

Special Article

Clinical Guidelines for Voluntarily Stopping Eating and Drinking (VSED)



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Abstract

As the care of patients with serious illness increasingly emphasizes clarifying goals of care, exploring quality of life, and minimizing patients' symptom burden, voluntarily stopping eating and drinking (VSED) has emerged as a topic of increasing interest for patients who face a diminishing quality of life. It is an option for those with serious illness that is legal in every state in the country, but for which there are few published comprehensive guidelines—and none specific to the American medical system—even as public awareness and the number of inquiries regarding this action increase. In addition to the ethical questions raised by the practice and support of VSED, there are also clinical, logistical, institutional, social, religious, spiritual, and administrative considerations for clinicians who are asked to respond to patients' inquiries about VSED and who discuss this option in end-of-life care. With these clinical guidelines, we seek to provide practical recommendations for clinicians who consider providing support to their patients who contemplate and/or undertake this effort to hasten death. J Pain Symptom Manage 2023;66:e625–e631. © 2023 The Authors. Published by Elsevier Inc. on behalf of American Academy of Hospice and Palliative Medicine. This is an open access article under the CC BY-NC-ND license (<http://creativecommons.org/licenses/by-nc-nd/4.0/>).

Key Words

Voluntarily stopping eating and drinking (VSED), clinical guidelines, quality of life, patient autonomy, hastened death, end of life (EOL)

Key Message

These are the first published comprehensive clinical guidelines for voluntarily stopping eating and drinking (VSED) in the United States.

Introduction

With palliative care's growth around the world over the last several decades, the care of many individuals with serious illness has increasingly focused on clarifying their goals of care and attending to their pain and nonpain symptoms. As discussions about quality of life have become more common, so too have patients' questions regarding their options for avoiding an existence characterized by what they determine to be an unacceptable quality of life. A growing number of

patients, family members, and clinicians have inquired about the option of voluntarily stopping eating and drinking (VSED), and while there are no laws preventing a person from taking this action, there are also no published comprehensive guidelines in the United States or Great Britain to assist clinicians when responding to inquiries about this option.¹

As a group of clinicians and academicians from across the United States, we have fielded many inquiries about VSED and have come to recognize the need for pragmatic guidance for clinicians on this topic. In response to this need, we developed a set of clinical guidelines that provides practical assistance for clinicians practicing in multiple settings and specialties. Considerable debt is owed to the Royal Dutch Medical Association (KNMG) and the Dutch Nurses' Association (V&VN) which have published a comprehensive

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guide for physicians, nurses, and other caregivers to help them in assisting patients who aim to hasten death by stopping eating and drinking.² The following clinical guidelines were developed in part to adapt this work to the American context, in which laws (such as those pertaining to medical aid in dying, not to mention euthanasia), institutional structures (such as the hospice system of care and long-term care facilities), and attitudes differ from those in the Netherlands.

Because our aim was to develop practical guidelines that could be used efficiently by busy clinicians, our work group included both academicians (P. T. M., R. M., and T. E. Q.)—the latter two of whom also worked extensively in both palliative medicine and clinical ethics—as well as nonacademic clinicians. These clinicians have worked for many years with patients seeking assistance with VSED and include a family physician (P. R.), a palliative medicine physician and hospice medical director (H. W.), and a nurse doula who has attended the deaths of many patients who completed VSED and who frequently receives inquiries from patients and clinicians regarding this practice (N. S.). T. E. Q. and P. T. M. are also two of the coeditors of a recent textbook analyzing VSED from clinical, ethical, legal, and institutional perspectives.³

After performing a comprehensive literature review, our group met 18 times between February 2022 and May 2023 to prioritize and develop these guidelines. On two separate occasions, we submitted our guidelines for review to colleagues with expertise in law (Pope), clinical medicine (Gruenewald, Horowitz, Sandler), public policy (Miller), and biomedical ethics (Diekema, Tate).

Definition of VSED

VSED is a deliberate, self-initiated action by a patient with decision-making capacity (DMC) 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.⁴ This action is typically undertaken by a patient with a serious illness associated with a life expectancy of months or years. VSED is characterized by the exercise of a specific choice at a specific time and is dependent on the patient having sufficient decisional capacity at the time that VSED is initiated.

VSED is clinically distinct from comfort feeding only, an approach to the care of patients with advanced illness that does not require decisional capacity. It is also distinct from voluntarily stopping eating and drinking by advance directive (VSED-AD), which is undertaken when patients no longer have decisional capacity but is consistent with preferences and instructions

indicated in the past. The additional complexities of VSED-AD incurred by lack of real-time DMC as well as full comprehension of what is occurring are beyond the scope of these guidelines.

When VSED is Considered

Ethical Considerations

VSED is legal in the United States and may be undertaken by patients with a clearly-defined terminal illness associated with a prognosis of months to several years.^{1,4,5} It may also be sought by a patient who has a diagnosis, such as dementia, that is associated with progressive decline and a prognosis of many years as well as an anticipated quality of life deemed by the patient to be unacceptable.

The ethical questions raised by supporting a patient with a longer prognosis are not the focus of these clinical guidelines; however, clinicians should be aware that ethical concerns associated with providing clinical support for VSED generally increase with patients whose natural life expectancy is greater.⁶ Comprehensive evaluation of the patient's reason for seeking VSED is especially important in these situations, as this may identify aspects of suffering, including mental health and spiritual issues that can be addressed and ameliorated. Patients may benefit from appropriate therapy and support and should be encouraged to explore these options before pursuing VSED.

DMC is required for a patient to begin VSED. Ethical concerns increase when DMC is unclear, such as in the case of mental health disorders, especially if not optimally treated. Clinicians must verify that the patient truly understands the diagnosis, as well as the risks, benefits, and alternatives to VSED. When evaluating a request to provide clinical support for VSED, a clinician should seek to understand the patient's reasons for considering VSED. The clinician should confirm that the patient is not being coerced, and that VSED is aligned with the patient's own values.

In order to demonstrate capacity to pursue VSED, a patient should be able to indicate the following:

- 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, as well as the extent to which those can be managed.
- Consistency over time in choosing to pursue VSED.
- An understanding of the social and emotional challenges that may accompany VSED.

Finally, clinicians may struggle with their own roles and responsibilities when responding to patients'

inquiries about VSED. They may also be uncertain as to whether they should introduce VSED to patients as one of many “potentially relevant treatment options.”⁵ While it is beyond the scope of these guidelines to address all of the arguments favoring and opposing clinician support of patients pursuing VSED, consultation from specialists in psychiatry, palliative medicine, and/or clinical ethics should be strongly considered when there is ambiguity pertaining to the patient’s mental health, DMC, and/or the clinician’s role in VSED.

Current Symptom Management

VSED is usually pursued in response to suffering associated with symptoms resistant to optimal palliative interventions or a quality of life that is unacceptable to the patient and cannot be improved by palliative care. Therefore, prior to and during evaluation of VSED as a potential choice, all reasonable palliative options should be offered, including those addressing mental, emotional, and spiritual well-being. It is ultimately the patient’s choice whether that care is sufficiently effective to lead them not to choose VSED.

Prognosis With and Without VSED

Because VSED can be accompanied by physical, emotional, social, and logistical challenges, patients should be provided with the most accurate prognostic information available without VSED being undertaken.

Since it takes time to complete VSED, pursuit of this option is rarely useful for patients with days to a very few weeks remaining to live and severe physical symptoms refractory to conventional symptom management methods. In such cases, specialty palliative care and/or hospice consultation with intensive symptom management is advised.

Clinicians and patients should be aware that the general range of survival once VSED has begun is 7–21 days, most commonly 10–14, recognizing that estimates should be tailored to the individual patient’s clinical status.^{2,3,5,7}

Anticipating Difficulties Once VSED Has Begun

It is important for those contemplating VSED to understand that once begun, VSED may pose physical, emotional, and ethical challenges for patients, family members, and caregivers. Patients’ resolve to continue VSED may fluctuate once they have begun the process.^{8,9} Additionally, a patient’s ability to fully understand and articulate their choices regarding their care may begin to decline after VSED has started, particularly in the late stages. Therefore, patients are encouraged to thoroughly discuss and document their intention to abstain from nutrition and hydration once VSED has begun, including after DMC has been lost. This is discussed further in section “Addressing ambivalence” below.

Family, Social, Religious, Spiritual, and Caregiving Considerations

Whenever possible, it is important for a patient to have the support of close family members and/or friends. There is anecdotal evidence that lack of family/social support for a patient’s decision to pursue VSED may result in increased emotional distress for the patient once the process of VSED has begun. Patients should also be prepared to have caregivers who can provide 24/7 support for up to several weeks. It is generally very difficult for a single caregiver to fulfill this responsibility, and assistance from others, including experienced death doulas and hospice staff, may be extremely beneficial. Because all members of the clinical team may experience additional emotional and moral burdens when caring for a patient whose death is planned, particular attention should be given to their support as well. In addition, some patients may find it important to discuss VSED with their trusted religious and spiritual leaders.

Hospice Support

Hospice programs provide important medical, nursing, social, spiritual, and bereavement support to patients and their families at the end of life, and often play a critical role in providing end-of-life care in the residential setting. Because a prognosis of six months or less is necessary for most patients to access hospice care, most hospices will not provide direct care to patients with a prognosis greater than six months prior to the initiation of VSED. However, many hospices will enroll patients who have already begun VSED. Clinicians are strongly encouraged to contact their local hospice agency to discuss the potential for hospice referral and enrollment of patients who are planning to start VSED.

Where VSED Takes Place

Patients contemplating VSED live in a variety of settings, including institutions such as skilled nursing facilities and adult family homes. Professional staff in institutional settings may have a range of knowledge of and philosophical support for VSED and may feel bound by professional licensure requirements to offer food and hydration on a regular basis. There may remain some uncertainty regarding whether food and hydration constitute medical treatments and therefore may be declined as a whole, or whether they represent “basic” or “ordinary” care, and thus should be offered regularly.^{3,5} While there is comprehensive guidance that provides a checklist and best practices for long-term care (LTC) facilities to honor residents’ requests for VSED support,¹⁰ challenges may remain for LTC facility residents who desire support in pursuing VSED. Clinicians are encouraged to advise patients and family

members to seek open discussion with facility administrative leadership about ensuring staff support for a patient prior to beginning VSED. If it is not an option for a patient to remain in a LTC facility while pursuing VSED, clinicians should encourage patients and family members to investigate and consider options for private residential living. Similarly, patients who are considering entering a facility and who wish to preserve their future option to pursue VSED may wish to discuss this with facility administrators prior to entry.

When to Begin VSED

See section "Start date" below.

Portable Medical Orders (POLST, MOLST, COLST, etc.)

Portable medical orders for life-sustaining treatment should be completed prior to the start of VSED. These should indicate a patient's preference for code status of "Do Not Resuscitate" (DNR), comfort measures, and, when applicable, no artificial nutrition and hydration.

Durable Power of Attorney for Healthcare

Patients should be encouraged to appoint a durable power of attorney for healthcare (DPA-HC), also referred to as a Health Care Proxy, and to indicate individuals, in order, to serve as back-ups should the primary DPA-HC be unavailable. Parents of adult children should be encouraged to specify which (if any) children, in which order, should serve as DPA-HC. In choosing a DPA-HC, patients should confirm that the person they select is willing to support their intention to pursue VSED.

Patient Advocacy Organizations and Death Doulas

Clinicians are encouraged to familiarize themselves with area patient advocacy organizations that provide resources and support for patients pursuing VSED and to refer patients to these organizations. Additionally, clinicians are encouraged to refer patients to a death doula experienced with VSED, when available, who may provide invaluable coordination and comprehensive support in addition to that provided by family/friend caregivers and hospice staff.

When VSED Has Been Chosen

Preliminary Steps for the Medical Provider

- Review the expected length of the VSED process, including how it may be affected by diagnosis,

physical condition, and strictness of adherence, especially avoiding all fluids.

- Advise patients who consume large amounts of alcohol of the risk for alcohol withdrawal syndrome.
- Discuss treatment of pain, anxiety, and other symptoms. Review the possibility that the patient may experience delirium, which—if accompanied by requests for hydration or nutrition—may result in prolonging, delaying, or curtailing the VSED process, as it is difficult and may be inappropriate for caregivers to refuse to provide nutrition or hydration if requested. (see further discussion in section, "Addressing ambivalence.")
- Discuss discontinuation of medical devices, particularly an implanted defibrillator.

Start Date

Deciding when to begin the VSED process is often difficult because of the many details needed to be considered and planned.

Three primary considerations include:

- The acuteness of the underlying disease.
- The time needed to prepare for VSED.
- The possibility of a narrowing window of time during which the patient has sufficient cognitive capacity to initiate VSED.^{2,11} It is helpful to guide patients in identifying specific, measurable "markers" of capacity, physical ability, and degree of suffering that would assist the patient in deciding when to start VSED.

Preparations for VSED often include:

- Medical consultation and support.
- Hospice referral and clarification of the hospice's willingness to enroll a patient who intends to pursue VSED.
- Consultation with a death doula experienced with VSED who will support the patient and family throughout the entire process.
- Hiring caregivers, ideally those experienced with VSED
- Legal consultation if there are concerns about family members' or others' support of patient's decision.
- Determining where patient will reside while pursuing VSED.
- Obtaining necessary supplies and equipment, including mist humidifier, mouth lubricant, eye drops, small spray bottle, and mouth swabs.
- Informing chosen family members, friends, and others who comprise a person's inner circle of support of patient's decision, start date, and specific ways in which they can be supportive.

Hospice Enrollment

See section "Hospice support" above. Hospice enrollment can be extremely helpful for patients pursuing VSED. Clinicians are strongly encouraged to contact their local hospice directly to discuss medical eligibility and enrollment.

Environment

See section "Where VSED takes place" above. Careful consideration should be given to a patient's environment. Many people wish to pursue VSED in their own home, surrounded by familiar sights and sounds, personal items, and people they love. This may not be feasible if sufficient caregiving is not available. On the other hand, healthcare facilities, assisted living facilities, and adult family homes may have prohibitions against VSED or may be unable to provide 24/7 caregiving.

Typical Phases

VSED typically involves three stages:^{2,4,6,7,12}

1. *Early*: In the early stages of VSED, the patient is alert and oriented, able to interact with their circle of support, and can easily tolerate or be distracted from occasional hunger pangs and increasing thirst and dryness. Prior to the start of VSED, it is helpful for patients to identify the ways they prefer to be comforted and distracted. Throughout the VSED process, but especially during the early and middle stages, these favored approaches are truly helpful. This is also a time for final important conversations, recollections, sharing of family stories, and celebrating the patient's life.
2. *Middle*: This stage is often the most difficult. With increasing dehydration, the patient becomes weak, fatigued, lightheaded, and begins to sleep for longer periods of time. The patient may suffer from agitation, confusion, and hallucinations. Delirium is not uncommon. Medications, massage, and acupuncture may mitigate these symptoms; seizures should always be treated promptly with appropriate medication.
3. *Transition/late*: This stage is marked by loss of consciousness as organ systems fail and is similar to the late dying process in other settings.

Symptom Management

1. *Dry mouth and throat*. This is by far the most common and troublesome symptom.^{2,3,4,6,8,12}

Both humidifying the surrounding air and providing meticulous mouth care are important in reducing discomfort. When a patient is conscious, teeth, gums, and

tongue should be brushed regularly. In addition, the mouth may be moistened with spritzes of water from an aerosol bottle top or with moistened mouth sponges or artificial saliva, and lips should be lubricated at regular intervals.

For patients with decreasing consciousness, moistened mouth sponges, frozen teething rings to hold in the mouth, frozen wet washcloths held to the face, frozen drops of coconut oil, and lip balm can all be helpful.

It is important that patients and caregivers are aware that even small amounts of water or ice chips can markedly prolong the dying process, so hydration in any form should be minimized for patients who remain committed to completing VSED. It may help to review the benefits of dehydration, including decreased respiratory secretions, less bother with urination, and decreased edema.

2. *Hunger*. Hunger tends to be most intense in the first few days and may correlate with the time of day. Some clinicians report that decreasing intake of calories at least one week prior to beginning VSED can reduce hunger.

We are all used to punctuating our days with meals, so when not eating, days seem much longer. It is therefore very helpful to provide as much sensory and mental stimulation as the patient desires during this early phase, including visits with loved ones, music, movies, reminiscing over photo collections, etc. Focusing on the other senses can ameliorate the loss of the sensations of taste and oral stimulation. Prior to the start date, patients can be asked to identify ways they derive comfort and pleasure using their other senses by offering a checklist of possible distractions that involve senses other than taste.

3. *Constipation and cramping*. At the beginning of the process, many patients find it useful to do some sort of bowel cleanse to decrease the chance that stool will collect and harden in the colon as dehydration proceeds. Ideally the method chosen would not include a large amount of hydration. Instead, bisacodyl, polyethylene glycol, or enemas can be used.
4. *Medication side effects, and the effects of withdrawing medications*. As dehydration proceeds, blood levels of medications will be affected. There is no substitute for frequent reassessment of symptoms to determine whether medication doses need to be modified. Medications taken solely to reduce long-term health risks should be tapered or discontinued prior to beginning VSED. Additionally, taking oral medications with water may prolong the VSED process. Palliative care, hospice, and/or pharmacy consultation is recommended to

reduce medication burden to the minimum required for comfort, and to develop alternative, nonoral routes of administration (transcutaneous, rectal) of medications essential for comfort when appropriate. Highly concentrated oral/sublingual medications, including opioids for pain or dyspnea, benzodiazepines for anxiety, and antipsychotics for disturbing delusions or hallucinations are recommended.

5. *Muscle soreness and pain.* Early in the process of VSED, patients should be encouraged to remain active if practical and safe. When it is not, providing help with repositioning is useful. A discussion concerning what measures the patient has previously used for comfort (massage, acupuncture, turning, positioning, etc.) can be instructive. One may consider analgesics, benzodiazepines, or other medications as needed, taking care to minimize concomitant liquid intake.
6. *Fatigue and weakness, lightheadedness, and loss of balance.* These are to be expected and will increase as days go by. Safety measures, including the use of a walker and gait belt are advised. As symptoms advance, patient care must be given at the bedside, including toileting with a bedside commode, use of incontinence products, and body care while in bed. These increased needs for assistance should be discussed and planned for with family, loved ones, and/or hired caregivers.
7. *Confusion, anxiety, and agitation.* As dehydration progresses, these symptoms can be extremely distressing to patient and caregivers. Prevention and preparation are key and anticipatory teaching for the patient and caregivers regarding confusion and agitation should be provided.

Patients feel secure when their inner circle of support is harmonious and steady. Ideally all family members, at least those who are present, support the patient's decision. The patient's immediate surroundings will also have a calming effect if it contains familiar objects such as a few well-known photos or pictures. Finally, it is reasonable to use anxiolytics and/or antipsychotics for management of confusion, anxiety, or agitation that is refractory to nonpharmacologic interventions.

8. *Hallucinations.* Patients and their caregivers should be apprised of the possibility that hallucinations – or what some call end-of-life dreams and visions – may occur. These may be peaceful, engaging, and comforting for the patient, in which case they should be seen as part of the process of dying rather than as signaling a need for intervention. However, if they cause the patient agitation and distress that does not respond to

gentle, loving support, they may be eased with antipsychotic medications.

9. *Final phase.* The final phase of VSED typically lasts one–two days. In this phase, particular attention should be given to nonverbal expressions of pain, restlessness, and agitation. Placement of a Foley catheter may reduce the need for frequent changes of clothing and bedding. Positional changes are often distressing, and so should be minimized. Continued education of family members about the physical changes they see in their loved one is important. It is also helpful to inform caregivers and others present in the room that patients are often able to hear even after they become unresponsive.

Addressing Ambivalence

It is important for caregivers to discuss with the patient the possibility that the patient may at some point request food and drink, and to plan how such a request should be addressed. This plan might include the identification of a specific, trusted person to respond to all such requests and/or a short, rehearsed sentence that reminds the patient of the reason they chose VSED.^{4,13} Some patients have found it helpful to make a short video addressing the reasons they chose VSED, which can be used to remind themselves during the process itself. It may even be helpful to practice this plan with the patient and family members before the start date of VSED. Ideally this information would be prepared and shared in a way so that all caregivers are informed.

During the VSED process the patient may need to be gently reminded that fluid intake would be against their previously-stated wishes. If a patient with sufficient DMC still requests rehydration, this should be acknowledged by both patient and caregivers as a postponement of VSED.

If the patient indicates a wish to drink later in the process—when they clearly lack DMC—the same palliative measures used previously can be employed. If these are not sufficient to calm the patient, very small amounts of fluid can be offered, along with medication for anxiety or pain. This usually allows the patient to settle and sleep. Severe, agitated delirium is rare but very distressing for all involved and may necessitate consideration of proportionate palliative sedation. If a surrogate decision-maker is convinced that the patient would now stop VSED if they had DMC, rehydration should be provided. If the patient then regains capacity, the goals of care should be readdressed.

Not providing hydration when requested requires certainty that the patient lacks sufficient DMC. The risk of honoring repeated requests for hydration is

prolonging the VSED process for a patient who may then choose to reinstitute it, while the risk of not honoring them is denying a patient something to which they have every right. Choices about these relative risks should be considered by patient, caregivers, and clinical team prior to the start of VSED (see "Family, social, religious, spiritual, and caregiving considerations").

When VSED Has Occurred

Death Certificate

The death certificate should be completed by indicating that death occurred naturally and that the immediate cause was dehydration. The primary serious illness(es) causing the patient to pursue VSED should be listed as contributing co-morbidities.

Bereavement of Family and Caregivers

Because VSED results in a planned death, bereavement may have different characteristics than in other circumstances.¹⁴⁻¹⁷ Use of hospice and community bereavement resources is recommended.

Clinical Staff Support

Professional caregivers and hospice personnel should be offered comprehensive guidance and support before, during, and after their work with a patient who pursues VSED. Professionals of all types may benefit from support that incorporates an understanding of VSED's particular characteristics.

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