

Palliative Care Planning for Dementia



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Shortly after diagnosis of dementia (with patient and health representative):

- Discuss diagnosis with family and provide education regarding expected course and prognosis (consider using the [FAST](#)¹ or [GDS](#)² tools). Average life expectancy between 4-8 years.
- Confirm health care [representative](#)³, power of attorney and will, and encourage patient to name a health care representative, encourage [Section 9](#)⁴ agreement (i.e. includes life/death decisions) rather than [Section 7](#)⁵ agreement.
- Discuss/explore any potential [genetic/hereditary](#)⁶ component if onset of Alzheimer's prior to 60 years old
- Discuss goals of care (with family present):
 - Specifically what is most important to the patient? What gives them "quality" of life? What are they hopeful for as they look to the future given the context of their illness?
 - What are they worried about or fearful of?
 - What is important to know about them as a person to [maintain their dignity](#)¹⁶ as they get sicker from their dementia?
 - If they had to trade-off between "comfort" vs "life prolongation", which feels most important to them at this time?
 - When the person gets sicker with their dementia, where are they hoping to go? Home with care? Hospital? Hospice? Residential care? Where do they want to be at the end of their life? Do they have any specific wishes for the end of their life and what they want that to look like?
 - Discuss Code status ([MOST](#)⁷/CPR – and if choose "No CPR", ensure have community [No CPR order](#)⁸ at home on the fridge and that [family is aware](#)⁹). Consider using [Go-Far CPR survival calculator](#)¹⁰ to estimate neurologic survival after in-hospital CPR.
 - If patient or family asks about [Medical Assistance in Dying](#)¹¹ (MAID¹²), ensure patient and family are aware that this can currently only occur in the context of a competent patient and cannot be decided in advance. VIHA Brochure and patient request form can be found [online](#).



Later in advanced dementia (with patient and health representative):

- Re-discuss goals of care in the context of their prior expressed wishes:
 - What did the patient previously express as their priorities as they got sicker?
 - Discuss whether transfer to hospital is desirable and the goals regarding where the person would like to be at the end of their life and how best to support them in their chosen setting to minimize [burdensome transitions](#)¹⁴ in the final weeks/months of life.
 - Complete ["Expected Death at Home Form"](#)¹⁵, as necessary.
 - Discuss falls and [approaches](#)²⁰ to [reduce the risk](#)²¹ as well as what to do in the event of a major injury (e.g. hip fracture).
 - Given their current situation, reassess how they can best maintain the patient's dignity at this time. ["What do I need to know about you as a person to give you the best care possible?"](#)¹⁶
- Discuss the [role of food and fluids](#)¹⁷ at the end of life – specifically IV fluids and tube feeding ([current evidence](#)¹⁸ suggests that feeding tubes do not improve survival, functional status nor prevent aspiration and are associated with higher incidence of new pressure ulcers and less frequent healing of existing ulcers).
- Discuss role of antibiotics to treat infections in the context of their goals of care (ie. comfort vs. life prolongation). Infections can often be treated in the current place of care [without transfer](#)¹⁹ to hospital.
- Discuss inappropriate medications in those at FAST Stage 7+, identifying medications that may be causing harm or only reducing long term risks, and those that are [optimizing daily quality of life](#)²². Consider using the tool [Medstopper](#)²³ and asking a pharmacist for help with deprescribing.
- Discuss what to expect as someone gets close to the end of their life – specifically irregular breathing changes and the normal cessation of oral intake.



Recurrent conversations at milestones of hospitalizations, annual check-ups, etc:

- Review goals of care through conversation with patient and family member-consider using [Fiero's 4 R's](#)²⁴ to explore goals.
- Review Code Status and complete necessary paperwork. ([MOST](#)⁷/CPR – and if choose "No CPR", ensure have community [No CPR order](#)⁸ at home on the fridge and that [family is aware](#)⁹). Consider using [Go-Far CPR survival calculator](#)¹⁰ to estimate neurologic survival after in-hospital CPR.
- Provide support for family caregivers, including [dementia support group/association resources](#)²⁵.
- Discuss current situation in the context of the patient's previously expressed goals of care; and determine/restate the goals at this time.
- Include the patient in conversations regarding the goals of care in keeping with their current capacity to participate.
- Monitor for complaints of signs of pain. Consider using the [PACSLAC](#)²⁶ or [PAIN-AD](#)²⁷ scales.

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References

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