

Voluntarily Stopping Eating & Drinking
 A Lesser Known but Widely Available End-of-Life Option in Maine

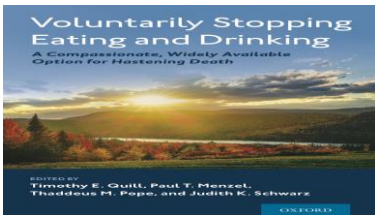
1

Maine-Health Ethics & Psychiatry Grand Rounds
 Thaddeus Mason Pope, JD, PhD, HEC-C
 October 18, 2022

2

nothing to disclose

3



4

October 2022

S	M	T	W	T	F	S
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2	3	4	5	6	7	8
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30	31					

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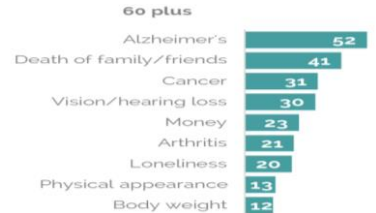
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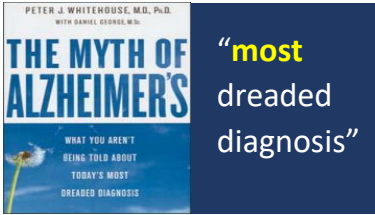
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fear of dementia

8

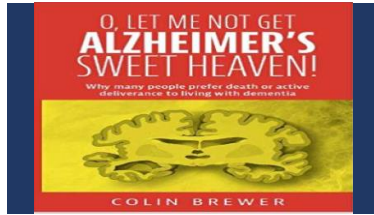


9



“most dreaded diagnosis”

10



11

20% AD biomarker & unimpaired want MAID at cognitive decline

Largent EA, et al. Attitudes Toward Physician-Assisted Death From Individuals Who Learn They Have an Alzheimer Disease Biomarker. JAMA Neurol. 2019;16(7):864-866.

12

many hasten death to avoid late-stage dementia

13

1990

14



15

2022

16

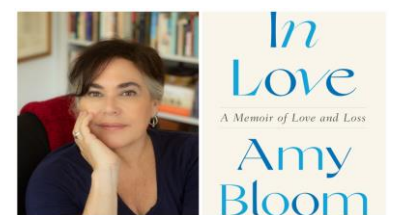
The New York Times

1. **ONE DAMN THING AFTER ANOTHER**
 by Amy Bloom
 Her husband's cancer nearly got her killed. Her 14-year-old son died. Her marriage fell apart. Her mother died. Her life was a series of disasters. How did she survive?
[READ MORE](#)

2. **ALLOW ME TO RETORT**
 by Amy Bloom
 Her husband's cancer nearly got her killed. Her 14-year-old son died. Her marriage fell apart. Her mother died. Her life was a series of disasters. How did she survive?
[READ MORE](#)

3. **IN LOVE**
 by Amy Bloom
 Her husband's cancer nearly got her killed. Her 14-year-old son died. Her marriage fell apart. Her mother died. Her life was a series of disasters. How did she survive?
[READ MORE](#)

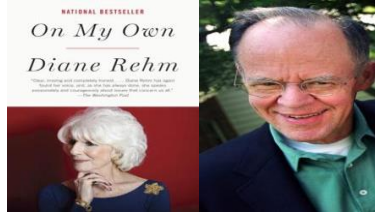
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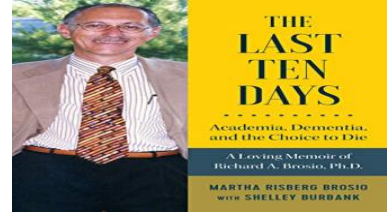
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high profile cases

19



20



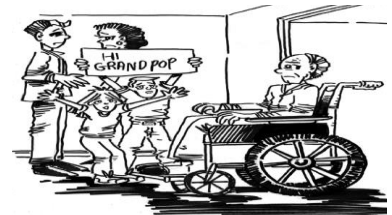
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DEMENTIA DIRECTIVE
I DO NOT WANT TO LIVE THROUGH THE LATER STAGES OF DEMENTIA . . .

22



23



24



25



26

growing **demand**
to avoid late-stage dementia

27

VSED

28

Voluntarily
Stopping
Eating &
Drinking

29

VSED to avoid
late-stage
dementia

30

Objectives

1. Explain the ethical and legal status of VSED as means for hastening death by a capacitated patient.
2. Identify the special ethical and legal challenges when the patient directs VSED through an agent or advance directive.
3. Understand how VSED meets a growing patient demand unmet by MAID and other end-of-life options.

31

Roadmap

32

5 parts

33

traditional
EOL options

34

MAID

35

VSED

36

limits of
VSED

37

VSED AD

38

Traditional
EOL options

39

refuse Tx

40

MV CANH
CPR antibiotics

41

self
if capacity

42

if **lack**
capacity

43

agent / surrogate
advance directive
POLST

44

but

45



46

~~refuse Tx~~

47

PSU

48

degree
mild → deep
unconscious

49

Duration
Temp → Perm
Respite Intermittent Continuous

50

PSU makes
Pt depend
on CANH

51

Pt usually
refuses
CANH

52

but

53



54



55

suffering
intolerable
refractory

56

suffering
physical
not existential

57



58

MAID

59

most discussed
end-of-life option

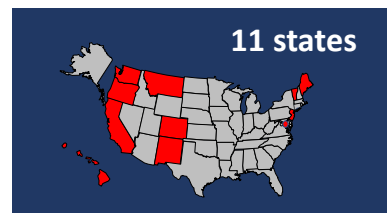
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ask & receive
prescription
drug

61

self-administer
to hasten death

62



63



64

but

65

cannot satisfy eligibility conditions

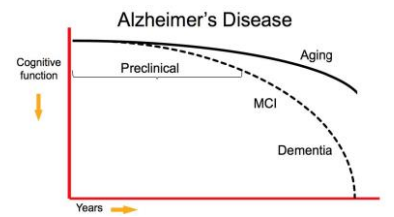
66

terminally ill
< 6 mo. prognosis

67

decisional capacity

68



69

terminal →
no capacity

70

capacity →
not terminal

71

~~MAID~~

72

sum up

73

~~refuse Tx
MAID
PSU~~

74

VSED

75

Voluntarily
Stopping
Eating &
Drinking

76

patient with
capacity

77

able to take food
& fluid by mouth

78

voluntary
decision
to stop

79

≠ ANH

80

≠ natural loss
appetite

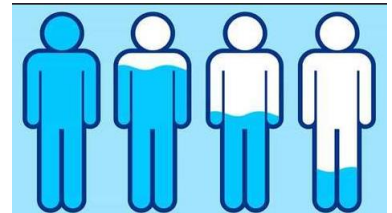
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deliberate choice
stop fluids
by **mouth**

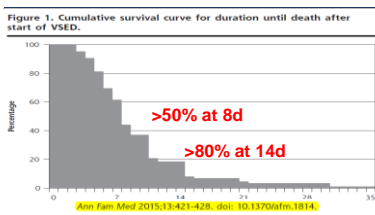
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goal = death
from dehydration

83



84



85

peaceful
comfortable

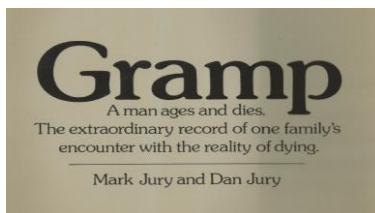
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1st person
narratives

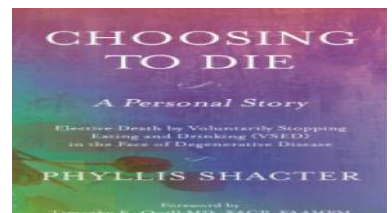
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books

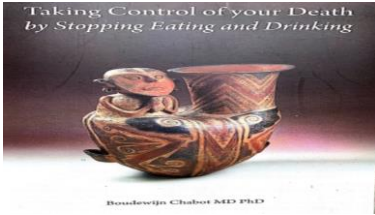
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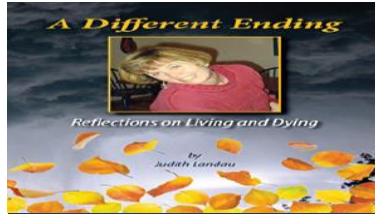
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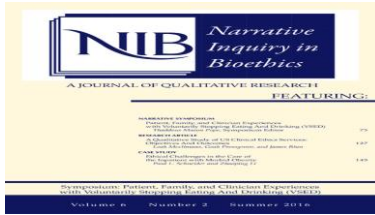
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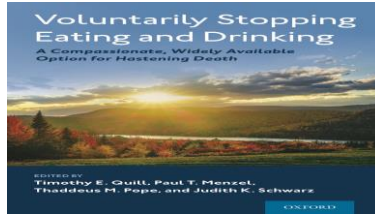
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100



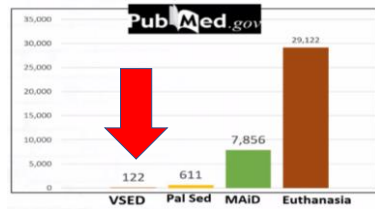
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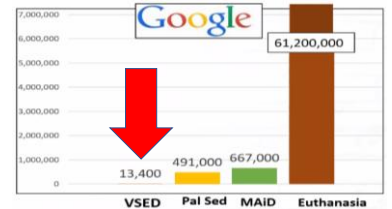
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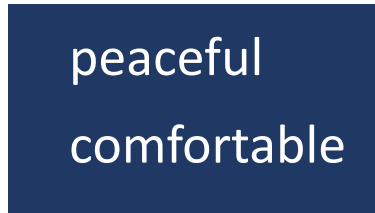
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105



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108

100 Oregon
nurses cared for
VSED patients

109

most deaths
“**peaceful** with
little suffering”

110



111

“**opportunity** for
reflection, family
interaction, and
mourning”

112

preferred
by many

113



114

even though MAID
available, “**almost**
twice” chose VSED

115

patients use
VSED where
MAID is legal

116



117

300 hospice & palliative care specialists

Shingo T, et al. *BMC Supportive & Palliative Care* 2017, 17:1

127

32%

experience with VSED

128



129

751 family physicians

Family physicians' perspective on voluntary stopping of eating and drinking: a cross-sectional study

130

33%

experience with VSED

131



132

700 family physicians

JOURNAL OF FAMILY MEDICINE • WWW.AAHPUBS.ORG • VOL. 33, NO. 5 • SEPTEMBER/OCTOBER 2015

133

46%

experience with VSED

134



135

255
palliative care
specialists

Hickman, N. E., Smith, M. J., & Smith, M. (2017). How many do we really need? An analysis of the current and projected needs for palliative care and hospice services in the United States. *Journal of Palliative Medicine*, 21(10), 144-151.

136

61%
experience with VSED

137

not just **more**
clinical experience


138

more position
statements

139

professional
society
endorsements

140

POSITION STATEMENT 

Nutrition and Hydration at the End of Life

Effective Date: 2017
Status: Revised Position Statement
Written by: AHA Center for Ethics and Human Rights
Adopted by: ANA Board of Directors

141

Austrian Palliative Society (OPG) themenschwerpunkt

Wien Med Wochenschr
https://doi.org/10.1007/s00107-018-0829-z

Freiwilliger Verzicht auf Nahrung und Flüssigkeit um das Sterben zu beschleunigen

Eine Stellungnahme der österreichischen Palliativgesellschaft (OPG)

Angelika Feilthuber · Dorothea Weisler · Alois Birkbömer

Erschienen: 8. September 2017 / Angenommen: 1. Februar 2018
© Springer-Verlag GmbH Austria, ein Teil von Springer Nature 2018

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JOURNAL OF PALLIATIVE MEDICINE
Volume 20, Number 1, 2017
May/June 2017, Inc.
DOI: 10.1097/jpn.2016.0290

Position Statement

International Association for Hospice
and Palliative Care Position Statement:
Euthanasia and Physician-Assisted Suicide

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 The Vision and Voice of
Women in Medicine
since 1915

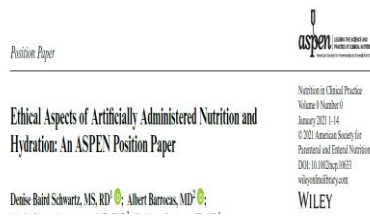
American Medical Women's Association

144



e-SPEN guideline
 ESPEN guideline on ethical aspects of artificial nutrition and hydration
 Christiane Druml ^{1,2}, Peter E. Balmer ³, Wilfried Druml ¹, Frank Oehmichen ⁴

145



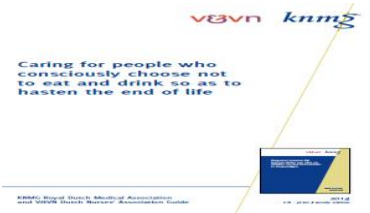
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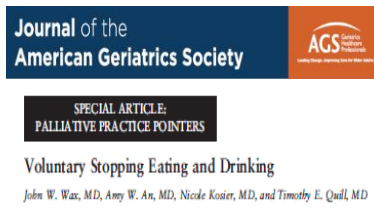
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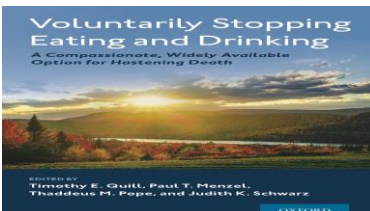
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150



151



152



153

VSED is an
EOL option

154

broadly
accepted

155

evidence
based

156

clinical → legal

157

VSED is
legal

158

sizable, settled,
and stable
consensus

159

5 points

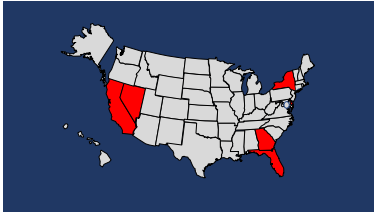
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on point
precedent

161

multiple
appellate
court decisions

162



163

same in other common law countries

164

SUPREME COURT OF SOUTH AUSTRALIA

(Application Under Various Acts re Rules Application)

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HLTD v J & ANOR

[2010] SASC 176

Judgment of The Honourable Justice Konrakis

15 June 2010

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IN THE SUPREME COURT OF BRITISH COLUMBIA

Citation: Bentley v. Maplewood Seniors Care Society, 2014 BCSC 165

Date: 20140203
Docket: S135854
Registry: Vancouver

Between:

Margaret Anne Bentley,
by her Litigation Guardian Katherine Hammond,
John Bentley and Katherine Hammod

Petitioners

166



167

is VSED legal?
asked & answered

168

plus

169

no need for direct, explicit authority

170

already legal existing rules

171

right to refuse
medical
treatment

172

right to
refuse
treatment

173

ventilator
dialysis
CPR
antibiotics
feed tube

174

right to
refuse
treatment **VSED**

175

not DIY

176

part of a broader
treatment plan

177

supervised by
licensed healthcare
professionals

178

recognized as
healthcare by
medical profession

179

more position
statements

180

more clinical
practice
guidelines

181

but

182

right to
refuse
treatment

VSED

183

relies on
premise

184

oral N&H =
“treatment”

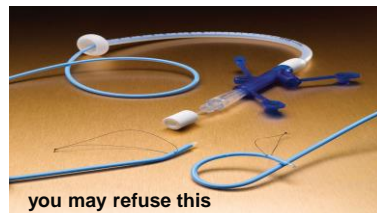
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oral N&H ≠
“treatment”

186

basic care

187



188



189



190

yes

191

right to refuse **any** intervention

192

does **not** matter whether food & fluid by mouth is "**medical treatment**"

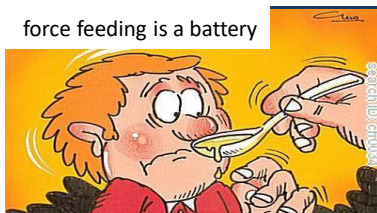
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right to refuse **any** intervention (medical **or not**)

194

right to refuse **any** unwanted contact

195



196



197

"bodily integrity is violated . . . by sticking a **spoon in your mouth** . . . sticking a needle in your arm"

198



199

In re Gardner
(Me. 1987)

200

“battery analysis ...
free ... nonconsensual
invasions of ... bodily
integrity”

201

plus

202

medical
profession
accepts VSED


203

law **delegates &**
defers to healthcare
professionals

204

when medical
profession says it is
appropriate → law
often **follows**

205

POSITION STATEMENT 

Nutrition and Hydration at the End of Life

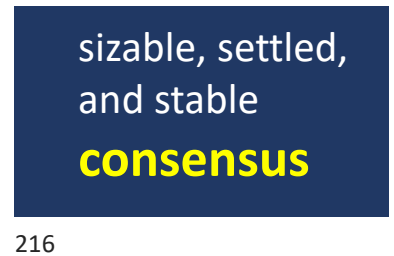
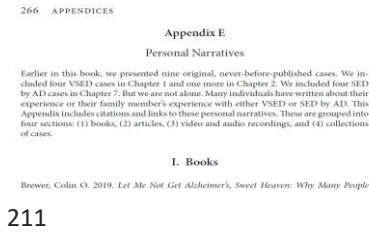
Effective Date: 2017
Status: Revised Position Statement
Written by: ANA Center for Ethics and Human Rights
Adopted by: ANA Board of Directors

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 **AMWA** The Vision and Voice of
Women in Medicine
since 1915

American Medical Women's Association

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VSED in
Maine

217



218

specific
cases

219



Karen
Trider

220



221

October 2018
liver cancer

222



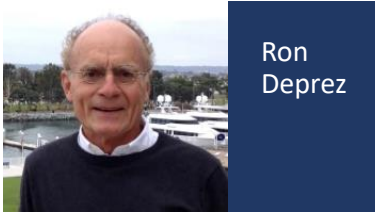
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“horrendous”
could not manage
symptoms

224

2018
1 year before MDWD
→ VSED

225



226



227

avoid late ALS
MAID
April 2020

228



229

would have
used VSED

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VSED → VSED for
dementia

231

Limits of
VSED

232



233

many used VSED
to avoid late-stage
dementia

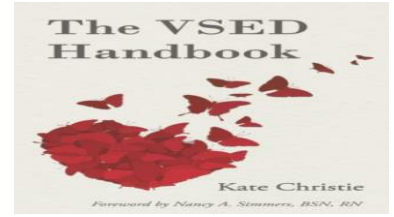
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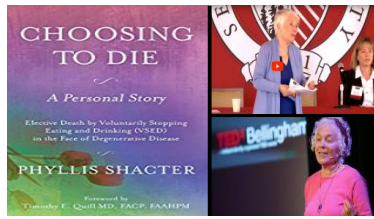
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too soon

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life still worthwhile

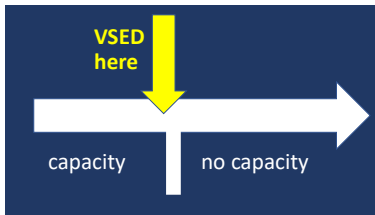
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earliness problem

246



247



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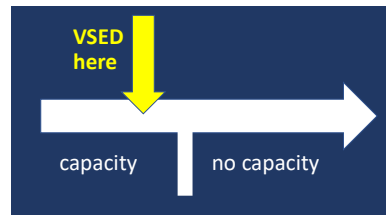
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but

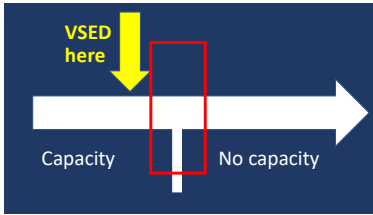
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251



252



253

premature
dying

254

current situation
acceptable

255

VSED **not** a
good option

256

at **that** time

257

not ready
to die yet

258

concerned
about **future**
circumstances

259

lack capacity
at future time

260



261



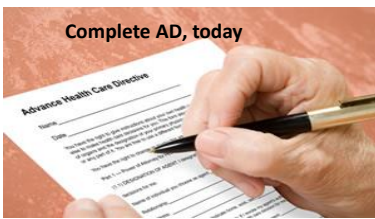
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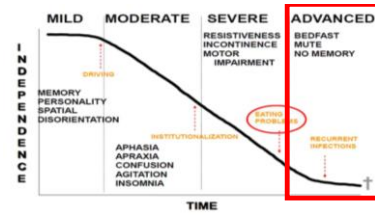
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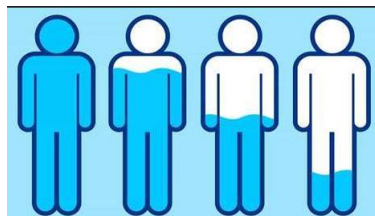
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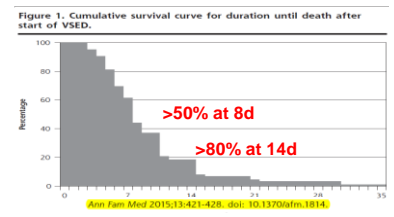
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FUNCTIONAL ASSESSMENT STAGING TEST (FAST) SCALE					
Stage	Stage Name	Characteristic	Stage	Stage Name	Characteristic
1	Normal Aging	No deficits whatsoever	6a		Needs help putting on clothes
2	Possible Mild Cognitive Impairment	Subjective functional deficit	6b	Moderately Severe Dementia	Needs help bathing
			6c	Severe Dementia	Needs help toileting
3	Mild Cognitive Impairment	Objective functional deficit interferes with a person's most complex tasks	6d		Urinary incontinence
			6e		Fecal incontinence
4	Mild Dementia	Instrumental activities of daily living (IADLs) become affected, such as paying bills, cooking, cleaning, traveling	7a		Speaks 5-6 words during the day
			7b		Speaks only 1 word clearly
			7c	Severe Dementia	Can no longer walk
5	Moderate Dementia	Needs help selecting proper attire	7d		Can no longer sit up
			7e		Can no longer smile
			7f		Can no longer hold up head

274



275



276



277



278

A Piece of My Mind

My Living Will

588 JAMA, February 28, 1996—Vol 275, No. 8

I, William Arthur Hermal, being of sound mind, desire that my life not be prolonged by extraordinary means if my condition is determined to be terminal and incurable. I am aware and understand that this writing authorizes a physician to withhold or discontinue extraordinary means.

basic of comfort and nutritional care. Even a detailed living will that includes the refusal of all active treatments such as cardiopulmonary resuscitation, antibiotics, artificial nutrition, and hydration may be inadequate in such a situation. I do not want to become a vacant-looking body, reflexively swallowing food and water placed in my mouth, and breathe inside while my life

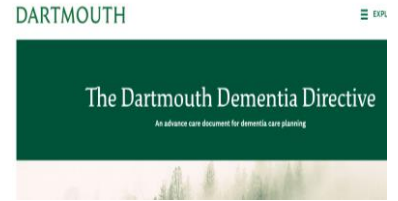
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280



281



282



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

283



284



The following document can be added to any advance directive to provide guidance regarding consent to or refusal of certain therapies. Once completed, signed and witnessed, it should be kept with the advance directive.

285



286

Support and promote life quality



lifecircle | Living will & additional personal statement

287



Introduction to our Supplemental Advance Directive For Dementia

288

NEVADA ADVANCE DIRECTIVE FOR ADULTS WITH DEMENTIA
PAGE 7 OF 10

PART 2. END-OF-LIFE DECISIONS ADDENDUM STATEMENT OF DESIRES.

4. I want to get food and water even if I do not want to take medicine or receive treatment. YES NO

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NEVADA ADVANCE DIRECTIVE FOR ADULTS WITH DEMENTIA
PAGE 7 OF 10

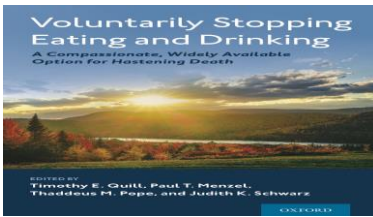
PART 2. END-OF-LIFE DECISIONS ADDENDUM STATEMENT OF DESIRES.

4. I want to get food and water even if I do not want to take medicine or receive treatment. YES NO

290



291



292

I counseled
on VSED ADs

293



294

1 "regular"
AD

295

2 capacity
at sign

296

3 clear on
what

297

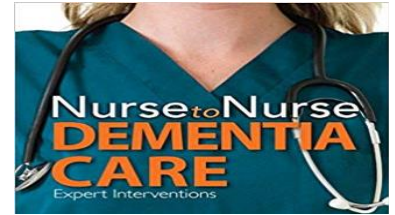


Margot Bentley

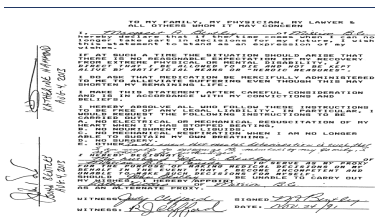
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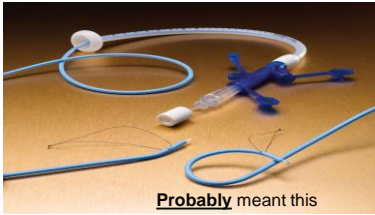
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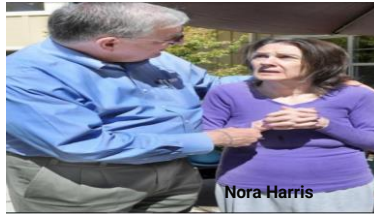
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306



307



308



309

PART 1: POWER OF ATTORNEY FOR HEALTH CARE

I revoke all prior advance health care directives and durable powers of attorney for health care signed by me. This document shall not be affected by my subsequent incapacity. I am not a patient in a skilled nursing facility, and I am not a conservatee.

1.1 NAME AND ADDRESS OF PRINCIPAL. My name and address are:
 Nora R. Harris, 83 Arnold Drive, Novato, CA 94949

PART 2: INSTRUCTIONS FOR HEALTH CARE

2.1 END-OF-LIFE DECISIONS. I direct that my health care providers and others involved in my care provide, withhold, or withdraw treatment in accordance with the choice I have marked below:

a. I Choose **NOT To Prolong Life.** If I initial this line, I do not want my life to be prolonged and I do not want life-sustaining treatment to be provided or continued if any of the following conditions apply:

310

family **unable**
 to enforce AD

311

be specific

312

Oral food & fluids
 Nutrition & hydration by **mouth**
 Hand- feeding
 Spoon- feeding
 Normal feeding

313

Be clear on
what you want

314

4 clear on
when

315

5 how
measure
when

316

6 clear on
why

317

7 clear on
where

318

8 show
understand

319

9 Ulysses
clause


320

10 discuss
agent

321

11 copies &
registry

322

12 

323



324

turn to
law & ethics

325

Legal?

326



327

explicitly permitted

328



329

NEVADA ADVANCE DIRECTIVE FOR ADULTS WITH DEMENTIA
PAGE 7 OF 10

PART 2. END-OF-LIFE DECISIONS ADDENDUM STATEMENT OF DESIRES.

4. I want to get food and water even if I do not want to take medicine or receive treatment. YES NO

330



331

“health care”
“personal circumstances”
Vermont § 9702(a)(12)

332

“services to assist in activities of daily living”
Vermont §§ 9702(a)(5), 9701(12)

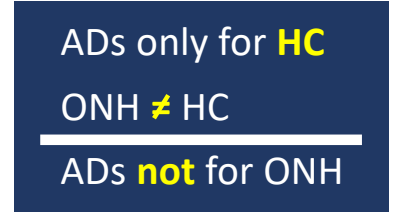
333



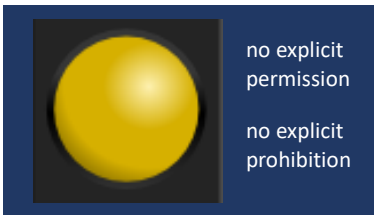
334



335



336



337



338



339



340



341



342

get your wishes followed when you cannot speak for yourself

343

2

344

document or person

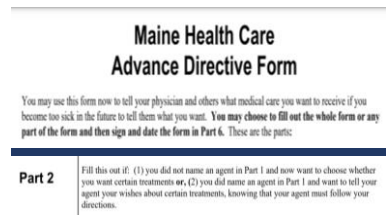
345

document

346



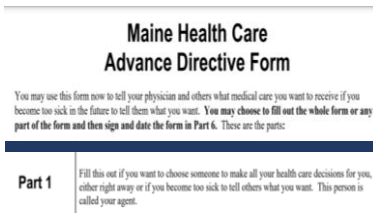
347



348

person

349



350

other types of surrogates

351

who
appoints

352

Who appoints	Type of SDM
patient	agent
legislature	surrogate
court	guardian

353

Who appoints	Type of SDM
Patient	Agent
Legislature	Surrogate
Court	Guardian

354

DM for VSED
must be **agent**

355

recap

356

incapacitated patient
may request VSED

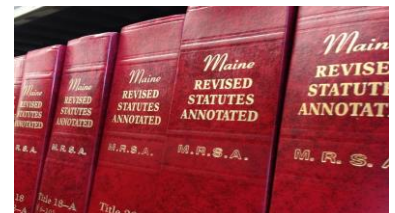
357

written instructions
or
decision of agent

358

Maine AD
is **binding**

359



360

“health care provider ... shall ... **comply** with an individual **instruction** of the patient”

5-808(4)

361

“health care provider ... shall ... **comply** with **decision** ... by a person ... authorized”

5-808(4)

362

unless CBO

363

binding
if valid

364

Is VSED AD
valid in Maine?

365

yes

366

document

367

“adult ... may give an individual **instruction** ... direction ... concerning a health care decision”

5-803(1), 5-802(9)

368

person

369

“agent ... make **any**
health care decision
the principal could
have made ”

5-803(2)

370

limit

371

“adult ... may give an
individual instruction ...
direction ... concerning
a **health care decision**”

5-803(1), 5-802(9)

372

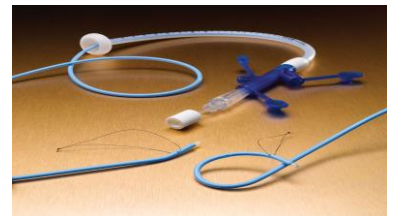
“agent ... make any
health care decision
the principal could
have made ”

5-803(2)

373

health care
decision

374



375

1985 living will
act did not permit
stopping ANH

376

1995 UHCDA
covers ANH

377

but

378



379

yes

380

3 reasons

381

1

382

VSED is part of broader treatment plan

383

PAVSED Palliated & Assisted Voluntarily Stopping Eating and Drinking

384

recognized as healthcare by medical profession

385

<p>POSITION STATEMENT</p> <p>Nutrition and Hydration at the End of Life</p> <p>Position Statement</p> <p>International Association for Hospice and Palliative Care Position Statement: Euthanasia and Physician-Assisted Suicide</p>	<p>VENVO <i>Assure</i></p>	<p>POSITION STATEMENT</p> <p>Position Statement</p> <p>International Association for Hospice and Palliative Care Position Statement: Euthanasia and Physician-Assisted Suicide</p>
<p>THE SOCIETY FOR POST-ACUTE AND LONG-TERM CARE MEDICINE</p>	<p>Journal of the American Geriatrics Society</p>	<p>AMWA The Vision and Voice of Women in Medicine since 1915</p> <p>American Medical Women's Association</p>

386

2

387

statutory text
defines “health
care” **broadly**

388

“Health care means **any** care,
treatment, service or
procedure to maintain,
diagnose or otherwise **affect**
an individual’s physical or
mental condition”

389

3

390

“**broadest**
possible
construction”

5-816

391

“**including**
custodial
care”

5-816

392

SO...

393

ME UHCDA

VSED
AD

394

ME
UHCDA

VSED
AD

395

even if VSED **were**
basic care
even if basic care
were excluded

396

still have
AD for VSED

397

non-statutory
VSED AD

398

In re Joseph V. GARDNER.
Supreme Judicial Court of Maine.
Argued Sept. 18, 1987.
Decided Dec. 8, 1987.

399

4 sources
of rights

400

~~state statute~~
federal constitution
state constitution
common law

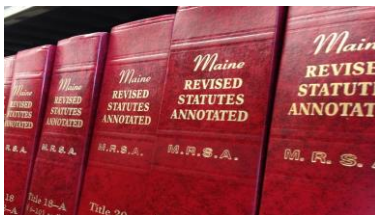
401

one more
option

402

out-of-state
VSED AD

403



404

reciprocity

405

“valid ... if it is valid under the laws of the **state** in which it was executed”
5-803(8)

406



407

Valid Vermont VSED AD is a valid **Maine** AD

408



409

~~non-statutory out state AD~~

410

VSED AD **complies** with ME UHCDA

411

assume you have a **valid** VSED AD

412



413

Revocation

414



415

big **challenge**
for dementia
directives

416

whose wishes
do we respect?

417

prior self
or
current self

418

now patient
or
then patient

419

incapacitated
veto

420



421

have patient
address this
in AD

422

3 options

423

option 1

424

“I want **my agent** to make this decision in consultation with my health care providers”

425

option 2

426

VSED → CFO

427

Comfort Feeding Only: A Proposal to Bring Clarity to Decision-Making Regarding Difficulty with Eating for Persons with Advanced Dementia

J Am Geriatr Soc. 2010 March; 58(3): 580-584

Eric J. Palecek, MSIV[†], Joan M. Teno, MD, MS[†], David J. Casarett, MD, MA[‡], Laura C.

428



429



430

option 3

431

Ulysses clause

432

ignore my
future self

433

stick to VSED
plan in the AD

434

no hand feeding **even if**
“appear to cooperate in
being fed by opening
my mouth”

435



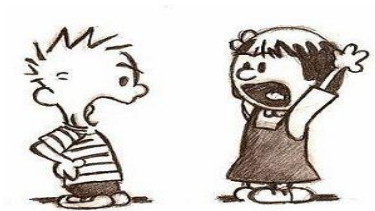
436

with Ulysses,
prior self
prevails

437

but

438



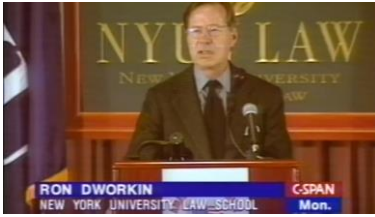
439

1990s

440



441



442



443



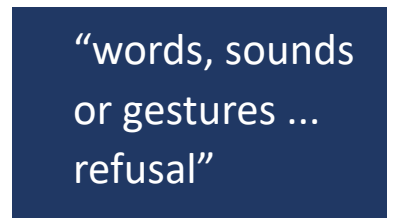
444



445



446



447



448



449



450

“words, sounds
or gestures ...
refusal”

451



452



453



454



455

2019

456



457

duties to
current self
are primary

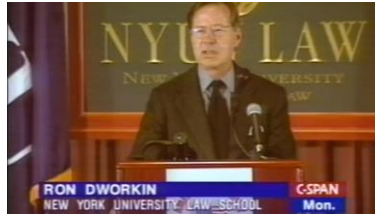
458

even if VSED
directive valid

459

2022

460



461

follow AD despite current best interest assessment

462

Ulysses in Maine

463



464

PART FIVE: WAIVER OF RIGHT TO REQUEST OR OBJECT TO TREATMENT

Section Five is a special provision that may be used by people who want their future responses to offered health treatment disregarded or ignored. You must have an agent to fill out this Section.

465



466

not needed in Maine

467

“an individual **with capacity** may revoke...”
5-804(1)-(2)

468

Pt **lacks** capacity when time to implement their VSED AD

469



470

cannot revoke

471

AD **continues** to control

472

even if word gesture utterance

473



MENTAL HEALTH ADVANCE DIRECTIVES

A User Guide for Maine Consumers

474

“This consent shall operate **even if** I pose verbal objections at the time”

475



476

request Tx in AD refuse at time

477

VSED AD

478

refuse Tx in AD
request at time

479

same
rule

480

AD **supersedes**
wishes -- unless
capacity

481

can revoke AD
only if capacity

482

 Canadian Journal of Bioethics
Revue Canadienne de Bioéthique

TM Paper, Can J Bioeth / Rev Can Bioeth 2021 4(2):65-68

COMMENTAIRE CRITIQUE / CRITICAL COMMENTARY (ÉVALUÉ PAR LES PARES / PEER-REVIEWED)

Medical Aid in Dying and Dementia Directives

Thaddeus Mason Pope¹

483

Ethics and law
Challenges in advance care planning: the
interface between explicit instructional
directives and palliative care
doi: 10.5694/mja2.50653

484

may honor
VSED ADs

485

ME clinicians
will see **more**

486

Conclusion

487

demand for
VSED AD

488



489

but

490



491



492

little guidance
courts, regulators

493

few institutional
policies & procedures

494



495

guidance & policies

VSED ADs

496

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W www.thaddeuspope.com

B medicalfutility.blogspot.com

497

materials from this
presentation are available

<http://thaddeuspope.com/vsed>

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