# Ethics Committees Are Not Just for Hospitals:

## Advancing Person-Centered Care in Long-Term Care Facilities

ASBH (Oct. 21, 2018)
Thaddeus Mason Pope, JD, PhD

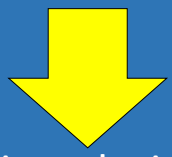
I **do** have a disclosure

Question 1

Does Armando have capacity?

Key **threshold** question

Patient has capacity to make decision at hand



Patient decides **himself**

What is "capacity"

3

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

Able to **make** a decision

Able to **communicate** a decision

**2** famous case examples

Lane v. Candura (Mass. 1978)


Doc thinks **stupid** decision

But . . . Pt **understands** the diagnosis & consequences

So, she **has** capacity

DHS v. Northern (Tenn. 1978)


Does **not** appreciate her condition

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

# Armando

Capacity - Step **1**

"I am not going to the hospital. I don't care if I have **gangrene**."

May appreciate **diagnosis**

"I have gangrene"

May appreciate **need** to treat

"My leg needs to be healed"

"**God** will heal my leg."

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

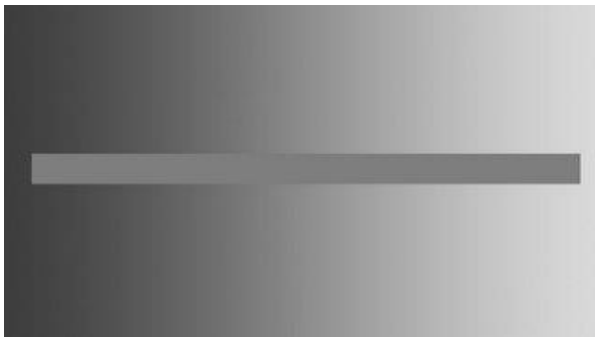
Able to make & communicate a decision

"I am not going to the hospital"

Plus

"Armando **understands** that he may have lung cancer and tells the doctor and the social services designee in **lucid moments** . . ."

"I **don't want** to have a lot of treatment or go to the hospital. I'm tired, and when my time is up, I am **ready to go**."



# Armando

Capacity - Step **2**

All patients **presumed** to have capacity

Clinicians must **rebut** the presumption

No need to **prove** capacity

Must prove **in**capacity

**Unclear** that can be done

Armando

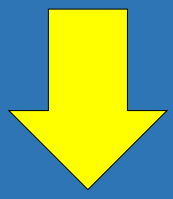
Capacity - Step **3**

**Even** if really lacks capacity

**Restore** capacity if possible

Recap

Armando has capacity



Armando decides

Question **2**

What if Armando **really** lacks capacity?

Is this an **emergency**?

If yes →

Proceed with **implied** consent

Cannot use emergency exception if know patient would **object**

We already determined Armando **lacks capacity** to object

Question 3

What if Armando **really** lacks capacity?

**Not** an emergency

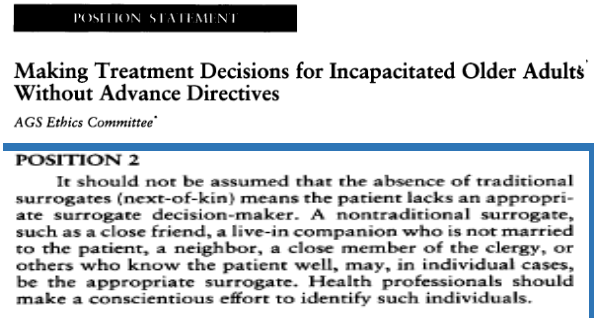
Find a surrogate

**No family** identified by patient or in any of his records. Has one sister in Florida but does not want efforts made to find or contact her. Parents both dead. No children, never married. **No close friends** identified by patient as potential surrogates."

That's what Karl **thinks**

**Diligent** search for surrogates

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



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, search may reveal **evidence** of patient's values, preferences

Question 4

What if you **cannot** find a surrogate?


Increasingly **common** situation

Patient **needs** treatment

**BUT**

**No** capacity

**No** surrogate

Patient **cannot** consent

**Nobody** else to consent

**Various terms**

"unrepresented"

"adult orphan"

Patient w/o proxy

Incapacitated & alone

Most prevalent

**"unbefriended"**

**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

The National Long-Term Care Ombudsman Resource Center

**Advocating for the Unbefriended Elderly**

An Informational Brief

August 2010

Jessica E. Brill Ortiz, MPA

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

AGS Geriatrics Healthcare Professionals

Leading Change. Improving Care for Older Adults.


**Big problem**

LTC estimates

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

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American Bar Association
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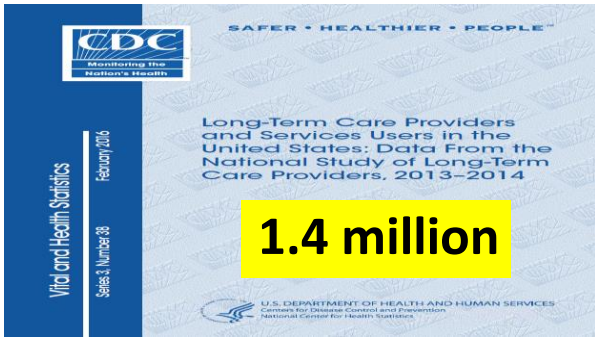
July 2003

# 3 - 4 %

U.S. nursing home population




# > 56,000

USA

# > 6700

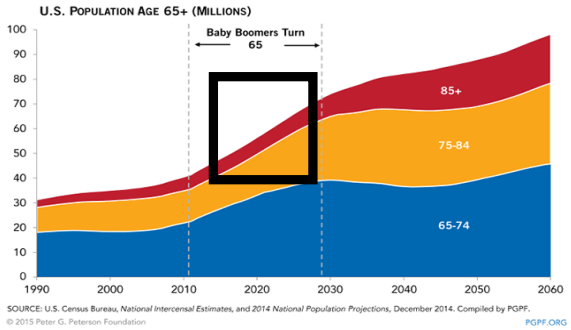
CA

Not just big, but

# Growing problem

# 4 key factors

# 1

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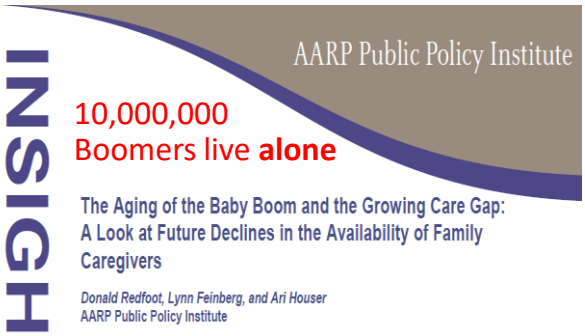


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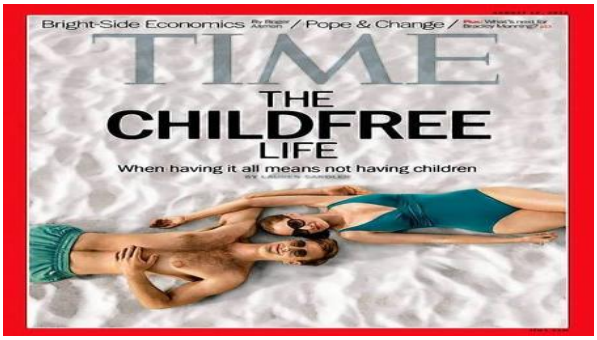
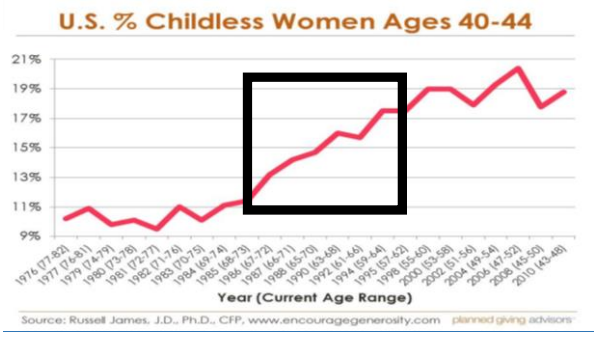



# 4

Others, like Armando, "have" family members

But Armando does not want them

They do not want Armando

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

**Who decides?**


Cal. H&S 1418.8 (1992)

IDT

Interdisciplinary team

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

# IDT acts as surrogate

# BUT

IN THE COURT OF APPEAL OF THE STATE OF CALIFORNIA
FIRST APPELLATE DISTRICT
DIVISION FOUR

| | | |
|---|---|---|
| CALIFORNIA ADVOCATES FOR NURSING HOME REFORM, et al.<br><br>Plaintiffs and Appellants,<br><br>vs.<br><br>KAREN SMITH, MD., MPH, as Director of the California Department of Public Health,<br><br>Defendants and Appellants. | ) | Case No. A147987<br><br>Alameda County Superior Court, Case No. RG13700100 |

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

IDTs **vary** in effectiveness & fairness

Most states have no 1418.8 or any mechanism

What happens in **those** states?

**2** common responses

**1**

Under-treatment

**Reluctant** to act without consent

Wait

Wait

some more

Until

**emergency**

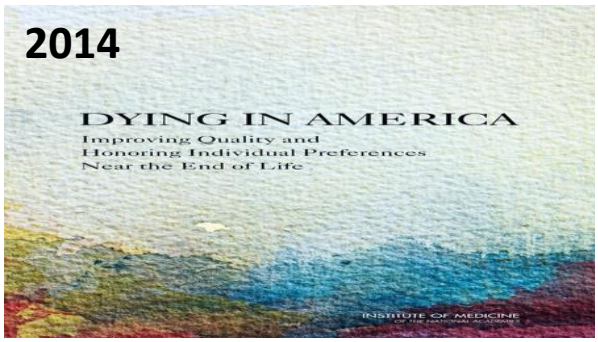
(implied consent)

**BUT**

**Longer** period suffering

**Increases** risks

**2014**




Ethically "**troublesome**

. . . waiting until . . .

condition worsens

into an **emergency**"

# 2

Over-treatment

Fear liability

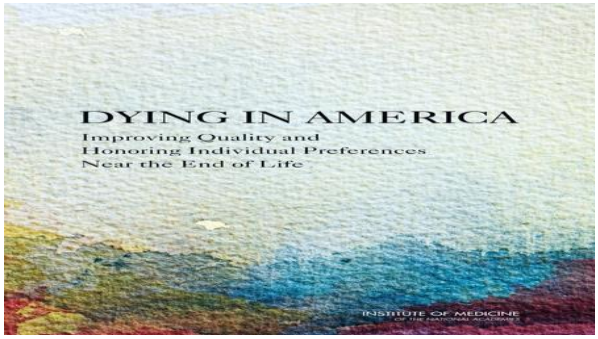
Fear regulatory sanctions

Treat aggressively

# BUT

Burdensome

Unwanted




"**compromises** . . . consideration of patient preferences or best interests"

# Takeaway

No consent → Bad conduct

**Need** a consent mechanism

# HEC

# Law


An Act

**2016**

HOUSE BILL 16-1101

BY REPRESENTATIVE(S) Young, Court, Esgar, Fields, Ginal, Kagan, Kraft-Tharp, Lontine, McCann, Mitsch Bush, Pabon, Pettersen, Primavera, Rosenthal, Ryden, Salazar, Singer, Vigil, Hullinghorst, Danielson, Duran, Klingenschmitt, Moreno;
also SENATOR(S) Lundberg, Aguilar, Crowder, Guzman, Heath, Hodge, Jahn, Kefalas, Kerr, Merrifield, Newell, Steadman, Todd.

Concerning medical decisions for unrepresented patients.


65th Legislature SB0092

**2017**

AN ACT ALLOWING FOR APPOINTMENT OF PROXY DECISIONMAKERS FOR CERTAIN HOSPITALIZED PATIENTS; ESTABLISHING PROCEDURES FOR NAMING PROXY DECISIONMAKERS; ALLOWING HEALTH CARE PROVIDERS TO SERVE AS PROXY DECISIONMAKERS; PROVIDING FOR REVIEW BY MEDICAL ETHICS COMMITTEES; PROVIDING IMMUNITY; PROVIDING DEFINITIONS; AND PROVIDING AN

# Without law

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

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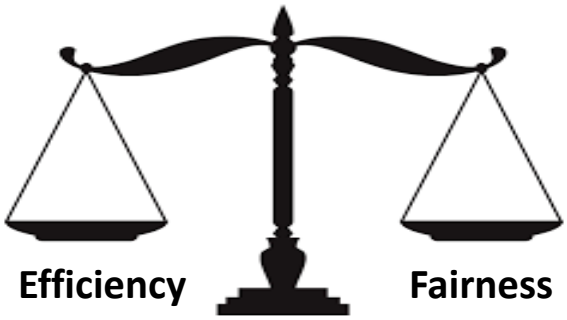
Leading Change. Improving Care for Older Adults.

**Use of Institutional Committees**

The best interest standard[38] is typically applied only as a last resort when there is no advance directive available and a surrogate decision maker cannot be identified. According

Institutional committees, such as ethics committees, should require the synthesis of all available evidence about unbefriended older adults' treatment preferences,




Fair

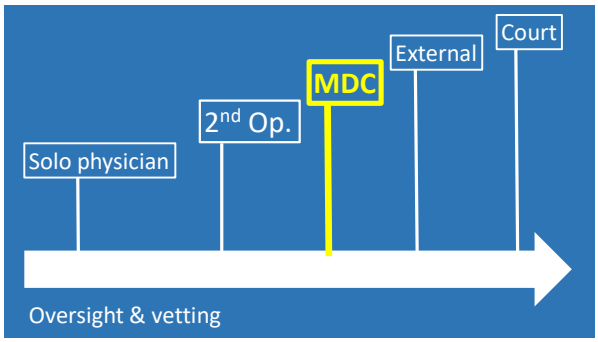
Expert
Neutral
Careful

Too fair → too slow

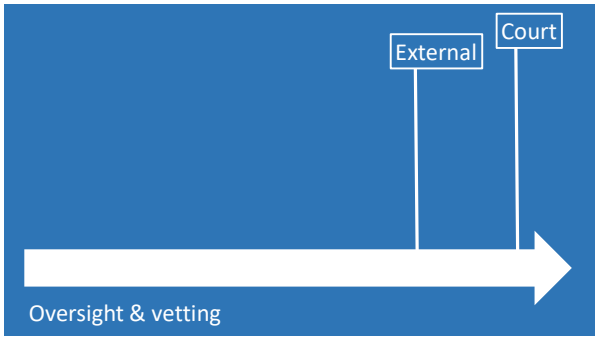
# Fast

Accessible
Quick
Convenient

Too fast → too unfair


Some mechanisms are **too slow**




Journal of Hospital Medicine
www.journalofhospitalmedicine.com
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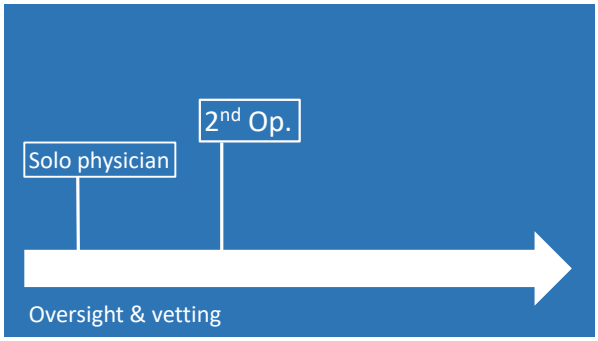
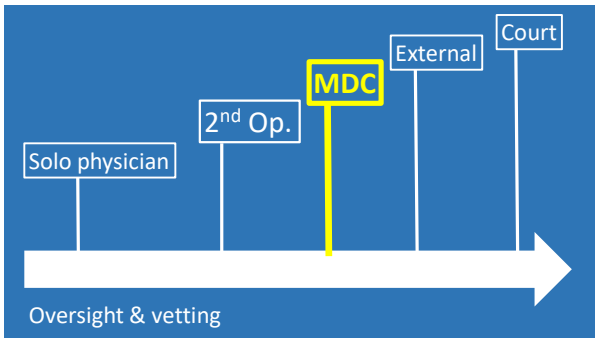
The Burden of Guardianship: A Matched Cohort Study

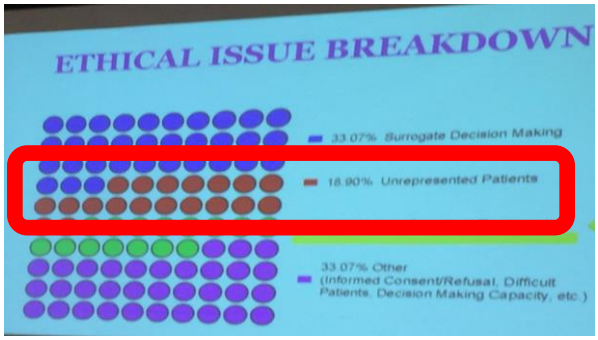
Daniel N. Ricotta, MD[1,2*], James J. Parris, MD, PhD[1], Ritika S. Parris, MD[1], David N. Sontag, JD, M. Bioethics[1], Kenneth J. Mukamal, MD, MPH[1]

Other mechanisms are **too fast**




**Conclusion**




Unrepresented patients in **LTC** should get the **same** respect

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"

SESSION **685 - The Unrepresented Patient: Where Institutional and Clinical Ethics Meet**

O Add To Itinerary

October 21, 2018, 11:30 AM - 12:30 PM | Disneyland Grand Ballroom

**DESCRIPTION**

Making healthcare decisions for unrepresented patients, those lack both decision making capacity and a legally appropriate surrogate, can be difficult. This panel presentation discusses one institution's experience in creating a policy for decision making for unrepresented patients and reviews data gathered from the clinical ethics consultation service for two years prior and after implementation of this policy. We will explore the moral obligations and ethical challenges this policy presented from the following perspectives: administration and hospital leadership, physicians and other clinicians, clinical ethics, and the law. We will also address the differences between moral and legal authority, the spectrum of unrepresented patients, and explicit/implicit biases that can occur when institutions make healthcare decisions for their patients.

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