### Ethics at End of Life: Dementia and VSED

Thaddeus Mason Pope, JD, PhD Mitchell Hamline School of Law

Minnesota Network for Hospice & Palliative
Care Conference - April 11, 2016







#### **Disclosures**

There are **no conflicts** of interest or relevant financial interests that have been disclosed by this presenter or the rest of the planners or presenters of this activity that apply to this learning session.

**Abstract** 

Patients with capacity may refuse life-saving and life-sustaining interventions. But what if the patient is not dependent upon any of these? What if the patient wants to avoid a life that they find intolerable, for example one with severe dementia? While physician aid in dying is prohibited in Minnesota, voluntarily stopping eating and drinking (VSED) is not.

Starting with a case presentation, this session will examine the medical, ethical, and legal aspects of VSED both when the patient requests it herself and when the patient requests it in advance through an advance directive or surrogate. The session will also outline how to handle clinicians' conscience based objections to VSED and other controversial services.

## **Learning Objectives**

Compare the legal and ethical distinctions between VSED, on the one hand, and medical aid in dying and withholding or withdrawing life-sustaining treatments, on the other hand

Describe the ethical and legal implications of VSED and how to respond to patient requests.

Evaluate claims for conscience based objections to VSED.

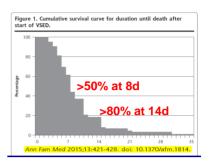
**Definition** 

3

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

Voluntary, **deliberate** decision to stop

**Intent:** death from dehydration



## Other names

#### **VSED**

Voluntarily stopping eating & drinking

#### **VRFF**

Voluntary refusal of food & fluid

#### **PRNH**

Patient refusal of nutrition & hydration

#### **STED**

Stopping eating & drinking

#### **VTD**

Voluntary terminal dehydration

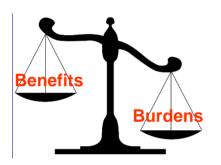
Why hasten death

Physical suffering

Pain
Nausea
Dyspnea
Paralysis
Foul-smelling wounds

## Existential suffering

Psychic pain Loss of control Anxiety Delirium Hopelessness



Self-defined quality of life

Pt own assessment

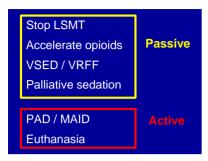
Pt own values

Pt own preferences

# Exit options

Decreasing order of acceptability

Stop LSMT
Accelerate opioids
VSED / VRFF
Palliative sedation (PSU)
PAD / MAID
Euthanasia



More uncertainty & reluctance than LSMT

Even CANH often treated specially



VSED underserved bad reputation











Not voluntary
Not complete
Not controlled

Peaceful Comfortable

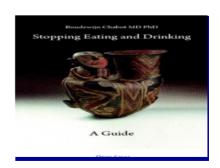


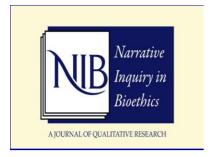
Anecdotal reports











# Peer reviewed literature

The NEW ENGLAND JOURNAL of MEDICINE

SPECIAL ARTICLE

Nurses' Experiences with Hospice Patients Who Refuse Food and Fluids to Hasten Death

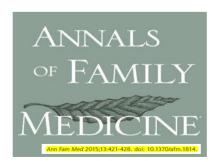
Linda Ganzini, M.D., M.P.H., Elizabeth R. Goy, Ph.D., Lois L. Miller, Ph.D., R.N., Theresa A. Harvath, R.N., Ph.D., Ann Jackson, M.B.A., and Molly A. Delorit, B.A.

One third of 300 responding OR nurses cared for VSED patient

Even though MAID available, "almost twice" chose VSED

"opportunity for reflection, family interaction, and mourning"

Most deaths: "peaceful, with little suffering"



"the literature mostly comprises commentaries and case reports" "This study . . . is the **most** comprehensive yet undertaken"

708 responding physicians

46% cared for a patient who VSED

Physicians' impression that dying process went according to the patient's wish

Yes 80 (71-87)
Partly 18 (11-27)
No 2 (0-8)

If partly or no, reason whys

Duration too long 11 (6-20)

Patient preferred PAS 3 (1-9)

Communication problems 1 (0-6)

Inability to say goodbye 1 (0-6)

Agitation 1 (0-6)

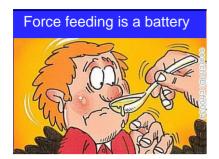
Legal concerns

Capacity

No capacity

Patient with capacity requests VSED now

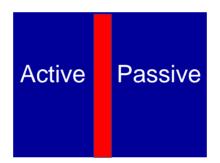


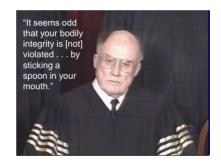


Does not matter whether food & fluid are "medical treatment"

2

VSED is **not** assisted suicide





3

VSED is **not** abuse or neglect





Uncertainty & reluctance among providers

Legal & ethical expert support nearly universal

Patient makes "advance"
VSED instruction



Trickier & more controversial

The New York Times | http://nyti.ms/1ujCDEh

HEALTH | THE NEW OLD AGE

Complexities of Choosing an End Game for Dementia

By PAULA SPAN JAN. 19, 2015



Why "advance" VSED



Not eligible for MAID

Cannot BOTH
Terminally ill
Capacity

Can you leave VSED instructions in a MN AD?



"Health care directive may include . . . health care instructions . . . appoint . . . agent to make health care decisions."

Minn. Stat. 145C.02

"Health care means any care, treatment, service, or procedure to maintain . . . or otherwise affect . . . physical . . . condition."

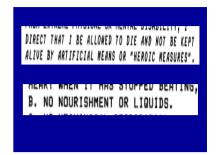
Minn. Stat. 145C.01(4)



Be very specific on the triggers







2

Do later requests for water revoke the AD?

Maybe





References

T.M. Pope, Prospective Autonomy and Dementia: Ulysses Contracts for VSED, 12(3) JOURNAL OF BIOETHICAL INQUIRY 389-94 (2015).

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

#### Thaddeus Mason Pope, JD, PhD

Director, Health Law Institute
Mitchell Hamline School of Law
875 Summit Avenue
Saint Paul, Minnesota 55105
T 651-695-7661

**F** 901-202-7549

 $\hbox{\bf E Thaddeus.Pope@mitchellhamline.edu}\\$ 

**W** www.thaddeuspope.com

**B** medicalfutility.blogspot.com

12