

# Cognitive Screening... and Then What?



Catherine Madison, MD

Ray Dolby Brain Health Center  
Sutter Health CPMC

(Advance Care Planning with a Dementia Diagnosis  
to Lessen Suffering)

# Outline

- Definition of a dementia
- Common signs
- Cognitive Screening
- How to get the conversation started
- Goals of Care Discussion
  - Advance Directives
  - POLST
  - Dementia Directive
- Summary



# Need for Screening

Why diagnose early a disease that is incurable?

- Substantial evidence of disease reduction with better management seen in HIV, heart disease and some cancers
- Earlier detection needed with history of 99.6% failure rate Alz investigational drugs 2002-2012
- Pathological changes may begin decade(s) before symptoms obvious
- Delaying onset dementia by 5 years could reduce projected Medicare costs by 50%

***Advance Care Planning can help reduce costs/suffering***

# Perspective

Hard to imagine anything as terrifying, depressing and anxiety provoking as knowing you have an incurable neurodegenerative disease that is going to silently steal your independence- ultimately leaving you unable to care for yourself...



# Common Signs

- Forgetting appointments
- Withdrawal from work or social activities
- Changes in personality
  - Changes in relationships
- Keeping up with bills
- Deterioration of time relationships

# Prospection

- Prospection: The ability to mentally simulate potential events at a future point in time
  - Retrieval of autobiographical details
  - Understanding relationships in time and space
  - Consideration of risks in different medical scenarios
- Marked impairment in dementia syndromes



# Anosognosia - Lack of Insight

- Comparing intake forms between 22 patients/confidants
  - Recent or long term memory
  - Attention/concentration
  - Organization/planning
  - Judgement/reasoning/problem solving
  - Language function
  - Orientation in space or time
- Judgement, reasoning or problem solving

The brain is the only vital organ that is not routinely assessed in clinical practice, yet good brain function is essential for clinician-patient partnership.

# Starting the Conversation

- “Have you been afraid that your life in the future would not be consistent with what you would want now and that you might be unable to express this perception?”
- “What’s most important to you as you think about how you want to live the rest of your life?”
  - Stay at home
  - Not be a burden
  - Be able to recognize family and friends
  - Receive good care with the potential to be content

*Lean into the conversation with an open attitude and genuine desire to learn...*

# Starting the Conversation

- Avoid joining the conspiracy of denial
- Can't make it OK, so don't make it worse
- 1702 Medicare beneficiaries deceased 2005-2010
  - Heart disease, cancer, dementia and other causes
  - Care costs to patient/family over 5 years 80% higher for a dementia diagnosis (\$61,522)

*Sincere respect and vulnerability typically produce more of the same:  
mutual respect and shared vulnerability*

# Advance Directives

- “We’ve already done that”

I do not want efforts made to prolong my life and I do not want life-sustaining treatment to be provided or continued: (1) **if I am in an irreversible coma or persistent vegetative state**; or (2) if I am **terminally ill** and the use of life sustaining procedures would serve only to artificially delay the moment of my death; or (3) under any other circumstances where the **burdens of treatment outweigh the expected benefits**. In making decisions about life sustaining treatment under (3) above, I want my agent to consider the relief of suffering and the quality of my life as well as the extent of the possible prolongation of my life.

# Advance Directives (cont.)

- “My doctor” or “My family” will decide

That agent will make health care decisions for me in the future, if and when I no longer have the mental capacity to make my own health care decisions. My primary care physician will determine when I am unable to make health care decisions for myself.

***ACP discussions should focus on the ability of people with dementia to maintain normal daily function as well as on their quality of life, instead of end-of-life-discussions only***

# POLST

- Conversation tool
  - Treatment wishes and goals for care can change over time
  - Usual course of treatment...
  - What a patient does NOT want
- Physician personal choices – 88.3% DNR\*
- Injuries from CPR
  - Resuscitation 2015; >2,000 autopsies:
    - Skeletal chest injuries found in 86% men, 91% women
    - Rib fractures in 77% men and 85% women

\* 2013: 1081 physicians

# Dementia Directive

Although it's a terminal disease, dementia often spreads through the brain slowly, over 20 years or longer. The point at which dementia patients can no longer direct their own care isn't predictable, stable or obvious.

Barak Gaster MD, University of Washington

Downloadable document [dementiadirective.org](http://dementiadirective.org)

2,000/month

Goals of Care similar to POLST, choosing a preference for

Mild

Moderate

Severe

# Dementia Directive

- Have you been afraid that your life in the future would not be consistent with what you would want now and that you would be unable to express this perception?
- Has filling out the Dementia Directive helped to address that concern?
- After filling out the Dementia Directive do you better understand the different stages of illness in a dementia?
- Did the Dementia Directive help you to reflect on each stage of the disease and what you would want for yourself in those circumstances?
- Did making your wishes known relieve some of the stress of coping with the illness?

# Dementia Directive

- Phone follow-up 16 patients
  - Understanding stages of illness – 14
  - Addressed concern – 12
  - Afraid for your future – 11
  - Relieve some stress in coping – 10
  - Reflect on course of illness - 10

# Dementia Directive

Complete the Dementia Directive we shared in our office visit today. This is not a legal document, but a good conversation tool that allows you to clearly outline your goals for care in the future if you were to develop a dementia. Specifically, it allows you to decide what level of care you want and do not want from your current frame of reference. Once this form has been completed, signed and dated, share with family members and then place with other important papers.

# Summary

- Tough conversations rarely go as planned anyway. So provide prompts, then focus on listening, reflecting, learning and working on a common objective.
- Don't try to speak truth to powerlessness. The difficulty we have both as patients and physicians is confronting mortality.
- Become comfortable with your talking points
  - Focus on goals and function
  - Focus on quality of life
- “You look uncertain about this...We don't need to decide today – at this moment. Let's talk more at our next meeting”
- Provide the Dementia Directive for all patients at age 65\*
- Try mindfulness: Paying attention in a non-judgmental manner, on purpose, to what matters most and bringing your whole self to the experience.

\*Incidence 3% ages 65-74

Thank you.



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Sutter Health CPMC Ray Dolby Brain Health Center  
45 Castro St., Ste 220, San Francisco, CA 94114  
[cpmc.org/brainhealth](http://cpmc.org/brainhealth)