

# Advance Care Planning and Issues of Capacity

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## Objectives:

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



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.”*

COMPETENCY

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

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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.



### 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.*



alzheimer's association

24/7 Helpline: 1.800.272.3900

Health Care Professionals and Alzheimer's

Detect cognitive impairment quickly and efficiently

Highlights

Medicare Annual Wellness visit - Detect cognitive impairment quickly and efficiently with our Cognitive Assessment Toolkit

Stage-specific educational packets just added - Educate patients and connect them with the Alzheimer's Association at the same time

New in Brief for Healthcare Professionals - My mother has Alzheimer's disease. Am I next? (PDF)

Appropriate use criteria for amyloid imaging - Learn about the appropriate use of amyloid PET imaging components and such from CME

Stay Connected with the Alzheimer's Association

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Community Resource Finder

Get easy access to a comprehensive listing of Alzheimer's and dementia resources, community programs and services.

START YOUR SEARCH

Alzheimer's Association Programs and Events

Housing Options

Care at Home

Medical Services

Community Services

Dementia Diagnostic Services

ADDITIONAL RESOURCES

How to Use This Tool

Learn More

Share Your Opinion

Provider Support

The Alzheimer's Association does not endorse any of the providers listed here. The information contained in the Community Resource Finder is thought to be reliable but is not guaranteed to be accurate. It is compiled from provider descriptions of their own services as well as other public data sources and is subject to change without further notice. For assistance in how to determine the best care option for your situation, call the 24/7 Helpline at 800-272-3900.

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Mini-Cog™  
Screening for Cognitive Impairment in Older Adults

MINI-COG™ INSTRUMENT ABOUT PERMISSION CONTACT REFERENCES

The Mini-Cog™ is a 3-minute instrument that can increase detection of cognitive impairment in older adults. It can be used effectively after brief training in both healthcare and community settings. It consists of two components: a 3-item recall test for memory and a simply scored clock drawing test. As a screening test, however, it does not substitute for a complete diagnostic workup.

Read more >

**Standardized Instrument**  
Download a printable version of the standardized tool.  
[Download](#)

**Administering the Mini-Cog™**  
Step-by-step instructions on how to administer the test in a typical healthcare setting.  
[Learn More](#)

**Scoring the Mini-Cog™**  
General instructions on how to score the test.  
[Learn More](#)

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ACT on Alzheimer's

acton.alz.org

MINNESOTANS WORKING TOGETHER ON THE IMPACTS OF ALZHEIMER'S

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[Request for Funding Application for New Action Communities Due September 1](#)

**Dementia Friendly Accomplishments**

Community support and change is spreading across Minnesota.

[Learn More](#)

**Video Tutorial: Cognitive Assessment**

Montreal Cognitive Assessment  
Video portrays a physician administering the MoCA cognitive assessment instrument because the patient has failed the Mini-Cog. View all ACT on Alzheimer's video tutorials [here](#).

**Dementia Friendly Community Toolkit**

Dementia Friendly Community Toolkit  
Animated video illustrates the steps involved in helping your community become dementia friendly when using the ACT on Alzheimer's Toolkit and community engagement process. Find the Toolkit [here](#).

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Minnesotans working together on the impacts of Alzheimer's

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### Dementia Friendly Toolkit

The ACT on Alzheimer's® Dementia-Friendly Communities Toolkit has four phases that guide communities in adopting dementia-friendly practices across the community.

**Convene** (6-8 weeks)  
**Assess** (6-8 weeks)  
**Analyze** (6-8 weeks)  
**ACT Together** (6-8 weeks)

**Action Phase 1:** Convene key community leaders and members to understand dementia and its implications for your community. Then, form an Action Team. (Up to 4 months)

**Action Phase 2:** Assess current community strengths and gaps concerning dementia using questionnaires in the toolkit. (Up to 2 months)

**Action Phase 3:** Analyze the community assessment findings and determine action priorities for your community. (Up to 2 months)

**Action Phase 4:** Create a community action plan and take action community-wide to become dementia friendly. (Up to 2 months)

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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



### 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*



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*



## 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?



# 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?



*What would Honoring Choices do?*



## Advance Care Planning

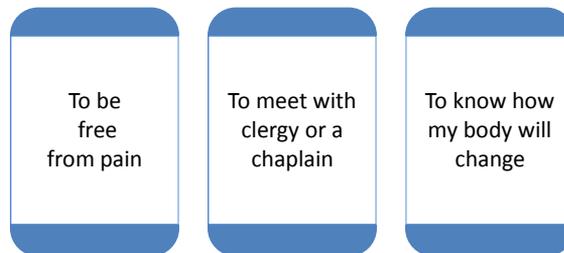
ACP comes down to three basic questions:

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)?



## Making ACP Dementia-Friendly

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



## Making ACP Dementia-Friendly

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



Support Honoring Choices and awareness of ACP!

Thank You



## References

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