VSED Advance Directives for Dementia: Are They Legal and Implementable?

Is There a Middle Ground?

swhpn ANNUAL FORUM

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1

OVERVIEW

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2

VSED Advance Directives for Dementia: Are They Legal and Implementable? Is There a Middle Ground?

April 28, 2025, 01:30 - 03:00 PM

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Thaddeus Pope

law professor
bioethicist

4

5

6

June 2019

Alzheimer's Dx

7

not want to live with late-stage dementia

8

SO …

9

June 2023

VSED

10

11

StarTribune

MPRnews
Stay Curious. Stay Connected.

KSTP.COM
EYEWITNESS NEWS

12

more attention in **your** community too

13

SO …

14

15

roadmap

16

4 parts

17

VSED

18

limits of VSED

19

VSED by AD

20

VSED by SDM

21

what is VSED

22

Voluntarily
Stopping
Eating &
Drinking

23

patient **with** capacity

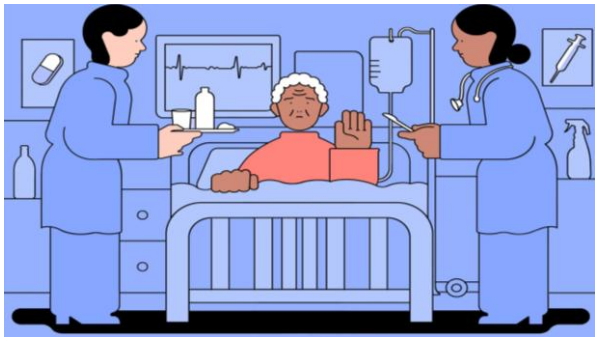
24

able to take food & fluid by mouth

25

voluntary **decision** to stop

26



27

≠ ANH

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≠ natural loss appetite

29

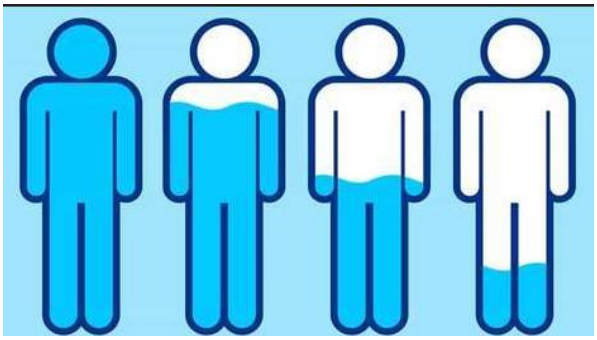
deliberate choice stop fluids by **mouth**

30

goal = death

from dehydration

31



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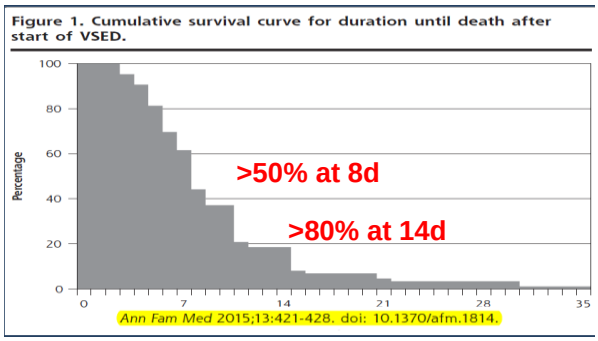

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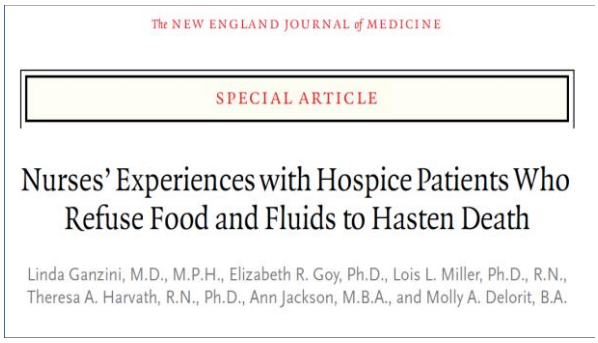
peaceful

comfortable

34



35

100 OR **nurses** caring for VSED patients

36

most deaths

"**peaceful** with little suffering"

37

confirmed in 2025

Switzerland
Netherlands
Germany

38

that's

Pt experience with VSED

39

VSED is **legal**

40

sizable, settled, and stable

consensus

41

court precedent

42

multiple appellate decisions

43

is VSED legal?

asked & answered

44

plus

45

do **not need** direct, explicit authority

46

already legal

existing rules

47

DEPARTMENT OF HEALTH

Combined Minnesota and Federal Hospice Bill of Rights

MINNESOTA HOSPICE BILL OF RIGHTS PER MINNESOTA STATUTES, SECTION 144A.751

48

"patients … have … **right to refuse** … treatment"

49

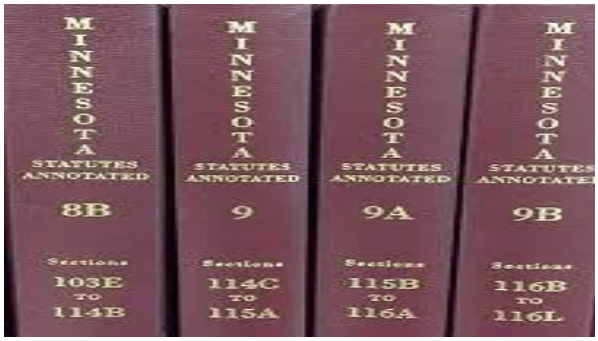
In the Matter of the CONSERVATORSHIP OF Rudolfo TORRES, Conservatee.

No. C1-84-761.

Supreme Court of Minnesota.

Nov. 2, 1984.

50



51

right to refuse treatment

52

ventilator
dialysis
CPR
antibiotics
feed tube

53

right to refuse treatment

VSED

54

not DIY

55

part of a broader **treatment** plan

56

supervised by licensed healthcare professionals

57

recognized as healthcare by professionals

58

more position statements

59

POSITION STATEMENT

ANA
AMERICAN NURSES ASSOCIATION

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

60

AMWA The Vision and Voice of Women in Medicine since 1915

American Medical Women's Association

61

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

62

aahpm

AMERICAN ACADEMY OF HOSPICE AND PALLIATIVE MEDICINE

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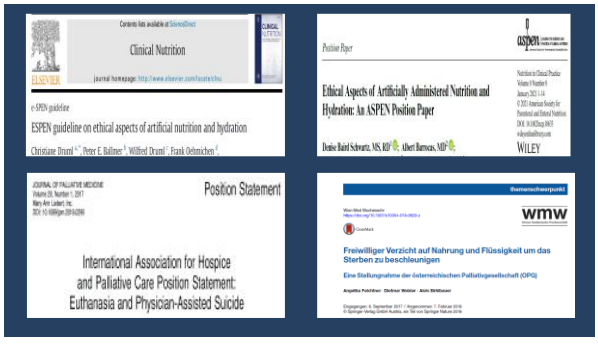

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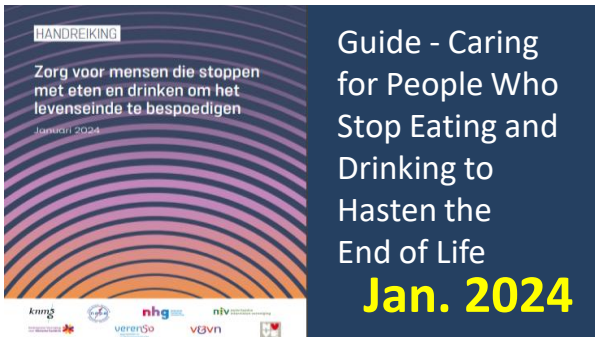
more clinical practice guidelines

66



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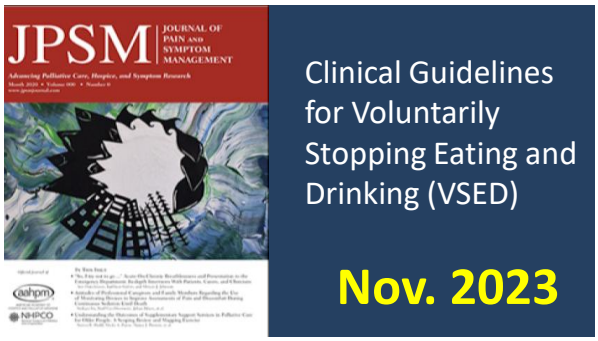

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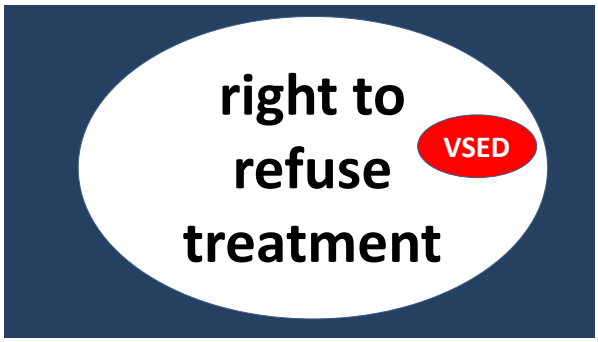

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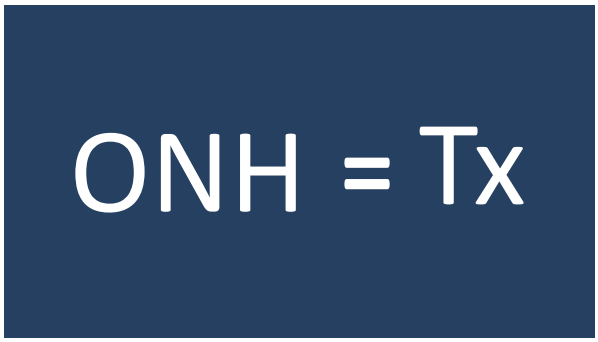

72

but

73

some
challenge
premise

74

oral N&H ≠
“treatment”

75

basic care

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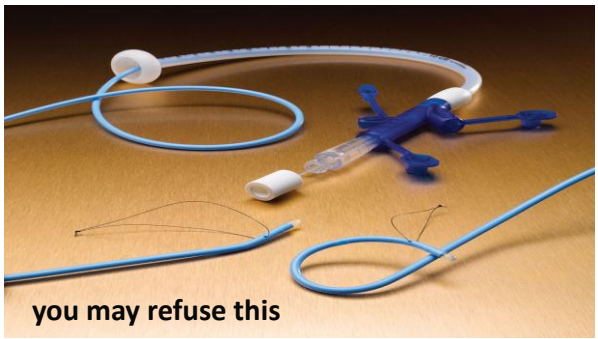


77

78

or this?

79

yes

80

right to refuse **any** intervention

81

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

82

right to refuse **any** intervention

83

medical **or not**

84

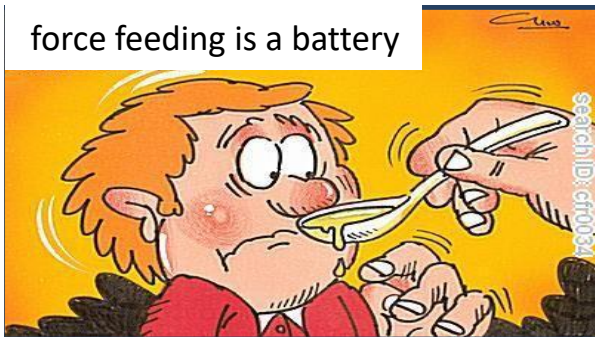
healthcare
or not

85

right to refuse
any
unwanted contact

86

force feeding is a battery



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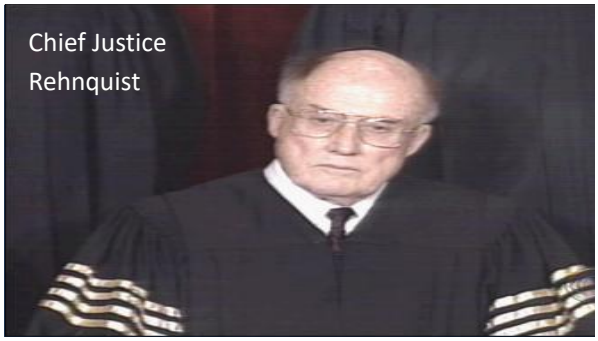

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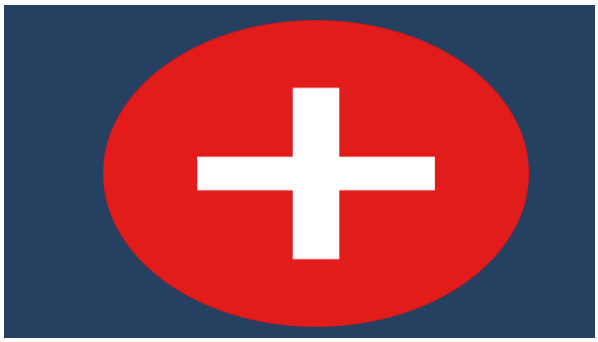
"bodily integrity is violated ... by sticking a **spoon in your mouth** ... sticking a needle in your arm"

89



90

Medicare Conditions of Participation for Hospice

91

92

"patient has a right to refuse care **or** treatment"

42 C.F.R. 418.52(c)(3)

93

VISITING NURSE SERVICE OF NEW YORK

VNSNY HOSPICE & PALLIATIVE CARE POLICY and PROCEDURE

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

94

"ethical and **legal** option"

95

because

96

"well-settled right ... to refuse **any** unwanted intervention"

97

98

VSED is legal & ethical

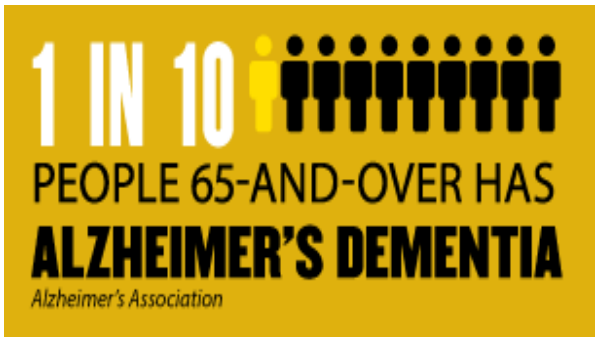
99

limits to VSED

100

101

102



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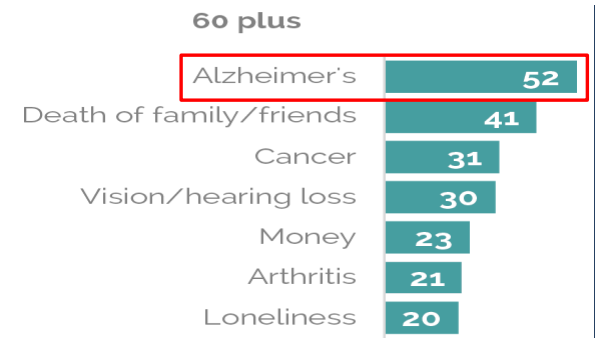

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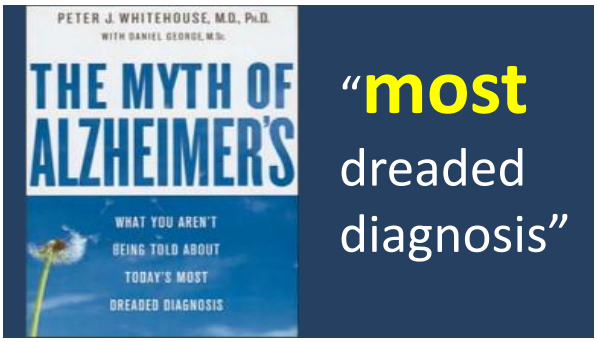

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many **used VSED** to avoid late-stage dementia

109

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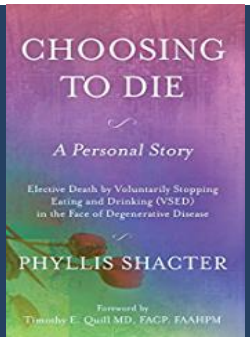

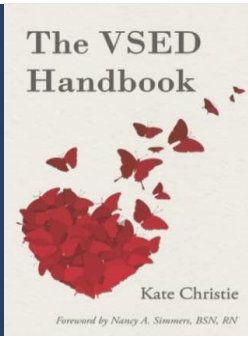

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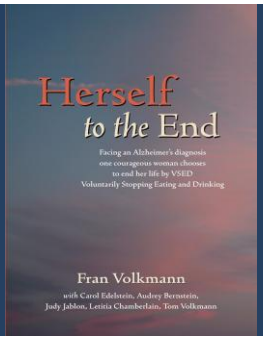

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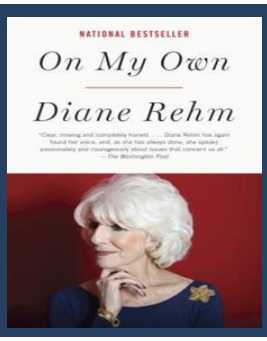
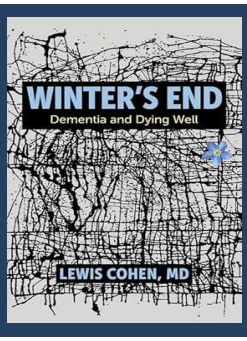




113

but

114

115

VSED while **still** have capacity

116

117

too **soon**

118

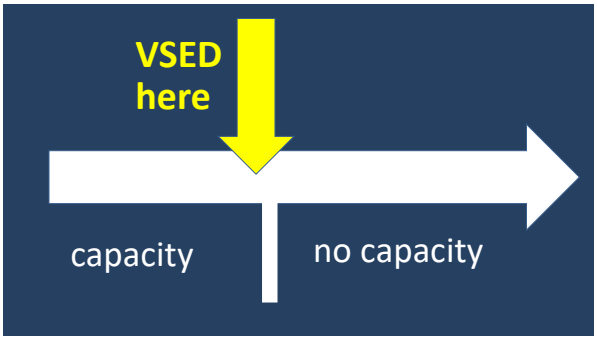
life **still** worthwhile

119

earliness problem

120

121



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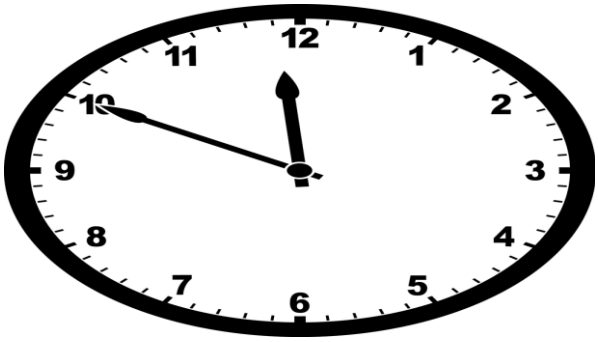

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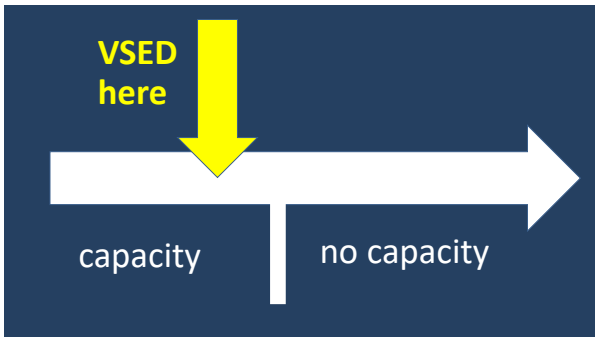

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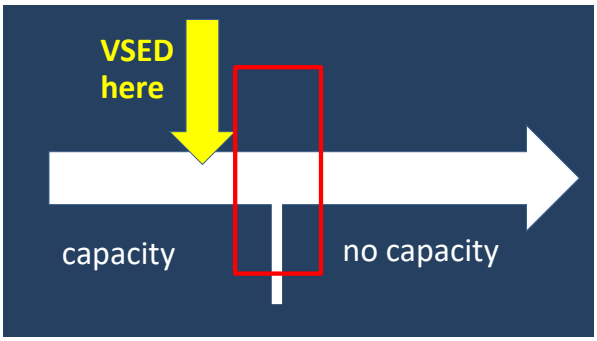

128

premature dying

129

current situation still acceptable

130

VSED **not** good option

131

at **this** time

132

not ready to die

133

concerned about **future** circumstances

134

lack capacity at future time

135

136

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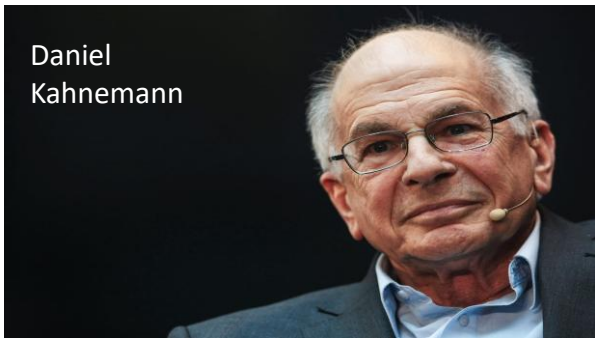

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VSED by AD

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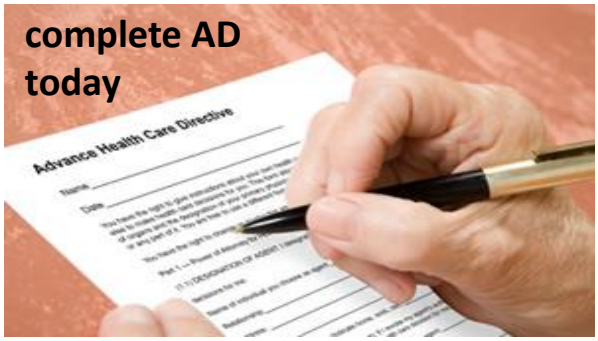

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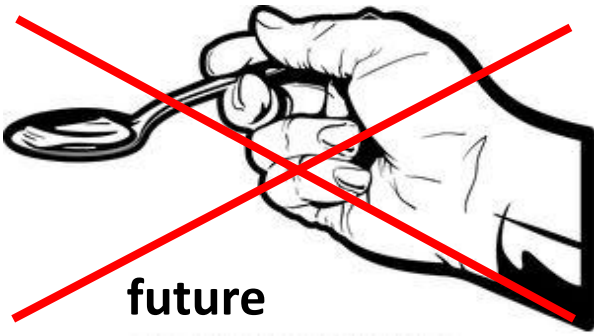

142

after patient loses capacity

143

at **point** Pt specifies

144

145

clinical triggers

146

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

147

functional triggers

148

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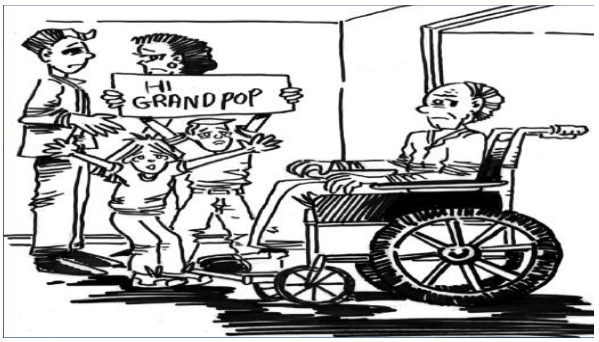

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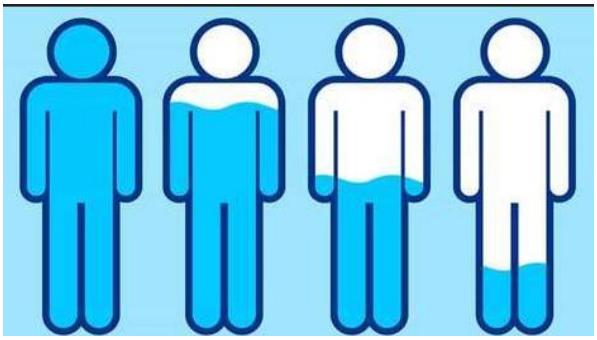

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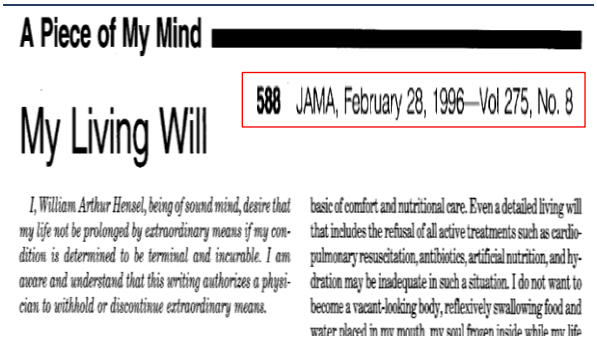


A Piece of My Mind

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

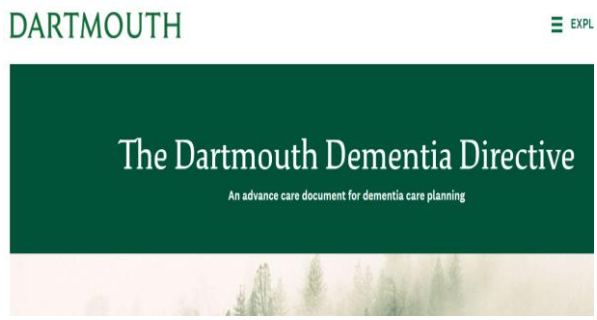
My Living Will

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

154

155



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End of Life Choices NEW YORK

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

157

end of life WASHINGTON

Your life. Your death. Your choice.

158

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.

159

exit VEREINIGUNG FÜR HUMANES STERBEN DEUTSCHE SCHWEIZ

160

Support and promote life quality

lifecircle

lifecircle | Living will & additional personal statement

161

FinalExit NETWORK

Introduction to our Supplemental Advance Directive For Dementia

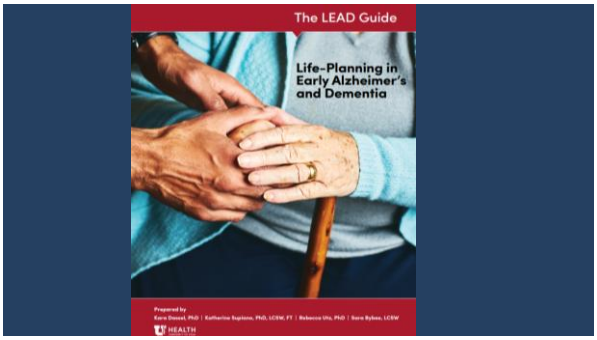
162

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 initialed and any of the choices 5, 6, or 7 are initialed, 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.

163



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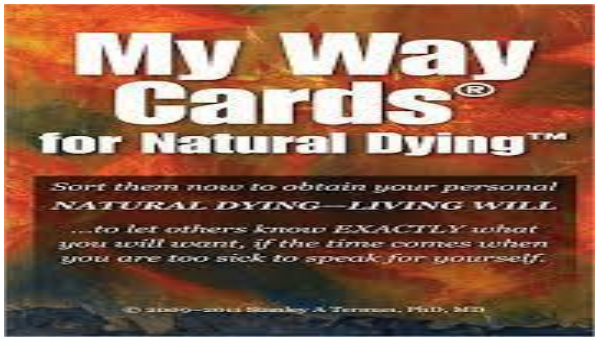

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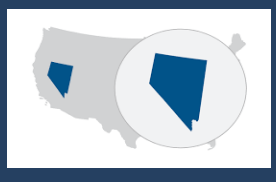
Power of Attorney for Adult with Dementia



Nev. Rev. Stat. 162A.870

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NEVADA ADVANCE DIRECTIVE FOR ADULTS WITH DEMENTIA
PAGE 7 OF 10

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

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

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APPLEGATE & DILLMAN ELDER LAW

Making the Case for a Dementia Directive

November 14, 2022

168

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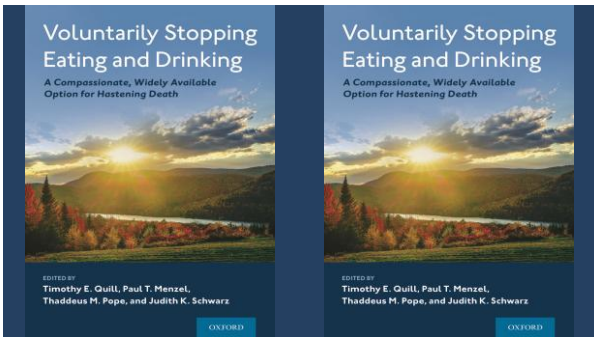

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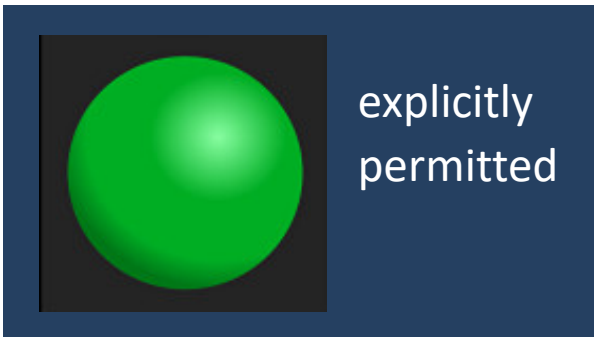

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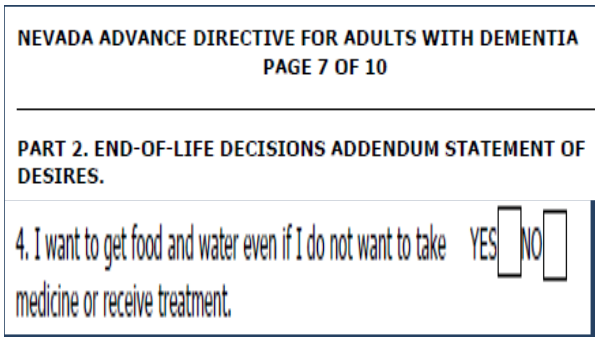

NEVADA ADVANCE DIRECTIVE FOR ADULTS WITH DEMENTIA
PAGE 7 OF 10

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

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

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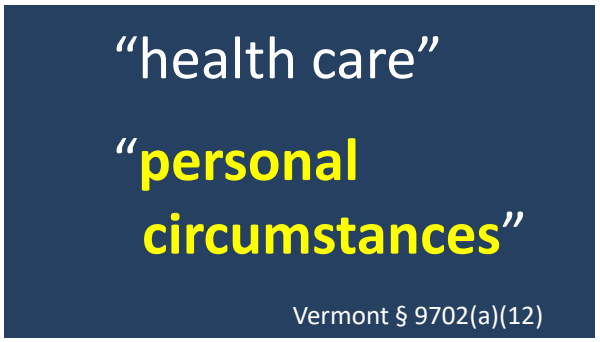
179



180

"services to assist in **activities of daily living**"

Vermont §§ 9702(a)(5), 9701(12)

181

182

"circumstances … **food & liquids** … discontinued"

183

that's green light states

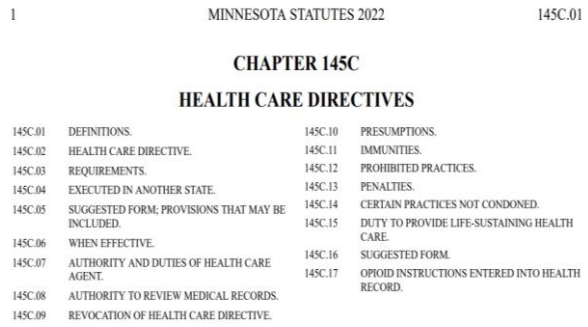
184

185

186

not explicit
& direct
like NV VT AZ

187



1 MINNESOTA STATUTES 2022 145C.01

CHAPTER 145C

HEALTH CARE DIRECTIVES

188

your AD can
address
health care

189

what's
"health care"

190

145C defines
"health care"
broadly

191

"**any** care …"

192

"**any care,** treatment, service, or procedure to … affect a person's physical … condition"

193

"health care" **includes** food & fluids

194

SO …

195

MN AD **may** direct VSED

196

and …

197

clinicians may & should **follow** them

198

that's yellow light states

199

200

201

CHAPTER 144A

LIFE-SUSTAINING PROCEDURES

Referred to in §142C.12B, 144B.6, 144D.4, 235B.2, 235E.1, 235F.1, 633.635, 707A.3, 726.24

Policy statement; see 85 Acts, ch 3, §1
See also chapter 144B concerning durable power of attorney for health care

144A.1 Short title.
144A.2 Definitions.
144A.3 Declaration relating to use of life-sustaining procedures.
144A.4 Revocation of declaration.
144A.5 Determination of terminal condition.
144A.6 Treatment of qualified patients.
144A.7 Procedure in absence of declaration.
144A.7A Out-of-hospital do-not-resuscitate orders.
144A.8 Transfer of patients.
144A.9 Immunities.
144A.10 Penalties.
144A.11 General provisions.
144A.12 Application to existing declarations.

202

"adult may execute a declaration … directing that **life-sustaining procedures** be withheld or withdrawn"

203

"life-sustaining procedure does **not include** …. **nutrition or hydration** except …. parenterally or … intubation"

204

so…

205

Iowa AD may **not** direct VSED

206

that's red light states

207

208

advance directive

ONH

209

advance directive

ONH

210

many **have completed** VSED ADs in these states

211

but

212

most Pts **lack** ADs

213

VSED by SDM

214

consent for VSED comes **not** from Pt in their AD

215

substitute decision maker

216

is that legal

217

218

219

220

CHAPTER 144B

DURABLE POWER OF ATTORNEY FOR HEALTH CARE

Referred to in §142C.2, 142C.12B, 144A.7, 144D.4, 144F.1, 144F.2, 144F.6, 235B.2, 235B.19, 235E.1, 235F.1, 633.556, 707A.3, 726.24

144B.1 Definitions.
144B.2 Durable power of attorney for health care.
144B.3 Requirements.
144B.4 Individuals ineligible to be attorney in fact.
144B.5 Durable power of attorney for health care — form.
144B.6 Attorney in fact — priority to make decisions.
144B.7 Authority to review medical records.
144B.8 Revocation of durable power of attorney.
144B.9 Immunities and responsibilities.
144B.10 Emergency treatment.
144B.11 Prohibited practices.
144B.12 General provisions.

221

DPAHC / agent

"make **health care** decisions"

222

"healthcare **does not include** … nutrition or hydration"

223

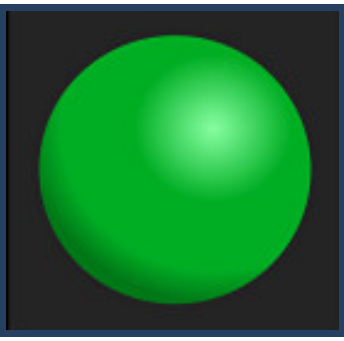
SO…

224

Iowa agents may **not** direct VSED

225

226



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SDM "make **any** health care decision"

228

229

conclusion

230

3 ways to authorize VSED

231

VSED by CAP-PT

232

VSED by AD

233

VSED by SDM

234

clinicians react **differently** to these 3 options

235

are you **confident** this patient wants VSED now

236

are you **comfortable** supporting VSED for this patient

237

VSED by CAP-PT

238

VSED by AD

239

VSED by SDM

240

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METHODS - STUDY OF NH STAFF

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This work was supported by the ***Zelda Foster Studies in Palliative and End-of-Life Care*** at New York University, Silver School of Social Work, through a Leadership Fellowship scholarship, awarded by the Zelda Program and the 291 Foundation.

The authors have no conflicts of interest to report

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Relevance

Over 50 percent of people living with a dementia diagnosis will die in nursing homes (Cross et al., 2020)

245

Research Question

What are perspectives of nursing home **staff** regarding implementation of *dementia-specific advance directives* that include the option of no assistance with feeding, once the ability to self-feed is lost?

246

FAST - 7

Respondents asked to keep in mind residents in the late stages of dementia - with a FAST dementia score of 7a (severe dementia, able to say 5-6 words daily)

247

Functional Assessment Staging Test

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

Reisberg B. Functional assessment staging tool (FAST). *Psychopharmacol Bull* 24: 653-9, 1988

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Dementia Advance Directive Language

Dartmouth (2021 version)

"I want to receive no nutrition if I cannot feed myself. I do not want to be offered food or fluids in any form if I cannot feed myself. However, I would be willing to receive oral comfort care in the form of mouth swabs or ice chips."

Note: I realize it may not be possible to honor this preference in every circumstance. For example, it may not be possible to honor this preference if I am in a facility that does not permit the withholding of nutrition or hydration, or if I clearly request to eat or drink, or appear receptive to eating and drinking (show signs of enjoyment or positive anticipation), such that I would become agitated or upset by non-feeding."

End of Life New York Option A

(as of 2/20/24)

"If unable to make informed decisions and feed myself "I want all medications and treatments that might prolong my life to be withheld or, if already begun, to be withdrawn, including cardio-pulmonary resuscitation and the provision of nutrition and hydration whether provided artificially or medically or by hand or by assisted oral feeding."

"If I am suffering from advanced dementia and appear willing to accept food or fluid offered by assisted or hand feeding, my instructions are that I do NOT want to be fed by hand even if I appear to cooperate in being fed by opening my mouth."

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Sample

12 staff members at 1 SNF in NE US

Professions:

- 3 CNAs
- 3 MSWs
- 3 RDs
- 2 RN Supervisors
- 1 MD

Experience in the field:

- 11 had at least 5 yrs
- 8 had 15+ years

Basic demographics:

- 10 women, 2 men
- 7 identified as white, 4 as Black,
- 1 undisclosed

250

Data Collection

Qualitative in person interviews, onsite during the workday

Open-ended semi-structured interview

< 20 minutes for nursing assistants
~ 40 minutes for others

251

Analysis

- Interviews tape recorded and transcribed verbatim
- Fundamental Qualitative Descriptive Content analysis (Sandelowski, 2000) [stay close to data]
- Both authors (ML and MBK) read all transcripts multiple times, developed coding scheme and applied it to all interviews to develop themes.

252

RESULTS

Meredith Levine, LMSW, APHSW-C
Senior Elder Justice Specialist
The Weinberg Center for Elder Justice
Riverdale, NY

253

Findings: Theme 1

- **"Self-feeding" is Confusing and Doesn't Take into Account Daily Fluctuations in Functional Ability Common in Advanced Dementia**

254

"Self-feeding" is Confusing and Doesn't Take into Account Daily Fluctuations in Functional Ability Common in Advanced Dementia

- *"Some people can just hold a cup, they can't hold utensils. Some people can just take small pieces with their fingers but don't use utensils…some just use spoons… there are just so many variabilities in terms of devices, where they can do different things, or pieces of it, but not the entire process that I wouldn't know where to go with this… Self-feeding is not just I do it or I don't."*

255

"Self-feeding" is Confusing and Doesn't Take into Account Daily Fluctuations in Functional Ability Common in Advanced Dementia

"Some residents are very independent in the morning, feed themselves and then at dinnertime due to sun-downing may need more assistance so it can vary tremendously. It's hard for a staff member to understand what to do in that situation since they're not consistently unable to feed themselves. It leaves a lot of questions and interpretation by the caregiver. ….. So I think it would be difficult because I think you'd feel torn about whether did someone truly try them today? Did someone make the effort today? Did they go back more than once? How far do you go?"

256

Findings: Theme 2

- **Consensus on the Importance of Honoring Resident Self-Determination, but Which Self?**

257

Which Self?

"And if, for instance – see that man sitting there, what if he made the will. And he's going to see food passing by, he's going to open his mouth and want the food. But I couldn't pass by and not feed him. I couldn't pass by and not feed him. How could I?"

"I think it would be very hard to have a resident clearly stating, "Can I have a cookie, can I have something to drink?" That means – yes, you made that decision then, you know what you wanted then, but at this point, right now, as a person, this is the place you are in, this is your mental state – you're able to enjoy it, you're able to ask for it. For me to say, I can't give it to you because 50 years ago, not knowing exactly what stage you'd be in, you decided you wouldn't want a cookie, or you wouldn't want a juice."

258

Findings: Theme 3

- **Potential for Harm - Residents, Family, Staff, Institution**

259

Potential for Harm

Resident
- Isolation during mealtime
- Causing discomfort and hunger
- Tools for financial exploitation and abuse

"My fear is always that it gets introduced to the poorest of the poor, the most uneducated, the people who are in the places where they can't get help or get better information or better medication."

Beneficiaries could pressure people into signing dementia directives to hasten death and protect their own financial interests: *"basically how fast can I get to the will?"*

Family
- Not knowing about directives, not understanding SED process or being uncomfortable with the process

"I could see if the family came in and saw that we were withholding food from the person, especially if it seemed like they wanted to eat, I could imagine that would be a very big problem"

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Potential for Harm (continued)

Staff
- Violation of religious beliefs:
  "For me, that would be a sin"
- Violation of core values:
  "I would not stand by and say – well, I would be watching you starve to death, which I cannot do"
- Conflict with professional identity:
  "I think as CNAs integral to their role is assisting with ADLs, so their role is about helping the individual who can't do their own ADLs. I think they would want to help feed the person who is just sitting there and looking and can't eat."

Institution
- Department of Health citations
  "I think [with the New York Directive], they might say that we're aiding and abetting people to commit suicide…I don't believe that, but DOH [Department of Health] might go there."

261

No Consensus on Preferred SED by AD Language

- 10 participants believed people should have the ability to complete SED directives – but all qualified their opinions by expressing serious concerns
- Some preferred flexibility in feeding; others preferred clarity
- One person wanted to add Dartmouth to their AD
- No one brought up the "now self's" incapacity as a reason to devalue their current wishes

262

Discussion: Logistical challenges

Staff struggled to understand what it means to "self feed"

Is it all or some of: knowing what a utensil is? what food is? able to get food to mouth? chew? Swallow? could all be considered part of self-feeding.

Do all parts need to be absent to be considered unable to self-feed?

263

Discussion: Logistical Challenges

Person living with dementia has fluctuating abilities throughout the day – how should staff respond?

How to write these medical orders and when? NPO?

264

Logistical Challenges

No best practices – each NH has to figure out their own internal policy for implementation.

High turnover in NHs over 3 shifts means there are a lot of people to keep on the same page

265

Moral challenges

- Perceived harm to "now-self" outweighs concern for "then-self's" self-determination
- Participating in "starvation" when someone wants to eat
- Lack of power for CNAs in this position – moral injury "a betrayal of what's right by someone who holds legitimate authority in a high stakes situation" (Shay, 2014).
- PHI reports that 90 percent of nursing assistants in the United States are women, 20 percent are immigrants, and over 50 percent identify as a racial minority. 36 percent rely on at least one form of public assistance (PHI National, 2019)

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Summary

Directives not ready for primetime – will be problematic to implement in NH.

Staff want to provide care consistent with a person's current wishes – don't want to force feed and don't want to withhold when resident appears hungry/appreciates food.

267

Summary (con't)

NH staff need to be at the table when dementia-specific advance directives are being developed.

Half of the people living with dementia are dying in NHs

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IS THERE AN ACCEPTABLE COMPROMISE?

269

Special Article

"Mr. Smith Has No Mealtimes": Minimal Comfort Feeding for Patients with Advanced Dementia

Hope A. Wechkin, MD, Paul T. Menzel, PhD, Elizabeth T. Loggers, MD, PhD, Robert C. Macauley, MD, Thaddeus M. Pope, JD, PhD, Peter L. Reagan, MD, and Timothy E. Quill, MD

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Abstract

While Comfort Feeding Only is appropriate for patients with advanced dementia, its emphasis on assistance hand-feeding that may prolong life for years fails to accommodate the preferences of those who do not want to continue living with this illness. Some have proposed advance directives to completely halt the provision of oral nutrition and hydration once a person has reached an advanced stage of dementia. However, these directives may fail to address patients' discomfort, caregivers' obligations, or current care and regulatory standards when patients reside in facilities. In response to these dilemmas, we introduce Minimal Comfort Feeding (MCF). Rather than offering food and liquids proactively as with Comfort Feeding Only, caregivers provide nutrition and hydration only in response to signs of hunger and thirst. While further study is required to define and negotiate challenges in operationalizing this approach, MCF provides a framework that resolves competing ethical and clinical considerations in caring for those with advanced dementia. J Pain Symptom Manage 2025;69:216–222. © 2024 The Authors. Published by Elsevier Inc. on behalf of American Academy of Hospice and Palliative Medicine. This is an open access article under the CC BY-NC-ND license (http://creativecommons.org/licenses/by-nc-nd/4.0/).

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Is there an acceptable compromise?

Comfort Feeding Only (CFO): no more food/water than is comfortable, scheduled meal times, nutritional goals are prolonging life. Not goal concordant with VSED by AD.

Minimal Comfort Feeding (MCF): only as much food/water to ensure comfort, no scheduled meal times, frequent oral hygiene, medication to relieve hunger/thirst. Goal concordant with VSED by AD.

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Comfort **F**eeding **O**nly, **M**inimal **C**omfort **F**eeding, and **VSED** by AD

	Comfort Feeding Only (CFO)	Minimal Comfort Feeding (MCF)	Stopping Eating and Drinking (SED) by Advance Directive
Definition	No more food and liquid than is comfortable	Only as much food and liquid as necessary to avoid discomfort	No food or liquid at all
Appropriate Patient	PWAD who did not previously express a wish to avoid living with AD	PWAD who previously expressed a wish to avoid living with AD	PWAD who has a written directive specifically rejecting any oral nutrition and hydration
Time to death	Up to years	Weeks to a few months	Days
Prolongs life	Yes	No	No
Scheduled hand-feeding	Yes	No	No
Informed Consent	Low to moderate requirement for additional discussion with surrogate and caregivers	Moderate to high requirement for additional discussion with surrogate and caregivers	High requirement for informed consent in form of clear written directive
Written directive required	No	No	Yes

Source: Wechkin, H.A., Menzel, P.T., Loggers, E.T., Macauley, R.C., Pope, T.M., Reagan, P.L., & Quill, T. (2025). "Mr. Smith has no mealtimes": Minimal Comfort Feeding for patients with advanced dementia. *J Pain & Symptom Management*, 69(2):216-222. Page 217.

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Wechkin et al's Instructions for MCF

1. Apply moistened oral sponges and lip lubrication at least every 4 hours while patient is awake. Brush teeth, gums, and mouth up to twice daily.
2. Provide social contact and therapeutic touch at least every 4 hours while patient is awake.
3. If patient falls asleep at any step, do not awaken or cajole the patient. When patient next awakens, start again at the first step in Routine MCF care.

If patient is awake and appears uncomfortable and/or signals a desire for food after receiving three cycles of the Response to Possible Thirst protocol, provide previously enjoyable food in a hand-feeding session that does not exceed 15 minutes. This may be repeated every 4 hours.

If patient is awake and appears uncomfortable despite medical management of pain, anxiety, and/or agitation and Routine MCF Care above, follow steps #1-3 below in order, repeating steps up to every 30 minutes as needed for a total of up to three cycles.

1. Provide sensory distraction (i.e. music, fidget blankets, ambient nature sound, aromatherapy, etc.)
2. Provide additional mouth sponges, frozen drops of coconut oil, frozen teething rings, and frozen wet washcloths.
3. Provide up to 2 ounces (60 cc) of fluid. Do not provide more fluid than patient easily accepts.

Source: Wechkin, et al (2025)"Mr. Smith has no mealtimes…PSM, 69(2), 216-222. Page 220.

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References

- Cross, S. H., Kaufman, B. G., Taylor, D. H., Kamal, A. H., & Warraich, H. J. (2020). Trends and factors associated with place of death for individuals with dementia in the United States. *Journal of the American Geriatrics Society*, *68*(2), 250–255. https://doi.org/10.1111/jgs.16200
- Levine, M., & Bern-Klug, M. (2024). "They make the will, but they want the food:" Staff perspectives on challenges in implementing dementia advance directives related to stopping feeding. *J SW in EoL & Palliative Care*, DOI: 10.1080/15524256.2024.2365368
- PHI national (2019). U.S. nursing assistants employed in nursing homes: Key facts 2019 - phi. (n.d.). Retrieved February 5, 2023, from https://www.phinational.org/resource/u-s-nursingassistants-employed-in-nursing-homes-key-facts-2019/
- Sandelowski, M. (2000). Whatever happened to qualitative description? *Research in Nursing & Health*, 23: 334-340.
- Shay, J. (2014). Moral injury. *Psychoanalytic Psychology*, 31(2), 182–191.
- Wechkin, H. A., Menzel, P. T., Loggers, E. T., Macauley, R. C., Pope, T. M., Reagan, P. L., & Quill, T. E. (2025). "Mr. Smith has no mealtimes": Minimal comfort feeding for patients with advanced dementia. *Journal of Pain and Symptom Management*, *69*(2), 216–222.

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DISCUSSION

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Discussion Questions: *Please elect a recorder to summarize responses in 1-3 sentences.*

1. How comfortable would you be to discuss **Minimal Comfort Feeding** with persons with early dementia or who are at risk for dementia as a future end-of-life option?

1. How acceptable would you anticipate **Minimal Comfort Feeding** to be for f***amilies*** of persons with advanced dementia?

2. In your clinical practice, how easy/difficult would implementation of **Minimal Comfort Feeding** be?

3. Would people would react negatively if they knew clinicians supported offering **Minimal Comfort Feeding** as an end-of-life option for people with advanced dementia?

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Research Invitation: *SW and Minimal Comfort Feeding*

You are invited to take a 8-10 minute survey of about 30 questions (multiple choice).

Anonymous. We don't ask your name or other information that could identify you. You can skip any questions. You can stop the questionnaire at any point.

Taking part in this study is completely voluntary. If you do not wish to participate in the study, please disregard this invitation.

If you decide to participate, you have two options. You can scan the QR Code (next page) and complete the survey online, or you can complete a paper version of the survey.

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Let us know if you prefer to complete the survey on paper.

The survey is intended only for people who attended the April 28th symposium.

Questions?
Mercedes Bern-Klug
University of Iowa
319 335-1265

Thank you!

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At the END of the symposium, please scan this QR Code to take the survey.