



Preparing for Voluntarily Stopping Eating & Drinking

Voluntarily stopping eating and drinking (VSED) is a method of hastening death that has become more socially visible in the last few years. 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. Don't overlook preparation; it is critical.

Step 1. Appoint a Healthcare Representative

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 representative (sometimes called a healthcare power of attorney, proxy, or surrogate) to give instructions and consent to certain procedures.

Often, your state's standard advance directive form will have a place to appoint a healthcare representative. Choose a representative—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 or with video, acknowledge the possibility of this happening and how you want your caregivers to respond. Provide 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 representative, 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 representative, 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 representative 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 representative, 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 already started VSED 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

End of Life Washington's website on VSED has a useful handout, a *Practical Guide to VSED*, that you can download, as well as a document with clinical guidelines for VSED:

www.endoflifewa.org/end-life-choices/vsed

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

Chabot's short book can be purchased from his website, www.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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