

Avoid Late Stage Dementia Advance Directives for Stopping Eating & Drinking

Thaddeus Mason Pope, JD, PhD, HEC-C
Arizona Bioethics Network • June 16, 2021

1

Thank you

2

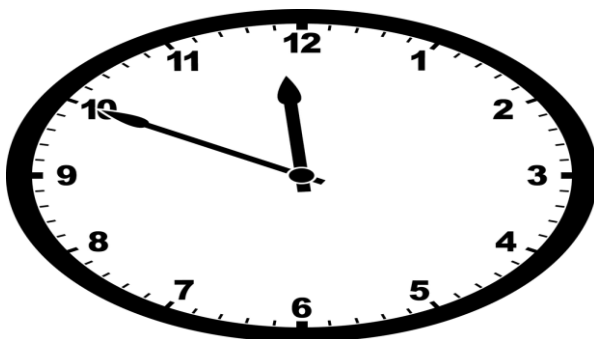
Do Clinicians Always Need Consent to Stop Life- Sustaining Treatment?

Arizona Bioethics Network
June 19, 2014

3

7 years

4



5

Time travel movies

6



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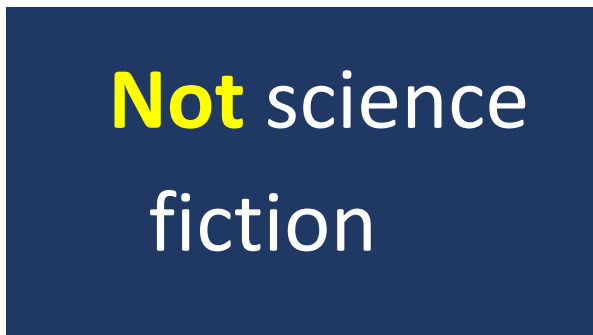
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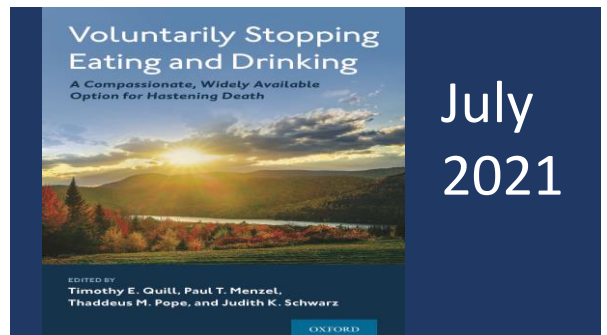
15



16



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18

Roadmap

19

4

20

Fear of
Dementia

21

Last resort
options

22

VSED

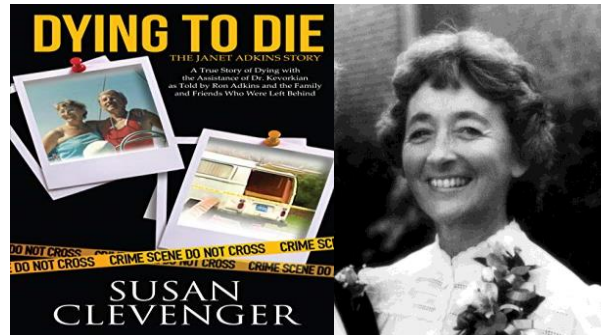
23

SED by **AD**

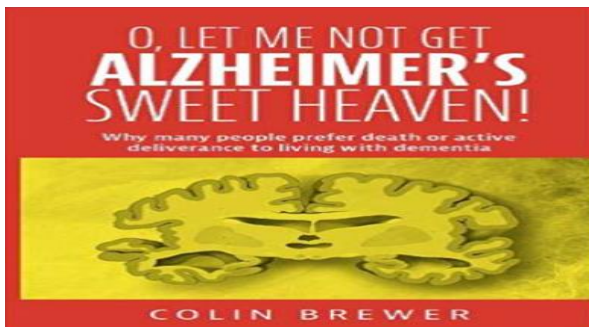
24

Fear of Dementia

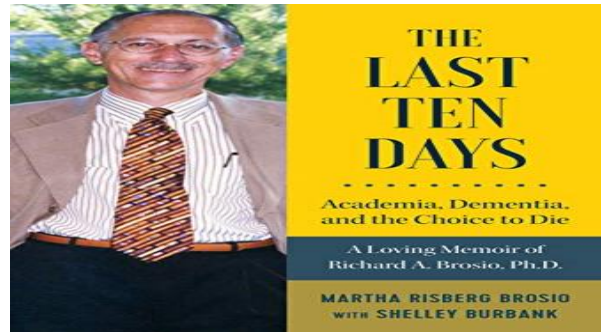
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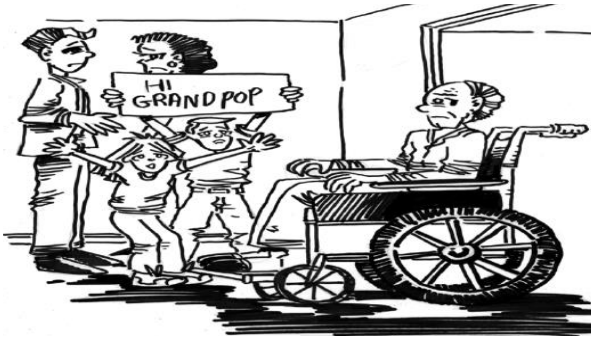
DEMENTIA DIRECTIVE

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

29



30



31



32



33

How to **avoid** late stage dementia

34

Last Resort Options

35

3 main options

36

Refuse Tx

37

MV CANH
CPR Antibiotics

38

Self
if capacity

39

If **lack**
capacity

40

Agent / Surrogate
Living Will
POLST

41

154 Ariz. 207
**Mildred RASMUSSEN by Douglas P.
MITCHELL, her Guardian ad
Litem, Appellant,**
v.
**Robert FLEMING, Pima County Public
Fiduciary, as Guardian for Mildred
Rasmussen, Appellee.**
No. CV-86-0450-PR.
Supreme Court of Arizona,
En Banc.
July 23, 1987.

42

BUT

43



44



45

~~Refuse Tx~~

46

MAID

47

Most discussed end-of-life option

48

BUT

55



56

“resident
of _____”

57



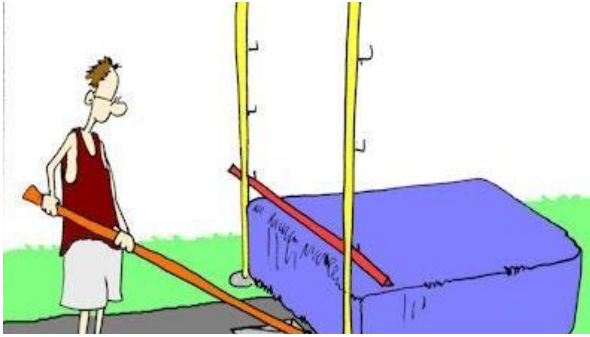
58

Confirmed
by attending
physician

59

- Driver license
- Voter registration
- Tax return
- Own or **lease property**

60



61

BUT

62

Cannot satisfy
eligibility
conditions

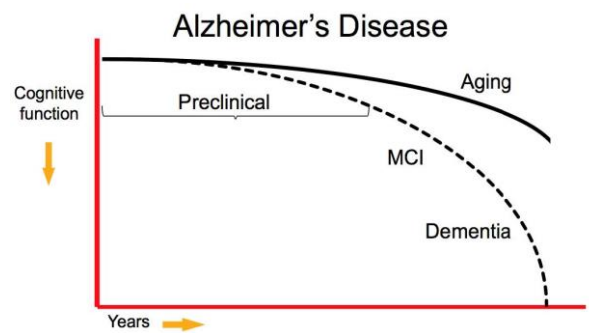
63

Terminally ill
< 6 mo. prognosis

64

Decisional capacity

65



66

Terminal →
no capacity

67

Capacity →
not terminal

68

~~MAID~~

69

PSU

70

Degree

Mild → Deep
Unconscious

71

Duration

Temp → Perm
Respite Intermittent Continuous

72

PSU makes
Pt depend
on **CANH**

73

Pt usually
refuses
CANH

74

BUT

75



76



77

Suffering
Intolerable
Refractory

78

Suffering
Physical
 Not existential

79

~~PSU~~

80

~~Refuse Tx
 MAID
 PSU~~

81

VSED

82

Voluntarily
Stopping
Eating &
Drinking

83

Patient **with**
 capacity

84

Able to take food
& fluid by mouth

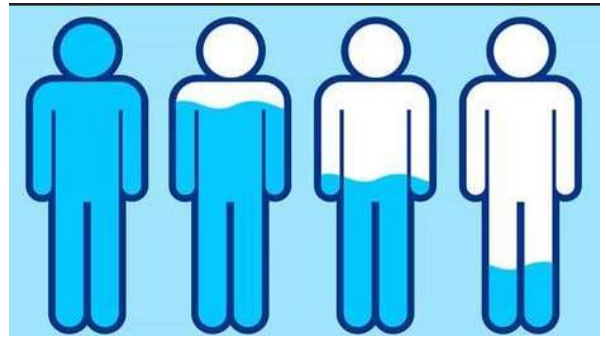
85

Voluntary
decision
to stop

86

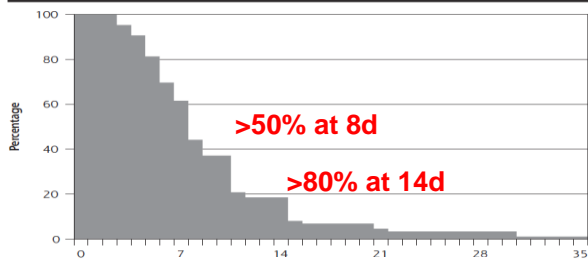
Goal = death
from dehydration

87



88

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



89

Peaceful
Comfortable

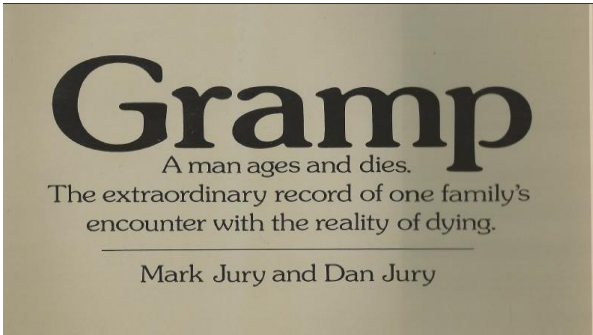
90

1st person narratives

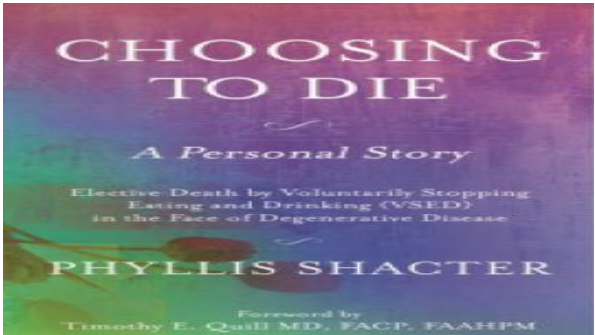
91

Books

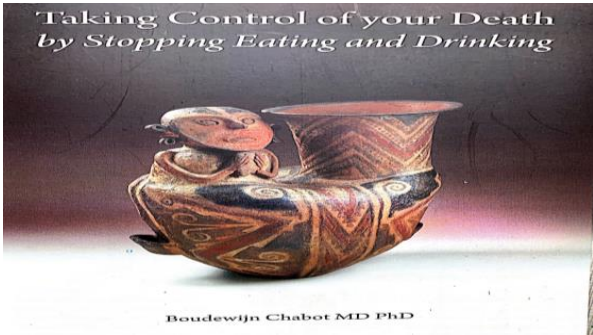
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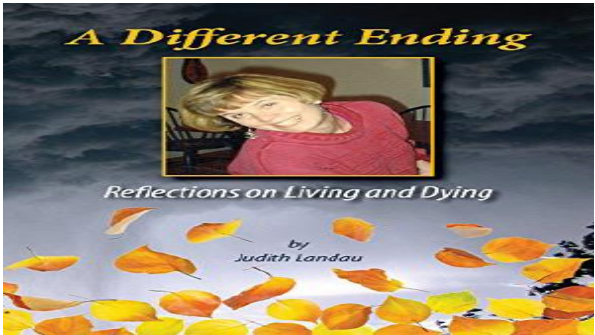
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Films

97



98



99

More stories

100



101

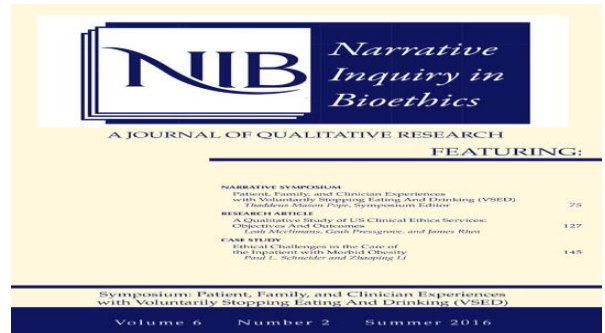


102



VSED Resources Northwest

103



104

Not only
1st person
narratives

105

**Objective
evidence**
patient experience

106

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.

107

100 Oregon
nurses cared for
VSED patients

108

Most deaths

“**peaceful** with little suffering”

109



110

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

111

Preferred
by many

112



113

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

114



115



116

The NEW ENGLAND JOURNAL of MEDICINE

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

More than $\frac{1}{2}$ deaths
from euthanasia

117



118

Clinical
status

119



120



121



122

300 hospice &
palliative care
specialists

Shinjo T, et al. *BMJ Supportive & Palliative Care* 2017;7

123

32%

experience with VSED

124



125

751 family
physicians

Retrospective Cohort Research Report
Journal of INTERPERSONAL
MEDICAL RESEARCH
Family physicians' perspective
on voluntary stopping
of eating and drinking:
a cross-sectional study
©SAGE

126

33%

experience with VSED

127



128

700 family physicians

ANNALS OF FAMILY MEDICINE • WWW.ANNFAMMED.ORG • VOL. 13, NO. 5 • SEPTEMBER/OCTOBER 2015

129

46%

experience with VSED

130



131

255 palliative care specialists

Hockstra, N. L., Strack, M., & Simon, A. (2015). Bewertung des freiwilligen verzichts auf nahrung und flüssigkeit durch palliativmedizinisch und hausärztlich tätige ärztinnen und ärzte. (Assessment of the voluntary waiver of food and liquid by physicians working in palliative care and primary care). *Zeitschrift für Palliativmedizin*, 19(02), 68-73. doi:10.1055/s-0034-1367571

132

61%

experience with VSED

133

Not just more clinical experience

134

More position statements



135

Professional society endorsements

136

Austrian Palliative Society (OPG)

themenschwerpunkt

Wien Med Wochenschr
<https://doi.org/10.1007/s10354-018-0629-z>



wmw
 Wiener Medizinische Wochenschrift

Freiwilliger Verzicht auf Nahrung und Flüssigkeit um das Sterben zu beschleunigen

Eine Stellungnahme der österreichischen Palliativgesellschaft (OPG)

Angelika Feichtner · Dietmar Weixler · Alois Birkbauer

Eingegangen: 6. September 2017 / Angenommen: 7. Februar 2018
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137

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

138

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

139



American Medical Women's Association

140



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,

141

Position Paper



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

Denise Baird Schwartz, MS, RD¹ ; Albert Barrocas, MD² 

142

Nutrition in Clinical Practice
 Volume 0 Number 0
 January 2021 1-14
 © 2021 American Society for
 Parenteral and Enteral Nutrition
 DOI: 10.1002/ncp.10633
 wileyonlinelibrary.com

WILEY

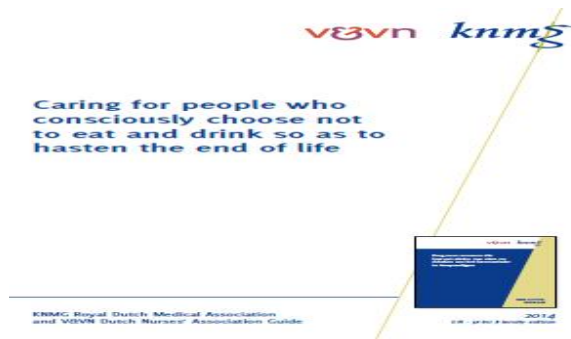


143

**More clinical
guidance**



144



145

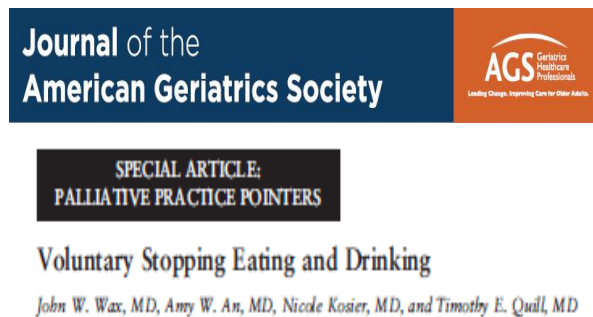
JAMA Internal Medicine | Special Communication | HEALTH CARE POLICY AND LAW

Voluntarily Stopping Eating and Drinking Among Patients With Serious Advanced Illness— Clinical, Ethical, and Legal Aspects

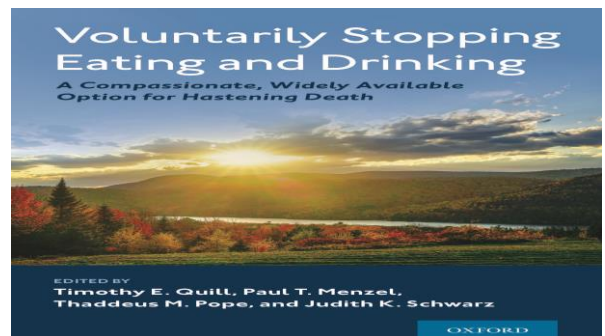
Timothy E. Quill, MD; Linda Ganzhi, MD, MPH; Robert D. Truog, MD; Thaddeus Mason Pope, JD, PhD

JAMA Internal Medicine January 2018 Volume 178, Number 1 123

146



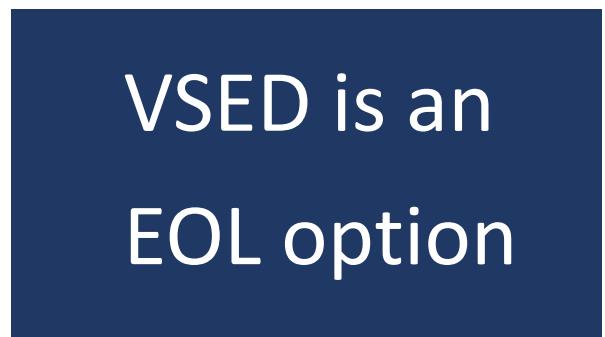
147



148



149



150

Broadly
accepted

151

Evidence
based

152

VSED in
Arizona

153



154



155



156

BUT

157



158

VSED while
still have
capacity

159

Too
soon

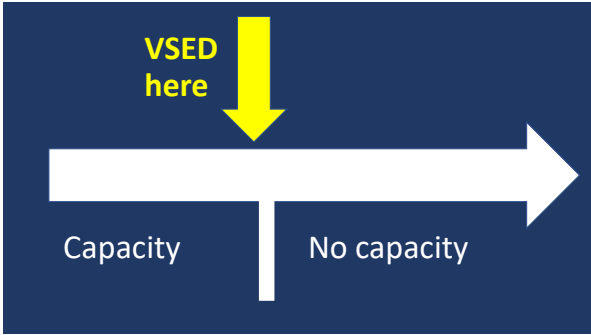
160

Life **still**
worthwhile

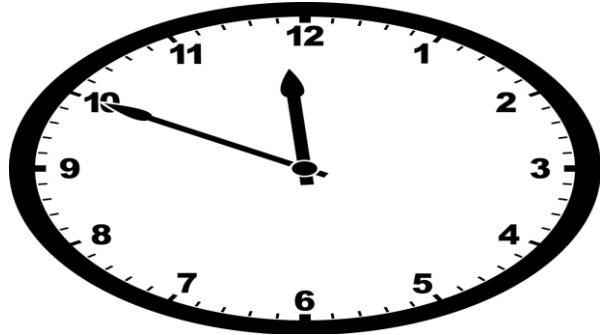
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162



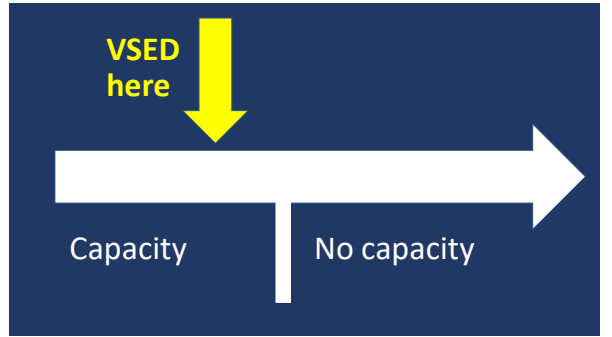
163



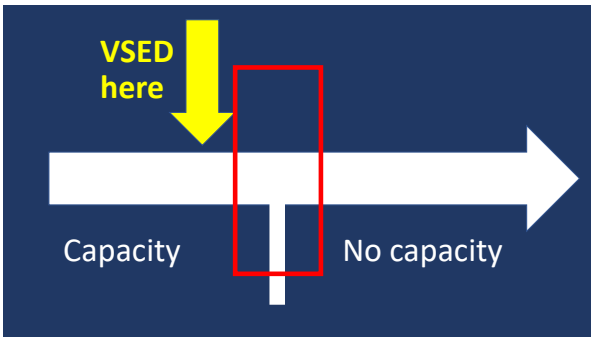
164



165



166



167

Premature
dying

168

SED by AD

169

Complete AD, today



170

Direct VSED in future

171

At **point** Pt specifies

172



173

Growingly
popular



174

A Piece of My Mind

My Living Will

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

I, William Arthur Henseel, 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. My soul frozen inside while my life

175



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

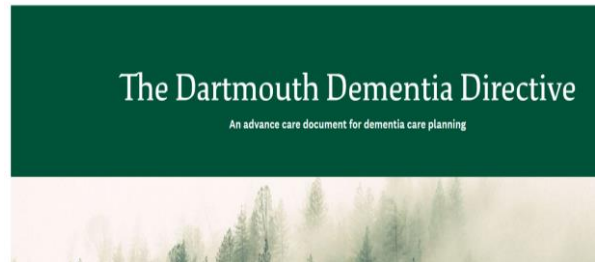
176



177

DARTMOUTH

EXPL



178

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.

179



180



181

**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.

182



**Introduction to our Supplemental
Advance Directive
For Dementia**

183

FinalExit
NETWORK

ABOUT SERVICES PARTNERS NEWS & EVENTS RESOURCES DONATE

The SADD Program

Any individual who wishes to use the SADD on their own can do so. In addition, any user may sign up to receive free legal assistance from FEN in procuring the enforcement of the document from hesitant healthcare providers and institutions.

FEN will provide access to its general counsel, Robert Rivas, to consult with users of the SADD and potentially to sign them up as participants in FEN's ongoing litigation initiative. To inquire into this program, contact Mr. Rivas at fenattorney@gmail.com and he will arrange to confer with you by phone.

184

Arizona AD

185

**prospective
autonomy**

186

Get your wishes
heard when you
can no longer
speak for yourself

187

2

188

Document
or
Person

189

Document

190

LW
POLST

191



192

HIPAA PERMITS DISCLOSURE TO HEALTH CARE PROFESSIONALS & ELECTRONIC REGISTRY AS NECESSARY FOR TREATMENT

Provider Orders for Life-Sustaining Treatment (POLST)

Follow these orders until orders change. These medical orders are based on the patient's current medical condition and preferences. Any section not completed does not invalidate the form and implies full treatment for that section. With significant change of condition new orders may need to be written.

Patient Last Name: _____ Patient First Name _____ Middle Init. _____
 Date of Birth: (mm/dd/yyyy) _____ Gender: M F Last 4 SSN: _____
 M F

C ARTIFICIALLY ADMINISTERED NUTRITION: *Offer food by mouth if feasible.*

Check One No artificial nutrition by tube. Long-term artificial nutrition by tube.

Additional Orders: _____

193

AD for SED
must be
 living will

194

Person

195

3

196

Who
 appoints

197

Who appoints	Type of SDM
Patient	Agent
Legislature	Surrogate
Court	Guardian

198



199



200

Ariz. Stat. § 36-3203(E)

“surrogate who is not the patient's agent ... **shall not** consent to or approve ... withdrawal of ... food or fluid”

201

Who appoints	Type of SDM
Patient	Agent
Legislature	Surrogate
Court	Guardian

202

SDM for SED
by AD must
be **agent**

203

Focus
Agents
LWs

204

Both

205

Arizona
legality

206



207



208



209

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

210



211



212



213



214

“living will ... control ... **health care** treatment decisions”

36-3201(10) 36-3261

215

“agent entitled ... make **health care** decisions”

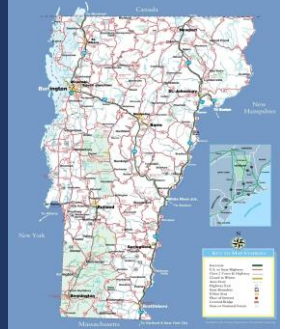
36-3223

216

Health care

217

Contrast



218

“health care”
“**personal circumstances**”

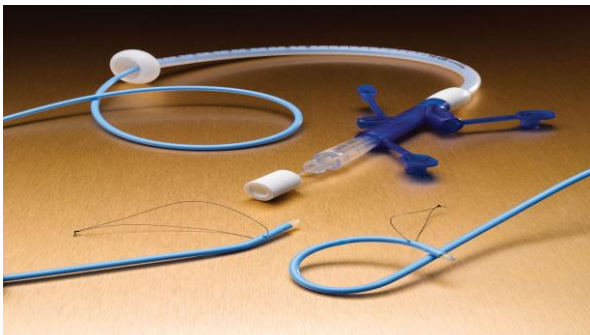
Vermont § 9702(a)(12)

219

“services to assist
in **activities of daily living**”

Vermont §§ 9702(a)(5), 9701(12)

220



221



222

Statute does not define
“health care”

But defines “health care
provider”

36-3201(7)

223

Provided by a “health
care provider” →
health care

224

**Belinda L. JETER, a married woman;
William R. Jeter, a married man,
Plaintiffs–Appellants,**

v.

**MAYO CLINIC ARIZONA d/b/a Mayo
Clinic Scottsdale and/or Center for Re-
productive Medicine, an Arizona corpo-
ration, Defendant–Appellee.**

No. 1 CA–CV 04–0048.

**Court of Appeals of Arizona,
Division 1, Department E.**

Oct. 27, 2005.

225

VSED is part of
broader
treatment plan

226

PAVSED

Palliated & Assisted Voluntarily
Stopping Eating and Drinking

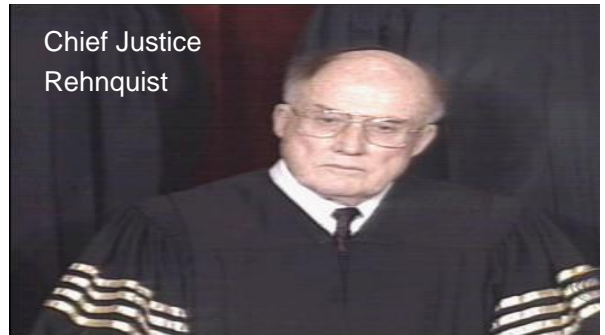
227

Recognized as
healthcare by
medical profession

228

<p>POSITION STATEMENT</p>  <p>ANA Nurses Association</p> <p>Nutrition and Hydration at the End of Life</p> <p>Effective Date: 2017 Status: Revised Position Statement Written by: ANA Center for Ethics and Human Rights Approved by: ANA Board of Directors</p>	 <p>Caring for people who consciously choose not to eat and drink so as to hasten the end of life</p> 	<p>Position Statement</p> <p>INTERNATIONAL ASSOCIATION OF HOSPICE AND PALLIATIVE CARE</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>SPECIAL ARTICLE: PALLIATIVE PRACTICE POINTERS</p> <p>Voluntary Stopping Eating and Drinking</p> <p>John W. Wan, MD, Amy W. Ai, MD, Nicole Kivimä, MD, and Timothy E. Quill, MD</p>	 <p>The Vision and Voice of Women in Medicine since 1915</p> <p>American Medical Women's Association</p>

229



230

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

231

“Basic” care

not “health” care

232

AZ statute

SED by AD

233

Still have AD for SED

234

Non-statutory AD for SED

235

154 Ariz. 207
Mildred RASMUSSEN by Douglas P. MITCHELL, her Guardian ad Litem, Appellant,
 v.
Robert FLEMING, Pima County Public Fiduciary, as Guardian for Mildred Rasmussen, Appellee.
No. CV-86-0450-PR.
 Supreme Court of Arizona,
 En Banc.
 July 23, 1987.

236

4 sources
of rights

237

AZ
statute

SED
by AD

238

Optional

239

~~State statute~~

Federal constitution

State constitution

Common law

240

BUT

241

“reliance on the provisions of an apparently genuine health care directive ... **immune** from criminal and civil liability and ... professional discipline”

36-3205

242

One more option

243

Out-of-state AD for SED

244



245

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

246



247

“valid in this state
if ... valid in the place
where ... adopted ...”
36-3208

248

Let’s assume
you have a **valid**
AD for SED

249

AZ AD
Non-statutory
Out state AD

250

Revocation

251



252

Incapacitated
veto

253

Big **challenge**
for dementia
directives

254

Whose
wishes do
we respect?

255

Prior self
or
Current self

256

Now Patient
or
Then Patient

257



258



Ulysses clause

259

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

260

With Ulysses,
prior self
 prevails

261

BUT

262



263

“A person **may revoke** his
 own health care directive or
 disqualify a surrogate by
 doing any of the following:”

36-3202

264

1. Making a **written revocation** ...
2. **Orally notifying** ... provider.
3. Making a **new health care directive**.
4. **Any other act** that demonstrates a specific intent to revoke ...

265

Any other act that demonstrates ... intent to revoke ...

266

Contrast



267

“A patient **having capacity** may revoke”

Cal. Prob. Code 4695

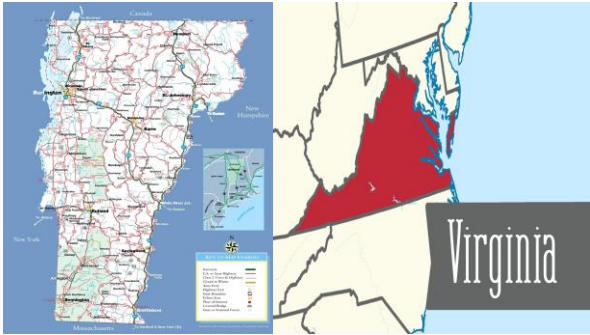
268

No Ulysses clause in AZ

269

Ulysses clauses elsewhere

270



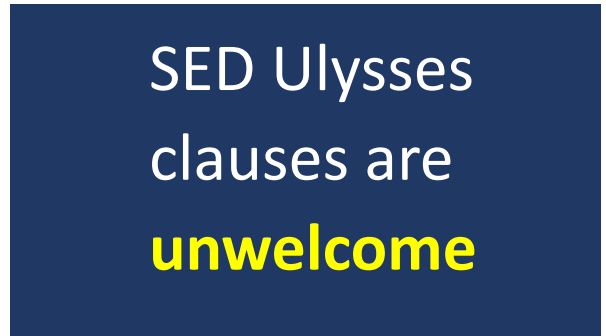
271



272



273



274



275



276

Duties to
current self
are primary

277

Even if VSED
directive valid

278

BILL C-7 – BILL C-7 – BILL C-7 – BILL C-7



**New medical assistance
in dying legislation
becomes law**

JUSTICE.GC.CA Canada

279

 BRITISH COLUMBIA | Ministry of Health

1645
2021/03/18

HLTH 1645 PAGE 1 OF 2

**Medical Assistance in Dying
WAIVER OF FINAL CONSENT**

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)

1. REQUESTOR INFORMATION

Last Name	First Name
-----------	------------

280

“words, sounds
or gestures . . .
refusal”

281



282

Recap

283



284

Plus

285

Conscience
based
objection

286

BUT

287



288

Write AD for SED
today

Not triggered for
5+ years

289

Practical Tips

290



291

1 “regular”
AD

292

2 capacity
at sign

293

3 clear on
what

294



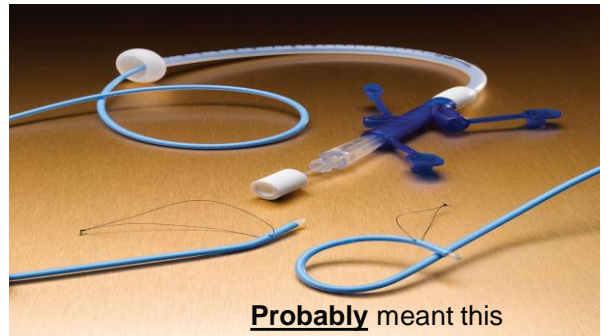
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PART 1: POWER OF ATTORNEY FOR HEALTH CARE

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:

None 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:

307

Family **unable**
to enforce AD

308

Be specific

309

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

310

Alternative

311

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.

312

4 clear on
when

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5 how
measure
when

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6 clear on
why

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7 clear on
where

316

8 show
understand

317

9 Ulysses
clause

318

10 “discuss agent”

319

11 copies & registry

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12



321

Conclusion

322

Demand for AD for SED

323

New

324

Little guidance
courts, regulators

325

No institutional
policies &
procedures

326

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327

327