WICKING DEMENTIA RESEARCH & EDUCATION CENTRE

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UNIVERSITY of TASMANIA

Dementia and a Palliative Approach to Care

Palliative Care Australia

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Overview

Understanding dementia as a terminal condition

Introduction to a palliative approach

Contemporary developments in palliative care

- Specialist palliative care
- Terminal care

Who can benefit from a palliative approach, where and by whom can it be provided

Palliative approach and dementia care, including place of end-of-life pathways

Consequences of Dementia:

Brain damage which results in progressive impairment of many aspects of life:

1. **Cognitive problems**
2. **Behavioural responses**
3. **Functional deficits**
4. **Movement problems**
5. **Psychiatric conditions**

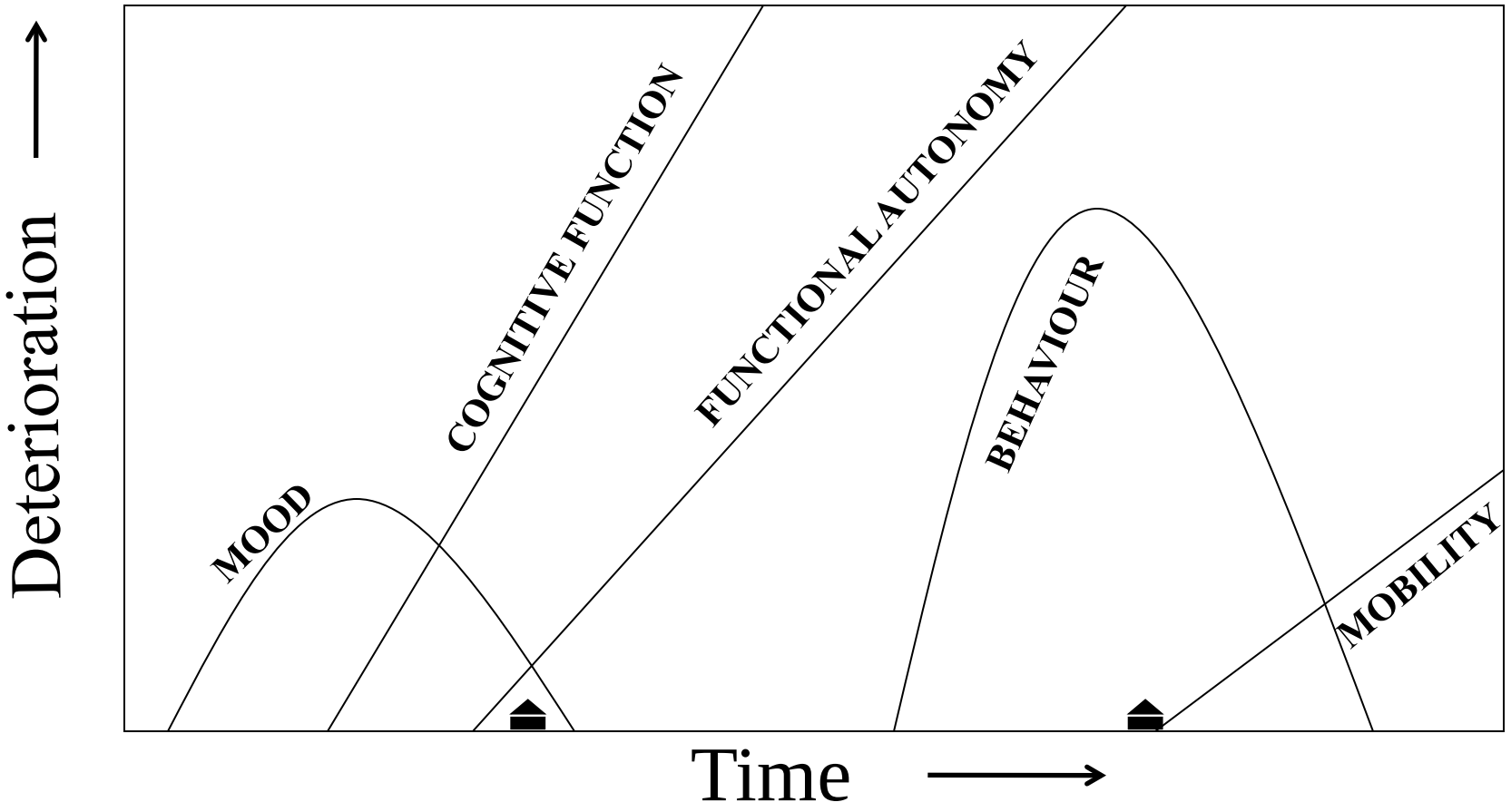
Dementia trajectory/journey to death

- characterized by **slow progressive decline**;
- only slight increase in functional loss as death approaches

Implications: "No abrupt changes that signal the onset of a terminal phase..." Different to the path of someone with untreatable cancer

It can be difficult to recognise the dying phase

Alzheimer's progression



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Dying *of* dementia: implications of brain cell death

<u>Reduction in/cessation of eating and drinking:</u>

- **Problems with chewing and swallowing – muscles and nerves required no longer work in a coordinated fashion**

<u>Infections:</u>

Reductions in mobility, people become bed/chair bound

May not be able to report symptoms of an infection

- **Pneumonia -**
  - Reduction in the ability to cough, reduced ability to clear lungs and airways of bacteria

Dying *of* dementia: implications of brain cell death (cont')

Unable to hold self upright, difficult to clear airways

Aspiration of saliva or inhaling food, fluid into lungs (dysphagia-related)

- **Urinary infections – increased contact time with bacteria (incontinence pads, faecal incontinence)**

Strokes - for those with a history of dementia of vascular causes

How do dementia and palliative care go together?

If dementia is a terminal, life limiting condition, then it makes sense that a palliative approach to care provision is appropriate

So, what is a palliative approach?

A Palliative Approach aims to:

…improve the quality of life (QoL) of people with life limiting conditions such as dementia, and their families;

…reduce suffering through early identification, assessment and treatment of pain and other physical, cultural, psychological and spiritual needs;

...support the family throughout the illness journey and in bereavement; and

…is a proactive approach applicable at any point in the illness journey (DoHA 2006)

Who can benefit from a palliative approach?

Any person with a life limiting illness at any stage of that illness

Includes people with malignant (eg cancer) and non-malignant conditions *including* dementia

- Other groups who may benefit:
  - HIV/AIDS; MND; Parkinson's disease; COPD; advanced heart, renal, liver disease
  - Advanced frailty due to old age

Who can provide a palliative approach to care?

All health care professionals – client and family also regarded as part of team

Specialist Palliative Care

Those services with palliative care as their core specialty

Usually needed by a specific minority of people who need complex care

Input from specialist service usually provided in partnership with primary care provider (nursing staff, allied health, carers, GPs)

Terminal Care

Important, final phase of palliative care

Refers to the management of an individual in the last days or week/s of life

The person is in a progressive state of decline

Care process is more sharply focused on comfort and support

What a palliative approach is NOT …

It is NOT the same as terminal care

It is NOT only provided by specialist palliative care trained staff

It is NOT offered when "nothing else can be done" – this is NEVER true!!!

EoL Pathways – Relevance in Advanced Dementia?

Profound weakness
Withdrawal from the world
Reduced cognition
Reduced levels of consciousness
Reduced intake of diet and fluids
Difficulty with swallowing medications
Retained bronchial secretions
Increased nausea and vomiting
Terminal agitation
Reduction in urine output
Cessation of bowel movement

(Marie Curie PCI Signs of Terminal Phase, 2007)

PATHWAYS IN DEMENTIA?

Qld Govt (2011) RAC EoLCP

Three or more of the following indicate end of life is imminent:

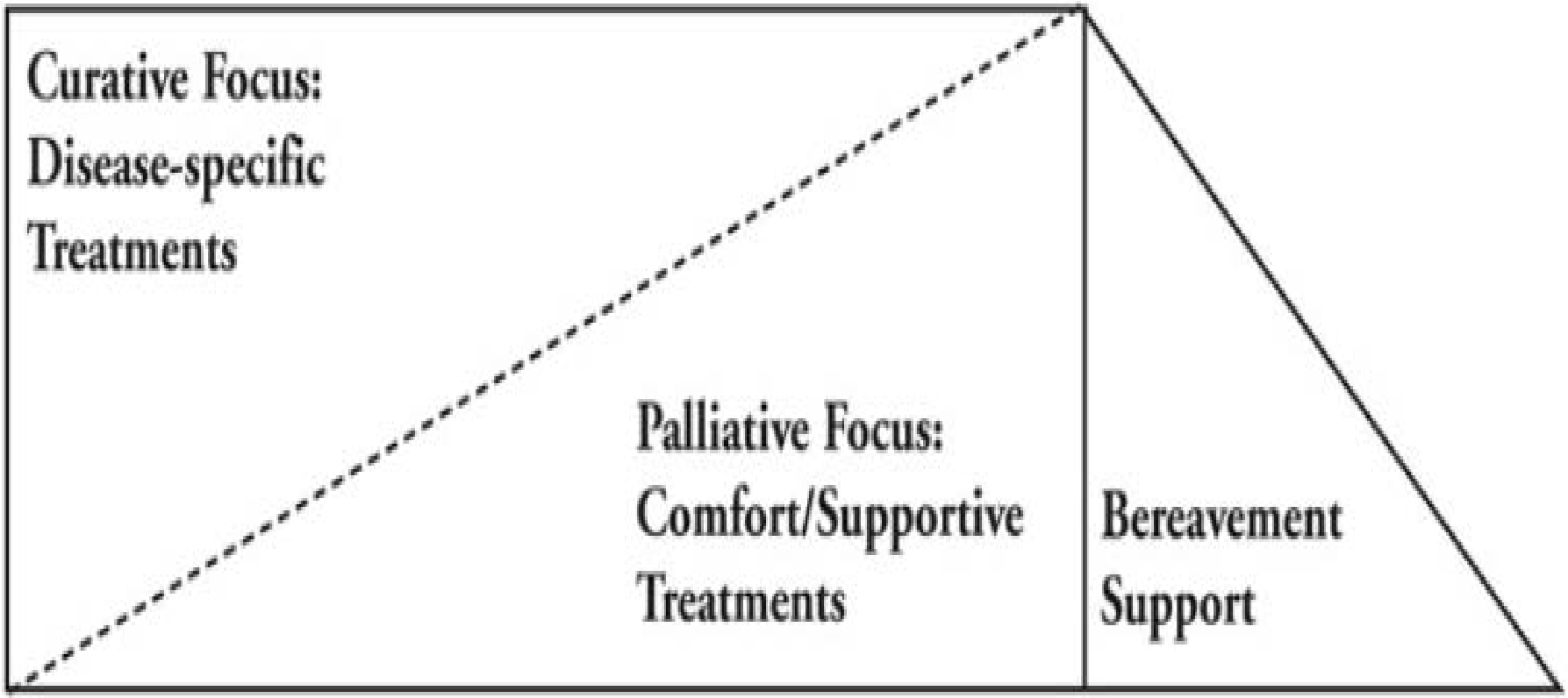
Experiencing rapid day to day deterioration that is not reversible
Requiring more frequent interventions
Becoming semi-conscious, with lapses into unconsciousness
Increasing loss of ability to swallow
Refusing or unable to take food, fluids or oral medications
Irreversible weight loss
An acute event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

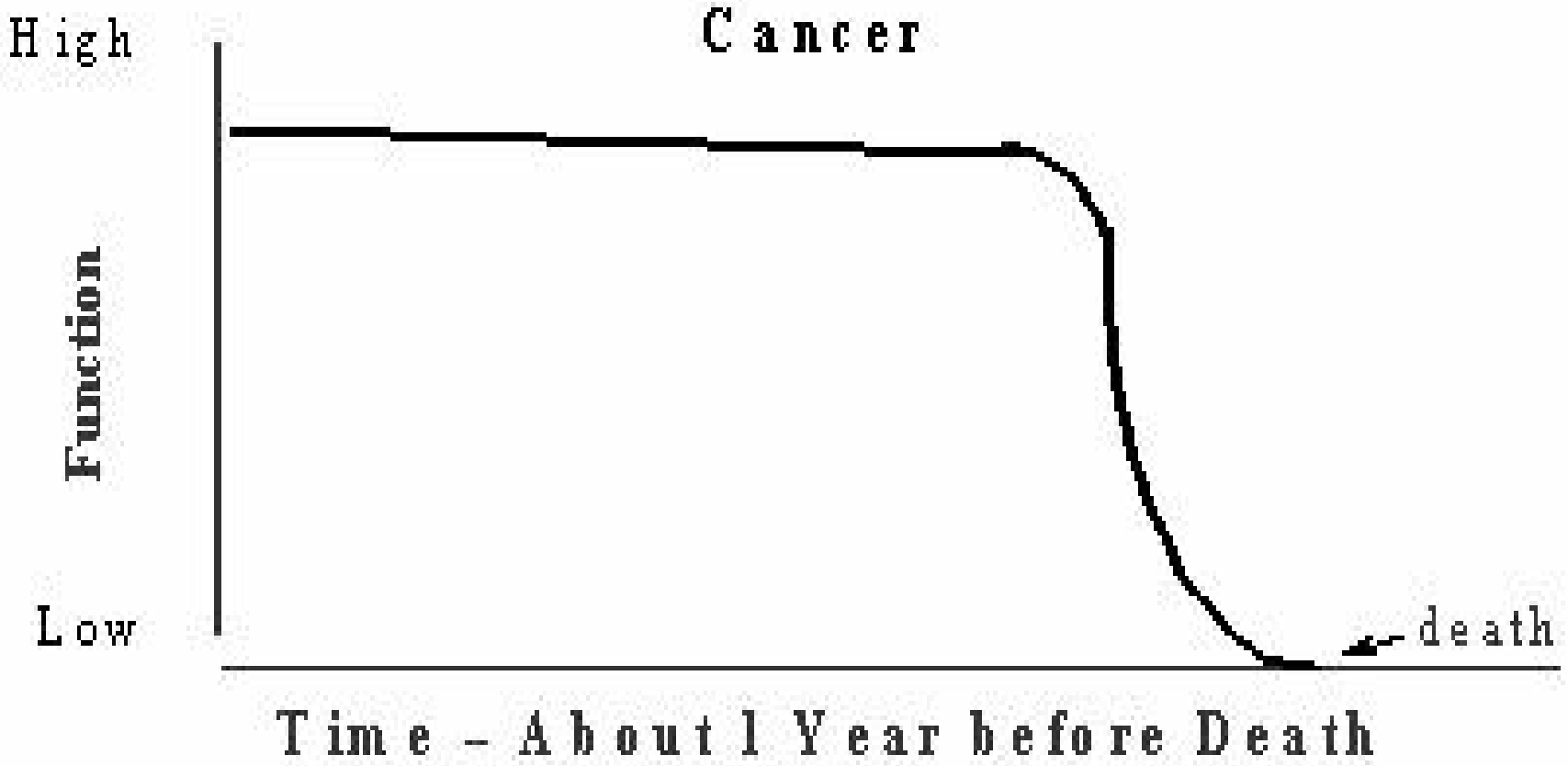
PATHWAYS IN DEMENTIA?

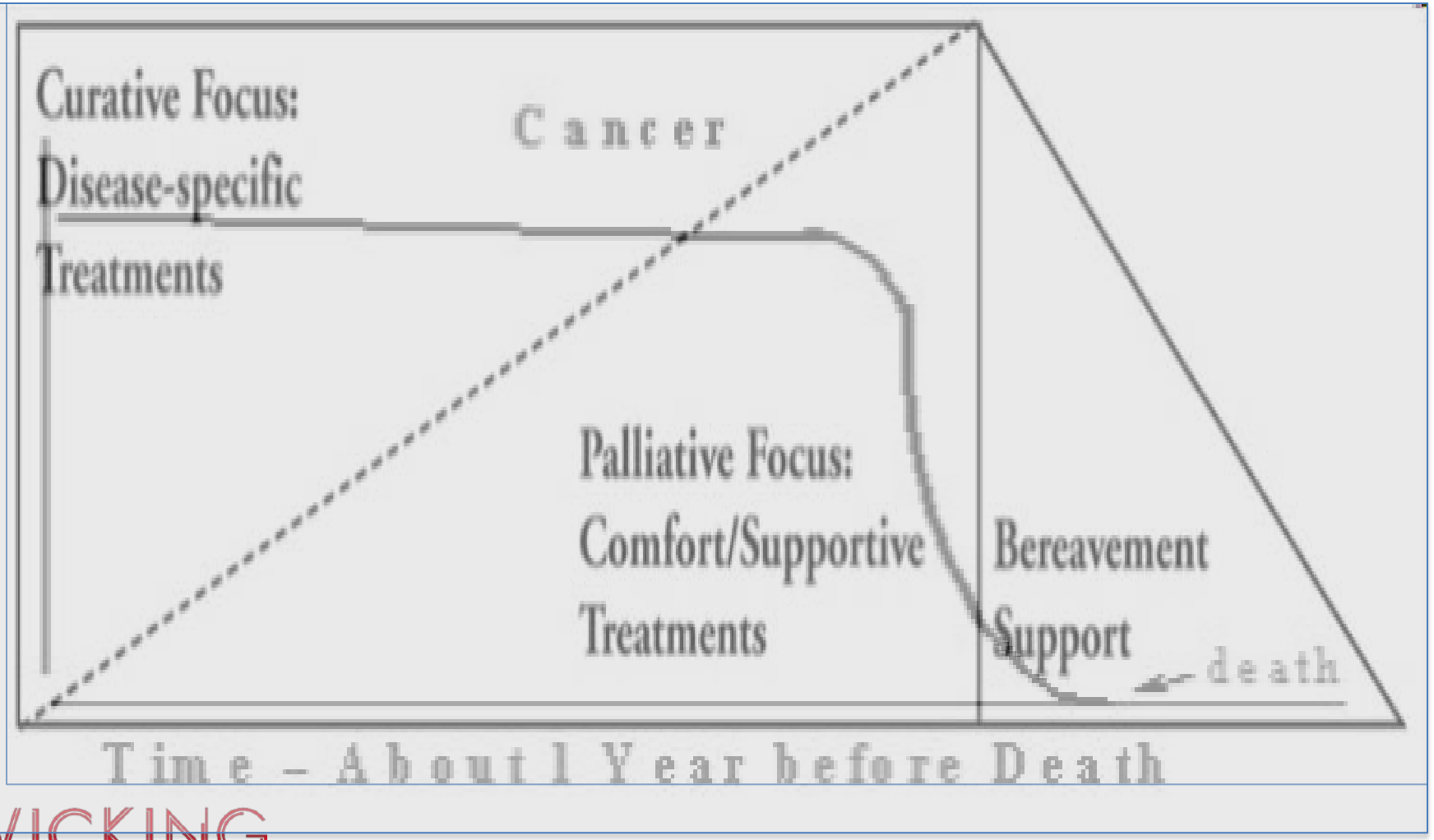
PWD may not exhibit signs of the dying phase until VERY late in the illness course – most of the above signs are present for PWD well before the terminal phase of life

If used, pathways MUST be incorporated into a palliative approach to the care of people with dementia

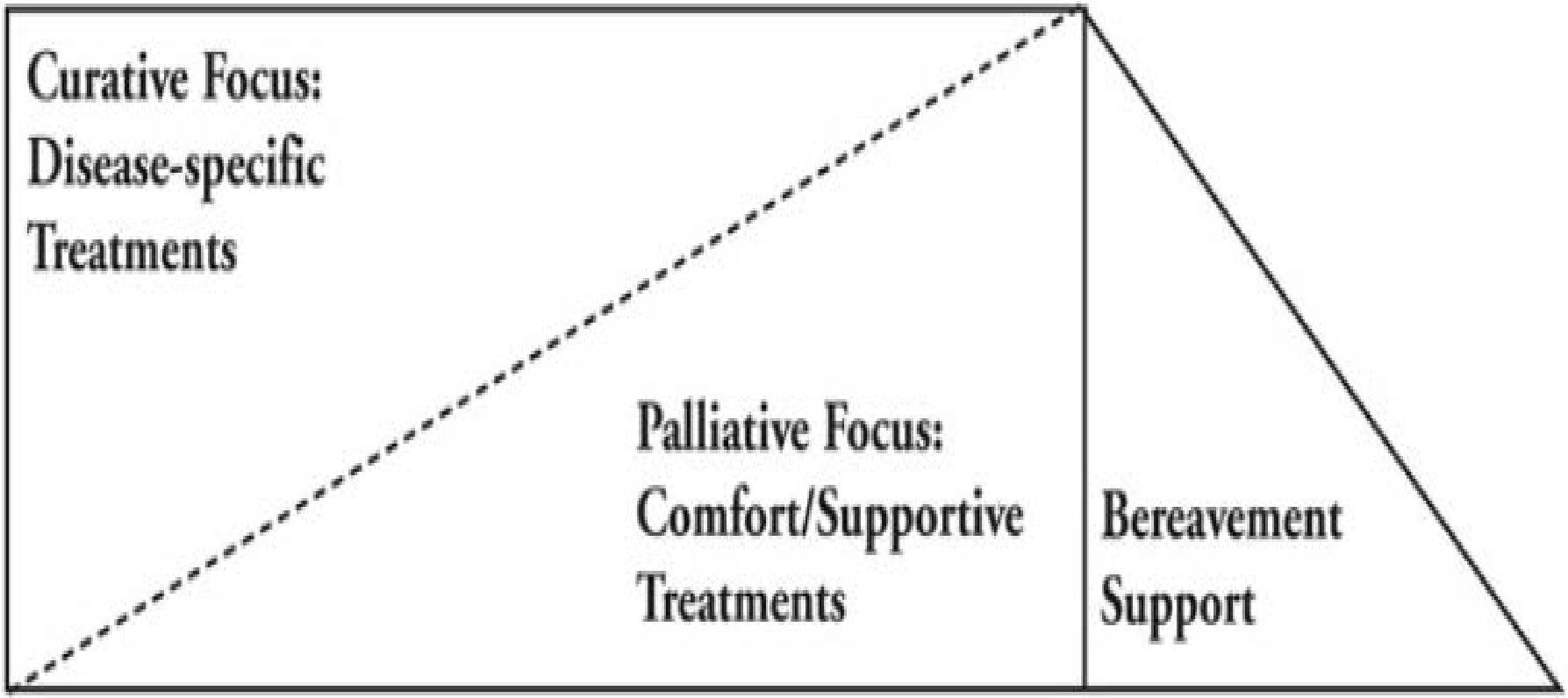
Contemporary Understanding of Curative/Palliative Care

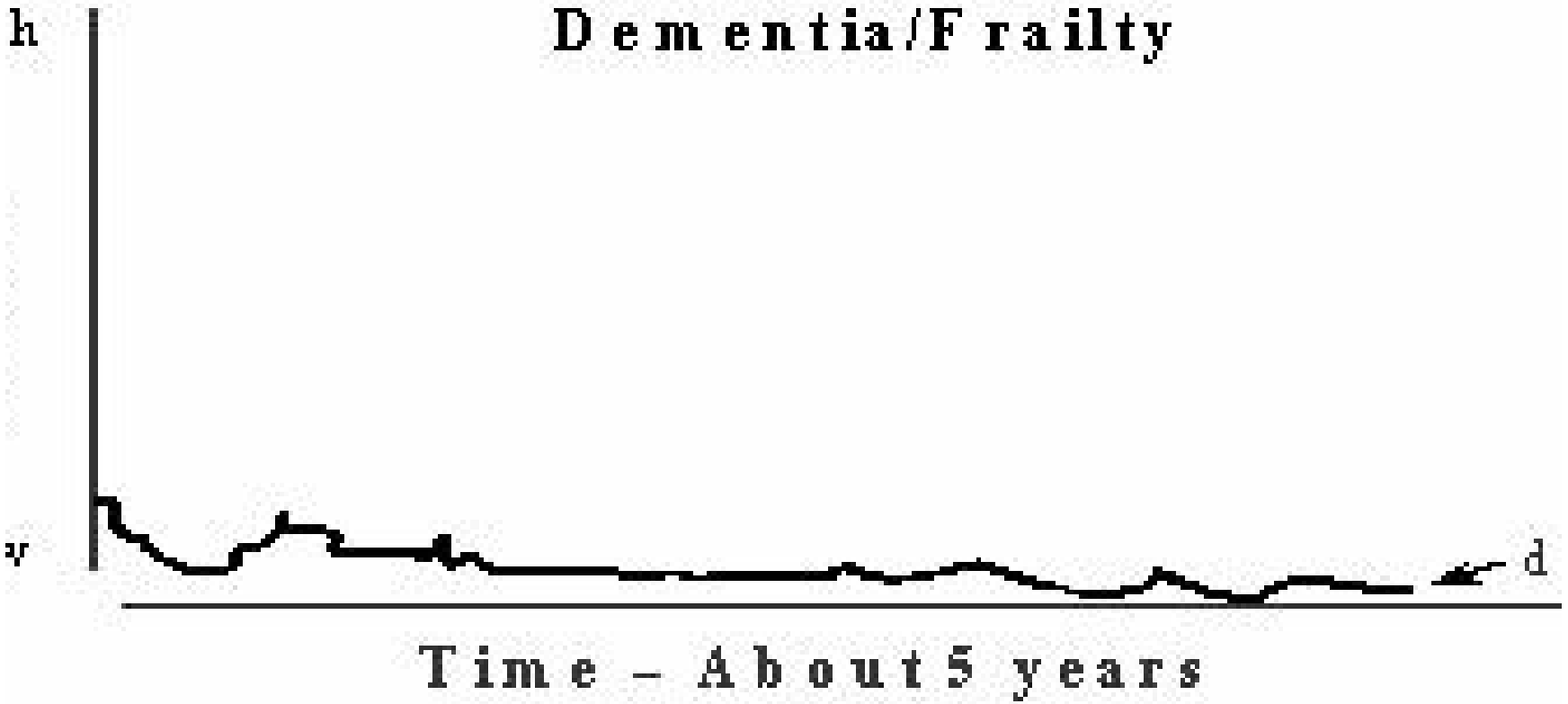


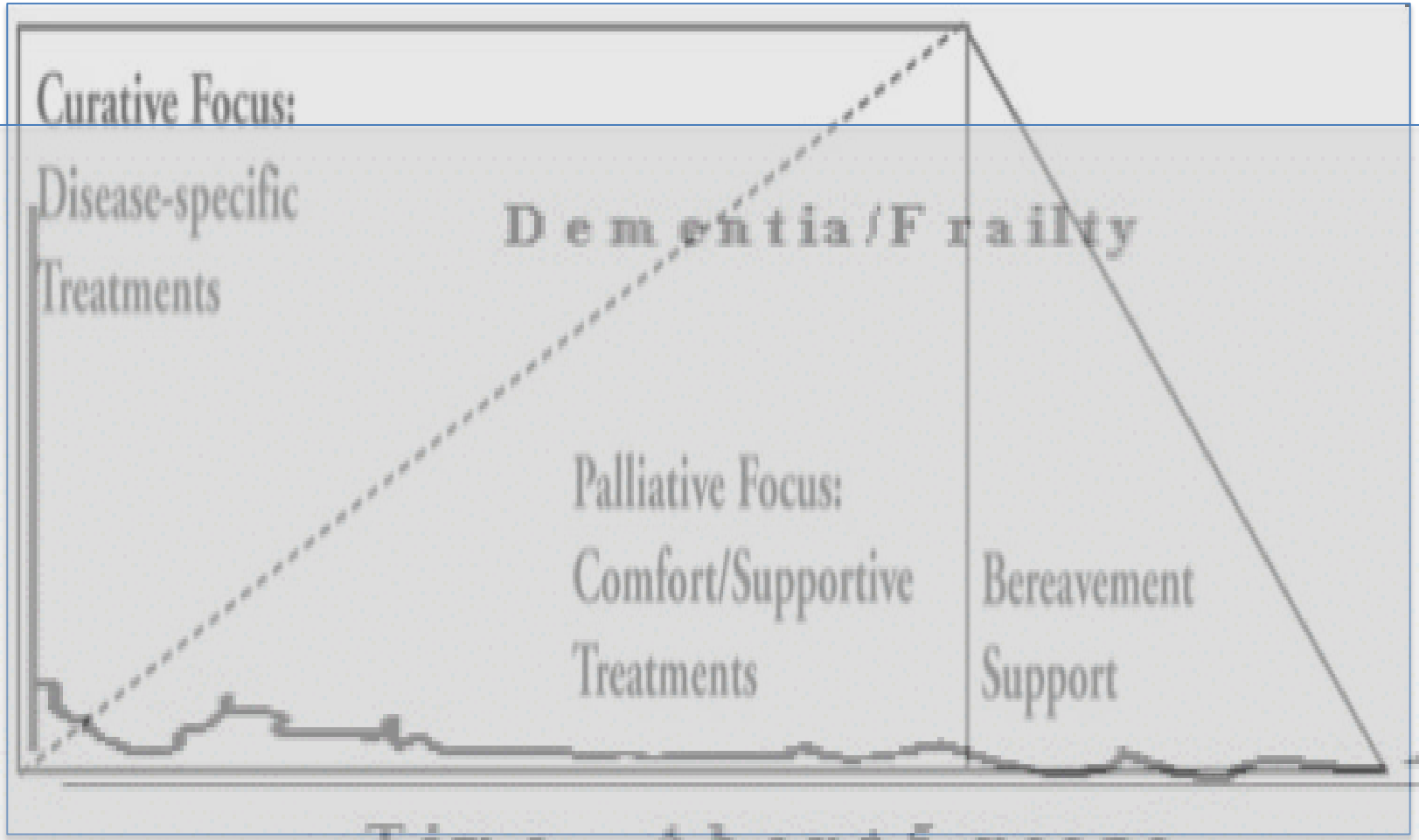

Cancer
High
Function
Low
death
Time – About 1 Year before Death


Curative Focus:
Disease-specific
Treatments
Cancer
Palliative Focus:
Comfort/Supportive
Treatments
Bereavement
Support
death
Time – About 1 Year before Death

Contemporary Understanding of Curative/Palliative Care




h
Dementia/Frailty
d
Time – About 5 years



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Why is a palliative approach important in residential care?

Shorter length of stay of increasingly dependent residents (approx 50% of residents die every 12 months; 30% die within 12 months of admission)

Over half of residents have some form of dementia (AIHW 2010)

More complex care needs (including for those with other illnesses ie multiple co-morbidities)

Average lifespan for those with dementia is 5 years from diagnosis to death (range is 6 months to 20 years)

Approx 90% of people in RACFs will exit via death (AIHW 2010)

Why is a palliative approach important in residential care (cont')?

Profile of residents is rapidly changing:

- Older ages when admitted
- Higher dependency
- More complex care needs from the time of entry
- Difficulty in recognising trajectory of progressive decline to death – especially for people with non-malignant conditions (e.g. dementia)

Benefits of a palliative approach to the care of people with dementia in RACFs

Promotion of a positive and open attitude towards death and dying – a different lens through which to view care

Fosters active and open discussions with family caregivers of PWD about deterioration, dying and the importance of planning for care

Focuses of quality of life rather than a "treatment as usual approach"

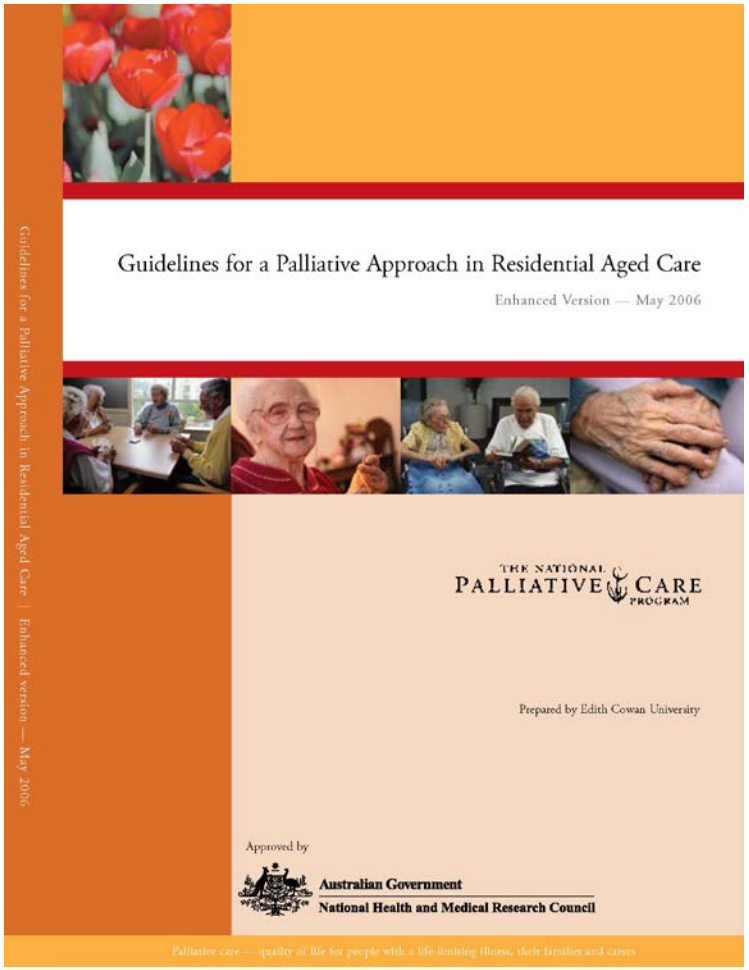
Provides a focus for collaboration with multidisciplinary team members to improve quality of care

Focuses on quality of living *and* quality of dying!

A Palliative Approach to care – best practice in RACFs

Best practice guidelines (DoHA 2006)

http://www.palliativecare.org.au/Portals/46/APRAC%20guidelines.pdf



Two key considerations in implementing a palliative approach for people with dementia in RACFs

Guidelines for a Palliative Approach in Residential Aged Care (DoHA 2006)

Section 5 – Advanced Dementia

Guideline 11:

- Remaining in familiar surroundings is beneficial for residents with dementia as this helps promote feelings of orientation and security

Guideline 13:

- The use of aggressive medical treatment of infections/ other illnesses is not recommended for residents with advanced dementia. Instead, a palliative approach is recommended, which might include short-term antibiotic therapy to improve symptoms and quality of life

Wicking Dementia Research & Education Centre

THANK YOU

http://www.utas.edu.au/wicking

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