

# Voluntarily Stopping Eating and Drinking



Care and Choice at the End of Life

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**Compassion & Choices** is the nation's oldest, largest and most active nonprofit working to improve care and expand options for the end of life.

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# Voluntarily Stopping Eating and Drinking (VSED)

Free will and the ability to choose are cornerstones of maintaining one's quality of life and dignity in their final days. Many people struggle with the unrelieved suffering of a chronic or incurable and progressive disorder. Others may decide that they are simply "done" after eight or nine decades of a fully lived life. A person may choose to control their own dying by making a conscious decision to refuse foods and fluids of any kind, including artificial nutrition and/or hydration. This option, sometimes known as VSED, can be chosen by a decisionally-capable adult who has the physical ability to eat and drink but consciously refuses foods and fluids in order to advance the time of their death. A determined and well-informed individual with significant caregiving and hospice support can successfully choose this end-of-life option. The U.S. Supreme Court has affirmed the right of a mentally capable individual to refuse medical therapies, including food and fluids.

The following general information is provided to inform those who may consider this option and should not be considered legal advice that applies to your specific situation. Information has been compiled based on the experiences of other Compassion & Choices' clients who chose this option, and from the findings of several small research studies of hospice patients who stopped eating and drinking as death neared.

## What Is the Process of Dying From VSED Like?

The exact process of dying from VSED unfolds in a unique way for each person and depends on physical, mental and emotional circumstances.

In the first few days of the fast, some people may remain as active as before but many soon will become weak, fatigued and increasingly sleepy. Once they begin to feel light-headed and weak, movement requires assistance in order to prevent falls or accidents. Weakness or dizziness may occur suddenly, which is why 24-hour care is recommended once the fast begins. Mental alertness is replaced by longer and longer periods of sleeping. In many cases individuals eventually cannot be roused and remain in an unconscious or coma state. Some individuals have periods of alertness throughout the process up until death. The dehydration from VSED affects the kidneys and the heart, and the other organ systems in the body begin to shut down.

Since VSED is a natural process of dying, individuals can have a range of symptoms and experiences. Some people express a sense of peace that they can "stop fighting" and describe feeling euphoria or pleasant light-headedness. Researchers believe there is an analgesic effect caused by dehydration that may explain this response. Other people may experience increased confusion, delirium or agitation during the process as the organs shut down and the chemicals in the body change. Unwanted symptoms can typically be managed with medications from the doctor or hospice.

Death from VSED is a natural process. As death nears, breathing becomes more shallow and irregular. Moaning or “rattling” breathing may occur, but is not believed to be an indication of pain or distress. The body may change temperature and there can be discoloration in the face (flushed red, or pale with bluish or yellowish tones), as well as purple or bluish mottling in the hands or feet.

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

It is difficult to predict exactly when the end will come — this depends on the person’s physical condition, age, medications taken, illness, height and weight ratio, fluid retention, ability to remain completely free of all fluids, and perhaps a readiness to “let go.” For a terminally ill person the process may take several days to several weeks after intake of food and water stops. Some people experience unconsciousness in as little as two to three days. For those without terminal illness the length of time to death tends to be longer. During the early stages of VSED the individual remains in control of the process and can stop VSED by resuming intake of food and fluids. Individuals and their loved ones who consider this option should understand the importance of stopping all fluids, including ice chips, once the fast has begun in order for death to occur within the shortest interval. Intake of even small amounts of food or water can prolong the dying process, but it is up to the patient to determine their own intake. Excellent oral care is important to ease the symptoms of dry mouth (see below).

Since the length of the process is unpredictable, some individuals plan ahead for how to make this time meaningful for themselves and their loved ones. They may choose favorite movies, music, poetry, or passages to read or have read to them. Photo albums or scrapbooks may be used to share memories or favorite stories. Some people have kept a journal, written notes to loved ones or created some type of “legacy project” to leave behind for loved ones. Caregivers may take turns providing gentle touch or massage, applying body lotion to keep the hands and skin hydrated. Planning ways to bring meaning, pleasure and comfort during this time may reduce the anxiety about the length of the process.

### **Is VSED painful? How can I receive medications without fluids?**

A person’s comfort level depends on many factors, including overall physical condition, age, disease progression, appetite before the fast, as well as emotional concerns. Caregivers or healthcare providers can usually manage any unwanted symptoms. The most frequently reported symptoms include thirst or dry mouth, occasional hunger, and feelings of uncertainty about the approach. Providing oral care on a regular schedule can help ease symptoms of dry mouth; use lip salve, mouthwash, oral sprays and gel like Biotene, soft toothbrushes, glycerin swabs or sponge swab, and rinses with cool water or another beverage of choice (not to be swallowed). Some people have reported that coconut oil (the type used for cooking) can be soothing on the lips, gums and tongue. Vaseline or non-petroleum based lip balm can be used to keep the lips moist. Use a humidifier in the room. Using ice chips or small sips of water may extend the length of the dying process. Caregivers can also use body lotions to hydrate the hands and skin. Hospice can provide symptom management can be consulted about additional resources and comfort measures.

It is important to review all medications with a physician before beginning the fast. Your physician may recommend that you avoid medications that may cause dry mouth or thirst. Stopping some medications, such as those for heart disease or diabetes, may secondarily speed up the dying process without increasing discomfort. Medications for pain, agitation, anxiety or other symptoms may be available in forms that don't require drinking fluids, such as sublingual drops, skin creams, skin patches or suppositories. People respond differently to medications, and it is important to inform doctors of any allergies or negative reactions to any medications. It may take healthcare providers some time to find the best medication or combination of medications to meet the individual's needs. Many medications used at the end of life have a sedative property and cause drowsiness, which may lessen possible symptoms of discomfort in the VSED process.

### **I don't like the idea of not drinking; can't I just stop eating? Isn't hydration important for comfort?**

A person can live for a very long time without eating, but dehydration (lack of fluids) speeds up the process. VSED is ultimately a process of dehydrating the body. Dying from a lack of food alone can be prolonged and more uncomfortable than dying from dehydration. Dehydration can reduce fluid overload in the body and may also diminish some of the respiratory distress of congestive heart failure and pulmonary edema. Less fluid in the body may also lead to less frequent episodes of coughing, choking and shortness of breath, thus contributing to comfort rather than suffering. The various techniques discussed above can ease symptoms of dryness.

## **How Should I Prepare for My VSED Decision?**

Learn as much as you can about this process before beginning. Here are some general guidelines:

- » You cannot do this alone. You will need 24-hour care during this process, and ongoing hospice care or oversight by your physician. Begin by discussing your end-of-life wishes and concerns with family, caregivers and your primary physician.
- » Be sure your advance directive paperwork is up to date and expresses your specific wishes. You can find advance directive resources on Compassion & Choices' website at [CompassionAndChoices.org/what-we-do/advance-directive](https://www.compassionandchoices.org/what-we-do/advance-directive)
- » You can also talk with your doctor or hospice nurse about completing an Out of Hospital Do Not Resuscitate (DNR) order and / or Physician Orders for Life-Sustaining Treatment (POLST) form.
- » Be sure all your caregivers know who to call when death occurs. We encourage you and your support persons to speak with your hospice regarding what takes place when death occurs. **You do not need to call 911 if you are in the care of hospice** or have a doctor identified who is willing to sign the death certificate.
- » You can add a statement to your advance directive declaring your voluntary and informed decision to refuse all further oral intake with the understanding that doing so will permit you to control your dying. This document should be signed, dated and witnessed, just as your state requires other advance medical directives to be signed and witnessed.

- » You may wish to write a letter or make a video in which you talk about your intentions to stop eating and drinking, and why you would like to control your death. This may be helpful in the event that your memory fails or cognitive changes impact a previously made decision.
- » Talk with your physician and/or hospice nurse to explain your end-of-life wishes, values and concerns. Be sure to describe your current condition and fears about further deterioration in your quality of life, and your desire for comfort care. If you are not currently on hospice you can discuss getting a referral to a supportive hospice from your doctor once you begin the fast and become eligible for this care benefit.
- » If your illness is not likely to cause death within six months and you do not have a terminal prognosis, your medical providers may require you to be evaluated for depression and decision-making capacity before offering their support. A psychiatric evaluation is routinely done to rule out serious depression, dementia, severe anxiety or other mental conditions that could prevent an informed choice about your own end of life. If you are a senior citizen, ask your physician for the name of a psychologist or psychiatrist who specializes in geriatric evaluations.
- » If you reside in a care facility discuss your wishes with the nursing director or social worker. You will need their agreement to support you. You will need to make arrangements for 24-hour care once the VSED process has begun. Make sure each care provider understands and is supportive of your plan to stop all oral intake. Whether a family member or a paid caregiver, everyone caring for you must understand and support the fast.
- » Acknowledge to your caregivers that if you request nutrition or hydration, they are ethically bound to provide it. However, you can discuss how they might respond in a way that reminds you of your original intention. For example, “OK, I’d be happy to get you some milk, but I just want to remind you that you wanted to stop eating and drinking to control your dying. Do you still want that milk?”
- » VSED can be modified in any way you choose — as long as you clearly understand and accept that it may prolong the dying process.
- » You may resume eating and drinking in the early stages of VSED, but later food and liquids can be taxing to your system, which has begun shutting down.
- » Complete all your business/financial tasks, and make funeral or memorial plans.
- » Discuss with your caregivers and loved ones what would make this time meaningful for you (favorite music, poetry or literature; personal stories or memories; gentle massage or touch; etc.)

## Is VSED Protected by the Law?

Personal autonomy and self-determination are the legal bases for end-of-life decision making. A decisionally capable person (meaning a person not suffering from dementia or mental illness that would prevent informed decision making) is allowed to refuse any unwanted treatment, even if that refusal will result in death. This includes individuals who do not have a terminal illness. For a person planning to do VSED who does not have a terminal illness it can be helpful

to receive a psychiatric evaluation for decisional capacity and to rule out depression or other conditions that may affect decision-making capacity. Once the individual is determined to have decisional capacity, their wishes can be written or videotaped and attached to their advance directive. This makes clear that the decision to not provide nutrition and hydration was made by the informed and decisionally capable individual, and is not an act of neglect or abuse by caregivers. If the individual reconsiders their decision and decides to resume eating or drinking after starting VSED, caregivers must honor that choice. This occasionally occurs when the person is ambivalent about controlling death, the process seems more arduous than expected, or cognitive changes undermine the ability to be self-determining.

If the person planning to undertake VSED has dementia, depression or other conditions impacting their decision-making capacity, VSED may pose challenges to caregivers. It is important to have frank conversations with your caregivers, medical providers and legal advisors about your wishes.

### **What obstacles might I face?**

Even though the U.S. Supreme Court has affirmed the right of a decisionally capable individual to refuse food and fluids, not everyone is understanding and supportive of this choice. Many factors including your physical condition, illness or disease progression, age, living arrangements, and geographic location may impact your ability to get support with this decision. Support is necessary, as you cannot safely do this alone.

This choice requires much personal determination and a willingness to “let go.” The process may be difficult if you are still receiving pleasure from food or if you feel unresolved or unfinished in any areas of your life. Since a decision to start VSED does not bring about an immediate death, you are able to change your mind during the initial stages of the process. You should discuss this possibility with your caregivers before you begin the fast. Caregivers can then remind you of your goal or share your letter or video, and then ask if you would still like what you requested. Remember that sips of water or sucking on ice chips may prolong the length of the dying process. Should you decide to stop the process, you can always begin it again in the future.