

# VSED Divulged

Legal, Ethical, and Clinical  
Status of the Voluntarily  
Stopping Eating and  
Drinking Exit Option

ICEL3 (March 8, 2019)  
Thaddeus Mason Pope

1



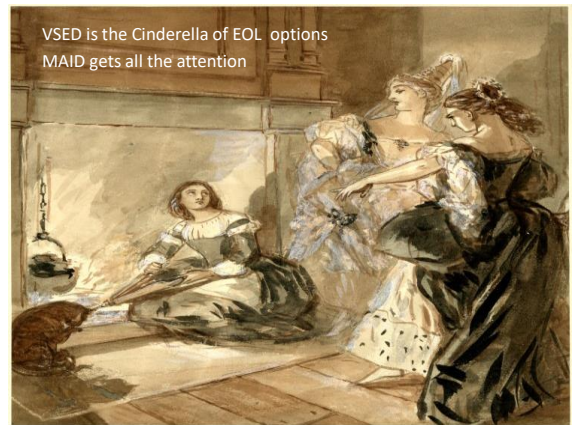
Kenneth Chambaere, Chair

Luc Delliens, Co-chair

2



3

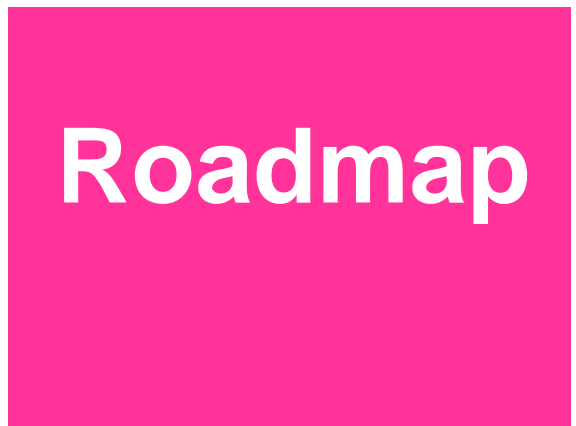


VSED is the Cinderella of EOL options  
MAID gets all the attention

4



5



6

5

7

Why we need  
**another** EOL  
exit option

8

What **is**  
VSED

9

Clinical  
status

10

Legal  
status

11

Advance  
VSED

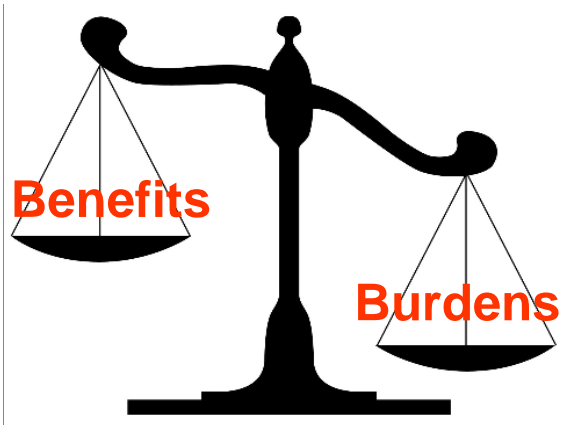
12

1 of 5

13

Why  
VSED matters

14



15

No other  
options

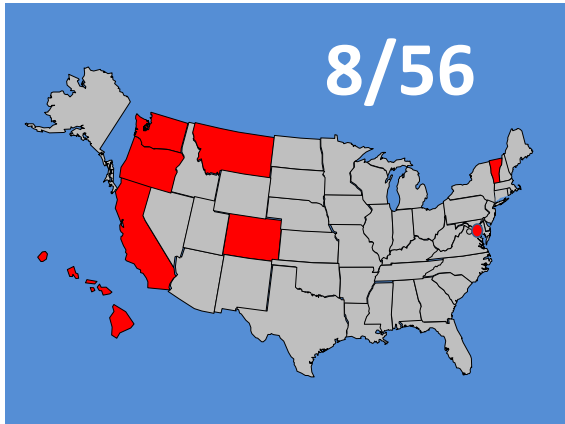
16

MAID

17



18



19



20



Trinity Term  
[2014] UKSC 38  
*On appeal from: [2013] EWCA Civ 961*

**JUDGMENT**

**R (on the application of Nicklinson and another)  
(Appellants) v Ministry of Justice (Respondent)**

21

**BBC** Sign in News Sport Weather Shop Reel Travel

**NEWS**

Home Video World UK Business Tech Science Stories Entertainment & Culture

England Local News Regions Wiltshire

**Right-to-die man Tony Nicklinson dead after refusing food**

© 22 August 2012

f b t e Sh

22

**Even** in  
MAID  
jurisdictions

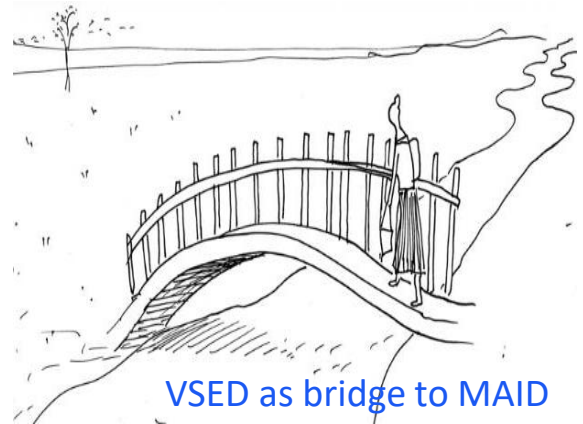
23

**Cannot** satisfy  
eligibility  
conditions

24



25



VSED as bridge to MAID

26

VSED as  
destination  
therapy

27

2 of 5

28

What is  
VSED

29

Voluntarily  
Stopping  
Eating &  
Drinking

30



31

German  
Sterbefasten  
Dutch  
Versterven

32

3

33

Physiologically  
**able** to take food  
& fluid by mouth

34

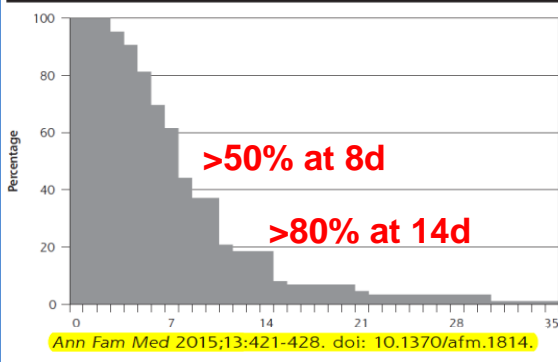
Voluntary,  
**deliberate**  
decision to stop

35

**Intent:** death  
from dehydration

36

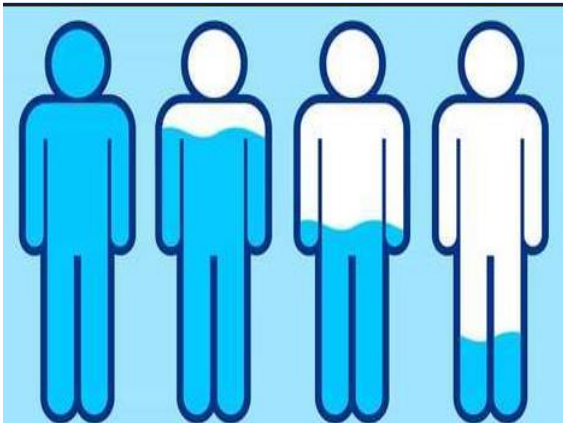
Figure 1. Cumulative survival curve for duration until death after start of VSED.



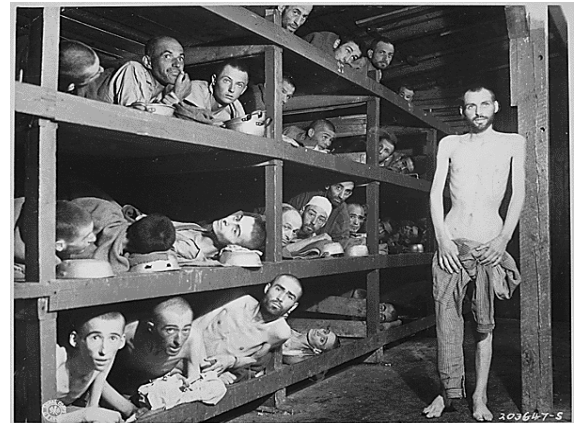
37

Patient experience

38



39



40

VSED is **not** starvation

41

Dehydration is complete and controlled

42

VSED  
peaceful

43

1<sup>st</sup> person  
narratives

44

Books

45

Gramp

A man ages and dies.

The extraordinary record of one family's  
encounter with the reality of dying.

Mark Jury and Dan Jury

46

CHOOSING  
TO DIE

*A Personal Story*

Elective Death by Voluntarily Stopping  
Eating and Drinking (VSED)  
in the Face of Degenerative Disease

PHYLLIS SHACTER

Foreword by  
Timothy E. Quill MD, FACP, FAAHPM

47

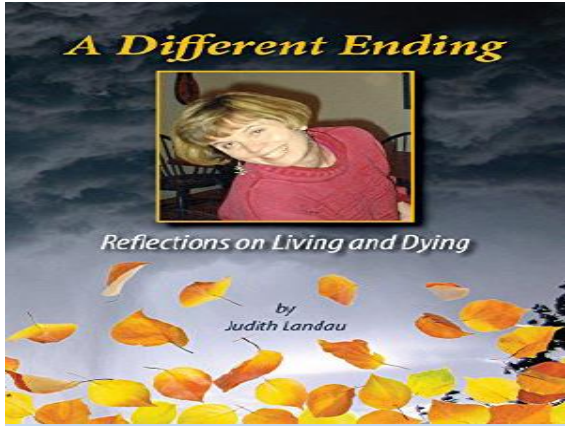
Taking Control of your Death  
by Stopping Eating and Drinking



Boudewijn Chabot MD PhD

48





49



50



Films - Dying Wish

51



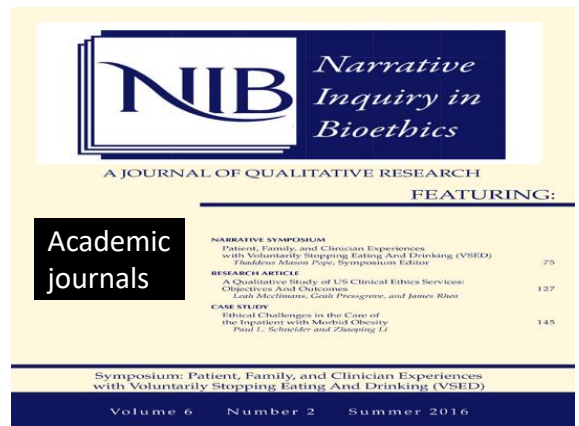
52



Phyllis Schacter

TED talks

53



54

**Not only**  
1<sup>st</sup> person  
narratives

55

**Objective**  
**evidence**  
patient experience

56

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.

57

100 Oregon  
**nurses** cared for  
VSED patients

58

Most deaths:  
"peaceful, with  
little suffering"

59



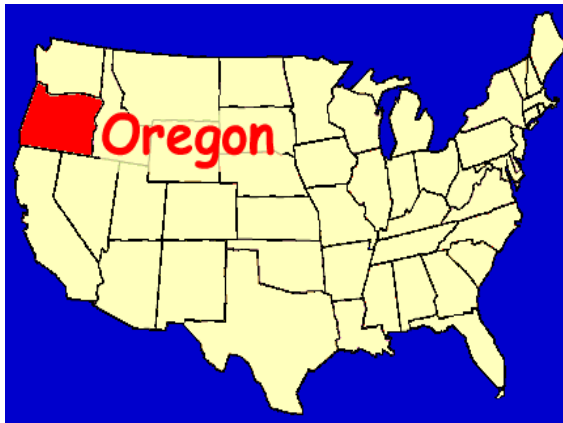
60

“opportunity for reflection, family interaction, and mourning”

61

**Preferred**  
by many

62



63

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

64

**Good option**

65

**3** of 5

66

# Clinical status

67

More experience



68



69



70

300 hospice & palliative care specialists

Shinjo T, et al. *BMJ Supportive & Palliative Care* 2017;0

71

# 32%

experience with VSED

72



73

# 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*, 16(02), 68-73. doi:10.1055/s-0034-1387571

74

# 61%

experience with VSED

75



76

# 35 palliative care experts (early)

Sabrina Fehn<sup>1</sup>

77

# 46%

experience with VSED

78



79

# 700 family physicians

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

80

# 46%

experience with VSED

81

# 0.4 to 2.1%

of **all** deaths

Onwuteaka-Philipsen BD, Brinkman-Stoppelenburg A, Penning C, de Jong-Krui GJF, van Delden JJM, van der Heide A. Trends in end-of-life practices before and after the enactment of the euthanasia law in the Netherlands from 1990 to 2010: a repeated cross-sectional survey. *Lancet*. 2012;380(9845):908-915.  
 Chabot BE, Goedhart A. A survey of self-directed dying attended by proxies in the Dutch population. *Soc Sci Med*. 2009;68(10):1745-1751.

82

THE NEW ENGLAND JOURNAL OF MEDICINE

CORRESPONDENCE

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

## More than ½ deaths from euthanasia

83

## More position statements

84

# Professional society endorsements

85

## Austrian Palliative Society (OPG) themenschwerpunkt

Wien Med Wochenschr  
<https://doi.org/10.1007/s10354-016-0629-z>



### Freiwilliger Verzicht auf Nahrung und Flüssigkeit um das Sterben zu beschleunigen

Eine Stellungnahme der österreichischen Palliativgesellschaft (OPG)

Angelika Felchtner · Dietmar Weibler · Alois Birklbauer

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

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## 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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American Medical Women's Association

89



90



Vote March 9

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

91

More clinical guidance



92

v&v knmg

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



KNMG Royal Dutch Medical Association and V&VN Dutch Nurses' Association Guide

93

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

94

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

95



COLLÈGE DES MÉDECINS DU QUÉBEC

96



**In sum**

97

VSED is an  
EOL exit  
option

98

Broadly  
accepted

99

Evidence  
based

100

**4** of 5

101

**Legal  
status**

102



103

No statutes  
Little caselaw

104

## 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 onus 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 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

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Legal &  
Patient right

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300-669 Howe Street  
Vancouver BC V6C 0B4  
[www.cpsbc.ca](http://www.cpsbc.ca)  
Telephone: 604-733-7758  
Toll Free: 1-800-461-3008 (in BC)  
Fax: 604-733-3503

### FINAL DISPOSITION REPORT OF THE INQUIRY COMMITTEE

February 13, 2018

CPS File No: IC 2017-0836

Complainant: Internal (referral from BC Coroners Service)

Subject Physician(s): Dr. Ellen Wiebe

107

**No need** for  
direct, explicit  
authority

108

**already** legal  
under **existing**  
rules

109

**Right to  
refuse  
treatment**

110

Well established  
4 decades

111

Vent  
Dialysis  
CPR  
Antibiotics  
Feed tube

112

**Right to  
refuse  
treatment**

VSED

113

**Not DIY**

114

Part of a  
broader  
**treatment** plan

115

**Supervised**  
by licensed  
healthcare  
professionals

116

**Recognized** as  
healthcare by  
medical  
profession

117

**More** position  
statements

118

**More** clinical  
practice  
guidelines

119

**PAVSED**  
**Palliated & Assisted**  
Voluntarily Stopping  
Eating and Drinking

highlights medical role

120

Recap

121

Oral N&H =  
“treatment”

122

BUT

123

Oral N&H  $\neq$   
“treatment”

124

Basic  
care

125

That's  
okay

126

Does **not** matter  
whether food &  
fluid is “**medical  
treatment**”

127

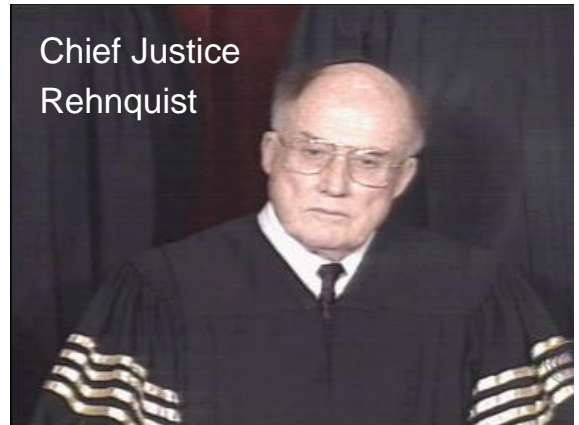
Right to refuse  
any intervention  
(medical **or not**)

128

Right to refuse  
**any**  
**unwanted** contact

129

Chief Justice  
Rehnquist



130

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

131

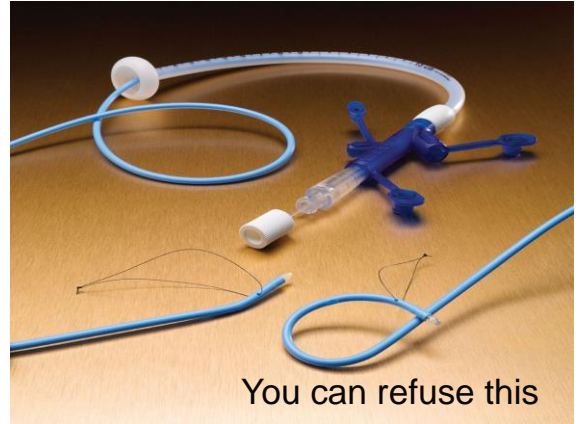
Force feeding is a battery



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# In sum

133



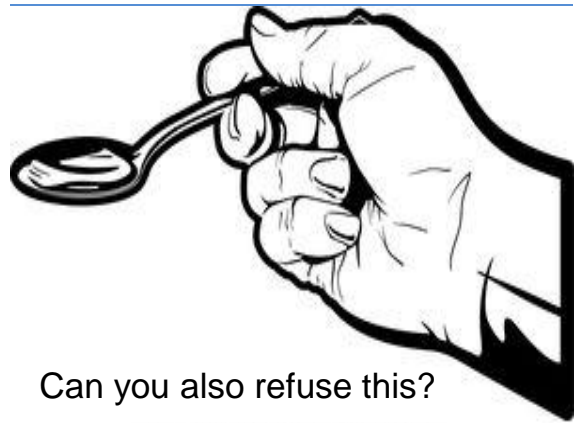
You can refuse this

134



Can you also refuse this?

135



Can you also refuse this?

136

# Consensus is "yes"

137

J Downie. *Can J Bioeth / Rev Can Bioeth*. 2010, 1(2):48-58

*Canadian Journal of Bioethics*  
*Revue canadienne de bioéthique*

ARTICLE (ÉVALUÉ PAR LES PAIRS / PEER-REVIEWED)

## An Alternative to Medical Assistance in Dying? The Legal Status of Voluntary Stopping Eating and Drinking (VSED)

Jocelyn Downie<sup>1</sup>

138

# Voluntary palliated starvation: A lawful and ethical way to die?

Ben White, Lindy Willmott and Julian Savulescu\*

376

(2014) 22 JLM 376

139



141

Action that might be misperceived	Mean rating of risk	SD	Actual number of physicians who were accused based on this action
Total sedation (the application of pharmacotherapy to induce a state of decreased or absent awareness [unconsciousness] in order to reduce the burden of otherwise intractable suffering)	4.1	1.1	2
Stopping artificially delivered nutrition/hydration	3.6	1.1	0
Stopping oral nutrition/hydration in a patient who can eat/drink when requested by the patient	3.3	1.2	0
Use of palliative and sedative medications in the process of discontinuing mechanical ventilation	3.2	1.3	6
Stopping dialysis	3.1	1.2	0
Use of barbiturates for symptom treatment	2.9	1.1	2
Use of opiates for symptom treatment	2.8	1.2	13
Use of benzodiazepines for symptom treatment	2.3	1.0	1
Other	N/A	N/A	6

143

Clinicians don't trust law professors as much as they should

140

JOURNAL OF PALLIATIVE MEDICINE  
 Volume 15, Number 3, 2012  
 © Mary Ann Liebert, Inc.  
 DOI: 10.1089/jpm.2011.0234

## Prevalence of Formal Accusations of Murder and Euthanasia against Physicians

600 palliative care physicians

142

Clarify VSED legality

144



5 of 5

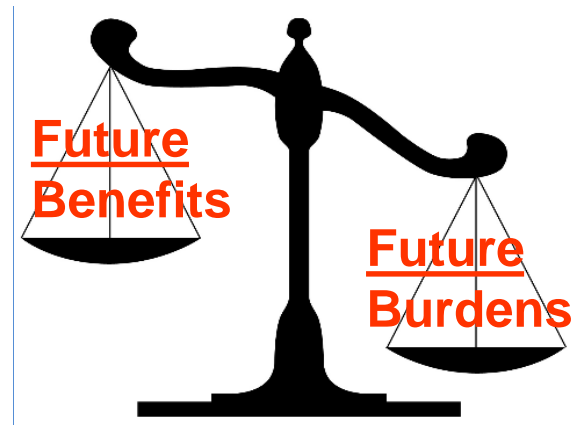
145

Advance  
VSED

146

Life is  
worthwhile  
**now**

147



148

**Challenge**

149

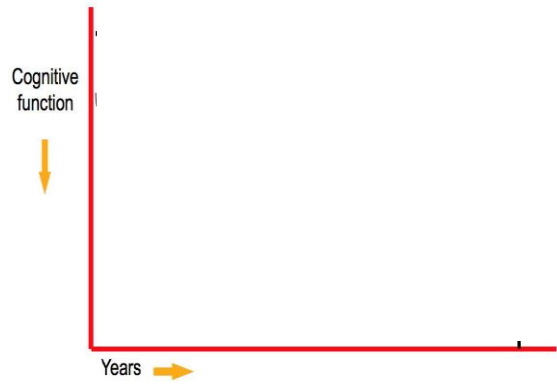
Lose capacity  
**before** life  
intolerable

150

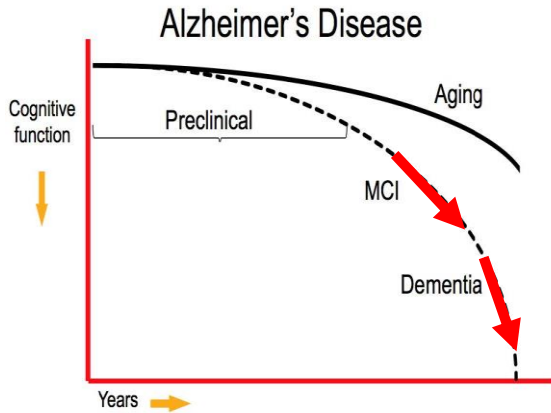
# Dementia

Progressive illness

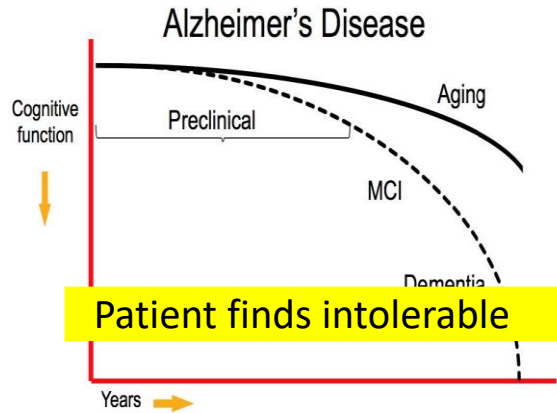
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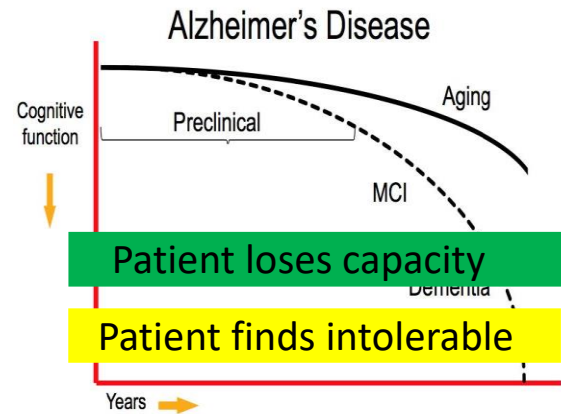
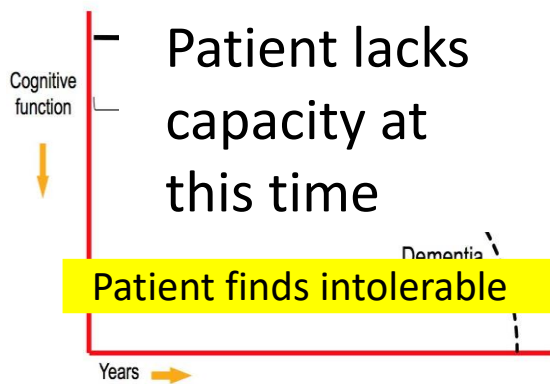
**When I see people in my close family or see my best friends, I do not know who they are.** [3.1]

155

(This patient is both incontinent and dependent on others to change his diapers.)

**I do not use bathrooms. I let my clothes get wet and dirty. Others must change my diapers (nappies).** [4.5]

156



Regular VSED  
is **not** good  
option

159

VSED while  
still have  
capacity

160

Too  
soon

161

Life **still**  
worthwhile

162

problem of

Premature  
dying

163

Issue with MAID too



164

Bigger  
problem with  
dementia

165

Solution

166

Advance  
VSED

167

Advance  
directive **now**  
for VSED **later**

168



169

Direct VSED  
in **future**

170

At a **point**  
you specify

171

**Advantage**

172

Death not  
hastened **until**  
point you find  
life intolerable

173

Is a VSED  
directive  
enforceable?

174

Generally,  
yes

175

Right to  
refuse **VSED**  
treatment

176

Seemingly  
bad  
precedent

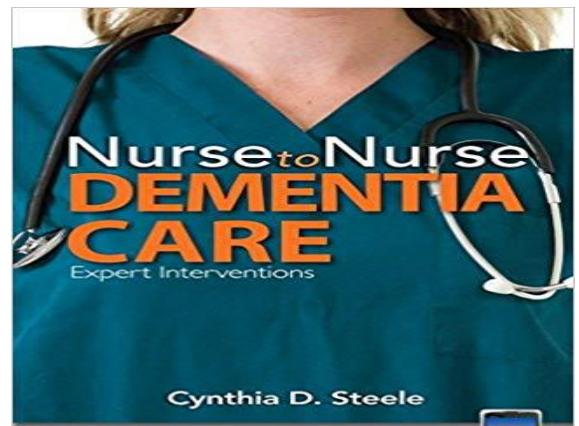
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TO MY FAMILY, MY PHYSICIAN, MY LAWYER & ALL OTHERS WHOM IT MAY CONCERN

I, Katherine Hammond, hereby declare that the following is true and correct. I wish this statement to stand as an expression of my wishes.

IF AT SUCH A TIME THE SITUATION SHOULD ARISE THAT THERE IS NO REASONABLE EXPECTATION OF MY RECOVERY FROM EXTREME PHYSICAL OR MENTAL DISABILITY, I DIRECT THAT I BE ALLOWED TO DIE AND NOT BE KEPT ALIVE BY ARTIFICIAL MEANS OR "HEROIC MEASURES".

I DO ASK THAT MEDICATION BE MERCIFULLY ADMINISTERED TO ME TO ALLEVIATE SUFFERING EVEN THOUGH THIS MAY SHORTEN MY REMAINING LIFE.

I MAKE THIS STATEMENT AFTER CAREFUL CONSIDERATION AND IS IN ACCORDANCE WITH MY CONVICTIONS AND BELIEFS.

I HEREBY ABSOLVE ALL WHO FOLLOW THESE INSTRUCTIONS TO BE FREE OF ANY LEGAL LIABILITY. IN PARTICULAR, I WOULD REQUEST THE FOLLOWING INSTRUCTIONS TO BE CARRIED OUT:

A. NO ELECTRICAL OR MECHANICAL RESUSCITATION OF MY HEART WHEN IT HAS STOPPED BEATING.  
 B. NO NOURISHMENT OR LIQUIDS.  
 C. NO MECHANICAL RESPIRATION WHEN I AM NO LONGER ABLE TO SUSTAIN MY OWN BREATHING.  
 D. NO SURGERY.  
 E. OTHER *in the event that mental deterioration is such that I am unable to occupy the mind of my family, I*

I HEREBY DESIGNATE John S. Bentz *John S. Bentz* TO SERVE AS MY PROXY FOR THE PURPOSE OF MAKING MEDICAL DECISIONS ON MY BEHALF IN THE EVENT THAT I BECOME INCOMPETENT AND UNABLE TO MAKE SUCH DECISIONS FOR MYSELF. SHOULD John S. Bentz BE UNABLE TO CARRY OUT MY WISHES, I HEREBY APPOINT John S. Bentz AS AN ALTERNATE PROXY.

WITNESS John Clifford SIGNED Katherine Hammond  
 WITNESS: R.D. Clifford DATE: Nov 24 19

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DIRECT THAT I BE ALLOWED TO DIE AND NOT BE KEPT ALIVE BY ARTIFICIAL MEANS OR "HEROIC MEASURES",

B. NO NOURISHMENT OR LIQUIDS.

182



183



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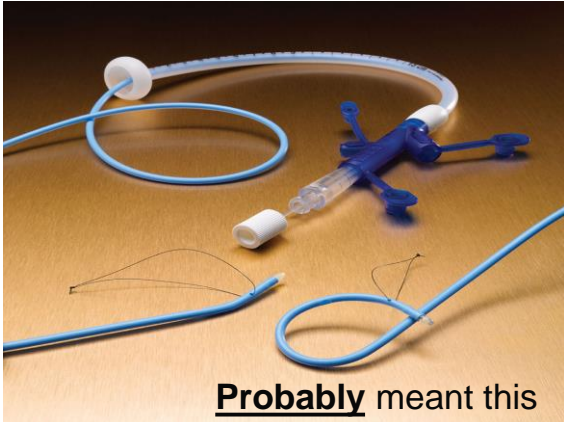
Family loses

185

DIRECT THAT I BE ALLOWED TO DIE AND NOT BE KEPT ALIVE BY ARTIFICIAL MEANS OR "HEROIC MEASURES",

B. NO NOURISHMENT OR LIQUIDS.

186



187



188



189

**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

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**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:

*Nora* 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:

190

Family **unable**  
 to enforce  
 VSED directive

191

**BUT**

192



**Fixable**  
problems

193

Be clear on  
the “what”

194

If you mean  
hand feeding,  
**say** “hand  
feeding”

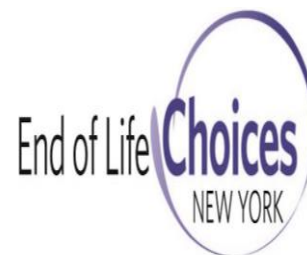
195

**Bigger  
problem**

196

Incapacitated  
**veto**

197



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

198

“If I am suffering  
from advanced  
dementia . . .  
**I do NOT want  
to be fed by hand”**

199

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

200



201

**Whose**  
wishes do  
we respect?

202

Prior self  
or  
Current self

203

VSED Ulysses  
clauses are  
**unwelcome**

204



Vote Mar. 9

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

205

Duties to  
**current self**  
are primary

206



Margot - stage 7 Alzheimer's

207

RTE REGIONAL  
EUTHANASIA  
REVIEW COMMITTEES

208

We must  
determine what  
incapacitated  
conduct counts

209

Ask  
Open mouth  
Swallow

210

# Conclusion

211



212



213

## Thaddeus Mason Pope, JD, PhD

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Mitchell Hamline School of Law  
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Saint Paul, Minnesota 55105

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C 310-270-3618

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W www.thaddeuspope.com

B medicalfutility.blogspot.com

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Materials from the cases discussed in this presentation are available at <http://thaddeuspope.com>

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## Medical Futility Blog

Since 2007, I have been blogging, almost daily, to [medicalfutility.blogspot.com](http://medicalfutility.blogspot.com). This blog focuses on reporting and discussing legislative, judicial, regulatory, medical, and other developments concerning end-of-life medical treatment conflicts. The blog has received **over 4 million** direct visits. Plus, it is redistributed through WestlawNext, Bioethics.net, and others.

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*Whether, When and How to Honor Advance VSED Requests for End-Stage Dementia Patients*, 19(1) AMERICAN JOURNAL OF BIOETHICS (2019).

*Voluntarily Stopping Eating and Drinking Is Legal—and Ethical—for Terminally Ill Patients Looking to Hasten Death*, ASCO POST (June 25, 2018).

*Voluntarily Stopping Eating and Drinking: Clinical, Psychiatric, Ethical and Legal Aspects*, 178 JAMA INTERNAL MEDICINE 123-127 (2018) (with Timothy Quill, Linda Ganzini, Bob Truog).

*Voluntarily Stopping Eating and Drinking (VSED) to Hasten Death: May Clinicians Legally Support Patients to VSED?* 15 BMC MEDICINE 187 (Oct. 2017).

217

*Voluntarily Stopping Eating and Drinking*, 6(2) NARRATIVE INQUIRY IN BIOETHICS 75-126 (2016) (symposium editor).

*Prospective Autonomy and Dementia: Ulysses Contracts for VSED*, 12(3) JOURNAL OF BIOETHICAL INQUIRY 389-394 (2015).

*Legal Briefing: Voluntarily Stopping Eating and Drinking*, 25(1) JOURNAL OF CLINICAL ETHICS 68-80 (2014) (with Amanda West).

*Voluntarily Stopping Eating and Drinking: A Legal Treatment Option at the End of Life*, 17(2) WIDENER LAW REVIEW 363-428 (2011) (with Lindsey Anderson).

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