

VOLUNTARILY STOPPING EATING & DRINKING (VSED)

(Adapted with permission from End of Life Choices Washington)

In the medical and legal community, it is commonly accepted that an individual who has the mental clarity to make healthcare decisions has the right to refuse medical therapies, food, and liquids. Individuals using this option can change their minds 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 arrange adequate support from your medical providers and caregivers. Also, make certain that your physician is willing to prescribe medication for pain and anxiety, should it become necessary.

End of Life Choices Oregon also recommends that you contact us at 503-922-1132 for additional support and guidance. An experienced volunteer can discuss the process with all involved and help develop a plan.

FREQUENTLY ASKED QUESTIONS

What does it mean to stop eating and drinking?

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

Do I need to be terminal prognosis?

No. A terminal prognosis, meaning death is expected in six months or less, is not required for an individual to utilize VSED. EOLCOR provides information and support to individuals without a six-month terminal prognosis, when (a) the person suffers from an incurable, progressive illness; and (b) the person is a legally competent adult, able to understand the risks and benefits of VSED.

Do I need my physician's permission to begin VSED?

No. You do not need a physician's permission, but it is important to have physician support during the process. They may need to prescribe medication for pain and anxiety. Also, ask your physician to refer you to hospice during the process.

Is VSED uncomfortable?

People's experience using VSED can vary greatly. Some 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. It is important that individuals choosing this process have adequate symptom management. Many people who are in a weakened state from disease will begin to go in and out of consciousness by the third day and later become comatose. Hunger pangs and thirst may occur in the first few days. (See the discussion of symptom management later in this document.)

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.

How long does it take?

If a person stops eating and drinking, death may come as early as a few days, but more commonly takes one to three weeks. If the patient continues to drink even small amounts, the process will take longer. It is difficult to predict exactly when the end will come – this depends on the person’s general condition, age, illness, and other factors.

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

It takes some determination, but we often find that people who make this choice are ready to “let go” and can be successful.

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 about all your medications. (See the discussion of medications later in this document.)

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.

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.

- Your physician is particularly important. Talk with him or her and make sure appropriate medication will be available to keep you comfortable.
- If you are already receiving hospice care, ask your nurses to help you prepare. If you are not on hospice, ask your physician for a referral 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 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.
- You may want to check with legal counsel about using VSED and having caregivers and family support you in hastening your death. There are no specific legal guidelines, protections, or immunities concerning VSED as there are with Oregon's Death with Dignity Act.
- EOLCOR volunteers will be available to offer information and guidance.

What should I do before I start?

We suggest the following:

- 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 are 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 and state in writing the circumstances under which it is your intention to stop eating and drinking to hasten your death. Clearly state that you want no food or fluids either by mouth, IV, or feeding tube. Have your physician sign POLST orders 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 your legal affairs, healthcare directives, and funeral/memorial plans are in order. Wrap up any unfinished business and say your goodbyes.

GENERAL INFORMATION ON STOPPING EATING AND DRINKING

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 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 B for a more detailed list of possible symptoms.)

Medications

Talk to your doctor about stopping all medications except those for pain or discomfort. You should talk to your physician or hospice nurse about all the medications you take and eliminate those that might contribute to thirst or dry mouth.

Caregiver Advice for Nursing Homes and Other Facilities

Problems have sometimes occurred when a person decides to stop eating and drinking and resides in a nursing home or other care facility. It is important that the person and family (or friends) meet with the facility director or supervisor to review the person's care needs and come to an agreement before starting. The caregiver should act as an advocate for the patient, making sure that his/her wishes are honored.

Recognize that not feeding a patient may be difficult for some staff members. Caregivers should be understanding but firm that they expect the staff to honor the wishes of the patient. Staff may exert subtle pressures (stopping by the patient's room with food or a drink) or act covertly to get the patient to eat or drink. Caregivers may need to be vigilant.

APPENDIX A: SAMPLE LETTER TO PHYSICIAN ABOUT INITIATING VSED

I want to have an honest discussion with you about how I can maintain control of my life 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 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 to end my life.
- 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.
- I request a hospice referral to support me in being comfortable during my last days at home.

- 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 in-patient facility that will support me in this process and continue to receive hospice care there.
- I need to know that this option will be available to me at the time of my choosing. I see the option I have described here 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 for my peace of mind 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 to be intolerable.

Specific questions:

1. May I count on you to support me if I proceed with my plan to voluntarily stop therapeutic medications, food, and fluids — when and if I decide that my suffering has become unbearable?
2. Would you refer me to hospice now, before I initiate my plan, in order to facilitate a smooth transition for my family and me?
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, please refer me to a physician who will support me.

APPENDIX B: MANAGING SYMPTOMS

A person using VSED may experience **some** or **none** of the following symptoms.

Here are some suggested ways to manage them:

Thirst Offer crushed ice or ice chips sparingly. Use humidifier in room. Ask hospice nurse or physician for artificial saliva, or oral sprays. Follow 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 patient 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 Viscous Xylocaine. 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 (Rare) Offer distractions. Avoid cooking smells in the room. 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 anti-anxiety 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.