

# A GUIDE TO MANAGING VSED AS AN END-OF-LIFE CHOICE

by VSED Resources Northwest



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This document offers a thorough description of the VSED process and explains in detail how to plan for each step, from making the decision to do VSED and setting the date to begin, through after-death care, honoring the body, and supporting the family. The intended audience for this document is a death doula or end-of-life guide, but it may also be useful for family members who are either seeking to hire a death doula to facilitate the VSED process or are considering managing the process themselves.

## Initial Client Conversation: Voluntarily Stopping Eating & Drinking

1. **Talk with client and family in detail.** You may need to dispel negative misinformation the client may have heard about VSED. Discuss the role of the death doula, VSED preparation, the VSED process itself (including range of time to complete), the importance of medical collaboration, the benefits of involving hospice, the process of selecting caregivers, the necessity of preparing a schedule, and possible approaches to medication and pain management. Also, talk about choosing a start date.
2. **Be upfront with family about the financial realities of the process.** Initially, the cost of caregivers for a 24-hour period sounds prohibitive to family members; however, paying \$30 - 40 per hour for maximum coverage for 10-14 days is still cheaper than even one month in a memory care setting or skilled nursing facility (SNF).
3. **Frankly address the challenges of VSED:**
  - The number of details involved in preparation for the process.
  - The length of the process, sometimes expressed as an emotional “marathon” for the family members who watch their loved one slowly decline.
  - The need for 24/7 caregiving, which can tax a family’s finances if resources are limited.
  - The memory and endurance the client must sustain in order to follow through with the VSED process. By day four or five, when the client might still be conscious, they often become confused due to dehydration and need frequent

reminders of what they are doing and why.

4. **Also address the benefits of VSED**, which center around the ability to choose an end of life that reflects the values, needs, and agency of the person carrying out VSED. As long as Washington State's Death with Dignity law does not cover neurological diseases or dementia, VSED will remain the alternative choice. The person who is facing their death after preparing for it in extensive detail is often freed to live each moment of their process with purpose and love.
5. **Address what happens if the client cannot follow through with the process.** By careful and explicit preparation, the person choosing VSED knows that they can stop the process during the first few days while still conscious. A doctor would need to be consulted as to how to begin slowly reintroducing fluids and food. Further assessment would also need to be made to determine the status of organ systems.

## **First Steps: Moving ahead with VSED**

1. **Document the client's choice.** Once the client has chosen to move ahead with the VSED process, encourage the family to make a video of the client talking about their decision. The video serves several functions: (1) as a legal record documenting the client's decision; (2) as a potential reminder to the client during the VSED process; and (3) as reassurance to a grieving family that this type of death was, indeed, what their loved one intended.
2. **Explain the purpose of recording two videos of different lengths:**
  - **The first video** should be longer (3-5 minutes) and should feature the client describing their reasons for doing VSED, such as family history with current diagnosis and/or skilled nursing facilities; markers met during the course of the disease, such as no longer being able to read, garden, visit with family, or travel; and any other personal reasons for choosing to hasten their death.
  - **The second video** should be shorter (around one minute) and should feature the client speaking to her/himself with VSED coaching tips. For example: "Hi, this is yourself. I'm reminding you that you chose to stop eating and drinking and die a natural death because you already have a terminal disease, and if you continued on you would..." Fill in with personal reasons, such as: forget your loved ones and yourself; end up in a memory care ward; be placed in a skilled nursing facility; or whatever else the client thinks would be personally motivating at difficult times of the process.
3. **Caregiver selection:** Guide the family in the selection of experienced caregivers, knowing that private caregivers may be the only option because some agencies

have policies governing staff assistance with VSED or Medical Aid in Dying cases.

Caregivers should be:

- Experienced with end-of-life caregiving and accompanying the dying
  - Available during the anticipated time of beginning VSED and for the following 3 weeks
  - Aware that the job will end when the client dies or stops the VSED process
  - Knowledgeable about VSED and preferably experienced with helping someone through the VSED process
  - Willing to meet with the family in person, knowing that a compatible match is important
  - Agreeable to NOT giving the client food or water and to immediately find a family member if the client asks for either
  - Respectful of client's spiritual views
  - Welcoming of family members and their interactions
  - Open to attending a gathering in celebration at the beginning of the VSED process for client, family, and caregiving team
  - Flexible with shifts and days, knowing that family member participation may vary from day to day and person to person, and that caregiver availability can also change
  - Able to maintain good self-care in order to be fully present and open-hearted with client and family
  - Willing to check in regularly with death doula (in person or by phone, text, or email) about their own well-being, with feedback about family interactions and any challenges.
4. **Meet with client's PCP ahead of time** (together with client, family member, and at least one primary caregiver) so that everyone is clear about start date, expectations, medications, and how to contact physician with questions, etc.

This is essential to:

- Foster good communication with physician about expectations and follow-up

- Have physician write prescriptions for liquid morphine, anti-delirium medicine, and liquid lorazepam to have all medications in the home prior to VSED start date
  - Request that the physician plan to make at least one home visit if possible. Families are very reassured and appreciative when the physician is personally supportive.
5. **Notify hospice nurse manager** (specifically) as early as possible about client's plans to VSED at home and request a hospice intake be completed as soon as is permitted. In the past, our local hospital's policy has precluded the admission of a VSED client until they are "sleeping most of the time" or until they've lost consciousness.
  6. **Evaluate family involvement:** Help family members evaluate the amount of caregiving they want to do—and are realistically capable of doing. Their role as family members is so important to the client, and it can become too heavy a burden for them to provide care AND deal with their own grief.
  7. **Legal and financial documents:** Encourage the client to consult with an attorney to make sure all legal and financial documents are in order. Some families choose to have an attorney draw up a "Release and Assumption of Risk" document, especially if there is not total agreement among family members regarding the VSED decision. As detailed above, it can also be valuable for the client to make a video stating their desire and reasons to use VSED.
  8. **After death care:** Discuss and make plans for professional assistance after the death, i.e. funeral home or cremation services. Talk with family about options that they can arrange themselves.

## **Pre-Start Planning: To-Do List for the Week before Start Date**

1. Meet with family and client before VSED start date so all are familiar with the VSED process, caregiving schedule, any after-death process or ceremony that is desired and plans for disposition of the body.
  - If possible, help family resolve any outstanding family issues.
2. Initiate steps for the client to shorten and improve the VSED process:
  - Reduce meal frequency and calories.
  - Do a colon cleanse or colonoscopy prep 1 or 2 days before start date because bloating and constipation are the major cause of pain during VSED.

- Drink only water and clear liquids after the prep until VSED start time to prevent stool from forming.
3. Help client create a list of all the ways they like to be comforted and distracted. Encourage client to post this list in their room as a reminder to family and caregivers. Urge them to be as specific as possible, referencing all their senses.
  4. Help client create a comfortable space:
    - Select and make a “nest” of the room where they will be throughout the VSED process, so it is a comforting, sacred space for them and has adequate room for a caregiver, caregiving supplies, and visitors.
    - Start as early as possible with a hospital bed in the room so that client has time to become accustomed to it, thus lessening the possibility of confusion or discomfort of changing beds later.
    - Suggest a sheepskin under the bottom sheet to provide comfort and decrease the development of pressure points and sores.
  5. Food smells and cooking sounds can be distracting, if not torturous, to someone who is not eating or drinking. Plan with the family so these smells and sounds are avoided. Also, do not leave food out to tempt the client, especially while she/he is still mobile. Signage in the kitchen may be helpful in remembering this. Some families move all meals outside the home during the first few days of VSED.

## **Pre-Start Planning Continued: Medications and Comfort Care for VSED**

1. Discuss with client and family the range of options regarding medication—i.e., easing pain vs. palliative sedation. This also needs to be discussed with the physician who is prescribing the medications as well as with all caregivers.
2. Consider alternative methods of pain relief such as acupuncture, Healing Touch, Reiki, massage, acupressure, aromatherapy, CBD, and marijuana.
3. Explain (and demonstrate to client and family members) mouth care for the client, including use of spray mist, oral foam swabsticks, and lip balm.
4. Make arrangements for use of a cold air humidifier to keep room air moist, thus adding comfort and easing breathing.
5. Help family members pick a consistent “point-person” to come into the room should the client need to be reminded about why they are not eating or drinking. This should be someone who can give the same message each time, such as, “You

*chose to stop eating and drinking so you would not have to live with dementia and move to a memory care setting. I can give you something to drink, but would it help if I just moistened your mouth with a spritz of cool water and wiped your face with a cool cloth?"*

6. If the client made a short video to be replayed as a reminder, discuss with the family and caregivers ahead of time where the video is stored and how it can be played for the client. Practice ahead of time so that this is an easy process for everyone involved.

## **Time to Start: Managing The VSED Process**

1. Hold a "Gathering of Intent" before starting the VSED process. This can include the client, family members, and caregivers and helps set the energy and intention of the group for the days ahead. The gathering also allows the group to honor the life of the client and celebrate their courageous choice.
2. Encourage family members and caregivers to practice good self-care. Frequent walks, adequate sleep, and regular meals will help family and caregivers be supportive and remain as healthy as possible during a difficult time.
3. Anticipate what family members will see happen to their loved one and prepare them, interpreting the physical and emotional changes that happen.
  - Share Barbara Karnes's booklets *Gone From My Sight* and *The Eleventh Hour*.
  - Prepare family members for the "death rattle" and for the physical sight of the client in a coma, as the sound of labored breathing and the sight of a loved one's mouth remaining open can be disturbing for those experiencing this for the first time.
4. Compile a notebook for professional caregivers with the expectation that all caregivers keep thorough notes about meds given, care given, family interactions, client reaction, and communication with physician or hospice.
  - Let family know that they are welcome to read the notebook and add comments.
  - If possible, leave the notebook in an accessible, consistent spot.
5. Keep hospice nurse manager informed of client's progress so an intake can be done as soon as the client meets hospice requirements.
  - Involve hospice as soon as possible because hospice can more easily expedite getting professional medical support and medications. Their presence is always

comforting to the family and reassuring to caregivers.

- Remind the family that the hospice nurse can pronounce death as well as call the mortuary, and that the death of a hospice patient is not investigated by authorities. *This can be comforting for those who worry about VSED legality.*
6. Determine ahead of time who would like to be present, if at all possible, at time of death.
  7. Ask family members prior to the death if they want to spend time alone with the body or if they wish to be accompanied by a family member or caregiver.

## **Completion: After-Death Care**

1. After the death, clear the room of all caregiving supplies and invite the family to be present with the body or to help wash and dress it, if requested.
2. Offer a leave-taking ceremony in preparation for the client's body to leave the house.
  - This can include simply reading a poem, putting a blossom in the client's hair, bowing in gratitude, humming a melody, and/or observing a moment of silence.
  - This honors the sacred space and the dying process that has occurred within the home.

## **Follow-up with Family**

1. Meet with family after the death to listen to and talk about the experience— what worked, what didn't, what was meaningful, what might have been confusing.
2. During the following week after death, help family members determine their next steps.
3. Review "What to Do in the First 48 Hours" brochure from hospice:
  - Friends and family to notify
  - Religious contacts
  - Professional groups
  - Employer

- Companies from which client received regular service
  - Attorney and accountant
  - Social Security
  - Obtain copies of the death certificate
  - Obituary writing and submission
  - Decisions about final arrangements
  - Location of important documents
4. Help family members assess their need for:
- Self-care
  - Grief support
  - Rest and sleep

## **FOR MORE INFORMATION**

The VSED Resources Northwest website, <http://vsedresources.com/>, contains additional VSED resources, from guides and videos to articles and podcasts. You may also call us at (360) 919-6363 or email us at [info@VSEDresources.com](mailto:info@VSEDresources.com) to set up a consultation. Our goal is to advocate for VSED as an end-of-life choice and to empower those who, in the face of terminal illness or unacceptable suffering, wish to choose how their life ends.

