





# **Dementia as a Terminal Illness**

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# Dementia as a Terminal Illness

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**Dementia**

**Cancer**



# Dementia as a Terminal Illness

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## **Dementia**

- Long interval between diagnosis and death

## **Cancer**

- Variable interval between diagnosis and death



# Dementia as a Terminal Illness

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## **Dementia**

- Long interval between diagnosis and death
- Potential for “competing causes of mortality”

## **Cancer**

- Variable interval between diagnosis and death
- Competing causes much less frequently seen



# Dementia as a Terminal Illness

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## Dementia

- Long interval between diagnosis and death
- Potential for “competing causes of mortality”
- Little opportunity to affect disease course

## Cancer

- Variable interval between diagnosis and death
- Competing causes much less frequently seen
- Variable, but sometimes considerable, opportunity to lengthen life.



# Approach to all terminal illness

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- Time is precious
- Identify values as they relate to the trajectory of illness: early, middle, late
- Use values to plan ahead



# Approach to all terminal illness

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- Need to weigh quality vs. quantity of life
- All interventions need to have their benefits and burdens considered carefully
- Recognize endstage disease





# Dementia as a Terminal Illness

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- *Proximal* time is precious:
  - Period of capacity in decision-making is likely limited.



# Dementia as a Terminal Illness

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- *Proximal* time is precious:
  - Period of capacity in decision-making is likely limited.
  - Need for arrangements for future medical, legal and personal affairs.



# Dementia as a Terminal Illness

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- Appoint a *Health Care Agent*:
  - who knows me best?
  - who will advocate for my values?



# Dementia as a Terminal Illness

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- Appoint a *Health Care Agent*:
  - who knows me best?
  - who will advocate for my values?
- What do I want my agent to consider in making decisions for me?



# Dementia as a Terminal Illness

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- Legal and financial affairs - elder law attorney
  - Legal tools for asset management
  - Naming power of attorney for finances and legal affairs



# Dementia as a Terminal Illness

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- Planning for the future:
  - What is important to me now, later?
  - What choices will my condition pose?
  - What would I choose for myself? What about when there are no good options?
  - Who do I want to speak for me in the future?



# Dementia stages

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- Early: living at home with intermittent assistance, supervision
- Middle: more significant assistance needed; 24-hr. caregiver presence or assisted living
- Late: community living is difficult and resource-intensive; assisted living or nursing home care is likely.



# Dementia issues - at any stage

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- Disruptive behaviors; e.g.,
  - Sleep/wake disturbance, wandering
  - Combativeness (usually defensive)
  - Socially problematic behaviors (disinhibition)
- Incontinence of bowel, bladder
- Mobility challenges, Falls





# Indications of endstage dementia

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- Inability to protect airway (choking)
- Disinterest in food. Inability to take food in (alone, or with assistance)
- Weight loss



# Considering medical events as potential “off-ramps”

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- Treatment of medical events may be foregone if “benefits” of treatment not valued for the current stage of dementia



# Considering medical events as potential “off-ramps”

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- Treatment of medical events may be foregone if “benefits” of treatment not valued for the current stage of dementia
- Identifying a “threshold” function level beyond which you would like to be treated for comfort only can be very helpful to your Health Care Agent



# Dementia stages

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Resources for end-of-life planning:

*information, forms, instructions*

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Vermont Ethics Network

[www.vtethicsnetwork.org](http://www.vtethicsnetwork.org)

Resources for end-of-life planning:

*on talking with loved ones*

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The Conversation Project  
[www.theconversationproject.org](http://www.theconversationproject.org)

Discussion?!

