. (2007).
*Palliative Care and Aged Care: A
Guide to Practice*. Melbourne:
Ausmed Publishing.



“words like
“unresponsive position,
change 2 hourly,
refusing food and fluids,
skin integrity maintained,
bowels not opened today and refused medications
...have very little value”

instead choose a different kind of language such as

“yesterday J’s eyes followed me when I approached him to change his position he seemed to respond to gentle massage - he no longer looks as though he is afraid”

and

“spoke with Mr J’s family they are feeling exhausted, recommended they take a few days off they will phone each morning and evening to check on his condition”

and ‘food and fluid chart maintained for four days to be used as a basis for discussion in family meeting “



Four themes emerged:

- (1) targeted education can make a difference;
- (2) a team approach is valued;
- (3) clinical assessment tools are helpful;
- and
- (4) using the right language is essential.



An Australian Government Initiative


DEVELOP, TRIAL AND EVALUATE A
MODEL OF MULTI-DISCIPLINARY
PALLIATIVE CARE FOR RESIDENTS
WITH END-STAGE DEMENTIA



Funded by The Prince Charles Hospital Foundation




Queensland University of Technology

 The Prince Charles
Hospital Foundation

February 2008

Abbey, J. Sacre, S. Parker, D.
(2008). *Develop, Trial and Evaluate
A Model of Multi-Disciplinary
Palliative Care for Residents with
End-Stage Dementia*. Queensland:
QUT, Qld Health

Available from
<http://www.dementia.unsw.edu.au/>



..religious, spiritual, cultural differences which must all be discussed and documented in some kind of policy before you start



Hinton (1967) quoted in Davies, E and Higginson, J (2004)
World Health Organization Europe The Solid Facts Palliative
Care , WHO, Denmark, p.26

**‘The dissatisfied dead cannot noise
abroad the negligence they have
experienced’**



? When is life not worth living any more?

? What is quality of life?

? Is just being alive enough?



"Medical futility" refers to interventions that are unlikely to produce any significant benefit for the patient. Two kinds of medical futility are often distinguished:



Medical futility

- *quantitative futility*, where the likelihood that an intervention will benefit the patient is exceedingly poor, and
- *qualitative futility*, where the quality of benefit an intervention will produce is exceedingly poor.



An Australian Government Initiative



‘How people die remains in the memories of those who live on’

(Dame Cicely Saunders)



Eg Right to Life

Eg Comfortable with double effect

- *Belief in life at all costs.
- *Fear of the slippery slope
- *Belief that comfort care can equate to euthanasia

Moral framework

Fear of slavish worshipping of medical technology and biological life, without anyone asking the important questions of the purpose or goal of using any particular medical treatment.



- Engage and demonstrate executive level support.





Policy for Palliative Care Approach Policy in Residential Aged Care Facilities.
Key Words: Palliative Care Case Conference, Multidisciplinary, Dignity, Documentation.

Statement

The Palliative approach is defined as an approach that aims to improve the quality of life for individuals with life-threatening illness, and their families, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain, physical, cultural, psychological, social, and spiritual needs. The palliative approach incorporates a collaborative multi disciplinary team of medical, nursing and allied palliative care staff, the individual and family that determines appropriate care according to the goals, specific for each individual, planned at a Palliative Care Case Conference. Palliative care conference decisions are culturally based and recognize the resident's right to dignity during the terminal phase of their life and in death and for individual and family rights regarding end of life decisions.

Purpose

To recognize and maintain the resident's right to a dignified, comfortable and peaceful death.
To offer information, education and support that best suits the needs of each individual, their family and circumstances.
To ensure that there is clear documentation of planned care resulting from a Palliative Care Case Conference and evidence of ongoing assessment and review.

Scope

A palliative approach covers identification of the need for palliation, care during the terminal phase and death of a resident.
The priority is to identify when a palliative approach is considered appropriate by the resident (if possible) family and staff.
A case conference which includes the medical practitioner, family, resident (if appropriate) and multi-disciplinary staff is an essential element in planning the palliative approach.
All forms of the palliative approach should be considered and clearly documented, including pain management, nutritional requirements, and conservative medical treatment, spiritual and emotional care.
A palliative approach should provide holistic care reflecting Best Practice methods that meets individual needs and offers appropriate support to both the individual and family.

Family is defined in the Guidelines for Palliative Approach in Residential Aged Care (p.180) briefly family means "those closest to the patient in knowledge, care and affection".

Reference.

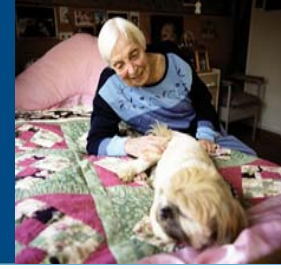
Australian Government Department of Health and Ageing 2004, Guidelines for Palliative Approach in Residential Aged Care, Rural Health and Palliative Care Branch, Australian Government Department of Health and Ageing, Canberra.

This policy was developed by staff at Ashworth House and Eventide RACFs Brisbane, 2006

Policy – agreed
by all



An Australian Government Initiative



Involve, educate, persuade

EVERYONE!!



An Australian Government Initiative



Knowledge = evidence + practitioner
wisdom + user/carer
expertise/preferences

Mike Nolan ACEBAC conference 2007

Nothing better than all
staff who will be
champions for the elderly





An Australian Government Initiative



Only one example of an education plan –
we also produced a cd-rom so that people
who could not get to education sessions
could view it at leisure



An Australian Government Initiative



Session

Welcome

Introduction to palliative care, the palliative approach, evidence based care and organisation's policy

Interactive session. Questions and answers (group will be provided with a 'test' that they mark themselves and we find the spots where particular emphasis is needed in learning) – What do we know, what don't we know, what do we need to know?

The role of the palliative care link nurse. Nursing management and symptom control- main issues

Medical management and symptom control- main issues

Pain assessment

Group work and experiential learning ;

- Ethical issues in palliative care
- The family from hell
- Refusing food

Report and debrief

Particular issues for palliative care and dementia

Group work Nursing issues in symptom control and management

- Bowel care/Mouth care
- Dysphagia/nutrition and hydration
- Dyspnoea/fatigue/nausea and vomiting

Report and debrief

The death process- what happens and how to manage- – spiritual, cultural, psychosocial issues and grieving

Conclusion. Feedback and questions from group



Palliative case-conferencing with the family, staff and the GP was the heart of the intervention and the main force for change



Palliative approach to care for people with end-stage dementia

- Agreement on the goals of care by team and family.
- Consideration of the disease trajectory of dementia (and co-morbidities).



Enhanced Primary Care Program overview

The Enhanced Primary Care (EPC) program was introduced to provide more preventive care for older Australians and improve coordination of care for people with chronic conditions and complex care needs. The program provides a framework for a multidisciplinary approach to health.



Enhanced Primary Care Program (EPC) **Multidisciplinary Case Conferencing**

An EPC case conference is a meeting of health and care providers to plan for the health and care needs of an individual patient with at least one chronic medical condition and complex multidisciplinary care needs requiring care from a GP and at least two other health or care providers.

Case conferences may be undertaken for patients in the community (community case conferences), patients being discharged into the community from hospital or day hospital facilities (discharge case conferences), or people living in Residential Aged Care Facilities

(Residential Aged Care Facility case conferences).



Case Conference△

In Aged Care Homes

Item **734 : 736 : 738**

Time

15-30 min

\$83.75

30-45 min

\$125.65

>45 min

\$167.45

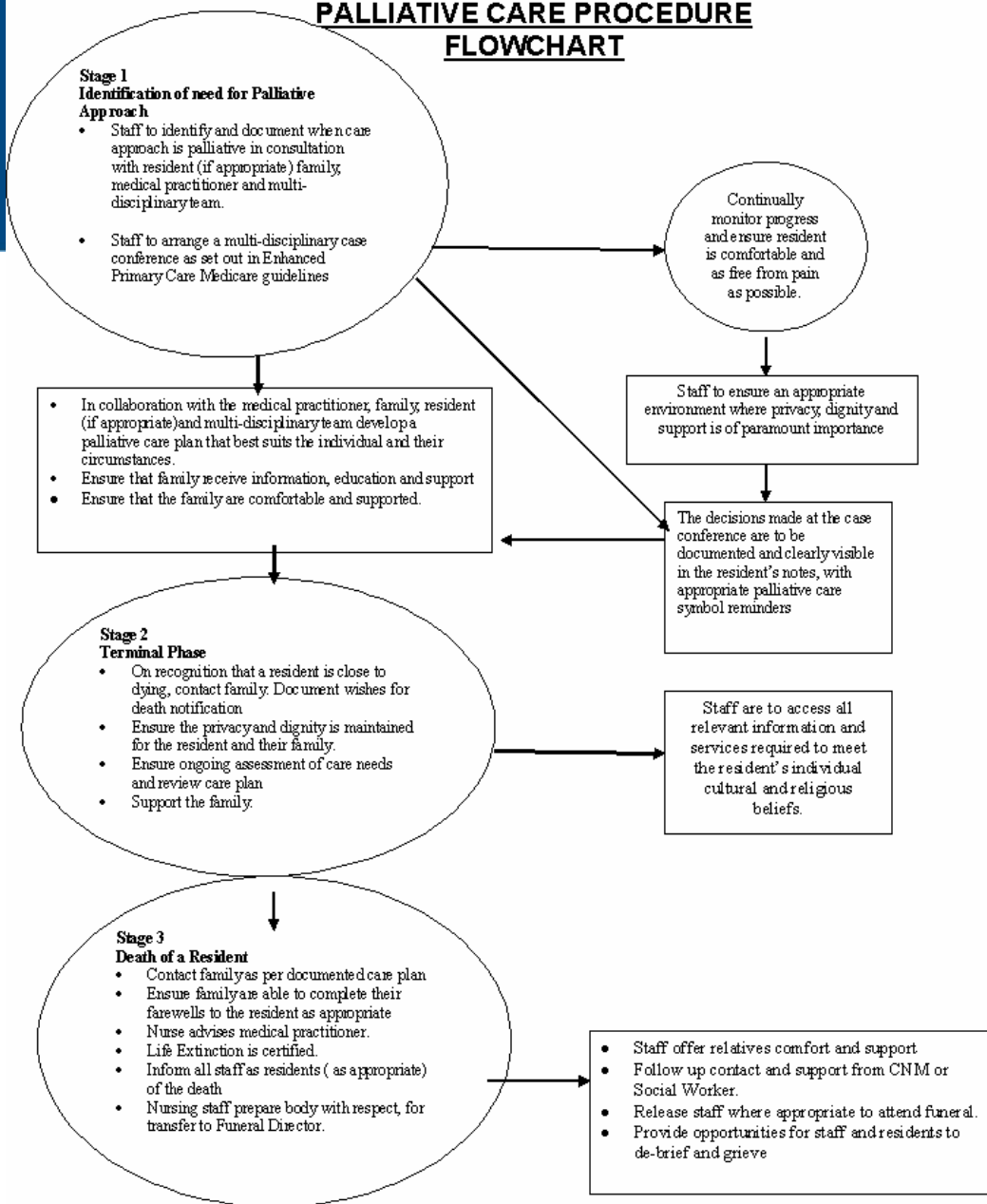
So – we organised 2x20 min back to back case conferences (and organised car park available ect)




Aims of the case conference

- Focus on a palliative approach
- Discuss a resident's history
- Identify the resident's multidisciplinary care needs
- Identify carer concerns
- Identify outcomes to be achieved by members of the case conference team

PALLIATIVE CARE PROCEDURE FLOWCHART



 <p>Queensland Government <small>Queensland's Future Starts Here</small></p> <p align="center">Palliative Care Plan</p>	NAME.....
	Please Affix ID Label
	HOUSE.....
	UR NUMBER.....
	D.O.B.

Produced by staff at Eventide and Ashworth House and Brisbane, May, 2006

Please circle the response

Advance Health Directive	YES	NO	
Filed in resident's chart	YES	NO	
Enduring Power of Attorney (Health Decisions)	YES	NO	Held by:
Filed in resident's chart	YES	NO	

Family notified of resident's condition & documented in progress notes	YES	NO	Person notified: Date:
GP consulted with family	YES	NO	GP: Family member: Date:
GP aware of AHD, EPA or resident's wishes	YES	NO	Date:

PERSONAL CARE

Personal Hygiene:	Oral Hygiene
Waterlow Score: Mattress & PR aids: Pressure Care:	Eye Care:
Continence Care:	Wound Care:
Nutrition & Hydration	

Created Date: 15/08/05	Version: 1
Review Date: 15/08/06	Document Control No:
Page 1 of 6	



First page of palliative care plan



Case conference: plan



- No advance health directive
- Funeral wishes documented
- Family agrees a palliative approach is appropriate
- No artificial hydration and nutrition
- Do not transfer to hospital
- Provide adequate pain relief – Oxycontin at present
- Keep family informed of condition



An Australian Government Initiative



Family informed of deterioration but did not want to be present
Transferred to the palliative care room
GP phone support or visit
Regular S/C morphine as unable to tolerate Oxycontin
Atropine for secretions
Staff satisfied with care provided



Case conference: plan



- Family acknowledge deterioration over recent months
- No pain at present but will monitor
- No transfer to hospital
- No resuscitation
- No artificial nutrition
- Don't give oral medications if refuses
- Keep family informed
- No advance health directive
- Funeral arrangements documented



What was achieved



- CVA – loss of swallow reflex
- Family notified and frequently visited
- Wife in same room but also has dementia
- GP considers transfer to hospital
- Family and nursing staff do not agree
- S/C fluids – trial
- Died with s/c in place
- Restlessness and agitation
- S/C morphine
- Family other than wife not present at death
- Family and staff disappointed that wishes were not followed



An Australian Government Initiative



Thank you for listening