WICKING DEMENTIA RESEARCH & EDUCATION CENTRE

Dementia and Palliative Care: A Good Fit? Current and Future Imperatives

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A Good Fit?

Dementia

An incurable, progressive, neurodegenerative disorder

Multiple causes, including Alzheimer's disease, vascular disease, Lewy body disease, Parkinson's disease, CJD, FTD, Huntington's disease – all are progressive and irreversible (as distinct from the 'pseudodementias', eg. B12 deficiency, hypothyroidism, etc)

Prognosis range 6 mths – 20 years

Average lifespan from diagnosis to death – 5 years

Second leading cause of death in Australia (ABS, 2015)

Consequences of Dementia:

Brain damage which results in progressive impairment of many if not all aspects of life including:

- Cognitive problems
- Behavioural responses
- Functional deficits
- Mobility problems
- Psychiatric conditions

Dementia affects the person and their families globally – a good fit?

Dying *of* dementia: implications of brain cell death

Profound weight loss:

- ↑ BMR
- ↓ ingestion
- Psychiatric symptoms
- Impaired sensorium/perception
- Evident in almost all those in advanced stage
- Cytokine involvement

Reduction in/cessation of eating and drinking:

- Problems with chewing/dysphagia – progressive impairment of motor/sensory functions necessary for ingestion

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

Infections -

- Reductions in mobility, bed/chair bound
- Impaired ability to report symptoms
- Malnourishment; dehydration

Pneumonia -

- Suppression of cough
- Impaired mobility
- Aspiration of food, fluids, saliva (dysphagia)

Urinary infections -

- Increased contact time with bacteria (incontinence pads, double incontinence)

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

Symptom burden

BPSD (including anxiety & depression)

Sleep disturbances

Delirium

Pain

Seizures

Dyspnoea

Constipation

Pressure injuries

Comorbidities…

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

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

Why is a palliative approach important for PWD 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)

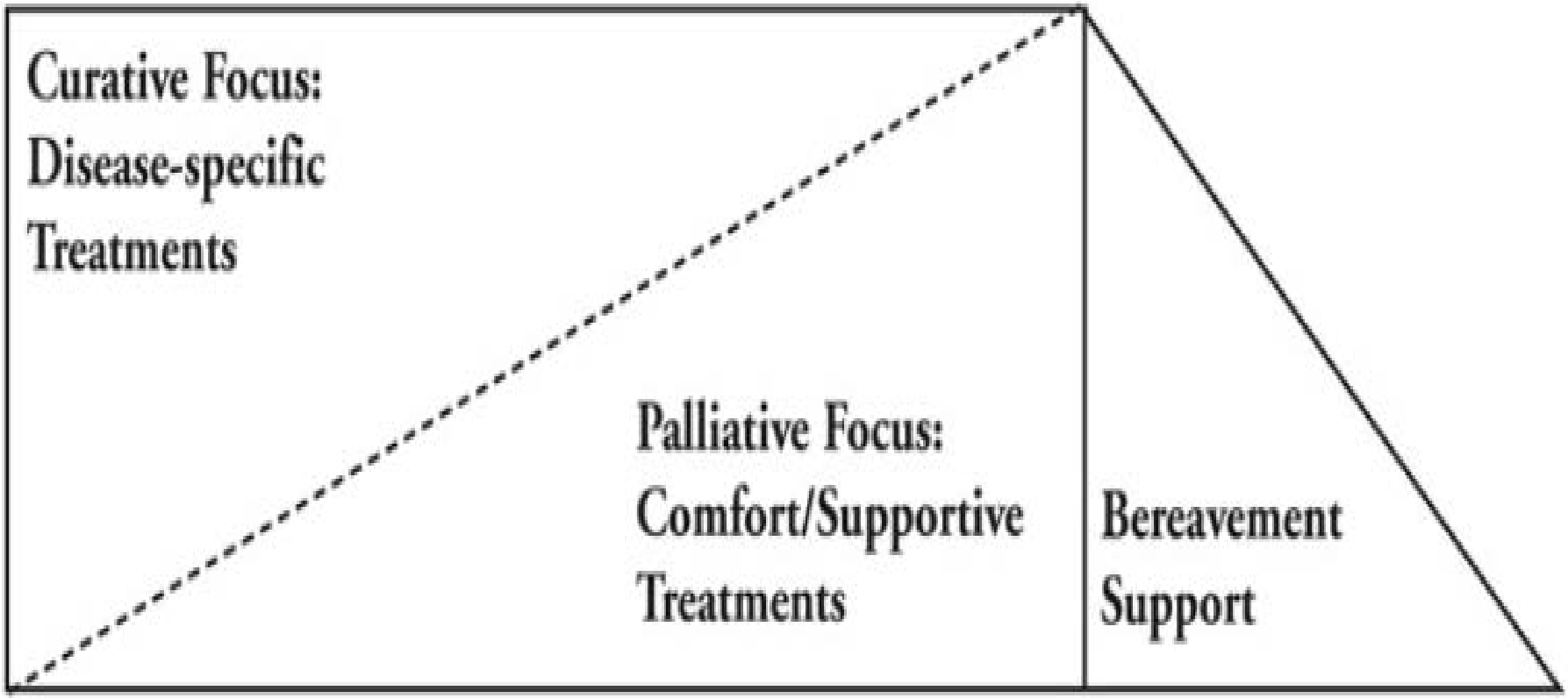
Over half of residents have some form of dementia (AIHW 2012); approx. 80% of the most dependant residents

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

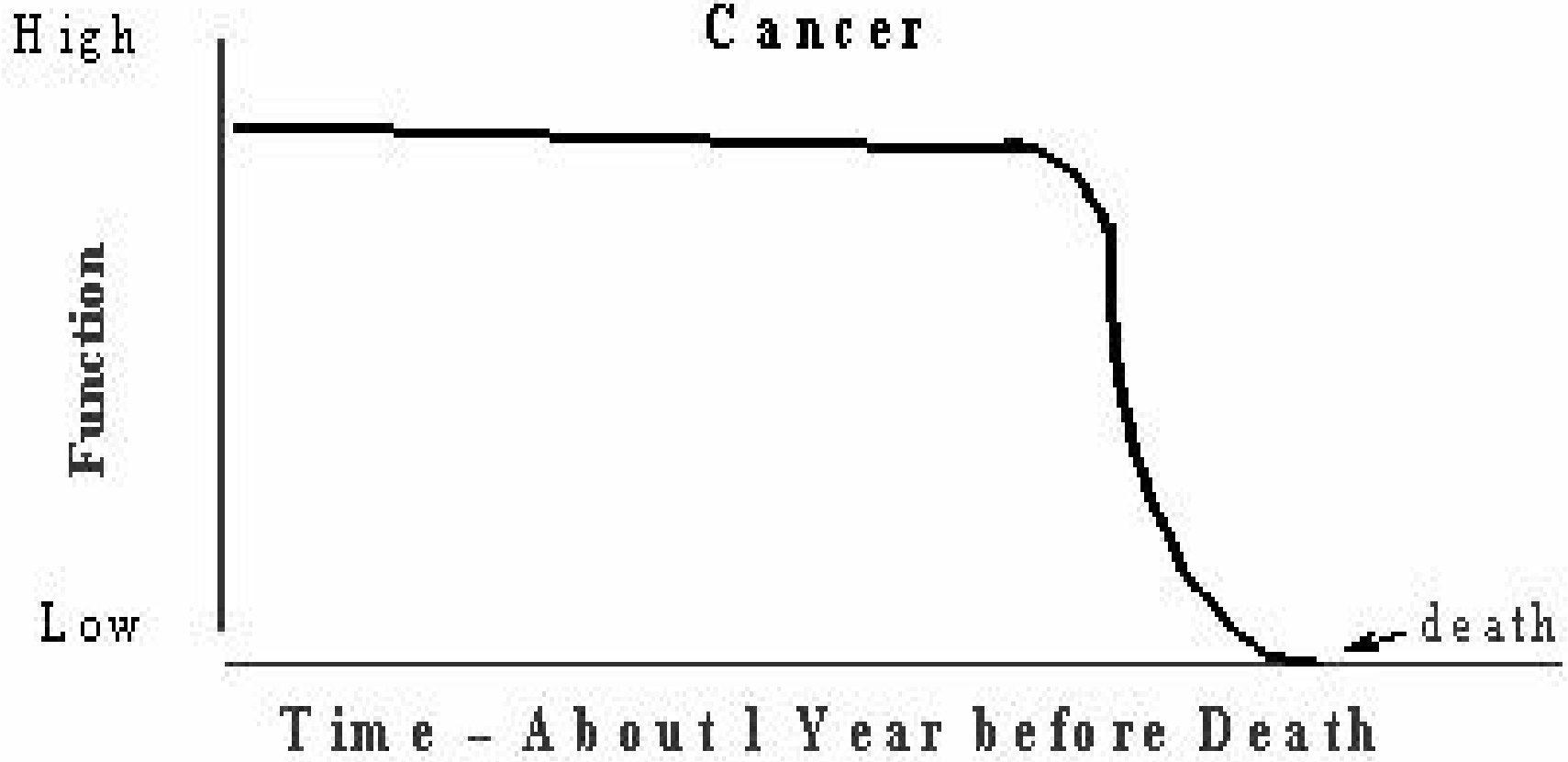
Average lifespan for those with dementia is 5 years from diagnosis to death (range is 6 months to 20 years)

More than 90% of people in RACFs will exit via death (AIHW 2012)

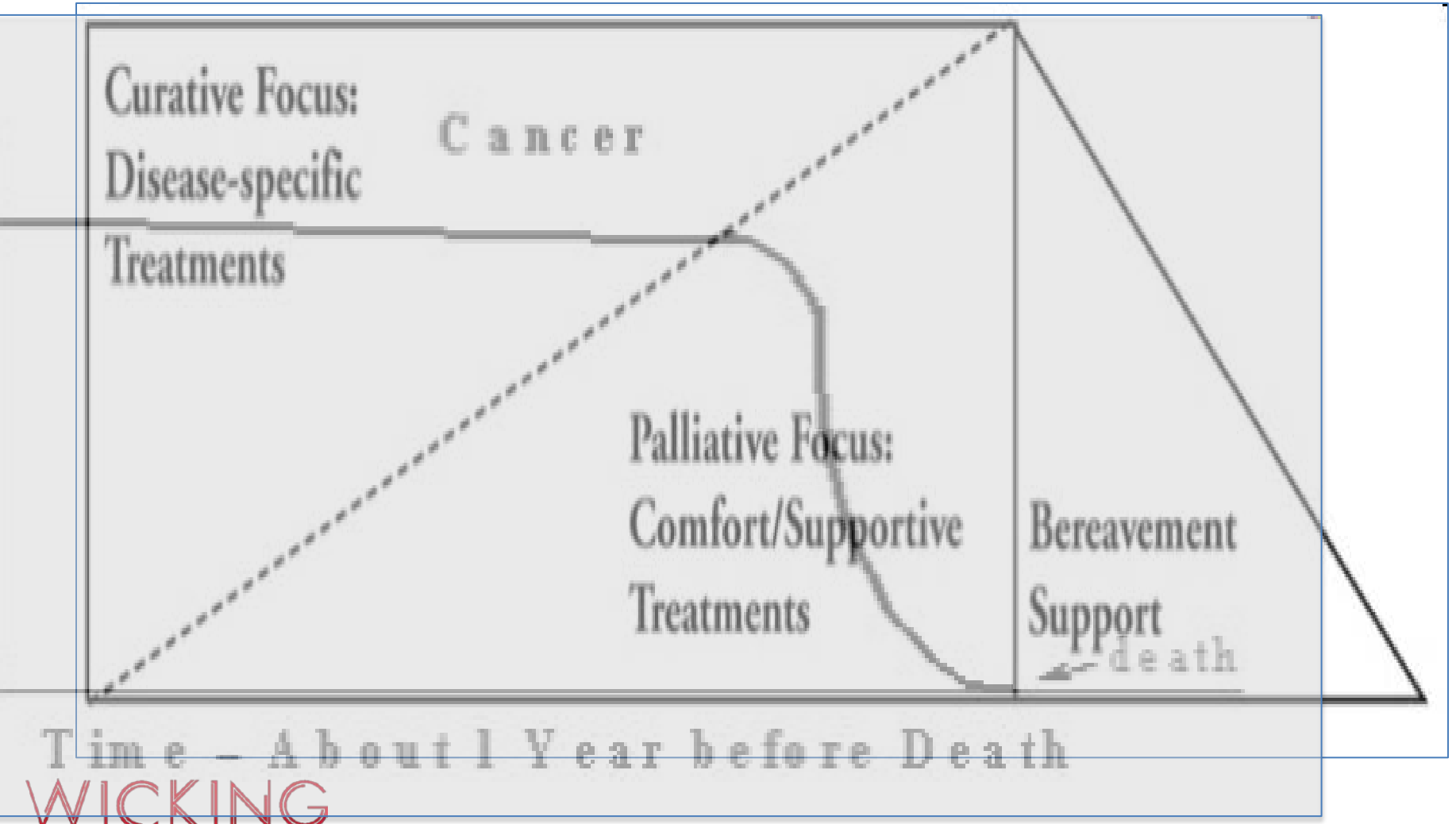
Contemporary Understandings of Curative/ Palliative Care



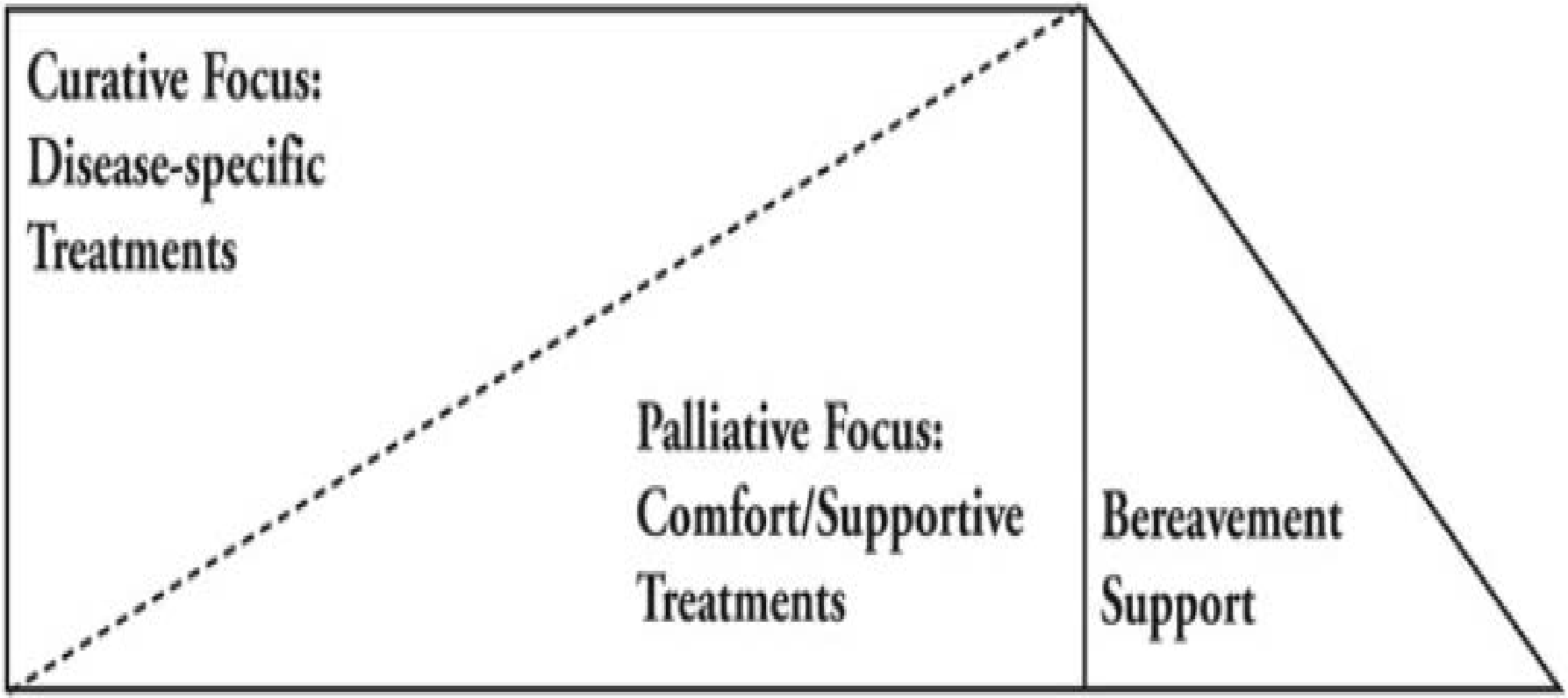
Cancer and functional decline



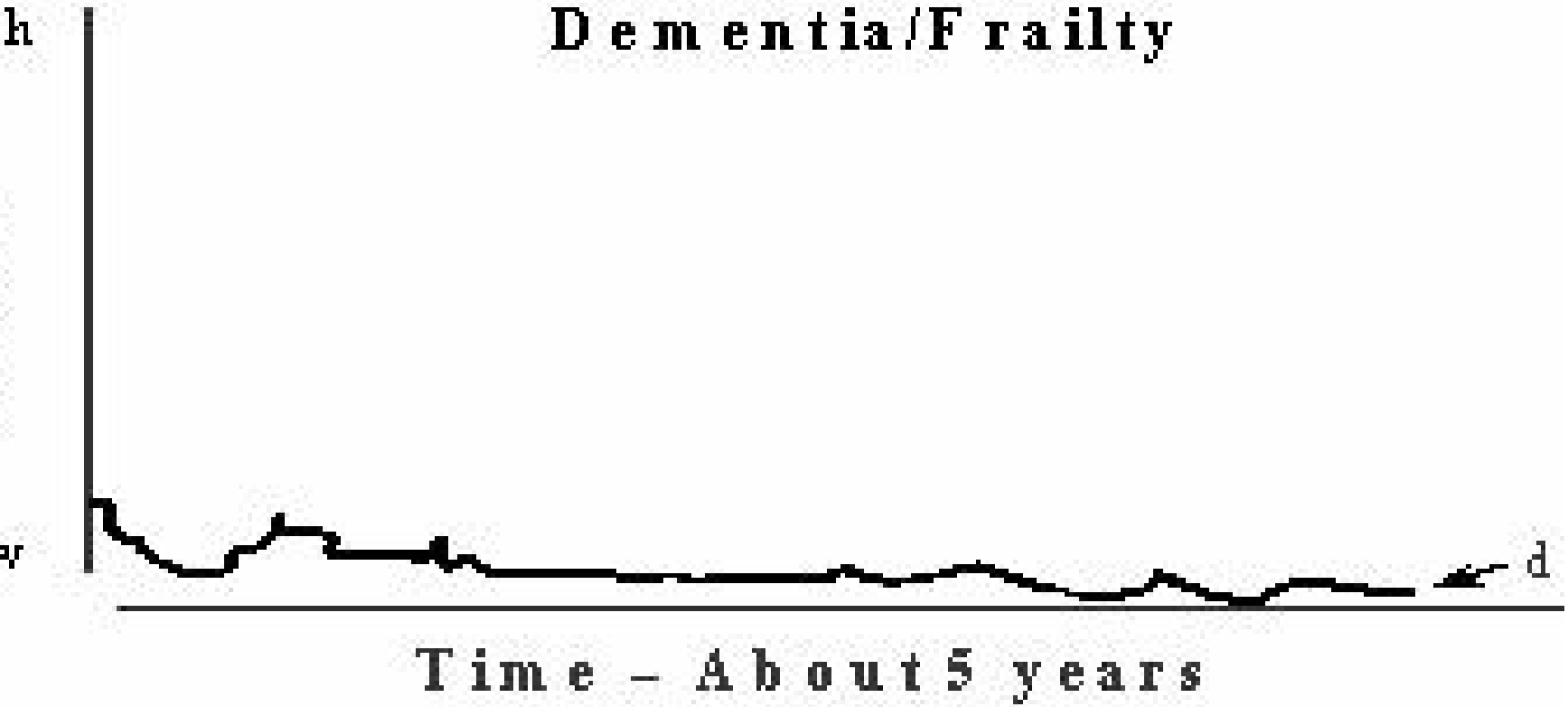
Interplay between cancer and palliative model



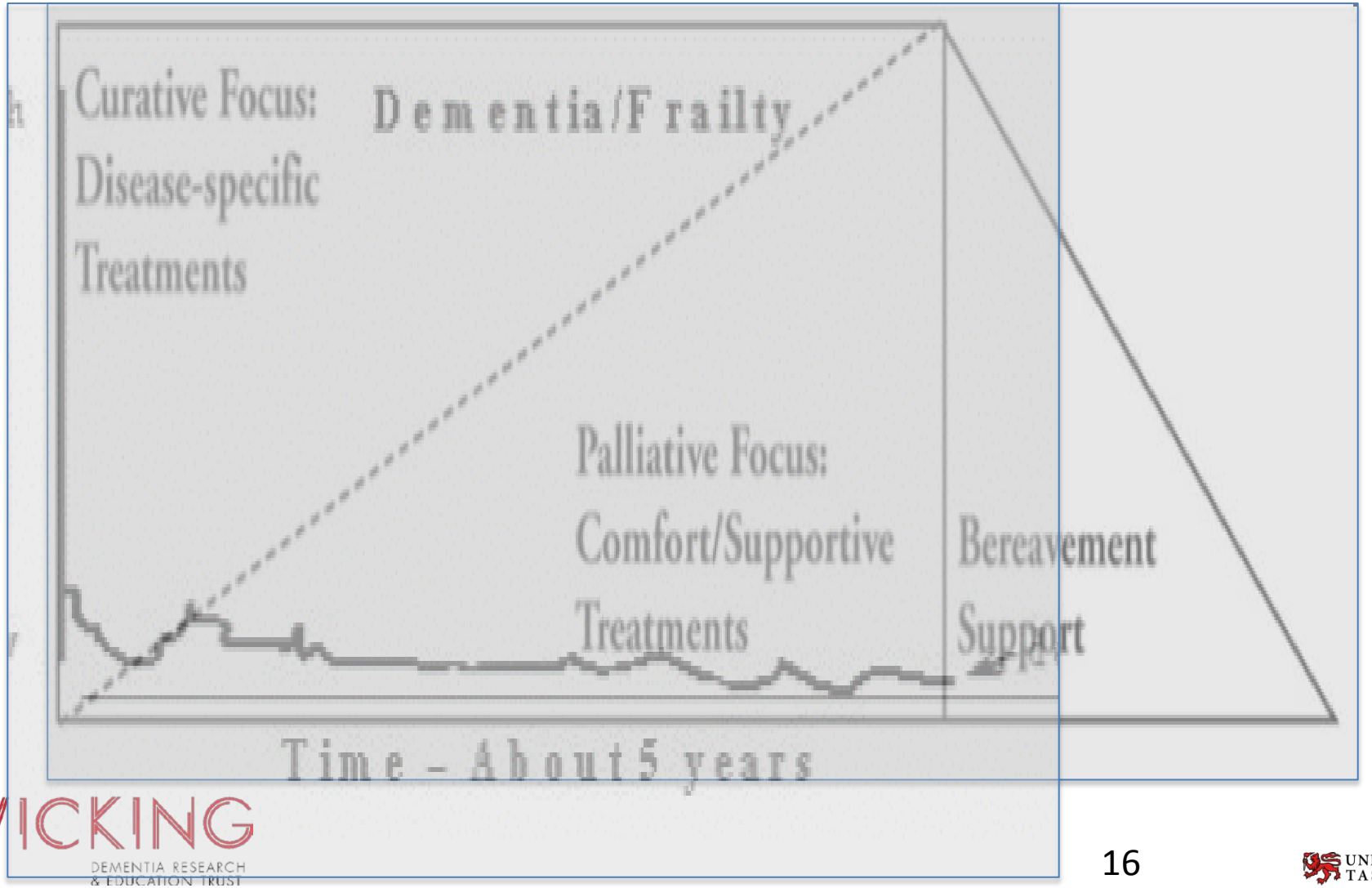
Contemporary Understanding of Curative/ Palliative Care



Dementia and functional decline



Interplay between dementia and palliative model



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..." (Mitchell et al 2009). Different to the path of someone with untreatable cancer

It can be difficult to recognise the dying phase

Tensions in the dementia/palliative care fit

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)

Tensions in the dementia/palliative care fit

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

Tensions in the dementia/palliative care fit

PWD (more than half of those resident in aged care) may not exhibit signs of a dying phase (if at all) 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, EOLCPs pathways MUST be incorporated into a palliative approach to the care of people with dementia – being mindful that a chart/recipe/ template/tool can be more attractive than a philosophy of care for the time poor using a 'tick and flick' approach to documenting care…

Increasing understanding… increasing fit?

- Knowledge of dementia's association with mortality is low
  - Lay knowledge – about 30%
  - Health worker knowledge – about 50%
  - Health student knowledge – uneven
- Preoccupation with behavioural issues for lengthy periods can distract focus from other, later symptoms
- Future wishes conversations are frequently not held
- Families may have been struggling to obtain diagnosis/support for many years prior to engaging with health system
- Capacity in the acute and aged care sectors is low
- Symptom management is as much about withholding interventions as intervening – not to be confused with benign neglect
- The terminal nature of dementia can be seen as yet another blow in what is a deeply stigmatising condition

A good fit?

Greater community awareness

Greater community/professional knowledge/understanding

Further research into dementia and palliative care fit

Increased resources into supportive care for this growing cohort – an estimated trebling in numbers by 2050; currently 50 million worldwide

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THANK YOU

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