

Top Ten Things
Clinical Ethicists Must
Know About VSED

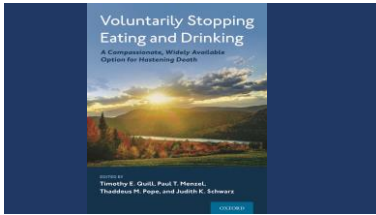
1

Thaddeus Pope
for
University of Washington
May 10, 2023

2

nothing
to disclose

3



4

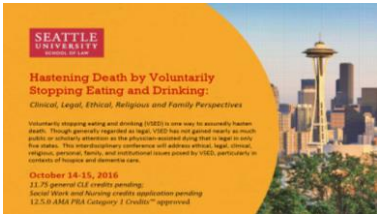


January 24, 2023

**Choosing to halt
nourishment: an end-
of-life decision**

VSED (Voluntary Stopping Eating and Drinking) is an option for people with decision-making capacity who want to manage their death.

5



6

At the End of Life:
Agency, Role, and Responsibilities
of the Physician/Advanced Practitioner

SEPTEMBER 13-14, 2019
University of Washington Campus
Husky Union Building (HUB), North Ballroom
Seattle, WA

7

2024

8

preface

9



10



11



12

never wanted
to live like this

13

cannot now
authorize VSED
b/c incapacity

14

but

15



16



17

may you honor it

18

frame around
this question

19

intro

20

April 2023						
S	M	T	W	T	F	S
				6	7	1
2	3	4	5	13	14	8
9	10	11	12	20	21	15
16	17	18	19	26	27	22
23	24	25	26	27	28	29

21



22



23



24

but

25



26

4 reasons

27

1

28

many still
ineligible

29

6-month
prognosis

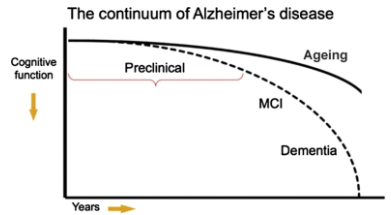
30

decisional
capacity

31



32



33

2

34

even **if**
eligible

35



36



37

waiting periods
& screenings

38



39



40

CBO
facility or clinician

41



42

patient's
own religion

43

3

44



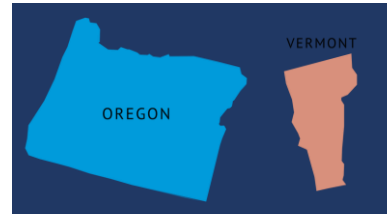
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46

no MAID **at all**
45 jurisdiction

47



48

4

49



50

no MAID
via **AD**

51



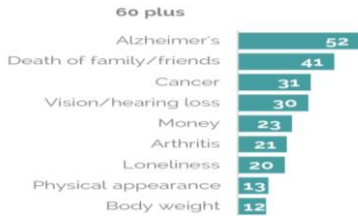
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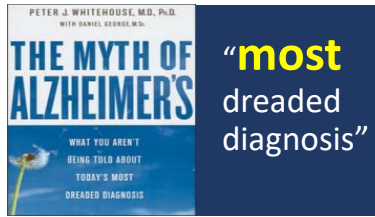
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fear of
dementia

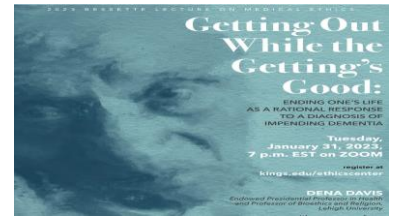
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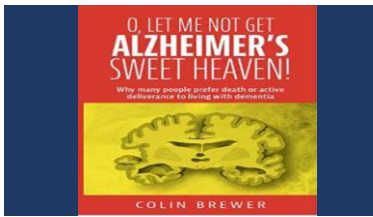
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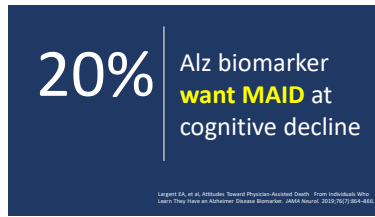
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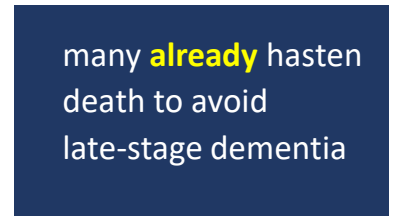
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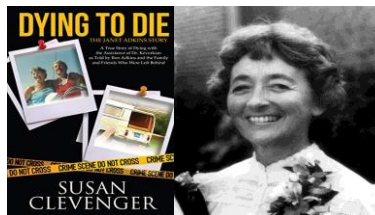
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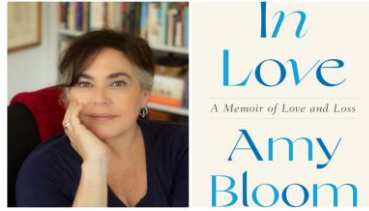
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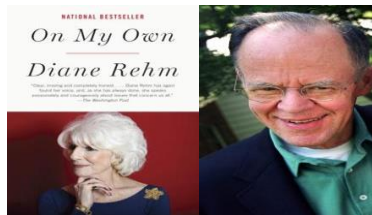
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66

high profile cases

67



68



69

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

70

in sum

71



72

to **avoid**
late-stage dementia

73

~~MAID~~

74

SO...

75

other
EOL options

76

VSED

77

VSED
by **AD**

78

The Seattle Times
Death with Dignity Act loopholes: Consider VSED option
Jan. 20, 2023 at 8:55 am | Updated Jan. 20, 2023 at 8:55 am
By *Letters editor*
The Seattle Times

79

roadmap

80

4 parts

81

what is VSED

82

status

law, medicine, ethics

83

VSED
by **AD**

84

remaining
challenges

85

VSED

86

Voluntarily
Stopping
Eating &
Drinking

87

patient **with**
capacity

88

able to take food
& fluid by mouth

89

voluntary
decision
to stop

90



91

≠ ANH

92

≠ natural loss
appetite

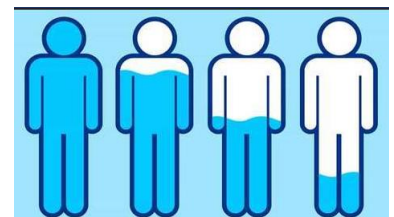
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deliberate choice
stop fluids
by mouth

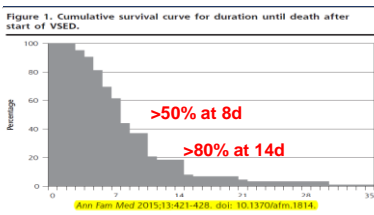
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goal = death
from dehydration

95



96



97

peaceful
comfortable

98

1st person
narratives

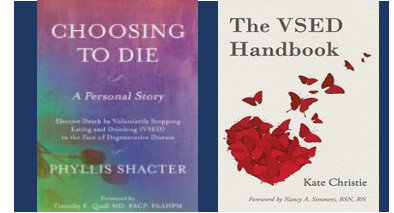
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books

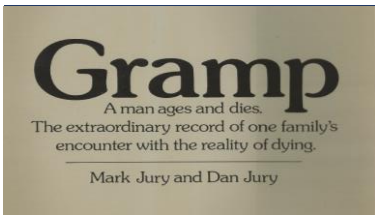
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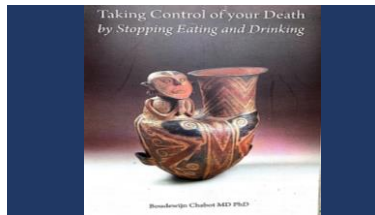
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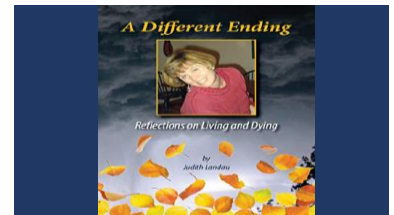
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103



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105

films

106



107



108



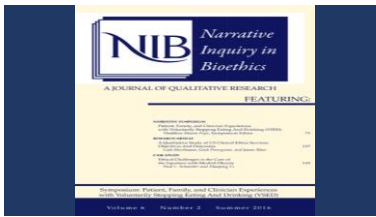
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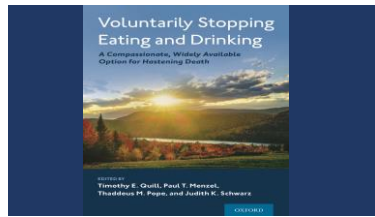
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111



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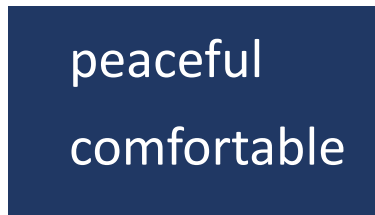
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114



115



116



117

100 Oregon
nurses cared for
VSED patients

118

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

119



120

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

121

preferred
by many

122



123

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

124

patients VSED
even where
MAID is legal

125



126

0.4 to **2.1%**
of **all** deaths

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The NEW ENGLAND JOURNAL of MEDICINE
End-of-Life Decisions in the Netherlands over 25 Years

> 1/2 deaths
euthanasia

128

end of life
WASHINGTON

Newsletter
Fall 2022

129

773 New Clients
(31% increase from 2021)

949 Clients Served
(25% increase from 2021)

746 Death with Dignity (DwD) Clients

27 Voluntarily Stop Eating and Drinking (VSED) Clients

293 Clients Used DwD Law
(27% increase from 2021)

16 Clients Used VSED
(33% increase from 2021)

130

good
option

131

clinical
status

132

more
experience

133



134



135

300 hospice & palliative care specialists

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

136

32%

experience with VSED

137



138

751 family physicians

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

139

33%

experience with VSED

140



141

700 family physicians

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

142

46%

experience with VSED

143



144

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(8), 44-52.

145

61%

experience with VSED

146

not just **more**
clinical experience

147

more position
statements

148

professional
society
endorsements

149

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

150

Austrian Palliative Society (OPG)

themenschwerpunkt

Wien Med Wochenschr
https://doi.org/10.1007/s00561-018-0109-z

Freiwilliger Verzicht auf Nahrung und Flüssigkeit um das Sterben zu beschleunigen

Eine Stellungnahme der österreichischen Palliativgesellschaft (OPG)

Angelika Freilinger, 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/jpm.0000000000000290

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

153



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

154

Position Paper

Ethical Aspects of Artificially Administered Nutrition and Hydration: An ASPEN Position Paper

Denise Baird Schwartz, MS, RD ¹; Albert Barrows, MD ²

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Nutrition in Clinical Practice
Volume 17 Number 1
January 2021 1-14
© 2021 American Society for
Parenteral and Enteral Nutrition
DOI: 10.1002/ncp.10023
wileyonlinelibrary.com
WILEY



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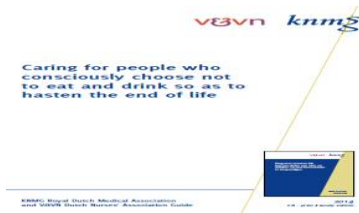
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“When unacceptable suffering persists ... despite ... standard palliative care ... consider ... **voluntary cessation of oral intake** if ethically acceptable to the patient and treating practitioners”
<https://aahpm.org/positions/padbrief>

158



159



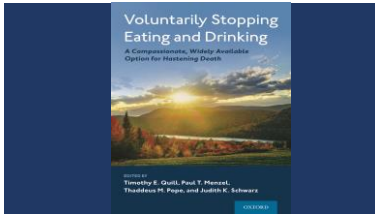
160

JAMA Internal Medicine | Special Communication | HEALTH CARE POLICY AND LAW
Voluntarily Stopping Eating and Drinking Among Patients With Serious Advanced Illness—Clinical, Ethical, and Legal Aspects
Timothy E. Quill, MD; Linda Garzini, MD, MPH; Robert D. Trug, MD; Theodossios Mason-Pope, JD, PhD
JAMA Internal Medicine January 2018 Volume 178, Number 1 123

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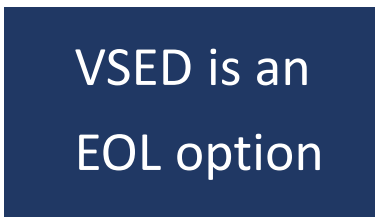
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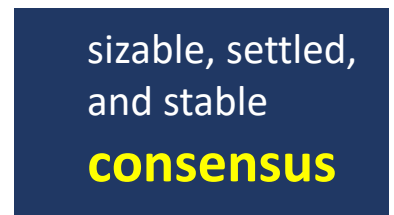
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169



170



171

5 points

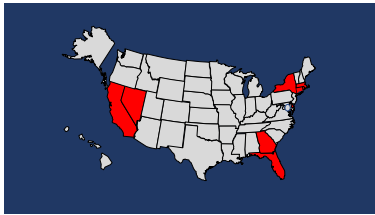
172

court precedent

173

multiple appellate decisions

174



175

same in other common law countries

176

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

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SUPREME COURT OF SOUTH AUSTRALIA
(Applications Under Various Acts or Rules: Application)

DISCLAIMER - Every effort has been made to comply with suppression orders or statutory provisions prohibiting publication that may apply to this judgment. The user remains on any person using material in the judgment to ensure that the broadest use of that material does not breach any such order or provision. Further enquiries may be directed to the Registry of the Court in which it was generated.

H LTD v J & ANOR
[2010] SASC 176
Judgment of The Honourable Justice Kourakis
15 June 2010

178

is VSED legal?
asked & answered

179

plus

180

no need for
direct, explicit
authority

181

already legal
existing rules

182

right to refuse
medical
treatment

183

**right to
refuse
treatment**

184

ventilator
dialysis
CPR
antibiotics
feed tube

185

**right to
refuse
treatment**

VSED

186

not DIY

187

part of a broader
treatment plan

188

supervised by
licensed healthcare
professionals

189

recognized as
healthcare by
medical profession

190

more position
statements

191

more clinical
practice
guidelines

192



VNSNY HOSPICE & PALLIATIVE CARE
POLICY and PROCEDURE

TITLE: VSED: Responding to a Patient's Desire to
Voluntarily Stop Eating and Drinking

193

“ethical and
legal option”

194

“well-settled right
... to refuse any
unwanted
intervention”

195

but

196

right to
refuse
treatment



197

relies on
premise

198

oral N&H =
“treatment”

199

oral N&H ≠
“treatment”

200

basic care

201



202



203



204

yes

205

right to
refuse **any**
intervention

206

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

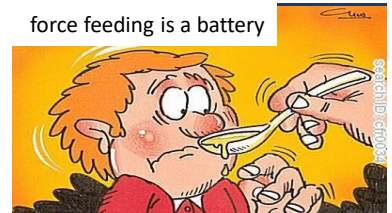
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right to refuse
any intervention
(medical **or not**)

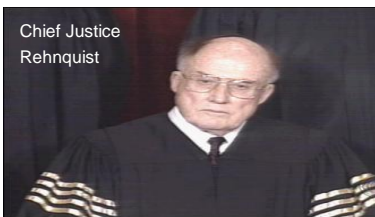
208

right to refuse
any
unwanted contact

209



210



211

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

212

plus

213

medical
profession
accepts VSED

214

law **delegates &**
defers to healthcare
professionals

215

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

216

no
sanctions

217

Appendix E
Personal Narratives

In this book, we presented nine original, never-before-published cases of VSED in Chapter 1 and one more in Chapter 2. We included one more in Chapter 7. But we are not alone. Many individuals have written about their family member's experience with either VSED or SED. This appendix includes citations and links to these personal narratives. These are grouped as follows: (1) books, (2) articles, (3) video and audio recordings, and (4) other resources.

218

used &
reported

219

no liability
no HC licensing
board discipline

220

recap

221

VSED is
legal

222

sizeable, settled,
and stable
consensus

223

limits
of VSED

224



225

many **used VSED**
to avoid late-stage
dementia

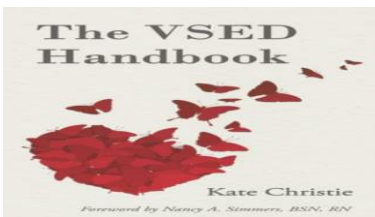
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231



232

but

233



234

VSED while **still** have capacity

235



VNSNY HOSPICE & PALLIATIVE CARE
POLICY and PROCEDURE
TITLE: VSED: Responding to a Patient's Desire to Voluntarily Stop Eating and Drinking

236

“where the patient **lacks** decision making capacity VSED **cannot** be initiated”

237



238

too **soon**

239

life **still** worthwhile

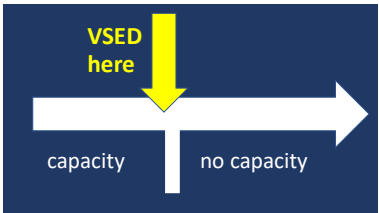
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earliness problem

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243



244

but

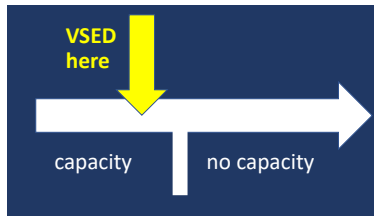
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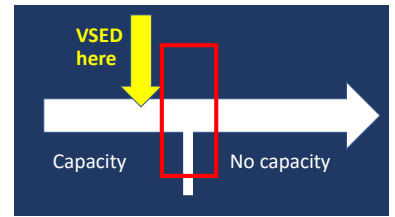
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247



248



249

premature
dying

250

current situation
still acceptable

251

VSED **not** a
good option

252

at **that** time

253

not ready
to die yet

254

concerned
about **future**
circumstances

255

lack capacity
at future time

256



257



258



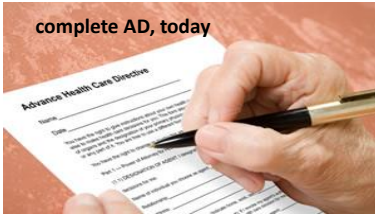
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VSED AD

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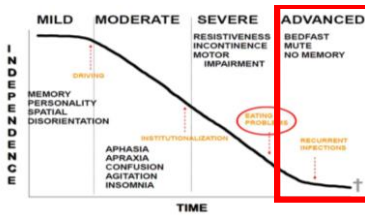
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263



264



265



266

at **point**
Pt specifies

267

clinical
triggers

268

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

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functional
triggers

270



271



272



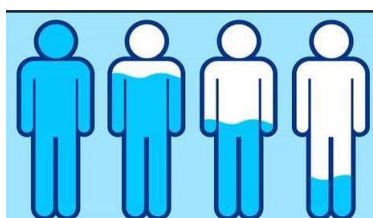
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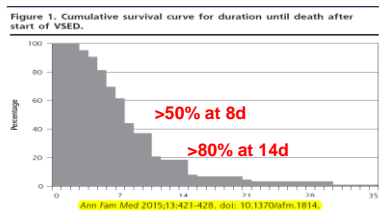
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277



278



279

A Piece of My Mind

My Living Will

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

I, William Arthur Broad, 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 shovled to my mouth, my mind frozen inside while my life

280

last 5 years

281

>13 VSED ADs

282

DARTMOUTH

The Dartmouth Dementia Directive

An advance care document for dementia care planning

283

End of Life Choices NEW YORK

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

284

end of life WASHINGTON

Your life. Your death. Your choice.

285

Dementia Provision Advance Directive Addendum

compassion & choices Care and Choice at the End of Life

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.

286

exit VEREINIGUNG FÜR HUMANES STERBEN DEUTSCHE SCHWEIZ

287

Support and promote life quality

lifecircle

lifecircle | Living will & additional personal statement

288



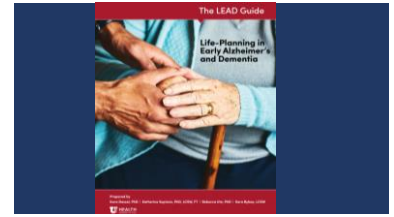
Introduction to our Supplemental Advance Directive For Dementia

289



4. ASSISTED FEEDING. If I am unable to feed myself, then spoon feed me whatever I seem to enjoy, and no more. Do not feed me or apply medical interventions, such as tubes and IVs, so that I might live longer.
If this sentence is initiated and any of the choices 5, 6, or 7 are initiated, the latter are not to be implemented if they put my agent or any of my caregivers at criminal risk.
5. WITHHOLD NUTRITION & HYDRATION if I show no desire to eat and/or drink. This includes medical interventions such as tubes and IVs. Do not encourage or entice me to eat or drink. Keep food odors out of my room.

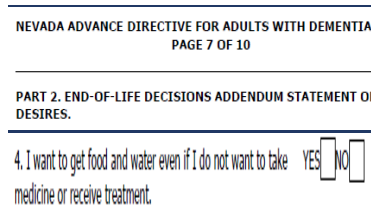
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291



292



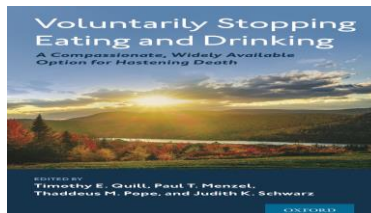
293



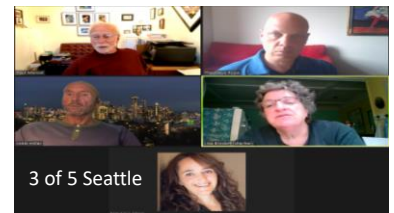
294



295



296



297

I counseled
on VSED ADs

298



299

1 "regular"
AD

300

2 capacity
at sign

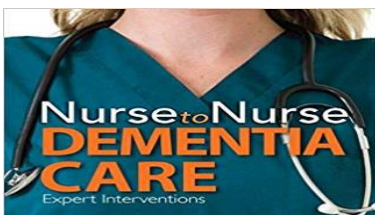
301

3 clear on
what

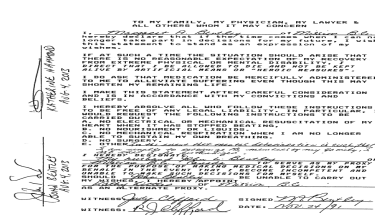
302



303



304



305

NO NOURISHMENT OR LIQUIDS.

306



307



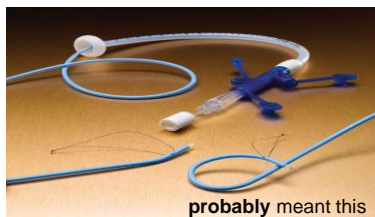
308

family **lost**

309

NO NOURISHMENT OR LIQUIDS.

310



311

family **unable**
to enforce AD

312

be specific

313

oral food & fluids
nutrition & hydration by **mouth**
hand- feeding
spoon- feeding
normal feeding

314

be clear on
what you want

315

<p>VSED</p> <p>refuse all oral assisted feeding</p>	<p>CFO</p> <p>feed so long interested & willing</p>
-------------------------------------------------------------------	----------------------------------------------------------------

316

4

clear on **when**

317

trigger

clinically defined

318

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

319

trigger

functionally defined

320



321

5

how **measure** when

322

6

clear on why

323

7

clear on where

324

8 show understand

325

9 Ulysses clause

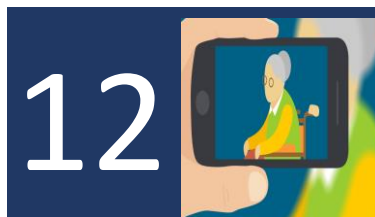
326

10 discuss agent

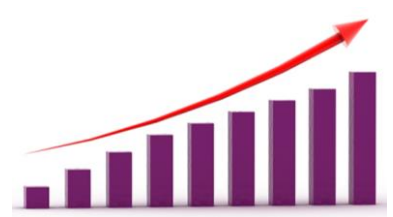
327

11 copies & registry

328



329

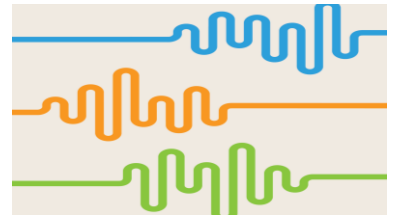


330

331

legal

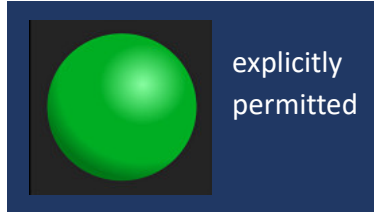
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333



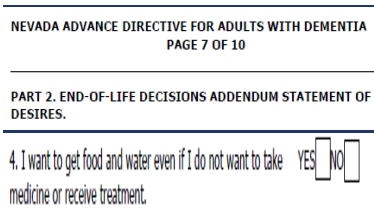
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335



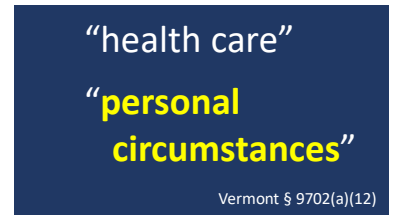
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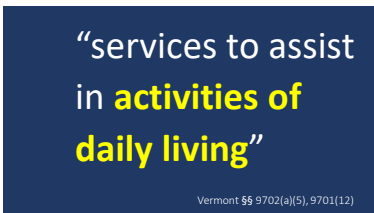
337



338



339



340




341



342

ADs only for **HC**
ONH **≠** HC
ADs **not** for ONH

343

 no explicit permission
no explicit prohibition

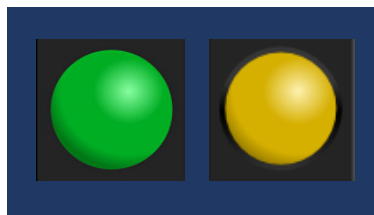
344




345

no living will
no terminal condition
no "life-sustaining treatment"

346



347

UW Medicine
Harborview Medical Center – University of Washington Medical Center
UW Medicine Primary Care – Valley Medical Center – UW Physicians
DURABLE POWER OF ATTORNEY HC
Page 1 of 4

U0289
UH0289 REV FEB 22 RCW 11.125.260

348

law → ethics

349

ethical

350

BIGGEST PROBLEM

351

conflict

352

prior self vs now self

353



354

3 problems with VSED dementia ADs

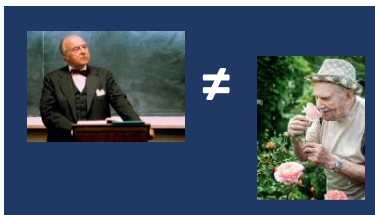
355

1

356

personal identity

357



358



359

too strong undercuts ADs contracts Medicare #

360

2

361

disrespects
interests of PWD

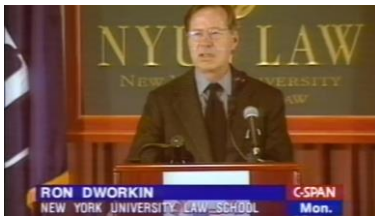
362



363



364



365

critical interests
vs
experiential interests

366

critical interests
life meaning & significance
career
family
gender expression

367

experiential interests
pleasure
enjoy playing golf

368

critical > experiential

369

prior self **vs** now self
critical *experiential*

370

3

371

 Error!

372

stereotypes & prejudices about future life with dementia
uninformed choices need not be respected

373



374

A Decision Aid
about
Goals of Care
for
Patients with
Dementia



375



376

sum up

377



378



379

**BIGGEST
PROBLEM**

380

revocation

381

patient **has**
VSED AD

382

now has
late-stage
dementia

383

SO...

384

time to
honor AD

385

assume you
proceed
to honor

386

but

387



388

big **challenge**
for dementia
directives

389

whose wishes
do we respect?

390

prior self
or
current self

391

now patient
or
then patient

392

incapacitated
veto

393

also problem for
VSED - begun
with capacity

394

whose wishes
do we respect?

395

prior self **vs** now self

396



397

2 stages

398

step 1

399

is there **really**
a past/present
contradiction

400



401

MAID

402

Palliative Care & Social Practice Original Research

How does Medical Assistance in Dying affect end-of-life care planning discussions? Experiences of Canadian multidisciplinary palliative care providers

Anita Ho, Joshua S. Norman, Soledad J. Jooliane, Kristie Sereta, Louise Twells

Publication: Palliative Care & Social Practice, 2023, Vol. 16, No. 1-4, pp. 1-10, 10.1177/24722901221104766, © The Author(s) 2023. Article reuse guidelines: sagepub.com/journalsPermissions

403

“is this someone who
wants MAID?
or is there **something
else going on?**”

404

VSED

405

readdress
symptom
management

406

remind patient
of her plan

407

request for fluid
may evaporate

408

step 2

409

I'm thirsty



410

if there **really is**
a contradiction

411



412

have patient
address this
in AD

413

3 options

414

option **1**

415

“I want **my agent** to decide”

416

option **2**

417

VSED → **CFO**

418

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.

419

VSED

420



421

CFO

422



423

option **3**

424

Ulysses
clause

425

ignore my
future self

426

stick to VSED
plan in the AD

427

“no hand feeding
even if I appear to
cooperate by opening
my mouth”

428



429

with Ulysses,
prior self
prevails

430

WashingtonLawHelp.org

9610EN |



**Mental health
advance directive**

431

4. When I may Revoke this Directive. RCW 71.32.080

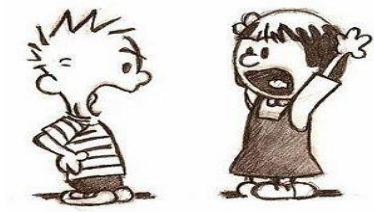
I intend that I be able to revoke this directive (choose only one):

- Only when I have capacity** understand that choosing this option means I may only revoke this directive if I have capacity. I further understand that if I choose this option and become incapacitated while this directive is in effect, I may receive treatment that I specify in this directive **even if I object at the time**
- Even if I am incapacitated** I understand that choosing this option means that I may revoke this directive even if I am incapacitated. I further understand that if I choose this option and revoke this directive while I am incapacitated, I may not receive treatment that I specify in this directive, even if I want the treatment.

432

but

433



434

1990s

435



436



437

2020s

438



439



440



441

“words, sounds
or gestures ...
refusal”

442



443



444



445

“words, sounds
or gestures ...
refusal”

446



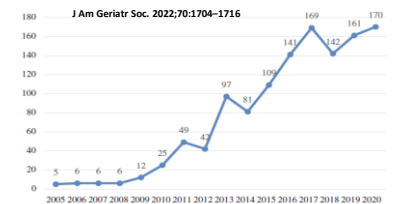
447



448




449



450

FEBRUARY 2023



**MEDICAL ASSISTANCE IN DYING IN CANADA:
CHOICES FOR CANADIANS**

**Report of the Special Joint Committee
on Medical Assistance in Dying**

451




THE SOCIETY
FOR POST-ACUTE AND
LONG-TERM
CARE MEDICINE

amda

453

2019

454

duties to
current self
are primary

455

despite
VSED directive

456

2023

457

JAMA 36 (2023) 33



JAMDA

journal homepage: www.jamda.com

Editorial
AMDA Updated Statement on Stopping Eating and Drinking by Advance Directives (SED by AD)

Board of Directors, Christopher E. Lachon CAE¹

AMDA – The Society for Post-Acute and Long-Term Care Medicine, Columbia, MO, USA

This article has been entered as the official policy of AMDA – The Society for Post-Acute and Long-Term Care Medicine. Stopping eating and drinking by advance directives (SED by AD) is a complex issue that requires careful consideration of all ethical principles. AMDA encourages all practitioners to carefully consider and evaluate each request for SED by AD individually in the context of clinical and biopsychosocial factors, within the ecosystem of facility, local, state, and federal policy.

458

follow AD despite
current best interest
assessment

459

conclusion

460

demand for
VSED AD

461



462

but

463



464

little guidance
courts, regulators

465

few institutional
policies & procedures

466



467

Voluntarily stopping eating and drinking—lack of guidance is failing patients and clinicians
Patients and physicians need clear information to navigate the complex processes in end-of-life care, say Linda Dylkes and colleagues
Linda Dylkes,¹ Simon Hodges,² Sarah Malik³

468



Voluntary stopping of eating and drinking in the age of medical assistance in dying; ethical considerations for physicians

Peter Allart, Daniel O.M. Kim and Philip Hebert

Palliative Care & Social Practice
2022, Vol. 16, 4-10
DOI: 10.1177/1022522121101070
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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

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materials from this presentation are available
<http://thaddeuspope.com/vsed>

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