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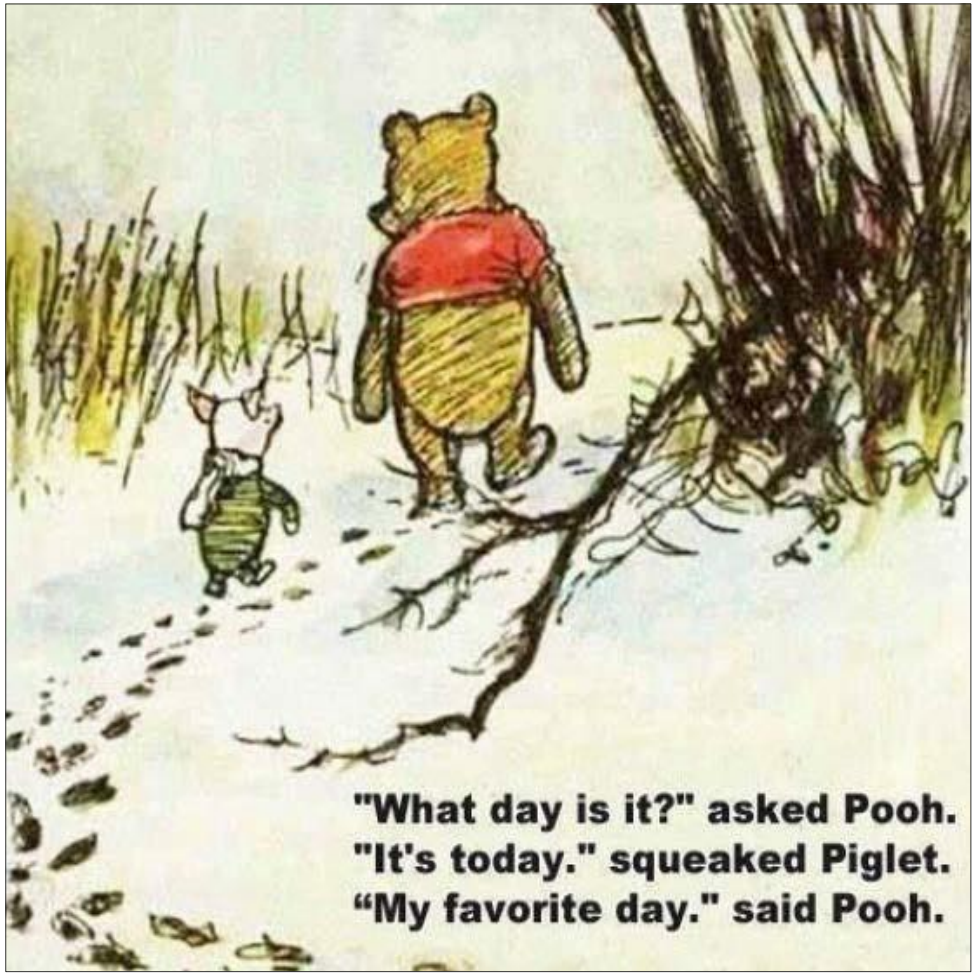
# PALLIATIVE CARE – A BROADER CONCEPT

## How to Support a Person Living with Dementia

Presenter: Michelle Allsop

Dementia has a physical, psychological, social, and economic impact, not only on people with dementia, but also on their carers, families and society at large.

**(WHO, 2017)**

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# Worldwide Statistics

Worldwide, around 50 million people (about twice the population of Texas) have dementia, and there are nearly 10 million new cases every year.

- Dementia is one of the major causes of disability and dependency among older people worldwide.
- Every three seconds someone in the world develops dementia.

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# Dementia in Australia

- **1 in 10** people over 65
- **2nd** leading cause of death of Australians

Estimated **459,000** Australians

Without a medical breakthrough, estimates likely to increase to:

- **590,000** by 2028
- **1,076,000** by 2058
- **3 in 10** people over the age of 85

(Dementia Australia, 2020)

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# Terms to know

***Delirium*** is acute confusion, usually reversible unless the person is near end of life - this is known as ***terminal delirium***. Delirium alters level of consciousness.

***Dementia*** is irreversible, progressive impairment in cognitive and physical function. Dementia does not alter consciousness.

***Mild cognitive impairment*** is a transitional stage between normal aging and dementia in which the person has short-term memory impairment and challenges with cognitive function.

***Sundowner Syndrome*** is nocturnal confusion.

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# What is Palliative Care?

- An approach that improves the quality of life of patients &  families facing problems associated with life-threatening illness.
- Prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain & physical, psycho-social, and spiritual dimensions.

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# The Beginning

***Our service aims to partner with you to provide the best care.***

- Based in the Perth Metropolitan area.
- Support Nationally and International. (Pre-COVID-19)
- Service provision business hours weekdays.
- Nursing telephone support out-of-hours.

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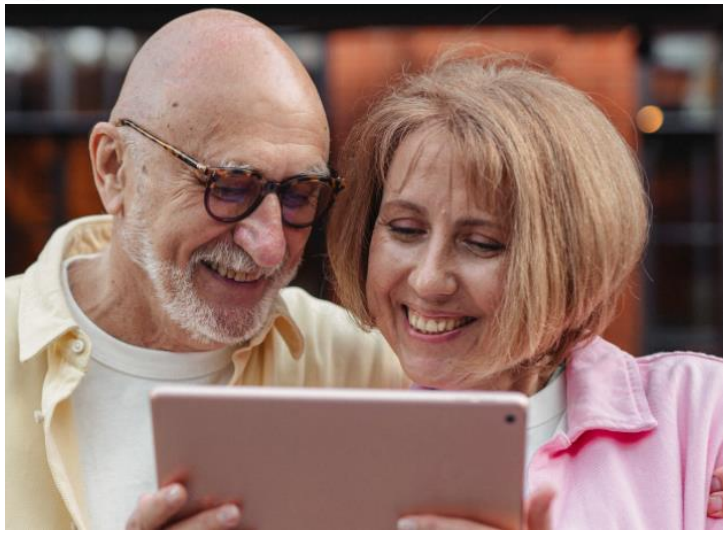
# Referrals

- The Referral Form
- Referral via the website or phone



# Referral Criteria

- Client/substitute decision maker agree to referral to Care Partnerships Australia www.carepartnershipsaustralia.com.au
- A diagnosis or symptoms of frailty
- Living at home or in care

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## Understanding where we are...

# Moderately severe dementia

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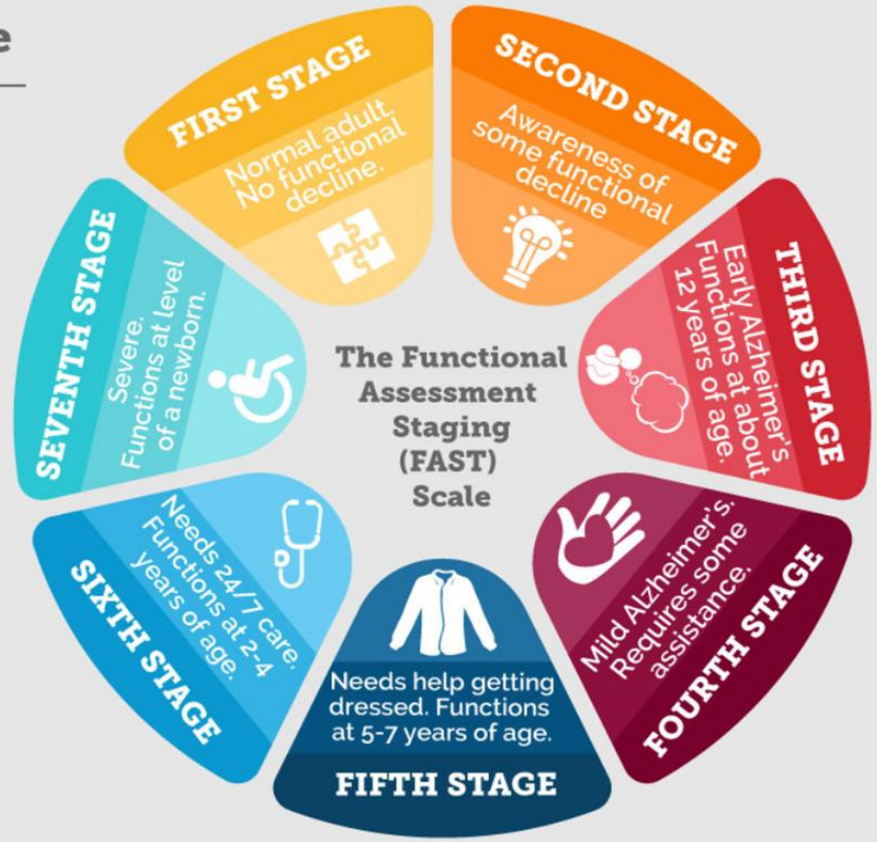
### The Stages of Alzheimer's Disease

To better understand how Alzheimer's disease affects the Hypothalamus and other regions of the brain, it's helpful to first have an understanding of the seven primary stages of this progressive disease.

*The FAST scale was developed at the New York University Medical Center's Aging and Dementia Research Center.*



# Stages of Dementia

| Stage | Stage Name | Characteristic | Expected Untreated AD Duration (months) | Mental Age (years) | MMSE (score) |
|---|---|---|---|---|---|
| 1 | Normal Aging | No deficits whatsoever | -- | Adult | 29-30 |
| 2 | Possible Mild Cognitive Impairment | Subjective functional deficit | -- | | 28-29 |
| 3 | Mild Cognitive Impairment | Objective functional deficit interferes with a person's most complex tasks | 84 | 12+ | 24-28 |
| 4 | Mild Dementia | IADLs become affected, such as bill paying, cooking, cleaning, traveling | 24 | 8-12 | 19-20 |
| 5 | Moderate Dementia | Needs help selecting proper attire | 18 | 5-7 | 15 |
| 6a | Moderately Severe Dementia | Needs help putting on clothes | 4.8 | 5 | 9 |
| 6b | Moderately Severe Dementia | Needs help bathing | 4.8 | 4 | 8 |
| 6c | Moderately Severe Dementia | Needs help toileting | 4.8 | 4 | 5 |
| 6d | Moderately Severe Dementia | Urinary incontinence | 3.6 | 3-4 | 3 |
| 6e | Moderately Severe Dementia | Fecal incontinence | 9.6 | 2-3 | 1 |
| 7a | Severe Dementia | Speaks 5-6 words during day | 12 | 1.25 | 0 |
| 7b | Severe Dementia | Speaks only 1 word clearly | 18 | 1 | 0 |
| 7c | Severe Dementia | Can no longer walk | 12 | 1 | 0 |
| 7d | Severe Dementia | Can no longer sit up | 12 | 0.5-0.8 | 0 |
| 7e | Severe Dementia | Can no longer smile | 18 | 0.2-0.4 | 0 |
| 7f | Severe Dementia | Can no longer hold up head | 12+ | 0-0.2 | 0 |

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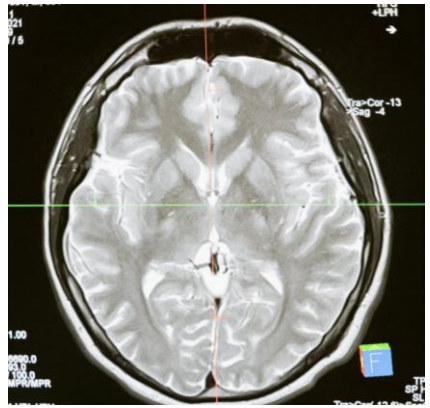
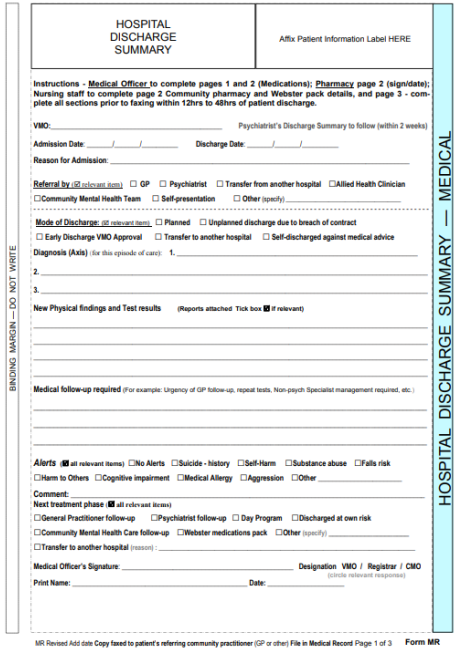
# Information and Contact

- Please provide addition information:
  - Recent medical letters
  - Scans
  - Blood results
  - Hospital discharge summary

- Complete referral form in as much detail as possible.
- First telephone contact next business day.
- Telephone support/advice available.





HOSPITAL DISCHARGE SUMMARY

Affix Patient Information Label HERE

Instructions - Medical Officer to complete pages 1 and 2 (Medications); Pharmacy page 2 (sign/date); Nursing staff to complete page 2 Community pharmacy and Webster pack details, and page 3 - complete all sections prior to faxing within 12hrs to 48hrs of patient discharge.

VMO: Psychiatrist's Discharge Summary to follow (within 2 weeks)

Admission Date: Discharge Date:

Reason for Admission:

Referral by (if relevant item) ☐ GP ☐ Psychiatrist ☐ Transfer from another hospital ☐ Allied Health Clinician ☐ Community Mental Health Team ☐ Self-presentation ☐ Other (specify)

Mode of Discharge: (if relevant item) ☐ Planned ☐ Unplanned discharge due to breach of contract ☐ Early Discharge VMO Approval ☐ Transfer to another hospital ☐ Self-discharged against medical advice

Diagnosis (Axis) (for this episode of care): 1. 2. 3.

New Physical findings and Test results (Reports attached Tick box ☒ if relevant)

Medical follow-up required (For example: Urgency of GP follow-up, repeat tests, Non-psych Specialist management required, etc.)

Alerts (☒ all relevant items) ☐ No Alerts ☐ Suicide - history ☐ Self-Harm ☐ Substance abuse ☐ Falls risk ☐ Harm to Others ☐ Cognitive impairment ☐ Medical Allergy ☐ Aggression ☐ Other

Comment:

Next treatment phase (☒ all relevant items)

☐ General Practitioner follow-up ☐ Psychiatrist follow-up ☐ Day Program ☐ Discharged at own risk ☐ Community Mental Health Care follow-up ☐ Webster medications pack ☐ Other (specify) ☐ Transfer to another hospital (reason)

Medical Officer's Signature: Designation VMO / Registrar / CMO (circle relevant response)

Print Name: Date:

MR Revised Add date Copy faxed to patient's referring community practitioner (GP or other) File in Medical Record Page 1 of 3 Form MR

BINDING MARGIN – DO NOT WRITE

HOSPITAL DISCHARGE SUMMARY — MEDICAL

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# What the Service Provides

**The client**

- Community palliative dementia support provided by a nurse and Allied Health
- The service holistically addresses symptom management issues utilising a relationship-centred approach.
- Recognising increased care requirements, utilising optimal package use
- Advance Care Planning
- Aim to reduce hospital admission/length of stay.
- Identification of deteriorating condition

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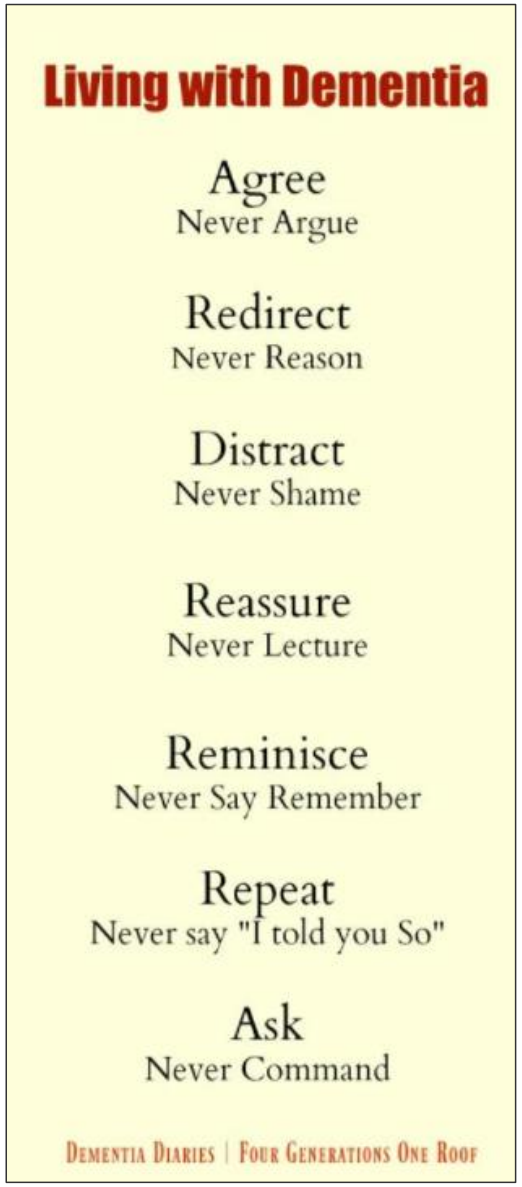
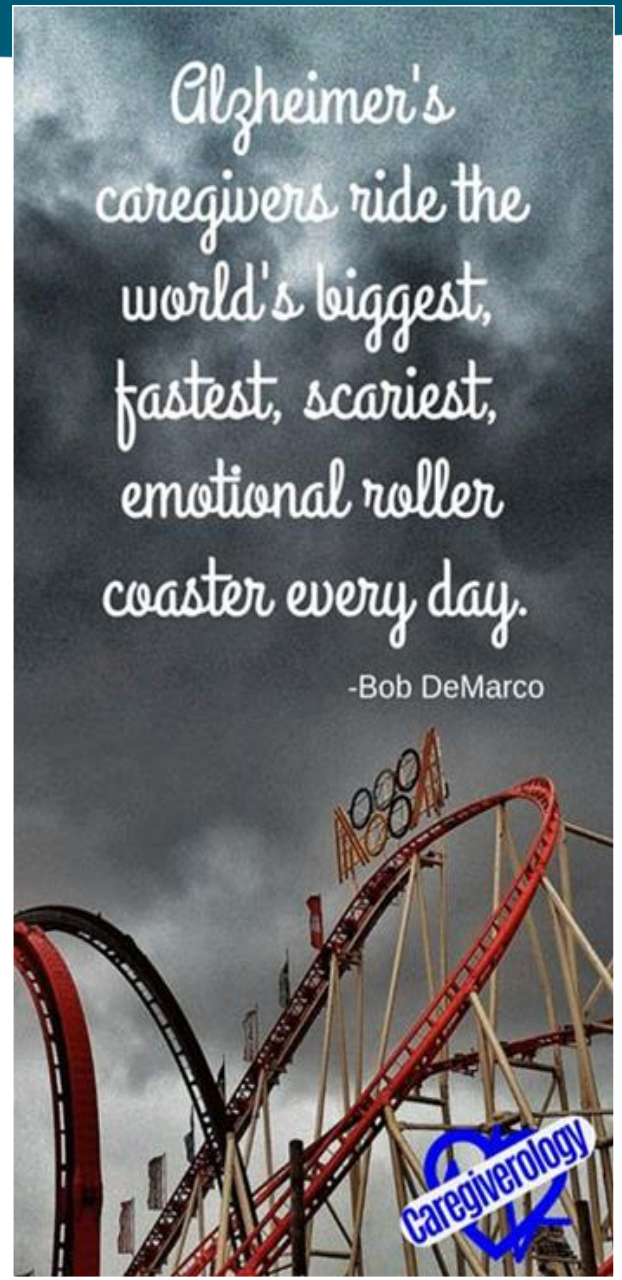


# The Family and Carer

- Identify carer strain and provide support.
- Promote and support confidence and capability.
- Optimise understanding through education and advance care planning.
- Communication is the lynch pin.
- Identify deteriorating condition, support and referral to medical specialist.
- Bereavement follow-up based on assessed risk of the bereaved and length of engagement with the service.
- Provide dementia and advance care planning resources.

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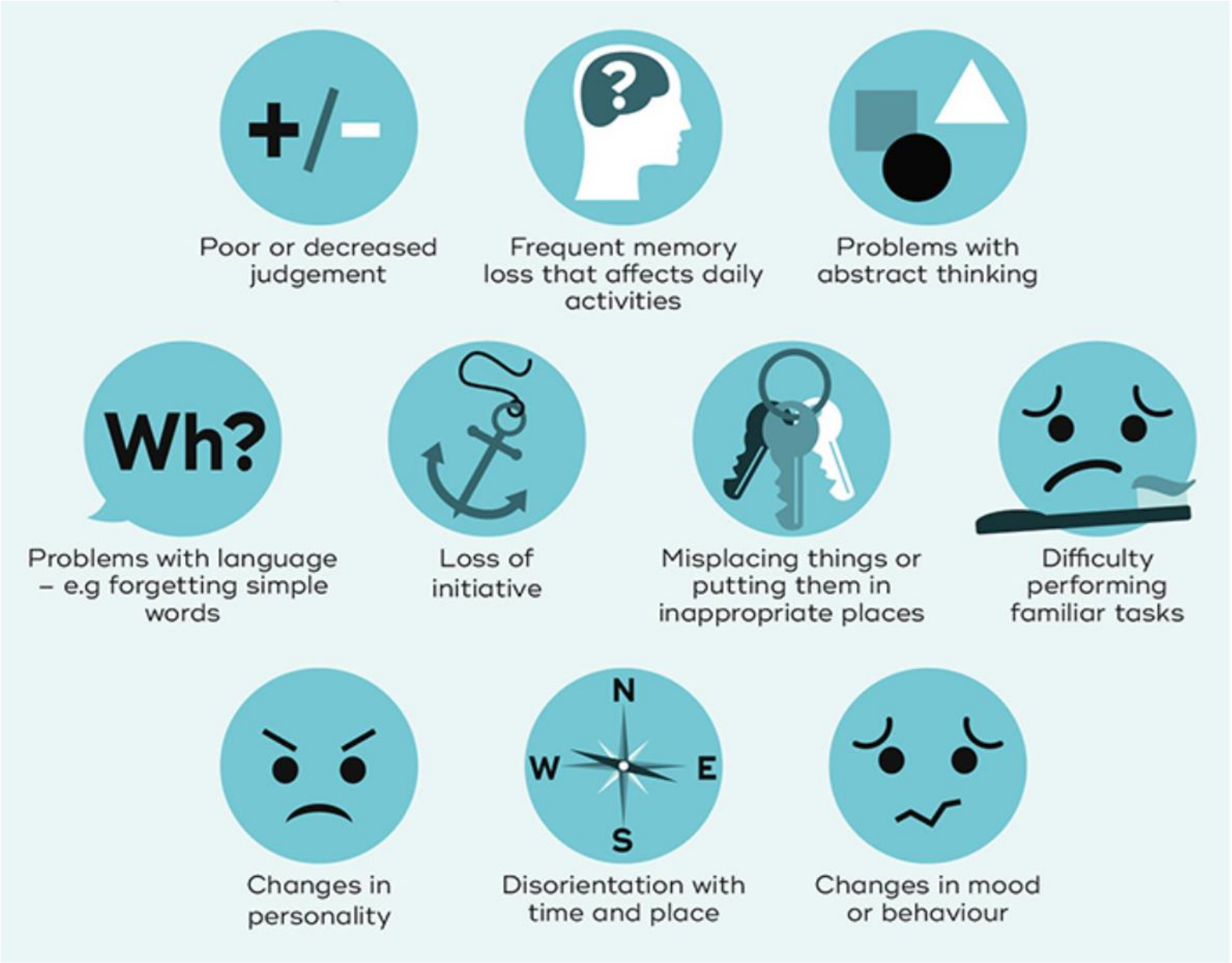
# Signs of Dementia

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# Focus on the Person Form

The form is for family carers to give information about the person with dementia, such as their preferences, needs, and daily routines. This assists hospital staff to provide more person-centred care.

Burton E, Slatyer S, Bronson M, et al.
Development and pilot testing of the “focus on the person” form: Supporting care transitions for people with dementia . Dementia. 2019;18(6):2018-2035. doi:10.1177/1471301217736594

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Focus on the Person

Information about: (FULL NAME)

A form to help family carers inform the hospital staff about a person living with dementia

Please check monthly and insert dates when checked

Please request or print a new form when full

**Who should complete this form?**

This form is for family carers to complete. You are a family carer if you are a relative or friend of the person with dementia—providing care, support, and/or advocacy. You may like to complete this form with the person who is living with dementia.

**What is the purpose of the form?**

If your relative or friend needs to go to hospital, the information you provide in this form will help the hospital staff provide person-centred care. Person-centred care values each person as an individual.[1] Information about the person's *usual* daily routines, needs, and preferences is important when providing person-centred care.

**Why is this information needed?**

The person with dementia may find communication challenging within the hospital. This information can help the staff tailor care for the person.

**What do I do with the form if the person for whom I provide care needs to go to hospital?**

If a trip to hospital is needed, the completed form should be given to the nurses.

1 Brooker D (2004) What is person-centred care in dementia? *Reviews in Clinical Gerontology* 13: 215–22.

**The remaining pages are for you to complete. Please tick the appropriate boxes and provide the additional information requested. Please use a black or blue pen and write in block letters. We recommend checking information monthly. Please use the 'UPDATES' sections to add any changes.**

DCRC Dementia Collaborative Research Centres · Curtin University · QUT Queensland University of Technology

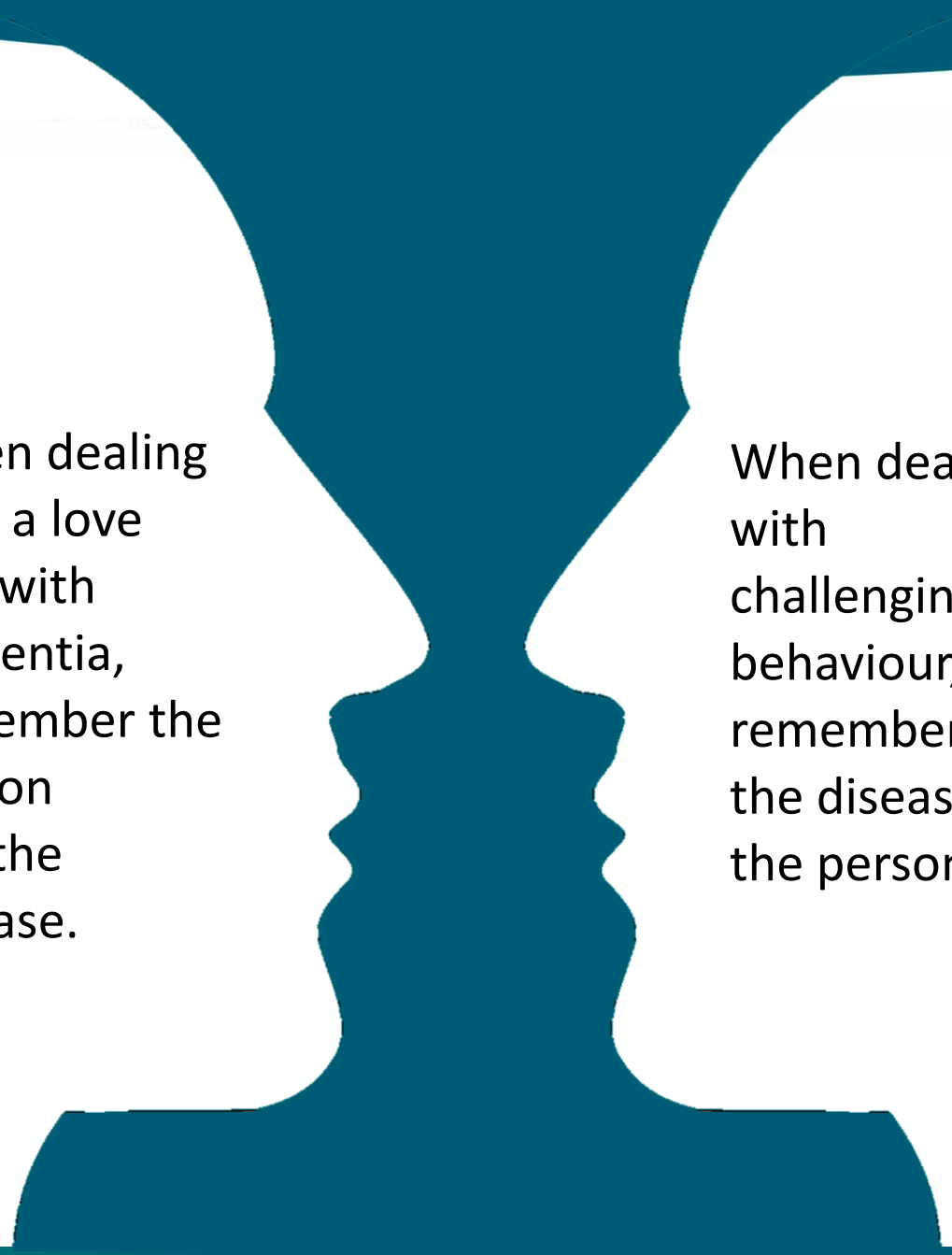
Translating Dementia Research Into Practice

# Communication is important

- Validation
- Redirection
- Body Language
- Reminiscence
- Therapeutic Lying

When dealing with a love one with dementia, remember the person not the disease.

When dealing with challenging behaviour, remember it is the disease not the person.



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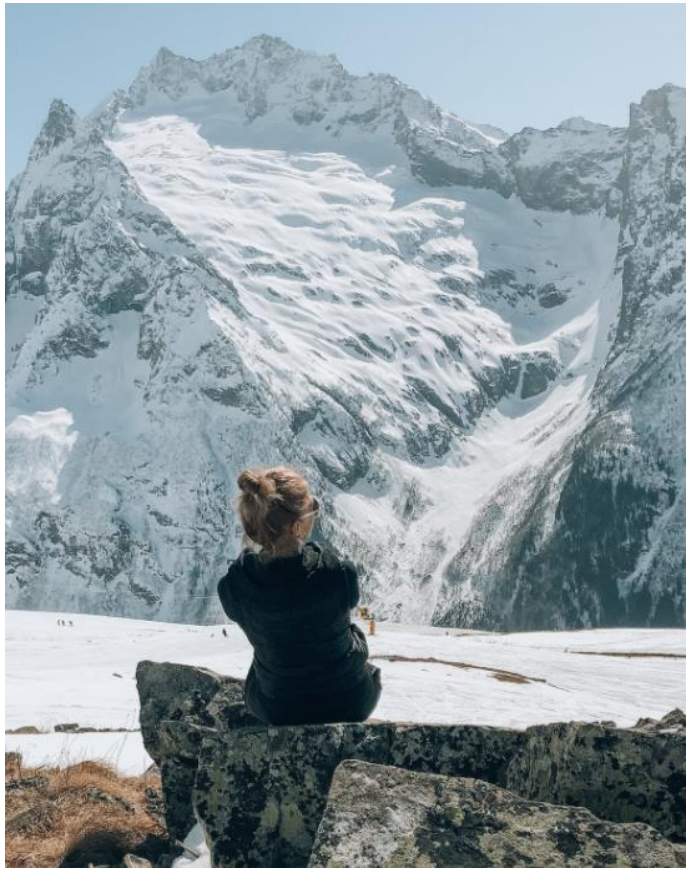
# What I have learned so far..

- Collaboration and building relationships is key.
- Increasing awareness is important – like this!
- Why families do want to keep their loved ones at home
- The enormous holistic complexity
- The cohort is small but growing.
- Fear in a name - timing confusion
- Health literacy - what are you seeing? What do you understand?
- To enable transitions to community Palliative Care services
- Acute setting issues - no dementia diagnosis; acutely unwell, family overwhelmed, terminal phase – someone to help stabilise at home



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## CASE 1: TRANSITIONS

Mrs A is a 66-year-old with Young Onset Alzheimer's Dementia.

# Complexity In a Case....

### BACKGROUND

- She lives alone.
- Referred from a private hospital to support her and the family – (admission for investigation of confusion and bladder prolapse).
- Issues during hospital admission with agitation, functional and cognitive decline.
- Mrs A - Hospital admission was a disaster! Never want to go through that again.
- COVID restrictions added to distress.

### REFERRAL to CARE PARTNERSHIPS AUSTRALIA

- Incontinent
- Agitation, function and cognition improved after a few weeks at home.
- Continence improved.
- Decision made for surgery – CPA support through surgery.
- Mrs A had many concerns and was very anxious about the surgery and admission.

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- Focus on the Person Form
- Contact with the Discharge Coordinator in hospital.
- Many advanced care planning discussions
- **Perth Care Companion Company** provide companion at home and in hospital.
- Feedback from carer
- Carer felt supported and was confident in the ability of the hospital to cater for Mrs A's needs.

# Recognising the small things - building memories

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## FAMILY COMMENTS

- Provision of many recourses and given much needed support and information
- Initially thorough history taking into consideration both the needs not only of Mum but also myself.
- Holistic review - considering all aspects of care and advance care planning
- Each review providing a plan to move forward

# Advance Care Planning

- 'Due to the nature of dementia and the constant changes as the illness progresses, it is reassuring and comforting to know the service is there to support and guide.'
- 'It has been great to recognise and be reminded of those happy times - picnicking as a family in the park; playing snakes and ladders with the children; baking cakes and cooking; time spent remembering.'

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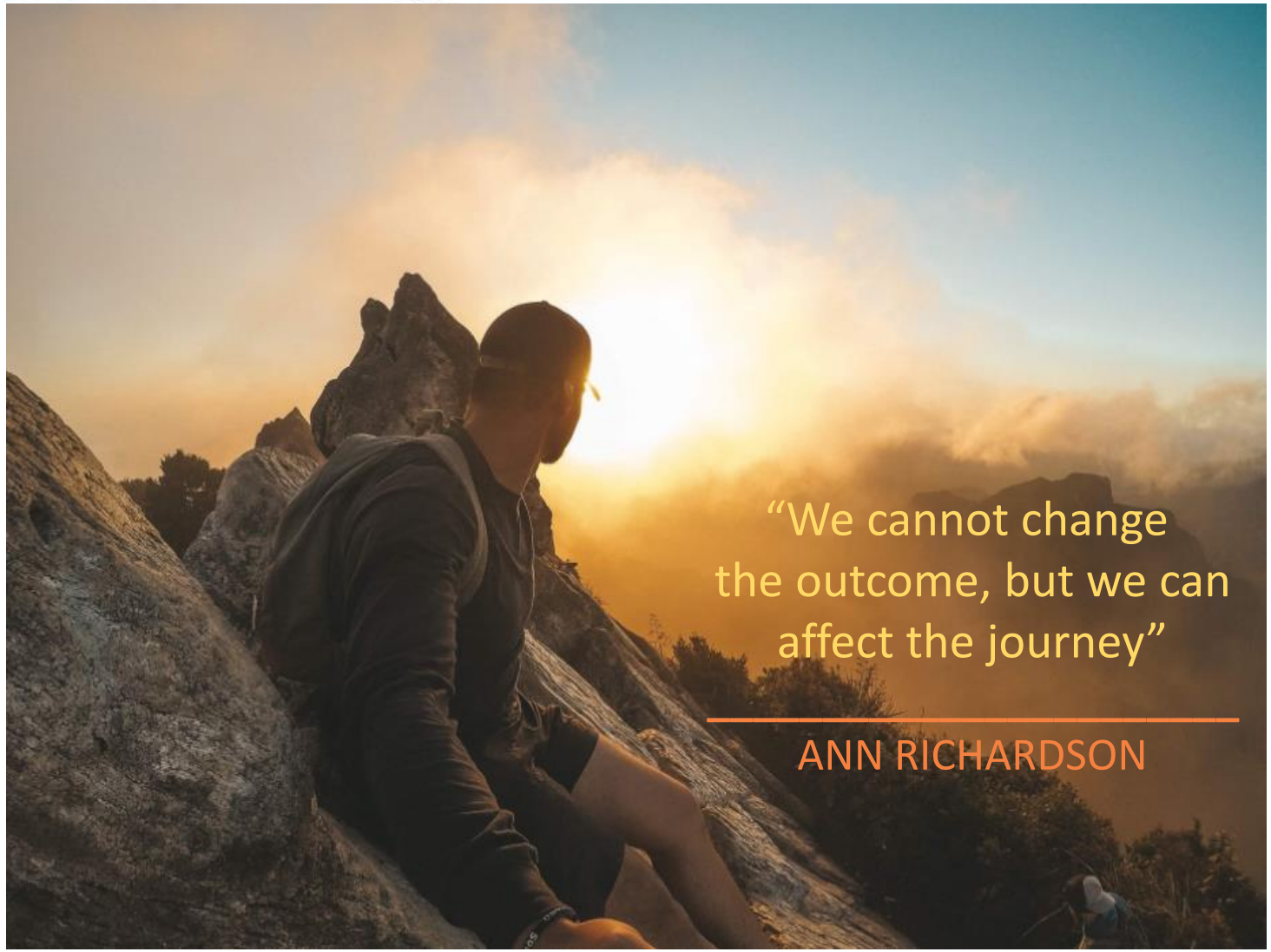
# Quality of Life

The goals of care are to:

1. Reduce suffering
2. Support the family

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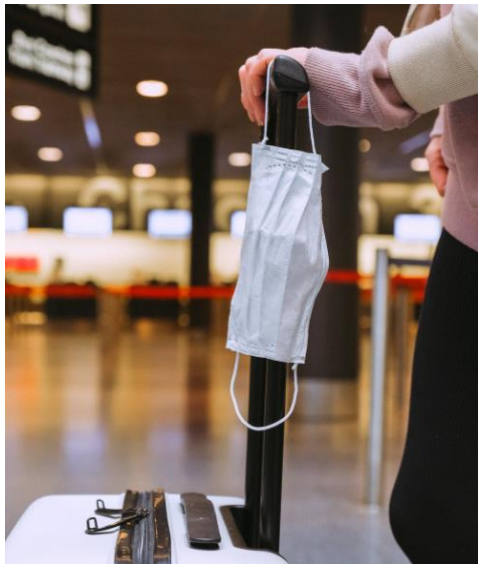
# COVID–19 Impact

## How has COVID-19 affected palliative dementia services?



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### Overall impact on client, carer, and the system

- No non-essential visits; only contact by phone
- Loss of body language, communication subtleties, and talk with carer.
- Not seeing the consumer, verbal vs non-verbal, and impact of stress and fear.
- Families cancelling appointments, carers in fear, and burden in the home
- Not go to hospital - fear of added stress from being admitted or families being unable to visit or having limited access.
- GP visits - only by phone
- Reduced family visits and less breaks or assistance with family members across border - interstate or overseas.
- Groups and day centres cancelled
- Closure of Memory Clinics - reduced diagnoses


# Care Partnerships Australia is Accessible

We build **relationship-centred** care partnerships where:

- Carers are valued receiving support and information.
- Everyone has a role to play in palliative care.
- Care is high-quality and evidence-based.

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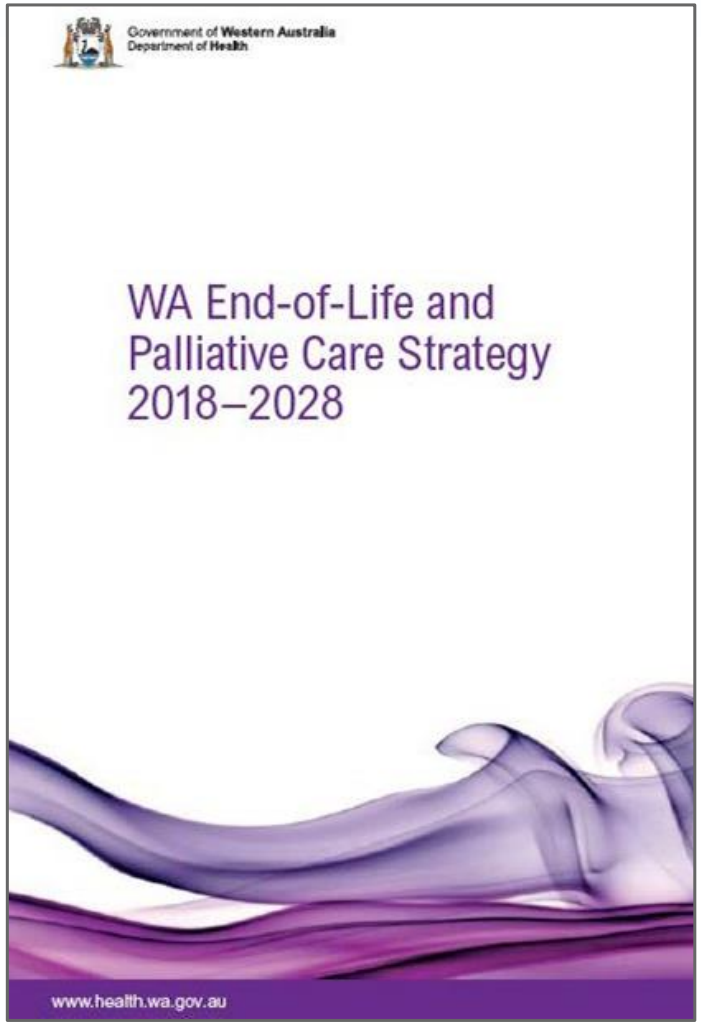
# Key Priorities

- **Care is accessible**
  - Improve access to care for all
- **Care is person-centred**
  - Seamless transitions/communication and Coordination/access to information
- **Care is coordinated**
  - Right care/time/place/from the right people
- **Families and carers are supported**
  - Part of the treating team; the outcome of the caring experience is positive.
- **Staff are prepared to care**
- **Community is aware and able to care**

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# Questions?

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