

Your life. Your death. Your choice

# **VOLUNTARILY STOPPING EATING & DRINKING (VSED)**

In the medical and legal community, it is commonly accepted that a competent individual has the right to refuse life-sustaining treatment, and this includes the right to decline to eat or drink. One of the advantages of this decision is that you may change your mind at any time and resume eating and drinking.

**Important:** If you are considering using 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.

End of Life Washington provides information and advice about VSED to help people and their families with planning. An experienced adviser may be able to make a visit to discuss the process with all involved and help you make a good plan.

### FREQUENTLY ASKED QUESTIONS

### 1. What does VSED mean?

It means voluntarily refusing to eat food or to drink any liquids with the understanding that this will result in death. If food and fluids are taken through a stomach tube or IV hydration, this means completely stopping these therapies.

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

No. A terminal diagnosis is not required for an individual to utilize VSED. However, for medical and other support your providers will need to be convinced that (a) you suffer from an incurable, progressive illness; 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 refer you to hospice as soon as you become eligible.

### 4. Isn't this 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 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. Thirst, however, may continue, but there are medications and products available to manage it. (See the discussion of symptom management later in this document.)

It is important that individuals choosing this process have adequate palliative (comfort) care to manage any symptoms that may arise.

# 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 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. It could take a younger, more robust person one to three weeks. If a person continues to drink even small amounts, the process will take longer.

# 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. (See the discussion of medications later in this document.)

# 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 honor it.

# 10. What kind of help will I need?

- You cannot do this alone. You will need the care of friends, family, or other caregivers during
  this process. If you reside in a care facility, you will need the agreement of the staff to provide
  support and assistance.
- Until you are receiving hospice care, your physician is very important. Talk with him or her about a referral to hospice as soon as you become eligible.

- If you are already receiving hospice care, ask your nurses to help you prepare. If you are not on hospice, ask your physician to tell you at what point in the process he or she would refer you to a local hospice provider.
- If your illness is not one that is likely to cause death within six months, your physician may want to evaluate you for depression or ensure you have the capacity to make informed decisions before helping you in this way. This will reassure family, physicians, and others that your mental status is sound and this decision is well considered.
- End of Life Washington will be available to counsel you and offer information.

# 11. What should I do before I start?

- Talk with friends and family members who might care for you during this process. Their support is crucial.
- Talk with your physician and/or hospice nurse to let them know of your plans. Ask if they will be
  willing to provide medications to keep you comfortable. It is unwise to begin the VSED process
  without a pledge of support from your medical providers that they will prescribe comfort
  medications. (See Appendix A for a sample letter you can send to your physician to start the
  process.)
- Complete an Advance Directive (found on the End of Life Washington website) and My Decision
  to Voluntarily Stop Eating and Drinking (Appendix B). Have your physician sign a Physician
  Orders for Life-Sustaining Treatment (POLST) form (available from End of Life Washington or
  your medical provider) to withhold life-sustaining therapies and all resuscitation efforts.
- If you reside in a care facility, discuss your wishes with the staff and nursing director. You will need their agreement to support you.
- Make sure all of your legal affairs, health-care directives, and funeral/memorial plans are in order. Wrap up any unfinished business and say your goodbyes.

# 12. What if the long-term care or other facility where I live tells me that I can't VSED or someone threatens to contact the police or report my caregivers to a social welfare organization such Adult Protective Services?

Because no federal or Washington statutory or case law directly addresses the legality of VSED, it isn't illegal. If you, your family, caregivers, or medical providers feel threatened by the efforts of anyone to undermine your right to VSED, contact End of Life Washington for assistance with legal or other advocacy.

# GENERAL INFORMATION ON VOLUNTARY STOPPING EATING AND DRINKING (VSED)

# 1. Managing Symptoms

Hunger and thirst tend to be experienced more by those who have had a healthy appetite up until they start this process. People near death have usually decreased their intake of food and fluids already and

tend to experience little or no hunger and thirst. Those near unconsciousness will likely have no symptoms.

Drinking any liquids will significantly slow the process and, as a result, make it more uncomfortable.

Agitation and delirium may occur. Hospice nurses and the patient's physician can make recommendations for treating these symptoms. (See Appendix C for a more detailed list of possible symptoms.)

### 2. Medications

Talk to your doctor or hospice nurse about stopping all medications except those for pain and discomfort. Also, eliminate medications that might contribute to thirst or dry mouth.

# 3. Caregiver Advice for Nursing Homes and Other Facilities

Problems have sometimes occurred when a person decides to VSED and resides in a long-term care facility such as assisted living or a nursing home. Ideally, find out whether or not a facility will support a resident's decision to VSED before being admitted.

It is important that the resident and family or other primary caregivers meet with the facility director or supervisor to review the resident's care needs and come to an agreement before starting the process. Caregivers should act as advocates for the resident, making sure that his/her wishes are honored.

Recognize that not feeding a resident may be difficult for some staff members or that some facilities may not be willing to support a resident's decision to VSED, particularly if the resident has not been diagnosed with a life-ending illness, is not very elderly, or is not already relatively close to death.

Caregivers should be understanding but firm that they expect the staff to honor the wishes of the resident. Staff may exert subtle pressures (stopping by the resident's room with food or a drink) or act covertly to get the resident to eat or drink. Caregivers may need to be vigilant. It may even be necessary to transfer to another facility that will honor the person's right to VSED.

If you have problems with your nursing home or other facility, you may want to contact the Long-Term Care Ombudsman in your area. To learn more about the Washington State Long-Term Care Ombudsman Program, go to www.waombudsman.org or call (800) 562-6028.

#### APPENDIX A:

# SAMPLE LETTER TO 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 \_\_\_\_\_\_ that I may be forced to endure. (For

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.

example, loss of independence, loss of dignity, inability to care for myself, immobility, etc.)

- 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 this 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 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 asked for their support for whatever I decide 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.

# **Specific questions:**

- 1. May I count on you to support me if I proceed with my plan to voluntarily stop eating and drinking if and when I decide that my suffering has become unbearable?
- 2. Will you refer me to hospice as soon as I become eligible?
- 3. Do you see any barriers that might prevent me from carrying out this plan?
- 4. 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?

# 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 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 health care agent's or other legal surrogate decision maker's decisions about life-sustaining treatment to be honored, 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 or 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 later, I would change my mind.

Signature		Printed Name	Date
Statement of Witnesses	;		
have completed this documarriage, or adoption, an far as I know, I am not a b	ument voluntarily. I and the health can be not the health can be neficiary of his/her health care	affirm I am at least 18 yea re agent named in an Adv er will or any codicil, and I e, and I am not an employ	/her to be of sound mind and to rs old, not related to by blood, ance Directive for Health Care. As have no claim against the estate. I see of the physician or a health care
WITNESS 1		WITNESS 2	
Signature	Date	Signature	Date
Printed Name	Phone	Printed Name	Phone
Address		Address	
NOTARIZATION {options	al}		
STATE OF WASHINGTO	ON County of _		
I certify that I know or have signed this document and mentioned in this document	d acknowledged it to	encethat o be his/her free and volui	ntary act for the uses and purposes
Dated this	day of	, 20	_
	NO	TARY PUBLIC in and for	the State of Washington
	Rac	siding at	

My commission expires \_\_\_\_\_

# APPENDIX C: MANAGING SYMPTOMS

A person using VSED may experience **some** or **none** of the following symptoms. Here are some suggested ways to manage them:

**Thirst** Use humidifier in room. Ask hospice nurse or physician for artificial saliva, or oral sprays.

Follow your physician's recommendations for giving morphine if ordered for pain, as it

can also relieve the sensation of thirst.

**Dry Mouth** Offer mouth rinse (to spit out): saltwater, hydrogen peroxide, and water, or mouthwash

(nonalcoholic). 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. Ask your physician about avoiding Glycerin, which is drying. Ask your doctor for liquid Benadryl or Xylocaine Viscous (lidocaine). Avoid medications that

cause dry mouth, or ask your physician about this.

**Dry Skin** You may consider using a humidifier in the room. Use unscented moisturizer on skin. A

soft mattress or extra padding on the bed may reduce discomfort.

**Hunger** Offer distractions. Avoid cooking smells in the room.

Nausea Nausea is very rare. Offer distractions. Avoid cooking smells in the room. The scent of

rubbing alcohol may reduce nausea. Ask your doctor if anti-nausea suppositories might

be helpful.

**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 – the person will only urinate small amounts. Weakness will increase as the

days progress.

**Agitation** (Rare) Ask your doctor about sedatives or antianxiety medication. Talk with the person,

read to them, provide music, etc.

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.

### **CARE FOR THE CAREGIVERS**

Caring for the dying is exhausting, both emotionally and physically. The person will not need you at the bedside every minute. It is important to recognize that many dying people withdraw from the world and desire only a little contact with others. Sometimes all they require is simple and occasional reassurance. Pace yourself, and ask other family members and friends to give you a break. Hospice can also provide volunteers to sit with the person for several hours at a time, so you can rest.