

Things to consider:

Voluntarily Stopping Eating and Drinking (VSED) for individuals, families and caregivers

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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. For more than 40 years we have sought to change attitudes, practices and policies so that everyone can access the information and care they need. Compassion & Choices is committed to collaborating with legislators from every state and political party who seek to honor their constituents by engaging in this mission with us.

Introduction

Many people struggle with unrelieved suffering from an incurable and progressive disorder, disease or illness. Others may reach a challenging stage of frailty after eight or nine decades of a fully lived life. Compassion & Choices supports people at these stages exercising their right to choose end-of-life care that reflects their values, priorities and beliefs.

A determined and well-informed individual can successfully choose the legally defensible end-of-life option of voluntarily stopping eating or drinking. VSED is when a mentally capable individual decides to control their own dying by making a conscious decision to refuse foods and fluids of any kind, including artificial nutrition and hydration, in order to advance the time of their death. While it is a natural way of dying, someone engaging in VSED needs and deserves caregiving and support for adequate symptom management, comfort care and emotional support. Compassion & Choices offers guidance for how best to secure this support before embarking on a VSED journey.

Voluntarily Stopping Eating and Drinking (VSED)

What is VSED?

A person who chooses to voluntarily stop eating and drinking (VSED) is choosing to forgo all forms of nutrition and hydration in order to control how and when they die.

Is VSED right for me?

Typically, VSED is a choice made by adults approaching life's end who want more control over the timing and manner of their death. Most people who choose this option for dying are already near the end of life due to illness or advanced age, in serious or accelerated physical health decline, or facing impending cognitive decline from diseases like dementia. They may be already experiencing a loss of appetite. Others have refused or ceased artificial nutrition and hydration. Sometimes dying people choose VSED because they are not eligible for or cannot access medical aid in dying where they live. Beginning the VSED process is not a way to become eligible for medical aid in dying. To learn more about medical aid-in-dying eligibility, visit: CompassionAndChoices.org/medical-aid-in-dying

What do I need to know about VSED?

Every experience of VSED is different. Because VSED is a natural process, the symptoms and timeline can vary from person to person. For some, it can feel like a gradual, peaceful transition. For others, it may be more physically and emotionally challenging. Age, overall health, medications, illnesses, body type, fluid retention, and even a person's readiness to let go can all influence how the process unfolds.

If you choose VSED, you should plan carefully to be sure you receive adequate symptom management, comfort care and emotional support. Hospice services, end-of-life doulas and caregivers can help you during your process. It's important that your care team and loved ones who will be involved are on board with your decision and have open, ongoing conversations about how they can collaborate to achieve your wishes.

What steps can I take to have a peaceful VSED journey?

- > Research and understand VSED experiences
- > Discuss with family, loved ones or caregivers
- > Document in an advance directive and, if possible, make a short phone video to show your well-thought-out intentions
- > Secure a supportive care team

Does a doctor need to support my VSED journey?

No. VSED is a natural dying process and doesn't require a doctor or clinician to participate. However, it can help significantly to have clinical support.

Although VSED is a legally defensible end-of-life option, you do not necessarily have the right to clinical assistance for VSED. Some clinicians might not be comfortable continuing to treat a patient who is voluntarily stopping eating and drinking. Some might not even be aware of VSED as an end-of-life care option.

Compassion & Choices advocates for patients to have frank and open conversations with their clinicians without fear of negative consequences so that they may find the care and support they need. If your clinician shares that they cannot support your wish for VSED, thank them for listening. Ask them if they know of someone that might be able to help. Call your local hospice to see if they can recommend someone. Also, if you choose a hospice for support, their medical director can be your clinician.

What should my medical providers know?

Even if your medical provider supports your VSED journey, they may still need information or resources related to VSED. For more information to guide clinicians, [click here](#).

What should my family and friends know?

It is important to have a support network around you when you choose VSED. How will you convey your desire to choose VSED to those individuals? Here are some tips:

- > **Ground the conversation in your values:** Start by sharing why you are considering VSED. Discuss your values and what matters most to you as you near the end of

your life. Framing the decision in the context of your beliefs can help others understand your choice. Find more advice on how to talk to your provider here.

- > **Involve your chosen support system early:** Including your support network early can help cultivate understanding and connection and avoid feelings of exclusion.
- > **Prepare for a range of emotions:** Your loved ones may respond with a wide range of emotions, from surprise to grief. Acknowledge those emotions and reaffirm your decision.
- > **Share credible information:** Many people are not familiar with VSED. Provide materials like this one or the resources provided below to your support network so they can research on their own.
- > **Name your healthcare proxy:** Designating someone who will honor your wishes is incredibly important and including them in these conversations is critical.

What should my hospice know?

Start discussing your interest in VSED with your current or potential hospice care providers early on. Explain your wishes, values and concerns, and your desire for comfort care.

Hospice providers may choose not to continue caring for a patient who wants to pursue VSED, or they might agree to continue care but lack proper training to support a VSED patient. Others might enthusiastically and capably assist a patient through the VSED process.

Even if you are enrolled in hospice, you will need to make arrangements for 24-hour care once the VSED process has begun. In addition to healthcare providers, your care team might be family or friends who understand the process and have been instructed on how to give appropriate comfort care. Make sure each care provider understands and is supportive of your plan to stop all forms of food and hydration. Whether a family member or a paid caregiver, everyone caring for you must understand what measures are needed to undertake and complete VSED.

If facing any pushback from a hospice provider on your decision to VSED, call [Compassion Legal](#).

What if I'm not currently eligible for hospice?

VSED is more difficult if you have a longer prognosis and lack hospice care. In these cases, you need a caregiver(s) who is committed to honoring your wishes and assisting you constantly throughout the process.

Hospice eligibility requires a prognosis of less than six months. If your illness is not likely to cause death within six months, some hospices will not admit you until you have stopped eating and drinking. You can accept that approach or look for another hospice that will admit you before you start VSED. Either way, at some point in your process, you will likely become eligible for hospice, and it is helpful to preestablish a relationship with a hospice provider to become a part of your care team when the time is right.

Regardless of your prognosis, your medical providers or hospice administrators may require you to be evaluated for decision-making capacity and psychological conditions, like depression, before giving their support or admission to hospice. If you are an older adult, ask your physician for the name of a psychologist or psychiatrist who specializes in geriatric evaluations.

What if I'm in a residential facility?

Ideally, before moving into a residential care facility, you should inquire to ensure that the facility and its staff will support you in your end-of-life care wishes, including if you choose to undertake VSED. Consider including a [rider to your residential agreement with the assisted living facility](#). Having this rider in place helps ensure that an assisted-living facility will respect your wishes for end-of-life care.

If you currently reside in a skilled nursing 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 food and fluids. You might also discuss your desire not to be taken to places where food is being served and for staff and family not to bring food or drink into your room. Whether a family member or a paid caregiver, everyone caring for you must understand and support the fast.

Support for VSED in residential care can vary depending on the type of facility and the level of care they are licensed (and contracted) to provide, the laws and regulations that govern them, and the policies of the building itself.

- > In independent and assisted living facilities, medical support might be limited. Some might offer support for VSED if you are enrolled in hospice.
- > Skilled nursing facilities provide around-the-clock medical care and assistance for people with complex health needs. You will likely struggle to find support for VSED in this environment, especially if you are admitted for a short-term rehabilitative stay.
- > If facing any pushback from a residential facility about choosing VSED, contact [Compassion Legal](#) for help.

What if I have a dementia diagnosis?

Because VSED is voluntary, you need to be able to make your own decision to undertake it. If you have mild dementia, you are probably able to make a VSED decision. In moderate dementia you may or may not be able to make a decision. In severe dementia you will not be able to make this decision. Physicians can evaluate you for decision-making capacity.

Healthcare providers typically determine whether a patient's decisional capacity is intact through interviews, which might include multiple conversations with more than one clinician.

What if I begin VSED, then ask for food or water during the process?

Your caregiver is ethically bound to provide nutrition or hydration as requested by you, the patient. However, before you begin VSED, you can discuss how they might respond to your request in a way that reminds you of your original intention while leaving the option to eat or drink open. 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?" Caregivers could also play your recorded video statement as a reminder of your goal.

Before you begin VSED, you can also discuss with your caregivers your desire to receive minimum comfort hydration should you repeatedly ask for a drink after the process has begun. You might also consider adding a similar statement to your advance directive. Although an advance directive cannot be a sole basis for honoring your wishes to VSED, documenting your intention can be helpful to your caregivers should you ask for food or hydration or become incapacitated during the process.

What if friends or family are hesitant to support me?

Friends and family may be hesitant to support your decision based on many factors, including a lack of understanding or knowledge about VSED and the process. Describing her partner Joan's VSED journey, Fran Volkmann provides a helpful analogy:

“One member of our core group, Audrey, distinguished between being on the *outside* and the *inside* of the situation in which we found ourselves. When people first hear of a decision like Joan's, it comes as a bolt out of the blue and their initial reaction can be one of horror or dismay. As they learn more, they are brought into the inside, and their responses become far more nuanced, less judgmental, and in our experience, often pointedly supportive.”

There may be loved ones who remain hesitant to support you or even stand against your choice. In those cases, you may choose to honor their choice and excuse them from the process. It may be worthwhile to note their exclusion from your healthcare decision-making in your advance directive.

If your [healthcare proxy](#) or alternate proxy will not support your VSED decision it is important to consider changing proxies. It's important that your care team and loved ones who will be involved are on board with your decision and have open, ongoing conversations about how they can collaborate to achieve your wishes.