
What does palliative care mean and does dementia need it?

National Council for Palliative Care

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Plan

- I. To explain what palliative care means for people with dementia
 - II. To explain why palliative care is necessary
 - III. To indicate why a palliative care approach might be relevant from diagnosis to death (or perhaps not)
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I. Well, what does it mean?

- 'Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual'

World Health Organization (2002) *National Cancer Control Programmes: Policies and Managerial Guidelines*, WHO: Geneva; p. 84

<http://www.who.int/cancer/media/en/411.pdf> (accessed 4 Jan 2008)

And what does that mean for
people with dementia?

e.g. ‘...the prevention and relief of
suffering by means of early identification
and impeccable assessment and
treatment...’

Perhaps it suggests the biomedical approach

- For example, memory clinics and mild cognitive impairment (MCI)
 - Acetylcholinesterase inhibitors and new anti-dementia agents
 - A national network of dementia research (DeNDRoN): <http://www.dendron.org.uk/>
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The ups and downs of the biomedical model

- The achievements of biomedicine
- A narrow approach to dementia care
 - emphasizes illness,
 - positions people with dementia *and their carers* as patients
 - encourages ‘a process of diagnostic overshadowing ...where all actions and expressions are attributed to the labelled condition’

(Downs, M., Clare, L. and Mackenzie, J. (2006) In: *Dementia: Mind, Meaning, and the Person*, (eds. Hughes, Louw and Sabat). Oxford: OUP; p. 240)

Person-centred dementia care: taking the psychosocial view

- An important corrective to the biomedical view (Kitwood 1997, Brooker 2004, Sabat 2001, 2006)
 - However,
 - Drug therapy works (anti-dementia drugs and antidepressants)
 - Different types of dementia
 - Physical symptoms in severe dementia
 - Genetic variation in response to treatment
 - Immunization!
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Nevertheless,

- ‘Viewing dementia from the perspective of the person-centred approach where the expression of the disease and its experience are viewed as the result of a dialectical process between neurological impairment, individual psychology, physical and mental health, and the social and physical environment keeps the person at the centre of all our efforts to help. It focuses on the person’s abilities and strengths and suggests a citizenship model of inclusion. It views a person’s experience as a valuable source of information...’

(Downs *et al.* 2006, p. 252)

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A putative solution

- The biopsychosocial model (Engel, 1980)?
 - But what about the spiritual (and hence palliative care)?
 - Hospice care and facing death
 - Existential anguish
 - Religious practices
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Palliative care similar to person-centred care (and brings in biomedicine)

Psychological needs
(Kitwood, 1997)

- Attachment
- Comfort
- Identity
- Occupation
- Inclusion

WHO Definition (1990)

- Support
- Symptom control
- Integration
- Affirmation
- Holism

□ Small, N., Froggatt, K. and Downs, M. (2007).
Living and Dying with Dementia: Dialogues about Palliative Care. Oxford: OUP.

How do we compare? (1)

- Palliative care approach
 - Palliative interventions
 - Specialist palliative care
 - Dementia care
 - ?
 - Terminal care
-

How do we compare? (2)

- Palliative care approach
 - Palliative interventions
 - Specialist palliative care
 - Dementia care
 - Behavioural and psychological signs of dementia
 - Terminal care
-

So what *should* palliative care mean for people with dementia? (WHO 2002)

- A team approach:
 - to relieve distressing symptoms;
 - to affirm life and to see dying as a normal process, to be neither hastened nor postponed;
 - to integrate the psychological and the spiritual;
 - to offer a support system to help patients live as actively as possible and to help the family cope, including during bereavement;
 - to enhance quality of life, which might positively influence the course of the illness;
 - to become involved early in the course of the illness and to work in conjunction with other therapeutic approaches
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II. But why is palliative care necessary?

Is it necessary? (1)

- McCarthy et al (1997)
 - 40% of people die in the community
 - <2% of people in hospices have dementia
 - Suboptimal treatment of symptoms
 - Carers need considerable support pre-bereavement
 - a host of common symptoms and signs experienced by people with dementia in the last year of life: confusion, urinary incontinence, pain, low mood, constipation and loss of appetite.
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Is it necessary (in the USA)? (2)

- Mitchell et al (2004)
 - Greater use of non-palliative interventions
 - Inadequate treatment of some symptoms
 - Lack of advance care planning
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Is it necessary? (3)

- Retrospective case-note studies demonstrate inadequate palliative care in both psychiatric and acute hospital wards
 - (Lloyd-Williams, 1996; Sampson *et al*, 2006)



Seemingly yes!

- ❑ *“Every person with a progressive illness has a right to palliative care”* (WHO, 2004)
 - ❑ *“Lack of palliative care for non-cancer sufferers ... greatest inequity of all in palliative services”*
(Health Committee of House of Commons, 2004)
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What's the evidence that a palliative care approach works?

(Sampson, Ritchie, Lai, *et al.* 2005)

- 30 review articles
 - Only 4 eligible for full appraisal
 - Only 2 met full criteria
 - Equivocal evidence of the efficacy of a palliative model of care in dementia
 - Increased interest, but little evidence: ethical difficulties, prognostic uncertainty, lack of clear outcome measures
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Volicer et al, 1986

- Description of care programme
 - Diagnostic criteria: DSM III-R
 - Number: 43
 - Control group: No
 - Randomised: No
 - Result: No significant increase in mortality
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Lloyd-Williams & Payne, 2002

- Description & adoption of guidelines
 - Diagnostic criteria: Not stated
 - Number: 27
 - Control group: No
 - Randomised: No
 - Result: Significant decrease in prescription of antibiotics and an increase in prescription of analgesia
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Volicer et al, 1994

- Prospective cohort trial
 - Diagnostic criteria: DSM III-R
 - Number: 114 intervention 50 traditional care
 - Control group: Yes
 - Randomised: No
 - Result: Higher mortality in dementia special care unit, but lower observed discomfort, fewer transfers to acute medical settings and lower costs
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Ahronheim *et al*, 2005

- Randomized controlled trial
 - Diagnostic criteria: Not stated
 - Number: 48 intervention 51 control
 - Control group: Yes
 - Randomised: Yes
 - Result: Intervention no influence on length of hospital stay or reduction in painful interventions
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But what else might palliative care involve?

- Advance care planning
 - Predicting death
 - Physical health
 - Pain
 - Infections and fevers
 - Artificial nutrition and hydration (ANH)
 - Resuscitation
 - Families and carers
 - Psychological, social and spiritual needs
 - Ethics
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So,

III. In what way is a palliative care approach relevant from the time of diagnosis until death?

A conceptual problem

- How do we characterize the care that is due to people with dementia in such a way as to capture all its possible, desirable and necessary aspects?
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NICE-SCIE

on palliative care in dementia

- ‘Dementia care should incorporate a palliative care approach from the time of diagnosis until death. The aim should be to support the quality of life of people with dementia and to enable them to die with dignity and in the place of their choosing, while also supporting carers during their bereavement, which may both anticipate and follow death.’
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Pursuing PEACE

- Shega, J. W., Levin, A., Hougham, G. W. *et al* (2003) Palliative excellence in Alzheimer care efforts (PEACE): a program description. *Journal of Palliative Medicine*, **6**, 315-320
 - Sachs, G., Shega, J. & Cox-Hayley, D. (2004) Barriers to excellent end-of-life care for patients with dementia. *Journal of General Internal Medicine*, **19**, 1057-1063
-

Questions for palliative care:

- Is not the palliative care approach in connection with dementia no more than good quality (old fashioned) person-centred dementia care?
 - What is it that is distinctive about palliative care over the whole course of a chronic disorder?
 - Once it moves away from its roots in caring for the dying, 'palliative care' can start to seem like (albeit laudable) flag-waving. (Should it wither away?)
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Some answers

- Need for expertise in dealing with the end of life
 - There is something that does define palliative care across the course of a chronic illness
 - Non-aggressive (is it?)
 - Being with (but we do to)
 - Non-curative?
 - End-of-life (effect on patients?)
 - Spiritual?
-

A suggested solution: supportive care

- ‘... it has been argued that palliative care, as a component of comprehensive supportive care, can play a part at all stages of disease. In many cases, there is an overlap of curative and life-prolonging therapy and then a further overlap as life-maintaining priorities take over....’



Continued...

- ‘...At all stages there is a place for supportive care, ... If we use this approach, seeing palliative care as having a contribution – within a supportive care framework – even when curative or life-prolonging therapy is the first priority of clinicians, then the contribution of palliative care to dementia care becomes more relevant throughout the illness.’

Small, N., Downs, M. and Froggatt, K. (2006). Improving end-of-life care for people with dementia – the benefits of combining UK approaches to palliative care and dementia care. In: Bère M. L. Miesen and Gemma M. M. Jones (eds), *Care-Giving in Dementia – Research and Applications, Volume 4*, Routledge, London and New York; pp. 365-392.

Supportive care

Ahmedzai, S. and Walsh, D. (2000). Palliative medicine and modern cancer care. *Seminars in Oncology*, **27**: 1-6.

Ahmedzai, S.H. (2005). The nature of palliation and its contribution to supportive care. In: *Supportive Care in Respiratory Disease* (eds. S.H. Ahmedzai and M.F. Muers), pp. 3-33. Oxford: Oxford University Press.

Supportive care

- Multidisciplinary
 - Interdisciplinary
 - Possibly virtual
 - No dichotomies:
 - cure/care
 - high tech/low tech
 - biological/social
 - patient-centred/carer-centred
 - 'being with'/'doing to'
 - Continuity of care
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Conclusions (1)

- The idea of multidisciplinary teams providing *comprehensive and continuing supportive care* is a suitable way to characterize the nature of the care due to people with dementia.
 - Such a model allows room for the full benefits of the palliative care approach and good quality end-of-life care to be harnessed and accommodates the biopsychosocial and spiritual dimensions of holistic care from the time of diagnosis.
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Conclusions (2)

- Do we really need a model at all?
 - What do models do?
 - Guide thought and action
 - Make a political statement
 - What does palliative care offer that is really useful to dementia specialists?
 - Advance care planning
 - Bereavement
 - Spirituality
 - Management of complex **physical** and psychosocial problems
 - Care of the dying
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