

Voluntarily Stopping Eating and Drinking (VSED): Clinical Guidelines

presented by members of

The VSED Clinical Guidelines Writing Group

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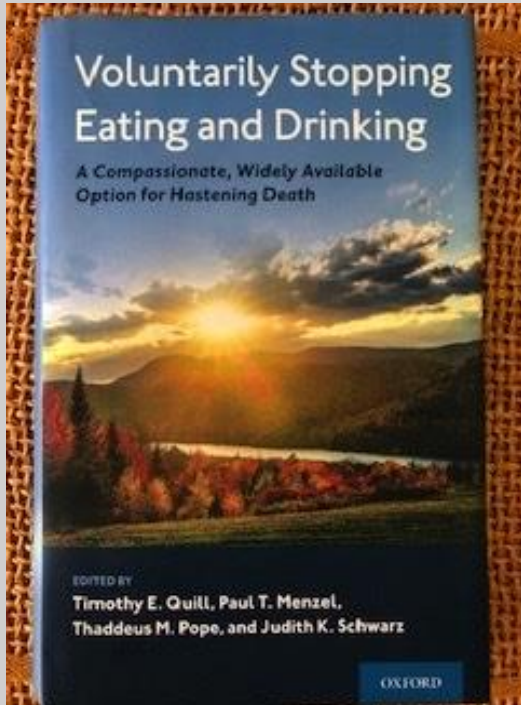
Nancy Simmers, RN

The Portland All-City Palliative Care Lecture Series 2023

Portland, Oregon

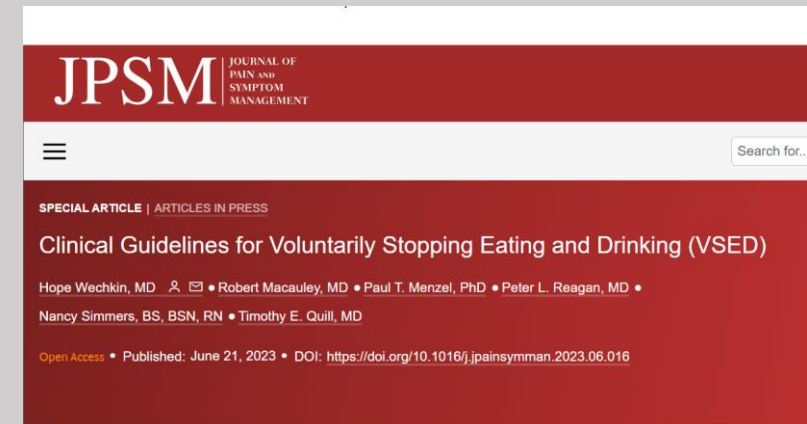
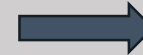
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Who We Are



The VSED Clinical Guidelines Writing Group

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What We'll Discuss

- Definition of VSED
- Comparison of Medical Aid in Dying (MAiD) with VSED
- Preparation for VSED
- Considerations when VSED Has Been Chosen
- Stages of VSED
- Addressing Ambivalence
- After VSED
- Ethical Considerations
- (V)SED by Advance Directives

Robert

- 73-year-old retired architect with Progressive Supranuclear Palsy (PSP)
- Referred to Palliative Care clinic by neurologist
- Inquired about eligibility for medical aid in dying (MAiD)
- Prognosis: approximately 3 years
- Voluntary Stopping Eating and Drinking (VSED) introduced



Francisco de Goya, *Self Portrait with Dr. Arrietta*

Robert



Lovis Corinth, *Vater Franz Heinrich Corinth auf dem Krankenlager*, 1888

- Returned to Palliative Care clinic every 3 months with family
- Date chosen to stop eating and drinking; met with Palliative Care physician 2 weeks prior to confirm decision
- Admission to Hospice planned for day after VSED started
- Received medical, nursing, social work, CNA and chaplain support from Hospice
- Died at home surrounded by family 11 days after VSED initiated, 10 months after first Palliative Care visit
- Wife received bereavement support from Hospice

VSED: A Definition

A deliberate, self-initiated action by patients **with decision-making capacity** to hasten death in the setting of suffering refractory to optimal palliative interventions, prolonged dying that the person finds intolerable, or expected deterioration or suffering, due to an irreversible illness, that the person regards as unacceptable.

J Am Geriatr Soc 2018 Mar; 66(3):441-445. doi: 10.1111/jgs.15200.



Laurits Andersen Ring, *The Sick Man*

VSED: What It's Not



- Decreased oral intake as a natural result of disease
- Comfort Feeding Only
- Voluntary Stopping Eating and Drinking by Advance Directive
- Medical Aid in Dying (MAiD)

MAiD vs. VSED

	Medical Aid in Dying (MAiD)	VSED
Required prognosis	6 months or less	None specified
Required participation of medical providers	1 prescribing physician; 1 consulting physician	None required
Average time to complete	15 days + average 30 minutes following ingestion (except with exemption)	Average 10-14 days
Average cost	\$700 + (medications)	\$0 - \$2000+ (doula support)
Clinical burden in addition to disease burden	Usually low	Variable; generally higher than MAiD
Prevalence	431 prescriptions written, 246 known ingestions (Oregon, 2022)	Unknown
Legal structure regarding suicide/death certificate completion	Clear	Unclear

Initial Considerations



Lauren Schwartz, *The Decision*

- Current Symptom Management
- Prognosis without VSED
- Prognosis with VSED (Range: 3-21 days; average 10-14 days; underlying clinical status has an effect)
- Decisional Capacity
 - an understanding of the **underlying diagnosis and prognosis without VSED**
 - an understanding of the **potential physical challenges** associated with VSED, including thirst and dryness of the mouth and throat, and the extent to which they can be managed
 - **consistency over time** in choosing to pursue VSED
 - an understanding of the **social and emotional challenges** that may accompany VSED

Further Considerations

Clinical Considerations

- Continuation of pre-VSED medications necessary for comfort/withdrawal prevention (i.e. anti-depressants, Parkinson's medications, steroids, etc.)

Family, Social, and Caregiving Support

- Coordination (consider Doula support)
- Expect 24/7 care required x several weeks
- Consider hired caregivers, hospice and doula support
- Family/friends' understanding of and support for VSED

Religious and Spiritual Context

- Role of faith community
- Beliefs, traditions and practices around dying and death

Location

- Private home vs. institution



Abbie Rabinowitz, *Care*

Hospice Involvement



Edvard Munch, *The Infirmary at Helgelandesmoen*

- Early research and discussion with hospice agency
- Hospices differ regarding when in the VSED process they will accept patient onto service
- Clear communication with patient/family regarding Hospice's role

Getting Organized

- POLST: DNR, Comfort Measures
- Consider supplementary Advance Directive for VSED and/or video
- Durable Power of Attorney: Ensure understanding and support
- Consider contacting patient advocacy organization, possibly death doula



Gilles Crann Piorr'art, *Paperwork*, 2021

VSED Phases

Phase 1

Approx. Days 1-4

- Symptoms of anxiety, restlessness, silence, perhaps shortness of breath
- Celebrations and goodbyes
- Possible reconsideration of decision and option to stop process

Phase 2

Approx. Days 5-9

- Most difficult phase
- Thirst increases, some delusion, some loss of capacity, potential agitation
- Remain in bed - weakness
- Symptom management important and essential
- Point where one must move forward through process

Phase 3

Approx. Days 10-14

- Body is actively dying
- Asleep majority of time, may move into coma
- Ongoing holistic care and comfort measures for symptoms
- Focus moves to those losing a loved one
- Begin acting on plans for final passing



Cliff Joseph, *Ancestral Affirmation*, 1987

After Death



Edvard Munch, *Death in the Sickroom*, 1895

- Death Certificate
 - Cause of Death: Dehydration/Inanition, secondary to _____ (underlying condition)
- Family/Caregiver Bereavement
 - May have features specific to circumstances surrounding death
- Professional staff support

The Role of a Death Doula



Tobias Fonseca, *Flower Heart Spring*

- **Non-medical team member**
- Tracks the **big picture** of the process
- **Advocates** for the dying person
- **Collaborates & communicates** with all care team members
- **Facilitates** a holistic approach and identifies resources
- Sets an atmosphere of peace & calm and **follows** the client's desires
- **Continually assesses** needs of the client, family and care team
- **Educates** family about VSED, dying process, after-death options
- **Problem solves** the unexpected as it happens

Lessons Learned

- Every individual is unique; as is each VSED case
- VSED not to be entered into lightly; it's a marathon
- Plan and prepare as best we can; trust the process
- Communication paramount with all who are involved
- Particular issues: safety, comfort, level of sedation, fluid intake
- Significance of hospice involvement & collaboration
- Practice ahead of time: mouth care, requests for water
- Expect the unexpected



Art Class Oil Painting teacher and Art Students, 1900

Addressing Ambivalence

When decision making capacity is present:

- Expect and prepare for requests for food/drink
- Identify primary person to respond
- Reminders
- Video

When decision making capacity is absent:

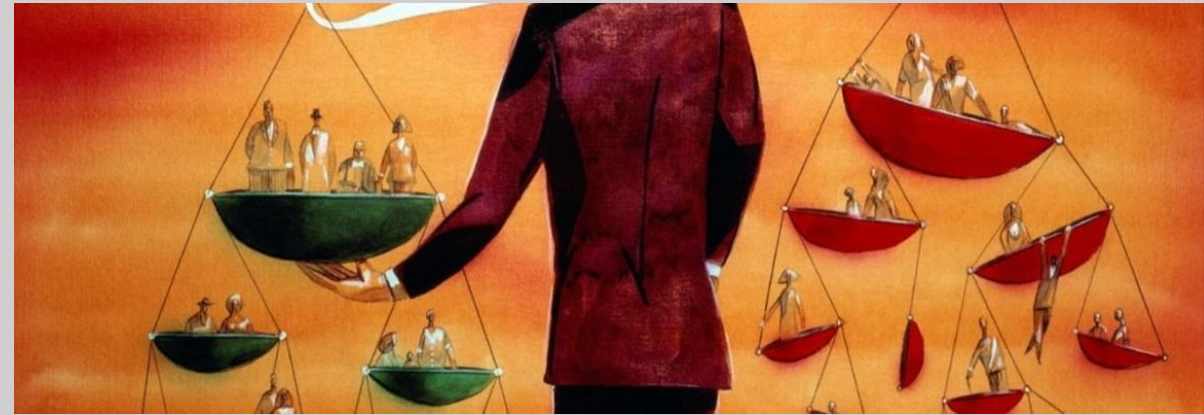
- Start with measures above
- Offer ice chips
- Offer small amounts of fluid
- Err on the side of rehydration



Pablo Picasso, *Science and Charity*, 1897

Ethical Considerations with VSED

- **Respect for Autonomy vs. Non-maleficence**
- **Prognosis:** The longer the prognosis, the greater the ethical complexity
- **Ambivalence:** Capacity and intent may change over time
- **Underlying mental illness**
i.e.: Patients for whom provider and/or hospice has not supported VSED:
 - 65-year-old woman with history of CVA, untreated major depression, suicidal ideation
 - 60-year-old man with history of complex pain and suicidal ideation
 - 74-year-old man with Parkinson's disease and suicidal ideation
 - 85 year old woman with untreated depression



The Next Frontier: (V)SED by Advance Directive

“One option for ensuring that one does not live years in severe dementia is to use advance directives to withhold food and water by mouth. The driving element behind VSED is that forcing people to ingest food is as objectionable an intrusion on bodily integrity, privacy, and liberty as imposing unwanted medical treatment. Thus, if incompetent people do not lose their rights to refuse life-saving treatment, and if people when competent have just as strong a right to VSED as they do to refuse life-saving treatment, then people do not lose their right to VSED when incompetent either. They only have to exercise it by AD.”

Paul T. Menzel and M. Colette Chandler-Cramer, “Advance Directives, Dementia, and Withholding Food and Water by Mouth,” Hastings Center Report, 12 May 2014.

SED by AD in Practice: Some Questions

- Is providing food and hydration really medical care?
- “Then-self” vs. “Now-self”
- How is contemplation different from initiation? Should they be given the same weight?
- What about the moral distress of caregivers, including professional caregivers?
- Do behaviors reflect a desire or a reflex?
- Shouldn't “Comfort Feeding Only” be sufficient? (This is the position of the Society for Post-Acute and Long-Term Care Medicine.)
- Does SED by AD make “pre-emptive VSED” or suicide less likely to occur?



Agnieszka Dolata, *Uncertainty*

Questions for Discussion



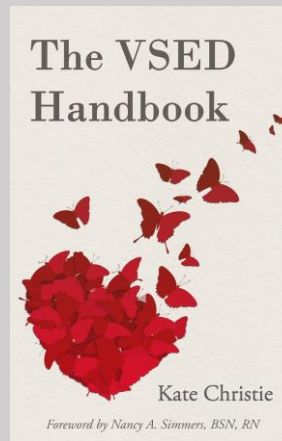
Jaruwat Normrubporn, *Orange Dress in Cafe*

- What barriers (if any) exist in your community/healthcare system for patients who wish to pursue VSED?
- What concerns (if any) do you have about VSED? About SED by AD?
- What else?

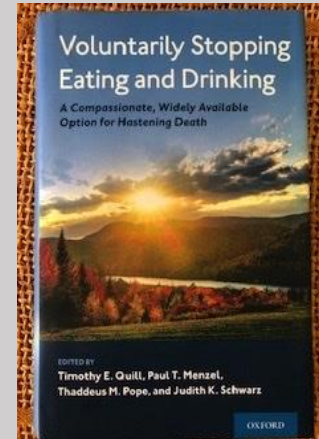
VSED Resources



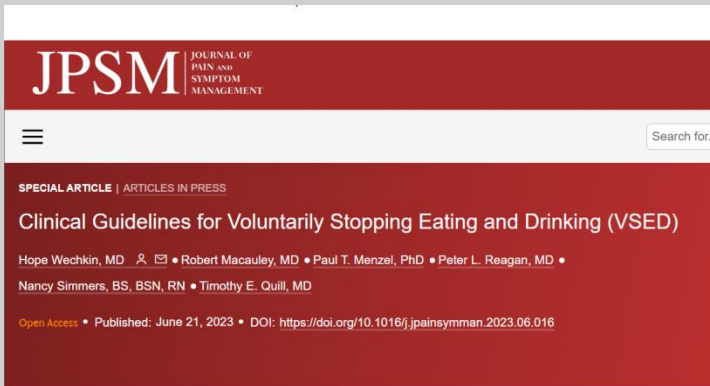
VSED Resources Northwest
VSEDresources.com
360.9196363



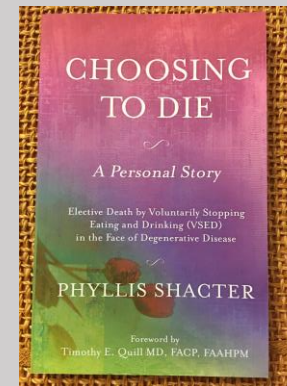
The VSED Handbook, by Kate Christie
Orderable through Amazon and
VSED Resources NW, \$15



Voluntarily Stopping Eating and Drinking,
ed. Quill, Menzel, Pope and Schwarz
Orderable through Oxford University Press,
\$65



Clinical Guidelines for Voluntarily Stopping Eating and Drinking (VSED),
Journal of Pain and Symptom Management
[https://www.jpasmjournal.com/article/S0885-3924\(23\)00565-1/fulltext](https://www.jpasmjournal.com/article/S0885-3924(23)00565-1/fulltext)



Choosing to Die, by Phyllis Shacter
Available through Village Books,
Bellingham WA, \$16