

## VSED and Hospice Care: A Case Study

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If a patient decides to forgo eating and drinking in order to hasten his or her own death, how should a hospice respond?

From a legal standpoint, “voluntarily stopping eating and drinking” (VSED) is an option for individuals in all 50 states *and* distinct from the natural reduction in nutritional intake that accompanies the dying process. It is a voluntary decision by patients with decision-making capacity, with the explicit intention of hastening death.<sup>1</sup>

While legal, however, the peer-reviewed literature does not reflect strong ethical consensus about whether, how, and for what reasons hospices should or should not participate in patients’ care decisions about VSED.

The NHPCO Ethics Advisory Council offers the following case study and questions in the spirit of fostering robust discussion on this difficult ethical issue. The Council also encourages each hospice to explore these questions in their organizational ethics committees, with the ultimate goal of establishing a policy or guidelines to address VSED so staff is prepared when such situations arise. Some resources that may help inform these internal discussions are provided at the end of this article.

### The Case of Dr. S

Dr. S was a 58 year-old well-respected gynecologist who was admitted to hospice home care on November 1. He had been diagnosed with amyotrophic lateral sclerosis (ALS) three years prior. Progressive weakness in his arms forced him to retire from his work just one year after diagnosis. As he lost total functional use of his arms and shoulders, Dr. S became dependent for all care. He remained able to stand and walk 10 to 15 feet with one assist. At the time of admission, his respiratory status and swallowing were not impaired. His appetite was good and the only medication he required was baclofen for muscle spasms.

Dr. S lived with his second wife and had two adult children from his first wife, both of whom were involved in his life. His first wife died from ALS 15 years earlier. Within days of admission, the patient requested transfer to the hospice house. During his first month there, he went home via ambulance once or twice weekly for evening meals with his family. By December, his lower extremities were weaker and he required a two-person assist for transfers.

In January of the next year, Dr. S began telling the hospice staff that he was planning to go on a “fast” sometime in the near future. He stated that his plan was to refuse all nutrition and hydration and to discontinue most of his medications, with the purpose of “hastening his death.” At a meeting with the hospice staff and his family, he confirmed that the head of an ALS support group counseled him that through these efforts he should pass away

peacefully “within 10 to 14 days.” Dr. S’s wife and children were quietly supportive of his plan. However, Dr. S was not ready to start the fast until after he received an award from a local group honoring his contributions to the community. The ceremony was planned for later that month.

An impromptu meeting of the hospice ethics committee convened the following week. In the meeting, clinical staff and committee members wrestled with conflicting thoughts and powerful feelings regarding Dr. S’s proposed plan of care. Some strongly believed that a core element of the philosophy of hospice care was to allow patients to die “on their own terms,” and that Dr. S’s wishes should be honored and supported by the team. Others strongly believed that hastening death — by whatever means — was directly contrary to the hospice philosophy of care, and that the team should explain to Dr. S that it could not support his proposed plan to begin VSED. Interestingly, many present at the meeting explained that they held both beliefs simultaneously, and openly wrestled with distress in trying to resolve the perceived tension between the two.

Following the ethics committee meeting, it was explained to Dr. S that the hospice would not be able to hasten his death and would not participate by withholding nutrition, hydration or medications. The staff would continue to offer meals three times a day, as well as prescribed medications as ordered. Dr. S would make the choice to either accept or refuse nutrition, hydration, and medications, and this would be documented at every shift. The staff would treat him with respect and provide the same level of comfort care afforded all patients at the hospice house. Dr. S and his wife understood and agreed to the plan, if and when he chose to fast.

Dr. S attended the award ceremony, and soon after began telling the staff that he planned to start the fast on either February 15 or 22. On February 11, Dr. S’s son approached his hospice nurse and expressed concern, referring to the plan as “assisted suicide.” The son was counseled that voluntarily stopping eating and drinking was not assisted suicide and it was his father’s choice and right. However, the son’s statement clearly added to the staff’s struggle with accepting Dr. S’s plan.

Dr. S began his fast on February 19. After three days, Dr. S decided to modify his plan, hydrating with sips of water. His baclofen was offered in transdermal form, but he refused and took only ibuprofen. Dr. S remained quite comfortable and continued to enjoy going out to the sunroom and gardens. He refused most medications, including lorazepam, because, in his words, it made him “too sleepy to enjoy the gardens.”

In numerous conversations with the medical team at the hospice house, Dr. S talked about his reasons for fasting, which he summed up as “can’t garden, can’t work, no reason to live.” He did not seem to realize the impact of these statements, which were often spoken in the presence of his adult children. As time went on, he became frustrated and angry. The nursing staff became even more uncomfortable when he frequently said to them, “I’ll give you \$100 for a Coke,” to which they always replied, “I can get you a Coke anytime, if that’s what you want.”

On March 6, 18 days into his fast, Dr. S was on the verge of tears, “I am going nowhere,” he cried out. “This is taking too long!” The ALS support group counselor continued to visit Dr. S, but less frequently at this point. Dr. S continued to refuse most medications offered for comfort.

One week later, Dr. S’s primary physician reiterated her continued support for the hospice staff and urged the staff to continue to offer medication in appropriate amounts for appropriate reasons. She stated that the patient’s choice to hasten his death put everyone, including herself, “in a precarious position.”

Over the next five weeks, Dr. S had a steady, very slow decline. He remained alert and oriented with only intermittent signs of confusion. Consistent with his wishes, hospice staff continued to get him dressed and, with

the aid of a Hoyer lift, into his wheelchair until three days before he transitioned into an active phase of dying. He died comfortably with his family at his side, on April 14 — approximately eight weeks after he began his fast.

## Discussion Questions

1. Given the hospice philosophy of supporting the goals of the patient, what ethical issues do you think emerge in the case of Dr. S?
2. When he began his fast, Dr. S's death was not imminent; his functional decline was accelerating, but he had a prognosis of several months until death. Is a patient's projected time until death ethically relevant when considering if and how hospice teams should support a choice to begin VSED? Why or why not?
3. The hospice staff in this case honored the wishes of Dr. S by not placing trays of food in front of him. However, the staff did ask him three times a day if he wanted food just in case he changed his mind. Does this response by the care team cross the line in not respecting Dr. S's wishes? Why or why not?

Six members of the NHPCO Ethics Advisory Council contributed to this article: Patrick T. Smith (co-chair); Elizabeth Collins (co-chair); Tim Cox; Deborah Jacques; Bonnie Meyer; and Kate Pepin. To learn about the Council and its work, visit the [NHPCO website](#).

### References:

<sup>1</sup> Quill, T. E., Lo, B., & Brock, D. W. (1997). A comparison of voluntarily stopping eating and drinking, terminal sedation, physician-assisted suicide, and voluntary active euthanasia. *JAMA*, 278(23), 2099-2104.

### Resources to Inform Further Discussion

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