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Dementia – a National Health Priority



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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



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Dementia and Palliative Care Conference Practical and Ethical Considerations

**An ANF (Victorian Branch), Palliative Care Victoria and
Palliative Care Nurses Special Interest Group Forum**

Friday 19 June 2009

ANF Conference Centre

ANF House, 540 Elizabeth Street

Melbourne

**Why a palliative approach is required for
people with dementia and why and how is it
different .**



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- **What is dementia ?**
- **What is palliative care?**
- **Do you die from dementia?**
- **How prevalent is dementia?**
- **What is the prognosis after diagnosis?**



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What is dementia ?

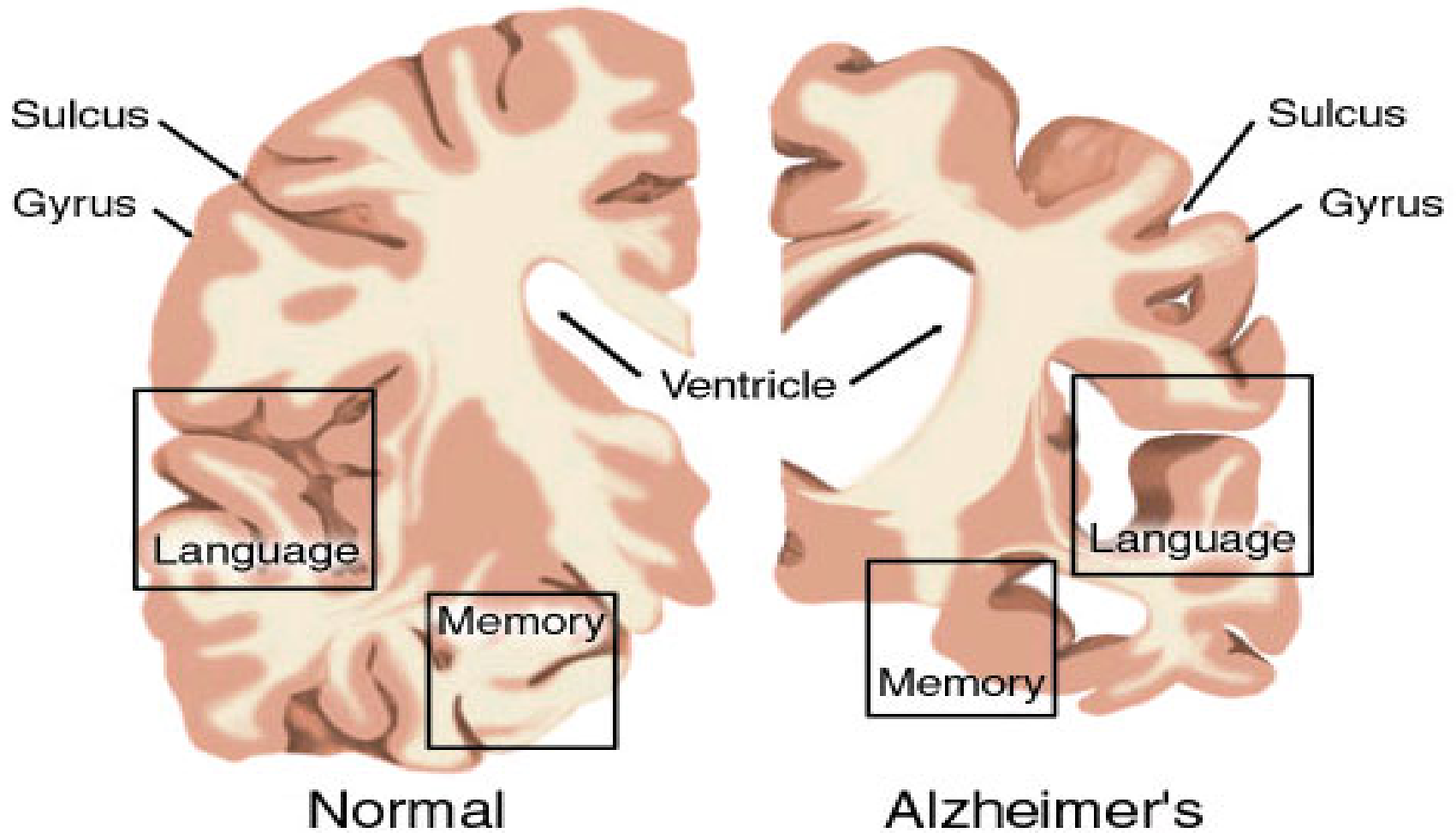
'A syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement. Consciousness is not clouded. The impairments of cognitive function are commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour, or motivation. This syndrome occurs in Alzheimer's disease, in cerebrovascular disease, and in other conditions primarily or secondarily affecting the brain.'

Dementia is not a single specific disease and therefore affects people differently and with varying impact of their families and carers

The International Statistical Classification of Diseases and Related Health Problems (ICD), 10th Revision (WHO 1992a:312)



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What is palliative care for people with dementia?

Care that provides comfort and assists in retaining a person's dignity and individuality



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Do you die from dementia?

- life threatening illness & dementia
- dementia & a co-morbidity
- dementia as part of another disease process
- die from dementia





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...37 % of the death certificates didn't list dementia as the main cause of death or a contributing factor. .
...dementia underrepresented on death certificates.. further exacerbates the issue of dementia not being a terminal illness
...can lead doctors and relatives to make ill-informed decisions about patients at the end of life.

SOURCES: Susan Mitchell, M.D., associate professor of medicine, Harvard Medical School, and senior scientist, Hebrew SeniorLife, Boston; Claudia Kawas, M.D., member, Alzheimer's Association medical and scientific advisory council, and professor of neurology and neurobiology and behavior, University of California, Irvine; Dec. 10, 2008, *Journal of the American Medical Association*

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THE NATIONAL COUNCIL FOR PALLIATIVE CARE

for dementia
training • development • admiral nurses

Age Bands	65 to 74	75 to 84	85+
Cancer			
Number of deaths	33305	43330	20474
Number with dementia	977	3800	5951
% with dementia	2.90%	8.80%	29.10%
Circulatory			
Number of deaths	31548	71469	67962
Number with dementia	941	6319	19992
% with dementia	3.00%	8.80%	29.40%
Respiratory			
Number of deaths	9615	21019	18239
Number with dementia	283	1817	5224
% with dementia	2.90%	8.60%	28.60%

www.fordementia.org.uk

www.ncpc.org.uk



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How prevalent is dementia?

...the number of people with dementia will grow from over 175,000 in 2003 to almost 465,000 in 2031 (nearly 40% increase)



Australian Institute of Health and Welfare (AIHW) 2006. Dementia in Australia: National data analysis and development. AIHW cat. no. AGE 53. Canberra: AIHW.

Australian Institute of Health and Welfare

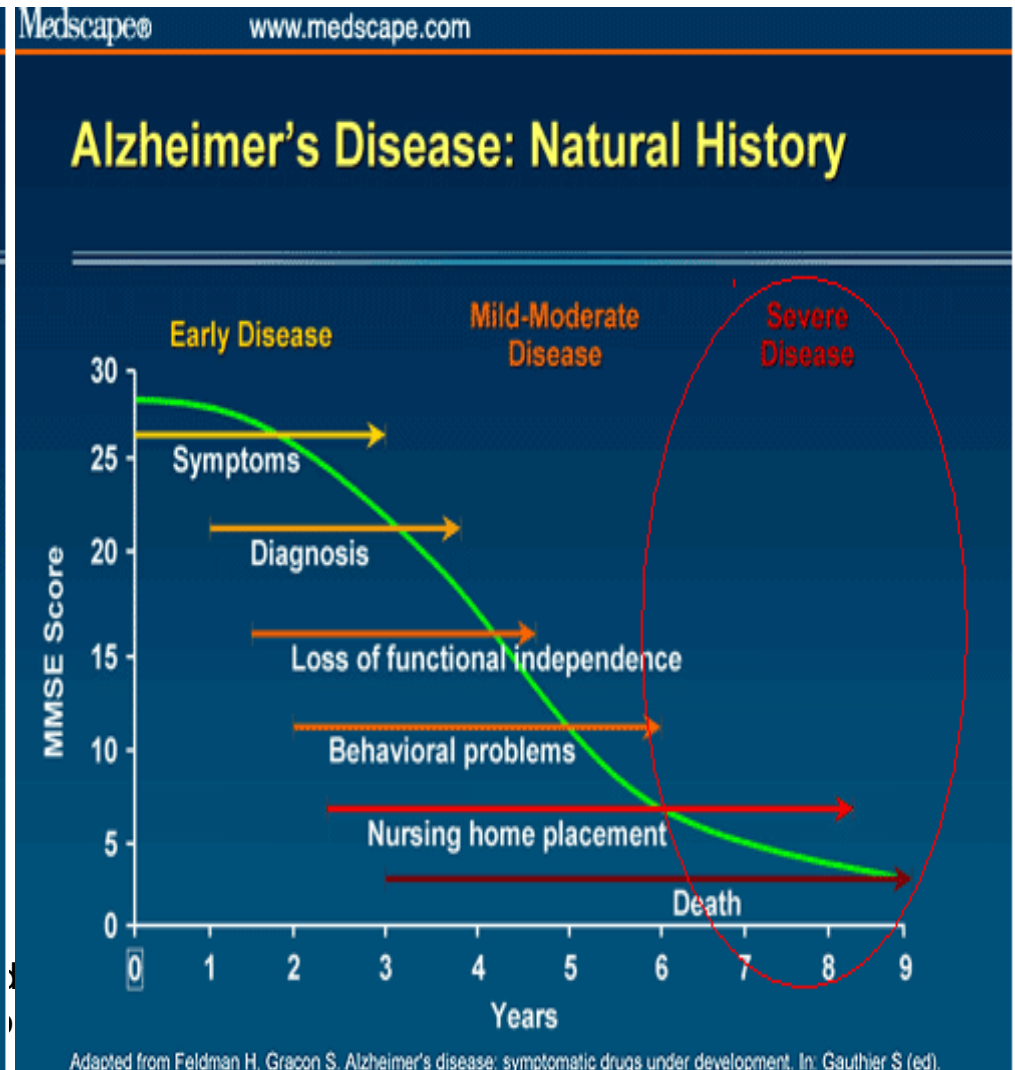
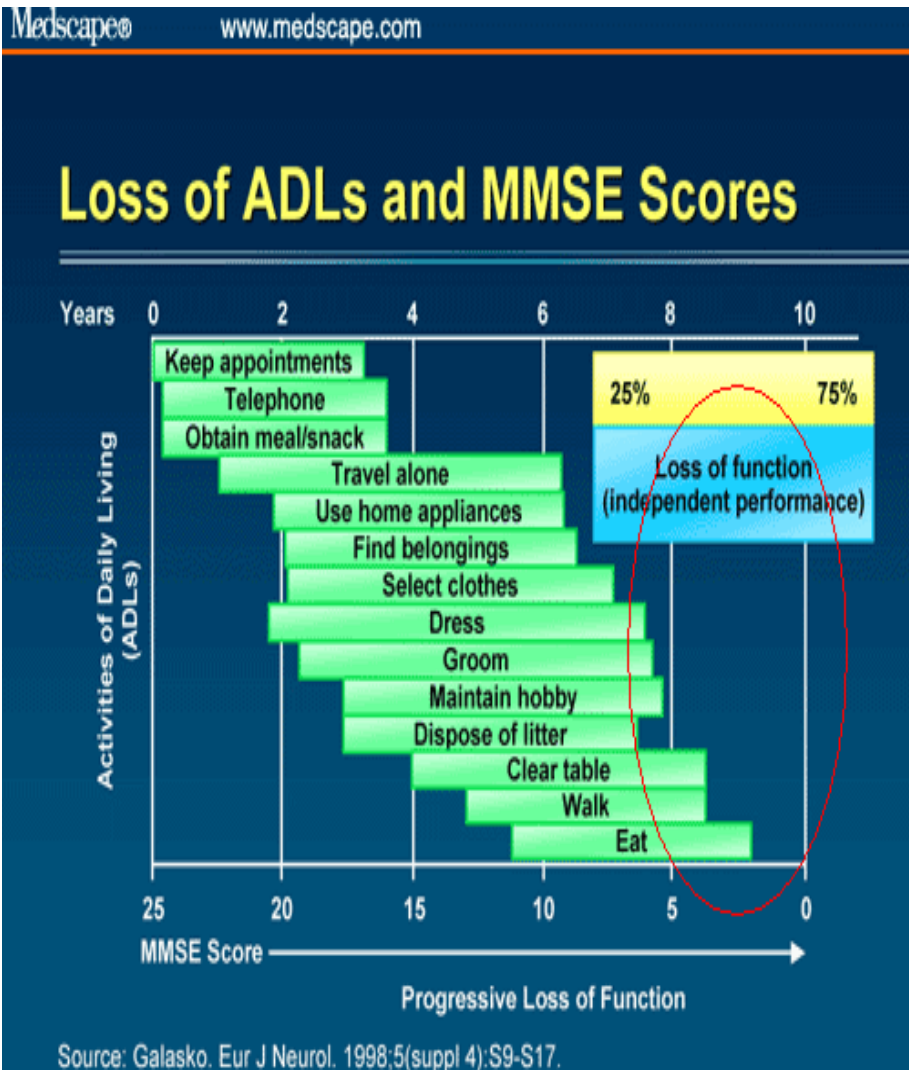
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What is the prognosis after diagnosis?

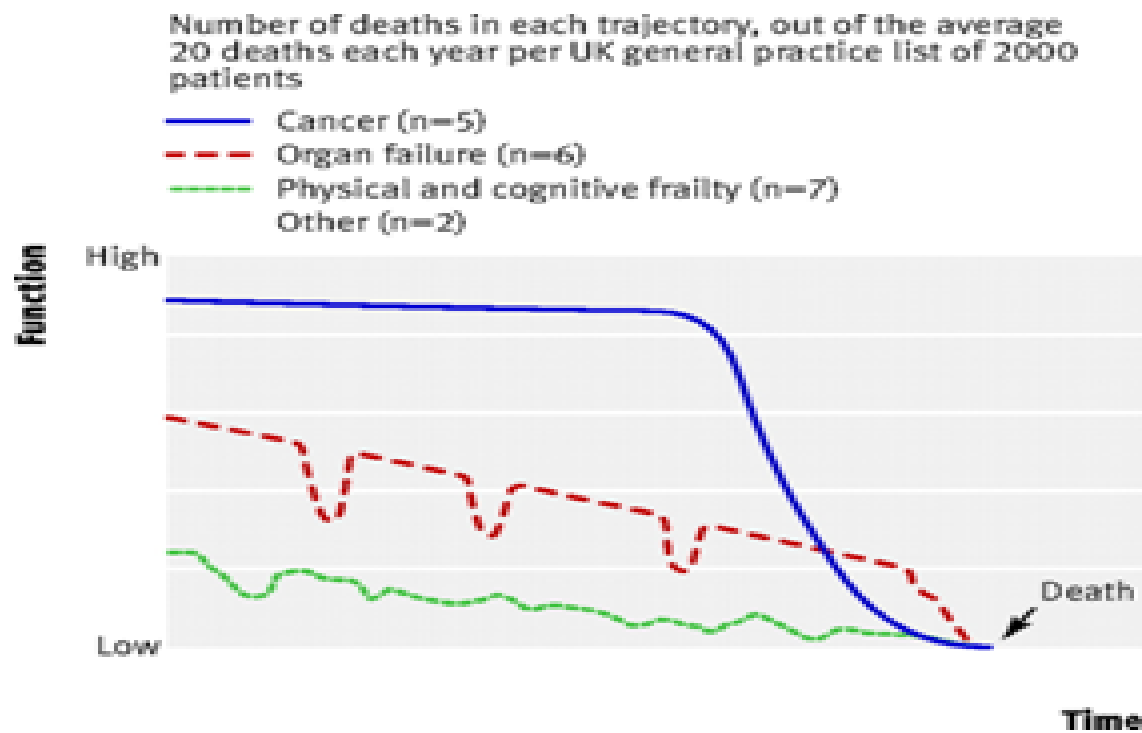




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Figure 1: The three main trajectories of decline at the end of life



Murray, S. A et al. *BMJ* 2008; 336: 958-959

BMJ

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Medicare Criteria

1. Stage 7 or beyond according to the FAST scale
2. Unable to ambulate without assistance
3. Unable to dress without assistance
4. Unable to bathe without assistance
5. Urinary or fecal incontinence, intermittent or constant
6. No meaningful verbal communication, stereotypical phrases only, or ability to speak limited to six or fewer intelligible words

Patients must also have had one of the following within the past 12 months:

- Aspiration pneumonia;
- Pyelonephritis or other upper urinary tract infection;
- ‘Septicemia’;
- Decubitus ulcers, multiple, stage 3-4;
- Fever, recurrent after antibiotics; or inability to maintain sufficient fluid and calorie intake with 10 percent weight loss during the previous six months or serum albumin ,2.5 gm/dl

American Journal of Hospice and Palliative Medicine ©
<http://ajh.sagepub.com>
Predictors of six-month survival among patients with dementia: An evaluation of hospice Medicare guidelines
R. Schonwetter, B. Han, B.J.Small, B. Martin, K. Tope and W.E. Haley

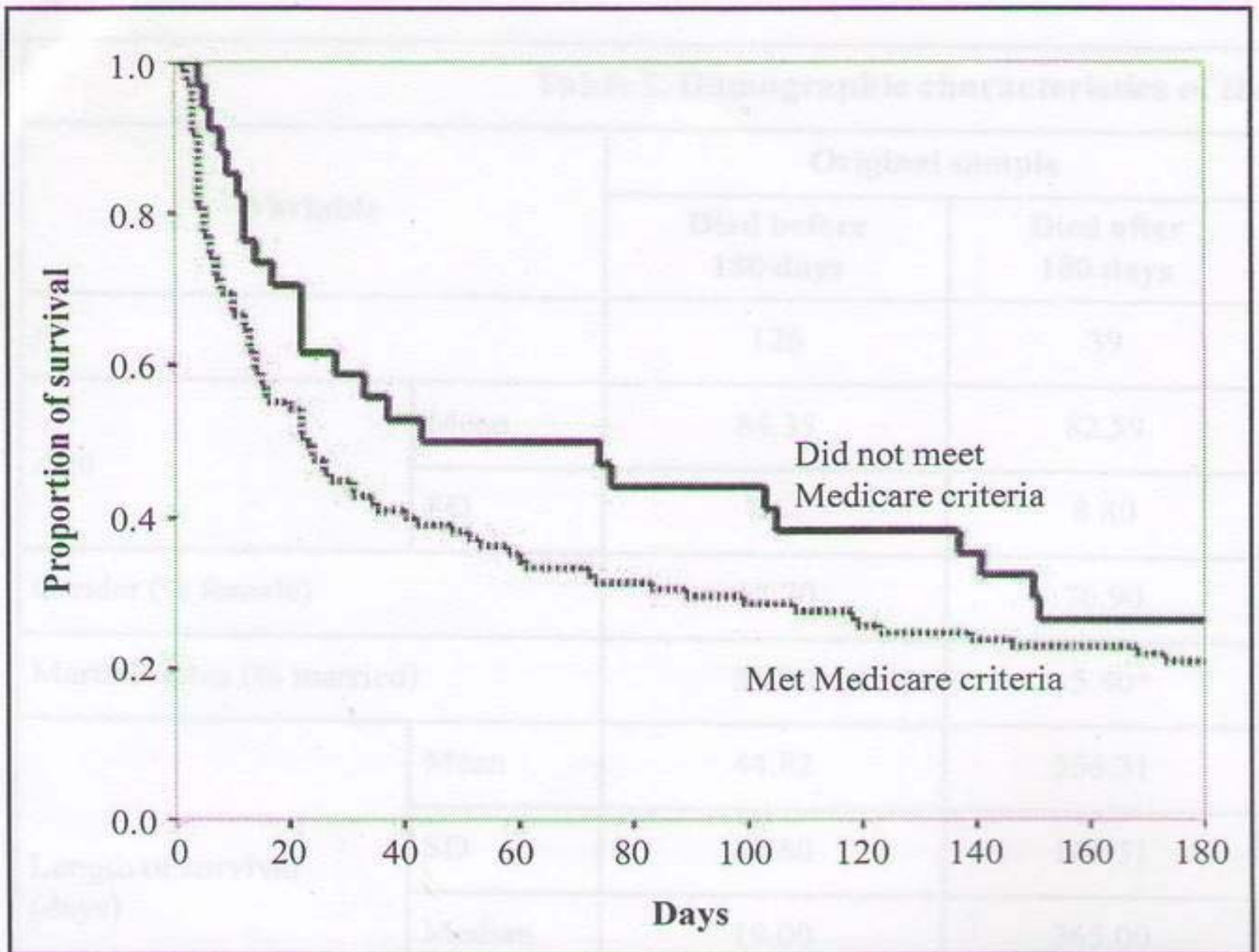


Figure 1. Survival curves for patients with dementia who did and did not meet hospice Medicare criteria.








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**Would this daughter talk
about her mother like this
if her mother had cancer?**

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	Cancer	Dementia
Testamentary capacity present?		X
Trajectory clear and known?		X
Retains personality/personhood		X
Pain measurement well managed and understood		X
Readily accepted palliative care interventions?		X



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Prognostication



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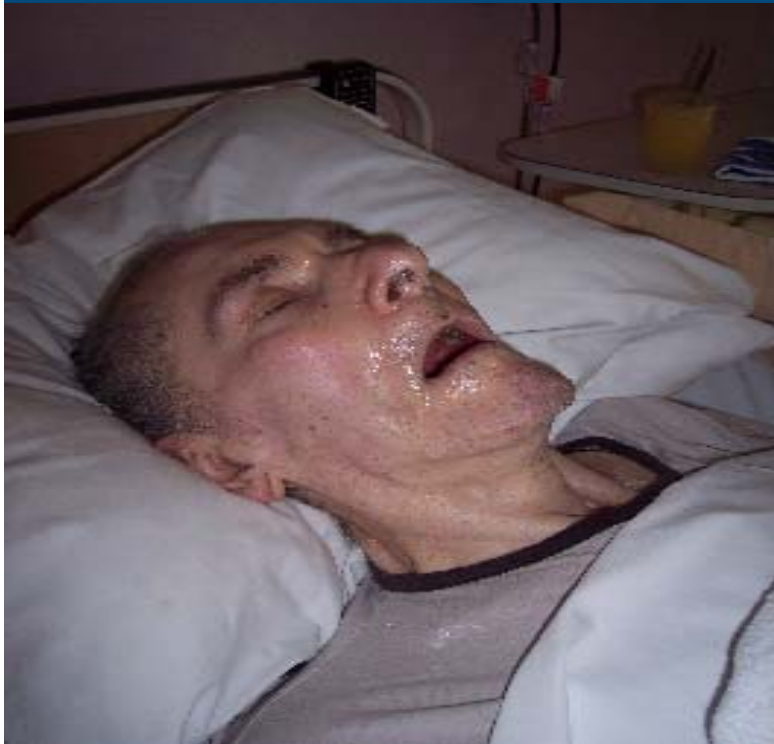
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Severe dementia

“Most studies of dementia deal with light to moderate stages of the condition, while relatively little attention has been paid to its most severe stages”

Boller, Verny, Hugonot-Diener & Saxton (2002) Clinical features and assessment of severe dementia . A review. *European Journal of Neurology*,9;125-136

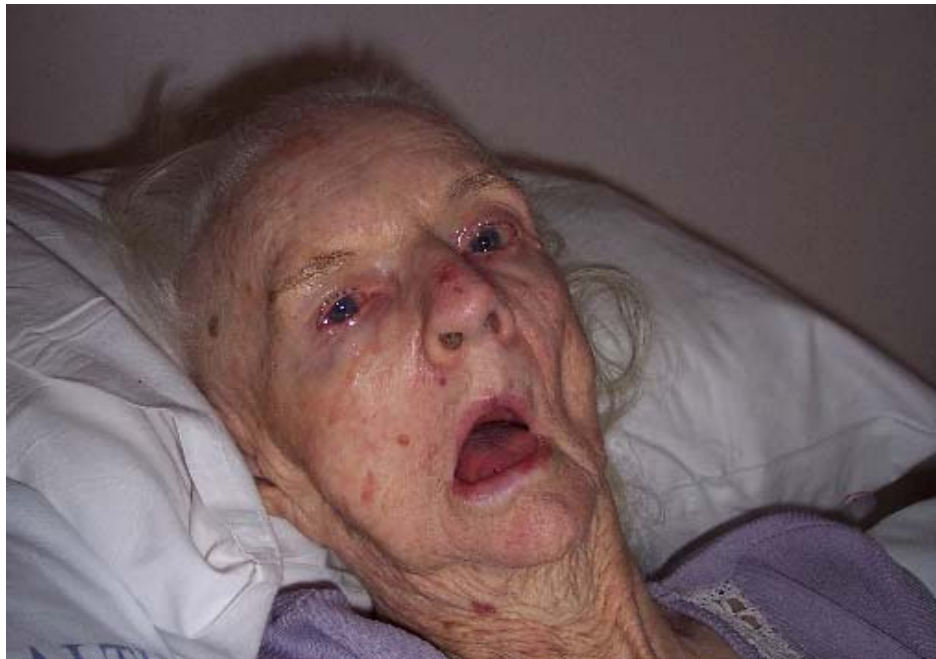




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Defining severe dementia



van Der Steen, J. Volicer, L., Gerritsen, D., Kruse, R., Ribbe, M and Mehr, D. 2006, Defining severe dementia with the Minimum Data Set, International Journal of Geriatric Psychiatry, 21, pp1099-1106

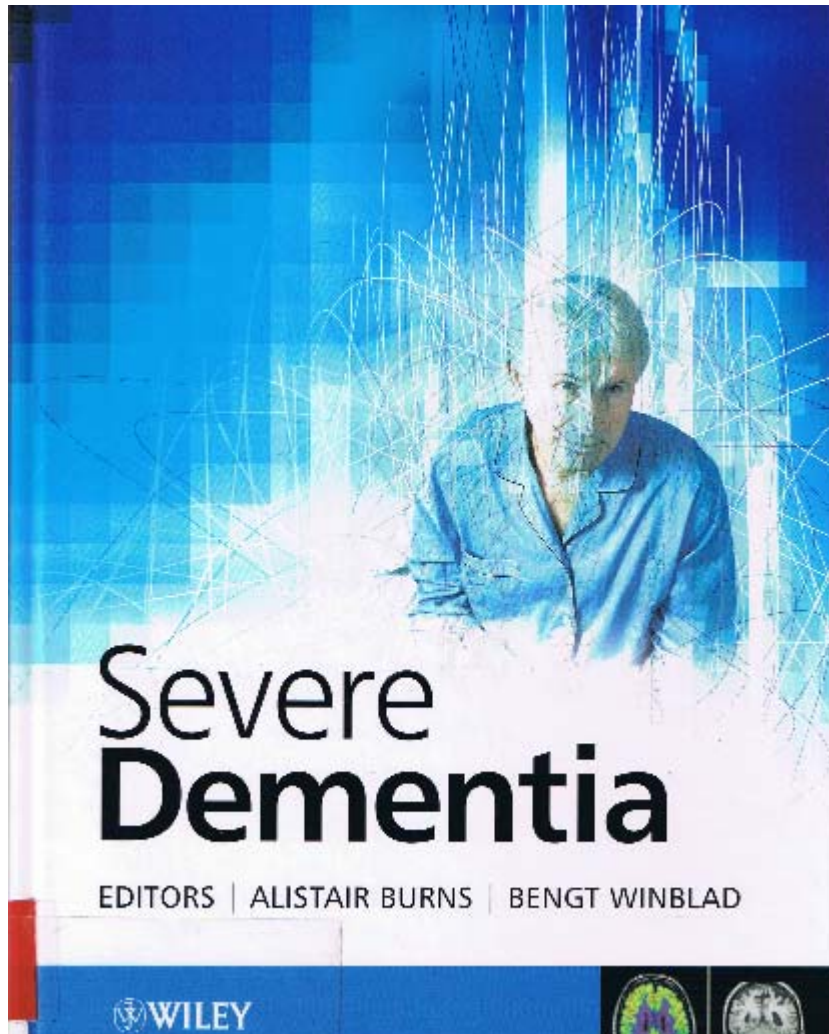
“Clinicians usually distinguish three stages of dementia – mild, moderate and severe – but there is considerable variation in definitions”

“...conceptually, staging dementia severity and measuring cognitive impairment are not equivalent”

(p. 1102)



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‘Diagnosis challenging’
p17

‘Few studies’ p17

**‘Severe impairment
battery (SIB) OK
MMSE>10. Useful in
drug trials’** p16

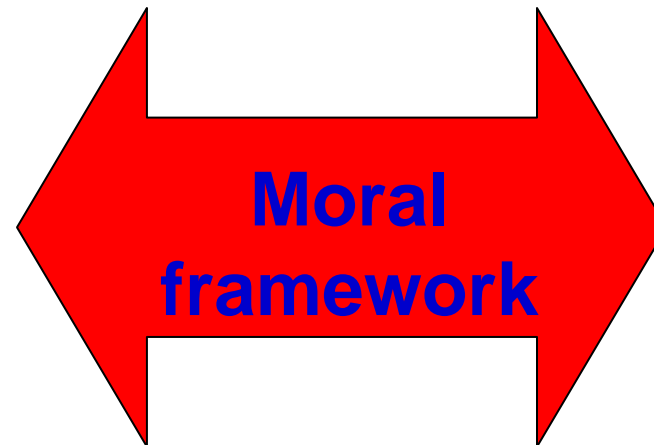
**‘More widespread
research needed’** p113



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



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.



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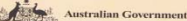
Guidelines for a Palliative Approach in Residential Aged Care
Enhanced Version — May 2006



THE NATIONAL
PALLIATIVE CARE
PROGRAM

Prepared by Edith Cowan University

Approved by



Palliative Care and Dementia
Alzheimer's Australia
Discussion Paper 7
February 2006



Guidelines for a Palliative Approach in Residential Aged Care

▪Rural Health and Palliative Care Branch, Australian Government Department of Health and Ageing Canberra, Australian Government Department of Health and Ageing Enhanced Version 2006,

Consumer information from the Alzheimer's Association



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How is the daughter going
to cope as her mother
slowly dies with dementia?

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**‘How people die
remains in the
memories of those who
live on’ (Dame Cicely
Saunders)**



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Complicated grief is more than a normal grief reaction, ... it means that painful emotions are so long lasting and severe that the person has trouble accepting the death and resuming their own life it can often have a serious toll leading to depression and other illnesses.



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Aroma Therapy



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Doll therapy

Community members Neil & Evon Jones & Carinya staff Laura Fleming & care manager Shirley Waldhuter with some of the therapy dolls being introduced to residents at Helping Hand Aged Care Carinya.

<http://clare.yourguide.com.au/news/local/news/general/doll-therapy-success/402918.aspx>



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Touch and Love



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- **Fresh air**
- **Wind on the face**
- **The warmth of the sun**

Can the bed go outside?





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MUSIC

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Finally:

Goodbye

**Rest in
Peace**



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Thank you

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