Legal Briefing: Voluntarily Stopping Eating and Drinking

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ABSTRACT

This issue’s “Legal Briefing” column covers recent legal developments involving voluntarily stopping eating and drinking (VSED). Over the past decade, clinicians and bioethicists have increasingly recognized VSED as a medically and ethically appropriate means to hasten death.1 Most recently, in September 2013, the National Hospice and Palliative Care Organization (NHPCO) called on its 2,000 member hospices to develop policies and guidelines addressing VSED.2 And VSED is getting more attention not only in healthcare communities, but also in the general public. For example, VSED was recently highlighted on the front page of the New York Times and in other national and local media.3 Nevertheless, despite the growing interest in VSED, there remains little on-point legal authority and only sparse bioethics literature analyzing its legality. This article aims to fill this gap. Specifically, we focus on new legislative, regulatory, and judicial acts that clarify the permissibility of VSED. We categorize these legal developments into the following seven categories:

1. Definition of VSED
2. Uncertainty Whether Oral Nutrition and Hydration Are Medical Treatment
3. Uncertainty Regarding Providers’ Obligations to Patients Who Choose VSED
4. Judicial Guidance from Australia
5. Judicial Guidance from the United Kingdom
6. Judicial Guidance from Canada
7. Case of Margot Bentley

1. Definition of VSED

What Is VSED?

Voluntary stopping eating and drinking (VSED) refers to a conscious and deliberate decision, by a capacitated patient suffering from advanced illness or an extremely debilitating medical condition, to intentionally refrain from receiving food or fluids by mouth, with the purpose of hastening death. VSED has been variously referred to by several other names, including: (a) voluntary refusal of food and fluids (VRFF), (b) voluntary terminal dehydration, (c) voluntary death by dehydration, (d) terminal dehydration, (e) stopping eating and drinking, (f) patient’s refusal of hydration and nutrition, and (g) indirect self-destructive behavior.4 As with many concepts in bioethics, not all of these parallel phrases are normatively neutral. Most recently, Julian Savulescu referred to it as voluntary palliated starvation.5 In order to qualify as VSED, a decision to stop eating and drinking must be fully autonomous and self-directed, but medical support is often required, such as mouth care and palliative measures.6

Individuals choose VSED for various reasons. Some patients are motivated by physical factors such as debility, weakness, and pain. Other patients have emotional reasons such as: (a) weariness with the dying process, (b) desire to control the circumstances of death, (c) feeling that quality of life is poor, (d) desire to die at home, and (e) feeling that life lacks meaning.7 Individual patients usually experience a combination of these and other factors.8 While some people equate VSED with suicide, patients who
choose it often see it as more akin to refusing or discontinuing life-sustaining therapy.\(^9\)

It is important, at the outset, to make clear what VSED is not. It is distinguishable from the natural process whereby people in the final days or weeks of life lose interest in food or become unable to tolerate it physically. It also does not apply to individuals who are unable to take nourishment by mouth with or without assistance and who are dependent on artificial methods of nutrition and hydration. Finally, as the word “voluntary” indicates, it does not refer to the withholding of food or liquids from a capacitated person who actively desires food and drink.

**Who Chooses VSED?** Via public referenda in 1994 and 1997, Oregon became the first state to establish a right to aid in dying (AID). With AID, a physician writes a prescription for a life-ending medication for a terminally ill, mentally capacitated adult. One survey of hospice nurses in Oregon indicates that patients who chose VSED, relative to those who chose AID, were an average of almost 10 years older, less likely to have cancer, and more likely to suffer from neurological disease.\(^10\) From a social and emotional standpoint, patients who chose VSED were statistically less likely to be very concerned with controlling the circumstance of their death, less likely to be preoccupied with an impending loss of dignity, more prepared to die, and more likely to lack social support. (But nearly 90 percent of respondents reported that the families of most or all of the patients who chose VSED accepted the patient’s choice.\(^11\))

**How Does VSED Hasten Death?** Once the decision to VSED has been implemented, most patients live for seven to 14 days. Precisely how long a particular patient lives is typically related to his or her physical condition at the start of the fast.\(^12\) Feelings of hunger and thirst usually subside after the first day or two and can generally be controlled through mouth care, such as chewing on ice chips or swallowing very small amounts of water.\(^13\) The process can cause delirium or anxiety toward the end of life, but also euphoria and tranquility.\(^14\) Hospice nurses in the aforementioned Oregon study reported that VSED patients suffered less and were more at peace in their last weeks than patients who opted for AID.\(^15\)

**What Are the Advantages of VSED?** In addition to typically being a peaceful way to die, VSED has other advantages.\(^16\) It offers the same protections for autonomy, bodily integrity, and self-determination as other end-of-life options such as AID or refusal/cessation of mechanical life-sustaining interventions. But in contrast to those mechanisms, VSED does not require the overt participation of a physician. That is, while supportive measures and palliative care are often necessary to achieve a “good death” by VSED, physicians do not have to prescribe lethal medication or otherwise actively hasten a patient’s death. Since the legality of AID remains undetermined in 45 states, VSED is an increasingly attractive choice.\(^17\)

Not only are there fewer barriers to accessing VSED, there are fewer functional requirements for patients. For example, VSED does not require the ability to swallow a pill or slurry (a mixture of powdered barbiturate and water). Moreover, because a patient can be expected to live for days or weeks after stopping eating and drinking, there is more time to say goodbye to loved ones, put one’s affairs in order, and, potentially, change one’s mind.

For these reasons, the Royal Dutch Medical Association (KNMG) recently issued guidelines that accept VSED as a humane way to die: “A patient who has a strong wish to die may decide for himself to deny food and drink. In that case, the patient is making a conscious choice to hasten death. Studies . . . show that the conscious denial of food and drink, when combined with effective palliative care, can offer a dignified death. The KNMG endorses this view.” Furthermore, these guidelines do not recognize VSED as assisted suicide, but rather more akin to a refusal of life-prolonging treatment: “When a patient dies due to not eating and drinking this constitutes a natural death.”\(^18\)

Notably, the KNMG guidelines clarify that patients who choose VSED have a right to appropriate care from their physician. Physicians must “provide the patient with reliable information, preparing him for the process, supervise him and alleviate suffering, including if complications arise.” The guidelines require that the physician act as a good care-provider, even if the physician does not agree with the patient’s decision. The objective is that the physician “alleviates the suffering as much as possible and is accessible and available to the patient.”

**What Are the Criticisms of VSED?** VSED is not without critics, however.\(^19\) Some object to it on the grounds that they consider it suicide.\(^20\) Of course, this is also the case for far more common palliative treatments. Actions such as stopping dialysis or stopping clinically assisted nutrition and hydration are frequently characterized as being euthanasia, murder, or killing.\(^21\) Some dispute the claim that VSED is a peaceful way to die.\(^22\) Others argue that it devalues the lives of individuals with disabilities (or impairments, as some prefer) by suggesting that loss of function or ability makes people seem to be less valuable or even expendable.\(^23\) Such critics are particularly concerned that VSED may be used as a “cover”...
for family members or caregivers who want to starve an elderly individual to make it look as though this was the patient’s choice.

Other commentators are not opposed to VSED, but call for more research. One recent meta-review concluded that “VSED has hardly been examined in the past 20 years.” The authors describe the available articles as “heterogenous and inconclusive,” representing a “patchwork rather than a picture.”

Indeed, VSED has been under-examined compared to other end-of-life options.

2. Uncertainty Whether Oral Nutrition and Hydration Are Medical Treatment

While many leading commentators have concluded that VSED is legal, the relative absence of explicit authoritative confirmation has left many healthcare providers uncertain. Two of the most significant unanswered questions are the following: (a) Do orally ingested food and fluids constitute medical treatment? (b) What are healthcare providers’ obligations to patients who choose VSED? We address the first question in this section and the second question in the next section.

The right to refuse life-sustaining medical treatment is well established in the American legal system. This right derives from constitutional privacy protections and individual state laws, but also from the legal principle that any intentional, unwanted touching constitutes battery. In the medical context, even procedures carried out for harmless, benevolent, or beneficial purposes may constitute battery if the provider knows, or should have known, that they would be offensive to the particular patient. Case law across jurisdictions supports the proposition that the artificial provision of nutrition and hydration constitutes medical treatment that may legally be refused or discontinued either by a competent patient or through a proper surrogate.

What is less clear, however, is whether the provision of oral nutrition and hydration constitutes medical treatment. It could be argued that any intervention performed upon an individual in a healthcare setting by healthcare employees for the purpose of sustaining life can be considered “treatment,” at least for the purposes of determining whether a patient has the right to refuse it. Moreover, spoon feeding requires inserting a foreign object into the mouth of a patient. If the patient resists and the feeder must resort to force to accomplish the task, this contact could potentially be classified as unwanted touching under the legal definition of battery.

At least two U.S. cases suggest that oral nutrition and hydration are medical treatment. First, Professors Norman L. Cantor and George C. Thomas, III, discuss an unpublished trial court opinion from 1987 that specifically upheld the right of a woman in her 80s to voluntarily stop eating and drinking based on the “right of an adult to determine what can be done to his or her own body.” In support of this holding, the court cites cases dealing with refusal of medical treatment.

More recently, in 2007, a Georgia court held that the executor of a woman who died from aspirating scrambled eggs that she was spoon fed in the hospital while recovering from hip surgery could not recover for medical battery, because the spoon feeding was part of the “treatment” to which the patient had consented when she signed a general consent form upon admission to the hospital. While the plaintiff failed to recover damages for the unwanted feeding, it was because the court treated food and fluids as “treatment” that had been accepted under the patient’s general consent.

On the other hand, some cases and commentators draw a sharp distinction between oral or “natural” feeding—even when it is assisted—and artificial delivery methods such as a nasogastric (NG) tube, percutaneous endoscopic gastrostomy (PEG) tube, or intravenous infusion. They argue that the former constitutes basic or ordinary care, as opposed to medical treatment. Moreover, some state statutes have specifically included language to distinguish assisted oral feeding from artificial nutrition and hydration.

Ultimately, it may not materially impact the legal analysis whether oral nutrition and hydration are medical treatment or not. Even if VSED does not constitute the refusal of life-sustaining medical treatment, providers have, at best, limited options for overcoming a competent patient’s decision to stop eating and drinking. Force feeding a patient or initiating artificial nutrition and hydration over a patient’s refusal would, as the foregoing discussion demonstrates, be legally impermissible. As the following section discusses, however, healthcare providers and others have additional means at their disposal to try to “leverage” consent to unwanted nourishment.

3. Uncertainty Regarding Providers’ Obligations to Patients Who Choose VSED

There is little on-point legal authority confirming the legality of VSED. Consequently, many care providers remain uncertain whether they may support or allow their patients and residents to VSED. Unsure about their duties with respect to VSED, many providers err in favor of preserving life. Perhaps no case better illustrates this than that of Armond and Dorothy Rudolph. The Rudolphs’ story
made national headlines in 2011, when their assisted living facility in New Mexico tried to evict them based on their decision to VSED. Coincidentally, New Mexico, more recently, became the fifth state to legalize aid in dying.35

The Case of the Rudolphs. The Rudolphs were an elderly couple with multiple health impairments. Mr. Rudolph was 92 years old and suffered from spinal stenosis. Mrs. Rudolph was 90 years old and had lost a great deal of her mobility after a broken hip. They both exhibited signs of early dementia. Both Mr. and Mrs. Rudolph had long been committed to the idea that they did not want a prolonged death with a loss of independence. They had communicated their end-of-life wishes to their children and had completed advance directives (ADs) stating that they did not wish to receive life-sustaining treatment for terminal illnesses with no reasonable hope for recovery.

In early 2011, the Rudolphs decided that the time had come for them to end their lives. So they commenced their plan to stop eating and drinking.36 Their son told the New York Times that this decision was carefully considered and not the result of depression on his parents’ part. He helped them draft a statement memorializing their intention and informed administrators at the Village at Alameda, the Rudolphs’ assisted living facility, of his parents’ decision.

The family was stunned when the administration responded by informing them that Mr. and Mrs. Rudolph would have to move out by the next day, especially since the contract the Rudolphs had signed with the Village required 30 days’ notice. The following day, the New York Times reported, someone in the facility’s administration placed a 911 call to report that the Rudolphs were attempting suicide and needed to be taken to a hospital. The paramedics who responded to the call, confused by what they found when they arrived on the scene, asked the University of New Mexico Emergency Medicine Department for advice. The doctor who took their call drove to the Village to speak with Mr. and Mrs. Rudolph at their bedsides, and concluded that neither needed to go to a hospital, as both “were able to very appropriately and eloquently explain their wishes and what they wanted to have done.”

The Rudolphs did move out of the assisted living facility and into a rented house where they spent their final days being cared for by family members and hospice professionals. Armond Rudolph died 10 days after he stopped eating and drinking, and Dorothy Rudolph died the following day.

The Rudolphs’ situation highlights an important area of uncertainty regarding VSED in the U.S. to-day. The legality of healthcare practitioners supporting a patient’s decision to forego nourishment and hydration by providing palliative care and comfort measures remains a contentious issue that has never been adequately addressed by American courts. Responding to the Rudolph case, Karl Polzer, senior policy director for the National Center for Assisted Living, said, “This is the first time we’ve heard of a situation like this. . . . It is important that assisted living communities have the right to choose whether this type of course of action is consistent with their philosophy and values.”37

Furthermore, the case of Armond and Dorothy Rudolph illustrates not only the uncertainty and legal risk averseness of healthcare providers. It also illustrates a significant reason that American courts have provided so little guidance on this subject. People choosing VSED at the end of life are unlikely to live long enough to see a legal action through the usually lengthy litigation process.38

The Case of A.B. v. C. On the other hand, individuals seeking to establish their rights to VSED before they are ready to forego nutrition and hydration will likely face another unique set of legal obstacles. For example, in the 1984 case A.B. v. C., a 54-year-old woman had been rendered quadriplegic by a fall. A.B. was unable to move her arms or legs, and therefore she was unable to feed herself.39 She was, however, alert and competent to make decisions on her own behalf.40 A.B. required frequent hospitalization due to recurrent infections and she wished to forego any additional medical treatment beyond the life support equipment already in place and any medication needed to control her pain.41 Also, she wished “to take only whatever nourishment she [chose], even to the extent of taking none at all.” When A.B. communicated her wishes to her doctor, however, he informed her that he considered himself ethically bound to provide treatment under such circumstances. He would, therefore, be unable to comply with her wishes. So, A.B. formally ended her treatment relationship with her physician. Next, A.B. sought legal orders to be certain that the hospital or other providers would not be able to force unwanted treatment or nourishment upon her, if and when she entered their care.42 Specifically, she petitioned a New York state trial court both for an order recognizing her right to refuse “medical care, treatment and nourishment” and for an order requiring her healthcare providers to comply with her AD if she required hospitalization and/or lost the capacity to advocate for herself.43

But the New York court refused to grant A.B.’s request due to the hypothetical nature of the relief
she sought. The court explained that it was “sympathetic with petitioner’s plight and would honor her request if it arose within the context of an actual and real controversy.” But since A.B. was not hospitalized and no controversy had yet arisen over her treatment, the court held that the orders she requested were beyond its jurisdiction. U.S. courts normally do not adjudicate claims that are not “ripe,” that rest upon contingent future events that may not occur as anticipated, or may not occur at all. For example, this was a fatal problem with early challenges to advance-directive laws that included clauses that restricted following an AD when a woman was pregnant; because the plaintiffs were not (yet) pregnant, terminally ill, or incapacitated.

NHPCO Case of Dr. S. A September 2013 case study published by the National Hospice and Palliative Care Organization (NHPCO) looked at this problem through the case of Dr. S, a 56-year-old retired gynecologist suffering from amyotrophic lateral sclerosis. Dr. S was unable to use his upper extremities or walk more than 10 to 15 feet without assistance. He decided to forego all nutrition and hydration, and most of his pain medication, in the interests of “hastening his death.”

Members of the hospice ethics committee struggled to reconcile the idea that their mission was to allow their patients to “die on their own terms” with the belief that hospice care should not be about hastening death. Dr. S ultimately did move forward with his fast, and the hospice chose a sort of middle path by regularly and consistently offering him food and fluids, but leaving the choice of whether to ingest them up to him.

Dr. S’s caregivers were troubled, however, because, by the 18th day of his fast, Dr. S became frustrated, angry, and depressed that the process was taking so long. His children were saddened when he made references to having “no reason to live” in their presence. He would frequently say to the nursing staff, “I’ll give you $100 for a Coke.” His caregivers responded to Dr. S’s requests for a Coke by assuring him that he could have one if that really was what he wanted. In short, Dr. S’s choice to stop eating and drinking was presented as fully voluntary and autonomous.

The NHPCO case study’s emphasis on the experiences of careproviders and family members highlights a fundamental issue: although VSED is inherently tied to the concepts of bodily integrity and autonomy, an individual patient’s decisions are never made in a vacuum. Dr. S’s careproviders took time to think through their beliefs about VSED and their obligations as careproviders; they also discussed his case thoroughly before deciding to honor his request. They kept the lines of communication open with Dr. S and continually reinforced the voluntary nature of his fast. While much is needed in terms of legal clarification and protection for patients who choose to forego oral nutrition and hydration and the professionals who care for them, this case demonstrates that open and honest communication remains a critical factor.

4. Judicial Guidance from Australia

Although U.S. case law clarifying the legal status of VSED is lacking, such cases have arisen in Australia, the United Kingdom, and Canada. These cases may be instructive to providers in the U.S. who are considering the legal questions raised by VSED.

In 2010, the Supreme Court of South Australia issued a ruling in the case of H Ltd v. J & ANOR. J was a 74-year-old woman suffering from post-polio syndrome and type 1 diabetes. Her condition had deteriorated such that she no longer had use of her right side. What movements she was capable of were limited and painful, and she was completely reliant on others for all of her basic needs.

In January 2010, J wrote to H Ltd, the aged care facility in whose high-care unit she resided, and informed it that she no longer wished to eat, drink, or take insulin. J cited a “despair which she could no longer endure.” She requested no foods and only fluids in quantities necessary for mouth care and comfort. Two months later, she executed an anticipatory direction ordering medical staff not to provide nutrition and hydration and specifying that she wished to receive only palliative care if she became unable to communicate her wishes. She named her children as her enduring guardians who would have the power to make treatment decisions on her behalf and she communicated her wishes regarding nutrition and hydration to them.

H Ltd initiated legal proceedings seeking clarification of its rights and responsibilities, specifically its potential legal exposure if it complied with J’s request. Unlike the U.S. court in A.B. v. C., the Australian court determined that the case presented a matter properly before the court. Unlike A.B., J was already a resident of H Ltd and she was actively asserting her rights at the time of the legal action. Moreover, H Ltd had a substantial and immediate interest in the outcome of the proceedings. The court’s opinion would give it greater legal certainty as it provided care for J, gave instructions to its employees, and offered explanations of the situation to residents and the public in case of a public controversy. So as to give H Ltd the widest latitude to rely on its decision, the court framed its opinion in terms of a “proper construction of the relevant laws,”
as opposed to specific instructions for actions that H Ltd should take.61

The court first established that Australian law included no common law duty to provide nutrition and hydration to a competent adult who refused it.62 Experts had established J’s competence and that she was not depressed.63 The court then examined the question of whether J’s plan constituted suicide and concluded that it did not.64 In doing so, the court “accept[ed] the distinction . . . between suicide and an individual merely speeding “the natural and inevitable part of life known as death” by refusing food and water.55 Furthermore, the court found there was no common law duty to feed oneself and there was a generally accepted legal right to refuse life-sustaining treatment.66 While not specifically categorizing orally ingested food as medical treatment, the court minimized the difference between food and medicine. “There is also a difference between the taking of food by natural means and the medical administration of nutrition. However, those differences do not appear . . . to be sufficient to sustain a distinction between suicide and the exercise of the right to self-determination.”67

In the final section of its opinion, the court examined J’s anticipatory direction under particular statutory provisions. Looking at the criminal neglect statute, it opined that the direction would constitute a “lawful excuse not to provide her with sustenance” and that a duty of care to a vulnerable adult does not extend to overcoming that person’s resistance.68 Likewise, the court found no justification for unwanted feeding under the Aged Care Act 1997.69 This act lays out providers’ responsibilities to provide meals, hygiene, emotional support, palliative care, and comfort care; its stated purposes include “the provision of funding for aged care and the promotion of high quality care and accommodation for the aged.”70 The court concluded that it was contrary to the principles of autonomy and independence embodied in the act to hold that a high care facility’s duty to feed its residents extends to those who lawfully and rationally choose not to eat.71

The South Australian court was careful to point out that H Ltd’s duties would be re-animated immediately upon revocation of J’s direction or upon H Ltd’s having reasonable grounds to believe the direction was no longer in force.72 Finally, under the Guardianship and Administration Act 1993, if J became incapacitated, her enduring guardians would have the power to make all the same decisions that J would have made while she had capacity. In fact, J’s children would be required to make medical choices that were consistent with “any specified conditions of [their] appointment.”73

5. Judicial Guidance from the United Kingdom

While the British courts have not offered as comprehensive a judgment as South Australia, they have provided some guidance. Monica Cooke was a former magistrate who had suffered from multiple sclerosis (MS) for 20 years. By 2012, she had progressively lost her ability to move, taste, and smell. Cooke had closely followed the case of Tony Nicklinson, who had unsuccessfully fought to legalize assisted dying.74 After losing before the High Court of Justice in August 2012, Nicklinson began to VSED and died six days later.75 Following Nicklinson’s path, Cooke also decided to VSED at the end of August. She died eight days later, on 7 September 2012.76

In October 2012, the West Somerset Coroner convened an inquest. Cooke’s husband testified that she made the decision in a “controlled and rational way.” Cooke wanted to “end her life when she chose. She balanced the ordeal she would suffer and the pain she knew she would cause her family against her future prospects of minimal independence and negligible dignity.”

The coroner found that “there is no dispute in my mind that her death was brought about somewhat prematurely by refusing food.” But he refused to issue a verdict of suicide, and instead adopted a narrative verdict. The coroner was impressed with the “very clear details of the debilitating effects of this illness, how a very sound person, mentally and physically, was reduced to a person whose quality of life was very poor.” He gave the causes of death as starvation and MS.

6. Judicial Guidance from Canada

Perhaps the most guidance on the legality of VSED is from Canada, where the courts have adjudicated three cases. We describe two in this section. Because of its significance, we separately analyze the case of Margot Bentley in the next section.

Manoir de la Pointe Bleue v. Corbeil. In 1992, a Canadian quadriplegic nursing home resident sought to both refuse medical treatment and to stop eating and drinking.77 The resident, Mr. Corbeil, was a 35-year-old man who was paralyzed below his shoulders following an all-terrain vehicle accident. The care facility brought an application for a declaration that it was required to respect his wishes. Although it is unclear precisely how Corbeil was assisted with feeding, he was not attached to any device, and was fed manually with help from facility employees.

The Superior Court of Quebec found Mr. Corbeil to be mentally capable of making treatment and care decisions. It ordered the nursing home to honor his
wishes on the grounds that he could not be compelled to eat or drink any more than he could be compelled to undergo interventions such as chemotherapy or dialysis. The court held that the staff at the care facility had no obligation and no right to provide food and liquids to Mr. Corbeil while he expressly refused consent for assisted feeding.

Attorney General v. Astaforoff. An earlier Canadian VSED case had been adjudicated by the British Columbia Court of Appeal, also in favor of the fasting individual. Mary Astaforoff, an inmate serving a sentence for arson, went on a hunger strike. The Attorney General of Canada sought an “order that the provincial authorities be compelled to provide her with such medical attention as is deemed appropriate in order to preserve her life and health.”

The trial court found Astaforoff competent: “Medical evidence indicates that she is rational and fully aware of what she is doing.” Consequently, the court refused to make the requested mandatory order.79 The Attorney General appealed. But the court of appeal dismissed the appeal, holding that prison officials could not force feed the inmate without her consent.80

7. Case of Margot Bentley

In February 2014, the Supreme Court of British Columbia issued a 44-page judgment that comprehensively assessed the legality of VSED.81 Citing the two cases described above, the B.C. court confirmed the legality of contemporaneous VSED by a incapacitated patient. “Canadian courts have found that an adult may refuse to eat or drink and die by dehydration and starvation if he is mentally capable of making the decision.” But the court’s analysis highlights some of the difficulties of advance planning in the VSED context.

Margot Bentley’s Decision to VSED. Margaret (“Margot”) Bentley was an 82-year-old retired nurse who cared for patients suffering from dementia during her career.83 Partially as a result of those experiences, she executed a Statement of Wishes in 1991. This document lays out her directions and preferences for her future healthcare should she ever become incapacitated.84 In it, she stated, “If at such a time the situation should arise that there is no reasonable expectation of my recovery from extreme physical or mental disability, I direct that I be allowed to die and not be kept alive by artificial means or ‘heroic measures.’”85 Mrs. Bentley listed specific instructions, including “no nourishment or liquids.” She designated her husband, John Bentley, and her daughter, Kathy Littler (now Katherine Hammond) as her surrogate medical decision makers should she become unable to make decisions for herself.

In 1999, Mrs. Bentley was diagnosed with Alzheimer’s disease and she told her family numerous times that she wished to be allowed to die when she reached a stage of advanced dementia. She repeatedly said her Statement of Wishes would legally permit that.86 By 2005, Mrs. Bentley’s condition had deteriorated to the point that she needed to be moved to a residential care facility. After her original care facility closed, she was moved to Maplewood House, a community care facility licensed by Fraser Health Authority (FHA).87 Mrs. Bentley had been in a near vegetative state since at least 2010. She did not recognize or respond to her family, speak, or make more than very limited physical movements. She spent her time “motionless in bed or slumped in a wheelchair.”88 Importantly for this discussion, she required spoon feeding by caregivers.

Dispute between the Bentley Family and Maplewood. Mrs. Bentley’s husband and daughter said they sent a copy of Mrs. Bentley’s Statement of Wishes to Maplewood House by at least the fall of 2011, along with a letter that specifically requested that no provision of nourishment or liquids be implemented, with comfort care as needed.89 Initially, the family members said that they reached an agreement with the facility and Mrs. Bentley’s physician to cease the oral provision of food and liquids.90 They were later informed, however, that FHA had intervened and refused to allow the feedings to be stopped.91

Mr. Bentley and Ms Hammond, Mrs. Bentley’s designated medical decision makers, responded by requesting a transfer to a palliative care facility. Such a facility was located and willing to accept Mrs. Bentley, but the FHA denied the request.92 The family had several meetings with Maplewood personnel and FHA representatives between late 2011 and early 2013. But they were unable to reach an agreement. Ms Hammond alleged that Leanne Lange, a clinical specialist in adult abuse and neglect for the FHA, told her that if the family tried to transfer Mrs. Bentley, “we will physically stop you.”93

In July 2013, Mrs. Bentley’s doctor came across a “police order” in her patient file that stated: “In the event that John Bentley (spouse) and/or Katherine Hammond (daughter) attempt to remove or remove Margot Bentley from the premises of Maplewood House, then the Abbotsford Police must be contacted to report that Margot Bentley is being removed or has been removed in contravention of the Adult Guardianship Act and must be returned to the care of Fraser Health immediately.”94 FHA’s decision appears to have been based on a legal opinion it obtained regarding Mrs. Bentley’s case, which is referenced and summarized in the FHA’s Clinical Ethics Consult for Margaret Bentley.95
The lawyer who provided the opinion apparently told FHA that orally ingested food and fluids fall under the heading of basic care and that a court would be unlikely to rule in favor of Mrs. Bentley’s family, because her Statement of Wishes from 1991 was “not legally binding under current legislation.” Consequently, any staff who participated in discontinuing Mrs. Bentley’s feedings could face liability.96

The FHA also procured an Assessment of Incapacity for Mrs. Bentley under the Adult Guardianship Act.97 The final report, from 6 March 2013, rated Mrs. Bentley as stage 7 Alzheimer’s, or very severe cognitive decline (severe dementia) on the Global Deterioration Scale for Assessment of Primary Degenerative Dementia.98 Deborah O'Connor, PhD, RSW, considered Mrs. Bentley’s family’s argument that her chewing and swallowing was purely reflexive. She also considered FHA staff members’ argument that by sometimes accepting food and sometimes closing her mouth to keep the spoon from entering her mouth, Mrs. Bentley did exercise some choice in the matter.99

Dr. O’Connor ultimately adopted a middle position. She concluded: “I was able to determine what food Mrs. Bentley preferred—suggesting that she does have some means for communicating. I was also able to determine when she was clear that she did not want more food. However, there was a grey space where it was unclear how much she was responding reflexively to continued prompting and hence, unable to exert a choice. Erring on the side that she does retain some capacity here, my suggestion would be that fewer attempts be made to convince her to continue eating.”100

Lawsuit by the Bentley Family. In August 2013, Mrs. Bentley’s husband and daughter petitioned the Supreme Court of British Columbia, seeking to cease the provision of oral nutrition and hydration to Mrs. Bentley. First, they also sought a declaration that the oral provision of nourishment and liquids constituted the provision of healthcare under the Health Care Consent Act, Adult Guardianship Act, and Representation Agreement Act.101 Second, the Bentley family sought an order to comply with Mrs. Bentley’s Statement of Wishes, including the no nourishment or liquids provision. Third, they sought a declaration that Mrs. Bentley’s 1991 Statement of Wishes and her orally expressed wishes constituted a “lawful excuse” that relieved caregivers of their ordinary duties to provide food and fluids under the Criminal Code.102 Finally, they asserted that feeding and hydrating Mrs. Bentley contrary to her expressed wishes violated her rights under the Charter of Rights and Freedoms of the Canadian Constitution.103

FHA responded to the petition on 11 September 2013, opposing all orders sought.104 It asserted that the orders and directions it received from Mrs. Bentley’s family were inconsistent. For example, a signed but unwitnessed living will of uncertain date (but probably post-dating Mrs. Bentley’s Statement of Wishes) specifically refused “tube feeding” and other means of artificially prolonging life, but explicitly accepted “basic care.”105 FHA further asserted that Mr. Bentley agreed to continue oral feeding in January 2012, and that he and Ms Hammond consented to continued feeding with reduced prompting on or around April 2013.106 The FHA also cited two intervention orders from 2009 and 2011, executed by Mrs. Bentley’s husband, directing that Mrs. Bentley receive “supportive measures.”107 The FHA framed its position as seeking clarification of which orders actually should be followed.108

The FHA also denied that there ever was an agreement to stop Mrs. Bentley’s feeding and insisted that it was the Maplewood staff, not FHA, who objected to stopping the feeding, and that the FHA did not control the employees of Maplewood.109 Moreover, the FHA denied that it thwarted any transfer attempts other than those to a private residence.110 According to the FHA, one proposed alternate facility refused to accept Mrs. Bentley when it learned she was not to be fed, and a hospice palliative care physician examined Mrs. Bentley and determined that she did not meet hospice residential care criteria.111 The FHA described the “police order” as merely an emergency protocol in case Mrs. Bentley’s family attempted to move her to a private residence before the matter had been settled.112

In keeping with the March 2013 assessment of Mrs. Bentley’s capacity for choosing whether or not she wished to eat, “FHA’s position is that the offering of food or liquids is part of comfort care or basic care, but there will come a point in time when feeding will no longer be necessary for comfort or may itself cause discomfort, and FHA would agree that it is no longer appropriate to offer food to Margot at this point. Prior to this point, to cease offering food would be to actively bring about a patient’s death when that patient is not otherwise actively dying.”113

The FHA argued that Mrs. Bentley’s accepting food, chewing, swallowing, and showing food preferences demonstrated her “consent” and constituted a defense to a common law battery claim.114 The FHA argued that this consent constituted independent decision making that overrode the decisions of Mrs. Bentley’s representatives,115 and that, if a family member or anyone else was determined to be her legally recognized decision maker, that person...
would have to act in accordance with Mrs. Bentley’s wishes, which were still unclear from all of the conflicting documents. The FHA also argued that hand feeding does not constitute healthcare, and should not be regarded as such, when applying statutory law to VSED.

The Province of British Columbia also filed a response to the Bentley petition. It emphasized that hand feeding does not constitute healthcare,” and it noted the potential liability of Mrs. Bentley’s caregivers, should her feeding be stopped. The province’s healthcare arguments were grounded not only in a reading of the definition of “healthcare” in the Health Care Consent Act, but also in an argument that defining feeding as healthcare broadly would require obtaining informed consent every time an individual patient received nourishment in a healthcare setting. The province advanced a public policy argument that this would require an overly burdensome amount of documentation. The province argued that, under the Criminal Code, caregivers who participated in a patient’s VSED could face criminal liability for either counseling a person to commit suicide, aiding and abetting suicide, or culpable homicide.

The Judgment of the SCBC. In December 2013, the Supreme Court of British Columbia (SCBC) held three days of hearings. In February 2014, it issued a judgment denying the petition of Mrs. Bentley’s husband and daughter that she not be given nourishment or liquids. The court recognized that the family had significant evidence Mrs. Bentley would not have wanted such things in her then-current state. But the court held that such evidence did not matter, because Mrs. Bentley still had decision-making capacity to decide whether to eat. Obviously, as a consequence of being in stage 7 Alzheimer’s, Mrs. Bentley lacked capacity to make most medical and personal decisions. Yet, the court held that she retained capacity to accept or refuse food and fluids.

Notably, only three medical experts testified at trial: one for Mrs. Bentley and two for the FHA. But only the two expert witnesses testifying on behalf of the FHA had experience with Alzheimer’s. They testified that Mrs. Bentley was capable of consent and indicated that consent by opening or not opening her mouth. These experts explained that Mrs. Bentley’s behavior was not just reflexive when a spoon or cup was pressed to her lip, because she accepted different types and amounts of food and liquids on different days. She expressed a preference for certain flavors and stopped opening her mouth, apparently when she felt full. The court explained that it preferred the evidence of these experts to that of the Bentley family’s expert, a general physician.

The court concluded that Mrs. Bentley’s AD and other earlier expressed wishes were invalid in light of her “current consent.” She had capacity to consent to assistance with feeding, and she continued to give her consent. Consequently, the court held that her careproviders must continue to offer such assistance. This is a remarkably low test for decisional capacity.

Dicta of the SCBC. While that is the holding of the court, it proceeded to offer nearly 100 paragraphs of dicta (that is, the court answered several questions that were briefed and argued by the parties, even though those answers are not essential to the decision). Specifically, the court examined the four ways through which medical decisions can be made for an incapacitated individual: by guardian, healthcare agent, AD, and default surrogate.

First, the court noted that different Canadian provinces reached different decisions on whether assistance with oral feeding and fluids falls within the definition of healthcare. It concluded that, in B.C., oral nutrition and hydration is “personal care,” not healthcare. Still, the court observed that such a determination is not necessarily dispositive; an adult has a common law right to refuse consent to either personal care or healthcare services.

Second, the court held that Mrs. Bentley’s 1991 AD was not a valid “representation agreement.” This is the equivalent of a U.S. proxy directive or durable power of attorney for healthcare. While the court was prepared to overlook some defects in its execution, it was troubled because the AD was unclear. Specifically, while it was clear that Mrs. Bentley intended her named representatives to have authority to make healthcare decisions, it was unclear whether she intended them to also have authority to make personal care decisions.

Third, the court held that Mrs. Bentley’s 1991 Statement of Wishes was not valid as an instructional AD. Again, the document failed to conform to required execution formalities. And, again, its meaning was unclear. The court observed that the phrase “no nourishment or liquids” appears under a broader heading, “I direct that . . . not be kept alive by artificial means or heroic measures.” The court concluded that the best interpretation of the phrase “no nourishment or liquids” was that it did not refer to oral food and fluid. Instead, this phrase was just a specification of one specific type of “artificial means or heroic measures” that Mrs. Bentley did not want. Oddly, in reaching this conclusion, the court did not consider the relevance of a handwritten note on the AD: “In the event that . . . I am unable to recognize the members of my family, I ask that I be euthanized.”
Fourth, the court considered the family’s authority as a “temporary substitute decision maker.” This is the equivalent of a U.S. default surrogate. In B.C., as in the U.S., the law gives default surrogates a narrower range of decision-making authority than named “representatives.” Specifically, the B.C. statute permits temporary substitute decision makers to refuse “healthcare necessary to preserve life” only when there is “substantial agreement” among the patient’s healthcare providers that such a decision to refuse substitute consent is “medically appropriate.” Obviously, given the litigation, Mrs. Bentley’s providers did not agree with the family. Since their concurrence was necessary, the court concluded that Mrs. Bentley’s family lacked the authority to direct that she not be given nourishment or liquids.133

It is important to note that the outcome of this case turned on the facts. While the court denied the petition brought on behalf of Mrs. Bentley, it held that a healthcare provider could legally act on a patient’s advance directive to VSED. The patient must simply provide clearer and more precise instructions than Mrs. Bentley. The lesson for other B.C. residents is: (a) draft representation agreements that clearly give an agent authority to stop life-sustaining personal care; and (b) draft statements of wishes that clearly refuse “oral” nourishment or liquids “by mouth.” Similarly, individuals in most U.S. states can do the same thing. Only a handful of states restrict the authority of ADs and healthcare agents to medical treatment and exclude oral nutrition and hydration from the definition of medical treatment.

Perhaps the more significant (if not alarming) aspect of the court’s judgment is its holding on capacity. It seems remarkable to hold that, when a spoon or glass is pressed to the lips of someone with severe dementia, the mere opening of her or his mouth evidences decisional capacity to continue eating and drinking. Mrs. Bentley may have the capacity to “communicate a choice.” But this is just one component of capacity. She does not understand the relevant information, does not appreciate the situation and its consequences, and cannot reason about treatment or care options.134 While some jurisdictions permit Ulysses contract-type ADs to overrule future incapacitated objections, none permit overruling future incapacitated objections.135 If the test for capacity is really this low, then current “consent” will often trump even the clearest of prior instructions.

CONCLUSION

Medical, ethical, and legal commentators are reaching a near consensus that capacitated patients may make a contemporaneous choice to VSED. Far less clear is whether individuals can choose to VSED in advance, as an exercise of their prospective autonomy. Fortunately, physicians and philosophers are developing theories, tools, and maxims to help define how and when the practice of advance VSED can be legitimately and safely implemented.136

NOTES

4. Pope and Anderson, see note 1 above.
8. Quill and Byock, see note 6 above, p. 409.
9. Ibid., 410.
11. Ibid., 363.
13. Quill and Byock, see note 6 above, p. 410; Pope
and Anderson, see note 1 above, pp. 392-5.
14. Quill and Byock, see note 6 above, p. 410; Pope and Anderson, see note 1 above, pp. 389-92.
15. Ganzini et al, see note 7 above, p. 362.
16. B. Chabot and S. Braam, Uitweg (Amsterdam, the Netherlands, Niigh & Van Ditmar 2012).
20. See, e.g., Cruzan v. Dir., Mo. Dep’t of Health, 497 U.S. 261, 296 (1990) (Scalia, J., concurring) (“Starving oneself to death is no different from putting a gun to one’s temple as far as the common-law definition of suicide is concerned.”).
27. See Cruzan, 497 U.S. at 279. According to the Restatement of Torts, Second, “An actor is subject to liability to another for battery if (a) he acts intending to cause a harmful or offensive contact with the person of the other or a third person, or an imminent apprehension of such a contact, and (b) an offensive contact with the person of the other directly or indirectly results.” § 18. Restatement of Torts, Second (Philadelphia, Pa.: American Law Institute, 1965).
31. Morton v. Wellstar Health Sys., Inc., 653 S.E.2d 756, 757 (Ga. Ct. App. 2007) (The consent form read “AUTHORIZATION OF TREATMENT: I hereby consent to medical or hospital care encompassing diagnostic procedures and medical treatment as may be . . . ordered by physicians, employees, or agents responsible for such medical or hospital care. I further consent to treatment by authorized employees or agents of [Wellstar] who are assigned to my . . . care.”)
32. See Bentley v. Maplewood Seniors Care Society, 2014 BCSC 165 (holding that a long-term care facility’s assistance with eating and drinking is not medical treat-
ment); Barber v. Superior Court, 195 Cal. Rptr. 484, 490 (Ct. App. 1983) (“Medical procedures to provide nutrition and hydration are more similar to other medical procedures than to typical human ways of providing nutrition and hydration.”); McConnell v. Beverly Enterprises-Conn., Inc., 553 A.2d 596, 603 (Conn. 1989) (“The state statute implicitly contemplates the possible removal from a terminally ill patient of artificial technology in the form of a device such as a gastrostomy tube, but it does not, under any circumstances, permit the withholding of normal nutritional aids such as a spoon or a straw.”); In re Conroy, 486 A.2d 1209, 1236 (N.J. 1985) (“It is hard to shed the emotional symbolism of food. . . . However, artificial feedings such as nasogastric tubes, gastrostomies, and intravenous infusions are significantly different from bottle-feeding or spoon-feeding—they are medical procedures with inherent risks and possible side effects, instituted by skilled health-care providers to compensate for impaired physical functioning.”). Citations omitted.); Requena, 213 N.J. Super. at 485-86 (“A distinction should be made between natural feeding and artificial feeding. For a person to eat and drink in the usual way, either entirely under her own power or with the natural assistance of others, is part of the normal routine of living.”); In re Guardianship of Grant, 747 P.2d 445, 453 (Wash. 1987) (“Food and water are basic necessities of life; indeed, they also carry tremendous emotional significance . . . At the same time, however, we must recognize that nasogastric tubes and intravenous infusions are significantly different from typical human ways of providing nutrition.”). Citations omitted.

33. See, e.g., Del. Code Ann. § 2501(c) (“Artificial nutrition and hydration does not include assisted feeding, such as spoon or bottle feeding.”); Idaho Code Ann. § 39-502(3) (“Artificial nutrition and hydration” means supplying food and water through a conduit . . . but does not include assisted feeding, such as spoon feeding or bottle feeding.”); R.I. Gen. Laws Ann. § 23-4.10-1.1(2) (“Artificial feeding” means the provision of nutrition or hydration by parenteral, nasogastric, gastric, or any means other than through per oral voluntary sustenance.).

34. See section 2, above.


40. Ibid.

41. Ibid., 282-83.

42. Ibid., 283.

43. Ibid., 283, 282.

44. Ibid., 283. The court employed the concept of justiciability to deny A.B.’s request. “Justiciability” refers to the idea that a case must be “suitable for adjudication by a court.” B.A. Garner, ed., Black’s Law Dictionary, 9th ed. (St. Paul, MN: West Group, 2009). This case was not justiciable because it lacked ripeness, defined as “whether the harm asserted has matured sufficiently to warrant judicial intervention.” Warth v. Seldin, 422 U.S. 490, 499 n. 10 (1975). Because the American legal system is based on the application of law to facts, courts are reluctant to decide cases before the facts have fully developed to the point of an actual controversy.

45. A.B., 477 N.Y.S.2d at 283.


48. Ibid., 11.

49. Ibid., 12.

50. Ibid., 12.


54. Ibid., 4.

55. Ibid., 7.


58. Ibid., 7.

59. Ibid., 21.

60. Ibid., 25.

61. Ibid., 32.

62. Ibid., 36.

63. Ibid., 45.

64. Ibid., 47-65.

65. Ibid., 56 (quoting In re Joel Caulk, 480 A.2d 93, 100 (NH 1984)) (Douglas, J. dissenting).

66. Ibid., 57-8.

67. Ibid., 64.

68. Ibid., 73, 76.

69. Ibid., 88.

70. Ibid., 82, 79.

71. Ibid., 87-8.
72. Ibid., 91.
73. Ibid., 97.
74. Nicklinson, R (on the application of) v A Primary Care Trust [2013] EWCA Civ 961 (31 July 2013).
80. Ibid., 1983 BCCA 718.
82. Ibid., para. 140.
83. Brief for Petitioner, Bentley v. Maplewood Seniors Care Society, Pt. II, para. 21-22.
84. Ibid., Pt. II, para. 26, 30; Hammond Aff. para. 9.
85. Ibid., Exh. B.
86. Ibid., Pt. II, para. 30.
87. Ibid., Pt. II, para. 31, 10, 18.
88. Ibid., Pt. II, para. 33.
89. Ibid., Pt. II, para. 35-36.
90. Ibid., Pt. II, para. 37.
91. Ibid., Pt. II, para. 38.
92. Ibid., Pt. II, para. 40. FHA’s 21 December 2012 letter explained, “The reason for this decision is because you indicated that in both [a residential care facility or Ms. Bentley’s home] Margot would not be provided with food unless she communicates, in some way, her desire to be fed. From Fraser Health’s clinical knowledge of Margot, we know that if Margot is not fed by hand by a caregiver then her basic nutritional needs will not be met. The failure to provide Margot with her basic nutritional needs will meet the definition of ‘neglect’ in the Adult Guardianship Act.” Ibid., Exh. J.
93. Ibid., Pt. II, para. 42.
94. Ibid., Exh. I.
95. Ibid., Exh. D, 9-10.
96. Ibid., 9. The legal opinion itself is not part of the official record of this case, and the plaintiffs have never viewed the original, because the FHA asserts that it is protected by solicitor-client privilege. Ibid., Pt. I, para. 48; Exh. F.
97. Ibid., Exh. L.
98. Ibid., Exh. L, App. 1, p. 33.
99. Ibid., Exh. L at 31-32.
100. Ibid., 32.
101. Ibid., Pt. I, para. 8-17.
103. Ibid., Pt. I, para. 23. (The petition specifically cites Mrs. Bentley’s freedom of conscience; religious freedom of thought and belief; and her rights to life, liberty, and security of the person, equal protection, and equal benefit of the law without discrimination.)
105. Ibid., Pt. IV, para. 3.
106. Ibid., Pt. IV, para .1(g), (i).
107. Ibid., Pt. IV, para. 6.
108. Ibid., Pt. IV, para. 17.
110. Ibid., Pt. IV, para. 24. 27.
111. Ibid., Pt. IV, para. 31. 33. (She was not actively dying, she was expected to live beyond four months, she was well cared for where she was, her symptoms were well controlled, and a new environment could cause her distress.)
112. Ibid., Pt. IV, para. 38-9.
113. Ibid., Pt. IV, para. 48.
114. Ibid., Pt. V, para. 52.
115. Ibid., Pt. V, para. 55.
116. Ibid., Pt. V, para. 56.
117. Ibid., Pt. V, para. 54.
119. Ibid., Pt. V, para. 10, 12, 19-27.
120. Ibid., Pt. V, para. 31-40.
121. Bentley v. Maplewood Seniors Care Society, 2014 BCSC 165, paras. 60 and 153.
122. Ibid., paras. 5-7.
123. Ibid., paras. 22-30.
124. Ibid., para. 20.
125. Ibid., para. 49.
126. Ibid., paras. 50, 59.
127. Ibid., para. 54.
128. Ibid., para. 60.
129. Ibid., paras. 62-81.
130. Ibid., para. 84.
131. Ibid., paras. 90-102.
132. Ibid., paras. 103-13.
133. Ibid., paras. 114-20. The statute does not address whether temporary substitute decision makers can consent to personal care necessary to preserve life. The court held that they do not have that authority. Ibid., paras. 121-45.
136. P.T. Menzel and M.C. Chandler-Cramer, “Advance Directives, Dementia, and Withholding Food and Water by Mouth” (in submission, readers may contact menzelpt@plu.edu). Menzel and Chandler-Cramer rightly note that the strategy of employing VSED in dementia through ADs has emerged fairly recently. Stanley Terman has been a steadfast and early advocate. See his various materials at www.Caring Advocates.org and in S.A. Terman, The Best Way to Say Goodbye: A Legal Peaceful Choice at the End of Life (Carlsbad, Calif.: Life Transitions Publications, 2007).