

A Fading Decision

Mrs. F, seventy-five, was diagnosed with Alzheimer's. She and her spouse often discussed how to handle the progression of the disease. She was adamant about not coming to the point where she would be unable to recognize herself, her husband, or their son and daughter. Their children lived a day's flight away and had their own responsibilities, and she did not wish to be dependent solely on family or others for bodily care. She would not be an emotional, physical, or financial burden on them. She did not, under any circumstance, want to spend her final years in a nursing home. She decided to die in a manner and at a time of her choosing.

The manner she chose was voluntarily stopping eating and drinking (VSED), and she chose a specific date on which to carry out her plan. She asked her husband to promise, should she ever waver and request nutrition or hydration, to remind her of the reasons she had chosen for pursuing this path.

Mrs. F's ability to function was beginning to wax and wane. Sometimes she was her old self, and sometimes she had no recollection of her past identity. Her functioning was not impaired enough, however, and she was not thought near enough to the end of her life, for her to be admitted to a hospice. Instead, she and her husband relied ever more heavily on the support of friends and

supported by her husband and children, decided to hasten death by means of VSED so as to avoid her worst fears. But she waited a bit too long. Sometimes she remembered why she had chosen VSED; at other times, she did not. Her old identity was fading in and out, and she was gradually assuming a new one.

Informed consent requires that a patient be informed of the risks and benefits of a proposed course of action, understand that information, and be able to consent to it. The ability to consent requires being able to appreciate the medical situation and its possible consequences.

With her former identity, Mrs. F did not wish to face a steady decline into total loss of self-awareness, dependence

occasionally hired professional medical caregivers to attend to her at home.

After she voluntarily stopped eating and drinking, the couple's promise created a dilemma for her professional caregivers. She asked for food and drink. Her husband and family reminded her of the reasons she had chosen VSED: "Remember, you didn't want to live in a nursing home, and you didn't want us to be responsible for caring for you at home. You believe that stopping eating and drinking will allow you to die with dignity." Although they also asked Mrs. F, "What do you want to do?," the family asked the professional caregivers to respect her original choice to stop eating and drinking. Mrs. F still evidenced decision-making capacity but often did not recall having chosen VSED. She again requested food and drink, from family and the professional caregivers.

These caregivers were faced with the dilemma of whether to give their patient food and drink or to listen to her husband, her surrogate decision-maker. Her case raises the question of whether and how to carry out VSED for a patient whose advanced dementia makes disciplined voluntary action difficult.

on others for the care of bodily functions, and the unwelcome prospect of spending the rest of her life in a nursing home. She had not yet reached that point when she began VSED.

With her newer identity, having little or no idea where Alzheimer's would ultimately take her, she apparently wished to live. In this in-between state, she had some degree of decisional capacity. She was aware of what was going on but not fully aware of the implications. It is not clear whether she was having second thoughts about her decision or simply forgetting and getting hungry.

One of the questions in this case is about the effect of asking her what she wants to do and reminding her of what she *had* wanted. When Mrs. F's family

commentary

by Ross Fewing

This situation took place at a difficult point in the disease trajectory, when the patient's identity was in transition. Mrs. F was neither fully who she had been nor who she was becoming.

An advance directive and a durable power of attorney for health care, supported by good ongoing family communication, can make the decisions for end-of-life care much easier to navigate. A person facing Alzheimer's can lay out what he or she does or does not wish when no longer able to speak autonomously. Mrs. F, with full capacity and

reminded her of her decision and asked, “What do you want to do?” their question revealed that they believed she retained some degree of decision-making capacity. It indicated an assumption that she could assess the burdens and benefits and decide whether to proceed with VSED. To remind her of her earlier decision is to speak to the old identity: it seeks to honor her earlier decision. For Mrs. F’s new identity, the reminder could carry an element of coercion. If

she wants food now, to tell her that she had wanted to avoid eating may be confusing and frightening. If she is simply forgetting, however, it may be helpful.

The situation also creates a problem for professional caregivers. To whom do they listen? Ideally, VSED should be used only by those who are able to exercise their autonomy and before their identity begins to wobble.

Like the family, the professional caregivers are negotiating a gray area. If Mrs.

F has not yet crossed the threshold from capacity to complete incapacity, they should respect her request for food and drink. If her request is strong enough, they could even decide to bring her food and drink regularly and let her decide, occasion by occasion, whether to take it. For Mrs. F’s old identity, however, to bring food regularly is to challenge her anew each day. It makes retaining her old identity harder, and it might be painful to her.

commentary

by Timothy W. Kirk

Mrs. F’s deliberate, proactive decision to engage VSED to hasten her death is a legal choice in all fifty states. Patients who have decision-making capacity can make a considered choice to stop eating and drinking, and such a choice should be respected.

The challenge in the case of Ms. F is that VSED requires a sustained, voluntary effort to refuse food and fluids until the patient loses consciousness. After a VSED patient loses consciousness, voluntary eating and drinking is, of course, not possible and, consistent with her previously expressed and documented wishes, artificial nutrition and hydration can be withheld.

By definition, VSED requires the capacity for voluntary action. Two necessary conditions for such voluntarism in the case of VSED are the capacity to make a free, informed decision resonant with the basic tenets of decision-making capacity and the ability to execute that decision by sustaining and exercising a preference consistent with the decision over time. If Mrs. F could not do both, and it appears she could not, then she was likely not capable of the kind of voluntary, sustained decision-making and execution required for VSED to hasten her death.

Mrs. F’s husband was promoting Mrs. F’s previously expressed wishes by reminding her of her prior decision to refuse food and fluids and explaining to her the reasons for that decision. If they were comfortable doing so, Mrs.

F’s health care providers could have done the same. Doing so would have provided Mrs. F with important information necessary to make a deliberate decision each day about whether to eat and drink. Such reminders to a patient like Mrs. F may be persuasive, but as long as the patient understands that she is free to make the decision, they are not coercive.

In cases like Mrs. F’s, hired caregivers should not honor the family’s request to withhold food and fluids from the patient if she decides to eat or drink. Voluntary oral feeding is not medical treatment that requires the informed consent of a patient with formal decision-making capacity. Rather, all patients are assumed to have the right of assent regarding voluntary eating and drinking. Therefore, a request by a surrogate decision-maker to withhold feeding from a patient who wishes to eat should not be honored. Similarly, a request by a surrogate decision-maker to feed a patient who does not wish to eat should also not be honored. Simply stated, patients have the right to eat or not eat as they wish.

Because eating and drinking are not complex medical interventions and carry with them minimal risk, the capacity to make decisions about voluntary oral intake requires minimal cognitive function. Indeed, health care providers routinely offer food to (or, if necessary, hand feed) patients with minimal cognitive or expressive function: patients who have experienced a traumatic brain injury, had a cerebrovascular accident, or have advanced dementia. If such patients accept food, this is taken as a

gestural expression of assent to eating. If such patients purposefully clamp their mouths shut, this is taken as a gestural expression of refusal to eat. So, even if the dementia of a patient who once decided on VSED progresses to the point where she persistently lacks orientation to person, place, and time, her family and hired caregivers should *not* respect a surrogate decision-maker’s request to withhold voluntary oral feeding if she is expressing a preference contrary to such a request.

Mrs. F’s husband was, to all appearances, acting out of goodwill in an attempt to honor his wife’s previously expressed wishes. Doing so in a manner that conflicted with her current wishes, however, was a distortion of respecting her autonomy. In its truest form, autonomy is an expression of self. While Mrs. F might not have recalled her prior wishes, including her plan for VSED, she was still capable of forming and expressing preferences based on her current goals and values. Therefore, it was her current preferences, and not those she expressed earlier in the course of her illness, that should have guided her caregivers’ actions regarding eating and drinking.

commentary

by Alan Meisel

There's no easy solution to this case, and my suspicion is that scenarios like it will be increasingly common. As more people become familiar—from dealing with their own parents, grandparents, or other relatives and friends—with the kind of long decline that will afflict many of us, many will have discussions of the kind that Mrs. and Mr. F had and will face the kinds of dilemmas that Mr. F, his children, and Mrs. F's hired caretakers did.

Law has not yet grappled with these issues in any formal way—through judicial decisions, legislation, or administrative regulations. And because of the complexity of the situations and the multitude of different factual variables that come into play in any particular case, it is not clear that law can any more prescribe solutions than can any of the other relevant domains of human endeavor.

That said, perhaps there are some useful lessons that can be gleaned from almost four decades of legal developments related to medical decision-making near the end of life. First, have the

conversation—the conversation about how one wishes to have one's end come about. Have it with witnesses, have it with interested parties, and try to make sure that all of them are on board. Mrs. F, it appears, did try to do all, or as much of this as, she could. The fact that not all of her caretakers may have bought into this plan may only reflect the difficulty of knowing in advance who those caretakers would be.

Try to document the conversation. If we know anything about advance directives—living wills and health care powers of attorney—we know their limitations. We know that events often fail to unfold as we contemplate and wish; we know that no matter how many contingencies we plan for, we cannot foresee all of them. We know that words, whether written or oral, are subject to varying interpretations. Still, written, audio, or video documentation of Mrs. F's wishes might have proved helpful. They might have proved helpful in fortifying Mr. F's resolve, in convincing her caretakers of what her wishes were, and perhaps they might even have proved helpful in reminding Mrs. F of what her wishes were and the reasons for them.

Finally, one contingency that might be worth expressly contemplating and planning for—one which this case

naturally suggests—is the possibility of changing one's mind at a time when one is no longer the person one was, and attempting to account for that possibility in a “Ulysses contract.” Just how to craft that language is itself a bit mind-boggling: “When the time comes to implement my wishes, if my decision-making capacity is questionable and I appear to be resisting the implementation of my plan to end my life by voluntarily stopping eating and drinking, I nonetheless want my contemporaneous wishes to be ignored and my plan to end my life implemented.” Had Mrs. F made such a statement and had it been documented, it would have provided guidance to her family and caretakers about how to proceed unless, of course, she also said—when her decision-making capacity became questionable and she requested food and water—“I want you to ignore my request to ignore my request for food and water.” In other words, “I hereby revoke the irrevocability of my earlier wishes.”

That should make it clear how complicated this is.

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