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Facing Dementia in the Community and the Clinic: New Challenges for Aging Societies

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Thaddeus Mason Pope
JD, PhD, HEC-C

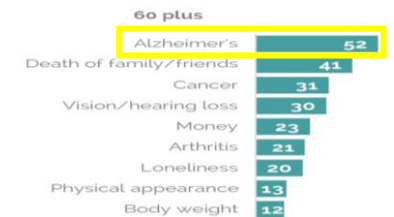
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fear of dementia

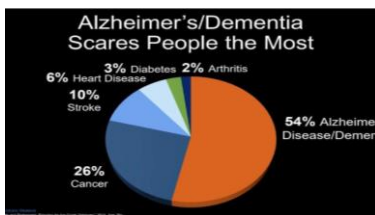
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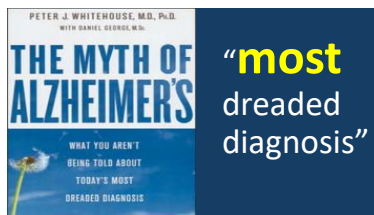
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hasten death to avoid late-stage dementia

9

When People Facing Dementia Choose to Hasten Death: The Landscape of Current Ethical, Legal, Medical, and Social Considerations in the United States

BY EMILY A. LARGENT, JANE LOWERS, THADDEUS MASON POPE, TIMOTHY E. QUILL, AND MATTHEW K. WYNIA

10

Options for Hastening Death That Involve Medical Personnel	
Relieving potentially life-sustaining interventions	Definition: The routine stopping or not starting any potentially life-sustaining intervention. These interventions commonly include cardiopulmonary resuscitation, mechanical ventilation, vasopressor inotropic support, dialysis, enteral, intravenous, and tube-feeding, and pain management. The procedure, which usually incorporates both an oral and written advance care directive, is not a form of physician-assisted suicide. It is a form of passive rather than active life-sustaining intervention due to passive death.
Voluntarily stopping eating and drinking (VSED)	Definition: This entails choosing to stop eating and drinking by mouth with the knowledge of hastening one's own death. A decision can be an explicit or implied one. It is not a form of physician-assisted suicide.
Medical aid in dying (MAID), in U.S. jurisdictions where legal	Definition: This involves the prescription of a lethal dose of medication by a physician or other qualified health care provider to an individual with a primary diagnosis of dementia who meets the self-administration requirements and criteria to independently meet the capacity requirements and other jurisdiction-specific requirements. Other requirements must be met, including a primary diagnosis of dementia that is sufficiently advanced to meet the capacity requirements. The medical assistance administration of lethal medication at the request of a patient is not self-administration. This involves documentation of oral later preference by an individual and a written preference to request physician administration of oral
Voluntarily written advance directives*	
End-of-life advance directives**	

11

FACT SHEET

IT'S YOUR LIFE. IT'S YOUR CHOICE.
DYING WITH DIGNITY
CANADA

Dementia and medical assistance in dying (MAID)

Medical assistance in dying (MAID) has been a legal option for qualifying people

Can someone with dementia access MAID?

YES. In some cases, a person with dementia or another capacity-limiting condition can access MAID. The most important thing to know is that a person must have decision-making capacity during their eligibility assessment. If someone has already lost capacity and is not regaining that capacity, then MAID is no longer an option for them.

12

outside Canada
 MAID is rarely
 an option

13

VSED

14

roadmap

15

5 parts

16

what is
VSED

17

what is
 VSED by AD

18

growingly
popular

19

legality of
VSED by AD

20

VSED by
surrogate

21

what is
VSED

22

Voluntarily
Stopping
Eating &
Drinking

23

patient **with**
capacity

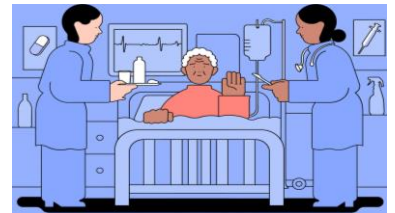
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able to take food
& fluid by mouth

25

voluntary
decision
to stop

26



27

≠ ANH

28

≠ natural loss
appetite

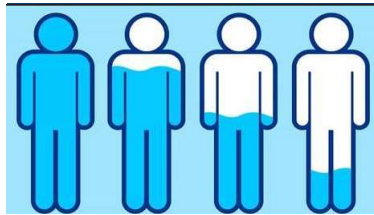
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deliberate choice
stop fluids
by **mouth**

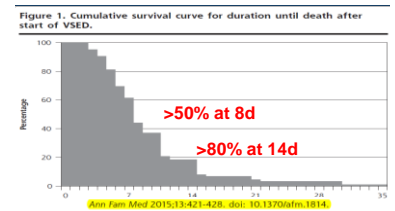
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goal = death
from dehydration

31



32



33

VSED is
legal

34

sizable, settled,
and stable
consensus

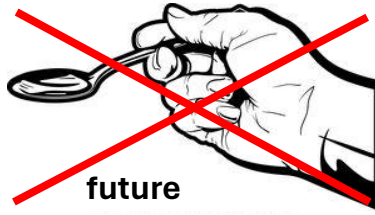
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what is
VSED by AD

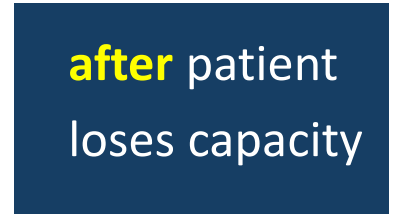
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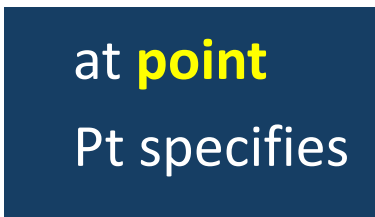
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FUNCTIONAL ASSESSMENT STAGING TEST (FAST) SCALE					
Stage	Stage Name	Characteristics	Stage	Stage Name	Characteristics
1	Normal Ageing	No deficits whatsoever	6a		Needs help pulling on clothes
2	Possible Mild Cognitive Impairment	Subjective functional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

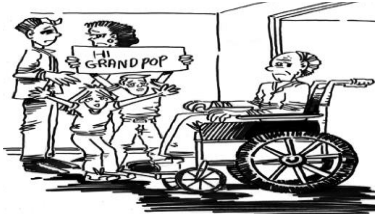
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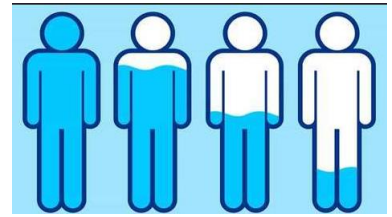
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prevalence
VSED by AD

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50

A Piece of My Mind

My Living Will

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

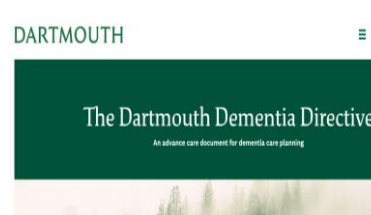
I, William Arthur Bernal, being of sound mind, desire that my life not be prolonged by extraordinary means if my condition is determined to be terminal and incurable. I am aware and understand that this writing authorizes a physician to withhold or discontinue extraordinary means...

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 and down inside while my life...

51

>14 VSED ADs

52



53

End of Life Choices NEW YORK

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

54



55



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.

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57

Support and promote life quality



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

lifecircle | Living will & additional personal statement

58

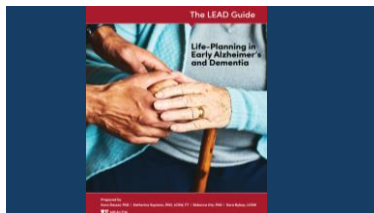


4. **ASSISTED FEEDING.** If I am unable to feed myself, then spoon feed me whatever I seem to enjoy, and no more. Do not feed me or apply medical interventions, such as tubes and IVs, so that I might live longer.

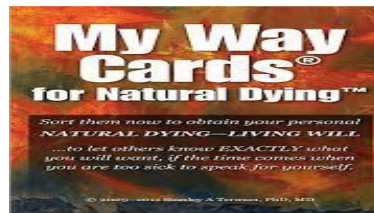
If this sentence is initialed and any of the choices 5, 6, or 7 are initialed, the latter are not to be implemented if they put my agent or any of my caregivers at criminal risk.

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.

60



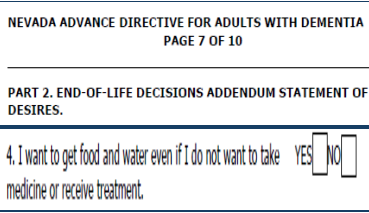
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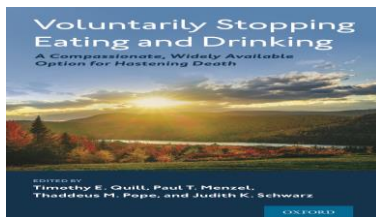
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74

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

75



76

but

77



78

VSED while
still have
capacity

79



80

too **soon**

81

life **still**
worthwhile

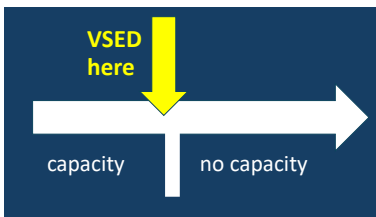
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earliness
problem

83



84



85



86

but

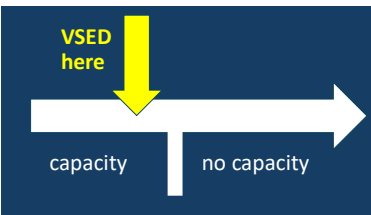
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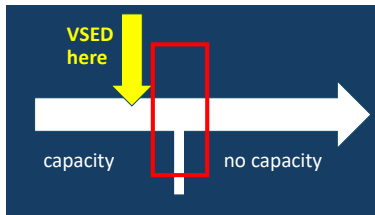
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91

premature
dying

92

current situation
still acceptable

93

VSED **not** a
good option

94

at **this** time

95

not ready
to die yet

96

concerned
about **future**
circumstances

97

lack capacity
at future time

98



99



100



101



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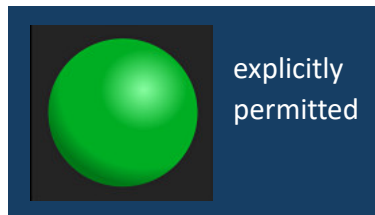
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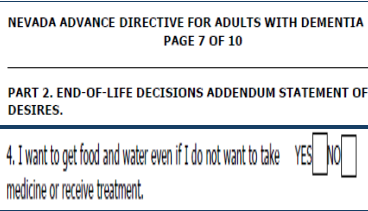
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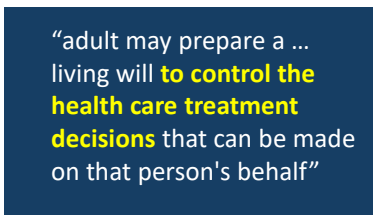
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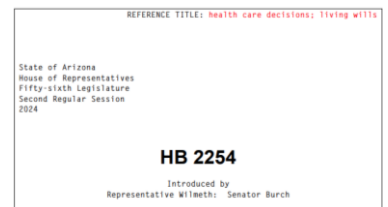
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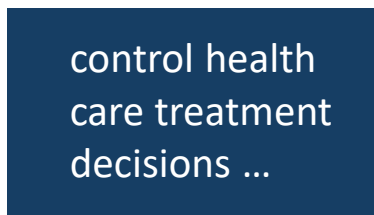
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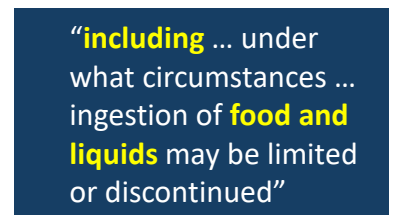
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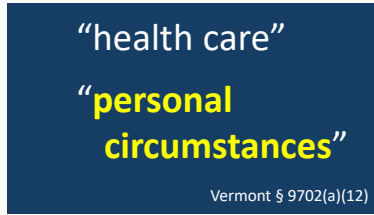
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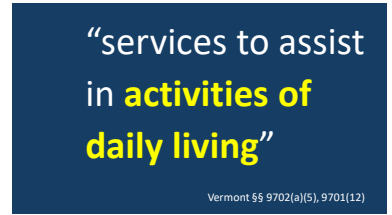
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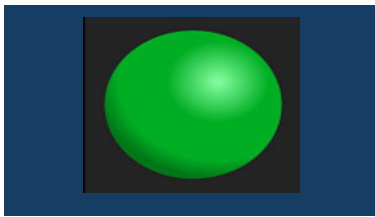
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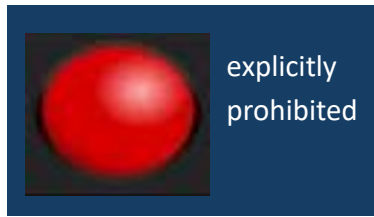
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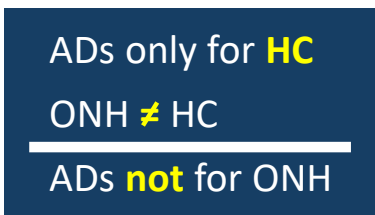
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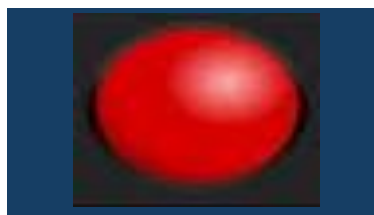
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right to refuse
health care
treatment in AD

127

but

128



129

ventilator
dialysis
CPR
antibiotics
feed tube

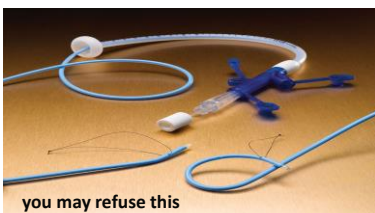
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oral N&H =
“treatment”

131

basic care

132



133



134



135

not explicit
and direct
like NV AZ VT

136

that's okay

137

AD laws do not
separately address
ICD, MV, dialysis,
antibiotics...

138



139

1	MINNESOTA STATUTES 2022	145C.01
CHAPTER 145C		
HEALTH CARE DIRECTIVES		
145C.01	DEFINITIONS.	145C.30
145C.02	HEALTH CARE DIRECTIVE.	145C.31
145C.03	REQUIREMENTS.	145C.32
145C.04	EXERCISED IN ANOTHER STATE.	145C.33
145C.05	SUGGESTED FORMS; PROVISIONS THAT MAY BE INCLUDED.	145C.34
145C.06	WHEN EFFECTIVE.	145C.35
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		145C.98
		145C.99
		145C.100

140

your AD can
address
health care

141

145C defines
"health care"
broadly

142

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

143

"health care"
includes food
& fluids

144

SO ...

145

MN ADs **may**
direct VSED

146

and ...

147

clinicians may
& should
honor them

148

**BIGGEST
PROBLEM**

149

t

150

prior **vs** now
self self

151

patient **has**
VSED AD

152

time to
honor AD

153

but

154



155

whose wishes
do we respect?

156

prior self
or
current self

157

now patient
or
then patient

158



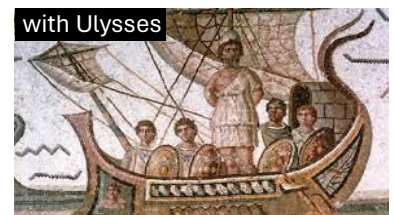
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ignore my
future self

160

stick to VSED
plan in the AD

161



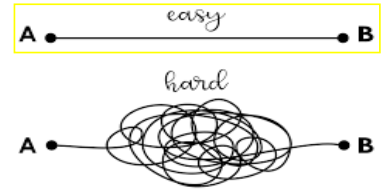
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prior self
prevails

163



164



165

no need for a
Ulysses clause
in the AD

166

incapacitated
objections are
already legally
irrelevant

167

1 MINNESOTA STATUTES 2022 145C.01

CHAPTER 145C
HEALTH CARE DIRECTIVES

145C.01	DEFINITIONS.	145C.30	PRESUMPTIONS.
145C.02	HEALTH CARE DIRECTIVE.	145C.31	IMMINENT.
145C.03	REQUIREMENTS.	145C.32	PROHIBITED PRACTICES.
145C.04	EXERCISED IN ANOTHER STATE.	145C.33	PENALTIES.
145C.05	SUGGESTED FORMS; PROVISIONS THAT MAY BE INCLUDED.	145C.34	CERTAIN PRACTICES NOT CONDONED.
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145C.07	AUTHORITY AND DUTIES OF HEALTH CARE AGENT.	145C.36	SUGGESTED FORM.
145C.08	AUTHORITY TO REVIEW MEDICAL RECORDS.	145C.37	OPIOD INSTRUCTIONS ENTERED INTO HEALTH RECORD.
145C.09	REVOCACTION OF HEALTH CARE DIRECTIVE.		

168

“health care directive
... **remain in effect**
until the principal
modifies or revokes”

169

“principal
with ... capacity
... may revoke”

170

patient with late-
stage dementia
cannot revoke

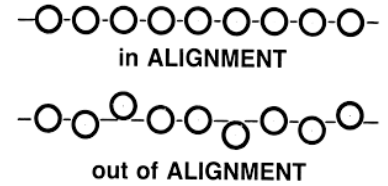
171

SO...

172

clinicians may and should **follow** her VSED directive

173



174



175

2019

176

duties to **current self** are primary

177

give water to LTC resident

178

despite VSED directive

179

but

180



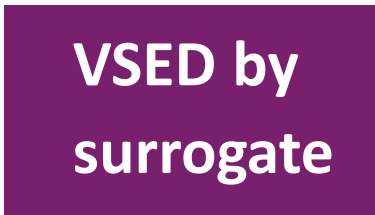
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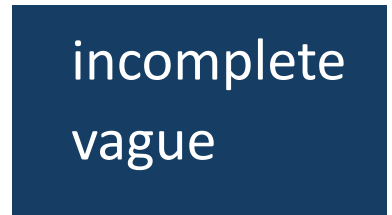
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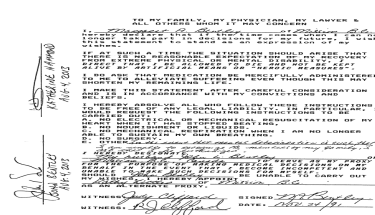
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186



187



188



189

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

190

or

191

not completed
 at all

192

patient not
 requesting VSED
 for themselves

193

surrogate requests
 VSED for Pt

194

Legal

Permitted by law
 lawful, allowed, recognized
 or not in violation of law
 in conformity with state
 regulations, principles,

195

surrogates may
 often make the
 same decisions
 as patients

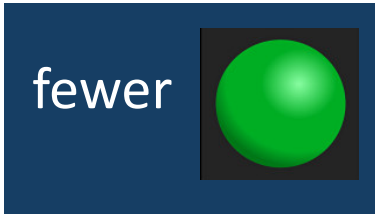
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but

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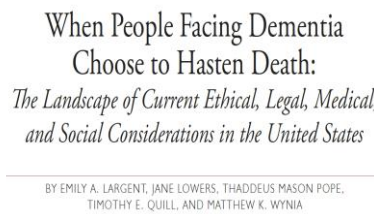
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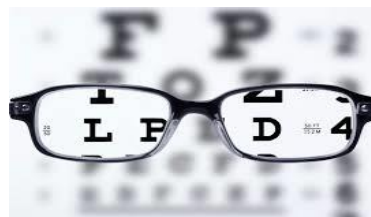
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When People Facing Dementia
Choose to Hasten Death:

210



211



212

Thank
you!

213

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materials from this
 presentation are available

<http://thaddeuspope.com/vsed>

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