

### **Thaddeus Pope**

**MNHPC** August 8, 2024

2





June 2019 Alzheimer's Dx

not want to live with late-stage dementia

5 6



## June 2023 VSED

8



## **StarTribune**

A good death for a Minnesota woman who championed the right to die with dignity

Cheryl Hauser showed us how to face the one part of life no one wants to talk about — the end.

IIINF 24, 2023 — 1:00F

10

## MPRNEWS Stay Curious. Stay Connected.

▲ Minnesota Now with Cathy Wurzer

Cathy Wurzer and Julia Franz · November 19, 2021 12:29 PM

A Minnesotan with Alzheimer's plans for death on her own terms

11



Family celebrates life of woman who voluntarily passed after Alzheimer's diagnosis

#### Joe Schmit KSTP

Updated: June 30, 2023 - 10:44 AM Published: June 29, 2023 - 10:45 PM



sendoff Services Resources Pre-Plan

#### SendOff Celebration



There are times in life (and in death) when we war our own way. After watching her beloved brother I Alzheimer's, Cheryl Hauser, who was diagnosed w knew she wanted to take a different path.

When the time came that her quality of life was in she would choose to die in her own terms, hasten process of VSED, or Voluntarily Stop Eating and D medically supervised, and incorporates hospice ca empowered choice, and to raise awareness and ec

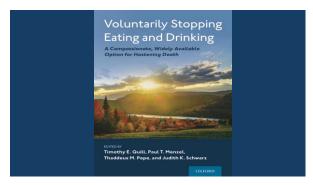
14





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17 18





19 20





21 22



what is VSED

23 24

VSED is legal

25

27

hospice eligibility

26

VSED by AD

VSED by AD is legal

28

what is VSED

**V**oluntarily

**S**topping

Eating &

**D**rinking

29

30

## patient with capacity

able to take food& fluid by mouth

32

31

33

voluntary decision to stop







35 36

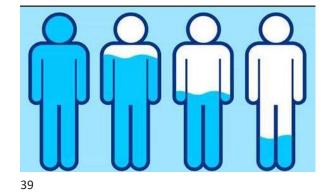
deliberate choice stop fluids by mouth

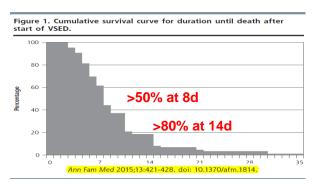
goal = death

from dehydration

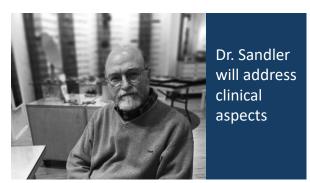
37

38





40



vsed is legal

41 42

## sizable, settled, and stable consensus

## court precedent

43

multiple appellate decisions

45 46

same in other common law countries

IN THE SUPREME COURT OF BRITISH COLUMBIA

Citation: Bentley v. Maplewood Seniors Care

Society, 2014 BCSC 165

Date: 20140203 Docket: S135854 Registry: Vancouver

Between:

44

Margaret Anne Bentley, by her Litigation Guardian Katherine Hammond, John Bentley and Katherine Hammod

Petitioners

47 48

#### 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 detected to the Registry of the Court in which it was generated with the property of the court in which it was generated to the property of the court in which it was generated to the property of the court in which it was generated to the property of the court in which it was generated to the property of the court in which it was generated to the property of the pr

H LTD v J & ANOR

[2010] SASC 176

Judgment of The Honourable Justice Kourakis

15 June 2010

49

51

is VSED legal?

asked &

answered

50



no need for direct, explicit authority

52

already legal
existing rules



## Combined Minnesota and Federal Hospice Bill of Rights

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

54

"patients ... have the right to refuse ... treatment"

55

In the Matter of the CONSERVATOR-SHIP OF Rudolfo TORRES, Conservatee.

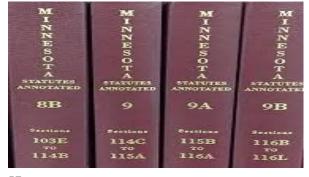
No. C1-84-761.

Supreme Court of Minnesota.

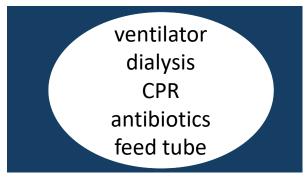
Nov. 2, 1984.

56

58



right to refuse treatment





59 60

# not DIY

part of a broader treatment plan

6

supervised by licensed healthcare professionals

recognized as
healthcare by
medical profession

63

64



Voluntarily stopping eating and drinking—lack of guidance is failing patients and clinicians

Patients and physicians need clear information to navigate the complex processes in end-of-life care, say Linda Dykes and colleagues

Linda Dykes, <sup>1</sup> Simon Hodes, <sup>2</sup> Sarah Malik<sup>3</sup>

65

Voluntary stopping of eating and drinking in the age of medical assistance in dying: ethical considerations for physicians

Peter Allatt, Daniel D.M. Kim and Philip Hébert

67

Palliative Care & Social

2022, Vol. 16: 1-10

DOI: 10.1177/ 26323524221112170

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68

## more position statements

69

#### POSITION STATEMENT



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

Effective Date: Status:

2017

Revised Position Statement

Written by: Adopted by:

ANA Center for Ethics and Human Rights

**ANA Board of Directors** 

70



American Medical Women's Association





JOLFINAL OF FALLIATIVE NECICINE Volume 2), Number 1, 2017 Way Ann Leibert, Inc. DOX 10.1984(pm.2016.009) Position Statement

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

73 74



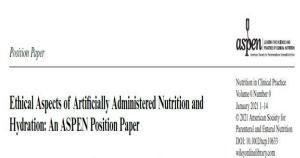


e-SPEN guideline

ESPEN guideline on ethical aspects of artificial nutrition and hydration

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

76



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



78

WILEY

## more clinical practice guidelines

Zorg voor mensen die stoppen met eten en drinken om het levenseinde te bespoedigen

January 2004

Internation 2004

Inte

80



Clinical Guidelines for Voluntarily Stopping Eating and Drinking (VSED)

Nov. 2023

Cohpring

A standard of Performent of Support and If such Markers Reporting the Use

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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

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## 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

VSED = Tx ONH





86

88

some challenge premise

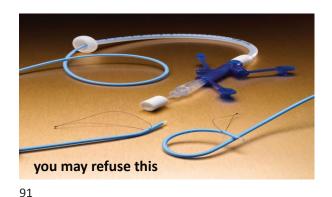
oral N&H = "treatment"

87

oral N&H 🗲 "treatment"

basic care

89 90





92





94

right to refuse any intervention

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

95 96

right to refuse

any intervention

97

99

medical or not

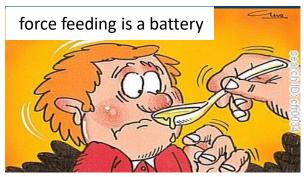
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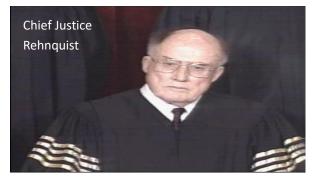
healthcare or not

right to refuse **any**unwanted contact

100

102





101

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



103

Medicare Conditions of Participation for Hospice



105 106

"patient has a right to refuse care or treatment"

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



VNSNY HOSPICE & PALLIATIVE CARE POLICY and PROCEDURE

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

108

"ethical and legal option"

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

110

109

recap

111

vsed is legal

112

sizable, settled, and stable consensus

113

assisted suicide



Minn. Stat. **609.215** 

116

"whoever . . .

assists another in taking the other's life ..."

117





Medical Practice Act

119 120

Minn. Stat. 147.091(1)(w)

"aiding suicide ...
grounds for
disciplinary action"

122

121



VSED = AS
AS = felony
VSED = felony

123 124





125 126



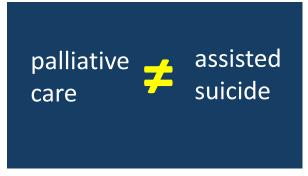
## no assisting

128





129 130





131

"provider ... who administers, prescribes ... medications or procedures to relieve another person's pain or discomfort . . . does not violate this section"



133 134





135 136

1000s of VSED deaths

no healthcarelicensing boarddiscipline

137 138

no criminal prosecutions

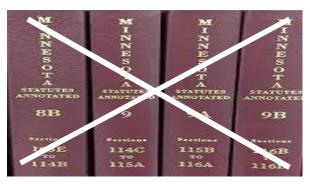
no medicalmalpractice

140



hospice

141 142





143

types of cases

145



146

already on hospice already eligible TI → begins VSED



147

not on hospicenot already eligible TI→ begin VSED

does VSED

make patient
eligible?

149 150





152

"most hospices will not provide direct care to patients with a prognosis greater than six months prior to ... initiation of VSED"

"However, many hospices will enroll patients who have already begun VSED."

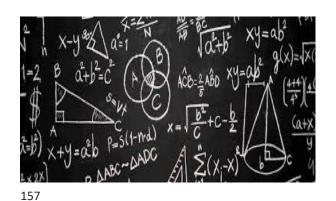
153 154



"As to Hospice eligibility, there was unanimous agreement that any patient who embarks on VSED becomes one of ours"

155 156

8/7/2024



VSED → death
< 14 days

14 days < 6 months

158



inanition

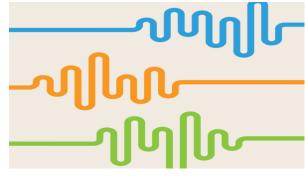
+

underlying

medical condition

160

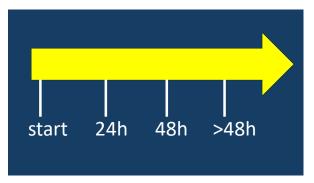
F50.89
other specified eating disorder



161 162

8/7/2024



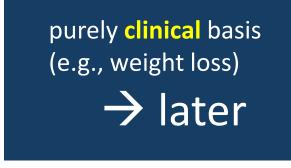


164

not assessing symptoms



165





167 168

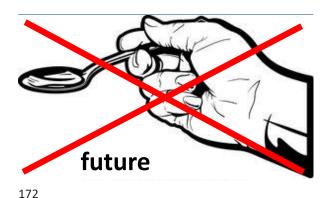
VSED by patient with capacity



169

170





171

after patient loses capacity

at **point**Pt specifies

173 174



## clinical triggers

176

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

## functional triggers

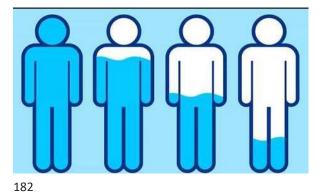
177 178





179 180





prevalence VSED by AD growingly popular 184

183

#### A Piece of My Mind

#### My Living Will

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

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

basic of comfort and nutritional care. Even a detailed living will that includes the refusal of all active treatments such as cardiopulmonary resuscitation, antibiotics, artificial nutrition, and hydration may be inadequate in such a situation. I do not want to 
become a vacant-looking body, reflexively swallowing food and 
water placed in mu month my soul frozon inside while my life

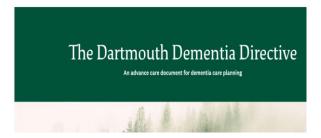
186

>14 VSED ADS

185

DARTMOUTH

EXPL





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

188



Your life. Your death. Your choice.

189

187

### **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.

190



Support and promote life quality



lifecircle Living will & additional personal statement

191 192



193

197

## Introduction to our Supplemental Advance Directive For Dementia



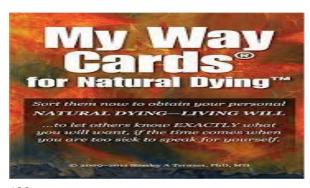
4. \_\_\_\_ASSISTED FEEDING. If I am unable to feed myself, then spoon feed me whatever I seem to enjoy, and no more. Do not feed me or apply medical interventions, such as tubes and IVs, so that I might live longer.

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.

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.

194





195 196



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

198



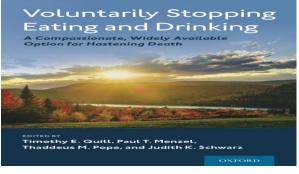
#### Making the Case for a Dementia Directive

November 14, 2022

199



200



201



202



why growing VSED by AD

204





206

208

## fear of dementia

207

60 plus Death of family/friends Cancer Vision/hearing loss 30 Money Arthritis Loneliness

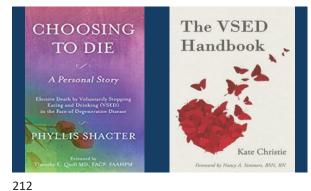
PETER J. WHITEHOUSE, M.D., PILD. "most dreaded diagnosis" OREADED DIAGNOSIS

many used VSED to avoid late-stage dementia

209 210

8/7/2024









213 214

> **VSED** while still have capacity



215 216

too soon

life still worthwhile

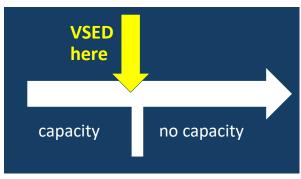
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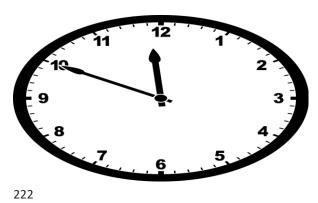
earliness problem

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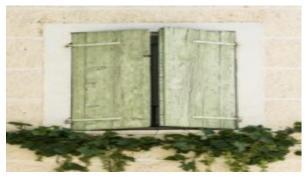


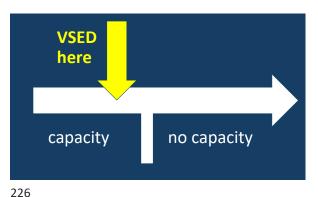


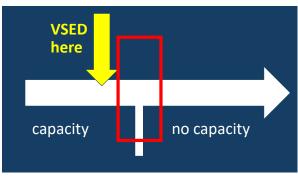
221













current situation
 still acceptable

VSED **not** a good option

230

232

229

at this time

not ready
to die yet

231

concerned about future circumstances

lack capacity at future time

233 234









238



<u>legality</u> of VSED by AD

239 240









243 244

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.



245 246

"health care"

"personal
circumstances"

Vermont § 9702(a)(12)

"services to assist in activities of daily living"

Vermont §§ 9702(a)(5), 9701(12)

247

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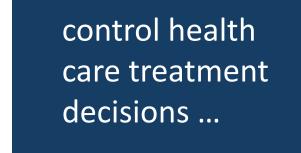


State of Arizona House of Representatives Fifty-sixth Legislature Second Regular Session

**HB 2254** 

Introduced by Representative Wilmeth: Senator Burch

250





251 252

"including ... how and under what circumstances the ingestion of food and liquids may be limited or discontinued"



254

253

# not explicit and direct like NV VT AZ

255

MINNESOTA STATUTES 2022

145C.01

#### CHAPTER 145C

#### HEALTH CARE DIRECTIVES

145C.01	DEFINITIONS.	145C.10	PRESUMPTIONS.	
145C.02	HEALTH CARE DIRECTIVE.	145C.11	IMMUNITIES.	
145C.03	REQUIREMENTS.	145C.12	PROHIBITED PRACTICES.	
145C.04	EXECUTED IN ANOTHER STATE.	145C.13	PENALTIES.	
145C.05	SUGGESTED FORM; PROVISIONS THAT MAY BE INCLUDED.	145C.14	CERTAIN PRACTICES NOT CONDONED.	
		145C.15	DUTY TO PROVIDE LIFE-SUSTAINING HEALTH	
145C.06	WHEN EFFECTIVE.	CARE.		
145C.07	AUTHORITY AND DUTIES OF HEALTH CARE AGENT.	145C.16	SUGGESTED FORM.	
		145C.17	OPIOID INSTRUCTIONS ENTERED INTO HEALTH	
145C.08	AUTHORITY TO REVIEW MEDICAL RECORDS.		RECORD.	
1450.00	BETTO CATION OF HEALTH OADE DIDECTION			

256

your AD can address health care

what's "health care"

257 258

145C defines "health care" broadly

"any care ..."

260

262

"any care, treatment, service, or procedure

259

to ... affect a person's physical ... condition"

"health care"
includes food
& fluids

261

SO ...

MN ADs may direct VSED

263 264



clinicians may & should honor them

266



conflict

268

prior vs now self

patient <mark>has</mark> VSED AD

269 270

\_, .

## time to honor AD



272

271





whose wishes do we respect?

prior self current self

275 276

now patient or then patient

277

279

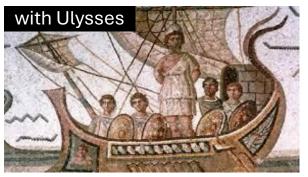


278

ignore my future self

stick to VSED plan in the AD

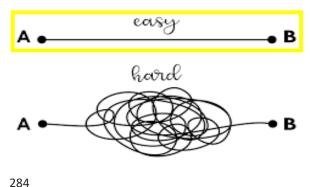
280



prior self prevails

281





no need for a
Ulysses clause
in the AD

incapacitated objections are already legally irrelevant

286

145C.01

MINNESOTA STATUTES 2022

REVOCATION OF HEALTH CARE DIRECTIVE.

285

145C.09

CHAPTER 145C

#### HEALTH CARE DIRECTIVES

145C.01	DEFINITIONS.	145C.10	PRESUMPTIONS.
145C.02	HEALTH CARE DIRECTIVE.	145C.11	IMMUNITIES.
145C.03	REQUIREMENTS.	145C.12	PROHIBITED PRACTICES.
145C.04	EXECUTED IN ANOTHER STATE.	145C.13	PENALTIES.
145C.05	SUGGESTED FORM; PROVISIONS THAT MAY BE INCLUDED.	145C.14	CERTAIN PRACTICES NOT CONDONED.
		145C.15	DUTY TO PROVIDE LIFE-SUSTAINING HEALTH
145C.06	WHEN EFFECTIVE.		CARE.
145C.07	AUTHORITY AND DUTIES OF HEALTH CARE AGENT.	145C.16	SUGGESTED FORM.
		145C.17	OPIOID INSTRUCTIONS ENTERED INTO HEALT
145C 08	ALTHORITY TO BEVIEW MEDICAL RECORDS	RECORD.	

"health care directive ... remain in effect until the principal modifies or revokes"

287 288

"principal
with ... capacity
... may revoke"

patient with latestage dementia lacks capacity

290

289

**SO**...

patient with latestage dementia cannot revoke

291 292

**SO**...

AD remains in force

293 294

clinicians may & should follow VSED directive

295

-O-O-O-O-O-O-O-O-

-0-0-0-0-0-0-0-

out of ALIGNMENT

296



2019

298

duties to current self are primary

give water to LTC resident

299 300



303



302

2023

JAMDA

JAMDA

JAMDA

Journal homepage: www.jamda.com

Editorial

AMDA Updated Statement on Stopping Eating and Drinking by Advance Directives (SED by AD)

Board of Directors, Christopher E. Laxton CAE\*

AMDA - The Society for Prot-Acate and Lung-Term Care Medicine, Columbia, MD, USA

JAMDA 24 (2023) 321

304

honor the VSED AD



305



Journal of Social Work in End-of-Life & Palliative Care

Journal of Social Work in End-of-Life & Palliative Care

155N: (Print) (Online) Journal homepage: www.tandfonline.com/journal/wawe20

"They Make the Will, But They Want the Food:" Staff Perspectives on Challenges in Implementing Dementia Advance Directives Related to Stopping Feeding

Meredith Levine & Mercedes Bern-Klug

308

307





309 310



VSED by surrogate

311 312



## not patient asking VSED

314

316

legally authorized decision maker

agent
default surrogate
guardian

315

Permitted by law law lawful, allowed, recognit or not in violation of law on conformity with station c



318



**SO**...









### NHPCO Ethics Advisory Council

"encourage each hospice ... establish policy or guidelines to address VSED so staff is prepared ..."

325 326





327 328

#### Thaddeus Mason Pope, JD, PhD, HEC-C

Mitchell Hamline School of Law 875 Summit Avenue

Saint Paul, Minnesota 55105

**T** 651-695-7661

C 310-270-3618

E Thaddeus.Pope@mitchellhamline.edu

W www.thaddeuspope.com

B medicalfutility.blogspot.com