Under-examined End-of-Life Option: Hastening Death by Voluntarily Stopping Eating and Drinking (VSED)

Dying in the Americas
Henderson, NV - Mar. 24, 2018

Thaddeus Mason Pope, JD, PhD
Mitchell Hamline Health Law Institute
Who am I?
I am a law professor
Who else?
Since 2012
Before that:
Georgetown bioethics
I am a law professor.

But I often speak and write directly to clinicians.
Advance Directives & POLST
Hastening Death – VSED
Hastening Death - MAID
Medical Futility
Surrogate Decision Making
Right to Die & UMT
Brain Death & Organ Donation
Conscience Based Objections
Healthcare Ethics Committees
THE RIGHT TO DIE
The Law of End-of-Life Decisionmaking
Third Edition

Alan Meisel
Kathy L. Cerminara
Thaddeus M. Pope
Medical Futility Blog

4 million pageviews
Introduction
More & more jurisdictions expanding EOL liberty
Most VISIBLE exit option

Medical aid in dying
MAID legal in 7 US states
Maybe soon 9
MAID illegal in 49
Other exit options
Dementia challenge raised repeatedly
Challenge even in these states
Cannot satisfy 2 conditions at same time
Terminal illness
“incurable and irreversible . . . condition . . . death within six months.”
Capacity
“solely and directly by the individual . . . not . . . advance directive”
BUT
Capacity → not terminal
Terminal ➔

no capacity
Arbitrary discrimination
At least 10 years away
Benelux

Netherlands

Belgium

Luxembourg
No “advance” MAID in the Americas
No help for dementia even here
SO:
again

Other exit

options
Voluntarily Stopping Eating & Drinking
MAID gets massive attention
neglected in academic & policy circles
Define VSED
Physiologically able to take food & fluid by mouth
Voluntary, deliberate decision to stop
Intent: death from dehydration
Figure 1. Cumulative survival curve for duration until death after start of VSED.

>50% at 8d

>80% at 14d
Bad rap
“Must legalize MAID . . . or else . . . VSED”
Actually
Peaceful
Comfortable
1st person narratives
NARRATIVE SYMPOSIUM
Patient, Family, and Clinician Experiences with Voluntarily Stopping Eating And Drinking (VSED)
Thaddeus Mason Pope, Symposium Editor

RESEARCH ARTICLE
A Qualitative Study of US Clinical Ethics Services: Objectives And Outcomes
Leah Mcclimans, Geah Pressgrove, and James Rhea

CASE STUDY
Ethical Challenges in the Care of the Inpatient with Morbid Obesity
Paul L. Schneider and Zhaoping Li

Symposium: Patient, Family, and Clinician Experiences with Voluntarily Stopping Eating And Drinking (VSED)

Volume 6 Number 2 Summer 2016
Frank Tugend and his grandson, Dan Jury, 1954.

Dan Jury and his grandfather, Frank Tugend, 1974.
Medical journals
SPECIAL ARTICLE

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

>100 Oregon nurses cared for VSED patients
Most deaths: “peaceful, with little suffering”
“opportunity for reflection, family interaction, and mourning”
Not for everyone
On My Own

Diane Rehm

“Clear, moving and completely honest. . . . Diane Rehm has again found her voice, and, as she has always done, she speaks passionately and courageously about issues that concern us all.”
—The Washington Post
Preferred by many
Even though MAID available, “almost twice” chose VSED
Good option
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
Voluntary Stopping Eating and Drinking

John W. Warz, MD, Amy W. An, MD, Nicole Kosier, MD, and Timothy E. Quill, MD
Growing professional society endorsements
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
International Association for Hospice and Palliative Care Position Statement: Euthanasia and Physician-Assisted Suicide
Freiwilliger Verzicht auf Nahrung und Flüssigkeit um das Sterben zu beschleunigen

Eine Stellungnahme der österreichischen Palliativgesellschaft (OPG)

Angelika Feichtner · Dietmar Weixler · Alois Birklbauer

© Springer-Verlag GmbH Austria, ein Teil von Springer Nature 2018
Legal concerns
Clinician involvement very important
BUT
Uncertainty & reluctance
Prevalence of Formal Accusations of Murder and Euthanasia against Physicians

> 600 palliative care physicians
<table>
<thead>
<tr>
<th>Action that might be misperceived</th>
<th>Mean rating of risk</th>
<th>SD</th>
<th>Actual number of physicians who were accused based on this action</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total sedation (the application of pharmacotherapy to induce a state of decreased or absent awareness [unconsciousness] in order to reduce the burden of otherwise intractable suffering)</td>
<td>4.1</td>
<td>1.1</td>
<td>2</td>
</tr>
<tr>
<td>Stopping artificially delivered nutrition/hydration</td>
<td>3.6</td>
<td>1.1</td>
<td>0</td>
</tr>
<tr>
<td>Stopping oral nutrition/hydration in a patient who can eat/drink when requested by the patient</td>
<td>3.3</td>
<td>1.2</td>
<td>0</td>
</tr>
<tr>
<td>Use of palliative and sedative medications in the process of discontinuing mechanical ventilation</td>
<td>3.2</td>
<td>1.3</td>
<td>6</td>
</tr>
<tr>
<td>Stopping dialysis</td>
<td>3.1</td>
<td>1.2</td>
<td>0</td>
</tr>
<tr>
<td>Use of barbiturates for symptom treatment</td>
<td>2.9</td>
<td>1.1</td>
<td>2</td>
</tr>
<tr>
<td>Use of opiates for symptom treatment</td>
<td>2.8</td>
<td>1.2</td>
<td>13</td>
</tr>
<tr>
<td>Use of benzodiazepines for symptom treatment</td>
<td>2.3</td>
<td>1.0</td>
<td>1</td>
</tr>
<tr>
<td>Other</td>
<td>N/A</td>
<td>N/A</td>
<td>6</td>
</tr>
</tbody>
</table>
Prohibited

Unsure

Permitted
Almost never: express prohibition
No U.S. jurisdiction expressly prohibits VSED
BUT

Absence of a red light

not good enough
Clinicians want express permission
No statutory permission
No judicial precedent
No red lights
No green lights

Lack of clarity & guidance
neglected in academic & policy circles
FINAL DISPOSITION REPORT OF THE INQUIRY COMMITTEE

February 13, 2018

CPS File No: IC 2017-0836

Complainant: Internal (referral from BC Coroners Service)

Subject Physician(s): Dr. Ellen Wiebe
Providers

ask
Is VSED legal?
Is VSED illegal?
Wrong

questions
Law is rarely binary
Risk assessment
Measure
Mitigate
2 case types
VSED now by patient with capacity
Advance directive for VSED later (when Pt lacks capacity)
VSED now, patient with capacity
Extremely low risk of sanctions – criminal, civil, regulatory
4 Arguments
Right to refuse medical measures
Well established

> 4 decades
Right to refuse medical
Vent
Dialysis
CPR
Antibiotics
Feed tube
Unclear
Vent
Dialysis
CPR
Antibiotics
Feed tube

ICD
Not DIY
Part of a broader treatment plan

Supervised by licensed healthcare professionals
P AVSED

Palliated & Assisted
Voluntarily Stopping Eating and Drinking
Highlights medical role in palliating symptoms

Highlights the direct care staff role in providing assistance
Recognized as healthcare by medical profession
More position statements (e.g. ANA, IAHPC)
More clinical practice guidelines
Caring for people who consciously choose not to eat and drink so as to hasten the end of life
Recap
ONH = “treatment”
Right to refuse medical VSED
BUT
Barely established
ANH = medical treatment
Medical b/c not “typical human”
Implies ONH is not medical
ONH ≠ “treatment”
Right to refuse medical
Right to refuse unwanted measures
Does not matter whether food & fluid is "medical treatment"
Right to refuse any intervention (medical or not)
Unwanted contact

Even if clinically beneficial
Battery
Patient consented to left ear

Physician operated on right ear

Mohr v. Williams (Minn. 1905)
Force feeding is a battery
“bodily integrity is violated . . . by sticking a spoon in your mouth . . . sticking a needle in your arm”
Move from legal bases, grounds for right
Respond to 2 main legal concerns
VSED is not assisted suicide
“Every person . . . aids, or advises, or encourages another to commit suicide, is guilty of a felony.”
Clinicians worry participation with VSED = assisting suicide
VSED ≠ AS
AS statutes

target active

conduct
Normally:

“Providing the physical means by which the other person commits . . . suicide”
VSED entails only passive conduct
Plus
Even if otherwise within scope

Exception
“Nothing . . . prohibit or preclude . . . prescribing . . . administering, . . . purpose of diminishing . . . pain or discomfort”
Everything clinician does in VSED expressly exempted from AS statute
0 cases
4 VSED is not abuse / neglect
Alleged risk
“The facility must provide each resident with sufficient fluid intake to maintain proper hydration and health.”

42 C.F.R. 483.25(j)
Tag F0327
The number and severity of deficiencies shown below relate only to the search terms, not necessarily all deficiencies against the home. **Important:** If you searched for a city or home name, results for that home may be spread over several pages. To improve results, select a state and sort by city.

<table>
<thead>
<tr>
<th>Date</th>
<th>Nursing Home</th>
<th>City</th>
<th>State</th>
<th>Def.</th>
<th>Severity Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sept. 22, 2015</td>
<td><strong>THE BROADMOOR AT CREEKSID&quot; (REPORT)</strong></td>
<td>The Woodlands</td>
<td>Tex.</td>
<td>2</td>
<td>K to L</td>
</tr>
<tr>
<td>April 28, 2015</td>
<td><strong>BRIARCLIFF HEALTH CENTER (REPORT)</strong></td>
<td>Tyler</td>
<td>Tex.</td>
<td>2</td>
<td>L</td>
</tr>
<tr>
<td>Aug. 7, 2013</td>
<td><strong>KINDRED TRANSITIONAL CARE AND REHABILITATION-RIDGM (REPORT)</strong></td>
<td>Fort Worth</td>
<td>Tex.</td>
<td>4</td>
<td>L</td>
</tr>
<tr>
<td>May 29, 2013</td>
<td><strong>PALMA REAL (REPORT)</strong></td>
<td>Mathis</td>
<td>Tex.</td>
<td>3</td>
<td></td>
</tr>
</tbody>
</table>

**Deficiencies With "Dehydrate"**

**By Severity**

- B: 2
- D: 326
- E: 115
- F: 36
- G: 180
- H: 12
- I: 1
- J: 43
- K: 47
- L: 10
BUT
I agree

I disagree
Over-treatment just as risky as under-treatment
Risk ~ 0
Risk ≠ 0
VSED now, patient with capacity
Advance directive for VSED later (when Pt lacks capacity)
Why
do it
Benefits

Burdens
Future Benefits

Future Burdens
What is it
Complete AD, today
Direct VSED in future
When reach point that you define as intolerable
You lack capacity at that time
That is “advance VSED”
Viable option?
Can you leave
VSED
instructions
in an AD?
Glendower: “I can call spirits from the vasty deep.”
Hotspur: “Why, so can I, or so can any man; But will they come when you call for them?”
You can write anything you want in an AD.

But ... will it be honored.
No specific permission for VSED
STOP
Sometimes, advance VSED is prohibited
Wis. Stat. 155.20

“A health care agent may not consent to the withholding or withdrawal of orally ingested nutrition or hydration . . .”
“Providing nutrition or hydration orally . . . is not health care”

NY Pub Health Code 2994-a
Autonomy
Autonomy

Prospective autonomy
No green (yet)

Some red
Is advance VSED request enforceable?
2 recent cases
Case 1
TO MY FAMILY, MY PHYSICIAN, MY LAWYER &
ALL OTHERS WHOM IT MAY CONCERN

I, Margaret A. Bentley of Mission B.C.
hereby declare that if the time comes when I can no
longer take part in decisions for my future, I wish
this statement to stand as an expression of my
wishes.

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

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

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

I HEREBY ABSOLVE ALL WHO FOLLOW THESE INSTRUCTIONS
TO BE FREE OF ANY LEGAL LIABILITY. IN PARTICULAR, I
WOULD REQUEST THE FOLLOWING INSTRUCTIONS TO BE
CARRIED OUT:
A. NO ELECTRICAL OR MECHANICAL RESUSCITATION OF MY
HEART WHEN IT HAS STOPPED BEATING,
B. NO NOURISHMENT OR LIQUIDS,
C. NO MECHANICAL RESPIRATION WHEN I AM NO LONGER
ABLE TO SUSTAIN MY OWN BREATHING.
D. NO SURGERY.
E. OTHER:
   In the event that mental deterioration is such that
   I am unable to recognize the members of my family, I
   ask that I be institutionalized.

I HEREBY DESIGNATE

My husband, Alex B. Bentley

OF

Mission, B.C., Canada TO SERVE AS MY PROXY
FOR THE PURPOSE OF MAKING MEDICAL DECISIONS ON MY
BEHALF IN THE EVENT THAT I BECOME INCOMPETENT AND
UNABLE TO MAKE SUCH DECISIONS FOR MYSELF.
SHOULD Alex Bentley BE UNABLE TO CARRY OUT
MY WISHES, I HEREBY APPOINT

Kathy Bentley OF Mission, B.C.

AS AN ALTERNATE PROXY.

WITNESS: Judy Clifford

SIGNED: Margaret Bentley

DATE: Nov. 24, 91

WITNESS: R. Clifford
DIRECT THAT I BE ALLOWED TO DIE AND NOT BE KEPT ALIVE BY ARTIFICIAL MEANS OR "HEROIC MEASURES".

B. NO NOURISHMENT OR LIQUIDS.
Facility refuses to honor
Family loses
DIRECT THAT I BE ALLOWED TO DIE AND NOT BE KEPT ALIVE BY ARTIFICIAL MEANS OR "HEROIC MEASURES".

8. NO NOURISHMENT OR LIQUIDS.
Probably meant this
Take home lesson
If you mean hand feeding, say “hand feeding”
Case 2
PART I: POWER OF ATTORNEY FOR HEALTH CARE

I revoke all prior advance health care directives and durable powers of attorney for health care signed by me. This document shall not be affected by my subsequent incapacity. I am not a patient in a skilled nursing facility, and I am not a conservatee.

1.1 NAME AND ADDRESS OF PRINCIPAL. My name and address are:

Nora R. Harris, 83 Arnold Drive, Novato, CA 94949

PART 2: INSTRUCTIONS FOR HEALTH CARE

2.1 END-OF-LIFE DECISIONS. I direct that my health care providers and others involved in my care provide, withhold, or withdraw treatment in accordance with the choice I have marked below:

a. I Choose NOT To Prolong Life. If I initial this line, I do not want my life to be prolonged and I do not want life-sustaining treatment to be provided or continued if any of the following conditions apply:

(Continue on next page)
Take home lesson
If you mean hand feeding, say “hand feeding”
Would better ADs have helped MB or NH?
Complexities of Choosing an End Game for Dementia

By PAULA SPAN    JAN. 19, 2015
Practical tips
Be very specific on the when
Be very specific on the what.
Tool 1
My Way Cards®
for Natural Dying™

Sort them now to obtain your personal
NATURAL DYING—LIVING WILL

...to let others know EXACTLY what
you will want, if the time comes when
you are too sick to speak for yourself.

© 2009–2011 Stanley A Terman, PhD, MD
I do not seem to know it is me when I look in the mirror. I cannot tell others anything about me. [1.1]
When I see people in my close family or see my best friends, I do not know who they are.

[3.1]
I do not use bathrooms. I let my clothes get wet and dirty. Others must change my diapers (nappies). [4.5]
The way I act now is hurtful or shameful.

I may yell insulting words or take off my clothes in front of strangers.

[4.6]
I cannot remember the important events of my life. If reminded, I don’t know why they are important. [1.2]
I have severe pain. But I cannot say what bothers me.

Doctors don’t see my pain. They do not treat my pain.

[2.6]
Tool 2
Advance Directive for Receiving Oral Food and Fluids in Dementia
Clear definitions and prompts
Tool 3
MY INSTRUCTIONS FOR ORAL FEEDING AND DRINKING
Few other tools
Voluntarily Stopping Eating and Drinking
Conclusion
VSED is important EOL option
Need more education & planning tools