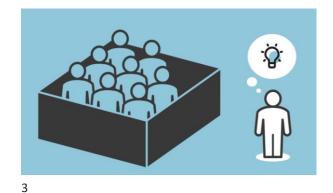
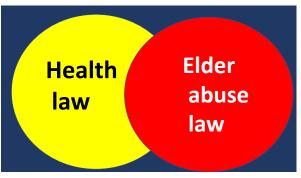
Legal and Ethical Considerations at End of Life

Thaddeus Mason Pope Weinberg Center for Elder Justice SPRiNG Alliance Symposium 2021



2





4

Advance care planning



5 6





Crime

8



But also

10



Unwanted medical treatment

12

Too little = harm

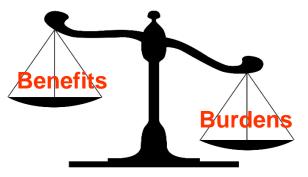
Too much = harm

How much is too much is value laden

Preference sensitive decision

16

14



Received: 4 May 2018 | Revised: 24 February 2019 | Accepted: 25 February 2019

DOI: 10.1002/pon.5054

REVIEW

WILEY

Quality of life versus length of life considerations in cancer patients: A systematic literature review

18

17

15

More burden than benefit

Unwanted

19

20



The New York Times

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

Paula Span

THE NEW OLD AGE APRIL 10, 2017

22

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 Mark Arsenault Globe Staff, Updated December 26, 2020, 2:48 p.m.

FLATHEAD ***** BEACON**



NEWS & FEATURES \mid SPORTS \mid OUTDOORS \mid ARTS & ENTERTAINMENT \mid OPIN

News & Features

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

BY ASSOCIATED PRESS // MAY 24, 2019

24

23



27

\$1 million Lanzetta v Montefiore Med. Ctr.

2021 NY Slip Op 21026

Decided on February 16, 2021

Supreme Court, Bronx County

Higgitt, J.

26

Don't want to discuss remedies Verdicts & settlements show UMT compensable injury

28

Unwanted

Medical error

29 30

Patient / resident

Safety

So...

32



How help your clients avoid UMT

34

How help your clients avoid UMT



35

Dignity

Control

37

38



When lose capacity

40

Roadmap

3

41

Why do ACP

What is ACP

43

How do ACP

1:15 - 2:15 ET

45 46



Why ACP

47 48

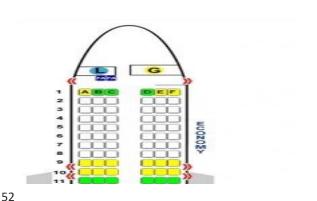
No plan → default rule

Default rules produce bad outcomes

50

49









53

Default rules for medical treatment probably bad for your client

Default
Aggressive
curative directed
therapy

56

Default

Aggressive

curative directed

therapy

PewResearchCenter Numbers, Facts and the

NOV. 21, 2013

Views on End-of-Life Medical Treatments

58

60

57

55

Personal Preferences for End-of-Life Treatment

% of U.S. adults who say they would tell their doctors to ... in each circumstance

- Stop treatment so they could die
- Do everything possible to save their lives
- Depends (vol.)/Don't know

If they had an incurable disease and were suffering a great deal of pain

All adults 57 35 8

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

59



Capacity

62

What is "capacity"

63

64

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

Able to make a decision

65 66

Able to communicate a decision

67

69



68

All patients presumed to have capacity

No need to **prove** capacity

70

Must prove incapacity

Sometimes obvious

71 72

5/13/2021





Often unclear

So,

75 76

Assess capacity carefully



77

Not all or nothing

79

Patient might have capacity to make some decisions but not others

80

Patient may lack capacity for complex decisions

Still have capacity for simpler decisions

81

82

Still have capacity to appoint agent /proxy



83

May fluctuate over time

Capacity in morning not afternoon

86



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.

88



Even if really lacks capacity

90

reversible

Restore capacity if possible

91

Table 7 Means to enhance capacity

Cause of confusion Possible intervention Alcohol or other substances intoxification Detoxification; supplement diet or other intake needs Altered blood pressure Treat underlying cause of blood pressure anomaly wi medication or other treatment Altered low blood sugar Management of blood sugar through diet or medication Treatment with medications and/or psychotherapy; su Anxiety Bereavement; Recent death of a spouse or Support; counseling by therapist or clergy; support gr loved one medications to assist in short term problems (e.g., s HEC Forum Bipolar disorder | DOI 10.1007/s10730-016-9317-9 Treatment with medications and/or psychotherapy; su

We prefer to hear from patient herself

93

Do not want 2nd best substitutes unless necessary Restore Preserve

95 96

16

92

Supported decision making

97



98

100

Patient still in charge

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

99

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.

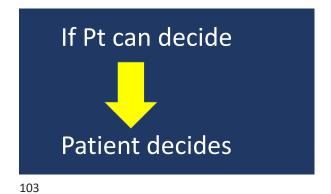
My name is:

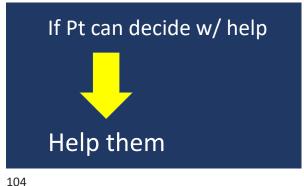
I want to have people I trust help me make decisions. The people who will help me are called supporters

My supporters are not allowed to make choices for me. I will make my own choices, with support. I am called the decider.

Growing

101 102





106

Will lose capacity

105

Can no longer make own decisions

Need a substitute Someone who can speak for Pt when she cannot speak for herself

107 108

Ideally, people appoint their own healthcare agents



110



109



Not completed

111 112

Before COVID-19



113 114

PewResearchCenter

NUMBERS, FACTS AND TRENDS SHAPING THE V

NOV. 21, 2013

Views on End-of-Life Medical Treatments

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

115

Preparation for End-of-Life Treatment, By Age

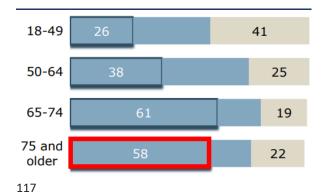
RESPECTING PATIENTS' PREFERENCES

Care

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



116



DOI: 10.1377/hithaff.2017.0175 HEALTH AFFAIRS 36, NO. 7 (2017): 1244-1251 02017 Project HOPE— The People-to-People Health 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

118

Systematic review of 150 studies
800,000 people

37%

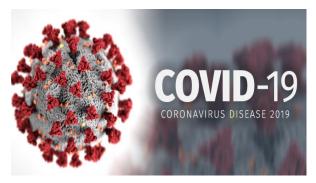
5/13/2021















Since COVID-19

128





130



Advance directive demand

More clients seek end-of-life plan guidance during pandemic, Spokane attorneys say

■ Virginia Thomas September 24th, 2020

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

May 26, 2020 | Olivia Covington

132



Vol. ■ No. ■ ■ 2020

Journal of Pain and Symptom Management 1

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 Atticus Speis, MS

West Virginia University, Morgantown, West Virginia

134



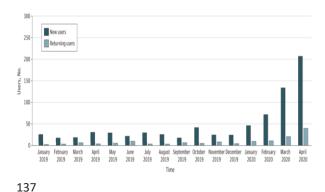
JAMA Open.

Research Letter | Geriatrics

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

Catherine L. Auriemma, MD; Scott D. Halpern, MD, PhD; Jeremy M. Asch, BA; Matthew Van Der Tuyn, MA; David A. Asch, MD, MBA

136





J Med Internet Res. 2020 Aug; 22(8): e21385. Published online 2020 Aug 11. doi: 10.2196/21385: 10.2196/21385 PMCID: PMC7423389 PMID: 32716900

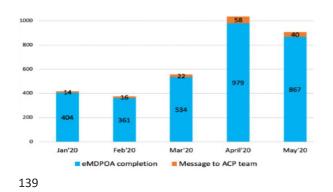
Advance Care Planning Among Users of a Patient Portal During the COVID-19 Pandemic: Retrospective Observational Study

Monitoring Editor: Gunther Eysenbach

Reviewed by Emmanuelle Belanger and Prasad Padala

Jennifer D Portz, PhD, II1 Adreanne Brungardt, MM, MT-BC, Prajakta Shanbhag, MPH, Elizabeth W Staton, MSTC, Seuli Bose-Brill, MD, 4

5/13/2021













5/13/2021















Not found

152

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

153

Assistant Secretary for Planning and Evaluation Office of Disability, Aging and Long-Term Care Policy

Fail to make & distribute copies

Primary agent

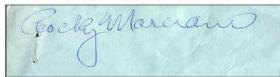
Attorney Clergy

Alternate agents Family members

Online registry

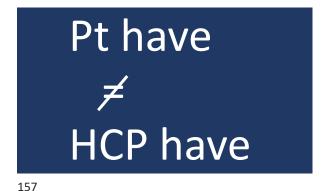
PCP

154



Complete Have

155 156





158

Completed AD
Have AD

Still may not have agent

159

160

Unavailable
Unable
Unwilling

Upshot

161 162

80% incapacitated patients have no agent



164

163

Default surrogate

3rd choice

165

166

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

Patient appoints in AD

167 168

Agent DPOAHC

Surrogate

169

170

Not chosen by patient

Chosen off a list

171

172

Almost all states specify a sequence



173

Spouse / partner
Adult child
Parent
Adult sibling
Close friend

Problems

176

175

Popular Choices

#1 Default Choice

#2 Choice

#3 Choice

177

Wrong surrogate

178

1

Priority sequence in list might not match your preference

179 180

Especially true for elder abuse victims

Spouse

"if not legally separated"

182

181

No automatic exclusions for other surrogates

2

184

183

Spouse / partner
Adult child
Parent
Adult sibling
Close friend

RESEARCH LETTER

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

JAMA April 7, 2015 Volume 313, Number 13 **1369**

186

uclear 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



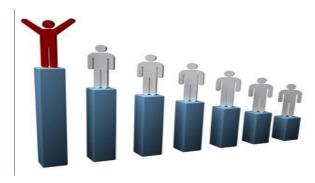
187

side the nuclear family	7761	7.1
lonnuclear 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



189 190

Spouse / partner
Adult child
Parent
Adult sibling
Close friend



191 192

Adult sibling might be better surrogate
But child trumps

193



194

Risks from no ACP

Risk 1
Wrong
surrogate

195 196

Risk 2
No
surrogate



197 198

Increasingly common situation

Hospitals & LTC challenged

200

199

Patient needs treatment

BUT

202

201

No capacity
No surrogate

Patient cannot consent

203 204

Nobody else to consent

Various terms

206

205

"unrepresented"

"adult orphan"

207

Patient w/o proxy

Incapacitated & alone

208

"unbefriended"

Incapacitated and Alone:

Health Care Decision-Making

for the Unbefriended Elderly

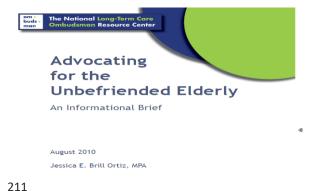
Naomi Karp and Erica Wood



American Bar Association Commission on Law and Aging

July 2003

209



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



Leading Change. Improving Care for Older Adults.

212

AMERICAN THORACIC SOCIETY DOCUMENTS

Making Medical Treatment Decisions for Unrepresented Patients in the ICU

An Official American Thoracic Society/American Geriatrics Society Policy Statement

3 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 Lp, David C. Magnus, Lynn F. Reinike, Jamie L. Shirkey, Mark D. Slegel, Renee D. Slagheton, Rebecca L. Sudore, Anta J. Tarzian, J. Davif Thomton, Mark R. Wicclair, Eric W. Widera, and Douglas B. White; on behalf of the American Thoracic Society and American Caristrices Society.

THIS OFFICIAL POLICY STATEMENT WAS APPROVED BY THE AMERICAN THORAGE SCORETY FEBRUARY 2020 AND THE AMERICAN GERIATRICS SCORETY JANUARY 2020

213



214

Definition
Prevalence
Causes

Definition

2 conditions

215 216



Lack capacity

218



Lack agent or surrogate

220

Nobody to consent to treatment

Big problem

221 222

Hospital estimates

16% ICU admits

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

glas B. White, MD: J. Randall Curtis, MD, MPH: Bernard Lo, MD: John M. Luce, MD

5% ICU deaths Life Support for Patients without a Surrogate Decision Maker:

> 25,000 US, each year

226

224





End of Life Care Audit -Dying in Hospital

National report for England 2016

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
٠	Attempts were made to contact the nominated person important to the patient but were unsuccessful	53%	200

228

227

223

LTC estimates

229

231

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

230

232

3 - 4 %

U.S. nursing home population

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

Us. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Content of Breast Certal and Partment Services (Care Providers, 2013–2014)

> 56,000 USA



233 234



Growing
problem

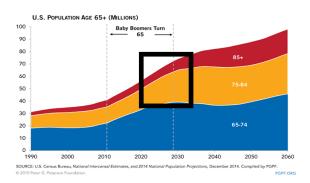
236

235





237 238





239 240



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

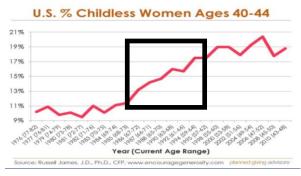
241



242









245 246

Others "have" family

Able but unwilling

248

250

247

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

Willing but unable

249

SDM lacks capacity

We have many unrepresented

251 252

What's the problem

Risks & **Harms**

Cannot advocate for self

Have no substitute advocate

255 256

254

Making Treatment Decisions for Incapacitated Older Adults Without Advance Directives

AGS Ethics Committee

253

"highly vulnerable" "most vulnerable"

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

WINSOR C. SCHMIDT*

"unimaginably helpless"

257



Nobody to authorize treatment

260

259



3 common responses

262

1

Undertreatment

263 264

Reluctant to act without consent



266

265

Until emergency

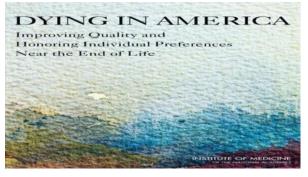
(implied consent)

BUT

267 268

Longer period suffering

Increases risks



269 270

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

2

271

Overtreatment

273

Fear liability

Fear regulatory sanctions

274

272

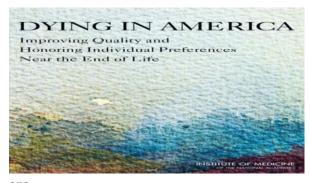
Treat aggressively

BUT

275 276

Burdensome Unwanted

277



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



279 280

No discharge to appropriate setting



281 282





284

Best way to protect the unrepresented is to prevent them from becoming unrepresented



285 286

No ACP >

default rules

Default rules → create risks

287 288

Wrong surrogate

289

291

No surrogate

290

UMT

Value discordant treatment

292

So...

Help your clients plan

293 294



2 parts to AD

296

298

Appoint agent Record wishes

Appointing agent more important

Enough

THE FAILURE OF THE LIVING WILL

by Angela Fagerlin and Carl E. Schneider

In pursuit of the dream that patients' exercise of autonomy could extend beyond their span of competence, living wills have passed from controversy to conventional wisdom, to widely promoted policy. But the policy has not produced results, and should be abandoned.

HASTINGS CENTER REPORT

297

299

March-April 2004

Annals of Internal Medicine

Perspective

Controlling Death: The False Promise of Advance Directives

Advance directives promise patients a say in their future care but actually have had life effect. Many experts thane problems with completion and implementation, but the advance directive compet that may be fundamentally staved. Advance directives simply prasuppose more control over future care than it maletic. Medical others cannot be predicted in olded, making most prior instructions difficult to stagit, inselvant, or even mislanding. Furthermore, many process either on one know patients' without or do not pursue those without officially. Thus, unexpected problems asso often to defeat advance directives after only limited burnt, advance care plant or only misla business. Evaluate advance directives after only limited burnt, advance care plant. rhould amphissize not the completion of directives but the emtoral preparation of patients and families for future crites. The estimatistic Albert Carriss might suggest that physicism should warn patients and families that momentuse, unforeseable dedsions lie ahead. Than, when the orbit hits physicians should provide guidance; should shap make decisions deeple the inevitable uncattarities; should share exponsibility for those decisions, and, above all, should outsignedly see patients and families through the tearsome experience of shrips.

Am Intern Med. 2007;147:51-57. For author affiliation, see end of text.

energen (r.s.)

Respond dynamically

Easy

301



Wishes for Health Care: Short Form¹
Minnesota Health Care Directive²
See other side for completion directions

	, ,	An institution of the Year Cities Medical Society.	See other side for completion directions				
Fu	ıll Name:		Date of birth:				
1.		•	as my primary (main) health care agent. This person will make healti nicate or make these decisions myself:				
	Name		Relationship				
	Cell ph	one	Other phone				

303



Wishes for Health Care: Short Form¹
Minnesota Health Care Directive²

ıll Name:	Date of birth:					
A COLUMN TO THE PROPERTY OF THE PARTY OF THE	appoint the following person to serve as my primary (main) health care agent. This person will make health care decisions for me if I cannot communicate or make these decisions myself:					
Name	Relationship					
Cell phone	Other phone					
(Optional): I appoint this person agent is not available:	n as m ^r a lternate health care agent in the event my primary health care					
Name	Relationship					

304

302

Who?

Knows the patient

305 306

Cares about patient

Willing to serve

307

308

Willing to honor patient wishes

Able to serve

health - live nearby

309

310

Good advocate

Other part AD

311

Record wishes

"living will"

314

313

Record treatment
You want
You do not want

Lots of paper forms, e-forms & apps

315 316

Some are more treatment focused

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.
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.									

317 318

Others are more goal focused



Part 3: My Hopes and Wishes (Optional)

319

321

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

322

Hear from patient herself

Best DM for you

is you

323 324

Purpose

Goal concordant care

New growing

type of AD

326

Get Tx you want

Avoid Tx you don't want

325

328

327 3

Dementia directive



329 330



End-of-life option

332

Ask & receive prescription drug

Self-administer to hasten death

333

334

Cannot satisfy eligibility conditions

Terminally ill

< 6 mo. prognosis

335 336

Decisional capacity

337

339

Terminal →
no capacity

338

Capacity >
not terminal

So...

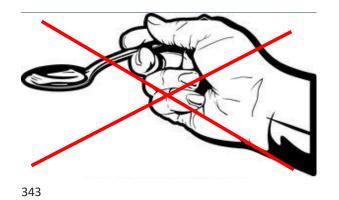
340



Direct VSED in future

341

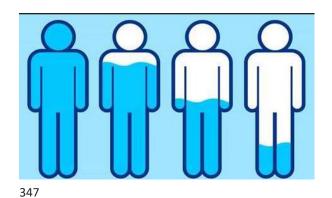
342

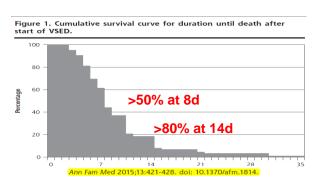


At a **point** you specify









Peaceful comfortable



ABOUT THE ADVANCE DIRECTIVE FOR RECEIVING ORAL FOOD AND FLUIDS IN DEMENTIA

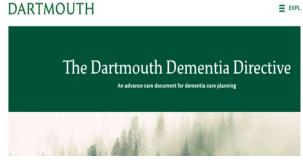
350



349

Introduction to our Supplemental
Advance Directive
For Dementia

351



352

Dehydration

looks like neglect

But **no duty**when refused

353 354

That's ADs

Appoint agent **Record wishes**

355

Help your clients

356

SW or JD

(or RN NP PA MD...)

357

Advance directive

358

Appoint agent & alternate

359 360

Record values & preferences



361

Make it legal

Witnessed or notarized

363

364

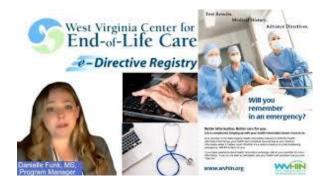


Make it findable

366

Copies to agents, EHR

367



368





370







Videos help resolve disputes over AD validity & meaning

374





376

September 3

AD names agent

"companion"



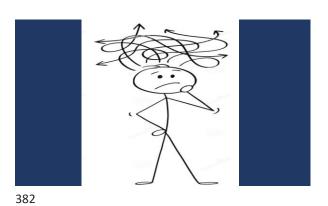
377

October 16 AD names new agent



379







Completed Signed Witnessed/notarized Shared Video

383 384



Review

386

388



Death of family / friend **Divorce New Diagnosis** Significant **Decline** health **New Decade** Change of domicile



390

Desperado

Not agent

391

392

"I want ___ to take no part..."

STOP

394

393

After complete or update AD

POLST

395

396

Provider

Orders

Life

Sustaining

Treatment

397

Supplements AD

Does not replace

398



For whom

400

402

Primarily for those expected to die in next year

Terminal illness

Advanced chronic progressive illness

Frailty

401

Advantage over AD

Transportable order set

403 404

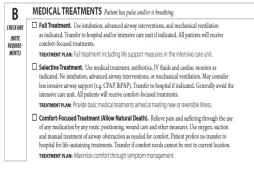
Immediately actionable

No need to "translate" into orders

405 406



407 408



SIGNATURE OF PHYSICIAN / APRN / PA My signature below indicates to the best of my knowledge that these orders are consistent with the patient's current medical condition and preferences. ALLITEMS REQUIRED NAME (PRINT) PHONE (WITH AREA CODE) SEND FORM WITH PATIENT WHENEVER TRANSFERRED OR DISCHARGED, FAJED, PHOTOCOPED ON ELECTRONIC VERSIONS OF THIS FORM ARE VALUD. Minnesota Provider Orders for Life-Sustaining Treatment (POLST). www.polstmn.org PAGE 10F2

409 410

> You cannot complete POLST but you can advise client

Getting ready

411 412

> Know your state statute

Review top 5 forms

413 414

Complete your own

Complete with family

415 416

Review facilitator guide

ADVANCE DIRECTIVES:
COUNSELING GUIDE
FOR LAWYERS
Commission on Law and Aging American Bar Association

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420



PREPARE is a step-by-step program with video stories to help you:

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419

Have a voice in YOUR medical
care.



Conclusion

Elder abuse can happen even at hands of wellmeaning licensed health professionals

Mitigate that risk with ACP

421 422

Thaddeus Mason Pope, JD, PhD, HEC-C

Mitchell Hamline School of Law 875 Summit Avenue Saint Paul, Minnesota 55105

T 651-695-7661

C 310-270-3618

E Thaddeus.Pope@mitchellhamline.edu

W www.thaddeuspope.com

B medicalfutility.blogspot.com