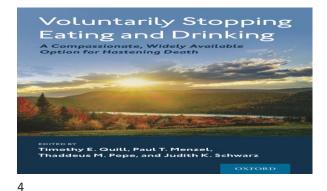
### Voluntarily Stopping Eating and Drinking

A Lesser Known but Widely Available End-of-Life Option



2

## nothing to disclose



3





5 6



# sessions

8



# minutes

10

MAID other RTD

1090 125

appropriate

11 12











most live in non-MAID jurisdictions

17 18





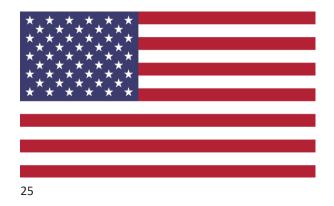
21



2

many in MAID jurisdictions are ineligible

23 24



### 6-month prognosis

26





even if eligible





patient's own religion

32



waiting periods & screenings

34



no MAID via AD

35 36

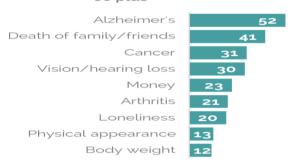




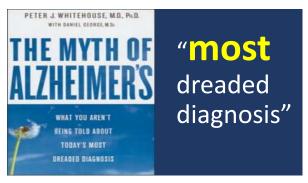
# fear of dementia

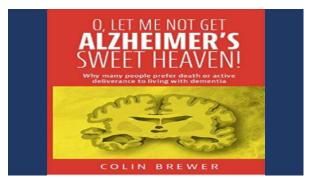
39

#### 60 plus



40





41 42

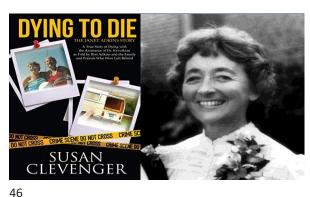


many hasten death to avoid late-stage dementia

44

48



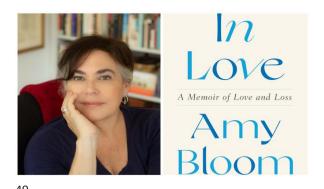


45



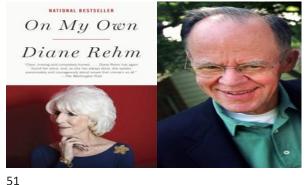
47

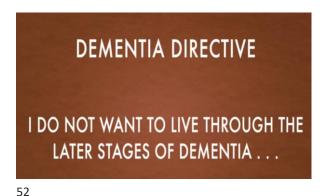
The New York Times



### high profile cases

50









54 53



57

late-stage dementia



SO...

other EOL options

58

60

VSED

Roadmap

59



3 parts

62

what is VSED

status

law, medicine, ethics

64

63

61

VSED by AD

**VSED** 

66

**V**oluntarily

**S**topping

Eating &

**D**rinking

67

69

patient with capacity

68

able to take food& fluid by mouth

voluntary
decision
to stop

70

72





natural loss

appetite

71

deliberate choice stop fluids by mouth

goal = death

from dehydration

73

74

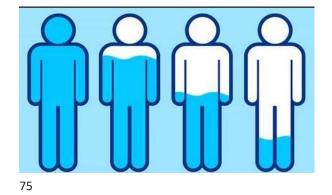
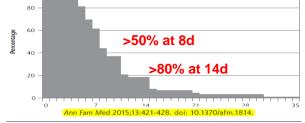


Figure 1. Cumulative survival curve for duration until death after start of VSED.



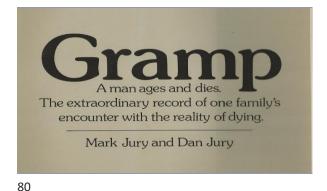
76

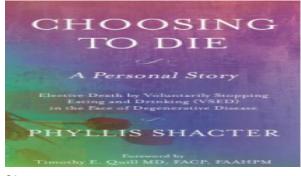
peaceful comfortable

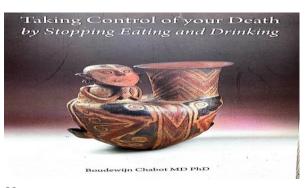
1<sup>st</sup> person narratives

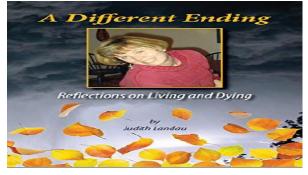
77

















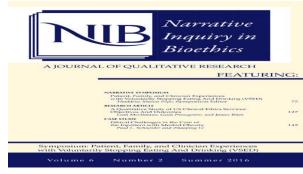
## more cases

87

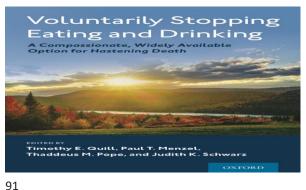


88





89 90



not only 1st person narratives

92

94

### objective evidence

patient experience

peaceful comfortable

93

The NEW ENGLAND JOURNAL of MEDICINE

SPECIAL ARTICLE

Nurses' Experiences with Hospice Patients Who Refuse Food and Fluids to Hasten Death

Linda Ganzini, M.D., M.P.H., Elizabeth R. Goy, Ph.D., Lois L. Miller, Ph.D., R.N., Theresa A. Harvath, R.N., Ph.D., Ann Jackson, M.B.A., and Molly A. Delorit, B.A.

100 Oregon nurses cared for **VSED** patients

95 96

### most deaths

"peaceful with little suffering"

97

99



98

"opportunity for reflection, family interaction, and mourning"

## preferred by many

100



even though MAID available, "almost twice" chose VSED

101 102

patients VSED
even where
MAID is legal

103

105

107

Wadden Islands
Terschelling
Viceland
Texel
Den Helder o

Worth SEA
Leiden o Utrecht
Offine Haage o Offine Haade o O

O.4 to 2.1%

of all deaths

Oneutesta Philipsen BD, Brinkman-Stoppelenburg A, Penning C, de Jeng-Krul GP, van Delden JJM, van der Heide A. Trends in end definition in the Northerlands from 1000 Bs 2010, a repeated cross-sectional in the Northerlands from 1000 Bs 2010, a repeated dring attended by proseles in the Dutch population, 50c 567 Affeet.

The NEW ENGLAND JOURNAL of MEDICINE

End-of-Life Decisions in the Netherlands over 25 Years

>½ deaths euthanasia





108

104

106

## good option

## clinical status

110

109





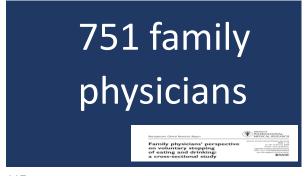


300 hospice & palliative care specialists

113 114









117 118





119 120

10/31/2022





palliative care

specialists

Heatin, N. L. Stock, M. & Stock, A. (2015) Receiving polliarity medicinal stock of fine and after polliarity medicinal stock of the collection of medicinal stock of fine and after polliarity medicinal stock of fine a

61%
experience with VSED

123 124

not just more clinical experience



125 126

# professional society endorsements

127

129

#### POSITION STATEMENT



#### Nutrition and Hydration at the End of Life

Effective Date: 20

Status: Revised Position Statement
Written by: ANA Center for Ethics and Human Rights

Adopted by: ANA Board of Directors

128



JOURNAL OF PALLIATIVE MEDICINE Volume 20, Number 1, 2017 Mary Ann Liebert, Inc. DOI: 10.1089/jpm.2016.0290 Position Statement

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

130



American Medical Women's Association



e-SPEN guideline

ESPEN guideline on ethical aspects of artificial nutrition and hydration

Christiane Druml a.\*, Peter E. Ballmer b, Wilfred Druml c, Frank Oehmichen d,

Position Paper



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

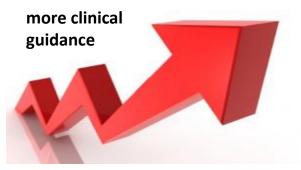
Denise Baird Schwartz, MS, RD<sup>1</sup>; Albert Barrocas, MD<sup>2</sup>;

133

135

Nutrition in Clinical Practice Volume 0 Number 0 January 2021 1-14 © 2021 American Society for Parenteral and Enteral Nutrition DOI: 10.1002/ncp.11633 wileyonlinelibrary.com





Caring for people who consciously choose not to eat and drink so as to hasten the end of life

136

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 Ganzini, MD, MPH; Robert D. Truog, MD; Thaddeus Mason Pope, JD, PhD

JAMA Internal Medicine January 2018 Volume 178, Number 1 123

Journal of the American Geriatrics Society

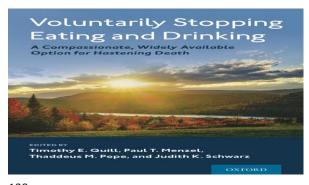


SPECIAL ARTICLE; PALLIATIVE PRACTICE POINTERS

Voluntary Stopping Eating and Drinking

John W. Wax, MD, Amy W. An, MD, Nicole Kosier, MD, and Timothy E. Quill, MD

138





VSED is an EOL option

broadly accepted

141 142

evidence based

clinical -> legal

143 144

VSED is legal

145

147

sizable, settled, and stable consensus

146

5 points

court precedent

148

multiple appellate decisions



149 150

### same in other common law countries

151

#### 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

152

#### SUPREME COURT OF SOUTH AUSTRALIA

(Applications Under Various Acts or Rules: Application)

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

#### H LTD v J & ANOR

[2010] SASC 176

Judgment of The Honourable Justice Kourakis

15 June 2010

153

### is VSED legal? asked & answered

154



155

no need for direct, explicit authority

already legal
existing rules

right to refuse medical treatment

158

157

159

right to refuse treatment

ventilator dialysis CPR antibiotics feed tube

160

right to refuse treatment

not DIY

161 162

part of a broader treatment plan

supervised by licensed healthcare professionals

163

164

recognized as
healthcare by
medical profession

**more** position statements

165 1

166

more clinical practice guidelines



167 168



## relies on premise

170

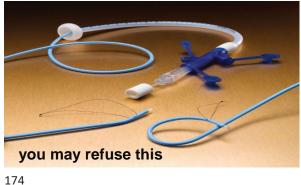
oral N&H =
"treatment"

oral N&H ≠ "treatment"

171

172

basic care



173







right to refuse any intervention

178

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

right to refuse

any intervention

(medical or not)

179 180





184



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



medical profession accepts VSED

185 186

law delegates & defers to healthcare professionals

when medical profession says it is appropriate → law often follows

188

190

187

189

no sanctions Appendix E

Personal Narratives

this book, we presented nine original, never-before-published carr VSED cases in Chapter 1 and one more in Chapter 2. We include es in Chapter 7. But we are not alone. Many individuals have writter e or their family member's experience with either VSED or SED includes citations and links to these personal narratives. These are gons: (1) books, (2) articles, (3) video and audio recordings, and (4)

used & reported

no liability

no HC licensing board discipline

191 192



VSED is legal

194

193

sizable, settled, and stable consensus



196

195

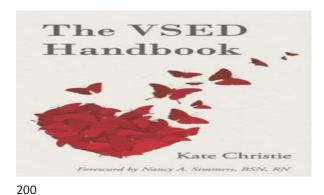


many used VSED to avoid late-stage dementia

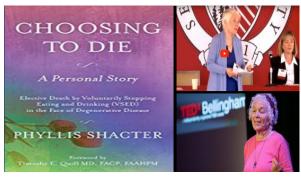
197 198

10/31/2022













VSED while still have capacity



206

too soon

life still worthwhile

208

207

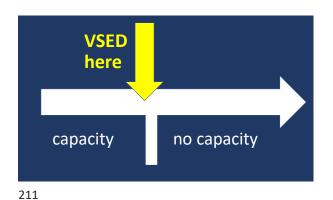
205

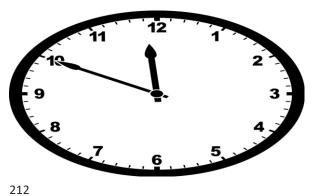
earliness problem



209 210

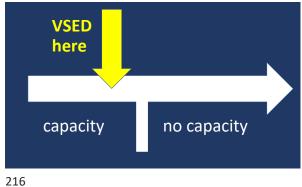
10/31/2022

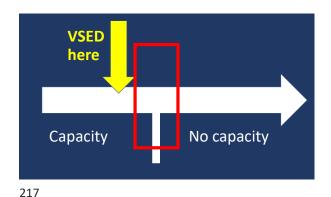












## premature dying

218

220

**current** situation still acceptable

VSED **not** a good option

219

at that time

not ready
to die yet

221 222

concerned about future circumstances

223

lack capacity at future time

224





225 226





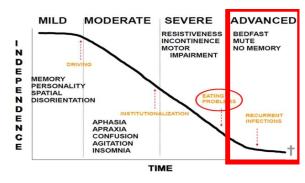








232





233 234

# at point Pt specifies



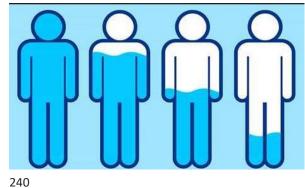
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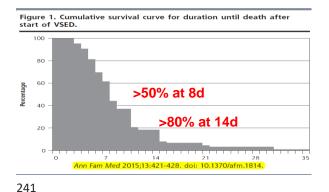


237 238

Stage	Stage Name	Characteristic	Stage	Stage Name	Characteristic
1	Normal	No deficits whatsoever	6a	Moderately Severe Dementia	Needs help putting on clothes
	Ageing	nevenue acadata (A)	6b		Needs help bathing
2	Possible Mild Cognitive Impairment	Subjective functional deficit	6c		Needs help toileting
			6d		Urinary incontinence
	Mild	Objective functional deficit	60		Faecal incontinence
3	Cognitive Impairment	interferes with a person's most complex tasks	7a	Severe Dementia	Speaks 5-6 words during the day
4	Mild Dementia	Instrumental activities of daily living (ADLs) become affected, such as paying bills, cooking, cleaning, travelling	7b		Speaks only 1 word clearly
			7c		Can no longer walk
			7d		Can no longer sit up
5	Moderate Dementia	Needs help selecting proper attire	7e		Can no longer smile
			71		Can no longer hold up head



239 24



VSED AD

242



A Piece of My Mind

#### My Living Will

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

I, William Arthur Hensel, 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 mr month my soul frozon inside while my life

244

last 5 years

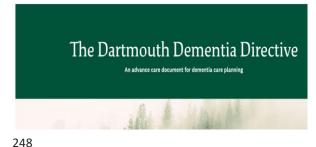
>10 VSED ADS

245 246



DARTMOUTH

**EXPL** 



247



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

249



Your life. Your death. Your choice.

250

#### **Dementia Provision**Advance Directive Addendum





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.



251 252

Support and promote life quality





Advance Directive

For Dementia

lifecircle Living will & additional personal statement

253

254

#### 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 YES NO medicine or receive treatment.

255

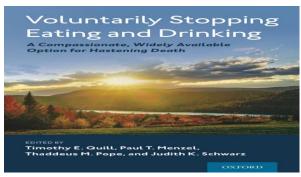
NEVADA ADVANCE DIRECTIVE FOR ADULTS WITH DEMENTIA
PAGE 7 OF 10

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 YES NO medicine or receive treatment.

256





257 258

### I counseled on VSED ADs



260

262

259

261

"regular" AD

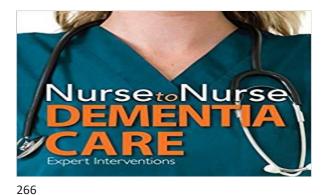
2 capacity at sign

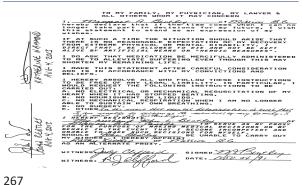
3 clear on what

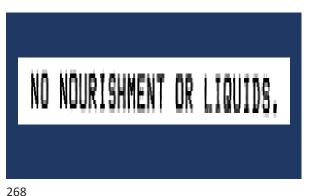


263







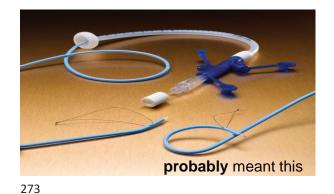












### family unable to enforce AD

274

be specific

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

275 276

be clear on what you want

clear on when

278

277

how measure when

6 clear on why

279 280

clear on where

S show understand

281 282

Ulysses clause

10 discuss agent

284

1 1 copies & registry

283

285

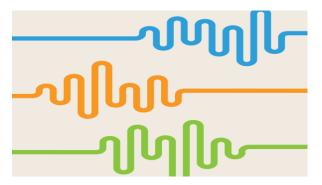


286



law & ethics











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.

294



"health care" "personal circumstances" Vermont § 9702(a)(12)

296

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



297 298

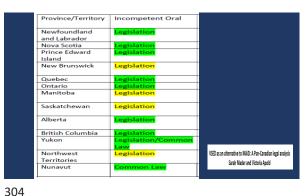


ADs only for HC ONH ≠ HC ADs not for ONH

299 300











305 306

patient has VSED AD

now has late-stage dementia

308

307

SO...

time to honor AD

310

309

but



311

big challenge for dementia directives

whose wishes
do we respect?

314

313

prior self current self now patient or then patient

315 316

incapacitated **Veto** 



317 318

have patient address this in AD

3 options

320

319

option 1

"I want my agent to decide"

321 322

option 2

VSED → CFO

323 324

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<sup>\*</sup>, Joan M. Teno, MD, MS<sup>†</sup>, David J. Casarett, MD, MA<sup>‡</sup>, Laura C.

325







328





### Ulysses clause

### ignore my future self

332

331

stick to VSED plan in the AD

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

333 334



with Ulysses, prior self prevails

335 336







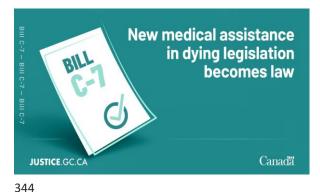






2020s







If the Requestor loses capacity and MAiD is administered in accordance to the terms of this agreement, Prescriber must fax this and all required forms to the BC Ministry of Health at 778-698-4678 and to the health authority MAiD Care Coordination Service (if required) within 72 hours of confirmation of requestor's death. Retain original in requestor's health records.

Written arrangement between the Requestor named below and the MAiD Prescriber na with section 241.2(3.2) of the Criminal Code of Canada (The waiver of final consent is ONL reasonably foreseeable)

345

"words, sounds or gestures ... refusal"

346





347 348



"words, sounds or gestures ... refusal"

350





351 352







353 354



356

duties to

current self

are primary

357

despite

**VSED** directive

358

2022

follow AD despite current best interest assessment

359 360

# Conclusion

## demand for VSED AD

361 362





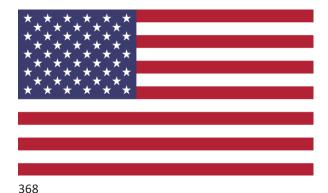
364



little guidance courts, regulators

365 366

## few institutional policies & procedures



367



Palliative Care & Social Practice

Palliative Care & Social Practice
Palliative Care & Social Practice
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Palliative Care & Social Practice
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P

370

contrast MAID



371 372







#### 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