

## **The Voluntary Stopping Eating and Drinking Process (VSED)**

In the medical and legal community, it is commonly accepted that a competent individual has the right to refuse any treatment, which includes the right to decline to eat food or drink liquids. If you are considering using Voluntary Stopping and Eating and Drinking (VSED) to end your life, it is very important that you first obtain adequate support, both from your medical providers, your caregivers and – especially – a hospice provider.

Knowing when to start VSED is often a challenge. The essential quality needed for this is having the mental capacity to follow through with the process. Someone diagnosed with mild cognitive impairment or dementia may need to be followed closely by a physician to help determine the optimal timing. The difficult decision is that the individual will most likely need to give up some quantity of living versus possible years of unacceptable conditions of living. In other words, it is said that you “have to give up good days in order to avoid bad years.”

### **Frequently Asked Questions**

#### **1. What does VSED mean?**

Voluntary Stopping Eating and Drinking, VSED, means voluntarily refusing to eat any food or to drink any liquids with the understanding that this will result in death. If food and fluids are currently being taken through a stomach tube or IV hydration, this means completely stopping these therapies in addition to stopping ingestion of any food or drink.

#### **2. Do I need to be terminally ill (meaning death within six month is expected)?**

No. A terminal diagnosis is not required for an individual to utilize VSED. However, for medical staff to provide support, they will need to be convinced that (a) you suffer from an incurable, progressive condition; and (b) you are a legally competent adult able to understand the risks and benefits of VSED at the time VSED will begin.

#### **3. Do I need my physician’s permission to begin VSED?**

No. You do not need a physician’s permission, but it is very important to have a physician willing to support you by prescribing anti-anxiety and other helpful

medications, and refer you to hospice as soon as you become eligible. See Appendix A: “Letter to my physician about Voluntary Stopping Eating and Drinking.”

#### **4. Isn't it uncomfortable?**

The experience of people using VSED can vary greatly. Some people who choose to stop eating and drinking may find a sense of peace when they can finally “stop fighting.” However, this process can also be rigorous, and it is not the right choice for everybody. Hunger and thirst tend to be experienced more by those who have had a healthy appetite up until they start this process.

Hunger pangs may occur in the first few days but usually go away after that. Thirst, however, may continue, but there are medications and products available to manage it (see suggestions below).

It is important that individuals choosing this process have adequate palliative (comfort) care to manage any symptoms that may arise. Your physician or hospice can prescribe these.

#### **5. I don't like the idea of not drinking- can't I just stop eating?**

A person can live for a very long time without eating, but dehydration (lack of fluids) is what speeds up the process. Dying from lack of food alone can be more prolonged and uncomfortable than dying from dehydration.

#### **6. How long does it take?**

It is difficult to predict exactly when the end will come; this depends on the person's general condition, age, illness and many other factors. If a person is already close to death and/or already very weak or frail, death may come as early as a few days. The average length of time VSED takes is 10-15 days with a range of 5-20. Nothing more specific can be projected as it depends on each patient's medical condition, weight, self-discipline.

#### **7. It seems like this would take a lot of willpower. Does it?**

It takes some determination and requires a commitment, but we often find that people who make this choice are ready to “let go” and are able to be successful. Many people who are at the end-stage of an illness lose interest in eating and drinking as part of the natural dying process.

## 8. Should I keep taking my medicines?

Your physician may recommend that all medications be stopped, except for those for pain or other discomfort. Stopping medications for heart problems or diabetes, for example, may speed up the process. It is a good idea to talk with your physician or hospice provider about all your medications.

## 9. What about my friends and family – what will this be like for them?

We suggest that you talk with your close family members and friends early about your wishes and why you may want to take this course. Their active support in the process will be necessary. Ask them to read your completed “My Decision to Voluntarily Stop Eating and Drinking” document (Appendix B) and try to get a promise or commitment from them to support you.

### Starting the VSED Process

There are many ways to decide when to begin VSED:

- There may be clinical indications of your decline
- It may be the estimated time needed to get a support team in place and end of life documents in place
- Reaching a “marker” (a line in the sand) or a collection of markers may help determine a date
- It may be a trade-off of poor quality of life vs. option of death.

Decide on some **Markers**: Family and closest friends may help in the process of narrowing down the markers, or detect when the time has come. Below are conditions when some people consider death preferable to living.

- Loss of ability to provide self-care
- Inability to drive or travel
- Inability to toilet or bathe oneself
- Unable to walk, get in and out of a chair, or roll over in bed without assistance
- Need to move to a facility which provides greater care
- Unremitting pain
- Inability to walk independently

- Cannot operate a cell phone, television, computer
- Increasing difficulty to write or read
- Can no longer self-manage medications
- Struggle to track conversations
- No longer enjoys certain activities that they previously enjoyed such as gardening
- Cannot recall events or loved ones

The person could set a **target date**, e.g. after the holidays, after my next birthday, anniversary, arrival of spring, etc. Know that one can always move that date up or back. Ultimately, the decision needs to be made by the individual while they still have the mental capacity to do so as determined by a physician.

In general, it takes great consideration and contemplation to hasten one's death. It is a process to determine a specific date to start VSED, and that date could also be a moving target. One can change one's mind, or find what was once considered to be an unacceptable living situation is now tolerable.

One must take into consideration all of the coordination, planning, preparation and availability of care support that is necessary to have in place ahead of time. Sometimes health conditions change suddenly and a plan will need to be enacted quicker than initially anticipated.

### **Phases of the VSED Process**

#### **The Early Phase: DAYS 1-5**

Often the first three days will be "normal." Patient will be alert and perhaps active as before. Person will have some thirst (minor), hunger, perhaps difficulty urinating. Due to stopping some meds, the person may urinate more frequently.

Person might have symptoms of anxiety – restlessness, silence, perhaps shortness of breath. These can be managed with liquid medication administered under the tongue, provided by physician or hospice.

[There's time for the patient to change his/her mind in these first few days without damage to the body.]

### **Middle Phase: Approximately DAYS 5-10**

This is the hardest phase. This is the point of no return: patient will experience thirst, maybe have some delusion, begin to lose mental capacity, become agitated. Caregiving will need to be 24/7 in these last two phases. If family and friends are unable to cover completely, hired help may be necessary.

The patient will become weak and need more sleep.

Symptom management by the caregivers is essential.

Caregivers will do personal/comfort care for patient: bed/sponge baths, oral care, support and guidance

### **Late Phase: Approximately Days 10-15:**

The patient begins the “active dying” process. Patient is sleeping a lot. Caregivers will be managing around the clock, using comfort measures.

Comfort medications will continue to be given as needed.

### **Helpful Reminders for Yourself**

Make a **video** on your phone or tablet for your family, friends and caregivers, wherein you state your desire to use VSED to end your life and why. Say you are doing this of your own free will and need their support. Ask people not to offer you food or force feed you. This video can be shown to you if, during the VSED process, you forget what you are doing and ask for food – the video reminds you of your commitment. However, remember you can change your mind at any time before you start the VSED process or in the first few days of the VSED process.

A second video can be an “Atta Girl/Atta Boy” video – saying to yourself that “you can do this,” “you are strong and can handle anything,” etc. This is your “Pep Talk” when you begin to feel low and fear that you might not be able to see the process through.

Talk to your doctor and ask for his/her support in regard to medications and referral to hospice once the VSED process is started.

Assemble your **Posse** of friends and family who are willing and able to help you during this process. Designate a **Point Person** – this is the person who plans to

stay with you most of the time during the process with respite breaks given by other caregivers. Give all Posse members an idea of what will be asked of them. Even if you have not set a date, scope out their general availability. Ask them: Can you commit to 2 weeks or so that I can receive consistent care? Do you support my decision to use VSED to end my life? Do you understand you will need to be strong in NOT giving me food or drink even if I ask you to do so?

### **To Do List**

Make arrangements for your **funeral/cremation/green burial**. Make sure you have a signed (by you and your provider) POLST form (green form) easily visible in the home before starting. It is usually placed on the refrigerator. This is very helpful when/if EMS is called.

Assemble necessary and useful equipment and supplies (see suggested list below).

Optional: Have an “intention-setting” ceremony on the eve of starting VSED. Gather family, friends and caregivers to plan and commit to helping you. Celebrate yourself! Talk about significant life events, share photos and memories.

### **Information for your Caregivers:**

Caregivers get to see and experience a profound process. Caring for the person will be an opportunity to give the highest service one can give to another human being. It will allow the caregivers to reflect on their own life and begin the process of picturing their own end of life.

It is recommended that the Point Person begin a notebook. This will allow the noting of the person’s progress through the process, track caregivers coming and leaving, and record medications administered. All caregivers’ phone numbers should be in the notebook for all to see, to insure good coverage, and ensure any caregiver emergencies are covered. Record in this notebook the person’s cell phone or computer pass code in the event that the video, stating the desire to use VSED and asking for support, may be played for the person.

Start a calendar which can show all the caregivers' "shifts" on it.

**VSED Equipment to have on Hand\***  
**(Not all below is necessary to have a successful VSED death)**

**Safety and Accessibility**

Hospital bed (adjustable up and down)  
Bedside commode  
Walker  
Cool air humidifier  
Light-weight wheelchair  
Bath and shower seat  
Baby monitor

**Linens**

Sheepskin to cover mattress  
Stretchy mattress sheets  
Twin bed sheets (2 sets)  
Water-proof bed pads  
Washcloths  
Towels  
Draw sheets (a flat sheet), used to reposition person

**Medical Supplies**

Incontinence products  
Lip balm  
Lotion  
Eye drops  
Toilet wipes  
Large bath wipes, preferably those that can be warmed in a microwave  
Hair-washing supplies (Suggested: *No Water Shampoo and Conditioning Cap*, available on-line)  
Gait belt for support when walking  
Needle-less syringes for meds (usually supplied by the pharmacy)  
Fine mist atomizer spray bottles (available on-line)

*\*Courtesy of VSED Resources Northwest*

### **Comfort Measures While Doing VSED**

#### **Bed:**

- Clean sheets- soft and fresh
- Big down coverlet
- Favorite quilt or blankets
- Lots of comfy pillows
- Sheepskin to lie on

#### **Places to sit:**

- Rocking chair
- Recliner
- “Family” chair

#### **Room:**

- Room with a view
- Windows that can open for fresh air or sound of rain
- Drapes that can be opened or closed
- Overhead light
- Small lamps with soft light
- Candles
- Nightlight

#### **Things to wear:**

- Favorite slippers
- Fuzzy socks
- PJs
- Nightshirt or nightgown
- Shawl
- Favorite hat
- Gloves with or without fingers
- Scarf
- Bed jacket, robe

### **Tips and suggestions for Caregivers:**

If the patient is admitted to hospice in the early stages of starting the VSED process, hospice can usually get an adjustable hospital-type bed, a bedside commode, and other durable medical equipment as needed. Bed rails will be valuable in the Middle and Last phase. If the person is not receiving hospice care, these items can usually be rented from a medical supply company or borrowed from a local charity.

**Anti-anxiety and pain medications** will be prescribed either by hospice or the person’s physician. These meds may be started early in the VSED process for



symptom management. Check with the doctor or hospice nurse about frequency of administration.

**Hunger** can best be avoided by removing all smells and sounds of food in the house/apartment. Make sure you do not eat or drink in front of the patient.

**Thirst** is the biggest issue. Use humidifier in room. Ask hospice nurse or physician for artificial saliva or oral sprays. Follow the physician's recommendations for giving morphine if ordered for pain, as it can also relieve the sensation of thirst.

Rely on the Point Person to help manage thirst.

If the patient asks for something to drink, try the following:

- Remind them of why they're not drinking water and what their decision to do VSED means
- The second time they ask: Try to distract the patient – offer to read to them, take them for a walk, rub with lotion, reminisce, etc.
- The third time they ask: Offer a compromise such as 3-4 sprays out of a chilled mist bottle of water, spoonful of ice chips, sucking on a frozen teething ring
- The fourth time: show the video they made about why they are not drinking
- The fifth time: give them some water.

For dry mouth: offer water or mouthwash (nonalcoholic) which person then spits out. Brush teeth, tongue and gums with toothbrush. Remove debris from mouth. Moisten mouth with damp swab. Have the person suck on edge of wet cloth. Use lip moisturizers.

The drinking of water will prolong the dying process. But sometimes there is a compromise between a "total ban" and a few sips of water to ease suffering. Use your discretion. Be sure to record in the notebook any water that is given including date, time and amount.

For weakness: Encourage rest and sleep between periods of activity (if any). Help the person find a comfortable position by turning, placing pillows, etc. Obtain a

bedside commode or use a bedpan or pads – the person will only urinate small amounts. Weakness will increase as the days progress.

The person will usually become sleepy and more lethargic each day. Some people become unconscious after a few days; others stay clearheaded and awake until the end.

### **Other Help for Dry mouth and Skin:**

- Fine mist spray bottle, kept in fridge (available on-line), use sparingly in mouth
- Glycerin swabs for inside of mouth (available on-line or thru hospice)
- Ice chips
- Frozen baby teether
- Air humidifier
- Lip balm
- Saline nasal spray
- Body lotions/moisturizers
- Sheepskins or other padding on mattress
- Satin pillow case
- Soft toothbrush
- Incontinence pads for bed (available from drug store or hospice)

### **Emotional and Spiritual:**

- Play favorite music
- Reading – audible books (Library App on cell phone if a member of the local library)
- Gentle massages
- Meditation
- Mantras
- Singing
- Hand holding
- Any other ritual important to the person

## **List of Pleasures for the Patient during VSED\***

### **Things to Hear:**

- Conversation – about anything, familiar voices
- Hearing and retelling family stories
- Being read to: favorite books, poems, letters, cards, and newspapers
- Remembering out loud events from childhood, births, parenting, jobs, holidays, romance, challenges, celebrations
- Favorite radio programs
- Podcasts, Pandora
- Listen to music: radio, CDs, singing, Threshold Singers, Therapeutic Harpist
- Make music – sing keyboard, instrument, and rhythm games
- Favorite types of music

### **Things to touch:**

- Hands, faces, bodies of loved ones
- Little basket of natural things – feather, stones, shells, seeds
- Pets
- Stuffed toy
- Doll
- Blanket or shawl
- Cards and/or letters
- Computer/tablet games

### **Things to smell:**

- Essential oils in a diffuser
- Loved one's perfume
- Burning candles, not food scented
- Favorite soap

- Favorite body lotion
- Wood in a fireplace
- Fresh air
- Rain

**Do together:**

- Sit quietly and be present
- Cuddle in bed
- Hold hands
- Hug
- Body massage, foot massage, hand massage
- Manicure
- Put together puzzles
- Play card games, board games
- Write a legacy letter to grandchildren, best friends
- Draw
- Sing, play keyboard

**Things to look at or watch:**

- View from window
- Pictures of cherished people
- Favorite pictures of celebrations, milestones
- Looking at nature pictures together
- Comics
- TV or other electronics
- Favorite movies

*\*Courtesy of VSED Resources Northwest*

### Patient death:

If the person is on hospice, call their hospice office to notify them of the death and the presumed time of death. Hospice will notify the funeral home or the Point Person should contact the funeral home. Discuss with the family the **time** for the arrival of the funeral home personnel. They do not need to come right away as some family members and friends may want to spend additional time with their loved one. Ask that the funeral home call you with an estimated time of arrival. They may ask questions about stairs into the house/apartment, weight of the person, etc.

If the person is NOT on hospice, call 911, or if this is not necessary in your county, call the funeral home. If you do call 911, immediately say, "This is a non-emergency call. I want to report the expected death of a person using VSED (voluntarily stopping eating and drinking). Will you come to pronounce death?" The EMTs/police are very discreet and will simply ask to see the person, ask a few questions about who the doctor is, does the person have a POLST form on their refrigerator or other document that states person's desire to end his/her life. Show the video on the phone and the declaration of intent (Appendix B), if needed.

Call the End of Life Washington Volunteer to report the death.

Unused medications should be taken to a "take back pharmacy" or the sheriff's department for disposal.



**Appendix A:**  
**Letter to My Physician about Voluntary Stopping Eating and Drinking**

I want to have an honest discussion with you about how I can maintain control of my life and prevent unnecessary suffering as my illness progresses. Quality of life is more important to me than the number of days I have left to live. I am concerned about:

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that I may be forced to endure. (For example: loss of independence, loss of dignity, inability to care for myself, immobility, etc.)

As a result, when I determine that my suffering is beyond what I am willing to tolerate and I can only anticipate further decline:

I plan to voluntarily stop taking therapeutic medications, food and liquids.

I would like your support in pursuing this legal option.

I ask that you be willing to prescribe medications to manage my symptoms so that I may be kept comfortable until my inevitable death – even if this means I might sleep all the time.

As soon as I am eligible, I request a hospice referral to support me in being comfortable during my last days.

In the unlikely event that I do not die quickly and my care places an unacceptable burden on my loved, ones, I would like to be transferred to an inpatient facility that will support me in the process and allow me to continue to receive hospice care.

It would give me great peace of mind and comfort to know that this option will be available to me and my Durable Medical Power of Attorney at the time of my choosing. I see the option as preferable for my family and for myself. I have discussed this plan with my loved ones and have obtained their pledge of support for whatever I decided to do. I need your support of this plan so that I can proceed with enjoying whatever time I have left, free from fears about the decline in the quality of my life and suffering I consider intolerable.

May I count on you to support my plan to voluntarily stop eating and drinking if and when I decide that my suffering has become unbearable?

\_\_\_\_\_ Will you refer me to hospice as soon as I become eligible?

\_\_\_\_\_ Do you see any barriers that might prevent me from carrying out this plan?

\_\_\_\_\_ If you feel that you cannot, or will not, support me in this plan, will you refer me to a physician who will support me?

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Patient Signature

Date

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Physician Signature

Date



**Appendix B:**  
**My Decision to Voluntarily Stop Eating and Drinking**

I am making this document because I want my medical and long-term care providers, caregivers, family and other loved ones to respect, honor, support, and uphold my decision to voluntarily stop eating and drinking (VSED).

I am a person with capacity and have considered all the options that are available to me. I value life very much, but I believe that to continue living in certain circumstances is worse than death. I understand that stopping eating and drinking will result in my death.

I want my family and caregivers to refrain from eating in my presence and to try to prevent or limit any cooking odors or the smell of food from reaching and affecting me.

I do not want to be tempted, persuaded, cajoled, harassed, or coerced to eat or drink.

I do not want to be offered food or water; if I want them, I will ask for them.

I want my caregivers to focus on comfort care and pain and symptom management and I want to be allowed to die as peacefully as possible.

If the long-term care facility where I already reside will not honor my decision to VSED or attempts to undermine it, I want to be transferred to one that will or to the home of a family member or friend who supports my decision.

If I become unable to make decisions for myself as a result of a coma, being heavily medicated, or for any other reason, I want my wishes for life-sustaining treatment, including withdrawal of medically assisted artificial nutrition and hydration (for example, tube feeding, nasogastric tube, total parenteral nutrition) to be honored as documented in my health-care directive or my Physician Orders for Life-Sustaining Treatment (POLST) form.

If I did not make a health-care directive or POLST form or they cannot be located, I want my family, health care agents or other legal surrogate decision maker's decisions about life-sustaining treatment to be followed including those addressing medically assisted artificial nutrition and hydration.

I do not want others to substitute their choices for mine because they disagree with my decision to VSED nor because they think their choices are in my best interest. I do not want my intentions to be rejected because someone thinks that if I had more information when I started the VSED process, or if I had known certain medical facts that developed, I would change my mind.

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Signature	Printed Name	Date
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Statement of Witnesses:

The forenamed person is personally known to me and I believe him/her to be of sound mind and to have completed this document voluntarily. I affirm I am at

least 18 years old, not related to by blood, marriage, or adoption, and not the health care agent named in an Advance Directive for Health Care. As far as I know, I am not a beneficiary of his/her will or any codicil and I have no claim against the estate. I am not directly involved in his/her health care, and I am not an employee of the physician or a health care facility where the person making this document may reside.

**WITNESS 1**

**WITNESS 2**

\_\_\_\_\_  
Signature                      Date

\_\_\_\_\_  
Signature                      Date

\_\_\_\_\_  
Printed Name                      Phone

\_\_\_\_\_  
Printed Name                      Phone

\_\_\_\_\_  
Address

\_\_\_\_\_  
Address

**Notarization (optional)**

STATE OF WASHINGTON County of \_\_\_\_\_

I certify that I know or have satisfactory evidence that \_\_\_\_\_

signed this document and acknowledged it to be his/her free and voluntary act for the uses and purposes mentioned in this document.

Dated this \_\_\_\_\_ day of \_\_\_\_\_, 20\_\_\_\_\_

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NOTARY PUBLIC in and for the State of WA

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Residing at \_\_\_\_\_

My Commission expires \_\_\_\_\_

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