Better Decision Making for Incapacitated Patients without Surrogates

North Dakota Long Term Care Association
September 21, 2016

Thaddeus Mason Pope, JD, PhD
Mitchell Hamline School of Law

Disclosures

Nothing to disclose

Just **travel expenses** to develop new ATS-AGS Policy Statement on this

Objectives

3:00 – 5:00 pm

ETHICS SESSION

35. Better Decision Making for Incapacitated Patients without Surrogates

Speaker: Thaddeus Mason Pope, Mitchell Hamline School of Law
Content: Roughly 1 in 20 long term care residents lacks capacity and has no available legally authorized decision maker. How can and should LTC facilities and clinicians make treatment decisions for these individuals? This presentation first provides an overview of decision making capacity, surrogate decision making. It then evaluates the mechanisms for medical decision making when neither the patient nor any legally authorized substitute decision maker is available. *Recommended Audience: AI, BC, NF: Administrators, Nursing, Social Workers*

Decision making **capacity**

Surrogate decision making

Mechanisms for medical decision making when neither the patient nor any legally authorized substitute decision maker is available

The challenges of incapacitated patients without surrogates is caused & exacerbated by **the law**

But this is the NDLTCA "**ethics session**"

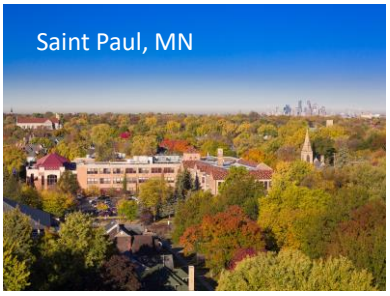
So, while the question of **who** is an authorized decision maker is largely framed by the law, this is **not** a legal presentation

In any case I am **not** licensed in ND

State Bar Association of North Dakota

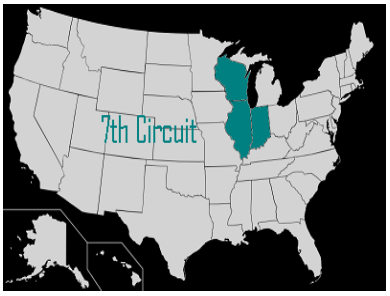
Who is the speaker?

Director, Health Law Institute
Mitchell Hamline School of Law



2012 - present

Before that:



I am a **law** professor.

But I often speak and write directly to **clinicians**

The NEW ENGLAND JOURNAL of MEDICINE

JAMA® The Journal of the American Medical Association

ATS

AMERICAN COLLEGE OF CHEST PHYSICIANS

Roadmap

3:00 PM
to
5:00 PM

7

Foundational background

1. Informed consent
2. Capacity
3. Substitute decision making

Identifying the problem

4. Who are "unbefriended"
5. Prevalence and causes

Risks & solutions

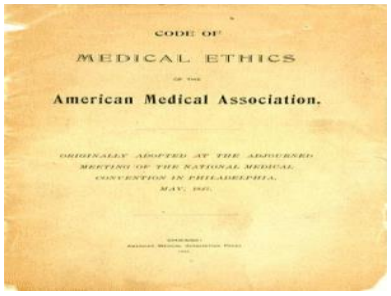
6. Risks & ethical challenges
7. Solutions

Unit 1 of 7

Informed Consent

History

1847


CODE OF
MEDICAL ETHICS
OF THE
American Medical Association.

ORIGINALLY ADOPTED AT THE ADJOURNED MEETING OF THE NATIONAL MEDICAL CONVENTION IN PHILADELPHIA, MAY, 1847.

Do **NOT** consider patient's "own crude opinions"

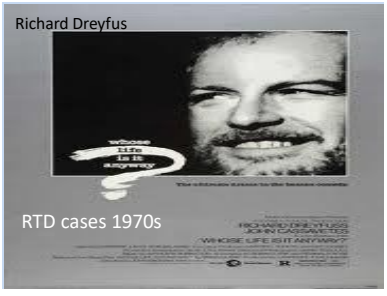
1905

Battery

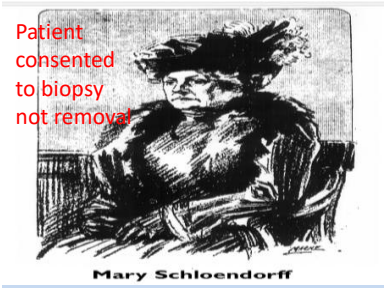
No consent **at all**

4 variations

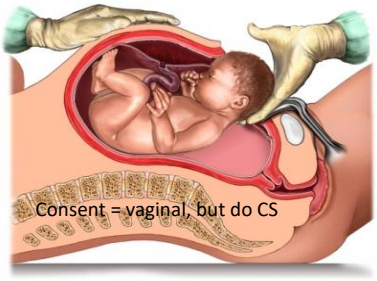
(1) No consent to **any** procedure



(2) Consent only to **different** procedure



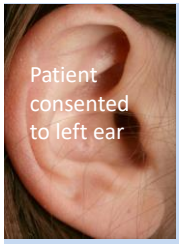
"Every human being of adult years and sound mind has a right to determine what shall be done with his own body . . . . "

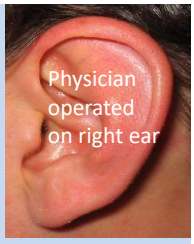


Seaton v. Patterson

(Ky. App. 2012)

(3) Same procedure, **different body part**





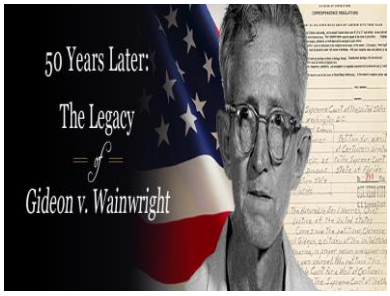
Mohr v. Williams (Minn. 1905)

(4) Same procedure, same part, **different doc**

As of **100 years ago**, law required physicians to get consent

It did not yet require that the consent had to be **informed**

1960s



1972

That was just a **historical** sketch,

Now, let's look at this **doctrinally**

Comparing battery & informed consent

Battery

PTF: "I did **not** consent to what doc did"

Informed consent

PTF: "I **did** consent . . . "

"**BUT** I would not have consented, **if** disclosure had been appropriate [non-negligent]"

Duty

Core complaint:

Physician failed to disclose information

But legally actionable only if physician had a **duty** to disclose that information

Inherent risks from proposed treatment

Probability

Severity

Benefits & risks of each **alternative**

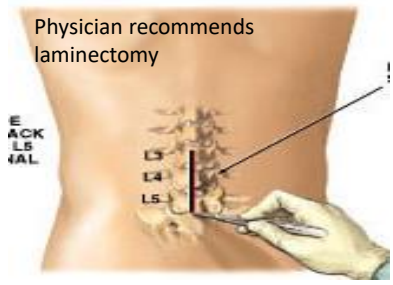
One alternative is doing nothing

ND reasonable patient standard

Duty measured by **patient** needs

Duty to disclose what would a **reasonable patient** consider important / significant in making this treatment decision

Canterbury v. Spence



1% risk paralysis

Reasonable prudent patient would want to know that risk

Therefore, physician has duty to disclose it

Duty measured by what **hypothetical reasonable patient** would deem material, significant in making this treatment decision

Unit 2 of 7

Capacity

Distinguish 2 related terms

Competence

Legal determination (by a court)

Global (all decisions)

Capacity

Clinical determination

Decision specific (**not** global)

What is capacity

Ability to **understand** the significant benefits, risks and alternatives to proposed health care

Ability to **make and communicate** a decision.

CHAPTER 23-06.5
HEALTH CARE DIRECTIVES

23-06.5-02. Definitions.

3. "Capacity to make health care decisions" means the ability to understand and appreciate the nature and consequences of a health care decision, including the significant benefits and harms of and reasonable alternatives to any proposed health care, and the ability to communicate a health care decision.

Decision specific

Fluctuates over time

Patient might have capacity to make **some** decisions but not others

Patient might have capacity to make decisions in **morning** but not afternoon

Capacity is a **clinical** decision

With legal consequences

3 case examples

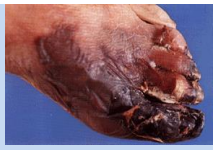
Lane v. Candura

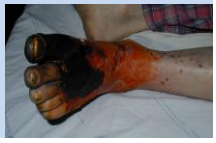
(Mass. 1978)

77yo Rosaria Candura

Gangrenous right foot and leg

Refuse consent for amputation





Doc thinks stupid decision

But she **understands** the diagnosis & consequences

So, she **has** capacity

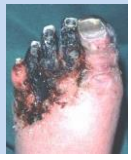
DHS v. Northern

(Tenn. 1978)

Mary Northern 72yo

Gangrene both feet

Amputation required to save life



Does **not** appreciate her condition

"Believes that her feet are black because of soot or dirt."

In re Maynes-Turner

(Fla. App. 1999)

Doc: "She might pose significant risks for herself on the basis of those decisions that she would make." So no discharge home.

Doc: "Cognitively she does reasonably well. She would seem to possess the necessary knowledge that would be required for restoration."

Significance of capacity

If patient's decision is not impaired by cognitive or volitional defect, providers **must respect** decision

Otherwise, not honoring choice = **paternalism**, violation of patient autonomy

All patients are **presumed** to have capacity

Until the presumption is rebutted

Example:

presumption of capacity

Patient has capacity to make the decision at hand

Patient decides **herself**

BUT patients often lack capacity

1. Had but **lost** (dementia…)
2. Not **yet** acquired (minors)
3. **Never** had capacity (mental disability)

Let's focus on the most common one for ND LTC

Adults who had but **lost** capacity

Unit 3 of 7

If patient **cannot** make her own decisions, she needs a **SDM**

3 main types SDM

1st choice – patient picks **herself**

Usually in an advance directive

"Agent"

"DPAHC"

Patient knows who
(1) They trust
(2) Knows their preferences
(3) Cares about her

2nd choice –
if no agent, turn to **default priority** list

"Surrogate"

"Proxy"

Most states specify a sequence

Agent
Spouse
Adult child
Adult sibling
Parent . . . . .

ND list is **longer** than most

9 categories deep

23-12-13. Persons authorized to provide informed consent to health care for incapacitated persons - Priority.

1. Informed consent for health care for a minor patient or a patient who is determined by a physician to be an incapacitated person, as defined in subsection 2 of section 30.1-26-01, and unable to consent may be obtained from a person authorized to consent on behalf of the patient. Persons in the following classes and in the following order of priority may provide informed consent to health care on behalf of the patient:
   a. The individual, if any, to whom the patient has given a durable power of attorney that encompasses the authority to make health care decisions, unless a court of competent jurisdiction specifically authorizes a guardian to make medical decisions for the incapacitated person;
   b. The appointed guardian or custodian of the patient, if any;
   c. The patient's spouse who has maintained significant contacts with the incapacitated person;
   d. Children of the patient who are at least eighteen years of age and who have maintained significant contacts with the incapacitated person;
   e. Parents of the patient, including a stepparent who has maintained significant contacts with the incapacitated person;
   f. Adult brothers and sisters of the patient who have maintained significant contacts with the incapacitated person;
   g. Grandparents of the patient who have maintained significant contacts with the incapacitated person;
   h. Grandchildren of the patient who are at least eighteen years of age and who have maintained significant contacts with the incapacitated person; or
   i. A close relative or friend of the patient who is at least eighteen years of age and who has maintained significant contacts with the incapacitated person.

3rd choice –
ask **court** to appoint SDM (rare)

"Guardian"

"Conservator"

SDM summary

Who appoints	Type of surrogate
Patient	Agent DPAHC
Legislature	Surrogate Proxy
Court	Guardian Conservator

How does the SDM decide?

Any type of SDM can usually make **any** decision patient could have made

Hierarchy

1. Subjective
2. Substituted judgment
3. Best interests

Subjective

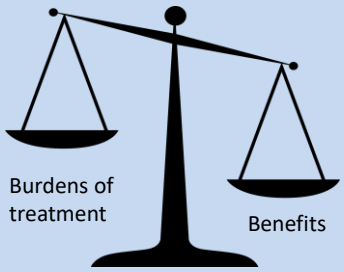
If patient left **instructions** addressing situation, follow those instructions

Substituted Judgment

Do what patient **would have** decide (if she could) using known values, preferences

Best interests

If cannot exercise substituted judgment, then objective standard



Unit 4 of 7

Who are unrepresented incapacitated patients?

Terminology

149

Unbefriended

Unrepresented

Adult orphan

150

Patient w/o proxy

Incapacitated & alone

151

Definition

152

3 conditions

153

1

Lack capacity

2

No available, applicable AD or POLST

3

No reasonably available authorized surrogate

Nobody to consent to treatment

Step by step flowchart

1

Does the patient have **capacity**?

If yes, then **patient** makes treatment decision.

If no, can patient decide with **"support"**?

If yes, then **patient** makes treatment decision.

If no, proceed

2

Is there an available AD or POLST

Does the AD or POLST clearly **apply** here

If yes, follow AD or POLST (but involve surrogate)

If no, proceed

3

If patient lacks capacity, a **SDM** must make the treatment decision.

Is there a court-appointed guardian?

If so, is the guardian reasonably available?

If no guardian . . .

Is there a healthcare agent (DPOAHC)?

If so, is the agent reasonably available?

If no agent . . .

Is there anyone on the default surrogate priority list?

If so, is the surrogate reasonably available?

Have social workers diligently searched for surrogates

If yes, then →

Nobody to consent to treatment

4

Is the situation an emergency

If yes →

Is there any reason to believe the patient would object

If no, proceed on basis of **implied** consent

5

Is there an functioning guardianship system?

Usually

Not

If so, seek a court appointed guardian

Even if a guardian is forthcoming, may need to make decisions in the **interim**

How often are **you** seeing this?

Unit 5 of 7

Prevalence & causes

Big problem

16% ICU admits

Decisions to limit life-sustaining treatment for critically ill patients who lack both decision-making capacity and surrogate decision-makers*

Douglas B. White, MD; J. Randall Curtis, MD, MPH; Bernard Lo, MD; John M. Luce, MD

5% ICU deaths

ARTICLE | Annals of Internal Medicine

Life Support for Patients without a Surrogate Decision Maker: Who Decides?

> 25,000

Incapacitated and Alone:
Health Care Decision-Making for the Unbefriended Elderly

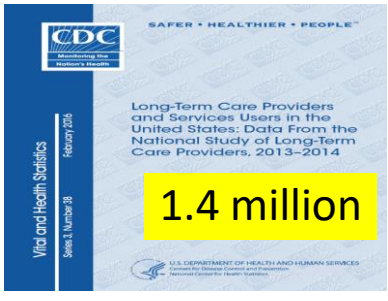
Naomi Karp and Erica Wood

American Bar Association
Commission on Law and Aging

July 2003

3 - 4%

U.S. nursing home population



> 56,000

in USA

> 500

(extrapolated)

GUARDIANSHIP FOR VULNERABLE ADULTS IN NORTH DAKOTA: RECOMMENDATIONS REGARDING UNMET NEEDS, STATUTORY EFFICACY, AND COST EFFECTIVENESS

300 to 700

WINSOR C. SCHMIDT*

Trust Fund is gratefully acknowledged. This Article is based on a Final Report submitted to the Human Services Committee, North Dakota Legislature: Winsor Schmidt, Study of Guardianship Services for Vulnerable Adults in North Dakota (May 30, 2012).

Royal College of Physicians | Marie Curie

Care and support through terminal illness

End of Life Care Audit – Dying in Hospital

National report for England 2016

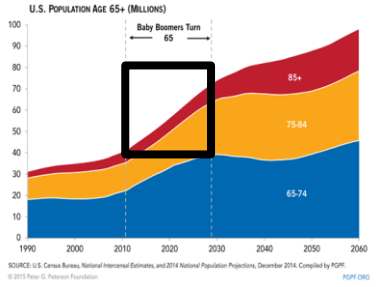
Table 14

	National audit (n=9302)	
3.4. Is there documented evidence that the cardiopulmonary resuscitation (CPR) decision by a senior doctor was discussed with the **nominated person(s) important to the patient** during the last episode of care?		
• YES	78%*	7219
• NO	18%	1706
• NO BUT	4%	377
If 'no but' during the last episode of care it was recorded that:		
• There was no nominated person important to the patient	47%	177
• Attempts were made to contact the nominated person important to the patient but were unsuccessful	53%	200

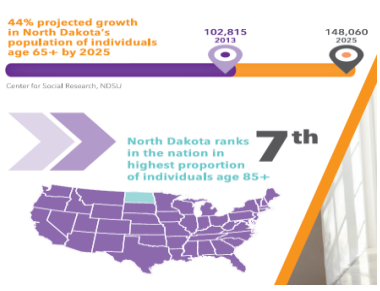
*81% if the 'NO BUTs' are excluded from the denominator

Growing problem

1



North Dakota has one of the **highest** percentages of older people



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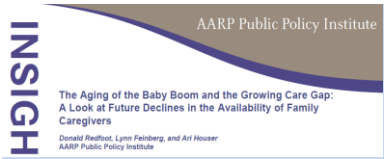
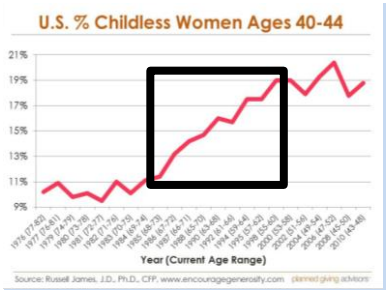


10,000,000
Boomers live **alone**

3



Key Findings

- The biggest fear (92 respondents) was having no one to speak up for them or act in their best interests when they could no longer do so for themselves

Ageing without Children survey results 2015

4

Others "have" family members

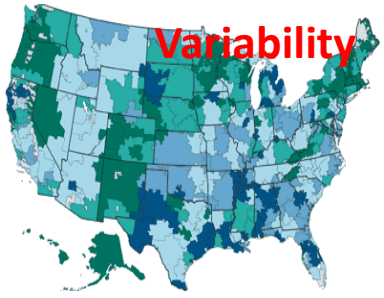
No contact (e.g. LGBT, homeless, criminal)

Also lack capacity

Unwilling

5

Law as causal factor



Variability from state to state

Some states will have **fewer** unrepresented patients

Some states will have **zero** unrepresented patients

Why?

Longer default surrogate lists

More relatives

Spouse
Adult child
Parent
Adult sibling
Grandparent / adult grandchild
Aunt /uncle, niece / nephew
Adult cousin

Close friend

Social worker
Ethics committee

Existence of public guardian system

Slow
Expensive

Unit 6 of 7

Ethical Problems

Nobody to authorize treatment

3 ways to respond

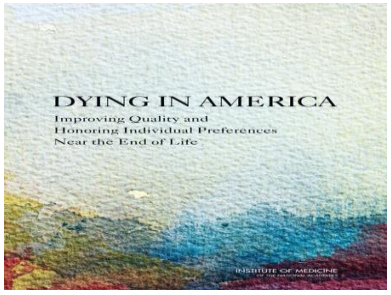
1

No treatment

Wait until emergency (implied consent)

Longer period suffering

Increases risks



Ethically "**troublesome** . . . waiting until the patient's medical condition worsens into an **emergency** so that consent to treat is implied . . ."

"compromises patient care and prevents any thorough and thoughtful consideration of patient preferences or best interests"

Under-treatment

2

Over-treatment

Physician acts **without** consent

Most common approach

Fear of liability

Fear of regulatory sanctions

Bias

COI

Careless

GUARDIANSHIP FOR VULNERABLE ADULTS IN NORTH DAKOTA: RECOMMENDATIONS REGARDING UNMET NEEDS, STATUTORY EFFICACY, AND COST EFFECTIVENESS

WINSOR C. SCHMIDT*

"unimaginably helpless"

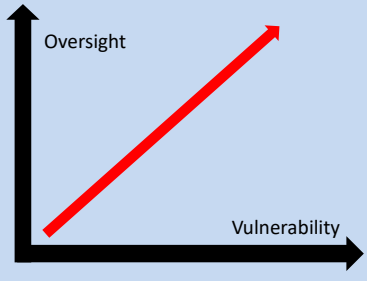
POSITION STATEMENT

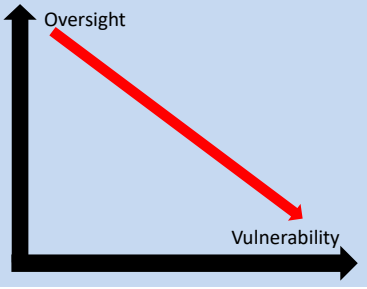
Making Treatment Decisions for Incapacitated Older Adults Without Advance Directives

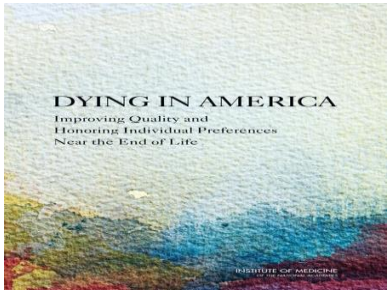
*AGS Ethics Committee**

"highly vulnerable"

"most vulnerable"







"Having a single health professional make unilateral decisions . . . is **ethically unsatisfactory** in terms of protecting patient autonomy and establishing transparency."

Prohibited in ND and some states

23-06.5-04. Restrictions on who can act as agent.

A person may not exercise the authority of agent while serving in one of the following capacities:

1. The principal's health care provider;
2. A nonrelative of the principal who is an employee of the principal's health care provider;
3. The principal's long-term care services provider; or
4. A nonrelative of the principal who is an employee of the principal's long-term care services provider.

30.1-28-11. (5-311) Who may be guardian - Priorities.

1. Any competent person or a designated person from a suitable institution, agency, or nonprofit group home may be appointed guardian of an incapacitated person. No institution, agency, or nonprofit group home providing care and custody of the incapacitated person may be appointed guardian. However, if no one else can be

3

Scrutiny

Vetting

California

IDT

1. Physician
2. Registered professional nurse with responsibility for the resident
3. Other staff in disciplines as determined by resident's needs
4. Where practicable, a patient representative

CANHR
CALIFORNIA ADVOCATES FOR NURSING HOME REFORM

Got struck as unconstitutional – inadequate due process

On appeal (A147987)

Legislation to add more oversight (S.B. 503)

"independent" medical consultant
+
"independent" patient advocate

(CANHR still not sat b/c "paid" by NH)

How do **you** handle this?

Unit 7 of 7

Solutions

In addition to new **laws**

POSITION STATEMENT

Making Treatment Decisions for Incapacitated Older Adults Without Advance Directives

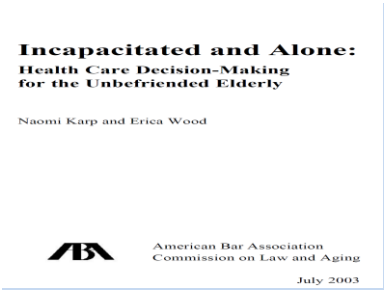
AGS Ethics Committee

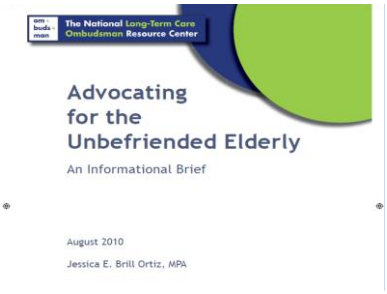
JAGS 44:986-987, 1996

© 1996 by the American Geriatrics Society

BACKGROUND

Geriatric practitioners are often faced with the problem of making treatment decisions for patients who lack decisional capacity. Ideally, the patient's wishes or value systems. In some cases, surviving family members have only remote knowledge of the patient's values, or are estranged, whereas close friends or others





2016

2017

Prevention

1

Advance care planning before lose capacity

2

Diligent search for surrogates

NHs, neighbors, service agencies

Access home, apartment

Personal effects

Health records, pension plans

Surrogates usually found for most **thought** to be unbefriended

POSITION STATEMENT

Making Treatment Decisions for Incapacitated Older Adults Without Advance Directives

AGS Ethics Committee

POSITION 2

It should not be assumed that the absence of traditional surrogates (next-of-kin) means the patient lacks an appropriate surrogate decision-maker. A nontraditional surrogate, such as a close friend, a live-in companion who is not married to the patient, a neighbor, a close member of the clergy, or others who know the patient well, may, in individual cases, be the appropriate surrogate. Health professionals should make a conscientious effort to identify such individuals.

Even if no surrogate found, search may reveal evidence of patient's values, preferences

The standard of decision-making regarding treatment should consider any present indications of benefits and burdens that the patient can convey and should be based on any knowledge of the patient's prior articulations, cultural beliefs if they are known, or an assessment of how a reasonable person within the patient's community would weigh the available options.

3

Assess capacity more carefully

Not all or nothing

Patient may lack capacity for complex decisions

But **have** capacity to appoint a surrogate

POSITION STATEMENT

Making Treatment Decisions for Incapacitated Older Adults Without Advance Directives

AGS Ethics Committee

POSITION 1

Except in cases of obvious and complete incapacity, an attempt should always be made to ascertain the patient's ability to participate in the decision-making process.

If you need a SDM

Mechanisms **short** of guardianship

Too expensive

Too slow

POSITION STATEMENT

Making Treatment Decisions for Incapacitated Older Adults Without Advance Directives

AGS Ethics Committee

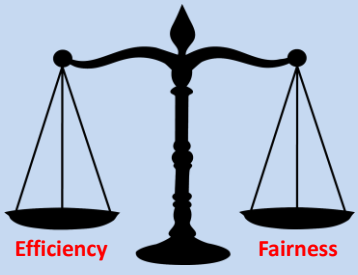
POSITION 3

After a conscientious effort has failed to identify an appropriate surrogate, a group of individuals who care for the patient may determine appropriate treatment goals and design a humane care plan to meet those goals. This group might consist of a multidisciplinary healthcare team, including physician, nurse, nurse's aide, clergy, and others who have worked most closely with the patient. If an institutional

Low - attending
Medium - proxy
High – proxy, 2d op, ethics committee

(a) guardian
(b) spouse
(c) adult child
(d) parent
(e) adult sibling
(f) adult relative
(g) close friend
(h) **clinical social worker** . . . selected by the provider's bioethics committee and must not be employed by the provider

Conclusion



Accessible, quick, convenient, cost-effective

Expertise, neutrality, careful deliberation

References

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