

## Voluntary Stopping Eating and Drinking (VSED)

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## Legal and Ethical Definitions

### Definition - VSED

**When a person  
—physically capable of taking nourishment—  
makes the decision to stop all oral intake with the  
goal of dying**

- Death is usually within 2 weeks.
- Legal under the principle of autonomy and the right to privacy.
  - Bouvia v. Superior Court, California Court of Appeals, 1986
  - State of Georgia v. McAfee, 1989

### VSED vs. Anorexia

- Voluntary refusal of eating and drinking is distinct from the anorexia—loss of appetite—seen in advanced disease and terminal illness.
- Loved ones mistake anorexia for voluntary refusal.
- We have a duty to educate patients and their families about anorexia in advanced disease and at end of life.

### Definition - Physician-Assisted Dying

- Physician provides the means by which a patient can end his or her life. This is usually a prescription for a large dose of barbiturates.
- Medical personnel do not need to be present—and usually prefer to be absent—for the act.
- Legal in Oregon and Washington.
- Allowed in Montana by case law.

### Definition - Euthanasia

- Greek = “Good Death”
- “The act or practice of killing or permitting the death of hopelessly sick or injured individuals (as persons or domestic animals) in a relatively painless way for reasons of mercy.”
  - Merriam-Webster's Collegiate Dictionary, 11<sup>th</sup> Ed.
- Euthanasia is not legal in the United States.

## Patient Right: Autonomy

### Autonomy

- “Every human being of adult years and sound mind has a right to determine what shall be done with his own body; and a surgeon who performs an operation without his patient’s consent, commits an assault.”
  - Scholendorff v. Society of the NY Hospital, 1914
- “It is the individual who is the subject of a medical decision who has the final say”
  - In this case, the right of a patient to refuse a potentially life-saving blood transfusion was upheld.
    - Erickson v. Dillgard, 1962

## Positions on VSED

## Position Statements on VSED

- AAHPM: VSED mentioned as a legal option in a statement on physician-assisted death.
- ACP-ASIM: “Responding to intractable terminal suffering: the role of terminal sedation and voluntary refusal of food and fluids.” Presented as legal alternatives to physician-assisted suicide.
  - Quill, T.E., & Byock, I.R. (1997)
- NHPCO: Brief affirmation of right to VSED in a statement on artificial nutrition and hydration at end of life.

## Position Statements on VSED

- HPNA: Mentions the right to refuse nutrition in a position statement on Artificial Nutrition and Hydration.
- American Nurses Association (ANA): “The acceptance or refusal of food and fluids, whether delivered by normal or artificial means must be respected” (2011).
  - This statement is consistent with the ANA’s expressed values and goals relative to respect for autonomy, relief of suffering and expert care at the end of life.

## Objections to VSED

- VSED is suicide, and suicide is wrong.
- Patients will learn of this option from their clinical team, so the clinical team is, in effect, recommending and supporting a suicidal act.
- VSED is not a “natural death.”
- VSED violates the principal of prolonging life and the sanctity of life.
- VSED is painful.

## Is VSED Suicide?

### Definitions of Suicide

- Deliberate killing of oneself
  - Derivation: suicidium “suicide,” from L. sui “of oneself” (gen. of se “self”) + -cidium “a killing”
- The act or an instance of taking one’s own life voluntarily and intentionally especially by a person of years of discretion and of sound mind
- Death caused by self-directed injurious behavior with any intent to die as a result of the behavior

## Is VSED Suicide?

“When VSED brings about death, the patient has introduced a fatal cause, dehydration, so the conduct has an element of suicide, absent when the patient merely rejects treatment.”

- Cantor, N.L. & Thomas, G.C. (2000)

## A Good Death

## A “Good” Death

- Free from avoidable distress and suffering for patients, families, and caregivers;
- In general accord with patients' and families' wishes;
- Reasonably consistent with clinical, cultural, and ethical standards
- Factors important for a good death include:
  - Control of Symptoms
  - Preparation for Death
  - Opportunity for closure or "sense of completion" of the life
  - Good relationship with healthcare professionals

*An appropriate death is a death that someone might chose for him or herself if he/she had the choice.*

- Institute of Medicine (1997)

## A “Good” Death

- To be able to retain control of what happens
- To be afforded dignity and privacy
- To have control over pain relief & other symptoms
- To have access to spiritual or emotional support
- To have control over who is present & shares end
- To have time to say goodbye, and control over other aspects of timing
- To know when death is coming, and to understand what can be expected
- To be able to leave when it is time to go, and not to have life prolonged pointlessly

- Smith, R. (2000)

## Attributes of a “Good Death”

(in order of frequency in the literature)

<b>being in control</b>	<b>beliefs and values honored</b>
<b>being comfortable</b>	<b>burden minimized</b>
<b>sense of closure</b>	<b>relationships optimized</b>
<b>value of the dying person affirmed</b>	<b>appropriateness of death</b>
<b>trust in care providers</b>	<b>leaving a legacy</b>
<b>recognition of impending death</b>	<b>family care</b>

- Kehl, K. (2006)

## Good Death, VSED, and Suicide

- “It is not right to impose a definition of an appropriate death on others. What is right for one person is not necessarily right for another.”
  - Lester, D. (2005)
- “Common sense supports thinking that dying too late can be a harm just as dying too soon can be. When death is the least-bad thing that can happen to a person, and nothing better can happen to him, it benefits him”
  - Stell, L. (1998)
- “Some self-killings could be construed as justifiable - as acts of self-defense against intolerable life circumstances or irremediable suffering”
  - Attig, T. (2005)

## VSED as Good Death

VSED is:

- Inherently deliberate; not impulsive or capricious.
- Inherently collaborative.
- Recognized as consistent with current medical, moral and legal practices.

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## Case Study 1: Mrs. C.

## History & Progression of the Illness

- 85 year-old woman diagnosed with lung cancer metastatic to the brain
- Refused repeat biopsy when the first one was negative
- Admitted to home hospice 2 weeks later
- She is ambulatory, independent in self-care, has a good appetite

## Social History

- Mrs. C. is a retired artist, lives alone.
- She is divorced, single, and has no children or close blood-relatives.
- Her proxy and POA is a former mentee.
- Middle to upper-middle class
- Atheist
- Deceased father was a member of the Hemlock Society.

## Course on Hospice

- She is homebound due to balance problems; cognitively intact; visual impairment worsening
- Over next 2 months, more difficulty ambulating, expressive aphasia, functional decline; Low-dose steroids started
- Appetite remains good
- With social worker reviews life and important relationships

## Choosing VSED

### Frustration

- During a physician visit, Mrs. C. expresses frustration at how long it is taking her to die.
- Euthanasia, physician-assisted suicide, and voluntary stopping eating and drinking are discussed.
- Pt's friend is given the name of Compassion and Choices.

### Decision

- MD asks Mrs. C. to wait for steroid taper.
- Mrs. C. does not, and stops eating 2 days later.
- She asks to be sedated on day 2 of her fast.
- She is medicated for agitation, but not with the goal of sedation.
- On day 3 she has more pain, which is relieved by sublingual morphine.

## End of Life

- She develops sacral erythema on day 3.
- She is less responsive on day 3 and last talks on day 4.
- She dies at 1:30 am on day 7.
- Proxy's evaluation of hospice mentions their frustration that the patient was not informed of the VSED choice earlier.

## Case Study 2: Mr. R.

## History & Progression of the Illness

- 83 year-old Polish man
- Diagnosed with an epiglottic tumor in 2008 (head and neck cancer)
- Prostate ca hx
- Coronary artery disease, BPH, legally blind
- Treated with 3 surgeries and chemotherapy
- Declined another surgery offered after he signed on to hospice on 8/11/10

## Social History

- Religion: Catholic
- Father was Jewish and died in the Warsaw Ghetto.
- Patient was a partisan fighter; his Catholic mother and sister also survived the war.
- Worked in the Merchant Marine and as a ship painter. He is a US veteran.
- Late in life married a Polish woman 27 years his junior. Wife works cleaning offices.
- **Low socio-economic class and socially isolated**

## Course on Hospice

- Occasional confusion and forgetfulness
- Depression, not on medications
- Does not express suicidal ideation.
- Chronically bleeding right neck mass
- Chronic Foley catheter
- Patient is withdrawn, preoccupied with his Foley catheter.

## Not Informed of Options

- During a patient visit on 9/17, RN speaks with NP at the VA and Effexor is ordered.
- On 9/18 the patient's wife comes home and finds the patient dead, sitting on the bathroom floor, with a belt around his neck.
- She removes the belt, then calls 911.
- Does not tell anyone about the belt until the RN and SW make a bereavement visit 2 days later.
- She expresses disbelief, anger, and guilt.

## Social Perceptions of Suicide

- Suicide implicates tragic, stigmatizing paradigms - lonely, uncared for person committing an act of desperation based on an inaccurate evaluation about the future (Stell, L 1998)
- “Suicide acts are expressions of despair and futility that are secretive, impulsive, and often violent in nature “ (Lieberman, EJ 2006)

## Case Study 3: Dr. M.

## Medical and Social History

- |   |   |
|---|---|
| <ul style="list-style-type: none"><li>• 66 year-old woman</li><li>• Diagnosed with Amyotrophic Lateral Sclerosis 14 years ago</li><li>• Non-ambulatory, communicates via computerized device, eating puree diet</li><li>• Uses non-invasive positive pressure ventilation for 4-5 hours daily to relieve fatigue and headache</li></ul> | <h3>Social History</h3> <ul style="list-style-type: none"><li>• Retired from her job as a university professor 4 months before admission to hospice</li><li>• Admitted to home hospice in March</li><li>• Divorced</li><li>• No religious affiliation</li></ul> |
|---|---|

## Course on Hospice

- Baclofen and Aspercreme PRN started for neck and shoulders with some relief.
- In July, Dr. M. agrees to start PRN oxycodone elixir with some relief of pain.
- In August patient has an episode of dyspnea, decreased responsiveness, and pallor.
- Episode related to anxiety over effort required for thrice weekly shower.

## Choosing VSED

### Early Conversation

- Worsening discomfort in neck and shoulders due to effort needed to sit up and to communicate.
- Increasing difficulty swallowing
- Eating is not pleasurable.
- In June, she asks about ending her life. Nurse advises her that voluntarily stopping eating and drinking is a legal option
- Aggressive symptom management continues

### Decision

- In September, Dr. M. asks about ending her life.
- She is reminded of the option to VSED.
- She decides to do this and her mood becomes upbeat.
- Her daughter returns from overseas.

## Preparation for VSED

- For 2-3 weeks, family members and friends made scheduled good-bye visits.
- More aides are hired for 24-hour care.
- RN reviews care plan with patient, family, and caregivers, including Dr. M's wishes should she become delirious and request food.
- On Monday, patient stops eating and drinking.
- All oral medications are discontinued.

## End of Life

- Day 1: Dr. M. has an increase in pain and takes 4 doses of oxycodone elixir.
- Day 2: Skin breakdown evident.
- Day 3: She remains lucid. Pain is still an issue. She does not c/o hunger.
- Day 4-5 (overnight): Dr. M. is delirious and asks for food.
  - Aide gives her something to drink.
- Day 6: Her bladder is distended and urine output minimal.
  - On-call nurse places a Foley.
- Day 7: Dr. M. dies at 5 pm, at home, with family and friends at the bedside.

## Depression and VSED

## Rational Decision-Making

- Can a depressed patient make a rational decision for VSED?
- Does a depressed person lack capacity to make health care decisions?

## Capacity & Principles of Bioethics

- In the case of an incapable patient, the principle of autonomy may not apply.
- The principles of beneficence/non-maleficence require that incapable people be protected from making decisions that are harmful or that they would not make they had capacity

## Depression

### DSM-IV Criteria for Major Depressive Episode

- Depressed mood
- Markedly diminished interest or pleasure in all or almost all activities
- Significant (>5% body weight) weight loss or gain, or increase or decrease in appetite
- Insomnia or hypersomnia
- Psychomotor agitation or retardation
- Fatigue or loss of energy
- Diminished concentration or indecisiveness
- Recurrent thoughts of death or suicide
  - Any or all of the above are often seen in terminally ill patients.

## Grief vs. Depression in Terminally Ill Patients

### Characteristics of Grief

Results from particular loss

Associated with disease progression

Patients retain capacity for pleasure

Grief comes in waves

Patients explore passive wishes for death to come quickly

Patients are able to look forward to the future

### Characteristics of Depression

Disease is generalized to all facets of life

Increased prevalence in patients with advanced disease  
Patients enjoy nothing

Depression is constant and unremitting

Patients express irritable & paranoid suicidal ideation

Patients have no sense of positive future

- Block, S. (2005)

## Assessing Depression

- Are you depressed?
  - What do you imagine is ahead of you with your illness?
    - measuring hopelessness
  - What are you most troubled by?
    - assessing sense of burden and guilt
  - What are you still able to enjoy?
    - assessing ability to feel pleasure
  - Using the self as diagnostic clue
    - Mirroring
- Chochinov, H.M. Wilson K., Enns G., et al. (1997)

## Practical Considerations

## Assessing Capacity

- Is the patient able to understand condition, proposed treatment and alternatives?
- Is the patient able to process information such as weighing the benefits and burdens of treatment or lack thereof?
- Is the patient able to articulate the relationship between personal values and the discussed choice?
- Is the patient able to communicate her voluntary decision?
- Is the patient's expressed wish consistent over time - i.e., not influenced by fleeting states that might impair capacity such as delirium, drugs, **depression**?

## Assessing Capacity

### Aid to Capacity Evaluation (ACE)

- Ability to understand medical problem
  - Ability to understand proposed treatment
  - Ability to understand alternatives (if any)
  - Ability to understand option of refusing treatment
  - Ability to appreciate reasonably foreseeable consequences of accepting or refusing proposed treatment
  - Ability to make decision not substantially based on delusions or depression
- University of Toronto's Joint Center for Bioethics (1996)

## Depression as Impediment to Capacity?

- Although fears of pain or suffering are frequently mentioned ... [as] reasons why people would request assisted suicide, research indicates that when people are actually facing death, these are not the primary motivators for these requests... **neither is clinical depression...**
  - Werth J.J., Gordon J.R., Johnson R.R. (2002)
- In major depression of mild to moderate severity, a patient's preferences regarding life-sustaining treatment are **NOT** significantly influenced by depression and **unlikely to change** with depression treatment
  - Kusz, H. & Dohrenwend, A. (2009)
- Although relatively high levels of depression and anxiety have been associated with decreased problem-solving, **clinical depression does not necessarily make a person incapable of making health care decisions.**
  - Sullivan, 1998 in Werth et al. (2000)

## Assessing VSED Requests

- Are we doing everything we can to make this patient comfortable, physically and spiritually?
- Are there any medical contraindications to VSED?
- Medication changes needed?
- Have we evaluated capacity and mood?
- Does the patient have unfinished business?
- Refer to advocacy group, such as Compassion and Choices.

## Considerations & Clinical Issues

### Practical Considerations

- Is there social support for VSED?
- Practical support at the bedside, custodial care?
- Educate patient and caregivers about what happens to the patient and symptom control.
- Clinicians available and willing to treat symptoms?
- Hospice care
- Affairs in order and funeral arrangements?

### Clinical Issues

- Stop all oral intake to minimize hunger pains.
- Sublingual medication administration continues.
- Provide good oral care; dry mouth is not relieved by fluids.
- Skin breakdown may occur as systems shut down.
- Urinary retention occurs at end of life or from opiates.
- Delirium

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