Advance Directives
Essential Tools for
a Win-Win-Win
Opportunity

Thaddeus Mason Pope JD, PhD, HEC-C March 9, 2023 nothing to disclose

3

1

2







4

5 6





8



7

91 years old pneumonia sepsis acute renal failure

10



Live your healthy



12

on admission, family

took in her AD

gave it to H staff

GEORGIA ADVANCE DIRECTIVE FOR HEALTH CARE

"no heroic measures" "no CPR"

15

13 14

11



intubated ventilator



16 17 18

feeding tube blood transfusions bronchoscopy tracheostomy

19



The Augusta Chronicle

Jury to decide if liability exists in case where woman's last wishes denied

Sandy Hodson shodson@augustachronicle.com Published 10:17 p.m. ET May 20, 2017

21







24

"clear objective of the Act is to ensure that ... the will of the patient ... not the will of the health care provider ... controls"





25 26 27







28 29



Ga. Stat. Ann. § 31-32-8 "decision made by ... agent ... shall be complied with"

. 32 33





34 35 36







37

The New York Times

The Patients Were Saved. That's Why the Families Are Suing.

Paula Span

THE NEW OLD AGE APRIL 10, 2017

40

43



Hospital Ordered to Pay \$400K in Do-Not-Resuscitate Lawsuit

A jury found St. Peter's Health in Helena and Dr. Virginia Lee Harrison negligent

41

38

SPOTLIGHT TEAM FOLLOW-UP

Hospital staff revived a man's stopped heart — and he sued

A successful 'wrongful prolongation of life' lawsuit in Montana, among other things, reflects the extent to which many Americans will go to gain — and enforce — their rights to control their final days.

By Hank Internal Cale Staff Under Committee 31, 2002 24 ft p.m.

42







44

45

value concordant healthcare

patients get treatment they want

also

46

47 48

patients do not get treatment they don't want too little = harm

too much = harm

49

50

51

54

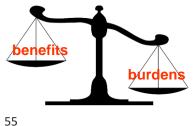
how much is too much is value laden



preference sensitive decision

52

53



types of value discordant healthcare

over-treatment under-treatment

56

57

happens to patients with decisionmaking capacity



incapacitated patients

58

59

60

cannot tell us what they want and do not want



key tool to mitigate value discordant treatment for incapacitated patients

61

62





follow-up question

66







68 69

role of ADs

problems & challenges

solutions & fixes

70 71 72



what is "capacity"

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

able to make a decision

able to communicate a decision



all patients
presumed to
have capacity

no need to **prove** capacity

must prove incapacity

sometimes obvious

83

86



82



often unclear

SO,

87

assess capacity
carefully

88

3 warning

WARNING

89 90

not all or
nothing

patient might have capacity to make some decisions but not others

patient may lack capacity for complex decisions

91

92

93

still capacity forsimpler decisions



still capacity to
appoint agent

94

95

96



may **fluctuate** over time

capacity in morning not afternoon

97

98





101

104

Making Treatment Decisions for Incapacitated Older Adults Without Advance Directives

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.

102

105



even if really lacks capacity

reversible

restore capacity if possible

Table 7 Means to enhance capacity

Came of confusion

Alcohol or other substances intoxification

Altered blood pressure

Altered low blood sugar

Altered low blood sugar

Antered sor blood sugar

Antered sor blood sugar

Antered sor blood sugar

Management of blood sugar blood sugar breagh diet or medication are of the treatment. Recent death of a spouse or loved one

Becavement; Recent death of a spouse or loved one

Bipolar disorder

Bipolar disorder

Bipolar disorder

Teamment with medications and/or poychotherapy; su groups.

we prefer to hear from patient herself

107 108

106

supported decision making

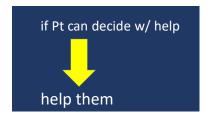


patient still in charge

109 110 111

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





112 113 114

Supported Decision-Making Agreement

This agreement must be read out loud or otherwise communicated to all parties to the agreement in the presence of <u>either</u> a notary <u>or</u> 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.





115 116 117



118



assess restore preserve

119

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



will lose capacity

121 122 123

123

120

can no longer make own decisions

need a substitute someone who can speak for Pt when she cannot speak for herself

124 125 126

ideally, people appoint their own healthcare agents



2 parts to AD

127

128 129

instruct appoint

instruct

FKA
"living will"

130

131

132

record treatment
you want
you do not want

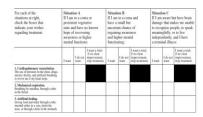
lots of paper forms, e-forms & apps



133 134

135

some are more treatment focused



others are more goal focused

136 137 138



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:

advantage

140 141

hear from patient
herself

best DM for you

is you



142 143 144



Annals of Internal Medicine

Perspective

JOURNAL OF PALLIATIVE MEDICINE Volume 23, Number 7, 2020 © Mary Ann Liebert, Inc. Notes from the Editor

Controlling Death: The False Promise of Advance Directives

Advance discribes primites patients as sign in their falses are set aboutly have held fill effect (Many specifie temp persistent with completen and implementations, but the advance discriber complete and implementations, but the advance discriber complete and implementations, but the advance discriber complete suppose more control over falses are than in marker. Medical implementations are the present control over falses are than in marker. Medical implementations of surface in production in deal, marker parties inference or strong present distributions, the suppose advance for such present falses and only present falses and presen

whole emphases not the completion of desirves but the empterior playation of plates and smiles for this cries. The evolunitiast Albert Camer legist suggest that physicans should complete and termine that movember, unless sales of the form is abased. Their, when the crine his, physicans should be plated on plant of plant and according steps in investible secutions in a last and according steps in investible secularity of the security of all check of completions are planted and similar through the featment legislation of the security of the secur

147

Advance Directives/Care Planning: Clear, Simple, and Wrong

R. Sean Morrison, MD, Senior Associate Editor

146

instruct appoint respond

dynamically to

clinical scenarios

1st choice –
patient picks
herself

149 150

148

health care agent

who?

6 attributes

151 152 153

knows the patient

cares about patient

willing to serve

154

155

156

willing to honor patient wishes

able to serve

good advocate

157

158

159

sum up

purpose
 of ADs

goal concordant care

160

161

mechanisms

163

record values & preferences

appoint agent & alternate

165

164

but





166 167 168

170

challenge 1 prevalence not completed

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

171

169

systematic review of 150 studies 800,000 people 37%



172 173 174

PewResearchCenter NAMERICA, FACTS AND TREMOS SHAPING THEY

Views on End-of-Life Medical Treatments

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

175

Preparation for End-of-Life Treatment, By Age

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

Written downNET written down or talked aboutNeither

176

All adults



177



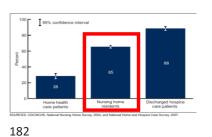


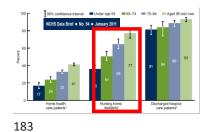


178 179 180

3/17/2023







65% > 37%

1 in 3 80yo NH residents have no AD



184 185 186

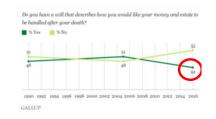


before COVID-19



189 187 188







190 191 192







193 194 195







196 197 198



THEINDIANA LAWYER

Life and death decisions: Pandemic increases focus on estate planning, health care advance directives

May 26, 2028 | Olivia Covington

200

203

206



201

How COVID-19 Changed Advance Care Planning: Insights
From the West Virginia Center for End-of-Life Care

Danielle Christina Funk, MS, Alvin H. Moss, MD, and Articus Speis, MS
West Virginia (Kniersky, Mognatum, West Virginia)

202

400%

Network Open.

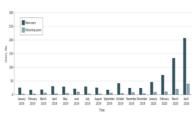
Research Letter | Geriatric

Completion of Advance Directives and Documented Care Preferences
During the Coronavirus Disease 2019 (COVID-19) Pandemic

Catherine L. Auriemma, M.D., Scott D. Halpern, M.D., Ph.D.; Jeremy M. Asch, B.H., Matthew Van Der Tuyn, M.A., David A. Asch, M.D., MSA

204





J Med Internal Res. 2009 Aug 220% of 20156.

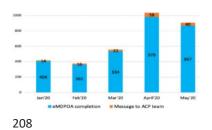
J Med Internal Res. 2009 Aug 220% of 20156.

Advance Care Planning Among Users of a Patient Portal During the COVID-19 Pandemic February Editor Service Study

Montaining Editor. Genther Epontain.

Reviewed by Emmanufie Duringer and Pasad Patient
James Rev. 2007 Aug 2016 Au

3/17/2023











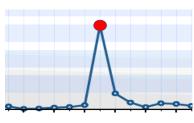


211

212







214 215 216



back to baseline

recap
obstacle 1

219

not completed



challenge 2 availability

220 221 222

218

even if AD completed



The New Old Age
Caring and Coping

OCTOBER 17, 2013, 6:00 AM

Where's That Advance Care Directive?

By PAULA SPAN

225

223





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

226 227 228

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

Documentation of Advance Care Planning for Community-Dwelling Elders

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

229

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

230



231

complete ≠ have Pt have ≠ HCP have BANK OF MONTREAL

MAN 29 1066

MONTREAL

MAN 29 1066

MONTREAL

MAN 29 1066

MONTREAL

232 233 234

make & distribute copies

primary agent
alternate agents attorney
family members clergy
PCP registry



235 236 237



challenge 3
updated

completed AD have AD

238 239 240





must **review**

241 242 243



364 Ga.App. 304 Court of Appeals of Georgia.

IN RE ESTATE OF Brenda Elizabeth STROTHER.

A22A0210 May 20, 2022

245



significant **Decline** health

new **Decade**

change of **Domicile**

246

6 Ds

247

250

Death of family / friend **Divorce** new **Diagnosis**

249

248

P LST PHYSICIAN ORDERS FOR LIFE-SUSTAINING TREATMENT (POLST) maxing physician is needed to two the Health Care Agon. See additional guidance under III on back of Jorn, Implementary served, below orders in K. C. and D. MEDICAL INTERVENTIONS: Parlient has puble and less in breath surrect Use no ficacion by any mote, positioning, wound care, and other no-

sum up

challenges

251 252

not completed
not found
not updated



medical error

253 2

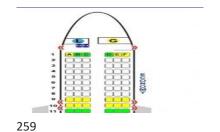
254 255

no plan > **default** rule

default rules produce bad outcomes



256 257 258







260 261

default rules for medical treatment probably bad for your patient

default

aggressive curative directed therapy



263

264

The Washington Post

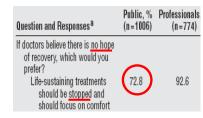
Most people want to die at home, but many land in hospitals getting unwanted care

265

262

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

266



harm 1

wrong

surrogate

267

no AD → UMT

harms without AD

270

268 269

80% incapacitatedpatients haveno agent



default surrogate

271 272

273

3rd choice

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

agent
appointed
in AD

274 275 276

default surrogate

3rd choice

not chosen
by patient

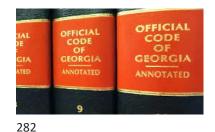
277 278 279



280

283

almost all states specify a sequence



281

Ga. Stat. Ann. § 31-9-2 adult child
parent
adult brother or sister
grandparent
grandchild
niece, nephew, aunt, uncle
adult friend

#1 Default Choice #2 Choice #3 Choice

284 285

204

problems

wrong
surrogate

1

286 287 288

Pt prefers someone off the list

289

RESEARCH LETTER

290

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

JAMA April 7, 2015 Volume 313, Number 13 1369

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

291



2

CIAL OFFICIAL CODE OF OF OF GEORGIA ANNOTATED

292 293 294



295

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

even if preferred surrogate on the list, not ranked

296 297

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

example

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

298

299

300





recap

301

304

302

303

risks from no AD wrong
surrogate

no NO surrogate

305



increasingly common situation

hospitals & LTC challenged

307

308

309

patient needs treatment



no capacityno surrogate

310

311

312

patient
cannot
consent

nobody else to consent

various terms

313

314

"unrepresented"

"adult orphan"

patient w/o proxy
Incapacitated & alone

"unbefriended"

316 317 318





American Bar Association Commission on Law and Aging July 2003

319

Advocating for the Unbefriended Elderly
An Informational Brief

Adgust 2010
Jossica E. Brill Ortiz, MPA

320

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



321

AMERICAN THORACIC SOCIETY DOCUMENTS

Making Medical Treatment Decisions for Unrepresented Patients in the ICU

An Official American Thoracic Society/American Geriatrics Society Policy Statement

Thaddaus M. Pope, Joshus Bernett, Shannon S. Casson, Lynette Coderquat, Andrew B. Cohen, Erin S. DeMartino, David M. Godfley, Paula Goodman-Crews, Marshall B. Hopp, Bernard Lo, David C. Magrus, Lynn F. Reinke, Jamie L. Shriey, March O. Siegel, Reveo C. Siguistion, Refecca L. Siegos, Antida. J. Tazian, Julyan Thomson, Mark R. Miccian, Eric W. Widera, and Douglas B. White, on behalf of the American Thoracic Society and American Genératics Society.

Тив ситок, лоцог въедени чио жителер ву тие Аменона Тисичас Society Features 2000 ию тие Аменона Белилис Society January 2000

who are they

lack capacity

323 324

322

lack agent or surrogate nobody to consent to treatment

big problem

327

325 326

hospital estimates 16% ICU admits

5% ICU deaths

328 329 330

> 25,000 US, each year

End of Life Care Audit -Dying in Hospital

National report for England 2016

332

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?

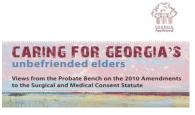
- NO BUT
- 1706 377

177

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

- . There was no nominated person important to the
- Attempts were made to contact the nominated person important to the patient but were unsuccessful

333



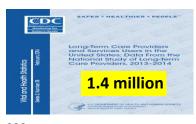






3 - 4 %

U.S. nursing home population



337 338 339







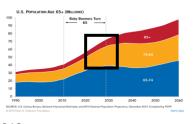
340 341 342



4 key factors



343 344 345



2



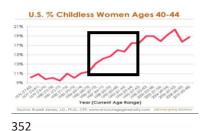
346 347 348



3



349 350 351



others "have" family

able but unwilling no **contact** (e.g. LGBT, homeless, criminal)

conversely

355

356

353

357

willing but unable

SDM lacks capacity

we have many unrepresented

358

359

what's the problem

risks & harms

cannot advocate for self

361 362 363

have no substitute advocate

364

Making Treatment Decisions for Incapacitated Older Adults Without Advance Directives "highly vulnerable" "most vulnerable"

"unimaginably helpless"

365

366

problem

nobody to authorize treatment



367 368 369

3 common responses

1

undertreatment

370

reluctant to act without consent

wait

until
emergency
(implied consent)

373

374

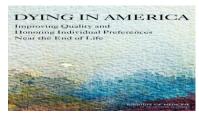
371

375

372



longer period suffering increases risks



376

377

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

2

overtreatment

379

380 381

fear liability
fear regulatory
sanctions

treat aggressively

but

382

383

384

burdensome unwanted



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

385

386



no discharge to appropriate setting



390 389







392 393

best way to protect the unrepresented is to prevent them from becoming unrepresented AMERICAN THORACIC SOCIETY DOCUMENTS

An Official American Thoracic Society/American Geriatrics Society Policy

Recommendation 1

Institutions should promote advance care planning to prevent patients at high risk from becoming unrepresented in the first place, both *I*) 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.

394 395 396



400

no AD → default rules

398

default rules → create risks

399

wrong surrogate no surrogate UMT

401 402

value **dis**cordant treatment



no AD \rightarrow lose other benefits

403 404 405

evidence based benefits

406

409

412

Vol. 56 No. 3 September 2018 Review Article Overview of Systematic Reviews of Advance Care Planning: Summary of Evidence and Global Lessons Geronimo Jimenez, MA, Woan Shin Tan, MSocSe, Amrit K, Virk, PhD, Chan Kee Low, PhD, Josip Car, PhD, and Andy Hau Yan Ho, EdD, PhD

407

410

less hospitalization

408

fewer ICU days more hospice lower costs

411

less family anxiety, depression

greater satisfaction

better quality of life

AD completed AD available



harm 3 misread AD

415

416

417

TRIAD studies

The Realistic

Interpretation of Advance Directives



common errors

418

419

420

majority of clinicians **incorrectly** interpreted AD & DNR orders as synonymous



421

422



AD ≠ DNR

2

424

majority of clinicians

incorrectly interpreted

DNR as "do not treat"

t



but

427

428

425

429

426

DNR ≠ do not treat that's **enough** on problems & challenges



430

431

fixes & solutions

many

Patient Self-Determination Act patients must be apprised of rights to AD on admission





















"none of the following persons may act as a witness ... the patient's health care provider ..."



451 452 453







RIN 2900–AQ97 Informed Consent and Advance Directives

456

"remove ... bar on ...
employees serving as
witness ... unnecessary
burden to completion of
advance directives"





457 458 459

federal, state & private fixes & solutions



to address **low**AD completion
rates

460 461 462

patient decision aids



misunderstand prognosis

463 464 465

imminently
relevant





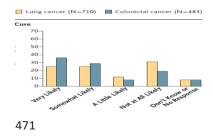
466 467 468





Patients' Expectations about Effects of Chemotherapy for Advanced Cancer

470



theory

472

patient decision aids

decision support tools

473 474

what are PDAs?

evidence based educational tools

2

475 476 477





during encounter

480

478 479



present options clearly & graphically



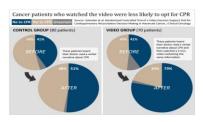
481 482 483



Breathing tube



484 485 486



do PDAs work? yes

487

488

489

robust evidence shows PDAs are highly effective >130 RCTs

30,000 patients
50 conditions

490

491

492



JOURNAL OF SURGICAL RESEARCH • MARCH 2019 (235) 350-366

A Review of Decision Aids for Patients Considering More Than One Type of Invasive Treatment

Kathleen A. Leinweber, BS, a Jesse A. Columbo, MD, MS, a,b,c,d,e 494



improved knowledge

496

more accurate expectations

more value congruent choice

498

497

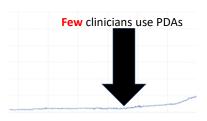
higher patient satisfaction

less decisional conflict less patient anxiety

499 500 501

what's the problem?

"**not** incorporated in mainstream care"



502 503 504

recognition endorsement





505

506

507



implementation adoption



509

seldom stagnant
incomplete elusive
infrequent rare

"significant and sustained adoption problem"



511 512 513













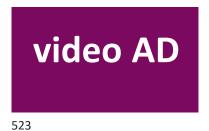
517 518 519



patient -> clinician

to address AD misinterpretation

520 521 522



GEORGIA ADVANCE DIRECTIVE FOR **HEALTH** CARE



524







528



validity meaning



529 531 530

someone claims
patient lacked capacity
to complete the AD





532 533 534



wants mother removed from life-sustaining treatment per her 1991 advance directive



535 536 537

says mother executed
a new advance directive
on Nov. 13, 2019 and
wants to live

later in time ADs revoke earlier ADs

but ... is the newer AD valid?

538 539 540

did Arline have capacity to complete?

video helped



541 542 543





September 3

AD names agent

"companion"

544 545 546



October 16

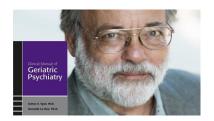
AD names

new agent



547 548 549







550 551 552

validity requires not only capacity but also voluntariness

someone claims patient coerced to sign AD



553 554 555

videos help prove AD validity

556

capacity voluntariness

meaning

557 558

what did the
patient want?

559

did she want it under **these** circumstances?

TRIAD VIII: Nationwide Multicenter Evaluation to Determine Whether Patient Video Testimonials Can Safely Help Ensure Appropriate Critical Versus End-of-Life Care

Fertinando L. Mirurchi, DO, FACEP* Timothy E. Cooney, MS,* Arrind Venkut, MD, FACEP,† David Wang, MD,‡ Thaddeus M. Pope, JD, PhD,§ Abru L. Fant, MD,§ Stanley A. Terman, PhD, MD,§

J Patient Safety 2017;13: 51–61

560

561

"adding a video
testimonial / message
... significant ... achieving
interpretive consensus"



conclusion

562

563

564

567

April 16, 2023

National Healthcare Decisions Day



565 566



NHDD.org
tips & strategies



568 569







571 572 573

more serious

574

advanced illness

more risk of UMT

greater
need to elicit &
document GOC

575 576



advance directives are **not** perfect

best means

to value congruent care for incapacitated patients

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