

# Decisional Capacity

**Lisa Vig, MD MPH**

Associate Professor of Medicine, Gerontology and Geriatric  
Medicine

Chair, Ethics Committee, VA Puget Sound Health Care System

## Disclosures

- No relevant conflicts of interest
- The views expressed in this presentation are mine and don't represent those of the Veterans Health Administration

## Objectives

- Identify 4 different realms where capacity may be assessed
- Explain the 4 decision-making abilities that are assessed in determining capacity to make medical decisions
- Name some common myths about decisional capacity
- Describe the concept of supported decision-making

## 5 M's of Geriatrics



**Mind**



**Mobility**



**Medications**



**Matters Most**



**Multi-complexity**

## 5 M's of Geriatrics



**Mind**



**Mobility**



**Medications**



**Matters Most**



**Multi-complexity**

It's Feb 29<sup>th</sup>!

Happy  
Leap Day!



Z. Nelson – unsplash.com

# Ethics, Capacity, and Informed Consent

“The capacity to make one’s own decisions is fundamental to the ethical principle of respect for autonomy and is a key component of informed consent to medical treatment. ”

Karlawish J, Assessment of decision-making capacity in adults, *UpToDate* 2015

## Types of Capacity



Financial capacity



Testamentary capacity



Dispositional capacity



Decisional capacity for medical decisions

## Financial Capacity



- Knowledge
  - Awareness of one’s assets and income
- Skills
  - Buying things one needs, paying bills
- Judgment
  - Older people and people with cognitive impairment at risk for financial exploitation

Adapted from VA Educational Series – Financial Capacity (can google it)

## Financial Abuse Cons/Scams

Name of Con or Scam	Example
Sweetheart or caretaker scam	Exploiter befriends elderly person and offers friendship, romance, sex, or assistance with household activities. After brief courting period, they steal cash or property.
Home repair contractor fraud	Exploiters calling themselves “contractors” offer to perform various tasks at a special discount. Once “repair” has begun, the victim is informed cost of job has exceeded the estimate.
Utility company impersonators	The exploiter says that service is likely to be discontinued unless a worker has access to the residence, then the impersonator enters the home to steal cash and valuables.
Pigeon drop scam	Older adult victim is approached by exploiter who claims they “just found” a bag full of large sums of cash. The exploiter may suggest that for the victim to keep the found cash, they must withdraw funds from their own accounts as collateral.
Handkerchief switch	Stranger approaches victim and asks for assistance in sending a large amount of cash to a charity or another country. They appear to put cash into a bag and tell the victim to do the same with “good faith” money (ie, to show intention to complete a deal) until they return, but they never return.
Bank scam	Exploiter indicates that there is an abnormality related to their account. Ultimately, the victim withdraws significant amounts of cash from their account to catch a thief in action. The exploiter “holds” the victim’s cash to “mark” the money as the scheme proceeds, but the victim never sees this cash again.
Other schemes	Telemarketing and mail fraud, predatory lending, identity theft, fiduciary abuse (eg, theft or embezzlement by guardians or attorneys-in-fact).

<sup>6</sup>Based on Bailly and Loewy.

Singh, Psychiatrist.com, 2023

## Financial abuse is prevalent!

- Financial abuse underreported
- Meta-analysis of 41,711 people 50+ cognitively intact
  - 1 in 18 scammed annually
- National Elder Mistreatment Study of 5,777 people 60+
  - 5% reported financial abuse in current or past year by a family member

Singh, Psychiatrist.com, 2023

## Financial Capacity



- Instruments to assess financial capacity exist – but most are lengthy
- Neuropsych, Speech, OT may be able to help
- Consider Adult Protective Services referral if concerns about exploitation

## Who is considered a vulnerable adult?

- 60 years of age w/inability to care for self
- Has a legal guardian or conservatorship
- Has a developmental disability (per legal defs)
- Admitted to any facility
- Receiving services from home health, hospice, or licensed home care agency
- Receiving care from a personal aide

<https://www.dshs.wa.gov/altsa/adult-protective-services>

## Testamentary Capacity



- Ability to complete a legal document
  - Will
  - Other documents completed in a lawyer's office
- Attorneys determine this

## Dispositional Capacity



- Assessment of the capacity to live independently
- Can the person explain the risks, benefits, and alternatives to going home?
- What does OT say?
- Good article – Bourgeios et al, *Psychosomatics*, 2017

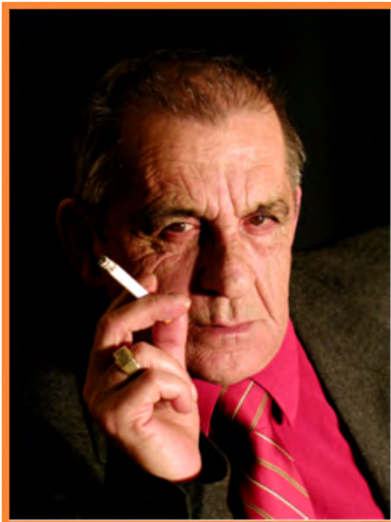
## Decisional Capacity for Medical Decisions





Patients  
need  
decision-  
making  
capacity to...

- Accept or refuse medical treatment
- Leave hospital AMA (against medical advice)
- Participate in research
- Complete an advance directive
- Request medication to end one's life (Death with Dignity)



Mr. G

76 year old man with mild dementia, cirrhosis, emphysema, peripheral vascular disease and a slow healing leg ulcer

Dressing changes are painful

He is confused at times, with periods of increased disorientation and difficulty maintaining attention (delirium)

Can Mr. G make a decision about pain management?



slido



Can Mr. G make a decision about pain management?

① Start presenting to display the poll results on this slide.

## Prevalence of incapacity from studies

• JAMA meta analysis	
• Healthy older patients	<3%
• Mild cognitive impairment	20%
• Medicine inpatients	26%
• Parkinson's disease	42%
• Nursing home residents	44%
• Alzheimer's disease	54%

Sessums, JAMA, 2011

## Prevalence of incapacity from studies

• JAMA meta analysis	
• Healthy older patients	<3%
• <b>Mild cognitive impairment</b>	<b>20%</b>
• Medicine inpatients	26%
• Parkinson's disease	42%
• Nursing home residents	44%
• <b>Alzheimer's disease</b>	<b>54%</b>

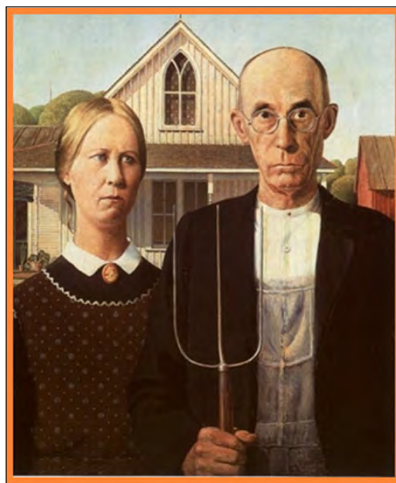
• Recognized by clinicians 42% of the time

Sessums, JAMA, 2011

## Debunking a myth about decisional capacity

- Dementia or other psychiatric diagnoses don't automatically mean someone is incapacitated
- "Age, eccentricity, poverty, or medical diagnosis alone shall not be sufficient to justify a finding of incapacity."  
Revised Codes of Washington (RCW) 11.88.010

## Determining Decisional Capacity



Wood 1930

## Determining decisional capacity

The four decision-making abilities:

Understanding

Appreciating

Reasoning

Choosing

## Steps in determining capacity

1) Find out what the patient already knows  
(Don't assume patient knows pertinent medical information)

- *Tell me about...*
- *your condition*
- *what's been going on*
- *why you are in clinic today*
- Pay attention to their cognitive status

## Steps in determining capacity

- 2) Does the patient want to make their own decisions?

## Patient involvement in decision-making

- Active decision-making role
- Shared decision-making with clinician
- Deferring decision-making to others

Degner, JAMA, 1997

## Steps in determining capacity

### 3) **Understanding** of risks, benefits, and alternative treatments

*How can we treat your problem?*

*Are there other options?*

*What have you been told about the risks and benefits of the different options?*

## Pearl

- Don't merely ask the patient if they understand
- Use **teach back** method

*"I'm not sure I explained that very well. To help me make sure I was clear, could you tell me in your own words what you've heard about the different options?"*

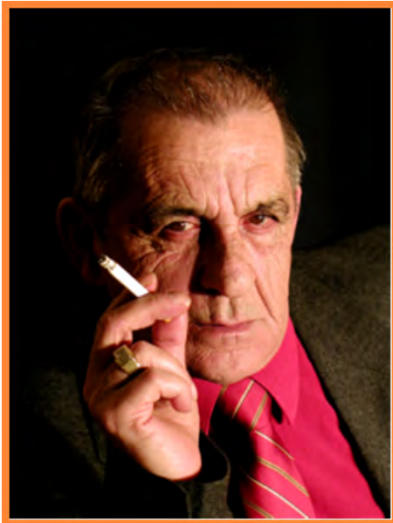
## Steps in determining capacity

- 4) **Appreciation** of how the treatment options apply to his/her own situation
  - What will happen if you get the treatment?*
  - What will happen if you don't get the treatment?*
  - What treatment makes the most sense for you?*

## Steps in determining capacity

- 5) **Reasoning** behind the choice
  - Why is that treatment the best choice for you?*
- 6) Make a **choice** and maintain it over time
  - What is the best treatment for you?*





Mr. G can

- 1) tell you he has a “sore” on his leg
- 2) point to where he has pain
- 3) tell you that a “pain pill” he gets doesn’t work (acetaminophen)
- 4) remember previously receiving a pill that made him sleepy and more confused, but that decreased his pain
- 5) say he wants that medicine

Determining  
decisional  
capacity

---

The four decision-making abilities:

---

Understanding

---

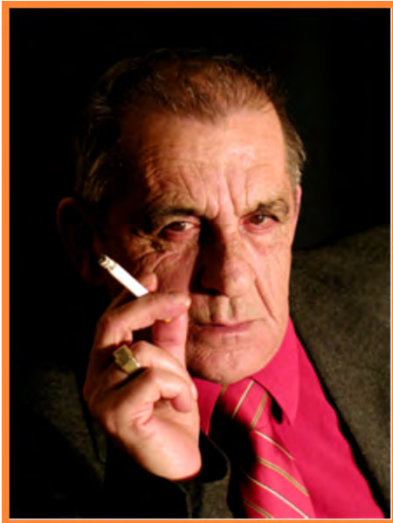
Appreciating

---

Reasoning

---

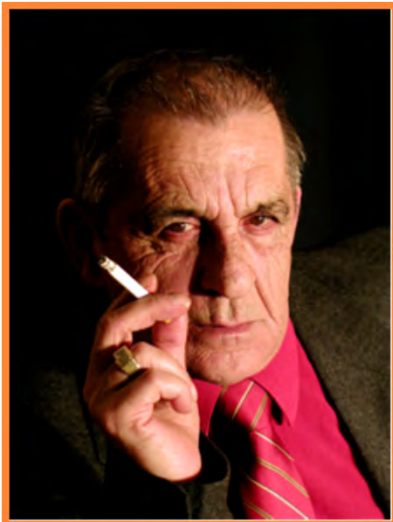
Choosing



Understanding  
Appreciating  
Reasoning  
Choosing

He can

- 1) tell you he has a “sore” on his leg
- 2) point to where he has pain
- 3) tell you that a “pain pill” he gets doesn’t work (acetaminophen)
- 4) remember previously receiving a pill that made him sleepy and more confused, but that decreased his pain
- 5) say he wants that medicine



- Mr. G’s wound heals, but he later develops lung cancer
- Treatment options include immunotherapy, chemotherapy, radiation
- Making a decision involves:
  - Weighing the risks/benefits/alternatives
  - Stats about chances of benefit
  - Info about potential side effects

## More about capacity

---

Capacity is decision-specific

---

Limited capacity is more common than global incapacity

---

A patient with dementia may be able to make some decisions, but not others

---

Incapacity not always permanent (ie delirium)

## More about decision-making capacity

- More stringent assessment when consequences more serious or irreversible
  - i.e. – Amputation or withdrawal of life-sustaining treatment

## Capacity in Patients Approaching the End of Life

- Study of 145 hospitalized people with advanced cancer
- 115 (79%) had decision-making capacity on admission
- 46 (40%) lost capacity prior to end of life discussions

Zaros, J Hospital Medicine, 2013

## More about decision-making capacity

- Refusing something in one's best interests  $\neq$  lack of capacity
- Lack of capacity not correlated w/ cognitive test score
- Documentation important

## Summary: Debunking some decision-making myths

- People w/cognitive impairment or mental illness aren't automatically incapacitated
- Capacity isn't an "all or nothing" phenomenon – decision specific
- Lack of capacity isn't always permanent (ie delirium)
- Refusing a recommended treatment doesn't mean incapacity

Adapted from Ganzini, 10 myths DMC, J Am Dir Assoc, 2004



Trac Vu @unsplash.com

## Another case

Mr. R. is a previously healthy, 90 yo man with no family, who had been living independently.

He is hit by a car and sustains a humeral fracture. He refuses an operation to fix it. Each day he waits, the arm will be harder to fix (and will decrease the possibility of his being able to continue to live independently).



He can explain that he has a broken arm, and that the surgery would repair it. He can repeat the risks and benefits of surgery.

## Determining decisional capacity

---

The four decision-making abilities:

---

Understanding

---

Appreciating

---

Reasoning

---

Choosing

## Another case

Mr. R. is a previously healthy, 90 yo man with no family, who had been living independently.

He is hit by a car and sustains a humeral fracture. He refuses an operation to fix it. Each day he waits, the arm will be harder to fix (and will decrease the possibility of his being able to continue to live independently).

He can explain that he has a broken arm, and that the surgery would repair it. He can repeat the risks and benefits of surgery.

Understanding  
Appreciating  
Reasoning  
Choosing



## Mr. R cont'd

Further questions reveal that he is scared of the surgeons and thinks they are only offering the surgery because they want to make money.

He is found to be paranoid and possibly psychotic.



Do you need all 4 decision-making abilities?

&  
How much of each decision-making ability do you need?

- Depends on the seriousness/irreversibility of the decision

Mr. R cont'd

Further questions reveal that he is scared of the surgeons and thinks they are only offering the surgery because they want to make money.

He is found to be paranoid and possibly psychotic.

**Now what?**





## Legal Hierarchy of Surrogates

### VA System (1004.01)

- DPOA
- Court appointed guardian
- Spouse
- Adult child
- Parent
- Adult sibling
- Grandparent
- Adult grandchild
- Close friend  
(someone who shows care/concern and is familiar w/ pt activities)

### WA State (RCW 7.70.065)


- Court appointed guardian
- DPOA
- Spouse
- Adult children
- Parents
- Adult siblings
- Adult grandchildren
- Adult nieces/nephews
- Adult aunts/uncles
- Involved other

## State Specific Legal Hierarchies of Surrogates

- American Bar Association, Elder Law Section
- [https://www.americanbar.org/content/dam/aba/administrative/law\\_aging/2019-sept-default-surrogate-consent-statutes.pdf](https://www.americanbar.org/content/dam/aba/administrative/law_aging/2019-sept-default-surrogate-consent-statutes.pdf)



Kusama



V.Soaes – unsplash.com

### Case - Mrs. C

- 82 yo woman with mild dementia who lives in an assisted living facility
- Brought to clinic by a caregiver for routine follow up
- Has had 3 admissions for CHF in the past 5 months
  - Required restraints due to delirium with agitation
- Renal function is worsening



## Mrs. C cont'd

- You are worried about her renal function and think decisions will need to be made soon about whether she would want dialysis or not
- You talk to her about her kidney function - she responds that she is urinating and her kidneys don't "hurt"
- She says her kidneys are "fine" and people need to stop making "such a fuss"



- Clinician's perspective
  - Mrs. C's kidneys worsening
  - Would she want dialysis in the future?
- Mrs. C's perspective
  - Kidneys are fine
  - People are making a fuss
- Clinician – Is she able to make a decision about dialysis?

## Steps in determining capacity

1) Find out what the patient already knows  
(Don't assume patient knows pertinent medical information)

- *Tell me about...*
  - *your condition*
  - *what's been going on*
  - *why you are in clinic today*
- Pay attention to her cognitive status

## Steps in determining capacity

2) Does the patient want to make her own decisions?

## Steps in determining capacity

Assess the patient's

### 3) **Understanding** of diagnosis or treatment options

Don't assume she's already been told everything

*I am worried about how your kidneys are working.*

*When kidneys aren't working, there are different things we can do. Some people want dialysis, which involves.....Some people don't want dialysis...*

## Steps in determining capacity

Assess the patient's

### 3) **Understanding** of diagnosis or treatment options

- Ask her to repeat back in her own words – noting if she mentions
  - her kidneys not working
  - ways to approach kidneys that aren't working
  - the risks/benefits/alternatives to dialysis

## Steps in determining capacity

Assess the patient's

- 4) **Appreciation** of how the treatment options apply to her own situation
  - *What will happen if you have dialysis?*
  - *What will happen if you don't have dialysis?*

## Steps in determining capacity

- 5) **Reasoning** behind the choice
  - Is the choice consistent with patient's values
  - *Why is that treatment the best choice for you?*
- 6) Make a **choice** and maintain it over time
  - *What is the best treatment for you?*

## Another approach

(Courtesy of Dr. Mark Siegler U Chicago)

What's your main medical problem right now?

What treatment has been recommended?

If you receive this treatment, what will happen?

If you don't receive this treatment, what will happen?

Why have you decided to/not to receive this treatment?

## Instruments

- ACE – Aid to Capacity Evaluation
  - Psychometric properties praised in JAMA study, but only referenced in 1 paper
  - 8 questions
  - Quick (10 mins) and clinically relevant
- MacArthur Competency Assessment Test
  - Psychometrics from 7 prior studies
  - Takes 30+ minutes to
  - Research focus
  - Need to purchase

## Aid to Capacity Evaluation (ACE)

1. Able to understand medical problem
2. Able to understand proposed treatment
3. Able to understand alternative(s) to proposed treatment
4. Able to understand option of refusing
5. Able to understand consequences of accepting and refusing treatment



## Mrs. C cont'd

- She can't make a decision about dialysis
  - Can't repeat back what you've said
  - Doesn't believe her kidneys aren't working
- Now what?



## Legal Hierarchy of Surrogates

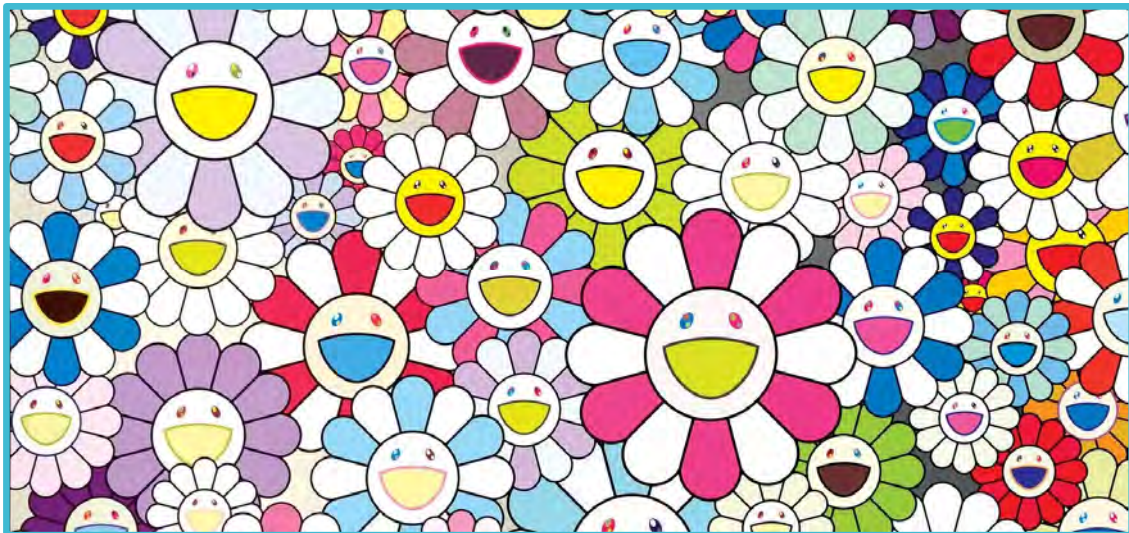
### VA System (1004.01)

- DPOA
- Court appointed guardian
- Spouse
- Adult child
- Parent
- Adult sibling
- Grandparent
- Adult grandchild
- Close friend

(someone who shows care/concern and is familiar w/ pt activities)

### WA State (RCW 7.70.065)

- Court appointed guardian
- DPOA
- Spouse
- Adult children
- Parents
- Adult siblings
- Adult grandchildren
- Adult nieces/nephews
- Adult aunts/uncles
- Involved other



T. Murakami

## What happens when a patient can't make their own decisions?

- Try to find a legal surrogate
- If can't find anyone
  - Follow state and/or organizational policies for making some decisions
  - Apply to the courts for guardianship OR consider supported decision-making
- Ideally, the patient should still **assent** to the treatment

## Some state hierarchies address issue of no surrogates

### Idaho

- In a medical emergency, attending physician or dentist may authorize and/or provide such care, treatment or procedure as he or she deems appropriate...

### Montana

- Another physician or APN designated by the attending health care provider if conditions are met, including certification of lack of decisional capacity and medical ethics committee approval of designation. §50-5-1304

### Oregon

- Att. Physician or attending health care provider, including naturopathic physicians, following prescribed requirements. (§§127.635 and 127.760)

## Supported Decision-making

Developed to promote independence in people with disabilities when they turned 18 to avoid guardianship



Picasso

## Supported Decision-making

- Alternative to guardianship
- Promotes an individual's autonomy and independence
- Protects individual rights

## Supported Decision-making

- Written document
  - Names of supporter(s) and relationship
  - Areas the person wants help with decision-making
  - How the supporter(s) will help

More info – [WashingtonLawHelp.org](http://WashingtonLawHelp.org)

## Supported Decision-making

### Example

My supporter may help me with making everyday life decisions relating to the following:

(Y/N) Obtaining food, clothing, and shelter.

(Y/N) Taking care of my health.

(Y/N) Managing my financial affairs.

(Y/N) Other matters: (*specify*)

My supporter is not allowed to make decisions for me.

To help me with my decisions, my supporter may:

1. Help me access, collect, or obtain information that is relevant to a decision, including medical, psychological, financial, educational, or treatment records;
2. Help me understand my options so I can make an informed decision; and
3. Help me communicate my decision to appropriate persons.

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

Alaska	Colorado	Delaware	Illinois
Indiana	Louisiana	Nevada	New Hampshire
New York	North Dakota	Rhode Island	Texas
Virginia	Washington	Washington, DC	Wisconsin

Supported Decision-Making  
Legal in....

Summary

- Defined 4 types of capacity
  - Financial, testamentary, dispositional, for medical decisions
- Debunked decision-making myths
- Described 4 decision-making abilities
  - Understanding, Appreciating, Reasoning, Choosing
- Discussed assessment of decisional capacity
- Reviewed options when a patient lacks capacity

Questions?



J. Rumimpunu at [unsplash.com](https://unsplash.com)