MEDICAL COLLEGE OF WISCONSIN

1

Unrepresented Patients

Definition, Prevention, and Legitimate Decision Making

2

Thaddeus Pope

June 19, 2026

3

4

nothing

to disclose

5

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-Crews, Marshall B. Kapp, Bernard Lo, David C. Magnus, Lynn F. Reinke, Jamie L. Shirley, Mark D. Siegel, Renee D. Stapleton, Rebecca L. Sudore, Anita J. Tarzian, J. Daryl Thornton, Mark R. Wicclair, Eric W. Widera, 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

6

We help the world breathe®
PULMONARY · CRITICAL CARE · SLEEP

LOGIN

ABOUT ▾ ADVOCACY ▾ PROFESSIONALS ▾ PATIENTS ▾

ATS Official Documents

Home ▸ ATS Official Documents ▸ Health Care Policy, Ethics, and End-of-Life Care

ATS Official Documents | Health Care Policy, Ethics, and End-of-Life Care

https://academic.oup.com/ajrccm/article/201/10/1182/8496358?searchresult=1

7

3 points

8

prevent patients from becoming unrepresented

9

patients who **seem** unrepresented probably are **not**

10

when Pt **really** is unrepresented, make Tx decisions **carefully**

11

12

value
concordant
healthcare

13

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

14

also

15

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

16

too **little**
= harm

17

too **much**
= harm

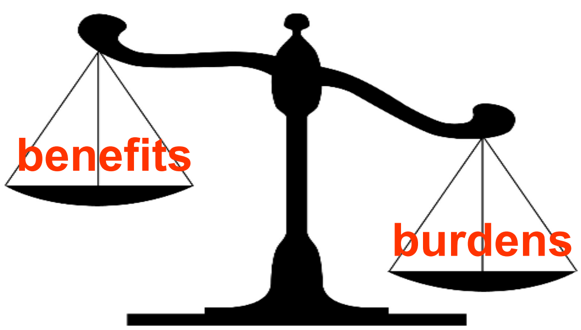
18

how much is
too much is
value laden

19

preference
sensitive
decision

20



21

2
types of
value
discordant
healthcare

22

over-treatment

under-treatment

23

happens to patients
with decision
making capacity

24

happens

more

25

to

incapacitated

patients

26

27

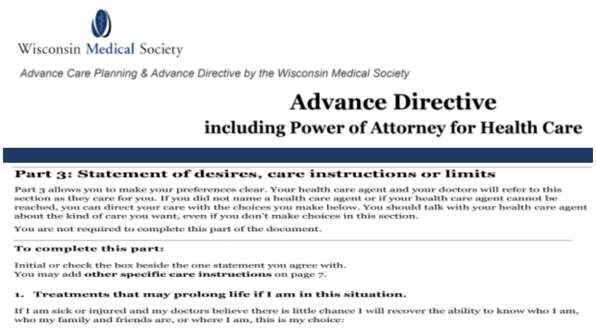
cannot tell us what they want & do not want

28

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

29

30


Wisconsin Medical Society

Advance Care Planning & Advance Directive by the Wisconsin Medical Society

Advance Directive
including Power of Attorney for Health Care

Part 3: Statement of desires, care instructions or limits

Part 3 allows you to make your preferences clear. Your health care agent and your doctors will refer to this section as they care for you. If you did not name a health care agent or if your health care agent cannot be reached, you can direct your care with the choices you make below. You should talk with your health care agent about the kind of care you want, even if you don't make choices in this section.

You are not required to complete this part of the document.

To complete this part:

Initial or check the box beside the one statement you agree with.
You may add **other specific care instructions** on page 7.

1. Treatments that may prolong life if I am in this situation.

If I am sick or injured and my doctors believe there is little chance I will recover the ability to know who I am, who my family and friends are, or where I am, this is my choice:

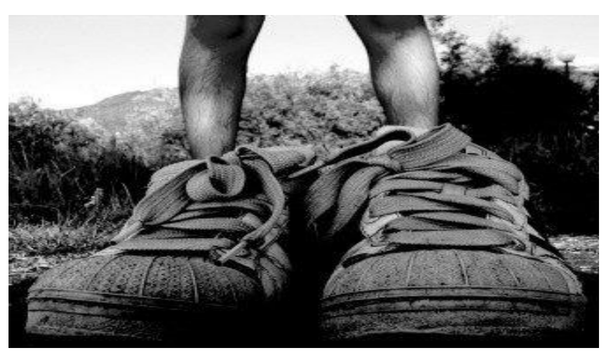
31

32

33

34

35



36

you could be unrepresented

37

38

try talk to **you**
to ascertain
what **you** want

39

if cannot

40

try to
identify you

41

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

42

if cannot

43

try to **find**
AD, POLST

44

so, **they** can
guide Tx

45

if cannot

46

try to find
other VGP
evidence

47

so, **it** can
guide Tx

48

if cannot

49

use **fair process** to decide Tx

50

51

52

53

how well does **current practice** measure up?

54

roadmap

55

6 parts

56

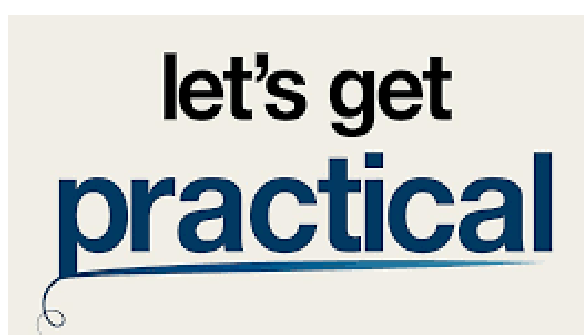
profile
population

57

demographics
empirical research

58

59



60

prevention

61

capacity

62

search for surrogates

63

search for ADs

64

if **cannot** prevent Pt from being unrepresented

65

decision making

66

profile

67

unrepresented patient

68

increasingly **common** situation

69

hospitals & LTC **challenged**

70

patient **needs** treatment

71

but

72

no capacity

no surrogate

73

patient

cannot

consent

74

nobody

else to

consent

75

various terms

76

adult orphan

77

patient w/o proxy

78

incapacitated & alone

79

incapacitated adult without advocate

80

JAMDA 25 (2024) 105019

ELSEVIER

JAMDA

journal homepage: www.jamda.com

Original Study

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

Check for updates

Jiyoun Song PhD, AGACNP-BC, APRN[a], Maxim Topaz PhD, RN[b,c,d],

81

INEADS

Incapacitated with No Evident Advance Directives or Surrogates

82

unbefriended

83

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

84

The National Long-Term Care Ombudsman Resource Center

Advocating for the Unbefriended Elderly

An Informational Brief

August 2010

85

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

AGS Geriatrics Healthcare Professionals

Leading Change. Improving Care for Older Adults.

86

2020 →

87

unrepresented

88

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

Gerontology & Geriatric Medicine
Volume 9: 1–8
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DOI: 10.1177/23337214221142936
journals.sagepub.com/home/ggm
SAGE

Rachel Brenner, MD[1,2], Linda Cole, MS[3],
Gail L. Towsley, PhD, NHA, FGSA[3], and
Timothy W. Farrell, MD, AGSF[2]

89

"noticeable shift
… unbefriended
to unrepresented"

90

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

91

2025

AGS Geriatrics Healthcare Professionals

92

unrepresented

term to use

93

who

are they

94

lack

capacity

95

lack

AD, POLST

96

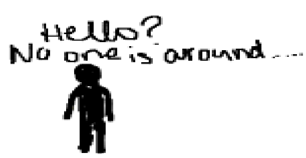
lack

any type SDM

97

nobody to consent to treatment

98



99

big

problem

100

hospital estimates

101

16% ICU admits

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

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

102

5% ICU deaths

ARTICLE | Annals of Internal Medicine

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

Douglas B. White, MD, MAS; J. Randall Curtis, MD, MPH; Leslie E. Wolf, JD, MPH; Thomas J. Prendergast, MD; Darren B. Taichman, MD, PhD; Gary Kuniyoshi, MD; Frank Acerra, DO; Bernard Lo, MD; and John M. Luce, MD

103

> 28,000

US, each year

104

GEORGIA Appleseed

CARING FOR GEORGIA'S unbefriended elders

Views from the Probate Bench on the 2010 Amendments to the Surgical and Medical Consent Statute

105

Royal College of Physicians | Marie Curie — Care and support through terminal illness

End of Life Care Audit – Dying in Hospital

National report for England 2016

106

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	$\boxed{4\%}$	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

107

Clin Gerontol. ; : 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], A D. Naik, MD[f], Eric Widera, MD[e], Jennifer Moye, PhD[g]

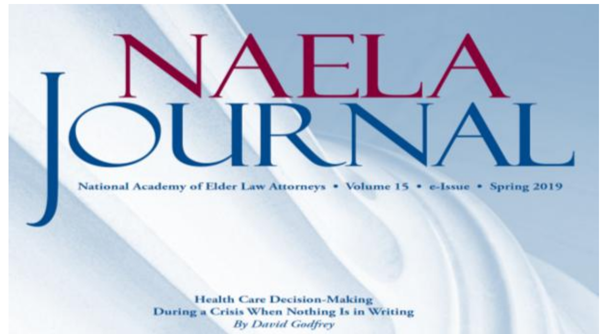
108

"clinicians … inpatient setting … encounter"

weekly 24.5%

monthly 36.7%

109



110

50% hospitalists
& intensivists

see **>1** unrepresented patient / month

111

112

113

that's
hospital
context

114

LTC estimates

115

Incapacitated and Alone:

Health Care Decision-Making for the Unbefriended Elderly

Naomi Karp and Erica Wood

American Bar Association
Commission on Law and Aging

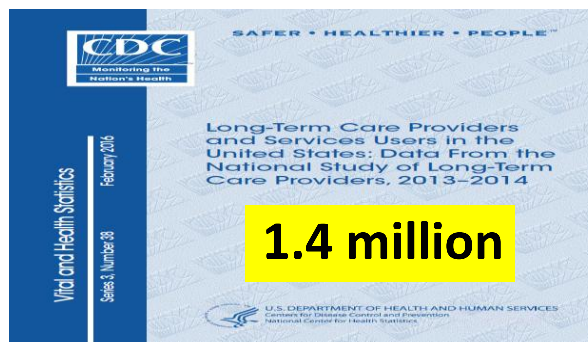
July 2003

116

3-4%

U.S. nursing home population

117



118

> 56,000

USA

119

120

1020

121

plus

122

temporarily

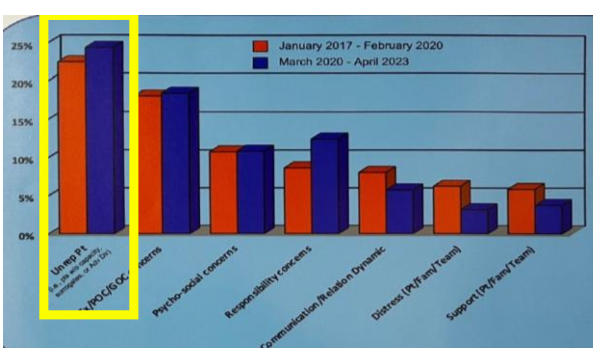
unrepresented

123

big

problem

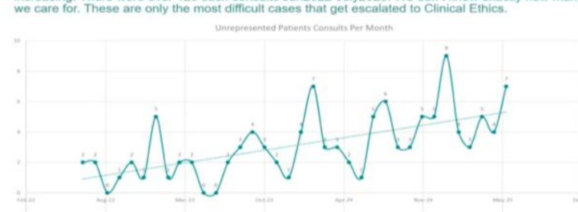
124



125

Unrepresented Patients Ethics Consults

Over the last few years, monthly Clinical Ethics Consults for unrepresented patients at IH have been increasing. There were over 120 such consults Jan2022-July2025. We don't know exactly how many we care for. These are only the most difficult cases that get escalated to Clinical Ethics.



3 per month

126

big
problem

127

also

128

growing
problem

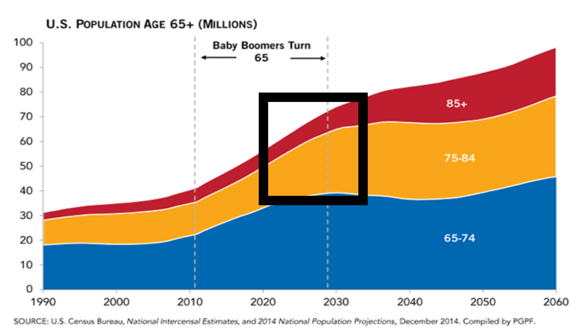
129

4 key
factors

130

1

131



132

2

133

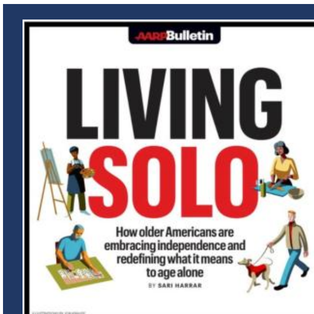
AARP Public Policy Institute

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

134

135



24
million

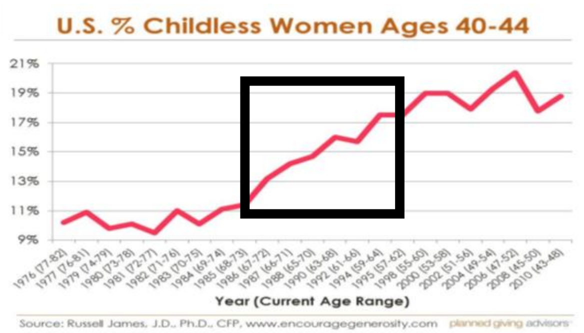
Nov. 2025

136

3

137

138



139

4

140

others
“have”
family

141

able but
unwilling

142

no **contact**

LGBTQ+, homeless,
criminal

143

conversely

144

willing but **unable**

145

SDM lacks **capacity**

146

147

we have **many** unrepresented

148

also

149

under-represented

150

have surrogate
but surrogate
limited in DM

151

what's the
problem

152

risks & harms

153

cannot
advocate
for self

154

have **no**
substitute
advocate

155

Making Treatment Decisions for Incapacitated Older Adults Without Advance Directives

AGS Ethics Committee

"highly vulnerable"

"**most** vulnerable"

156

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

WINSOR C. SCHMIDT*

“unimaginably helpless”

157

problem

158

nobody to authorize treatment

159

how do clinicians respond?

160

3 common responses

161

all 3 are **bad**

162

1

163

under-
treatment

164

reluctant to
act without
consent

165

wait

166

until
emergency
(implied consent)

167

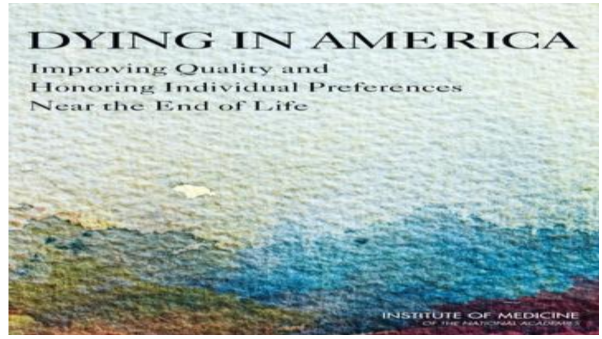
but

168

longer period suffering

increases risks

169



170

ethically “**troublesome**

... wait until ... worsens

into an **emergency**”

171

2

172

over-treatment

173

fear liability

fear regulatory sanctions

174

treat aggressively

175

default

aggressive

curative directed therapy

176

but

177

burdensome

unwanted

178

The Washington Post

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

179

Trauma Death

Views of the Public and Trauma Professionals on Death and Dying From Injuries

Lenworth M. Jacobs, MD, MPH; Karyl Burns, RN, PhD; Barbara Bennett Jacobs, RN, MPH, PhD, CHPN

Arch Surg. 2008;143(8):730-735

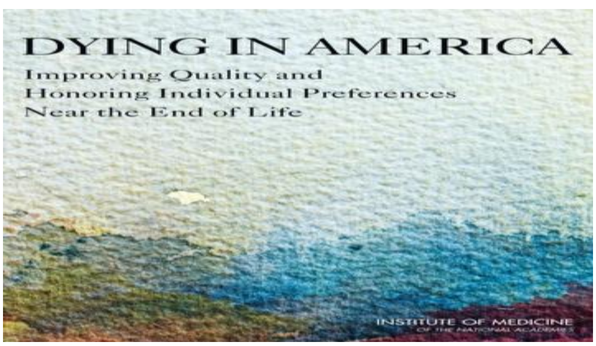
180

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

181

Unrep → UMT

182



183

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

184

3

185

no discharge to appropriate setting

186

187

188

189

unrepresented

↓

error & harm

190

undertreatment

overtreatment

no discharge

191

harms **other**
patients too

192

193

MEDPAGETODAY®

100 Days Trapped in Inpatient Legal Limbo

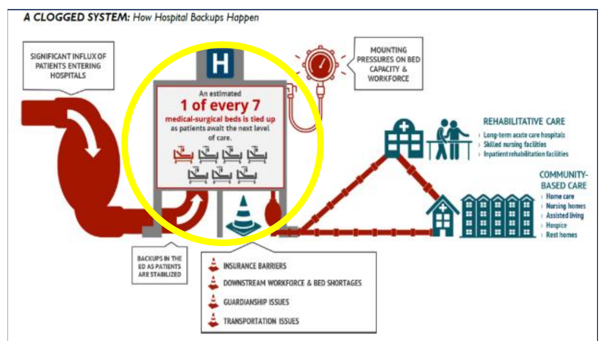
— Awaiting guardianship in the hospital long-term should not be the norm

by Gabrielle Kis Bromberg, MD, and Kathleen McFadden, MD

November 6, 2024

194

195



196

197

Report of the Working Group on Alternatives to Guardianship for Unrepresented Hospital Patients in Need of Treatment and Discharge Decisions

December 27, 2025

Submitted as Background in Support of House Bills 1062 and 1323

By the

Maryland Healthcare Ethics Committee Network

And the

Alternatives to Guardianship Working Group

198

199

200

prevention

201

202

best way to **protect** the unrepresented

prevent them from becoming unrepresented

203

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204

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.

205

206

207

example

208

209

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. Bell[1], A. Kazi[2], B. Joffe[3], S. Schepps[3], R. Horowitz[4], E. J. Yoo[5], D. Oxman[2]; [1]Internal Medicine,

210

211

Jefferson
Thomas Jefferson University
HOME OF SIDNEY KIMMEL MEDICAL COLLEGE

212

60 patients
H seeks
guardian

213

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

214

probably **had**
surrogate at NH

215

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%)

216

missed opportunity

217

name agent **before** lose capacity

218

Late Action
- Clinical Ethics is consulted on average day 6
- Surrogates are found in 48% of cases (and often could have been found earlier)

Health Care Agent Documentation
- System-wide, only 12% of all patients have an HCA documented prior to discharge

Missed Opportunities
- 52% had an IH encounter within the prior year in which they likely had capacity, but weren't asked about a surrogate decision maker

219

already supposed to be doing this

220

Patient Self-Determination Act

221

1990

222

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

223

CENTERS FOR MEDICARE & MEDICAID SERVICES

224

that's enough on

prevention

225

patient is **here** & seemingly unrepresented

226

last resort

227

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228

institutional mechanisms

229

230

but

231

232

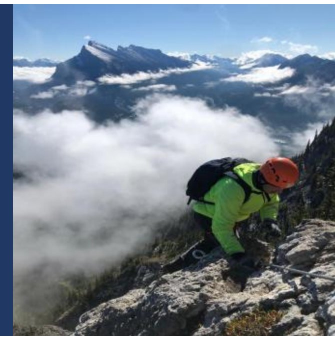
1st exhaust other DM

233

234

2 analogies

235



236

237

238

PSU only if suffering
intractable
refractory
other measures

239

SO …

240

241

242

seemingly unrepresented patients often are **not**

243

4 reasons we will dive into next

244

1

245

Pt may **not** be incapacitated

246

2

247

capacity might be **fixable**

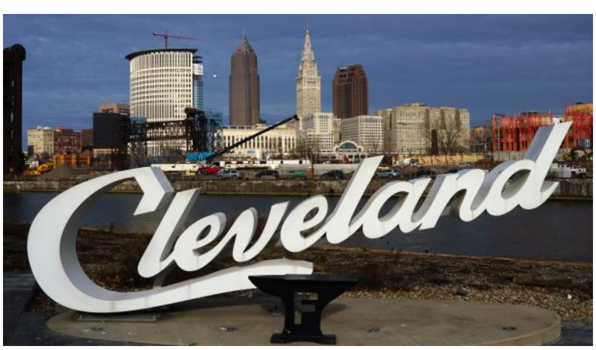
248

3

249

friends or family often **findable**

250



251

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 Blackstone[3] · Lauren McAliley[4] · Barbara Daly[3]

252

found family
in 6 cases **after**
hospital committee
was appointed

253

4

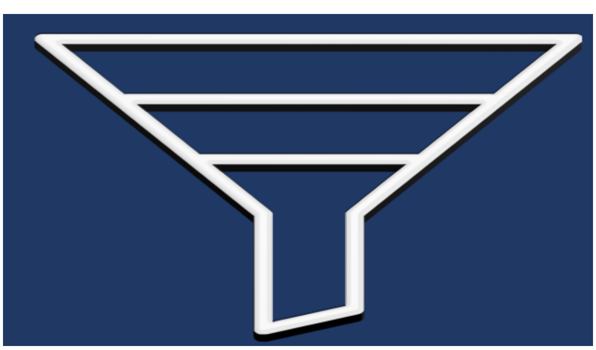
254

AD, POLST,
goals, prefs.
often **findable**

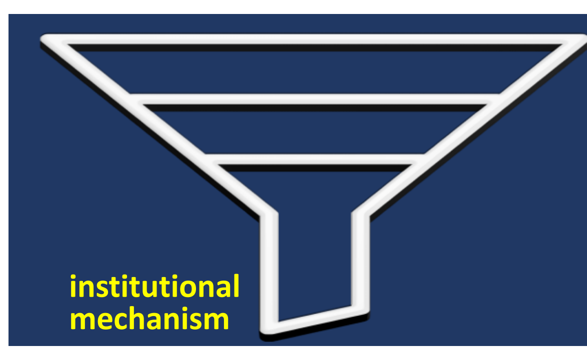
255

so…

256



257



258

259

260

261

262

NYC
HEALTH+
HOSPITALS

Bellevue

263

no identity

brain dead

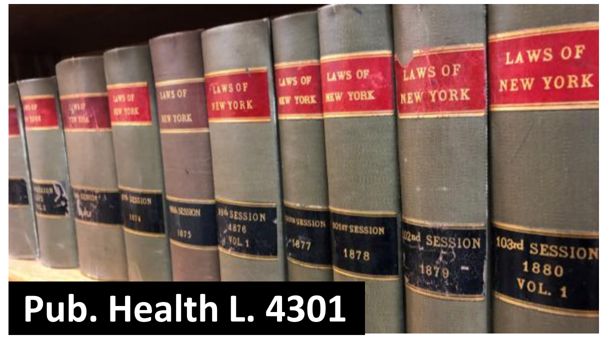
CEO authorizes OD

264

no FPA

no family authorization

265



266

(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 …

267

but

268

#10?

269

(i) 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 …

?

270

271

ME identified & notified family **after** OD

272

why didn't hospital do so **before**

273

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

274

negligent
reckless
careless

275

276

SUPERIOR COURT OF CALIFORNIA, COUNTY OF SACRAMENTO
Gordon D. Schaber Superior Court, Department 25
JUDICIAL OFFICER: HONORABLE JULIE G. YAP

Courtroom Clerk: L. Homsanith
Court Attendant: C. Levy
CSR: None

25CV009026
November 19, 2025
1:30 PM

WALKER, et al.
vs
COMMONSPIRIT HEALTH, A NONPROFIT CORPORATION, et al.

277

278

279

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)

280

LTC used IDT process

even though
daughter available

281

282

exhaust other DM tools - **before** using institutional DM

283

284

285

286

capacity

287

what is "capacity"

288

3

289

able to **understand** significant benefits, risks & alternatives to proposed health care

290

able to **make** a decision

291

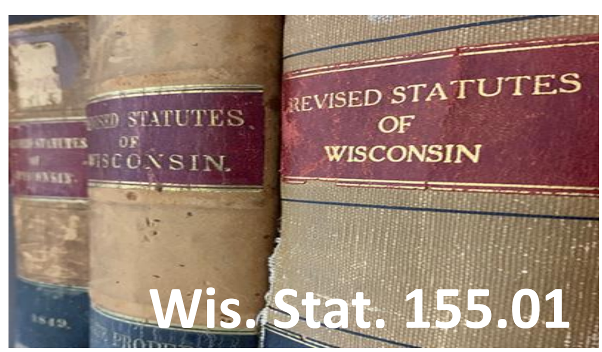
able to **communicate** a decision

292

patient **has capacity** to make decision at hand

patient decides **herself**

293



294

patients with capacity make their **own** healthcare decisions

295

all patients **presumed** to have capacity

296

no need to **prove** capacity

297

must prove **in**capacity

298

sometimes obvious

299

300

301

often

unclear

302

so…

303

assess capacity

carefully

304

AGS Geriatrics Healthcare Professionals

Leading Change. Improving Care for Older Adults.

305

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.

306

307

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 1-7, B, or C above)

308

309

310

not all or nothing

311

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

312

patient may lack capacity for **complex** decisions

313

still capacity

simpler decisions

314

315

still capacity to

appoint agent

316

Sumner Redstone

317

VIACOMCBS

CBS SHOWTIME nickelodeon MTV COMEDY CENTRAL BET

CBS ALL ACCESS PLUTO TV SIMON & SCHUSTER 5 10 telefe colors

318

319

320

321

322

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

323

324

may **fluctuate**
over time

325

capacity in
morning
not afternoon

326

MON	TUE	WED	THU
no capacity		yes capacity	

327

SO…

328

serial
assessments

329

time
limited
trial

330

331

even if really
lacks capacity

332

reversible

333

restore capacity
if possible

334

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 Moye[1] · Casey Catlin[1,2] · Jennifer Kwak[1] ·

335

Table 7 Means to enhance capacity

Cause of confusion	Possible intervention
Alcohol or other substances intoxification	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

336

Table 7 Means to enhance capacity

Cause of confusion	Possible intervention
Alcohol or other substances intoxification	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

337

we prefer to hear from patient **herself**

338

supported decision making

339

WISCONSIN LEGISLATIVE COUNCIL
ACT MEMO

2017 Wisconsin Act 345 [2017 Assembly Bill 655]	Supported Decision-Making Agreements

340

supported DM

$\neq$

substitute DM

341

patient still in charge

342

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**.

343

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

344

if Pt can decide

patient decides

345

if Pt can decide **w/ help**

help them

346

347

3

348

assess
restore
preserve

349

350

do not want 2nd
best substitutes
unless **necessary**

351

but

352

will lose
capacity

353

can no longer
make **own**
decisions

354

not just **potentially** incapacitated

355

definitely incapacitated

356

need a substitute

357

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

358

agents & appointed representatives

359

ideally, people appoint their **own** agents

360

but

361

not

completed

362

RESPECTING PATIENTS' PREFERENCES

DOI: 10.1377/hlthaff.2017.0175
HEALTH AFFAIRS 36,
NO. 7 (2017): 1244-1251

By Kuldeep N. Yadav, Nicole B. Gabler, Elizabeth Cooney, Saida Kent, Jennifer Kim, Nicole Herbst, Adjoa Mante, Scott D. Halpern, and Katherine R. Courtright

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

363

systematic review
of 150 studies

800,000 people

364

37%

365

366

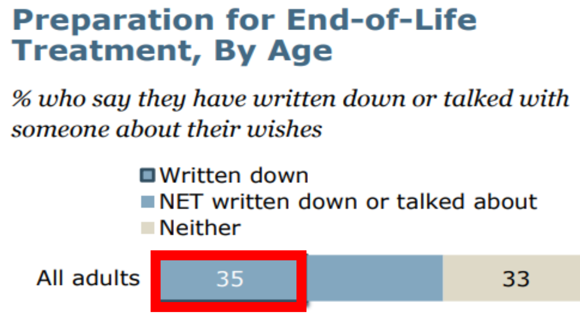
PewResearchCenter NUMBERS, FACTS AND TRENDS SHAPING THE W

NOV. 21, 2013

Views on End-of-Life Medical Treatments

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

367



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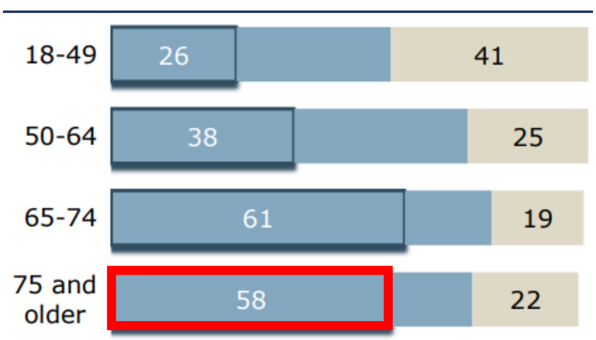

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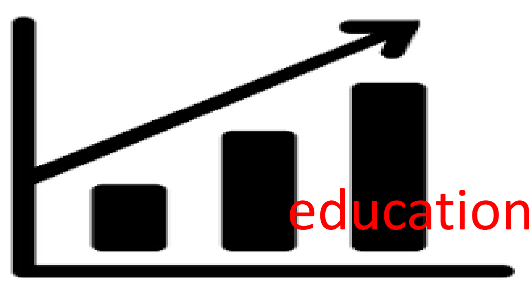

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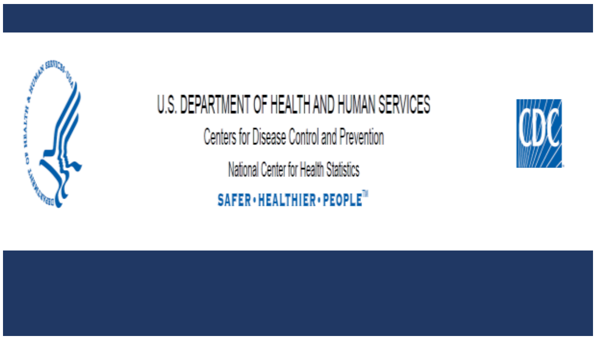

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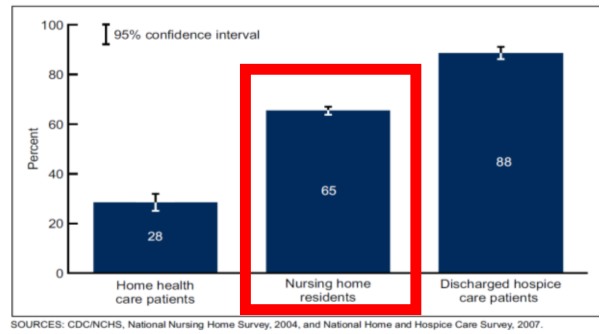

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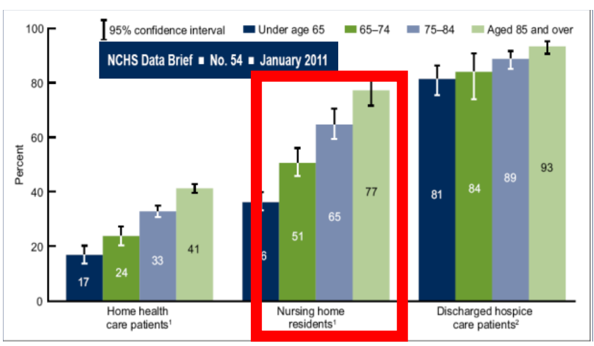


375

65% > 37%

376

1 in 3 80yo

NH residents

have **no** AD

377

378

even if AD completed

379

380

381

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

382

MISSING
ADVANCE DIRECTIVE

383

U.S. Department of Health and Human Services
Assistant Secretary for Planning and Evaluation
Office of Disability, Aging and Long-Term Care Policy

384

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

385

JOURNAL OF PALLIATIVE MEDICINE
Volume 13, Number 7, 2010
© Mary Ann Liebert, Inc.
DOI: 10.1089/jpm.2009.0341

Documentation of Advance Care Planning for Community-Dwelling Elders

Victoria Y. Yung, B.A.,[1] Anne M. Walling, M.D.,[1,4] Lillian Min, M.D., MSHS,[1] Neil S. Wenger, M.D., M.P.H.,[1,4] and David A. Ganz, M.D., Ph.D.[1,2,3]

386

"among patients who … completed an advance directive … **15%** … in the medical record"

387

388

complete

≠

have

389

Pt have

≠

HCP have

390

so…

391

80% incapacitated patients have **no** agent

392

393

default surrogate

394

no agent
↓
default surrogate

395

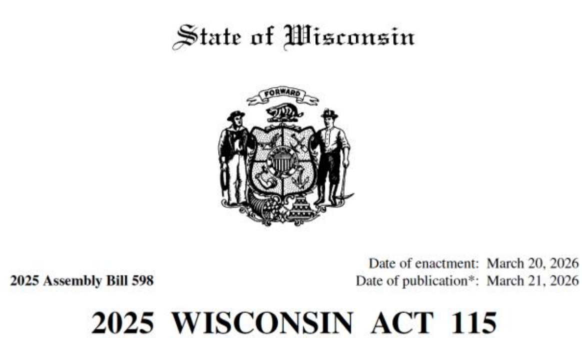
396

397

398

399

400



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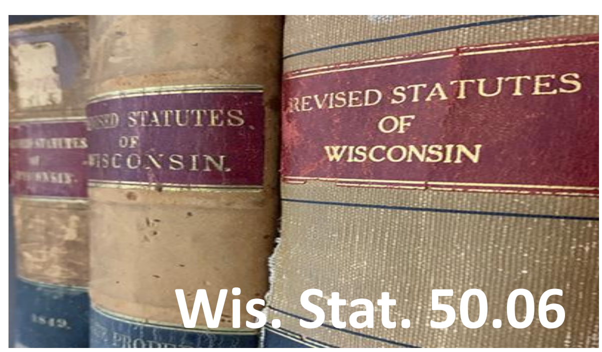


402

"patient representative"

403

NOK may d/c to post-acute **w/o** guardianship

404

clear **1000s** days of delay

405

406

but

407

Tx DM for **in**patients

408

default surrogate

409

2^{nd} choice – after agent

410

not chosen by patient

411

chosen off **a list**

412

State of Wisconsin
2023 - 2024 LEGISLATURE

2023 SENATE BILL 682

413

hospital-based **list**

414

415

medical error

416

no AD →

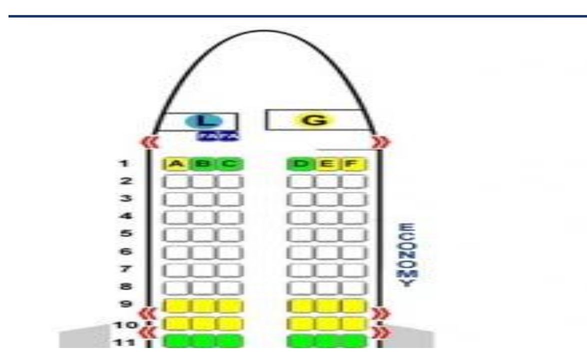
default rule

417

default rules produce **bad** outcomes

418

419



420

421

422

default
surrogate

423

3rd choice

424

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

425

2 errors

426

wrong surrogate

427

1

428

Pt prefers someone **off** the list

429

RESEARCH LETTER

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

JAMA April 7, 2015 Volume 313, Number 13 1369

430

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

431

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

432

2

433

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

434

435

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

436

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

437

437

example

438

438

adult **sibling** might be better surrogate

but **child** trumps

439

still

440

wrong surrogate **better** than no surrogate

441

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-Crews, Marshall B. Kapp, Bernard Lo, David C. Magnus, Lynn F. Reinke, Jamie L. Shirley, Mark D. Siegel, Renee D. Stapleton, Rebecca L. Sudore, Anita J. Tarzian, J. Daryl Thornton, Mark R. Wicclair, Eric W. Widera, and Douglas B. White; on behalf of the American Thoracic Society and American Geriatrics Society

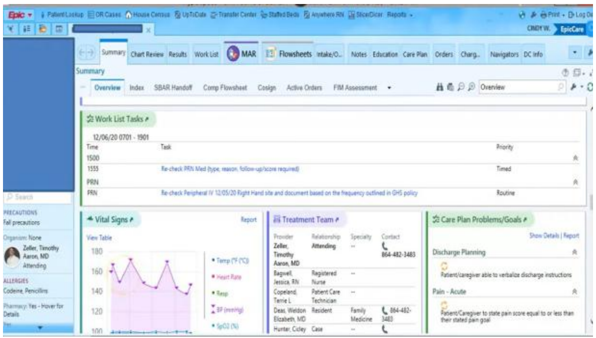
THIS OFFICIAL POLICY STATEMENT WAS APPROVED BY THE AMERICAN THORACIC SOCIETY FEBRUARY 2020 AND THE AMERICAN GERIATRICS SOCIETY JANUARY 2020

442

diligent search

443

444



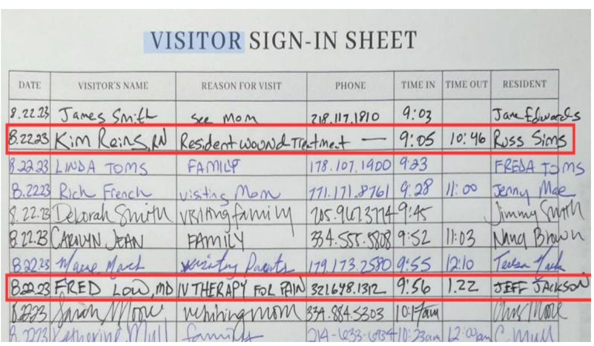
445

not just **your** records

+ referring facility

+ PCP

446

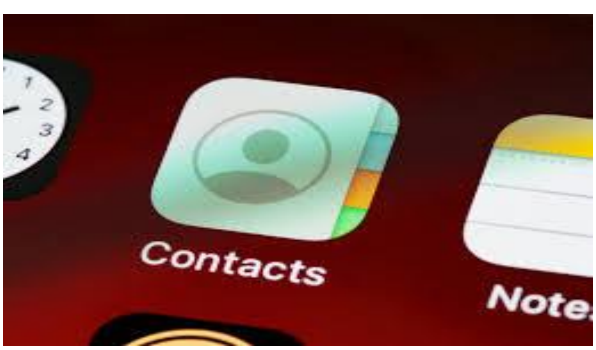


VISITOR SIGN-IN SHEET

DATE	VISITOR'S NAME	REASON FOR VISIT	PHONE	TIME IN	TIME OUT	RESIDENT
8.22.23	James Smith	See Mom	218.117.1810	9:03		Jane Edwards
8.22.23	Kim Reins, RN	Resident wound Treatment	—	9:05	10:46	Russ Sims
8.22.23	LINDA TOMS	FAMILY	178.107.1900	9:23		FREDA TOMS
8.22.23	Rich French	visiting Mom	771.171.8761	9:28	11:00	Jenny Mae
8.22.23	Deborah Smith	visiting family	205.967.3774	9:45		Jimmy Smith
8.22.23	CAROLYN JEAN	FAMILY	334.555.5808	9:52	11:03	Nana Brown
8.22.23	[illegible]	visiting Parents	179.173.2580	9:55	12:10	[illegible]
8.22.23	FRED LOW, MD	IV THERAPY FOR PAIN	321.678.1312	9:56	1.22	JEFF JACKSON
8.22.23	Sarah Moore	visiting mom	334.884.5303	10:17am		Chris Moore
8.22.23	Katherine Mull	family	214-633-6934	10:23am	12:00am	C. Mull

447

448



449

MILWAUKEE COUNTY

MILWAUKEE COUNTY
Health & Human Services

450

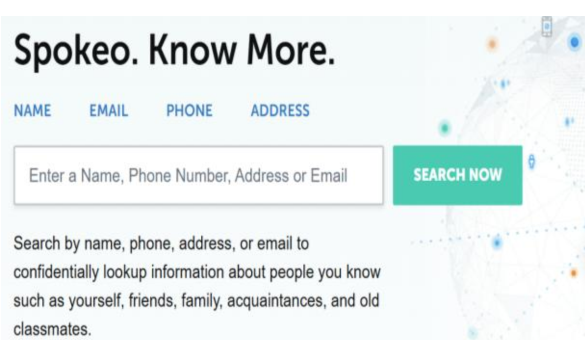
451

internet tools

452

453

454



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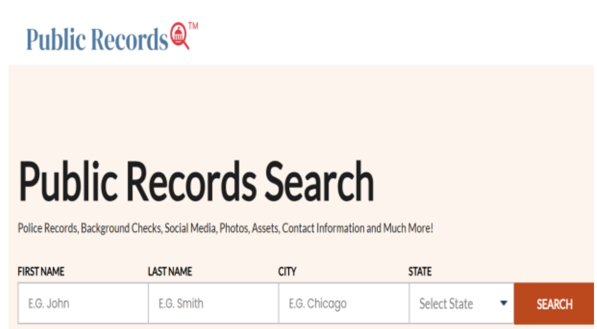

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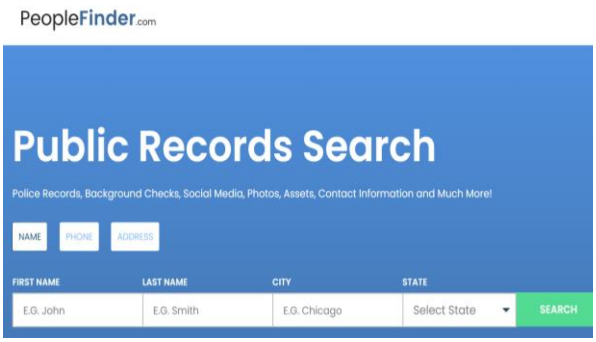

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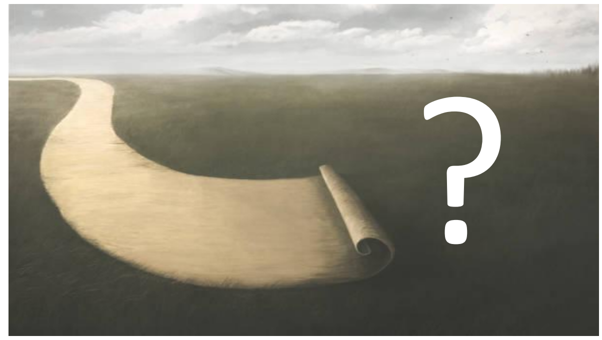

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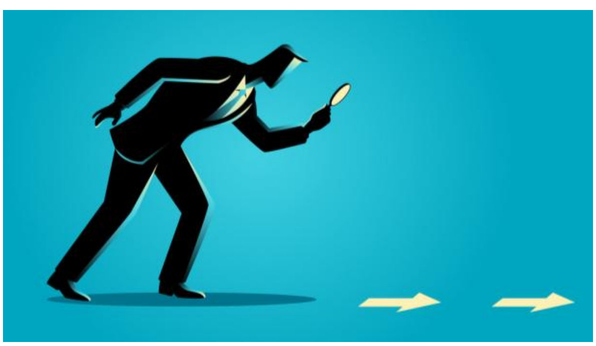


459

460

461

462

not available,

willing surrogate

still source GVP

463

464

AD search

465

466

appoint

instruct

467

~~appoint~~

instruct

468

FKA

"living will"

469

record treatment

you want

you do not want

470

lots of paper

forms, e-forms

& apps

471

some are

treatment

focused

472

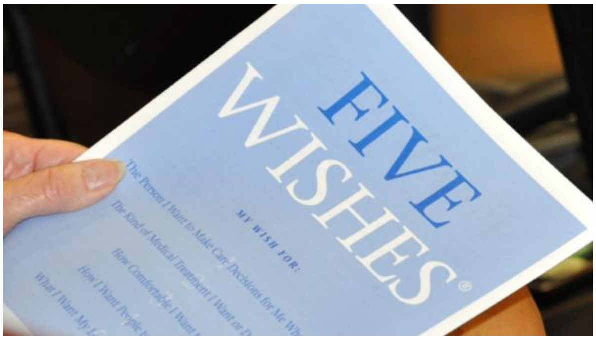
For each of the situations at right, check the boxes that indicate your wishes regarding treatment.	**Situation A** If I am in a coma or persistent vegetative state and have no known hope of recovering awareness or higher mental functions:			**Situation B** If I am in a coma and have a small but uncertain 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; if no clear improvement, stop treatment.	I want	I do not want	I want a trial; if no clear improvement, stop treatment.	I want	I do not want	I want a trial; if no clear improvement, stop treatment.
1. Cardiopulmonary 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 in the throat.									
3. Artificial feeding. Giving food and water through a tube inserted either in a vein, down the nose, or through a hole in the stomach.									

473

others are more

goal focused

474



475

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:

476

advantage

477

hear from patient

herself

478

best DM for you

is **you**

479

record values

& preferences

480

reasonable search

481

482

no AD, POLST

still source GVP

483

robot surrogates

484

485

2014

486

David Wendler

487

Patient Preference Predictor

488

population based

489

correlate

Pt age

Pt income

Pt gender

490

if **most** people with these traits would choose X, this Pt **probably** would too

491

492

yes

493

Georg Starke

494

Machine Learning–Based Patient Preference Prediction: A Proof of Concept

NEJM AI

Authors: Georg Starke, M.D., Ph.D., Laura Sc… Ph.D., Jérémy Baffou, M.Sc., Dorina Thar… and Ralf J. Jox, M.D., Ph.D. Author Inf…

Published September 18, 2025 | NEJM AI 2025;2(10)

495

PPP tests show **improves** SDM

496

497

It gets better ...

498

2026

499

David Wendler

500

Brian Earp

501

Patient
Preference
Predictor

502

add a P

503

personalized
patient
preference
predictor

504

P4

505

basis for prediction is broader

506

not just demographics

(age, income, gender)

507

includes information about this **specific Pt**

508

train P4 with **Pt specific** information

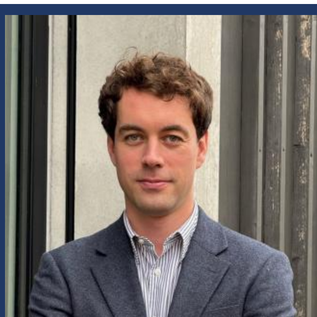
509

510

511

yes

512



Georg Starke

513

Machine Learning–Based Patient Preference Prediction: A Proof of Concept

NEJM AI

Authors: Georg Starke, M.D., Ph.D. , Laura Sc
Ph.D. , Jérémy Baffou, M.Sc. , Dorina Thar
, and Ralf J. Jox, M.D., Ph.D.   Author Inf

Published September 18, 2025 | NEJM AI 2025;2(10)

514

more testing

515

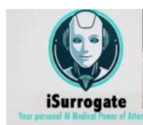
Muhammad Ahmad

516

517

Craig Klugman

518



Progressive Illness Care Planning Tool

Care Focus:
1. Palliative care (continue treatments
2. Hospice care (comfort-focused, stop
Select 1 or 2: 1

Treatment Limitations (type 'yes' or
Would you want to decline Dialysis? yes
Would you want to decline Feeding tube?
Would you want to decline Mechanical
Would you want to decline CPR? no

End-of-Life Priorities:
1. Remain at home as long as possible
2. Hospital-based care for aggressive
3. Comfort and dignity above all else
Select 1, 2, or 3: 2

519

testing

Craig v. i-Craig

520

521

AI surrogates are coming

522

523

no capacity
no agent
no surrogate

524

guardian
conservator

525

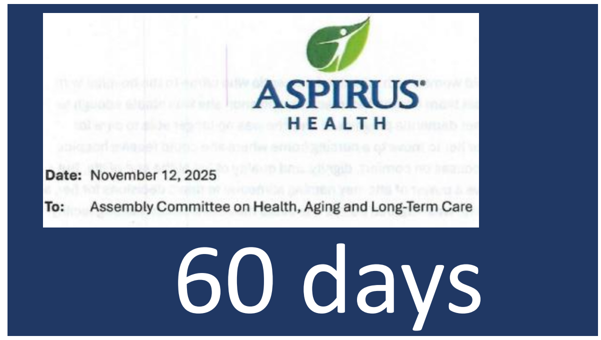
ask **court** to
appoint SDM

526

527

528

529



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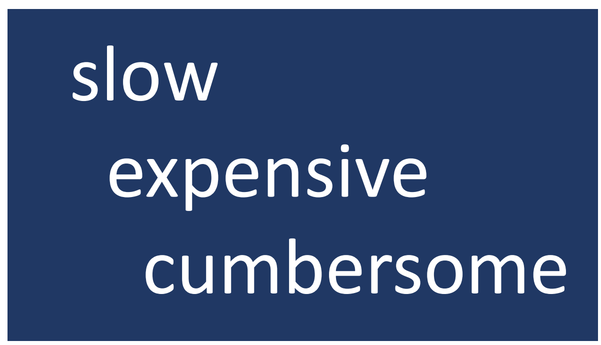

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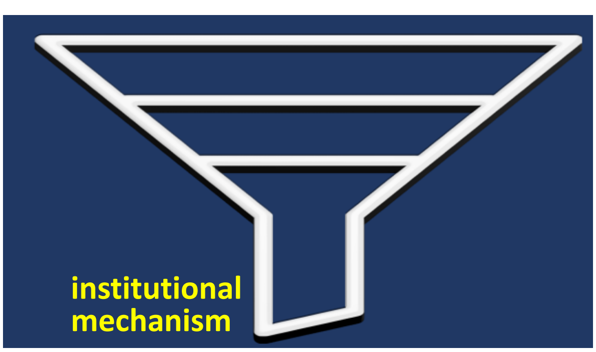

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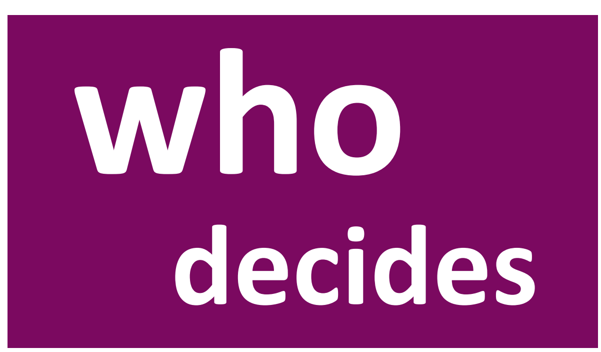


534

2 qualities

535

efficiency
&
fairness

536

537

538

fair A
efficient F

539

540

efficient A

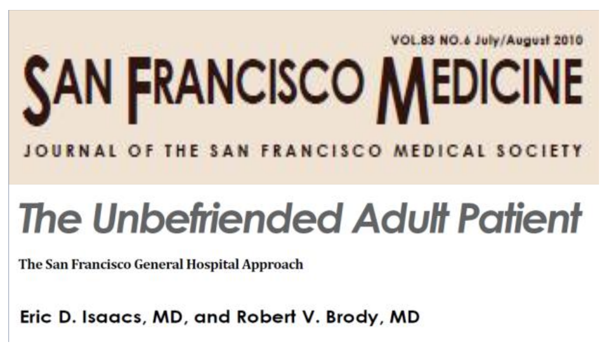
fair F

541

solo physician approach is **common**

542

543


VOL.83 NO.6 July/August 2010

SAN FRANCISCO MEDICINE

JOURNAL OF THE SAN FRANCISCO MEDICAL SOCIETY

The Unbefriended Adult Patient

The San Francisco General Hospital Approach

Eric D. Isaacs, MD, and Robert V. Brody, MD

544

“**attending physician** ... make decisions”

545

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

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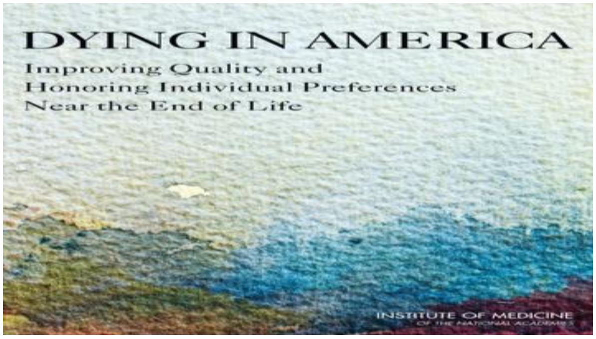

547

"having a **single health professional** make unilateral decisions ..."

548

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

549

2 reasons

550

bias & COI unchecked

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less carefully considered

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553

substance abuse
disability
poverty
mental illness
social isolation

554

2nd opinion

555

better

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557

external consent

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"clinical social worker
. . . selected by . . .
bioethics committee ...
not be employed"

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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-Crews, Marshall B. Kapp, Bernard Lo, David C. Magnus, Lynn F. Reinke, Jamie L. Shirley, Mark D. Siegel, Renee D. Stapleton, Rebecca L. Sudore, Anita J. Tarzian, J. Daryl Thornton, Mark R. Wicclair, Eric W. Widera, 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

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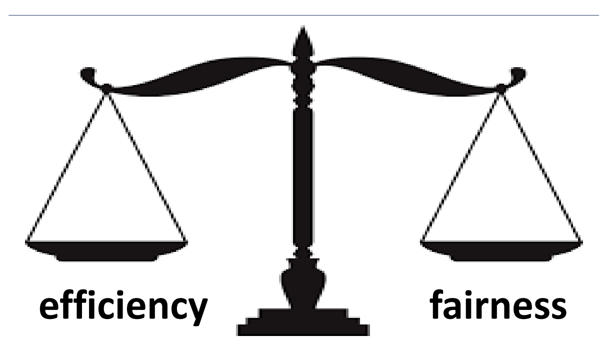

564

accessible
quick
convenient

565

expert
neutral
careful

566

that's
who

567

how
to decide

568

substituted
judgment
if possible

569

comply with
evidence of
patient's GVP

570

if cannot

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best interest

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

573

conclusion

574

575

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1

577

advance care planning
to prevent patients
becoming unrepresented

578

2

579

strategies to determine if
seemingly unrepresented
patient **really is**

580

careful **capacity**
assessments

581

diligent **searches** for
potential surrogates

582

diligent **searches** for AD, POLST, evidence of GPV

583

3

584

when prevention fails & **have** unrepresented patient

585

manage decision-making with a **diverse interprofessional, multidisciplinary** committee

586

use **all available information** on patient preferences & values

587

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