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Trajectory of Dementia – End of Life Care

Dr Melissa Abela

University of Tasmania

May 2021

Image Source: events.nsw.edu.au

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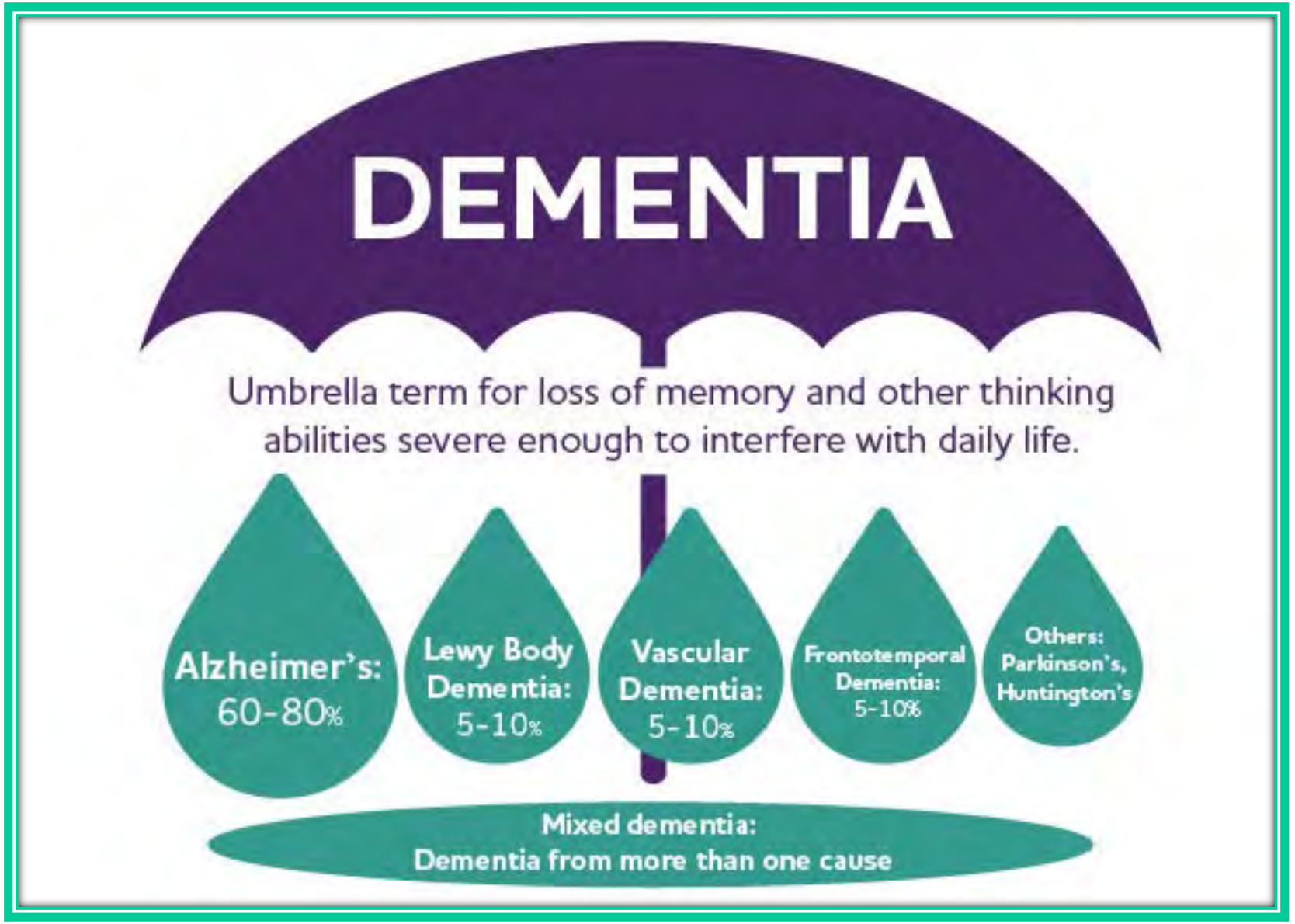

Source: https://familycaregiversonline.net/faq/faq-alzheimers-and-dementia/

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Life Expectancies *

Dementia	Life Expectancy (years*)
Alzheimer's Disease	4 - 8
Vascular Dementia	4
Dementia with Lewy Bodies	2–8
Frontotemporal Dementia	8
Parkinson's Disease	9-20

* Variable amongst all cases

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Diagnostic Assessment Tools

- **Psychogeriatric Assessment Scales Cognitive Impairment Scale (PAS-Cog)** - Used as a suite of assessment tools for funding applications in RACFs
- **Mini Mental Short Examination (MMSE)** – the lower the score, the more severe the dementia progression
- **Montreal Cognitive Assessment (MOCA)** –straightforward tool for diagnosis, arranging follow up and treatment plans. Proven to be useful for dementia
- **Global Deterioration Scale (GDS)** – also known as the Reisberg Scale
- **Functional Assessment Staging Tool (FAST)** – very similar to the GDS in that it works in line with the stage
- **Note all require specialist training to administer and interpret.**

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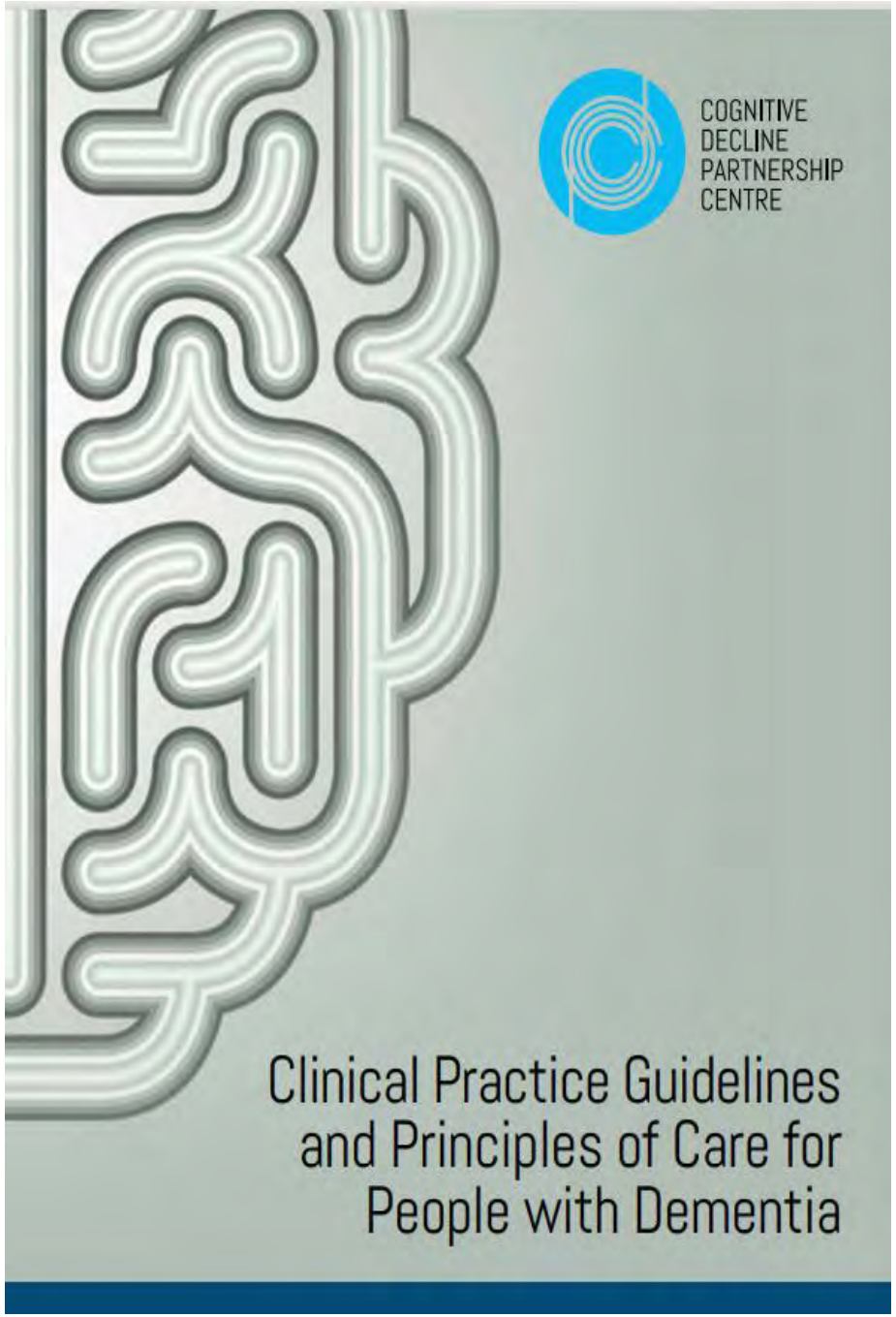
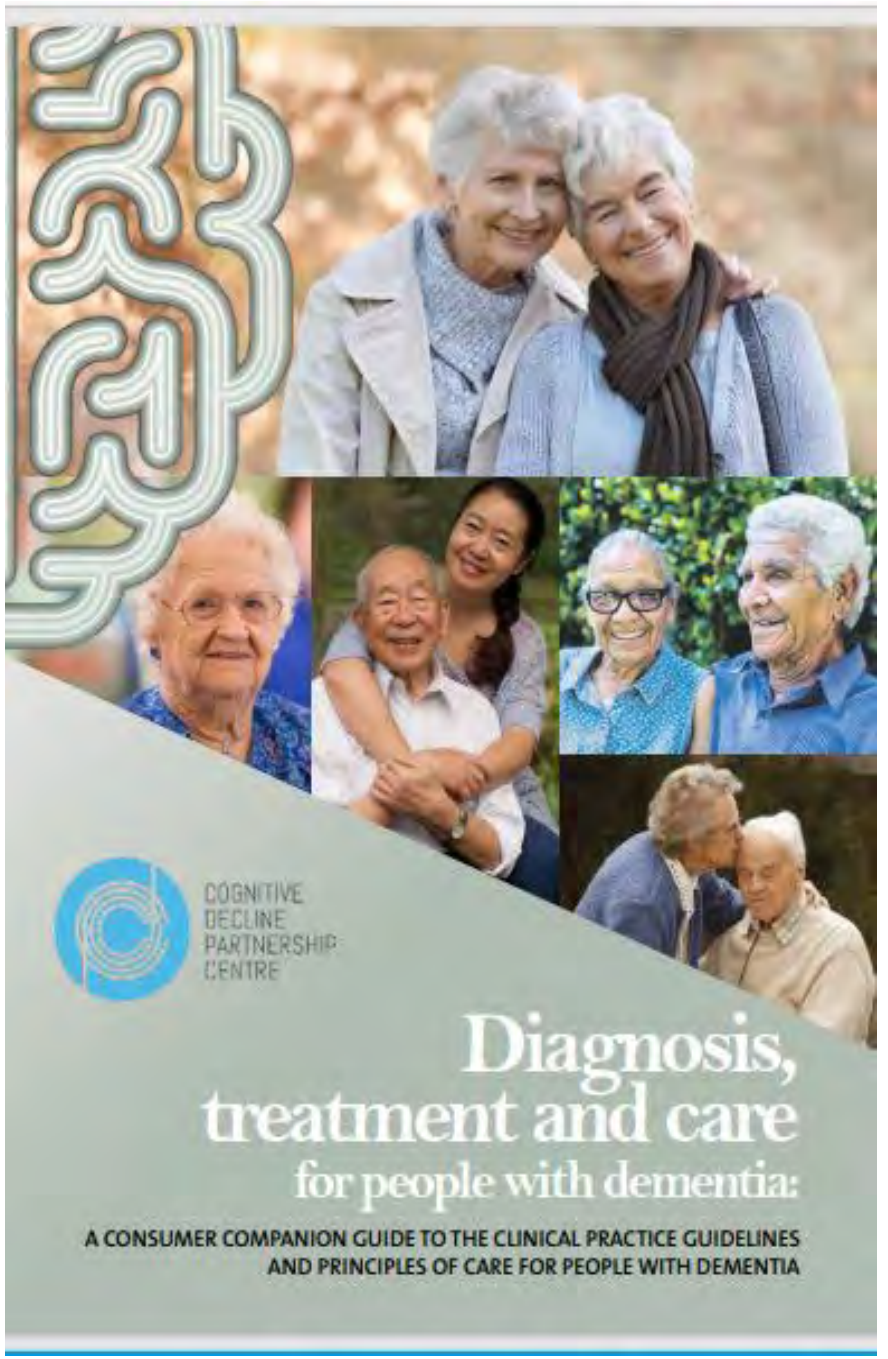
Guidelines





Clinical Practice Guidelines for Dementia (2016)

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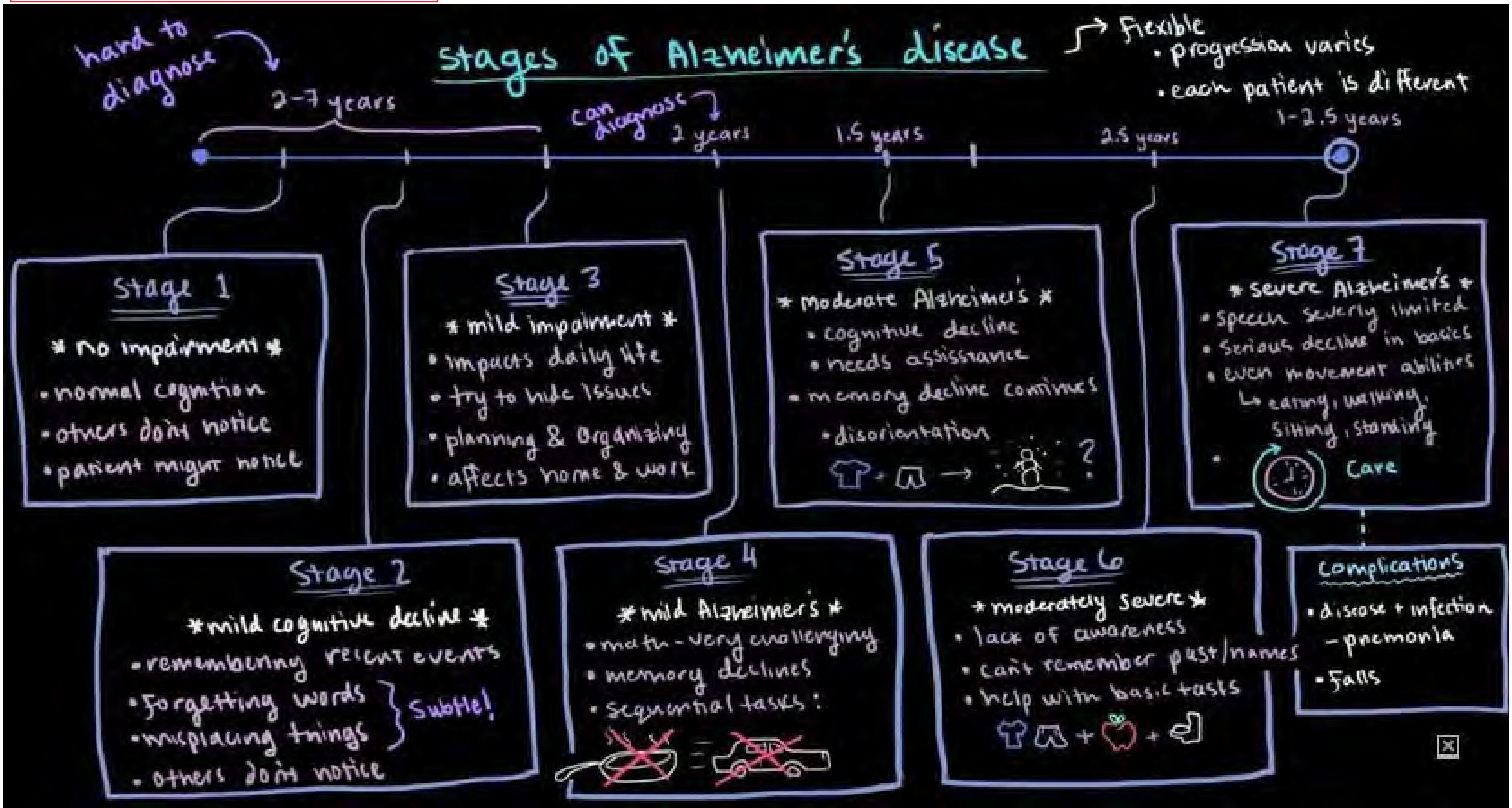
7 Stages of Dementia – Global Deterioration Scale (GDS)

	MEMORY LOSS	FUNCTIONAL LOSS
Stage 1	No subjective complaints of memory loss	Normal function
Stage 2	Very mild decline	Person may feel as tough they are having memory lapses but these are invisible to family and friends
Stage 3	Mild decline	Trouble remembering names and performing some complex activities. May lose or misplace valuable possessions
Stage 4	Moderate decline	Greater difficulty with performing complex tasks such as instrumental activities of daily living (managing finances, shopping). May be becoming moody or withdrawn
Stage 5	Moderately Severe decline	May still be independent with eating and toileting. May forget own address. May require assistance with choosing weather-appropriate clothing
Stage 6	Severe decline	Personality changes may take place. May need assistance with activities of daily living. Experiences disturbed sleep, May wander and become lost.
Stage 7	Very Severe decline	Likely need assistance with all aspects of care. May or may not retain verbal abilities. Muscles may become rigid, swallowing may be impaired.

Source: https://www.youtube.com/watch?v=K7dP25_Sebo, 20

7 Stages of Dementia – Global Deterioration Scale (GDS)



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Advanced Dementia (Stage 7)

- Severe + end stages of dementia
- Progressive immobility
- Reduced capacity to self care
- Poor nutrition which results in reduced fluid intake
- Increased risk of infections
- Skin Breakdown

Image:https:www.superguide.com.au/author/binabrownauthor

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> utas.edu.au/wickig

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"Recognising and introducing the plan for palliation before the imminent arrival of the point of death.

The bravery to discuss this early in the disease process while the person with dementia can contribute to the plan for their future journey"

(MOOC Participant)

Image: https://www.superguide.com.au/author/binabrownauthor

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A Palliative Approach to Dementia Care

Overall quality of life

Early recognition of pain and treatment for pain

Affirming life and treating dying as a natural process

Offering a support system to help the family cope during their loved one's illness

In dementia the end stages is not often identified.

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Challenges for Managing Advanced Dementia

- Lack of understanding about the terminal nature of dementia
- Hospitalisations, benefits and burdens of treatment vs a palliative approach ? Quality of life, delivering person-centered care
- Lack of awareness of end of life care options: - manage, kept comfortable in facility
- Difficulty in recognising the terminal phase
- Role of specialist palliative care- services (CNS) guide decision, not all facilities have this level of services
- Importance of communication with family and others
- Early advance care planning

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PALLIATIVE MEDICINE

Original Article

How is palliative care understood in the context of dementia? Results from a massive open online course

Palliative Medicine
2018, Vol. 32(3) 594–602

DOI: 10.1177/0269216317743433
journals.sagepub.com/home/pmj
SAGE

Fran McInerney, Kathleen Doherty, Aidan Bindoff, Andrew Robinson and James Vickers

Abstract

Background: A palliative approach to the care of people with dementia has been advocated, albeit from an emergent evidence base. The person-centred philosophy of palliative care resonates with the often lengthy trajectory and heavy symptom burden of this terminal condition.

Aim: To explore participants' understanding of the concept of palliative care in the context of dementia. The participant population took an online course in dementia.

Design: The participant population took a massive open online course on 'Understanding Dementia' and posted answers to the question: 'palliative care means …' We extracted these postings and analysed them via the dual methods of topic modelling analysis and thematic analysis.

Setting/participants: A total of 1330 participants from three recent iterations of the Understanding Dementia Massive Open Online Course consented to their posts being used. Participants included those caring formally or informally for someone living with dementia as well as those with a general interest in dementia

Results: Participants were found to have a general awareness of palliative care, but saw it primarily as terminal care, focused around the event of death and specialist in nature. Comfort was equated with pain management only. Respondents rarely overtly linked palliative care to dementia.

Conclusions: A general lack of palliative care literacy, particularly with respect to dementia, was demonstrated by participants. Implications for dementia care consumers seeking palliative care and support include recognition of the likely lack of awareness of the relevance of palliative care to dementia. Future research could access online participants more directly about their understandings/experiences of the relationship between palliative care and dementia.

Caring holistically to offer a support system for all

Multidisciplinary approach

Generalised awareness – reported as terminal care

Comfort = pain management

Not typically related to dementia care

Not sure how to provide EOL care for someone living with dementia

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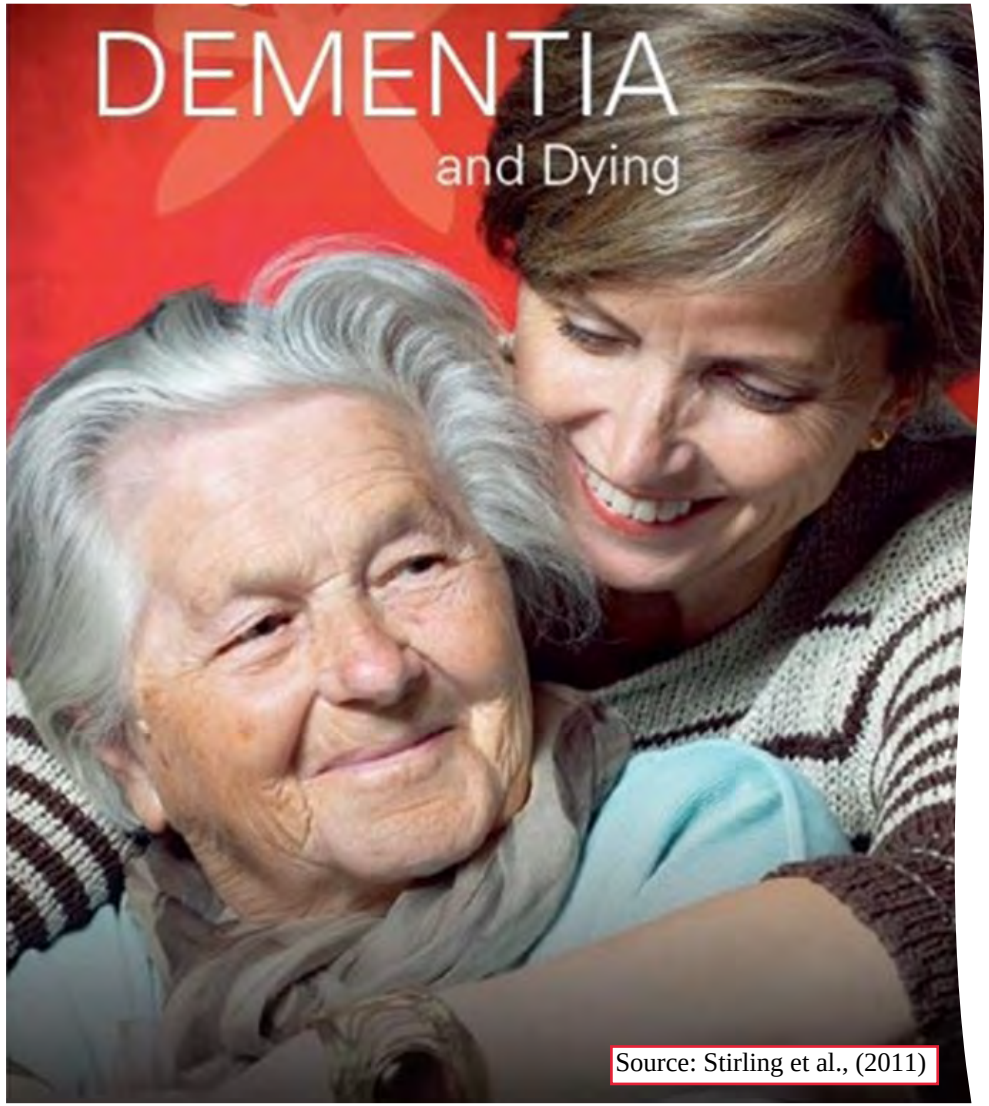
Talking about Dementia and End of Life Care



Source: Stirling et al., (2011)

- Dementia is a terminal illness with NO CURE
- Gradual decline with more acute illnesses
- Focus:
- Overall QoL
- Early recognition and treatment of pain/distress
- Affirming life and treating dying as a normal process

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Formal vs Informal Approach

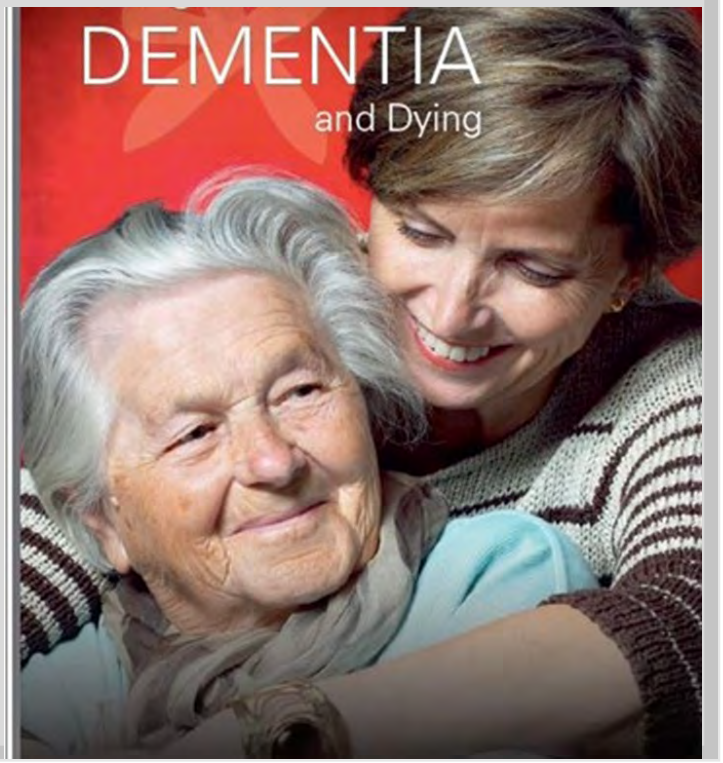
FORMAL

- Prepare
- Introduce
- Ask (Person centred approach)
- Flag the seriousness
- Inform about dementia and dying
- Allowing space
- Discuss Care
- Ongoing Dialogue
- Self Care - debrief

INFORMAL

❑Concern for your resident

❑Spontaneous but tactful approach



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Case Study

- 87 year old man with Alzheimer's Disease
- Diagnosed with hypertension, Osteoporosis, OA, deafness, hernia repair
- Living in RACF for 2+ years
- Psychogeriatric Assessment Scales (PAS) Cognitive Impairment Scale and Functional Assessment Staging Test (FAST) completed to indicate dementia in stage 5-7
- Six months of slow functional decline reported
- Admission to hospital with SOB, vomiting – diagnosis of pneumonia

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To hospitalise or not to hospitalise

- Is this an appropriate admission?
- What else can be done?
- What could have helped with this decision?
- What are the risks of hospitalisation?

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Risk Associated with Hospitalisation

- Reduced tolerance to hospital setting – due to changes to the brain
- Stressors such as fatigue, acute illness, pain, change in routing, or confusing stimuli – noise, lights, can trigger occurrence of behaviours (?)
- Behaviours become way of communication
- Aggressive behaviours may lead to chemical and physical restraints
- Longer LOS, pressure areas, infection, poor oral intake, apathy and withdrawal, higher delirium rates

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- On-going symptom management and support
- Daughter: very unsettled in hospital, bed rail use
- Return to facility: initially alert and happy, non-ambulant, decreased diet, minimal oral intake, restless, resistive to care, anxious, evidence of pain
- Restraint authority signed
- Bedbound: lifter x4, trolley bath

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Goals of Care – Comfort Care

- Limit interventions causing stress which led to comfort care
- Offer food and fluids as tolerated (comfort feeding)
- Deterioration and agitation over days; pain score of 7-8 (Abbey)
- Distress at nursing care (grimacing); pooling food and fluids
- Died 2 weeks post discharge

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Reflective Questions

- Three key words/phrases that you think describes a palliative care approach.
- Discuss common signs and responsive behaviours of advanced dementia.
- Discuss main ways discomfort and pain are currently managed.
- What is your vision, goal, aim when a resident is dying.