



Preparing for Voluntarily Stopping Eating & Drinking

Voluntarily stopping eating and drinking (VSED) is a well understood and socially accepted method of hastening death. It is not an easy path and it is not for everyone, but both individuals who have chosen this path and their loved ones who have spoken publicly describe their experience positively. Despite this, many in the general public are unaware of VSED, have never considered it for themselves or a loved one, and are less than enthusiastic when they are first introduced to the concept. Be prepared to educate your loved ones about VSED and why you are choosing this method of hastening your death.

Clarifying Misconceptions

Isn't it painful? No, not with palliative medical care. One can expect to feel hunger pangs during the first few days, but those come and go and then stop. Once the individual starts to become uncomfortable from dehydration, hospice can provide oral care and manage any pain or agitation that arises.

How long does it take? For someone who is already debilitated, death can occur within a few days, most die within two weeks, and for those who are robust or who take small amounts of liquid it can be longer.

The length of time sounds like torture! Actually, many people find the fasting period of VSED to be a positive experience. Unlike a chosen death via inert gas or medical aid in dying, VSED provides a gradual transition both for the dying individual and for the loved ones who can visit, say goodbye, and be together in that liminal, twilight space before death.

Do you have to go to a hospital? No, palliative and hospice care can be provided in the home.

But eating is one of the pleasures of life! It is, and simple pleasures should be enjoyed when they fit into the big-picture context of one's life, but at this point, other priorities have become more important.

Preparing for VSED

Like any other significant event, putting the pieces in place beforehand will make your dying experience smoother and allow those accompanying you to focus on sharing time with you, instead of being distracted with logistical challenges.

Step 1. Appoint a Healthcare Surrogate

It is essential that you appoint a person to make medical decisions for you when you are no longer able to make them yourself, which is what will happen when strong pain medication or

sedatives are needed to keep you comfortable. Once you lose capacity to make decisions for yourself, healthcare providers will look to your legally appointed healthcare surrogate (sometimes called a representative, proxy, or your agent under a durable power of attorney for healthcare) to give instructions and consent to certain procedures.

Every state has a law prescribing the requirements for a document to appoint a healthcare surrogate. Sometimes, the appointment of a surrogate is a component of a general advance directive; sometimes, each of these two components is separate. Choose a surrogate—not necessarily a loved one—who will be able to firmly reinforce that you do not want hydration in any form and that you do want aggressive symptom control and pain management.

Prepare Instructions for Confusion and Possible Delirium: In the later stages of VSED, it is not uncommon for the dying individual to become confused or experience periods of delirium and request fluids. This is a difficult situation for caregivers who are caught between the person's earlier, competently expressed wishes and the person's current, incompetent but thirsty wishes. Prepare for this situation in order to be sure your competently expressed wishes are honored and to protect your caregivers from accusations of neglect or maltreatment. In writing, acknowledge the possibility of this happening and how you want your caregivers to respond. Write explicit instructions, such as you first want caregivers to remind you of why you chose VSED, to provide increased care for oral dryness, and to treat any agitation or delirium before acquiescing to your request for fluids.

Step 2. Muster Personal Support

While you should be able to speak for yourself, the practical reality of human interactions is that a doctor or hospice is likely to be much more comfortable with a patient's decision to pursue VSED if the person has support. That can come from family members, friends, your healthcare surrogate, a death doula, and/or a nurse care manager. The support provides evidence that your decision is not rash or out of character and has been adequately considered. Be patient; this can take time. Don't expect people to embrace your readiness to die in a single conversation.

Also, when the time comes to embark on VSED, you will need advocates, including your healthcare surrogate, to support your wishes, to assist you as you become weaker, and to communicate with palliative care or hospice representatives. Dying by VSED is a communal undertaking and it is not reasonable or practical to pursue it alone.

Step 3. Find Medical Support

Medical support is critical for VSED; without proper palliative care, the process is likely to be awful for all involved. We strongly recommend that you have medical support identified before you begin VSED; unfortunately, that is often easier said than done. The law is clear that a competent adult may choose to stop eating and drinking, and that a competent adult and their healthcare surrogate may refuse medical treatment. However, while you are free to embark on VSED, doctors and hospices do not have a legal obligation to medically support you. When you ask a doctor or hospice if they will provide palliative medical support, they might say "no." Look for medical support gently and flexibly, as this is something you must ask for; demanding it won't work and is likely to backfire.

Your Doctor: The best place to start is with your doctor. If you have a terminal illness or are frail enough that a doctor could reasonably predict that you have less than six months to live, the doctor can provide a hospice referral immediately. If your condition is such that death is not reasonably expected in six months, you will need to plan with your doctor. Your doctor could provide palliative medical support directly, give you a referral for palliative care, or, after you have been fasting from both food and fluid for a few days, the doctor can genuinely say you are now within six months of death and provide a hospice referral.

End of Life Washington has a short document introducing VSED that includes a sample letter for approaching your doctor (see “Resources” at the end). Unfortunately, not all doctors are willing to support a patient who chooses this path, even if the doctor has worked with the patient for many years. If your primary care physician is not supportive, try reaching out to any specialists you are working with.

Organizations: If you’re having trouble finding a supportive doctor, another possibility is a death with dignity organization in your state. Many states have organizations geared toward either advocating passage of death with dignity legislation or supporting that legislation once it has passed. In some cases, they might be prepared to help people navigate the path to VSED. Even if they don’t directly offer that support, they might be able to suggest sympathetic healthcare providers or hospices that you could reach out to.

Death Doulas: While the advent of death doulas, at least in a formal sense, is relatively new, there is a growing number of people who work in this capacity (keep in mind this is a self-defined role). An experienced death doula is likely to have worked with a number of palliative care and hospice providers, and might be in a position to make connections on your behalf. You might find a local death doula through an internet search. There are at least two organizations that maintain directories: the International End of Life Doula Association and the National End-Of-Life Doula Alliance.

Hospices: You could try approaching hospices directly, as self-referral is possible. When looking for a hospice, start with those not associated with a hospital or organization that has a religious affiliation. Remember, hastening death is a politically sensitive topic, and many hospices are likely to be defensive and cautious if asked in an upfront manner. Again, unfair though it may be, you might have more luck if someone represents you, such as a nurse care manager, your healthcare surrogate, a death doula, or a family member or friend. The hospice is more likely to be comfortable if multiple people support your VSED choice; it gives them confirmation that your choice is well-considered. While it is risky to start VSED before having hospice care lined up, it might facilitate finding a hospice amenable to providing care if they are told that the patient has started VSED on their own and is seeking support.

Step 4. Prepare for Personal Care Needs

For VSED to go smoothly, one must prepare for both medical care and personal care. For a comfortable VSED process, it is critical to have good dry-mouth care. As you become dehydrated, the inside of your mouth will dry out and the sensation of a dry mouth triggers thirst. This is a problem for obvious reasons, and, if left untreated, the skin inside the mouth can blister painfully. Fortunately, there are a number of products that moisten the mouth without providing significant fluid. See the Chabot and Shacter resources listed at the end.

You should also assemble the supplies you will need for clothing, bedding, toileting, and hygiene. Shacter's resources are particularly helpful with this.

Step 5. Consider a Home Health Aide

Many people prefer to stay at home and that can work well, but you should consider the care you will need toward the end as you become weaker and more heavily sedated. Oral care is particularly important and there is also the basic care needed for one who is less mobile and then bedbound. You should consider whether your loved ones, as willing as they may be, are in the best position to provide that care. Hospice might help some with this, but a professional caregiver or home health aide can be extremely helpful, both for you and for your loved ones. Once you become weaker and possibly confused, you cannot be left alone. Hospices and death doulas are likely to have guidance for finding a home health aide.

Consider Your Location

If you live in a continuing care retirement community, an assisted living situation, or a care facility of some kind, you might consider, early in your planning, approaching the management, preferably having your supportive loved ones with you. Explain that you are considering VSED, give them a copy of Pope and Anderson's article (see "Resources"), and expect to have to educate them. They will likely need to discuss it internally, and they might want a psychiatrist's opinion that you are not clinically depressed or a legal indemnification of some kind. If you get the sense that management is hostile to the idea, consider moving to a private residence for the VSED process. While you are well within your rights to choose VSED, the powers-that-be can make it difficult. *The New York Times* reported the story of Armond and Dorothy Rudolph who, 4 days into their VSED fast, received an immediate eviction notice from their assisted living facility ("Deciding to Die, Then Shown the Door," Paula Span, August 24, 2011).

Unfortunately, regardless of where you live, if someone objects to the idea of a hastened death, they can raise questions about your competence, suggest you are being coerced, or accuse your caregivers of abuse. Social services must respond if they are alerted to the possibility of abuse, and you don't want your dying process disrupted with bureaucratic review or worse, a legal injunction. This is not a theoretical concern. Phyllis Shacter (see "Resources") describes a visit from Adult Protective Services during her husband's VSED fast.

Working with Palliative Care and Hospice

Care for an individual choosing VSED is beyond the scope of this document, but it is well understood and most hospices are familiar with the process. At the end of this document there are a few resources that provide useful information about what to expect and what types of products are useful to have before embarking on VSED.

When working with palliative care or hospice, remember that they respond to your needs, but do not usually treat them before they arise. The most important part of symptom management, including pain control, is staying in front of the symptoms. To be sure you are kept comfortable, speak up early in requesting pain control, and be persistent and firm. Medical support is there to

keep you comfortable, so neither you nor those caring for you should hesitate to speak up at the least sign of discomfort or agitation, and a little anticipation in this regard is not a bad idea.

Must VSED Be All or Nothing?

People approach VSED differently. Some live their lives normally until they are ready and then stop eating and drinking at a single point in time. Others transition by stopping eating for a few days or tapering their caloric intake, and then stopping fluids. You could take a few days to taper off fluids. Many who are already frail have been eating and drinking less as a natural result of their condition and so are already on the path when they embark on VSED. You can approach VSED in whatever way works best for you, but the critical thing to remember is that dehydration is what ultimately causes death. Fluid intake of any kind, including the moisture in food, will prolong the dying process.

Resources

Voluntarily Stopping Eating & Drinking (VSED), by End of Life Washington (2020)

This handout can be downloaded from End of Life Washington's website, endoflifewa.org/end-life-choices (scroll down to find the VSED document in PDF format). This introduction to VSED is a good place to start.

Stopping Eating and Drinking: A Guide, by Boudewijn Chabot MD PhD (2014)

Chabot's short book can be purchased from his website, dignifieddying.com, and provides a great deal of information very succinctly, including a summary of oral care measures and a table of often-used medications.

Phyllis Shacter's website, www.phyllisshacter.com, is dedicated to demystifying VSED and is based on her experience supporting her husband through VSED. Under "The VSED Choice," she provides a list of the caregiving supplies they used. Shacter's supply list anticipates practical care needs that will arise, including oral care, medication, and personal care.

Choosing to Die: A Personal Story: Elective Death by Voluntarily Stopping Eating and Drinking (VSED) in the Face of Degenerative Disease, by Phyllis Shacter (2017)

Shacter's book is about her husband, Alan's, choice to hasten his death by VSED rather than sink into Alzheimer's. It tells their story, describing their relationship, and elaborating on their evolving thought process and emotional experience. Whether or not that backdrop is of interest to you, the book includes a summary of the daily log of Leslie Powell Shankman, the Certified Nursing Assistant who was Alan's primary caregiver through his VSED process. That daily log is a good reality check for those embarking on VSED and for those who will care for them.

Voluntarily Stopping Eating and Drinking: A Legal Treatment Option at the End of Life, by Thaddeus Mason Pope and Lindsey E. Anderson (2011)

This article appeared in the *Widener Law Review* (17, p. 363). It is an in-depth examination of the legal status of VSED. Though it is long, have a printed copy available whenever you might be questioned about the legality of your choice. Download it from:

<http://open.mitchellhamline.edu/facsch/278>

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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 medical therapies, and this includes food and liquids. 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 and your caregivers, and that your physician is willing to prescribe medication for pain and anxiety, should it become necessary.

End of Life Washington also recommends that you call for good information on this. 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 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 would be to stop these therapies.

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

No. A terminal diagnosis is not required for an individual to utilize VSED. However, for EOLWA to provide information and counseling to a person who is not terminal within six months, our organization must be convinced that (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 at the time VSED is begun.

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 support you during the process by prescribing medication for pain and anxiety, if needed. Ask your physician to refer you to hospice during the process.

4. Isn't this uncomfortable?

People's experience 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. 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.)

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?

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.

7. 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 are able to be successful.

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 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.

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.
- Your physician is very 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 Washington's Death with Dignity Act.
- End of Life Washington will be available to counsel you and offer information.

11. 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 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 state in writing the circumstances under which it is your intention to stop eating and drinking in order 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 all of 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

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 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.)

2. 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.

3. 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 process. 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.

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 1.800.562.6028.

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:

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| 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.