#### Better Healthcare Decision Making for Incapacitated Patients without Surrogates

3rd Annual WINGS Minnesota Guardianship Summit

February 3, 2017

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





## Health law Bioethics Not guardianship



## Increasingly common situation

Minnesota hospitals & LTC challenged

Patient needs treatment

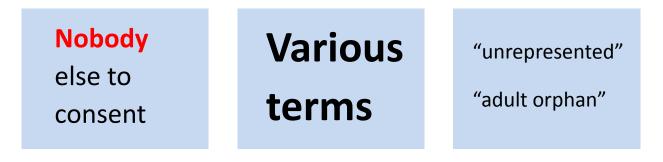
2/2/2017



No capacity

No surrogate

Patient cannot consent







August 2010 Jessica E. Brill Ortiz, MPA



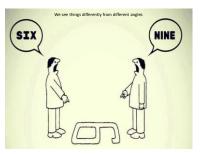
Leading Change. Improving Care for Older Adults.

AGS Position Statement: Making Medical Treatment Decisions for Unbefriended Older Adults

Timothy W. Farrell, MD, AGSF,<sup>12</sup> Eric Widers, MD,<sup>34</sup> Lisa Rosenberg, MD,<sup>5</sup> Casig D, Ruhin, MD, AGSF,<sup>6</sup> Anund D. Naé, MD,<sup>53</sup> Ursela Braun, MD, MPH,<sup>74</sup> Alexin Torke, MD, MS,<sup>7</sup> Inu Li, MD,<sup>10</sup> Caroline Vitale, MD, AGSF,<sup>11,23</sup> Joseph Shega, MD,<sup>134</sup>for the Ethics, Clinical Practice and Models of Care, and Public Policy Committees of the American Geriatrics Society

November 22, 2016

## My Perspective



I am a law professor.

But I often speak and write directly to clinicians





SYSTEM POLICY PROPOSAL: Decision Making for Unrepresented Patients with Impaired Decisional Capacity

> ↓ No

Fairview Lakes Medical Center Fairview Northland Medical Center Fairview Ridges Hospital Fairview Southdale Hospital Maple Grove Hospital Univ. Minnesota Masonic Children's Hospital University of Minnesota Medical Center Fairview Range Medical Center

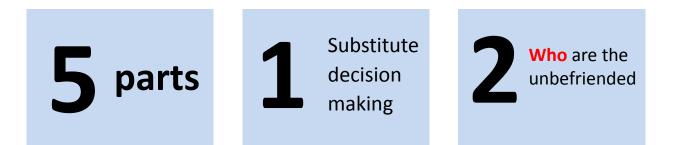


Perspective today – from the clinician

# Who?



## Roadmap



## **Risks** to patient safety

Prevention measures

5 Decision making mechanisms

## Unit 1 of 5

**Substitute** Decision Making

How to make healthcare decisions for patients without capacity



MINNESOTA STATUTES 2016

145C.01

#### CHAPTER 145C

145C.10 PRESUMPTIONS.

#### HEALTH CARE DIRECTIVES

#### 145C.01 DEFINITIONS. 145C.02 HEALTH CARE DIRECTIVE 14SC.11 D.D.M.NITIES.

- 145C.03 REQUIREMENTS. 145C.04 EXECUTED IN ANOTHER STATE. 
   1450.04
   EXECUTED IN ANOTHER STATE
   1450.12
   PROHIBITED PRACTICES.

   1450.05
   SUGGESTED FORM PROVISIONS THAT MAY BE
   1450.13
   PENALTIES.

- 145C.08 AUTHORITY TO REVIEW MEDICAL RECORDS.
- INCLUSED IN THE ANN DE INCLUSE MOLTON DATES NOT CONDONED 1490.06 INSENTIETE INCLUS DOTT TO PROVIDE LIFE-SISTALONDO REALTH CARDY AND DUTIES OF REALTH CARE CARE

145C/9 REVOCATION OF HEALTH CARE DIRECTIVE.

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

2/2/2017

Ability to make and communicate a decision If decision not impaired by cognitive or volitional defect, providers **must respect** decision Not honoring choice = **paternalism**, violation of patient autonomy

All patients are presumed to have capacity

Until the presumption is rebutted

Patient has capacity to make the decision at hand



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 Adults who had but **lost** capacity Mechanisms when patient cannot make her own decisions

Advance directive Agent / DPAHC Default surrogate

## Advance directive

Maybe left prior instructions

Advantage

Patient herself decided (earlier)

# BUT

Not completed Not found Not clear

## **Obstacle 1**

## Not completed

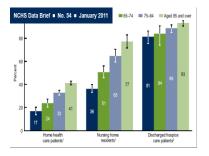


PewResearchCenter \_\_\_\_\_

### Views on End-of-Life Medical Treatments

Growing Minority of Americans Say Doctors Should Do Everything Possible to Keep Patients Alive

18-29	15%
30-49	33%
50-64	38%
65-74	61%
75+	58%



## **Obstacle 2**

## Not found

65-76% of physicians whose patients **have** advance directives do not know they **exist** 





#### Individuals fail to make & distribute copies

- Primary agent Alternate agents Family members PCP
- Attorney Clergy Online registry



## **Obstacle 3**

## Not clear



# Then

#### **Preferences vague**

"No ventilator" Ever Even if temporary

# Limits

### Enough

#### THE FAILURE OF THE LIVING WILL

by Angela Fagerlin and Carl E. Schneider

In pursuit of the dream that patients' exercise of autonomy could extend beyond their span of competence, living wills have passed from controversy to conventional wisdom, to widely promoted policy. But the policy has not produced results, and should be abandoned. ASTINGS CENTER REPORT

#### Annals of Internal Medicine

#### PERSPECTIVE

#### Controlling Death: The False Promise of Advance Directives Henry S. Perkine, MD

Adapta divides points plaints up in the future one but adaptate data the service of plasmatta and the service of plasmatta and the service of plasmatta and the service tonging the original service and service exercise and may be tongenetic to a service and the service tongenetic and plasmatta and the service tongenetic and plasmatta and the service service and the product and major and prior intervice service and the product and major and prior intervice and the service and the service and the service and the service service and the product and major and prior intervice and the service advance directives, as the case in this paper illustrates. Because advance directives offer only limited benefit, advance care planning.

Am Intern Mad. 2007;147:51-57. For author attilation, see end of text.

## 2 parts to AD

# Instruct Appoint



## Need a **SDM**

1<sup>st</sup> choice – patient picks herself

Patient knows who

- (1) They trust
- (2) Knows their preferences
- (3) Cares about her

"Agent"

"DPAHC"

# BUT

Usually in an advance directive Not completed Not found Not clear

## Still need a SDM

Default surrogate

### 2<sup>nd</sup> choice –

if no agent, turn to **default priority** list

"Surrogate"

"Proxy"

Most states specify a sequence Agent Spouse Adult child Adult sibling Parent . . . . No authoritative list in Minnesota

BUT

# Custom & practice

## Judicially endorsed

CASE TYPE INDICATOR: CIVIL - OTHER STATE OF MINNESOTA DISTRICT COUNT COUNTY OF RAMSEY SECOND JUDICIAL DISTRICT PROBATE DIVISION FILE MURBER: C7-94-1213

Z: JAMBS D. Butcher and Partia A. Butcher, individually and as parents and natural guardians of James D. Butcher, II. Plaintiff, Plaintiff, Plaintiff, Conclusions vs. of James Journal of The State State vs. of James And JUDGHENY Thomas Fahlngbaser, in his official capetity as Director, Reasey County Community Human official capetity as Director, Reasey County Community Human Services Department, Befondants. J. Plaintiffs are appropriate surrogate decision makers for all health care decisions for their son, and they are not required to petition for or be appointed guardians or conservators in order to continue making all health care decisions for their son,

#### consistent

with the standard of medical and ethical practice in the State of Minnesota.

Still need a SDM

## Guardian

3<sup>rd</sup>choice –

ask **court** to appoint SDM

### Last resort

# Not sufficiently responsive

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

WINSOR C. SCHMIDT\*

700

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).

## 3 types SDM

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

## <u>How</u> 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, follow them

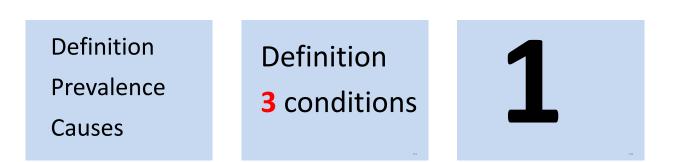
### Substituted Judgment

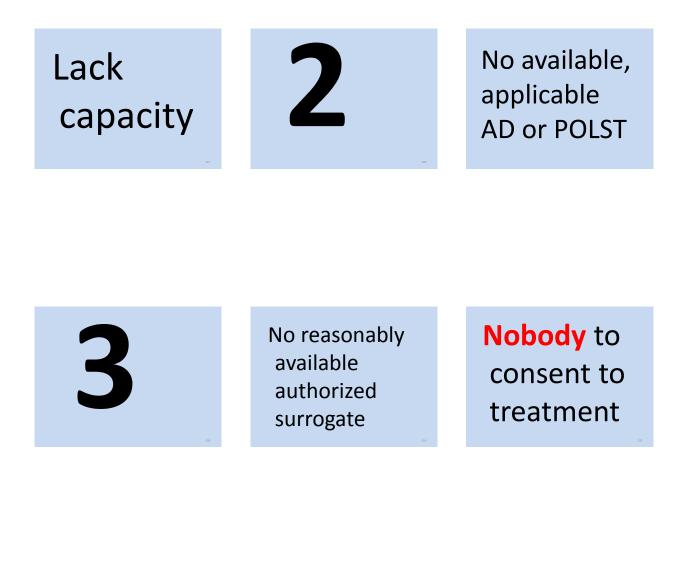
Do what patient would do (using known values, preferences)

#### **Best interests**

If cannot exercise substituted judgment, then **objective** standard







Step by step flowchart



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.



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

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

lf no, proceed

3	If patient lacks capacity, a <b>SDM</b> 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 $\rightarrow$

Nobody to consent to treatment



Is the situation an emergency

If yes  $\rightarrow$ 

Is there any reason to believe the patient would object If no, proceed on basis of **implied** consent

2/2/2017

5	

Is there an responsive guardianship system?

If so, seek a court appointed guardian

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

**Big** problem

Hospital estimates

## 16% ICU admits

Decisions to limit life-sustaining treatment for critically ill patients who lack both decision-making capacity and surrogate decision-makers® Dougla B. White, MO, J. Randal Carlin, MO, MPH; Benard Lo, MO, John M. Luce, MO

5% ICU deaths

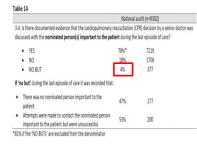
ARTICLE Annals of Internal Medici Life Support for Patients without a Surrogate Decision Maker: Who Decides?

## > 25,000



### End of Life Care Audit – Dying in Hospital

National report for England 2016



## LTC estimates

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

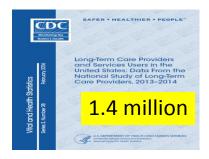
Naomi Karp and Erica Wood



American Bar Association Commission on Law and Aging July 2003



U.S. nursing home population







Extrapolate 5.5 / 320 1.7%

# 1400

#### THE COMMISSION ON END OF LIFE CARE

Final Report

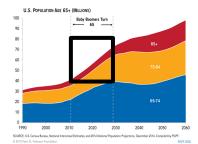
January 2002

The Commission on End of Life Care was staffed by the Minnesota Partnership to Improve End of Life Care and the Minnesota Department of Health.

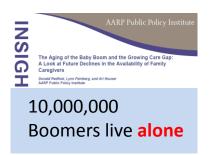
# Growing problem







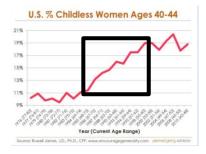






# 3







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



Others "have" family members



## Cannot advocate for self

Have **no** substitute advocate

#### POSITION STATEMENT

Making Treatment Decisions for Incapacitated Older Adults Without Advance Directives AGS Ethics Committee

"highly vulnerable" "most vulnerable"

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

WINSOR C. SCHMIDT®

"unimaginably helpless"

Problem

**Nobody** to authorize treatment



Reluctant to act without consent

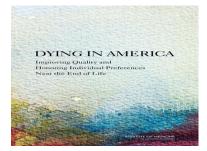
Wait

Until emergency (implied consent)

BUT

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 . . ."



**Over-treatment** 

Fear of liability

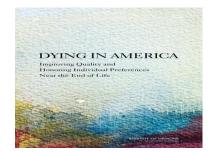
Fear of regulatory sanctions

Treat aggressively

# BUT

Burdensome

Unwanted



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



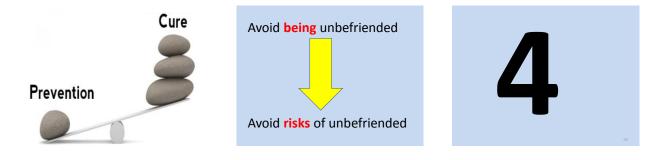
No discharge to appropriate setting





Unit 4 of 5

## Prevention measures





### Competence

Legal determination (by a court) Global (all decisions)

### Capacity

**Clinical** determination Decision specific (**not** global)

## Capacity

relevant in healthcare

## Not all or nothing

Patient might have capacity to make **some** decisions but not others Patient may lack capacity for complex decisions

But **have** capacity to appoint a surrogate

Decision specific



May **fluctuate** over time

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

#### 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.

Cause of con	fusion	Possible intervention	
	ther substances intoxification	Detoxification; supplement diet or other intake needs	
Altered blook	1 pressure	Treat underlying cause of blood pressure anomaly with medication or other treatment	
Altered low I	blood sugar	Management of blood sugar through diet or medication	
Anxiety		Treatment with medications and/or psychotherapy; support groups	
Bereavement loved one	Recent death of a spouse or	Support: counseling by therapist or elergy; support group; medications to assist in short term problems (e.g., skeep, dopression)	
Bipolar disor	der	Treatment with medications and/or psychotherapy; suppor groups	
Brain tumor		Surgery and medication	
Delirium	HEC Forum	Obtain standard labs; obtain brain scan if indicated; asses vitals; treat underlying cause; monitor and reassess over time	
Dementia	DOI 10.1007/s10750-016-9917-9	Treatment with medications for dementia; simplify environment; provide multiple clues within environment use step-by-step communication	
Depression		Treatment with medications and/or psychotherapy; add pleasurable activities to day; ECT if indicated; support groups	
Development	al disability	Education and training	
Difficulty he	aring	Use hearing amplifiers; have hearing evaluated; provide hearing aids; write information down; repeat information slow down speech; speak clearly and distinctly	
Difficulty see	ing	Use magnifying glass; have sight evaluated; provide glasse provide spoken information; repeat information; ensure sufficient lighting; use large print; have access to Bnilli materials	
Difficulty understanding English		Use translator	
Head injury		Treatments for acute effects (e.g., bleed, pressure, swelling as necessary; monitoring over time; rehabilitative speed rbwsied, occurational theranies	

More Advance care planning Before lose capacity: Record preferences and/or Name agent





NHs, neighbors, service agencies Access home, apartment Personal effects Health records, pension plans

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.

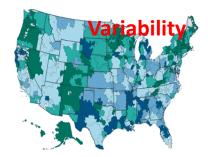
Better default surrogate laws

#### **Clinical** solutions

Better capacity assessment Diligent search for surrogates More advance care planning

## Legal solutions

Law as causal factor



Some states will have fewer unrepresented patients Some states will have **zero** unrepresented patients

Why?

Default surrogate laws



## More relatives

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

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 01-2601, 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 classes and in the patient. Persons in the following classes and in the following classes and provide informed consent to health care on behalf of the patient. a. The individual, if any, to whom the patient has given a durable pover of atomety that encompasses the authority to make health care docisions, unless as 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 spocies who has maintained significant contacts with the incapacitated person. e. Patients of the patient, who are at least eighteen years of age and who have maintained significant contacts with the incapacitated person. e. Patients of the patient, who are all least eighteen years of age and who have maintained significant contacts with the incapacitated person. e. Patients of the patient, including a segregatent who has maintained significant contacts with the incapacitated person. f. Adult brothers and sates of the patient who have maintained significant contacts with the incapacitated person.

- 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.

## Close friend

#### POSITION STATEMENT

Making Treatment Decisions for Incapacitated Older Adults Without Advance Directives AGS Ethics Co

#### 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.

JAMA April 7, 2015 Volume 313, Number 13 1369	102 042	92.9
Spouse	53 212	48.5
Adult child	22 495 14 031 12 304	20.5 12.8 11.2
Parent		
Sibling		
Outside the nuclear family	7761	7.1
Nonnuclear relative	3190	2.9
Niece or nephew	1134	1.0
Cousin	523	<1
Aunt or uncle	490 358 291	<1 <1 <1
In-taw		
Step-parent or step-sibling		
Grandparent	170	<1
Grandchild	166	<1
Other blood or legal relative	58	<1
Other relationship	4571	4.2
Friend	1854	1.7
Relationship outside marriage	1329	1.2
Ex-spouse	539	<1
Other	849	<1

## More flexible



"surrogate shall be identified by the supervising health care provider"

"criteria . . . in the determination of the person **best** qualified to serve as the surrogate"

Ability to make decisions Regular contact with patient Demonstrated care and concern Availability to visit the patient Availability to engage in face to

Availability to engage in face-toface contact with providers

## Limited





No default surrogate statute



# Custom & practice

CASE TYPE INDICATOR: CIVIL - OTHER STATE OF MINNESOTA DISTRICT COUNT COUNTY OF RAMSEY SECOND JUDICIAL DISTRICT PROBATE DIVISION FILE MUMBER: CT-94-1313

RI: James D. Butcher; and Patricia A. Butcher, individually medias parents and natural guardians of James D. Butcher; II, Plaintiffs, Vs. OF LAN AND JUDGKINY Thomas Pashingbauer, in his official capacity as Director, Services Department, and Remany County Community Ruman Services Department, and Rumany County Community Ruman



(reflects policies adopted through April 30, 2015)

#### 240.22 Decisions to Forego Life-Sustaining Treatment for Patients Lacking Decision-Making Capacity

The MINA endorses the ANA Council on Ethical and Judicial Affairs recommendations adopted at the 1991 ANA Annual Meeting as follows:

2. Without an advance directline that designates a proxy, the patient's family should become the surrogate decision-maker. Family includes persons with whom the patient is doesly associated. In the case when there is no one closely associated with the patient, but there are persons who both care about the patient and have some relevant knowledge of the patient, such relations should be involved in the decision-making process, and may be appropriate surrogates.

De facto flexibility





NJ IN NY NJ

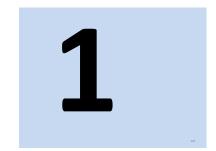
# Unit 5 of 5

Decision making mechanisms

Tried to **prevent** from being unbefriended

## Failed

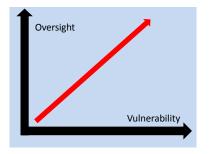
How to make healthcare decisions Solo physician Second physician Ethics committee External consent

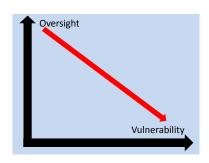


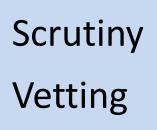
## Solo physician

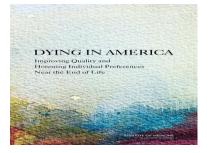
Most common approach

# Odd









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

### 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,
- 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
- A nonrelative of the principal who is an employee of the principal's <u>long-term care</u> services provider.

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

 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



# External consent





"clinical social worker . .. selected by the provider's bioethics committee and must not be employed by the provider"



Multidisciplinary

committee

#### S.B. 503

"independent" medical consultant + "independent" patient advocate

CANHR not sat b/c "paid" by NH

#### POSITION STATEMENT

Making Treatment Decisions for Incapacitated Older Adults Without Advance Directives AGS Ethics Committee

#### POSITION 3

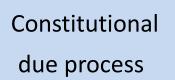
After a conscientious effort has failed to identify an appropriate surrogate, a group of individuals who care for the patient may determine appropriate treatment goals and design a humane care plan to meet those goals. This group might consist of a multidisciplinary healthcare team, including physician,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



Physician not attending with consensus ethics committee



# BUT



IN THE COURT OF APPEAL OF THE STATE OF CALIL FIRST APPELLATE DISTRICT DIVISION FOUR RNIA ADVOCATES FOR

ON APPEAL FROM THE JUDGMENT OF THE SUPERIOR COURT COUNTY OF ALAMEDA Hon. Evelio M. Grillo, Presiding

# 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

**Conclusion** 



Fair

Expertise, neutrality, careful deliberation

## Too fair → too slow

Accessible, quick, convenient, cost-effective Sacrifice some fairness for efficiency

### References

TM Pope, "Unbefriended and Unrepresented: Better Medical Decision Making for Incapacitated Patients without Healthcare Surrogates," *Georgia State University Law Review* 2017 (forthcoming). TM Pope, "Legal Briefing: Adult Orphans and the Unbefriended: Making Medical Decisions for Unrepresented Patients without Surrogates," *Journal of Clinical Ethics* 2015; 26(2): 180-88.

TM Pope, "Making Medical Decisions for Patients without Surrogates" *New England Journal of Medicine* 2013; 369(21): 1976-78. TM Pope & T Sellers, "Legal Briefing: the Unbefriended - Making Healthcare Decisions for Patients without Proxies – Part 1" *Journal of Clinical Ethics* 2012; 23(1): 84-96.

TM Pope & T Sellers, "Legal Briefing: the Unbefriended - Making Healthcare Decisions for Patients without Proxies – Part 2" *Journal of Clinical Ethics* 2012; 23(2): 177-92.

2/2/2017

#### Thaddeus Mason Pope, JD, PhD

Director, Health Law Institute Mitchell Hamline School of Law 875 Summit Avenue Saint Paul, Minnesota 55105

- T 651-695-7661
- **C** 310-270-3618
- E Thaddeus.Pope@mitchellhamline.edu

343

- **W** www.thaddeuspope.com
- **B** medicalfutility.blogspot.com