

Voluntarily Stopping Eating & Drinking (VSED)

a lesser known, widely available palliative option of last resort

PANEL

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VSED: Our Agenda

- **Context/Background:** Rob Horowitz, MD, FFAHPM
- **Clinical Aspects:** Judith Schwarz, PhD, RN
- **Legal Aspects:** Thaddeus Pope, JD, PhD, HEC-C
- **Ethical Aspects:** Paul Menzel, PhD
- **Discussion, questions, musings...**
- **Roundtable 3:30p CST: first 20!**



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VSED: Learning Outcomes

1. Understand major clinical challenges of VSED.
2. Appreciate that VSED is a legally permissible end-of-life option.
3. Recognize that VSED is an ethically permissible end-of-life option.

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Voluntarily Stopping Eating & Drinking (VSED)

a lesser known, widely available palliative option of last resort

- a process (typically 7 to 14 days) in which...
- a person with intolerable and intractable suffering...
- makes a capacitated and informed decision to stop eating and drinking ...
- in order to die ("hasten death").

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a lesser known, widely available **palliative option of last resort**

“intervention(s) ...for competent, terminally ill patients who are suffering intolerably in spite of intensive efforts to palliate and who desire a hastened death.”

Quill TE, et al. JAMA. 1997

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a lesser known, widely available **palliative option of last resort**

“intervention(s) ...for competent, ~~terminally ill~~ patients who are suffering intolerably in spite of intensive efforts to palliate and who desire a hastened death.”

1. **Voluntarily stopping eating and drinking (VSED)**
2. Palliative sedation (to unconsciousness)
3. Medical aid in dying (MAID)
4. Voluntary active euthanasia

Quill TE, et al. JAMA. 1997

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| Term | Count |
|------------|--------|
| VSED | 122 |
| Pal Sed | 611 |
| MAID | 7,856 |
| Euthanasia | 29,122 |

| Term | Count |
|------------|------------|
| VSED | 13,400 |
| Pal Sed | 491,000 |
| MAID | 667,000 |
| Euthanasia | 61,200,000 |

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a lesser known, **widely available** palliative option of last resort

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What VSED is NOT:

- Not withholding food/fluid
- Not for everyone
- Not advisable if unsupported
- Not a rapid death
- Not painful
- Not “starving to death”

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The WHY of a VSED choice

- Does not require a terminal diagnosis
- No legal jeopardy for those who remain present
- Similar to 'natural' death
- Does not require physician's permission
- Occurs over time

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Necessary Clinical Precursors

- Thorough exploration of reasons for VSED decision
- Careful capacity assessment
- An appointed health care agent + advance directive to stop food/fluids
- Understanding of VSED process by all involved
- A clinical partner for palliative oversight

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No one wants to be the food/fluid cop

- Plan while patient decisionally capable
- Prepare for potential of patient 'forgetting' decision
- Best fallback position: 'minimal comfort feeding'

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Clinical Management of VSED

Hunger: Generally transient (1-3 days)

Thirst: Generally persistent and progressive

- Moisturizers (saliva subs); sugar-free candies; cool teething ring; gum
- Swish and spit; caution: Ice chips add up quickly!
- Medications: low dose benzodiazepine, +/- opioid usually sufficient

Delirium: May include forgetting or forgoing the plan...

- Reminders, not prohibitions
- Medications: benzodiazepine, antipsychotic, opioid...
- Patient typically slips into coma during final hours-days

Dyspnea, pain, etc: End-of-life symptoms receive "routine" palliative management

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Challenges if patient is NOT terminally ill

- Can be difficult to obtain palliative oversight
- Sometimes patient must fast for several days before hospice agrees
- Duration of process may be longer
- Ought to complete AD to SED while capacitated

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Prerequisites for Successful VSED Outcome

1. The patient with intolerable and intractable suffering is well-informed, decisionally capable and DETERMINED
2. Family or friends understand and support decision, and commit to accompany patient
3. Palliative care oversight manages symptoms, supports patient and family, is poised for challenges
4. All enter the process with **patience** amidst the uncertainties that lie ahead

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Definition of successful VSED outcome

A peaceful death with:

- Minimal discomfort,
- Occurring in a predictable timeframe (days to weeks),
- Supported by good palliative care & psychosocial support

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VSED is legal

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Sizable, settled, & stable consensus

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Roadmap

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Types of proof
VSED is legal

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On-point
precedent

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Right refuse
medical
treatment

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Right refuse
any unwanted
intervention

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Medical
profession
accepts VSED

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No sanctions
imposed

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1 Proof of
legality

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On-point precedent

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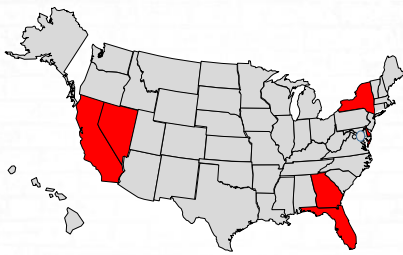
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Multiple appellate court decisions

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Same in other common law countries

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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 directed to the Registry of the Court in which it was generated.

H LTD v J & ANOR

[2010] SASC 176

Judgment of The Honourable Justice Kourakis

15 June 2010

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IN THE SUPREME COURT OF BRITISH COLUMBIA

Citation: *Bentley v. Maplewood Seniors Care Society*,
2014 BCSC 165

Date: 20140203
Docket: S135854
Registry: Vancouver

Between:

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

Petitioners

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Is VSED legal?
Asked &
answered

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2 Proof of
legality

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Right to **refuse**
medical
treatment

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No need for
direct, explicit
authority

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already legal
existing rules

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**Right to
refuse
treatment**

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Ventilator
Dialysis CPR
Antibiotics
Feed tube

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**Right to
refuse
treatment** **VSED**

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Not DIY

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Part of a broader
treatment plan

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Supervised by
licensed healthcare
professionals

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Recognized as
healthcare by
medical profession

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More position
statements

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More clinical
practice
guidelines

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BUT

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Right to
refuse **VSED**
treatment

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Relies on
premise

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Oral N&H =
“treatment”

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Oral N&H ≠
“treatment”

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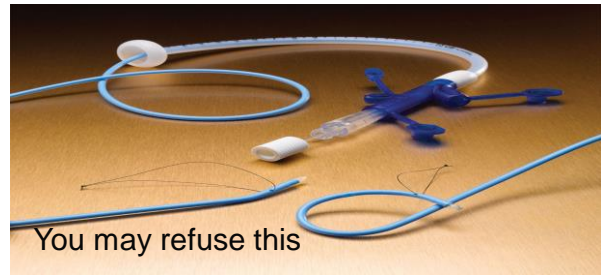
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Basic care

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You may refuse this

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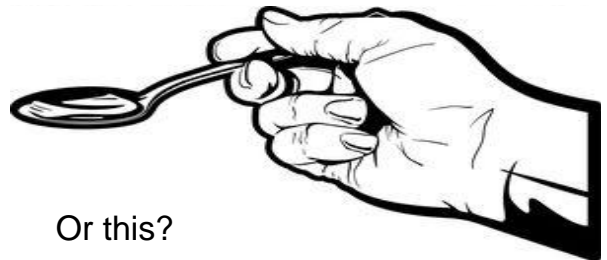
Can you also refuse this?



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Or this?

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Yes

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3 Proof of legality

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Right to refuse **any** bodily intrusion

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Irrelevant whether
food & fluid by mouth
is **treatment**

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Right to refuse **any** intervention (medical **or not**)

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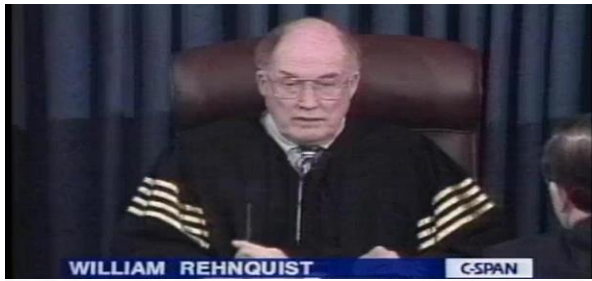
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Right to refuse **any** unwanted contact

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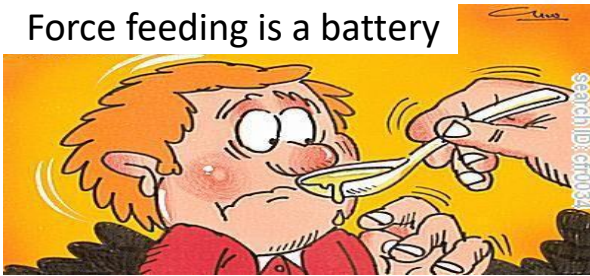
“bodily integrity is violated
... by sticking a **spoon in
your mouth** ... sticking
a needle in your arm”

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Force feeding is a battery



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4 Proof of
legality

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**Medical
profession
accepts VSED**

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Law **delegates &
defers** to healthcare
professionals

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When medical profession says it is appropriate → law often **follows**

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POSITION STATEMENT



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

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Position Paper



Ethical Aspects of Artificially Administered Nutrition and Hydration: An ASPEN Position Paper

Denise Baird Schwartz, MS, RD¹; Albert Barrocas, MD¹

Nutrition in Clinical Practice
Volume 0 Number 0
January 2021 1-14
© 2021 American Society for Parenteral and Enteral Nutrition
DOI: 10.1002/ncp.10633
wileyonlinelibrary.com

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5 Proof of legality

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No sanctions

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VSED used & reported

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Appendix E Personal Narratives

Earlier in this book, we presented nine original, never-before-published cases. We included four VSED cases in Chapter 1 and one more in Chapter 2. We included four SED by AD cases in Chapter 7. But we are not alone. Many individuals have written about their experience or their family member's experience with either VSED or SED by AD. This Appendix includes citations and links to these personal narratives. These are grouped into four sections: (1) books, (2) articles, (3) video and audio recordings, and (4) collections of cases.

I. Books

Brewer, Colin O. 2019. *Let Me Not Get Alzheimer's, Sweet Heaven: Why Many People*

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No liability

No HC licensing board discipline

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Recap

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VSED is legal

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Sizable, settled,
& stable
consensus

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3 minutes

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SED by AD

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What is that?

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Current situation
acceptable

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VSED **not** a
good option

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Not yet
ready to die

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Concerned
about **future**
circumstances

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Lack capacity
at future time

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So →

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What

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- Oral food & fluids
- Nutrition/hydration by mouth
- Hand- feeding
- Spoon- feeding
- Normal feeding

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When

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At point **Pt** specifies

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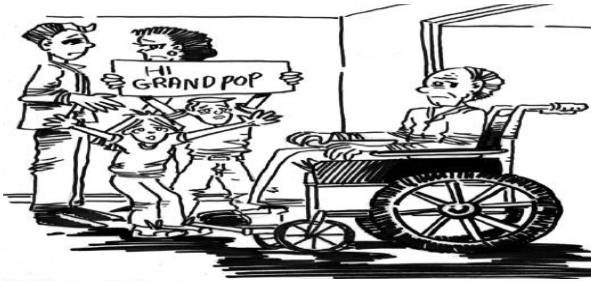
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Images from AD
planning tool

<http://caringadvocates.org/>

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Growingly
popular



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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 my mouth, my soul frozen inside while my life

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Last 4 years

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

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DARTMOUTH

EXPL

The Dartmouth Dementia Directive

An advance care document for dementia care planning

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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.

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Introduction to our Supplemental Advance Directive For Dementia

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NEVADA ADVANCE DIRECTIVE FOR ADULTS WITH DEMENTIA
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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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Surrogate wants
you to honor
AD for SED

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Generally you
should **follow**
advance directives

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AD for SED
valid AD?

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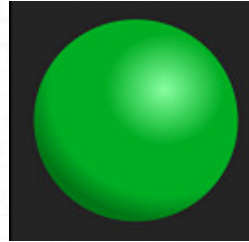


prohibited
unclear
permitted

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Explicitly
permitted

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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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Vermont

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“health care”
“personal
circumstances”

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Vermont § 9702(a)(2)

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“services to assist in activities of daily living”

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Suppose **valid** AD for SED

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incapacitated **veto**

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Whose wishes do you respect?

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prior self
or
current self

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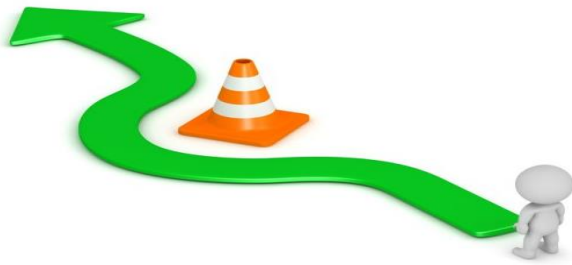
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now patient
or
then patient

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“No assist E&D *even if*
I appear to cooperate
by opening my mouth”

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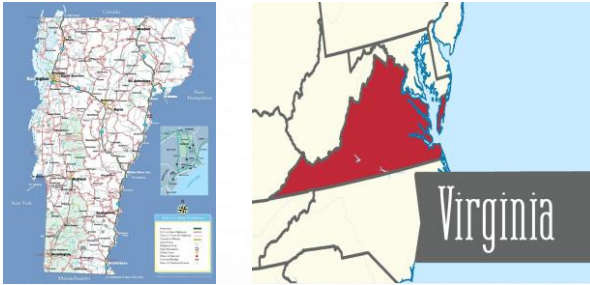
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With Ulysses,
prior self
prevails

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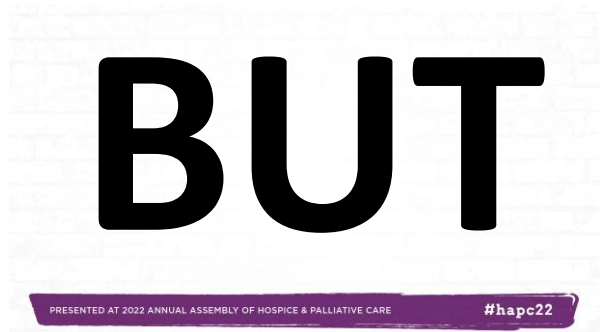
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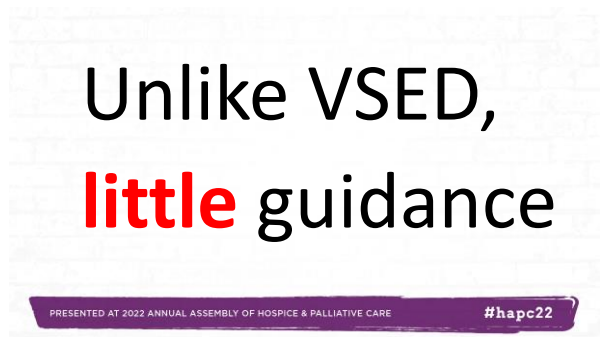
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Few institutional policies & procedures

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Thank you @ThaddeusPope

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VSED: Our Agenda

- **Context/Background:** Rob Horowitz, MD, FAAHPM
- **Clinical Aspects:** Judith Schwarz, PhD, RN
- **Legal Aspects:** Thaddeus Pope, JD, PhD, HEC-C
- **Ethical Aspects:** Paul Menzel, PhD
- **Discussion, questions, musings...**

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Labels: VSED *is* suicide.

- Suicide (def) = intentionally aiming at death + directly causing it
- VSED includes both elements.
- Different than
 - increasing morphine dosage. "Double Effect" – comfort intended, death only foreknown.
 - Refusing lifesaving treatment : one might live.

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Labels: VSED is *not* suicide.

- Associated with despair, irrational pessimism, secrecy, violent means. VSED is none of these.
- Typically seen as tragic. VSED is not, unless one already assumes it is.
- Parallel to MAID (Medical Aid in Dying). When it is permissible, we deem it not to be “suicide.”

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Even if VSED were suicide, would it be wrong?

- If in the circumstances death is not bad, why would it be wrong to
 - hasten it intentionally,*
 - with certainty ensure it, and*
 - be its primary and direct cause ?*
- If anything, wouldn't that be better?

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Assisting VSED

- Might it be wrong to *assist* a VSED, though not wrong for the patient to do it?
(Parallel in law: suicide, and assisting suicide.)
- VSED is better than just *not wrong* for person to do. VSED is patient's *moral and legal right*.
- If clinicians do not support it, they are failing to support patients in exercising their rights.

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Informing Patients of Option

1. Don't inform of VSED option:
 - VSED not a standard-of-care option.
2. Inform only if patient asks:
 - Danger of pressure if patient doesn't ask.
 - But patient may not know of option.
3. Always inform:
 - One of their legal options.
4. Use discretion (conflicting elements).

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Advance Directives for SED: change of mind? not same person?

Patient swallows food that's offered:

- She's not changed her mind *about her AD*.
- Her AD is still her AD. She is not a numerically different person, but still person who wrote AD.
 - Persons have “temporal extension” – fundamental to being a person.

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ADs for SED: then-self vs. now-self

AD from then-self now in conflict with now-self who

- wants to eat
- doesn't care about autonomy
- doesn't remember AD.
- But she is still person who wrote AD with a view about her life – which is now still her life.
- Must never treat her as if she was never competent – whole basis of ADs.
- Problem not unique to ADs for SED.

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ADs for SED: How to ...

Address:

- What to withhold, and when
- Palliative support options
- What to do if contrary desires are expressed
- Who is to interpret the above
- APPOINT A PROXY with authority to interpret and implement

Communicate with family & primary providers

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Voluntarily Stopping Eating & Drinking (VSED)

a lesser known, widely available palliative option of last resort

- **Context/Background:** Rob Horowitz, MD, FFAHPM
- **Clinical Aspects:** Judith Schwarz, PhD, RN
- **Legal Aspects:** Thaddeus Pope, JD
- **Ethical Aspects:** Paul Menzel, PhD
- **Take-homes, questions, musings...**

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VSED: Take-home Points

1. VSED enables a peaceful death for persons with intolerable and intractable suffering.
2. Successful VSED requires a decisionally capable, determined, informed person with excellent multidimensional support.
3. VSED is a legally permissible end-of-life option in all U.S. jurisdictions.
4. The validity of stopping eating & drinking by advance directive varies from state to state.
5. Assisting VSED is not unethical assistance in a suicide.
6. Generally, patients with intolerable and intractable suffering should be informed of the option of VSED, but judgment should be used.

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VSED: Selected References

1. Quill, T.E., Menzel, P., Pope, T., Schwarz, J. (2021). *Voluntarily Stopping Eating and drinking: A Compassionate, Widely Available Option for Hastening Death*, Oxford University Press.
2. Charget, J., Rosielle, D. A., & Marks, A. (2019). Voluntary stopping of eating and drinking in the terminally ill #379. *Journal of Palliative Medicine*, 22(10), 1281-1282.
3. Gruenewald, D. A. (2018). Voluntarily stopping eating and drinking: A practical approach for long-term care facilities. *Journal of Palliative Medicine*, 21(9), 1214-1220.
4. Christenson, J. (2019). An ethical discussion on voluntarily stopping eating and drinking by proxy decision maker or by advance directive. *Journal of Hospice and Palliative Nursing*, 21(3), 188-192.
5. Lowers, J., Hughes, S., & Preston, N. J. (2021). Overview of voluntarily stopping eating and drinking to hasten death. *Annals of Palliative Medicine*, 10, 3611-3616.
6. Gruenewald, D. A., & Vandekieft, G. (2020). Options of last resort: Palliative sedation, physician aid in dying, and voluntary cessation of eating and drinking. *The Medical Clinics of North America*, 104(3), 539-560.
7. Stangle, S., Schnepf, W., Büche, D., & Fringer, A. (2020). Voluntary stopping of eating and drinking in Swiss outpatient care. *Geropsych, 34(2)*, 73-81.
8. Quill, T. E., Ganzini, L., Truog, R. D., & Pope, T. M. (2018). Voluntarily stopping eating and drinking among patients with serious advanced illness—clinical, ethical, and legal aspects. *JAMA Internal Medicine*, 178(1), 123-127.
9. Stangle, S. (2021). Occurrence, experiences and attitudes about and the professional handling of voluntary stopping of eating and drinking: A convergent mixed methods study of people involved in Switzerland. Inaugural Dissertation, Witten/Herdecke University, Faculty of Health, Department of Nursing Science.

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Voluntarily Stopping Eating & Drinking (VSED)

a lesser known, widely available palliative option of last resort

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