# Advance Care Planning and Issues of Capacity

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Karen Peterson
Executive Director, Honoring Choices Minnesota

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**Objectives:**

- Competency vs. capacity
- Importance of diagnoses and timing
- Educational resources
- Recommended practices

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## *CAPACITY*

- **Medical** determination
- Can vary day-to-day
- Surrogate called upon when patient deemed to lack capacity

*"Capacity refers to an assessment of the individual's psychological abilities to form rational decisions, specifically the individual's ability to understand, appreciate, and manipulate information and form rational decisions."*

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## *COMPETENCY*

- **Legal** definition
- Incompetency is assigned by court
- Guardian is then appointed

*"Competency refers to the mental ability and cognitive capabilities required to execute a legally recognized act rationally"*



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A person should not be regarded as lacking capacity merely because they are making a decision that is unwise or against their best interests (*although an unwise decision could indicate a need for a formal assessment of capacity*).

The assessment needs to focus on the logic in the way the decision is made, not a judgement about the decision itself.

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## *DIAGNOSIS*

- **HUGE** issue
- Comes too late
- Not well explained

*Research shows that doctors frequently fail to diagnose, or even when they do, they often don't share the diagnosis.*

## *TIMING*

- **HUGE** issue
- (see Diagnosis)
- Changes day-to-day (hour-to-hour)

*Earlier diagnosis allows time for learning, planning, talking.*

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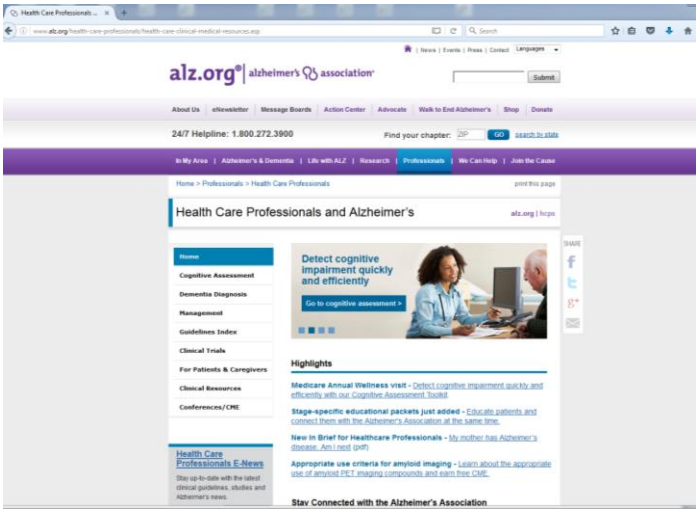


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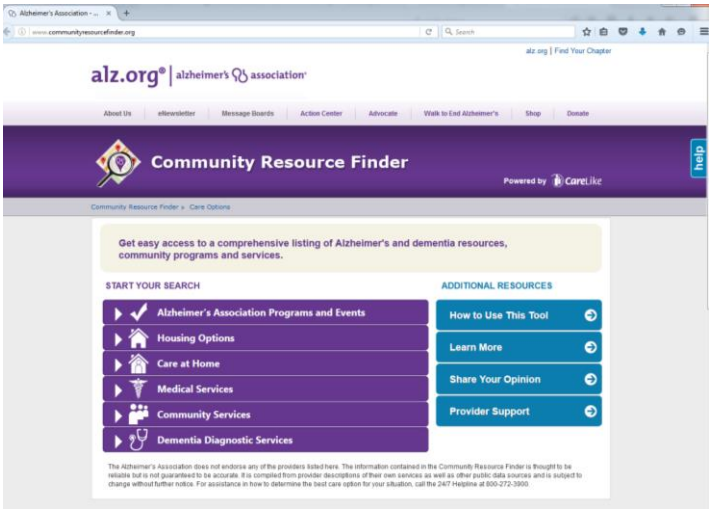
Capacity

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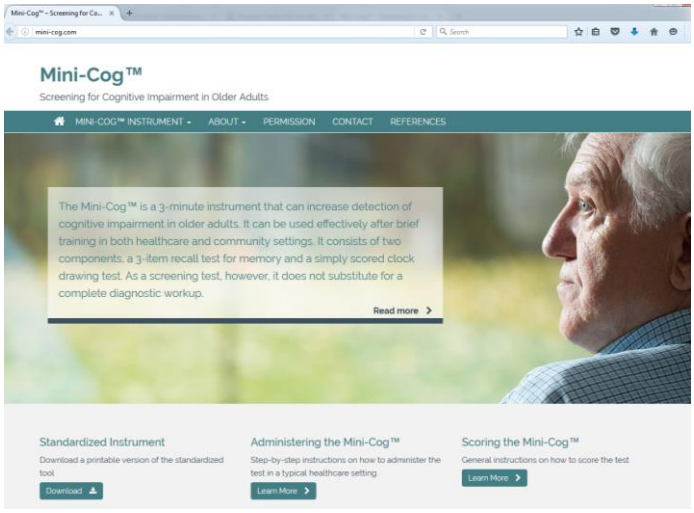


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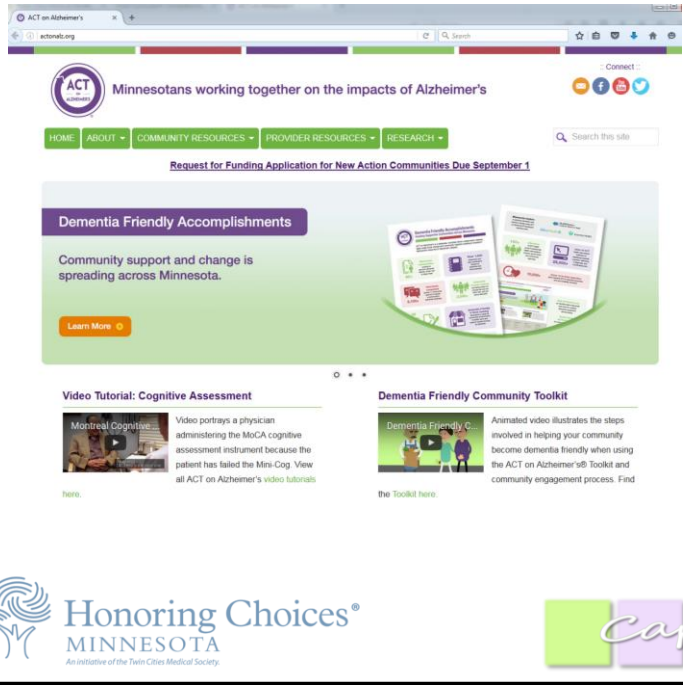


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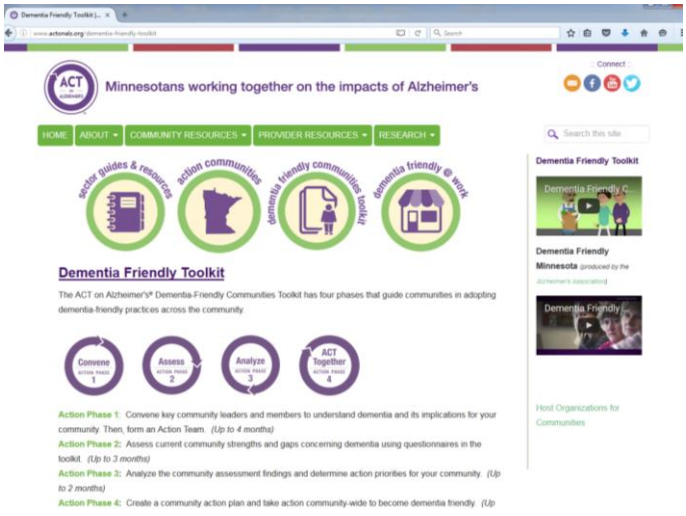


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Where's the Advance Care Planning?

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Barriers to dementia-specific advance care planning

- Dementia remains **poorly understood** by health care professionals, the public and people living with dementia and their families; there is a failure to appreciate that dementia is a **terminal** illness
- **Inadequate understanding of ACP (**common decisions, options, including EOL options)
- Advocacy groups advise people living with dementia to talk with their doctors and their lawyers, but are **not very specific** about which questions to ask
- **False assumptions** that it only makes sense to plan for dementia if you have been diagnosed with dementia, or that if you have been diagnosed with dementia you are no longer able to engage in advance care planning

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Barriers to dementia-specific advance care planning

- Advance directive forms do little to encourage people to consider **dementia-specific** advance care planning
- The high **literacy** level of advance directive forms
- Advance care planning for dementia can be **complex** and time consuming
- Facilitators need **special training** to assist with dementia-specific advance planning

*D.Vawter, MN Center for Health Care Ethics, 2016*

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Add-on to a traditional healthcare directive:

*"The Dementia Provision"*

If I remain conscious but **have advanced dementia** or fatal illness such that I am unable to communicate, swallow food and water safely, care for myself and recognize my family and other people, and it is very unlikely that I will regain these abilities, I would like my wishes regarding specific life sustaining treatments, as indicated in part 2 of my healthcare directive, to be followed.

*Compassion & Choices MN, 2016*

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# ACP-ED Tool

*(British research project, 2012)*

How have you been feeling since you were given your diagnosis?

What would you like to know about your care and treatment, how much information do you normally like to have? Are you the sort of person who likes to have all of the information, or would you prefer not to know too much?

Have you had any thoughts, discussions with your family or friends about what you would like to happen, if you became very ill and needed more support and care?

Do you have any specific religious or spiritual needs which you would like to be adhered to, wherever you are cared for, such as attending a local church or meeting place?

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# ACP-ED Tool

*(British research project, 2012)*

Do you have any specific cultural needs that people need to be aware of in relation to your care, or any specific dietary preferences such as being a vegetarian?

Would you like other people to be involved in your care? Family? Friends, significant others, professional caregivers?

If you became physically unwell, or if the changes that were happening to you became difficult to manage at home, where would you like to be cared for – residential care? Home? Hospice? Nursing Home?

Have you got any other concerns that have not been addressed or discussed with this document?

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# Advance Care Planning

ACP comes down to three basic questions:

1. Who do you trust to speak for you when you cannot?
2. Do you want life-sustaining measures (CPR) if your healthcare team agrees your chances of survival or recuperation are extremely slim?
3. What do you want your healthcare team to know about you (spiritual, cultural, personal)?

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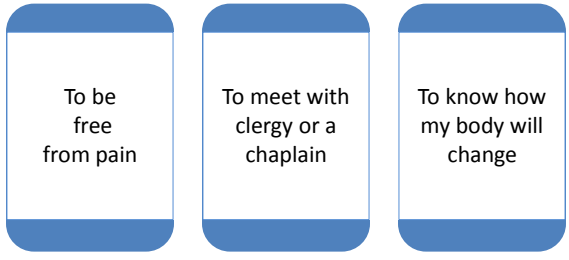
# Making ACP Dementia-Friendly

- Use Honoring Choices short form
- Use specially-trained facilitators
- Use conversation tools such as "Go Wish"

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# Making ACP Dementia-Friendly

- Timing is everything
- Do your homework
- Use short sentences
- Don't dilly-dally
- And more …. ?

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Support Honoring Choices and awareness of ACP!

Thank You

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# References

Act on Alzheimer's www.actonalz.org

Alzheimer's Association www.alz.org MN Chapter: www.alz.org/mnnd/

The Go Wish Game http://www.gowish.org/

Poppe, Michaela, Burleigh, Sarah, Banerjee, Sube. Qualitative Evauation of Advanced Care Planning in Early Dementia; PLOS One. Apr 2013; 8(4) (http://journals.plos.org/plosone/article?id=10.1371/journal.pone.0060412)

Freer, Jack. Competence and Decision-Making Capacity; 1997, UB Center for Clinical Ethics and Humanities in Health Care (http://wings.buffalo.edu/bioethics/man-dcm.html)

Leo, Raphael J. Competency and the Capacity to Make Treatment Decisions: A Primer for Primary Care Physicians; Prim Care Companion J Clin Psychiatry. 1999 Oct; 1(5): 131–141 (http://www.ncbi.nlm.nih.gov/pmc/articles/PMC181079/ )

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