



1

Ethical Issues in Caring for Unrepresented Patients

What Every Healthcare Professional Should Know

2

Thaddeus Mason Pope
JD, PhD, HEC-C

November 12, 2024

3

nothing
to disclose

4

AMERICAN THORACIC SOCIETY DOCUMENTS

Making Medical Treatment Decisions for Unrepresented Patients in the ICU An Official American Thoracic Society/American Geriatrics Society Policy Statement

Thaddeus M. Pope, Joshua Bennett, Shannon S. Carson, Lynetta Codrescu, Andrew B. Cohen, Erin S. DeMartino, David M. Godfrey, Paula Goodman-Criew, Marshall B. Kaga, Bernard Lu, David C. Magnus, Lynn F. Reinke, Jamie L. Shirley, Mark D. Siegel, Renee D. Stapleton, Rebecca L. Sudore, Anita J. Tancian, J. Daryl Thornton, Mark R. Wozniar, Eric W. Wolk, and Douglas B. White, on behalf of the American Thoracic Society and American Geriatrics Society

This journal policy statement was approved by the American Thoracic Society February 2022 and the American Geriatrics Society January 2022

5



6



7

Define what makes a patient "unrepresented"

Identify three reasons why unrepresented patients are highly vulnerable

Describe the importance of accurate, timely decision-capacity assessments

Explore ethical considerations related to decision-making for unrepresented patients.

8

potentially
unrepresented
patients

9

value
concordant
healthcare

10

patients **get**
treatment
they **want**

11

also

12

patients do **not**
get treatment
they **don't** want

13

too **little**
= harm

14

too **much**
= harm

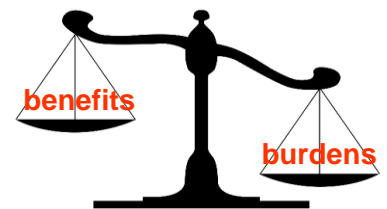
15

how much is
too much is
value laden

16

preference
sensitive
decision

17



18

2 types of value discordant healthcare

19

over-treatment
under-treatment

20

happens to patients **with** decision making capacity

21

happens **more**

22

to **incapacitated** patients

23



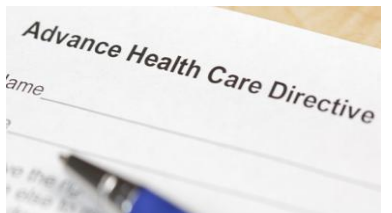
24

cannot tell us what they want & do not want

25

key **tool** to mitigate value discordant treatment for incapacitated patients

26



27

OFFICE OF THE DIRECTOR
Office of the State Public Health Director

Oregon Health Authority

Initial one option only

I want to try all available treatments to sustain my life, such as artificial feeding and hydration with feeding tubes, IV fluids, kidney dialysis and breathing machines.

I want to try to sustain my life with artificial feeding and hydration with feeding tubes and IV fluids. I do not want other treatments to sustain my life, such as kidney dialysis and breathing machines.

I do not want treatments to sustain my life, such as artificial feeding and hydration with feeding tubes, IV fluids, kidney dialysis or breathing machines. I want to be kept comfortable and be allowed to die naturally.

I want my health care representative to decide for me, after talking with my health care providers and taking into account the things that matter to me. I have expressed what matters to me in section B below.

28



29



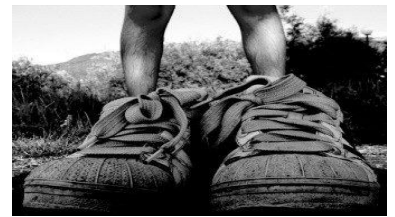
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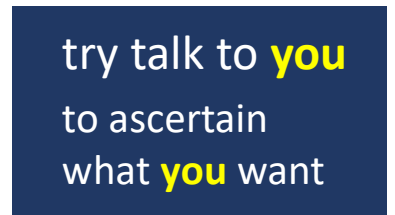
33



34



35



36

if cannot

37

try to
identify you

38

contact your **family**
so, **they** can guide Tx

39

if cannot

40

try to **find**
AD, POLST

41

so, **they** can
guide Tx

42

if cannot

43

try to find
other VGP
evidence

44

so, **it** can
guide Tx

45

if cannot

46

use **fair process**
to decide Tx

47



48



49

how well does
current practice
measure up?

50

roadmap

51

7 parts

52

profile
population

53

demographics
empirical research

54



55

let's get
practical

56

prevention

57

use provider
advocates **only**
last resort

58

capacity

59

search for
surrogates

60

search
for ADs

61

provider advocate
decision
making

62

profile

63

unrepresented
patient

64

increasingly
common
situation

65

hospitals & LTC
challenged

66

patient **needs**
treatment

67

but

68

no capacity
no surrogate

69

patient
cannot
consent

70

nobody
else to
consent

71

various
terms

72

adult orphan

73

patient w/o proxy

74

incapacitated & alone

75

incapacitated adult without advocate

76

JAMDA 23 (2014) 900-909



Original Study

Natural Language Processing to Identify Home Health Care Patients at Risk for Becoming Incapacitated With No Evident Advance Directives or Surrogates

Jiyoun Song PhD, AGACNP-BC, APRN¹; Maxim Topaz PhD, RN^{1,2,3}

77

INEADS
Incapacitated with No Evident Advance Directives or Surrogates


78

unbefriended

79

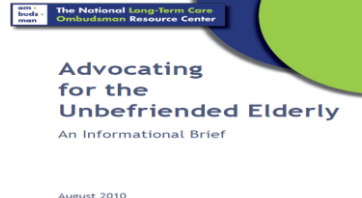
**Incapacitated and Alone:
Health Care Decision-Making
for the Unbefriended Elderly**

Naomi Karp and Erica Wood



American Bar Association
Commission on Law and Aging
July 2003

80



The National Long-Term Care Ombudsman Resource Center

**Advocating
for the
Unbefriended Elderly**
An Informational Brief

August 2010

81

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



Leading Change. Improving Care for Older Adults.

82



83



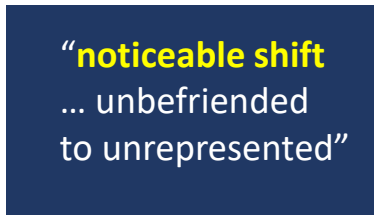
84

Adults Without Advocates and the Unrepresented: A Narrative Review of Terminology and Settings

Gerontology & Geriatrics Medicine
Volume 16(4)
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DOI: 10.1177/23337214231165916
journals.sagepub.com/home/ggm
SAGE

Rachel Brenner, MD^{1,2}, Linda Cole, MS¹,
Gail L. Towsley, PhD, NHA, FGSA¹, and
Timothy W. Farrell, MD, AGSF¹

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AMERICAN THORACIC SOCIETY DOCUMENTS

Making Medical Treatment Decisions for Unrepresented Patients in the ICU
An Official American Thoracic Society/American Geriatrics Society Policy Statement

Thaddeus M. Pope, Joshua Bennett, Shannon S. Carson, Lynette Cederquist, Andrew B. Cohen, Erin S. DeMartino, David M. Godfrey, Paula Goodman-Craves, Marshall B. Kapp, Bernard Lo, David C. Magnus, Lynn F. Renke, James L. Shroy, Mark D. Siegel, Renee D. Stappert, Rebecca L. Squires, Aron J. Tarczyn, J. Daryl Thornton, Mark R. Wiczar, Eric W. Winkler, and Douglas B. White, on behalf of the American Thoracic Society and American Geriatrics Society

This official policy statement was approved by the American Thoracic Society February 2020 and the American Geriatrics Society January 2020

87



88



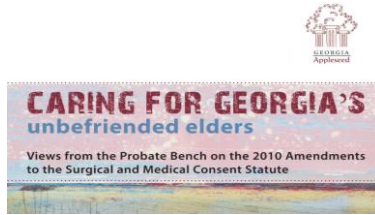
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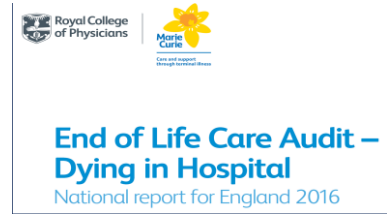
90

> 28,000
US, each year

100



101



102

3.4. Is there documented evidence that the cardiopulmonary resuscitation (CPR) decision by a senior 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

103

Clin Geriatr. : : 1-10. doi:10.1080/07317115.2019.1640332.

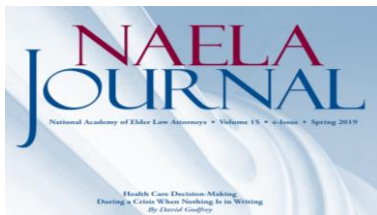
Caring for Unbefriended Older Adults and Adult Orphans: A Clinician Survey

Timothy W. Farrell, MD, AGSF^{a,b,c}; Casey Catlin, PhD^d; Anna H. Chodos, MD, MPH^e; D. Naik, MD^f; Eric Widera, MD^g; Jennifer Moye, PhD^g

104

“clinicians ... inpatient setting ... encounter”
weekly 24.5%
monthly 36.7%

105



106

50% hospitalists & intensivists
see >1 unrepresented patient per month

107



108

**every
single
day .**

109

that's
hospital
context


110

LTC
estimates

111

**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

112

3-4%
U.S. nursing home
population

113



SAFER • HEALTHIER • PEOPLE™

Long-Term Care Providers
and Services Users in the
United States: Data From the
National Study of Long-Term
Care Providers, 2013–2014

1.4 million

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
CENTERS FOR DISEASE CONTROL AND PREVENTION

Vital and Health Statistics
Special Feature #8
February 2016

114

> 56,000
USA

115



116

730

117

plus

118

temporarily
unrepresented

119

big
problem

120

also

121

growing
problem

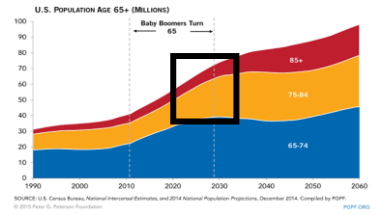
122

4 key
factors

123

1

124



125

2

126

AARP Public Policy Institute

10,000,000 boomers live alone

The Aging of the Baby Boom and the Growing Care Gap: A Look at Future Declines in the Availability of Family Caregivers

127



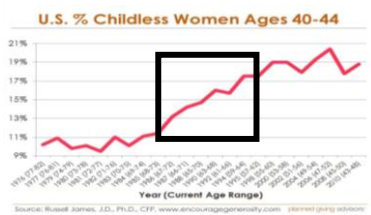
128



129



130



131



132

others
"have"
family

133

able but
unwilling

134

no **contact**
LGBTQ+, homeless,
criminal

135

conversely

136

willing but
unable

137

SDM lacks
capacity

138



139

we have **many**
unrepresented

140

what's the
problem

141

risks & harms

142

cannot
advocate
for self

143

have **no**
substitute
advocate

144

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

“highly vulnerable”
“**most** vulnerable”

145

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

Wesley C. Schmidt
“unimaginably helpless”

146

problem

147

nobody to authorize treatment

148

how do clinicians respond?



149

3 common responses

150



151

1

152

under-treatment

153

reluctant to
act without
consent

154

wait

155

until
emergency
(implied consent)

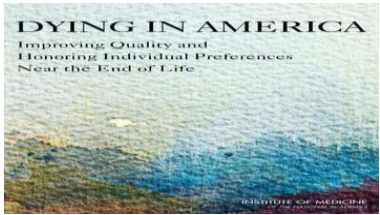
156

but

157

longer period
suffering
increases risks

158



159

ethically "**troublesome**
... wait until ... worsens
into an **emergency**"

160

2

161

over-
treatment

162

fear liability
fear regulatory sanctions

163

treat aggressively

164

default
aggressive curative directed therapy

165

but

166

burdensome unwanted

167

The Washington Post
Most people want to die at home, but many land in hospitals getting unwanted care

168

Trauma Death
Views of the Public and Trauma Professionals on Death and Dying From Injuries
Lanworth M, Jacobs, MD, MPPE, Karyl Barnes, RN, PhD; Barbara Bennett Jacobs, RN, MPPE, PhD, CHPIN
Arch Surg. 2008;143(8):730-735

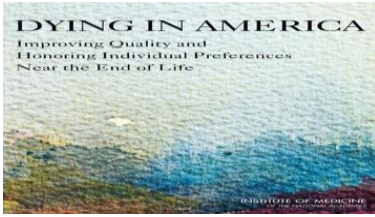
169

Question and Responses ^a	Public, % (n=1006)	Professionals (n=774)
If doctors believe there is <u>no hope</u> of recovery, which would you prefer? Life-sustaining treatments should be stopped and should focus on comfort	72.8	92.6

170

UNREP → UMT

171



172

“**compromises** . . . consideration of patient preferences or best interests”

173

3

174

no discharge to appropriate setting

175



176



177



178



179

unrepresented
↓
error & harm

180

undertreatment
overtreatment
no discharge

181



182



183

prevention

184



185

best way to **protect** the
unrepresented
prevent them from
becoming unrepresented

186

**AMERICAN THORACIC SOCIETY
DOCUMENTS**
**Making Medical Treatment Decisions for Unrepresented Patients in
the ICU**
An Official American Thoracic Society/American Geriatrics Society Policy
Statement
Thaddeus M. Pope, Joshua Bennett, Shannon S. Carson, Lynette Colesquillo, Andrew B. Cohen, Erin S. DeMartino,
David M. Goffrey, Paula Goodman-Crews, Marshall B. Kopp, Bernard Lu, David C. Magnus, Lynn F. Rankin,
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Mark R. Wootler, Eric W. Wolkstein, and Douglas B. White, on behalf of the American Thoracic Society and American
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This official policy statement was approved by the American Thoracic Society February 2020 and the American Geriatrics Society January 2020

187

Recommendation 1
Institutions should promote **advance care**
planning to prevent patients at high risk
from becoming unrepresented in the first
place, both 1) by helping adult patients with
decision-making capacity to identify
a preferred surrogate decision-maker and to
record their preferences and values in an
advance directive and 2) by ensuring that
such documents are available to clinicians
at the point of care.

188



189

OFFICE OF THE DIRECTOR
Office of the State Public Health Director



Initial care option only

- I want to try all available treatments to sustain my life, such as artificial feeding and hydration with feeding tubes, IV fluids, kidney dialysis and breathing machines.
- I want to try to sustain my life with artificial feeding and hydration with feeding tubes and IV fluids. I do not want other treatments to sustain my life, such as kidney dialysis and breathing machines.
- I do not want treatments to sustain my life, such as artificial feeding and hydration with feeding tubes, IV fluids, kidney dialysis or breathing machines. I want to be kept comfortable and be allowed to die naturally.
- I want my health care representative to decide for me, after talking with my health care providers and taking into account the things that matter to me. I have expressed what matters to me in section B below.

190



191



192

HEC Forum
<https://doi.org/10.1007/s10730-019-09387-3>

Making Medical Decisions for Incapacitated Patients Without Proxies: Part I

Cynthia Griggins^{1,2} · Eric Blackstone³ · Lauren McAliley⁴ · Barbara Daly³



Cleveland, Ohio

193



194



195

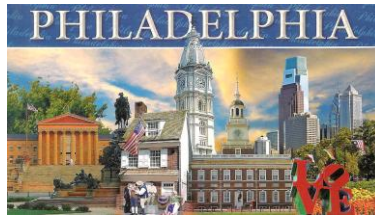
C103 DISPARITIES AND SOCIAL DETERMINANTS OF HEALTH IN PULMONARY, CRITICAL CARE AND SLEEP MEDICINE / Poster Discussion Session / Tuesday, May 21 02:15 PM-04:15 PM / San Diego Convention Center, Room 30C-E (Upper Level)

Are We Missing Opportunities to Avoid Guardianship Proceedings in Unrepresented Hospitalized Patients?



H. Bel¹, A. Kaz², B. Joffe³, S. Schepps³, R. Horowitz⁴, E. J. Yoo⁵, D. Omar², ¹Internal Medicine,

196



197



198

60 patients
H seeks
guardian

199

Residence Prior to Admission	
Private residence	28 (47%)
Undomiciled	14 (23%)
Nursing facility	12 (20%)
Group Home	1 (2%)
Unknown	2 (3%)

200

probably had
surrogate at NH

201

Residence Prior to Admission	
Private residence	28 (47%)
Undomiciled	14 (23%)
Nursing facility	12 (20%)
Group Home	1 (2%)
Unknown	2 (3%)
Recent Prior Encounter at Jefferson*	41 (68%)

202

missed
opportunity

203

name agent
before lose
capacity

204

already supposed
to be doing this

205

Patient Self-
Determination Act

206

1990

207

patients must be **apprised** of rights to AD on admission

208



209

that's enough on **prevention**

210

patient is here & seemingly unrepresented

211

last resort

212



213



214

provider advocate

215



216



217

many U.S. jurisdictions **lack** a solution

218



219

MEDPAGETODAY[®]

100 Days Trapped in Inpatient Legal Limbo
— Awaiting guardianship in the hospital long-term should not be the norm

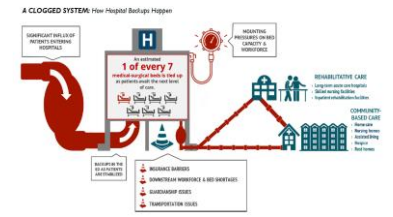
by Gabrielle Kis Bromberg, MD, and Kathleen McFadden, MD
November 6, 2024

220

A CLOGGED SYSTEM:
Keeping Patients Moving Through their Care Journey

MHA MASSACHUSETTS HEALTH & HOSPITAL ASSOCIATION
June 2023

221



222

MA needs guardianship reform default surrogates

223



224

already have right tools

225

focus on appropriate & optimal **use**

226

provider advocate

227

but

228



229

1st exhaust other DM

230



231

person appointed by a hospital ... may give informed consent ... **if**

232

if

233



234

“patient lacks
... ability”

235

“performed a
reasonable **search** ...
relatives and friends”

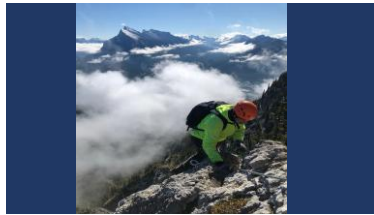
236

“performed a
reasonable **search**
for ... health care
instruction”

237

2 analogies

238



239



240



241

PSU only if suffering
intractable
refractory
other measures

242

SO ...

243

provider
advocate

244



245



246

seemingly
unrepresented
patients often
are **not**

247

4 reasons
we will dive
into next

248

1

249

Pt may **not** be
incapacitated

250

2

251

capacity
might be
fixable

252



253



254



255



256



257



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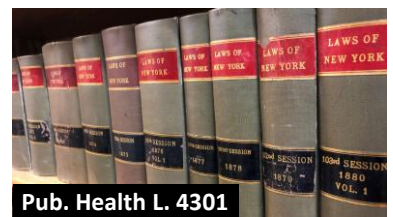
264

no identity
brain dead
CEO authorizes OD

265

no FPA
no family
authorization

266



267

- (i) the person designated ...
- (ii) the person designated as ... agent ...
- (iii) the spouse ...
- (iv) a son or daughter ...
- (v) either parent
- (vi) a brother or sister ...
- (vii) an adult grandchild ...
- (viii) a grandparent ...
- (ix) a guardian ...
- (x) any other person authorized ...**

268

but

269

#10?

270

(j) the person designated ...
 (ii) the person designated as ... age
 (iii) the spouse ...
 (iv) a son or daughter ...
 (v) either parent
 (vi) a brother or sister ...
 (vii) an adult grandchild ...
 (viii) a grandparent ...
 (ix) a guardian ...
 (x) any other person authorized ...



271



272

ME identified &
 notified family
after OD

273

why didn't
 hospital do so
before

274

Supreme Court, New York County, New York.
 Alberto ANAYA, Plaintiff,
 v.
 CITY OF NEW YORK, New York City
 Health and Hospitals Corporation, LiveOnNY
 Foundation, Kervens Louissant, New York
 University Langone Hospitals, Defendant.
 Index No. 154130/2023
 |
 Decided on August 21, 2024

275

negligent
 reckless
 careless

276



277

IN THE COURT OF APPEAL OF THE STATE OF CALIFORNIA
 FIRST APPELLATE DISTRICT
 DIVISION FOUR
 CALIFORNIA ADVOCATES FOR
 NURSING HOME REFORM et al.,
 Plaintiffs and Appellants,
 v.
 KAREN SMITH, as Director, etc.,
 Defendant and Appellant.

A147987
 (Alameda County
 Super. Ct. No. RG13700100)

278

LTC used IDT process
 even though daughter
 was available

279



280



281



282



283



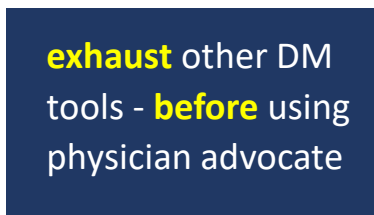
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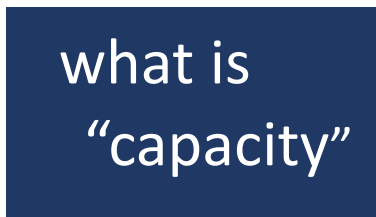
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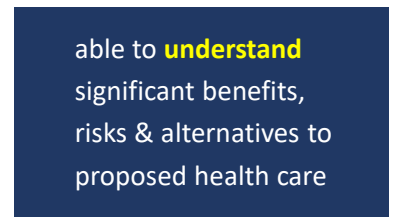
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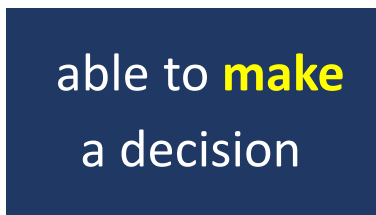
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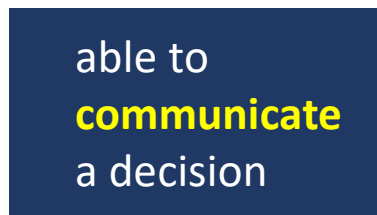
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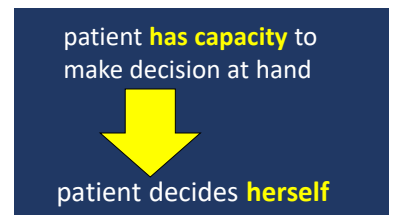
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295



296



297



298

“capable adults may make their **own** health care decisions”

299

all patients **presumed** to have capacity

300

no need to **prove** capacity

301

must prove **in**capacity

302

sometimes obvious

303



304



305

often unclear

306

SO...

307

assess capacity
carefully

308



309

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.

310



311

Capacity – Assess the patient's understanding of the following and document findings:
 A1. Ability to understand the medical problem. : Yes : No : Unsure Why are you in the hospital now? What have you learned from the medical team about your illness?
 A2. Ability to understand the proposed treatment. : Yes : No : Unsure What is the recommended treatment for your problem? What can we do to help you?
 A3. Ability to understand the alternatives to treatment. : Yes : No : Unsure Are there any other treatments available? What other options do you have?
 A4. Ability to understand the option of refusing treatment. : Yes : No : Unsure Can you refuse the treatment? Can we stop the treatment?
 A5. Ability to appreciate consequences of accepting or refusing treatment. : Yes : No : Unsure What could happen to you if you have the treatment? How could the treatment help you? Could the treatment cause problems or side-effects? Could you get sicker or die without the treatment?
 A6. Ability to weigh the risks, benefits and burdens of treatment options. : Yes : No : Unsure
 A7. Ability to rationally reason how to reach a decision to accept or reject treatment. : Yes : No : Unsure Can you tell me how you arrived at your decision? What factors helped you come to your decision?
 B. Is the patient able to communicate the above in her/his own words. : Yes : No : Unsure
 C. Is the patient consistent with her/his communication regarding the above? : Yes : No : Unsure
 Conclusion: Decision Making Capacity – Intact : Unclear : Lacks capacity (Consider lack of DMC if "No" was checked under sections A-7, B, or C above)

312

3 **WARNING**

313



314

not all or nothing

315

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

316

patient may lack capacity for **complex** decisions

317

still capacity **simpler** decisions

318



319

still capacity to **appoint** agent

320



321



322

September 3
AD names agent "companion"

323



324

October 16
AD names
new agent

325



326

later in time
ADs **revoke**
earlier ADs

327



328



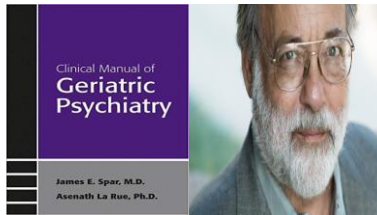
329

lacks capacity
Tx decisions

330



331



332

“alert”
“composed”

333

“**not** appear ...
confused about his
wishes *or* the reasons
for his wishes”

334



335

incapacitated for **most**
decisions - **still** capacity
to appoint agent

336



337

may **fluctuate**
over time

338

capacity in
morning
not afternoon

339

MON	TUE	WED	THU
no capacity		yes capacity	

340

SO...

341

serial
assessments

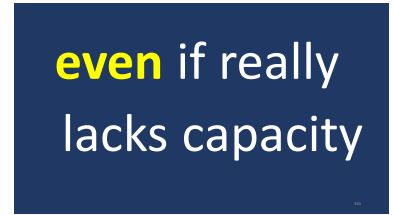
342



343



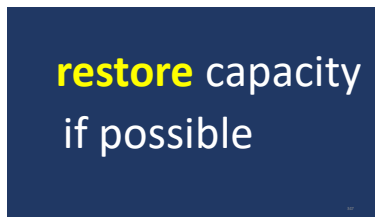
344



345



346



347

HEC Forum
DOI 10.1007/s10730-016-9317-9

Ethical Concerns and Procedural Pathways for Patients Who are Incapacitated and Alone: Implications from a Qualitative Study for Advancing Ethical Practice

Jennifer Move¹ · Casey Catlin^{1,2} · Jennifer Kwak¹ ·

348

Table 7 Means to enhance capacity

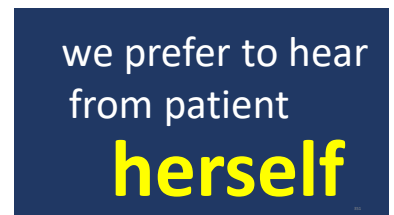
Cause of confusion	Possible intervention
Alcohol or other substances intoxication	Detoxification; supplement diet or other i
Altered blood pressure	Treat underlying cause of blood pressure; medication or other treatment
Altered low blood sugar	Management of blood sugar through diet
Anxiety	Treatment with medications and/or psych groups
Bereavement; Recent death of a spouse or loved one	Support; counseling by therapist or clergy medications to assist in short term probl depression)
Bipolar disorder	Treatment with medications and/or psych

349

Table 7 Means to enhance capacity

Cause of confusion	Possible intervention
Alcohol or other substances intoxication	Detoxification; supplement diet or other i
Altered blood pressure	Treat underlying cause of blood pressure; medication or other treatment
Altered low blood sugar	Management of blood sugar through diet
Anxiety	Treatment with medications and/or psych groups


350



351

supported
decision
making

352

supported DM

substitute DM


353

patient still
in charge


354

collaborate to help
understand situations
and choices, so can make
their **own** decisions

355

if Pt can decide

patient decides

356

if Pt can decide **w/ help**

help them

357

Supported Decision-Making Agreement
This agreement must be read out loud or otherwise communicated to all parties to the agreement in the presence of either a notary or two witnesses. The form of communication shall be appropriate to the needs and preferences of the person with a disability.
My name is: _____
I want to have people I trust help me make decisions. The people who will help me are called **supporters**.
My supporters are not allowed to make choices for me. I will make my own choices, with support. I am called the **decider**.

358

July 2020
Oregon Legislature Unanimously Approves SB 1606
Legislation to Guarantee People with Disabilities Access to Families and Support Staff while in the Hospital
Everyone deserves access to healthcare. People with disabilities have the right to have support from people they trust while they are in the hospital.
 Hospitals in Oregon must allow a patient with a disability to designate at least three support persons

359



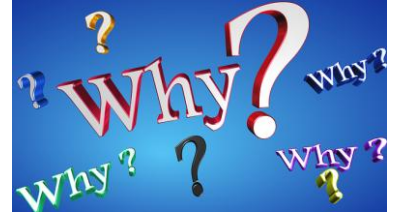
360



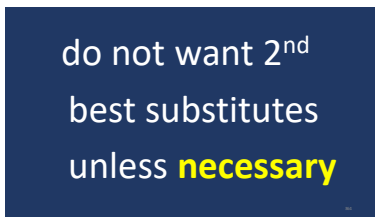
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362



363



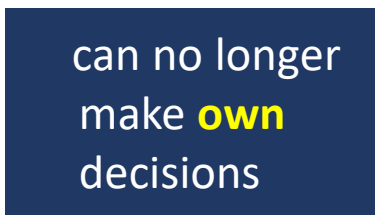
364



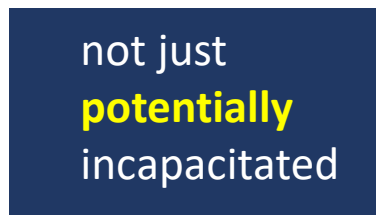
365



366



367



368



369

need a substitute

370

someone who can **speak for Pt** when they cannot speak for themselves

371

agents & appointed representatives

372

ideally, people appoint their **own** agents

373

but

374

not completed

375

RESPECTING PATIENTS' PREFERENCES

By Kathleen N. Yudin, Nicole B. Gebler, Elizabeth Cooney, Saida Kent, Jennifer Kim, Nicole Herbst, Adina Mante, Scott D. Halpern, and Katherine R. Courtney

Approximately One In Three US Adults Completes Any Type Of Advance Directive For End-Of-Life Care

DOI: 10.1093/ajhp/afz015
HEALTH AFFAIRS 38, NO. 7, 2019, 1244-1251
© 2019 American Medical Association
The People's Choice Health Foundation, Inc.

376

systematic review of 150 studies
800,000 people

377

37%

378



379

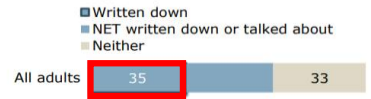
PewResearchCenter NUMBERS, FACTS AND TRENDS SHAPING THE U.S.

NOV 23, 2023
Views on End-of-Life Medical Treatments
Growing Minority of Americans Say Doctors Should Do Everything Possible to Keep Patients Alive

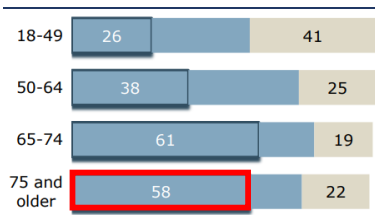
380

Preparation for End-of-Life Treatment, By Age

% who say they have written down or talked with someone about their wishes



381



382



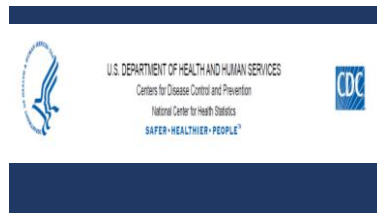
383



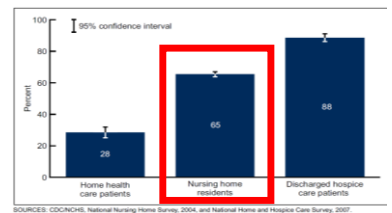
384



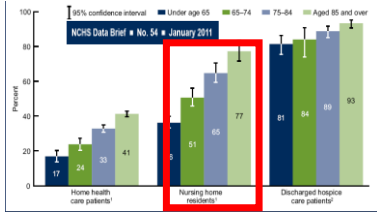
385



386



387



388

65% > 37%

389

1 in 3 80yo NH residents have **no** AD

390



391

even if AD completed

392



393



394

The New York Times
The New Old Age
 Caring and Coping

OCTOBER 17, 2013, 6:00 AM
Where's That Advance Care Directive?
 By PAULA SPAN

395



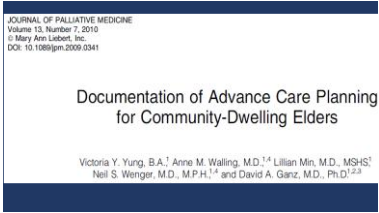
396



397

76% of physicians
whose patients
have ADs do not
know they exist

398



399

“among patients
who ... completed an
advance directive ...
15% ... in the medical
record”

400



401

complete
≠
have

402

Pt have
≠
HCP have

403

SO...

404

80% incapacitated
patients have
no agent

405



406

default
surrogate

407

no agent
↓
default surrogate

408

surrogate
search

409

default
surrogate

410

2nd choice –
after agent

411

not chosen
by patient

412

chosen off
a list

413



414

medical error

415

no AD →
default rule

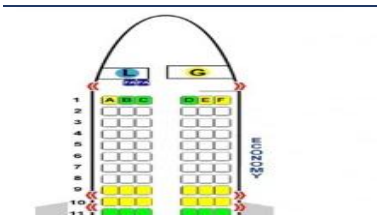
416

default rules
produce **bad**
outcomes

417



418



419



420



421

default surrogate

422

3rd choice

423

- 1. Pt make **own** decision
- 2. Pt **choose** who she trusts

424

2 errors

425

wrong surrogate

426

1

427

Pt prefers someone **off** the list

428

RESEARCH LETTER

Patients With Next-of-Kin Relationships Outside the Nuclear Family

JAMA April 7, 2015 Volume 313, Number 13 1369

429

Nuclear family member	102 042	92.9
Spouse	53 212	48.5
Adult child	22 495	20.5
Parent	14 031	12.8
Sibling	12 304	11.2

430

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	<1
In-law	358	<1
Step-parent or step-sibling	291	<1
Grandparent	170	<1
Grandchild	166	<1
Other blood or legal relative	58	<1

431

2

432

even if preferred surrogate **on** the list, **ranked** too low

433



434

adult child
parent
adult brother or sister
grandparent
grandchild
niece, nephew, aunt, uncle
adult friend

435

priority sequence in list might **not** match **Pt** preference

436

example

437

adult **sibling** might be better surrogate but **child** trumps

438

still

439

wrong surrogate **better** than no surrogate

440



441

“reasonable search ... relatives and friends”

442

guardian
spouse
adult child
parent
sibling
adult relative
adult friend

443

reasonable search

444

AMERICAN THORACIC SOCIETY DOCUMENTS

Making Medical Treatment Decisions for Unrepresented Patients in the ICU
An Official American Thoracic Society/American Geriatrics Society Policy Statement

Thaddeus M. Pope, Joshua Bennett, Shannon S. Carson, Lynetta Codrignani, Andrew B. Cohen, Erin S. DeMartino, David M. Goehry, Paula Goodman-Crews, Marshall B. Kaga, Bernard Lu, David C. Magnus, Lynn F. Reinke, Jamie R. Shirley, Mark D. Siegel, Renee D. Stapleton, Rebecca L. Sudore, Anita J. Tarant, J. Daryl Thornton, Mark R. Wozniak, Eric W. Wolkstein, and Douglas B. White, on behalf of the American Thoracic Society and American Geriatrics Society

This journal policy statement was approved by the American Thoracic Society February 2007 and the American Geriatrics Society January 2008.

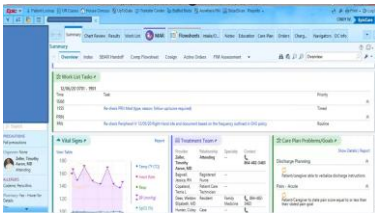
445

diligent search

446



447



448

not just **your** records
+ referring facility
+ PCP

449

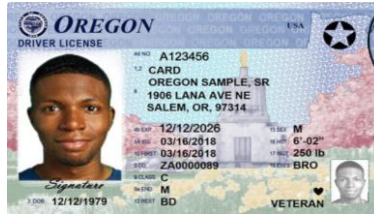
VISITOR SIGN-IN SHEET

DATE	VISITOR'S NAME	REASON FOR VISIT	PHONE	TIME IN	TIME OUT	RESIDENT
8-22-23	James Swift	see above	781-831-1910	9:02		Tom Edwards
8-22-23	KIM KANG	Resident consultant		9:05	10:46	Russ Soria
8-22-23	LISA TOMMS	FAMILY	111-107-1400	9:03		Russ Soria
8-22-23	Rick Franche	Wife of Res	111-111-8761	9:29		Russ Soria
8-22-23	Elizabeth Soria	Wife of Res	98-914-5746	9:47		James Swift
8-22-23	John Soria	Family	98-914-5746	9:52		James Swift
8-22-23	John Soria	Wife of Res	111-111-2581	10:55		Tom Edwards
8-22-23	FRED	Low ADVITARY	603-856-7092	11:56	11:22	STEP SAKSON
8-22-23	John Soria	Wife of Res	98-914-5746	10:56		Tom Edwards

450



451



452

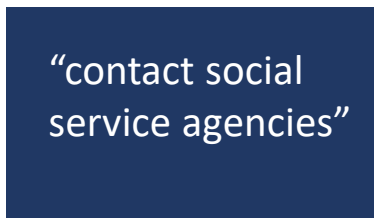


453



ORS 127.760

454



455



456



457



458



459



460



461



462



463



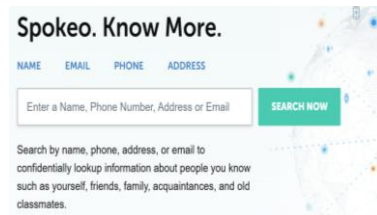
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465



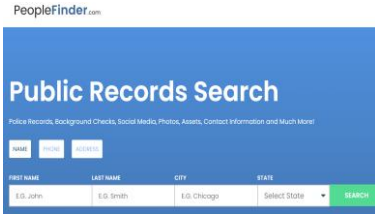
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467



468



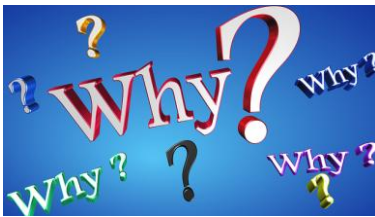
469



470



471



472



473



474

not available,
willing surrogate
still source GVP

475



476

AD search

477



478

appoint
instruct

479

~~appoint~~
instruct

480

FKA
"living will"

481

record treatment
you want
you do not want

482

lots of paper
forms, e-forms
& apps

483



484

some are
treatment
focused

485

For each of the situations at right, check the boxes that indicate your wishes regarding treatment.	Situation A If I am in a coma or persistent vegetative state and have no known hope of recovering awareness or higher mental functions:		Situation B If I am in a coma and have a small but uncertain chance of regaining awareness and higher mental functioning:		Situation C If I am aware but have brain damage that makes me unable to recognize people, to speak meaningfully, or to live independently, and I have a terminal illness:	
	I want	I do not want	I want a trial of the state improvement, and treatment.	I do not want a trial of the state improvement, and treatment.	I want a trial of the state improvement, and treatment.	I do not want a trial of the state improvement, and treatment.
1. Cardiorespiratory resuscitation. The use of pressure on the chest, drugs, electric shocks and artificial breathing to revive me if my heart stops.						
2. Mechanical respiration. Breathing by machine, through a tube, or by chest.						
3. Artificial feeding. Giving food and water through a tube inserted either in a vein, into the nose, or through a hole in the stomach.						

486

others are more
goal focused

487



488

Part 3: My Hopes and Wishes (Optional)
I want my loved ones to know my following thoughts and feelings:
The things that make life most worth living to me are:

My beliefs about when life would be no longer worth living:

489

advantage

490

hear from patient
herself

491

best DM for you
is **you**

492

record values
& preferences

493



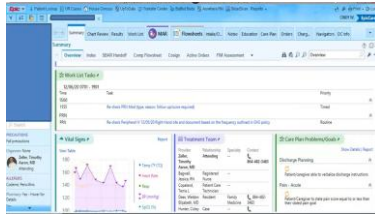
494

“reasonable search
... healthcare
instructions”

495

reasonable search

496



497

portable orders for life-sustaining treatment
Oregon POLST® Registry

PATIENTS AND FAMILIES • EDUCATION CENTER • OREGON POLST • CONTACT • OPR PROVIDER PORTAL

498



499

no AD, POLST
still source GVP

500

guardian
conservator

501

ask court to
appoint SDM

502

slow
expensive
cumbersome

503



504



505

directed
delegated
devolved

displaced

506

physician
advocate

507



508

who makes
decisions for
unrepresented
patients

509

how to
make those
decisions

510

who

511

“hospital may appoint a
health care provider ... to
give informed consent ...
on behalf of a patient
admitted to the hospital”

512



513



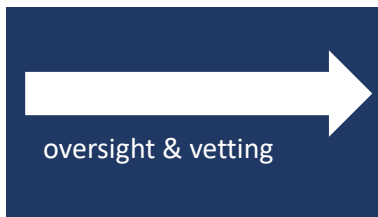
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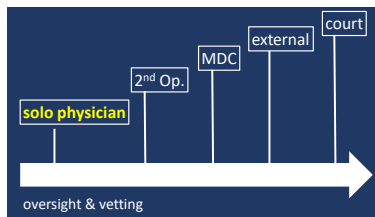
515

“**may not serve** as health care representatives ... attending ... provider ... or ... employee ...”

516



517



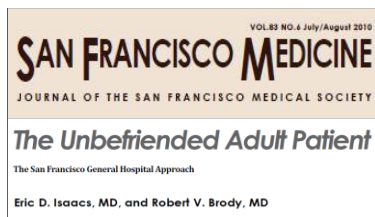
518

solo physician

519



520



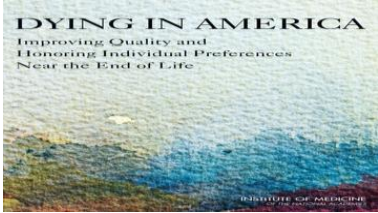
521

“**attending physician** . . . make decisions for the unbefriended adult patient”

522

“causes **angst** for the greater ethics community”

523



524

“having a **single health professional** make unilateral decisions . . .”

525

“**ethically unsatisfactory** in terms of protecting patient autonomy and establishing transparency”

526



527

2 reasons

528

bias & COI unchecked

529

less carefully considered

530



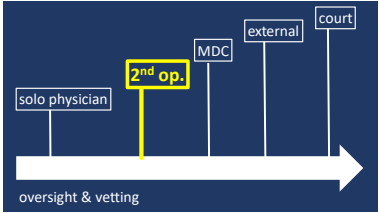
531

substance abuse
disability
poverty
mental illness
social isolation

532

second
physician
consent

533



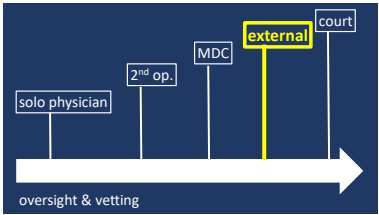
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better

535

external
consent

536



537



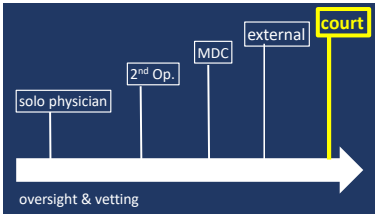
538

“clinical social worker
... selected by ...
bioethics committee ...
not be employed”

539

court

540



541



542



543

courts are
too slow

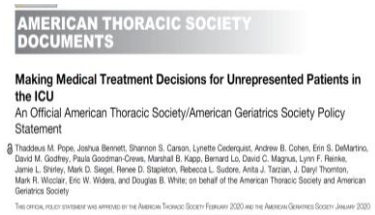
544

but other
mechanisms
are **too fast**

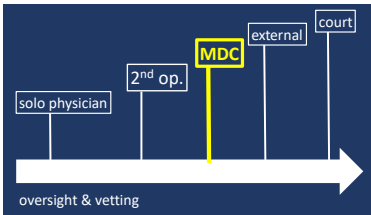
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546



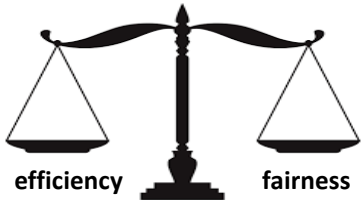
547



548

**multidisciplinary
committee**

549



550

accessible
quick
convenient

551

expert
neutral
careful

552



553



554

3 safeguards

555

physician
advocate

556

“received training in
healthcare **ethics**”

557

“received training ...
identification &
management of
conflicts of interest”

558

“person appointed ... is
the patient’s attending ...
appoint another ...
provider ... to participate
in making decisions ...”

559

who

560

how

561

substituted
judgment

if possible

562

“if a patient’s wishes ...
were made **known** during a
period when the patient
was capable ... **comply with**
those wishes”

563

“knows the patient’s **religious**
preference ... make reasonable
efforts to confer with a
member of the **clergy** of the
patient’s religious tradition”

564

if cannot

565

best
interest

566

is treatment **proportionate** in terms
of the benefits gained versus
burdens caused

quality of life

life expectancy

prognosis for recovery with and

567

prognosis for recovery with and without treatment
treatment options and the risks, side effects, and benefits of each
nature and degree of physical pain or suffering

568

THE AMERICAN JOURNAL OF BIOETHICS
2024, VOL. 54, NO. 7, 13-26
<https://doi.org/10.1080/13625750.2023.2204932>

Taylor & Francis
Taylor & Francis Group

TARGET ARTICLE

OPEN ACCESS

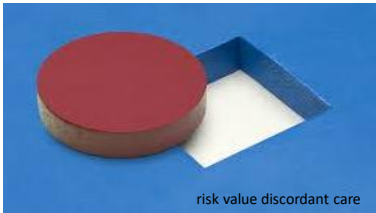
A Personalized Patient Preference Predictor for Substituted Judgments in Healthcare: Technically Feasible and Ethically Desirable

Brian D. Earp^{1,2,3,4}, Sebastian Porsdam Mann^{1,4}, Jemima Allen^{1,4}, Sabine Salloch^{1,4}, Vynn Suren¹

569

conclusion

570



571



572

AMERICAN THORACIC SOCIETY DOCUMENTS

Making Medical Treatment Decisions for Unrepresented Patients in the ICU
An Official American Thoracic Society/American Geriatrics Society Policy Statement

Thaddeus M. Pope, Joshua Bennett, Shannon S. Carson, Lynette Cedrazait, Andrew B. Cohen, Erin S. DeMartino, David M. Gotthey, Paula Goodman-Crews, Marshall S. Rapp, Bernard Lo, David C. Magnus, Lynn F. Renke, James L. Shroy, Mark D. Siegel, Renee D. Stapleton, Rebecca L. Squires, Ansh J. Tarcan, J. Daryl Thornton, Mark R. Wicclair, Eric W. Winkler, and Douglas B. White, on behalf of the American Thoracic Society and American Geriatrics Society

THE OFFICIAL POLICY STATEMENT WAS APPROVED BY THE AMERICAN THORACIC SOCIETY FEBRUARY 2020 AND THE AMERICAN GERIATRICS SOCIETY JANUARY 2020

573

prevent
manage

574

prevention

575

Offer **advance care planning** to prevent patients at high risk for becoming unrepresented from meeting this definition

576

Implement strategies to determine whether seemingly unrepresented patients **are actually** unrepresented,

577

including careful **capacity** assessments and diligent **searches** for potential surrogates

578

management

579

Manage decision-making for unrepresented patients using input from a **diverse interprofessional, multidisciplinary committee** rather than ad hoc by treating clinicians

580

Use **all available information** on the patient's preferences and values to guide treatment decisions

581

Manage decision-making for unrepresented patients using a **fair process** that comports with procedural due process

582



583

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

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