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Decision Making Capacity

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 Mayo Clinic | Geriatric Medicine | October 2019

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Case

An 82 year old female who is wheelchair dependent due to multiple sclerosis with a history of moderate dementia, diabetes mellitus and chronic kidney disease is evaluated at a skilled nursing facility for fatigue. Lab results demonstrate hyperkalemia in the setting of progressively worsening renal function. As the astute clinician on duty, you discuss the possibility of hemodialysis however she adamantly refuses. During your evaluation, you observe that she is only oriented to person and place. She thinks that George Bush is the current president. How do you proceed?

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Defining Capacity

- "Determination of an individual patient's ability to adequately make a specific decision."¹
- It is determined by the **process** of the patient's decision making instead of the final decision.²
- It is **dynamic**, and can be influenced by situational, psychological, medical, and neurological factors.²



1. Dauby BR, Dickerson BC. Dementia, decision making, and capacity. *Ann Rev Psychiatry*. 2017;29(6):279-279.
 2. Schein LL, Zaslavsky H, Jackson JC. Does the patient have medical decision-making capacity? *JAMA*. 2013;309(4):420-427. doi:10.1001/jama.2011.1027.1046

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Defining Competence

"Legal determination of whether an impaired mental capacity limits a patient's ability to make a legally relevant decision or action"¹

1. Dauby BR, Dickerson BC. Dementia, decision making, and capacity. *Ann Rev Psychiatry*. 2017;29(6):279-279. https://www.ncbi.nlm.nih.gov/pubmed/29171022. https://www.ncbi.nlm.nih.gov/pubmed/29171022. doi:10.1093/abp/kax001

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Why is it important?

- Capacity is **required** for informed consent
- Preserves **autonomy**
- Decision making capacity cannot be assumed.
- Many clinicians regularly **fail** to recognize lack of capacity.
 - Physicians predicted **lack of capacity in 42%** of patients who actually lacked capacity
 - Usually missed diagnosis, but they were correct when they made the diagnosis

Proceeding with intervention which patient does **not** want is assault.

Jones RL, Moller T. A guide to assessing decision-making capacity. *Clin Geriatr J Am Geriatr Soc*. 2014;62(12):1711-1715. doi:10.1111/cgs.12217. [doi]

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Who can determine capacity?

- **Any licensed clinician**

However, many clinicians lack formal training in evaluating capacity

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Capacity in Older Adults

- Normal cognitive aging, sensory impairment, mood disorders, social isolation place older adults at risk of impaired capacity.¹
- Impaired cognition is associated with loss of capacity to consent, seen in patients with Alzheimer's disease and MCI²
- It may be impaired for a **temporary time** (eg, critical illness)
- It may be intact for **some decisions** and not for others



1. Mory J, Marston DP, Callahan B. Assessment of capacity in an aging society. *Am J Psychol*. 2013;169(1):136-171. <https://www.ncbi.nlm.nih.gov/pubmed/23366475>.
2. Scarmeas GN, Grano T. The clinical presentation of dementia. In: *Handbook of clinical gerontology*. 4th ed. Boston: Springer; 2010:205-220.

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Prevalence of Incapacity

Table 1. Prevalence of Incapacity in Select Populations

Disease or Patient Care Setting	No. of Studies	No. of Patients	Patients With Incapacity		
			No.	% (95% CI)	Standard Deviation
Healthy elderly controls	16	1017	51	2.6 (1.7-3.9)	0.005
Mild cognitive impairment	1	147	29	20 (14-29)	0.03
Glioma patients	1	26	6	23 (6.9-59)	0.08
Medicine inpatients	8	816	212	26 (18-35)	0.11
Parkinson disease	4	148	62	42 (23-60)	0.13
Nursing home	5	346	152	44 (29-63)	0.08
Alzheimer disease	10	1425	770	54 (28-78)	0.13
Learning disabled	4	208	141	68 (41-97)	0.14

Abbreviation: CI, confidence interval.

Scarmeas GN, Zelinski E, Jackson JL. Does the patient have medical decision-making capacity? *JAMA*. 2011;306(6):629-637. doi: 10.1001/jama.2011.1021 [doi].

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Criteria for Consent to Medical Treatment^{1,2}

1. Patients must be given **adequate information** regarding nature and purpose of treatment, risks, benefits, and alternatives (including no treatment)
2. Patient must be **free of coercion**
3. Have **medical decision-making capacity**

1. Scarmeas GN, Zelinski E, Jackson JL. Does the patient have medical decision-making capacity? *JAMA*. 2011;306(6):629-637. doi: 10.1001/jama.2011.1021 [doi].
2. Scarmeas GN, Zelinski E. The clinical presentation of dementia. In: *Handbook of clinical gerontology*. 4th ed. Boston: Springer; 2010:205-220.

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Criteria for Medical decision-making Capacity^{1,2}

1. Patients must **understand the relevant information** about proposed diagnostic tests or treatment
2. Must **appreciate their situation** (including their underlying values and current medical situation)
3. Use reason to make a decision
4. Communicate their choice

1. Scarmeas GN, Zelinski E, Jackson JL. Does the patient have medical decision-making capacity? *JAMA*. 2011;306(6):629-637. doi: 10.1001/jama.2011.1021 [doi].
2. Scarmeas GN, Zelinski E. The clinical presentation of dementia. In: *Handbook of clinical gerontology*. 4th ed. Boston: Springer; 2010:205-220.

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Assessing Capacity

1. Does the H&P confirm that the patient can **communicate a choice**?

if NO → surrogate decision maker or seek guardianship

Scarmeas GN, Zelinski E. A guide to assessing decision-making capacity. *Care Clin J Med*. 2004;7(12):975-978. doi: 10.1097/cor.7b.12.975 [doi].

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Assessing Capacity

2. After presenting information, does the patient **understand** the key elements?
 - What is your medical illness?
 - What is the treatment being recommended?
 - What happens if you **accept** the treatment?
 - What happens if you **refuse** the treatment?
 - What are the alternatives?

if NO → surrogate decision maker or seek guardianship

Tip: Ask patient to rephrase information

Scarmeas GN, Zelinski E. A guide to assessing decision-making capacity. *Care Clin J Med*. 2004;7(12):975-978. doi: 10.1097/cor.7b.12.975 [doi].

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Assessing Capacity

3. Can the patient **appreciate** how the information **applies to them**?

- Can the patient assign **personal values** to the situation?
- Does the patient recognize **benefit** of intervention to them?
- Can the patient recognize **harms** of intervention to them?

if NO → surrogate decision maker or seek guardianship

Jones RC, Hollon T. A guide to assessing decision-making capacity. Clin Geriatr J Med. 2004;7(12):971-975. doi: 10.3949/cgr.7.12.971 [doi]

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Assessing Capacity

4. Can the patient **reason** through information **rationally** and **logically**?

- Can the patient **compare** different interventions rationally?
- Can the patient recognize the **consequences** of a decision?

if NO → surrogate decision maker or seek guardianship

Jones RC, Hollon T. A guide to assessing decision-making capacity. Clin Geriatr J Med. 2004;7(12):971-975. doi: 10.3949/cgr.7.12.971 [doi]

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Assessing Capacity

5. Is the patient's decision making capacity stable over time?

if NO → surrogate decision maker or seek guardianship

Jones RC, Hollon T. A guide to assessing decision-making capacity. Clin Geriatr J Med. 2004;7(12):971-975. doi: 10.3949/cgr.7.12.971 [doi]

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Capacity Assessment Tools

- May assist in determining capacity for informed consent
- Better **inter-rater reliability**
- Assess patient's ability to reason through a hypothetical medical decision making vignette¹
 - For example, patient is given a scenario with many medical treatment options and should use the information to choose a treatment

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Capacity Assessment Tools

Perform in office setting with moderate to strong level of evidence

<p>Aid to Capacity Evaluation (Stohler et al.)¹</p> <ul style="list-style-type: none"> • It uses patient's own medical situation and diagnosis or treatment decision • Consists of 8 questions, assess understanding of problem, treatment, alternatives, consequences of decision 	<p>Hopkins Competency Assessment Test (Jansofsky et al.)²</p> <ul style="list-style-type: none"> • Patient reads short essay that explains nature of informed consent, right to decision making, how certain decisions can impair decision making abilities, right to advanced directive • 6 questions: 4 open ended, 1 true or false, 1 sentence completion (less than 5/10 points suggests incapacity) 	<p>Understanding Treatment Disclosure (Fuchs et al.)³</p> <ul style="list-style-type: none"> • Patient given scenario (oral/written) medical condition & treatment options, asked 10 questions to assess understanding • Scenario presented again in parts, each part is presented separately, and patient is tested on four statements—asked to identify the two matching statements
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1. Stohler E, Shetter P, Binkoff M, et al. Assessment of patient capacity to consent to treatment. J Gen Intern Med. 1993;8(4):27-34.
2. Jansofsky J, McGee B, Folstein MF. The Hopkins competency assessment test: A brief method for evaluating patients' capacity to give informed consent. J Geriatr Psychiatry Neurol. 1994;7(2):130-136.
3. Fuchs L, Scahill M, McNeil J, et al. The understanding of treatment disclosure test: A brief method for assessing patients' capacity to give informed consent. J Gen Intern Med. 1994;9(4):243-247.

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Pseudo-incapacity¹

- When information provided in a way patient cannot understand (e.g. medical jargon)
- Poor therapeutic relationship
- Language barrier
- Health literacy
- Educational barrier
- Psychiatric illness
- Undiagnosed depression
- Cultural differences



1. Swanson LJ, Zaslavsky JL, Johnson J. Does the patient have medical decision-making capacity? J Gen Intern Med. 2011;26(10):459-467. doi: 10.1093/gim.2011.26.1027 [doi]

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Patient lacks capacity, now what?

- Can decision making capacity be **optimized**?
 - Treat reversible conditions e.g. delirium, medication effect
 - Shorten and simplify information
 - Use alternative modes of communication
 - Photographs, drawings
- Can it be **re-assessed** at a later date?
- Surrogate** decision-maker



Sources: Li, Zemborska H, Jackson JE. Does the patient have medical decision-making capacity? JAMA. 2011;306(6):420-427. doi: 10.1001/jama.2011.1023 [doi].

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Capacity in Nursing Home Patients

- Patients in nursing homes are often cognitively impaired and therefore lack decision making capacity
- Clinicians depend on previous advanced directives or designated decision makers (surrogates)
- Formal Surrogates** may be **court-appointed** or designated in **advanced directives**
- Informal surrogates** – based on hierarchy in state law
 - 1st Spouse 2nd Children 3rd Parent 4th Sibling

White Paper on Surrogate Decision Making and Advance Care Planning in Long-Term Care. H <https://pubs.org/andw/white-papers-and-resolution-positive-instances/white-paper-surrogate-decision-making.pdf>

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Capacity in Nursing Home Patients

- Patients in nursing homes have often lost independence (loss of control over daily schedules, ability to perform ADLs)
- Decisions that they still can make may be all that they have control over
- Encourage them to make decisions
 - Simple decisions that do not put their health at risk
 - Balance risk in poor decision against loss of autonomy
 - E.g. what to wear, what to eat.

White Paper on Surrogate Decision Making and Advance Care Planning in Long-Term Care. H <https://pubs.org/andw/white-papers-and-resolution-positive-instances/white-paper-surrogate-decision-making.pdf>

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Surrogate Decision-Maker

- Early identification of surrogate decision maker is recommended in patients at risk of lacking capacity

Sources: Li, Zemborska H, Jackson JE. Does the patient have medical decision-making capacity? JAMA. 2011;306(6):420-427. doi: 10.1001/jama.2011.1023 [doi].

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Take home points:

- Capacity assessment is important to preserve **autonomy**.
- Capacity assessment is especially important in **older adults**.
- It can be assessed by any clinician
- Capacity is dynamic**.
- Follow algorithm to assess capacity or use available tools
- Identify surrogate decision maker early

Decision making capacity:

- Understand
- Appreciate situation
- Reason
- Communicate decision

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