



# Critical Care Conversations in Dementia

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# Principals of Communication

- We treat patients not disease
- All healthcare flows through the relationship between the healthcare provider and patient
- The spoken language is the most important tool in medicine
  - Adapted from Eric Cassell – Talking with patients, MIT Press 1985
- Listen carefully and think about what you're going to say and how you'll say it.
- You can also communicate meaningfully without using spoken words.

# VIPS – people with Dementia....

- People with dementia and their families should be **V**ALUED
- People with dementia must be treated as **I**NDIVIDUALS
- The **P**ERSPECTIVE of the person with dementia must inform our understanding
- The persons **S**OCIAL Environment must be attended to

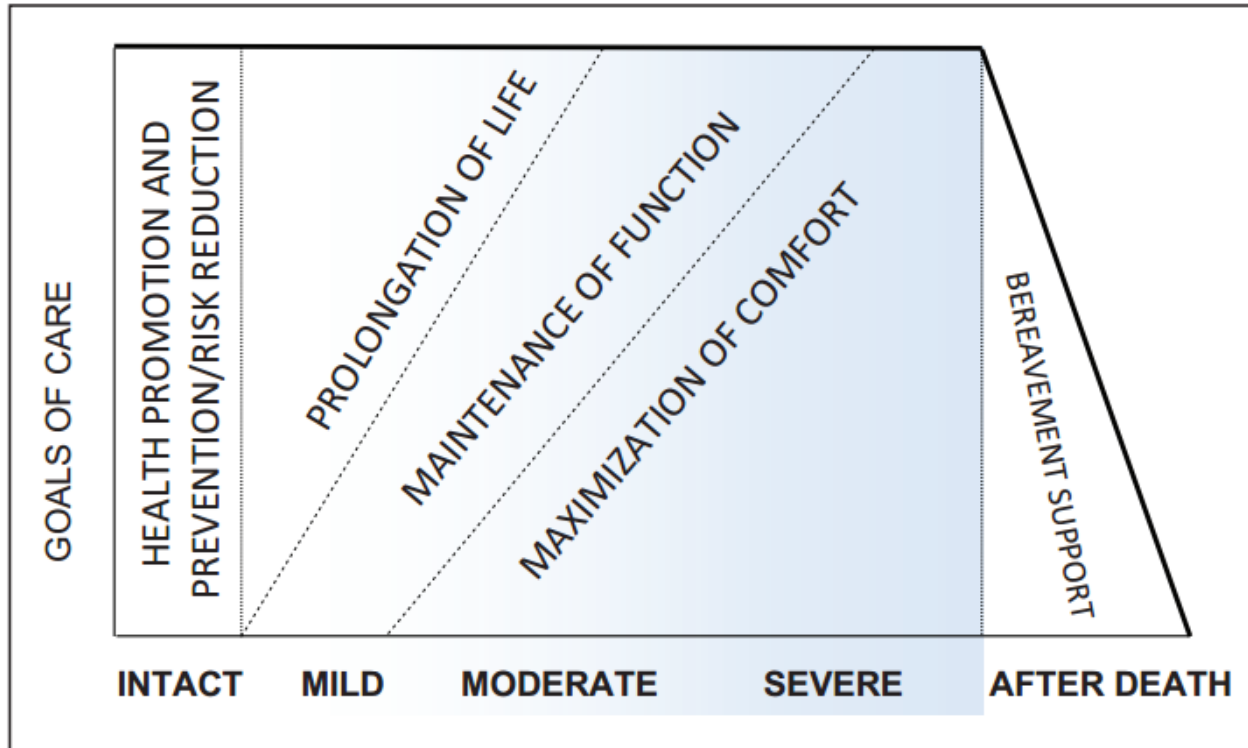
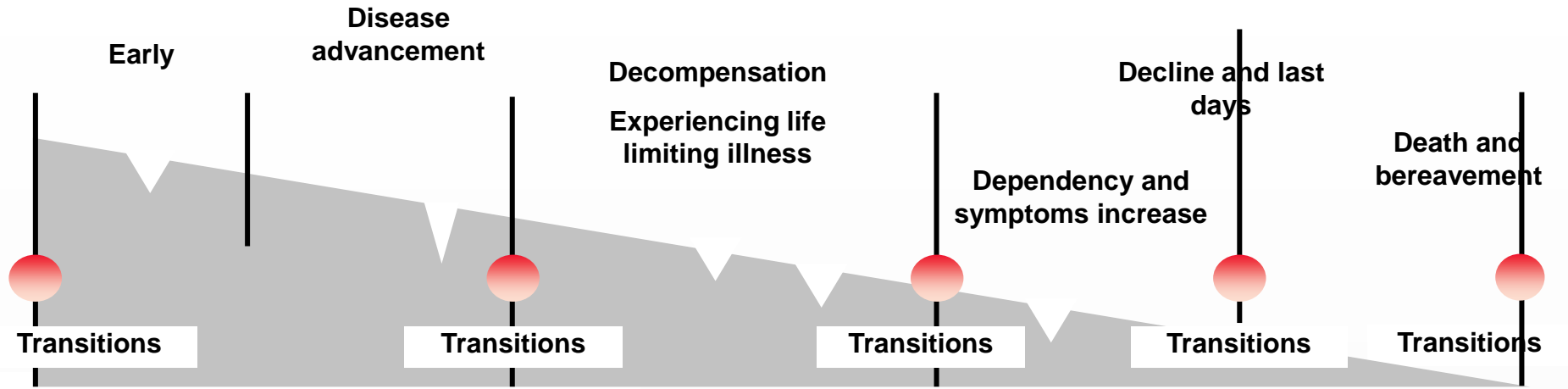


Brooker D. *Person-Centred Dementia Care: Making Services Better*. London: Jessica Kingsley; 2007. 160 pages

# Getting ready to communicate

- Minimize background noise
- Relax, be calm and present
- Think about how the person is feeling
- Introduce yourself
- Be aware of emotions
- Identify the emotional state
- Use visual aids and prompts
- Allow adequate time
- Check understanding
- Think about previous conversations and what helped you communicate well





**Figure 1.** Dementia progression and suggested prioritizing of care goals.

# Talking about what matters

- What do you know?
- What's Happening?
- What are you expecting?
- What matters?
- What would help?





# You will be a better communicator if you;

**Assess understanding:** “What you understand about your current health? What are you expecting as your illness changes?”

**Assess informational needs:** “Are you the kind of person who wants to know all the details about your illness or just an outline?”

**Assess decision-making style:** “Do you make decisions on your own or as a family?”

**And Adjust your communication accordingly...**

# Importance of getting language right

The words used to talk or write about dementia can have a significant impact on how people living with dementia are viewed and treated in our community.

- Appropriate language must be:
  - Accurate
  - Respectful
  - Inclusive
  - Empowering
  - Non-stigmatising.



Australia, D. (2021). *DEMENTIA LANGUAGE GUIDELINES*. [online] Dementia Australia. Available at: <https://www.dementia.org.au/sites/default/files/resources/dementia-language-guidelines.pdf> [Accessed 23 March. 2023].





# Communication in Case Conferences & Family Meetings

- Can improve...
  - Medication management,
  - Advance care planning,
  - Psychological support,
  - Family support
  - Terminal care.
- Triggers to identify people with advanced dementia where they or their family may benefit from a facilitated case conference include:
  - New or worsening symptoms
  - Functional or clinical decline
  - Return to the residential aged care facility following discharge from acute care or an emergency department presentation
  - Poor appetite or reduced oral intake, and
  - Family distress or disagreement about care.

# Does it Matter Who Decides? Outcomes of Surrogate Decision-Making for Community-Dwelling, Cognitively Impaired Older Adults Near the End of Life

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**Objectives:** To describe differences in end-of-life care for community dwelling, cognitively impaired older adults when children and spouses are involved in decision-making.

**Methods:** Retrospective observational study.

**Results:** Among 742 community-dwelling adults with cognitive impairment (mild cognitive impairment or dementia) prior to death, children participated in end-of-life decisions for 615 patients (83%) and spouses participated in decisions for 258 patients (35%), with both children and spouses participating for 131 patients (18%). When controlling for demographic characteristics, decedents with only a spouse decision-maker were less likely to undergo a life-sustaining treatment than decedents with only children decision-makers ( $P < 0.05$ ). There was no difference in the probability of in-hospital death or burdensome transfers across facilities across decedent-decision-maker relationships. Differences in rates of life-sustaining treatment were greater when we restricted to decedents with dementia.

**Conclusion:** Decedents with cognitive impairment or dementia were less likely to receive life-sustaining treatments when spouses versus children were involved with end-of-life treatment decisions but were no less likely to experience other measures of potentially burdensome end-of-life care.

# Everything must be done

Differential diagnoses of incongruent requests for care:

- Language barrier
- Low health literacy
- Not all options have been discussed
- Not understanding the normal process of dying
- Not understanding how the day-to-day events are manifestations of a terminal illness
- Differing values of what is quality of life and what is important at end of life (EOL)

# Key Messages

1. Ensure a patient centred care approach for your patients
2. Tailor your conversations accordingly
3. Be culturally aware and implement strategies to support people from different cultural backgrounds / respect diversity.
4. Implement VIPS when caring for people with dementia.
5. Be spiritually aware of patients and acknowledge their religious and spiritual needs for care delivery and in EOLC.
6. Be respectful of patient needs, respect individual values
7. Involve family within care planning and address patient wishes and goals
8. Ensure you are using appropriate, non-stigmatizing language when describing, talking and discussing a person with dementia