

**Caring for “Unrepresented Patients” - Strategies to Avoid Moral Distress and Substandard Care**

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## Terminology

Unbefriended  
Unrepresented  
Adult orphan

Patient w/o proxy  
Incapacitated &  
alone

## Definition

**3** conditions

**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 no,  
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**

**Big problem**

3 - 4% nursing home population



> 50,000

16% ICU admits

Decisions to limit life-sustaining treatment for critically ill patients who lack both decision-making capacity and surrogate decision-makers<sup>®</sup>  
Douglas B. White, MD, J. Randall Curtis, MD, MPH, Bernard Lu, MD, John M. Laine, MD

5% ICU deaths

ARTICLE | *Annals of Internal Medicine*  
Life Support for Patients without a Surrogate Decision Maker: Who Decides?  
Douglas B. White, MD, MPH, J. Randall Curtis, MD, MPH, John M. Laine, MD, Bernard Lu, MD, MPH, Thomas J. Pengiggen, MD, Bernard R. Taichman, MD, PhD, Greg Bergquist, MD, Frank Avella, DO, Bernard D. Roth, MD, and John M. Laine, MD

> 25,000

**End of Life Care Audit – Dying in Hospital**  
National report for England 2016

**Table 14**

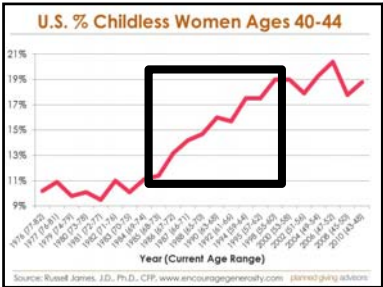
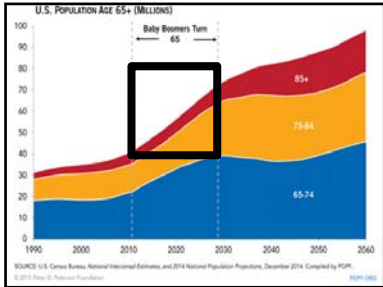
National audit (n=9302)	
3.4. Is there documented evidence that the cardiopulmonary resuscitation (CPR) decision by a senior doctor was discussed with the nominated person(s) important to the patient during the last episode of care?	
• YES	78%* 7219
• NO	18% 1706
• NO BUT	4% 377

If 'no but' during the last episode of care it was recorded that:

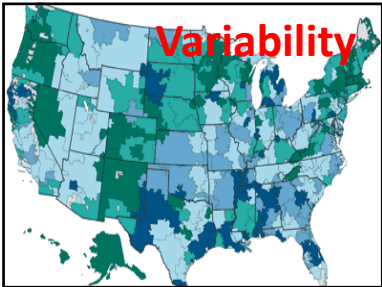
• There was no nominated person important to the patient	47% 177
• Attempts were made to contact the nominated person important to the patient but were unsuccessful	53% 200

\*82% if the 'NO BUT's are excluded from the denominator

**Growing problem**



**Law as causal factor**



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



**Ethical  
Problems**

Nobody to  
authorize  
treatment

**3** ways to  
respond

**1**

**No**  
treatment

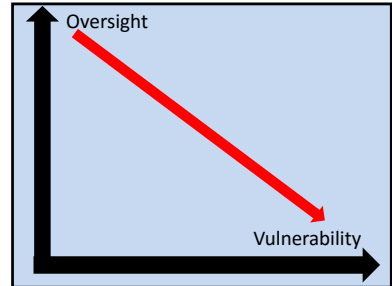
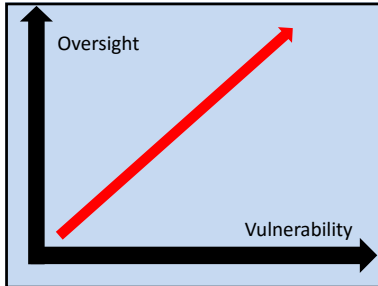
**Wait** until  
emergency  
(implied  
consent)

**2**

Physician acts  
**without**  
consent

Most  
common  
approach

Bias  
COI  
Careless



3

Scrutiny  
Vetting



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**      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 other

Geriatric practitioners are often faced with the problem of making treatment decisions for patients who lack deci-

2016

**AGS** Geriatrics  
Healthcare  
Professionals

Leading Change. Improving Care for Older Adults.



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## References

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.