

## Legal and Ethical Challenges in Honoring “Do Not Spoon-Feed” Requests

BY CATHY SUSKIN

In 1991, Margot Bentley did what Vermont Ethics Network (VEN) recommends all adults with decision-making capacity do. She considered the care she wanted at the end of life, signed an advance directive expressing her wishes and talked over her choices with her family. A nurse, Ms. Bentley had seen patients in the advanced stages of Alzheimer’s Disease and knew she would not want to live that way. Accordingly, she instructed in her advance directive that if she ever suffered from “extreme physical or mental disability,” she wanted to be “allowed to die.” Not only did she want no “artificial” life-sustaining treatments, but also “no nourishment or liquids.”<sup>1</sup> After that, she repeatedly reiterated this wish in conversations with her family, including after her diagnosis.<sup>2</sup>

Now 83 years old, Ms. Bentley is in the seventh and final stage of Alzheimer’s, her illness having been diagnosed over sixteen years ago. Unable to walk or talk and totally dependent on others for her care, her advance directive has become a focal point in a growing legal and ethical controversy over whether such documents may be used to refuse not just artificial nutrition and hydration (typically via feeding tube),

but also food and drink by mouth (“spoon-feeding”). Several years ago, when Ms. Bentley’s family, seeking to honor her wishes, asked Ms. Bentley’s nursing home to stop feeding her, the nursing home refused, and a legal battle ensued.

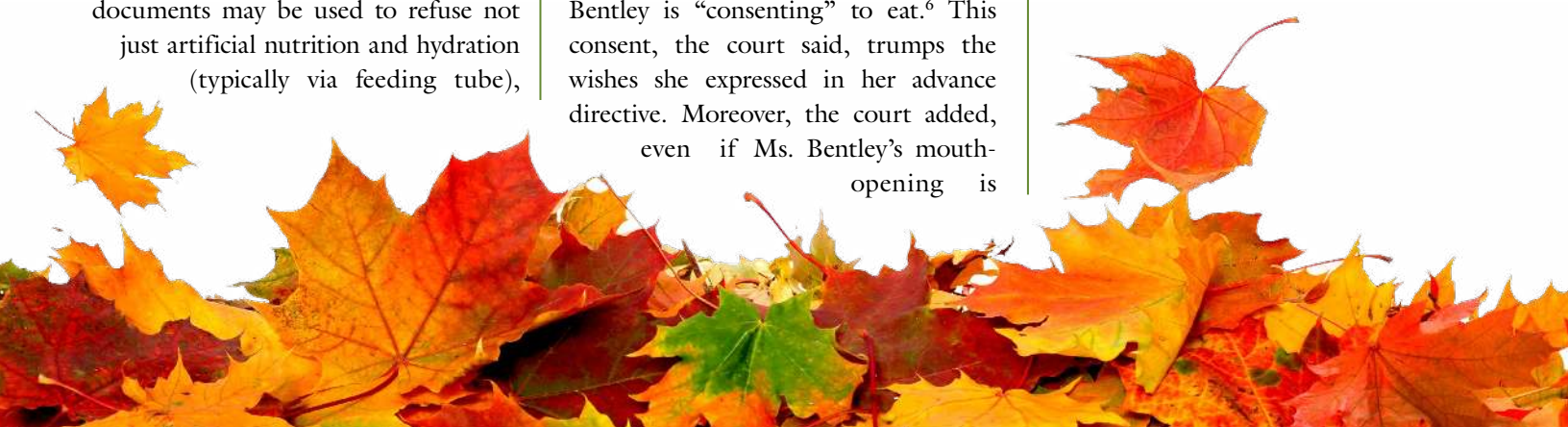
In an earlier edition of this newsletter, VEN explored the practice of Voluntarily Stopping Eating and Drinking (VSED).<sup>3</sup> In VSED, an adult who is capable of making the decision to do so voluntarily chooses to stop taking food and drink as a means of hastening death. While not without controversy, VSED is ethically and legally consistent with the right to refuse unwanted care. The issue in the Bentley case is whether the same principle applies to those who, like Ms. Bentley, request to stop eating and drinking in an advance directive (“SED by AD”).<sup>4,5</sup>

Last year, a court in Ms. Bentley’s native British Columbia said no. While leaving open the possibility that a health care provider could honor such a directive in a different case, the court held that by opening her mouth when an aide rests a spoon against her lip, Ms. Bentley is “consenting” to eat.<sup>6</sup> This consent, the court said, trumps the wishes she expressed in her advance directive. Moreover, the court added, even if Ms. Bentley’s mouth-opening is

mere reflex, spoon-feeding is “basic” or “personal” care, not “health” care within the meaning of the B.C. advance care statute; and even if spoon-feeding *is* health care, Ms. Bentley’s directive failed to adequately specify either her wish to forgo it or her desire to authorize her surrogate to refuse it for her. In the circumstances, the court said, withholding food and drink would constitute neglect under B.C.’s adult guardianship law.<sup>7</sup>

The Bentley case by no means settles the matter, but it touches on many of the ethical and legal issues involved in SED by AD as a potential end-of-life strategy. Proponents view the practice as providing a humane exit option, particularly for dementia. Opponents see it as a denial of basic, morally obligatory care or as suicide. Still others focus on the clinical realities of institutional care and the practical difficulties involved in implementing “Do-Not-Spoon-Feed” requests.<sup>8</sup> Because VEN has started receiving inquiries about the practice, we discuss the issues it raises in greater detail below.

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# HEALTH DECISIONS

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*The mission of the  
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a core component of  
health care and health care  
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## ISSUES IN “DO-NOT-SPOON-FEED” REQUESTS *continued from page 1*

As a recent New York Times article points out, dementia poses formidable obstacles for those who desire some control over their death.<sup>9</sup> The disease often progresses slowly, and involves a long period of extreme disability. But for those who find the prospect of life in such a state intolerable, end-of-life options are limited. Often there is no “plug to pull,” no medical treatments or life-sustaining technologies to decline. VSED is available only to those who currently possess decisional capacity, and dementia sufferers do not qualify for [Physician Assisted Death \(PAD\)](#).<sup>10</sup> As one commentator put it, for those who would prefer death over dementia, the disease “tends to become a trap. One wishes to end one’s life because one is demented, but [when that time comes] one cannot . . . end one’s life because one is demented.”<sup>11</sup>

Chief among the many unanswered questions about the acceptability of SED by AD is what some call the “then-self versus now-self” problem.<sup>12</sup> People affected by dementia and other progressive cognitive decline often become virtually unrecognizable as the person they used to be. Whereas their former self may have feared life in a severely debilitated state and may have expressed in a clear and unambiguous advance directive a strong desire to forgo food and drink by mouth once they reach a certain point, their later, demented self may appear to not much care one way or the other, or may by their behavior suggest that they continue to take pleasure in living (often the case with so-called “happy” dementias).<sup>13</sup> In short, the current self and the former self have different sets of desires.<sup>14</sup> Whose desires should prevail, those of the former self or those of the current self? This is not just a legal question, but an ethical one. Respect for autonomy is key, but whose autonomy? That of the person who used to be, or that of the person who is now? Given the difficulty of reconciling the sometimes conflicting interests of the earlier and later “selves,” even some advocates of SED by AD argue that withholding of food and drink by mouth should not be permitted until dementia is

far advanced.<sup>15</sup>

A related question is what is required to revoke a directive requesting SED. There is research to suggest that the wish to hasten death does not remain stable over time.<sup>16</sup> In Vermont an advance directive may be revoked “at any time,” either orally, in writing, or “by any other act evidencing a specific intent to suspend or revoke.”<sup>17</sup> Is a now-demented person required to vigorously and consistently resist all nourishment in order to evidence the required intent to revoke? What if he or she seems merely indifferent to being fed?<sup>18</sup> In people with restricted ability to communicate, it can be exceedingly difficult to judge whether behaviors like mouth-opening are willful or merely reflexive.<sup>19</sup>

And what of the duty of beneficence? Feeding is a fundamental expression of caring, one with deep emotional roots. Withholding food and drink from someone who is not actively refusing it is an extremely sensitive matter for both caregivers and family.<sup>20</sup> Providing nourishment is also an important part of institutional culture in nursing homes and other long-term care facilities, backed up by numerous legal and regulatory requirements designed to protect vulnerable populations from neglect and abuse. While Medicare regulations explicitly exclude from certification review providers who withhold nutrition and hydration pursuant to an advance directive,<sup>21</sup> the institutional emphasis in nursing homes is on maintaining residents’ health. To honor SED by AD would require not just extensive staff education and clear policies regarding, for example, conscientious objection, but also extremely close attention to both the specifics of each patient’s request and to individual variations in the natural progression of the disease.<sup>22</sup>

Another issue is whether advance directives protect refusals of care that are not, strictly speaking, “medical.” In the Bentley case, the court found that the advance directive statute at issue applied only to wishes regarding “health” care. Because

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spoon-feeding is “personal” care, the court said, it is beyond the scope of interests the statute protects.<sup>23</sup>

Vermont law is different. Under the Vermont advance directive statutes, “health care” includes not just “treatments,” but “any ... service...to maintain...an individual’s physical or mental condition, *including services ... to assist in activities of daily living.*” (Emphasis added.)<sup>24</sup> While the statute expressly excludes spoon-feeding as a form of “nutrition and hydration administered by medical means,”<sup>25</sup> providing food and drink by mouth is at least arguably a “service” to “assist” in an “activity of daily living” and therefore possibly subject to refusal. There is no Vermont case law on this point, however, leaving it unclear how Vermont courts would interpret a request for SED by AD (or for that matter the refusal of any other form of personal care, such as bathing, toileting or dressing). Even if Do-Not-Spoon-Feed requests fall outside the purview of Vermont’s advance directive statutes, a court could find a right to refuse in the common law of battery. At common law, any intentional non-consensual touching of one person by another constitutes battery.<sup>26</sup>

For Vermonters who wish to refuse spoon-feeding in the event they later develop dementia, the lessons of the Bentley case are several. First is that the expression of a wish for SED by AD is no guarantee that the wish will be respected. The approach is new and the circumstances in which such requests may be honored are not yet clear.<sup>27</sup> Moreover, the case suggests that those who wish to refuse spoon-feeding must be extremely specific in articulating not only their wish to refuse it, but also their surrogate’s authority to request a “Do-Not-Spoon-Feed” order on their behalf and the precise circumstances that would trigger the request. In addition, the case suggests that those who desire SED by AD may need to

document that this desire persisted over time. Margot Bentley reportedly repeatedly reiterated her desire for SED in conversations with her family over the years, but her advance directive was over 20 years old at the time her family sought to enforce it. The absence of a more recent directive may have raised a concern that her wishes changed. A final lesson of the case is that should institutional care be needed, surrogates will need to take care to choose a facility willing to honor SED by AD. While nothing in the Bentley decision suggests that care facilities *may* not honor such requests, some will *choose* not to, whether for religious or philosophical reasons, or because they believe the law prohibits it, or because they are simply not equipped to provide the careful oversight the practice requires.

None of the above should be taken to suggest that VEN endorses SED by AD. To the contrary, VEN’s position on this practice is neutral. As with other health care controversies, some people will strongly favor the practice, while others will equally strongly oppose it. Still others, recognizing the nuances involved in honoring such requests, will favor it in some circumstances, but oppose it in others. For now the practice remains an unsettled issue both ethically and legally. Anyone who wishes to incorporate a “Do-Not-Spoon-Feed” request into their advance care plan would do well to consult both their physician and an attorney experienced in this area.

1 *Bentley v. Maplewood Seniors Care Society*, 2015 BCCA 91, March 3, 2015 <http://www.courts.gov.bc.ca/jdb-txt/CA/15/00/2015BCCA0091cor1.htm>

2 *Bentley v. Maplewood Seniors Care Society*, 2014 BCSC 165, February 3, 2014 <http://www.courts.gov.bc.ca/jdb-txt/SC/14/01/2014BCSC0165.htm>

3 Suskin, C., “Voluntary Stopping of Eating and Drinking (VSED)”, Vermont Ethics Network *Health Decisions*, Winter 2015, Volume 23, No. 2 <http://www.vtethicsnetwork.org/newsletters/ven-newsletter-winter-2015.pdf>

4 By definition, an advance directive becomes effective only after a person has lost the ability to make care decisions for himself or has **chosen not to**. This is a significant difference, as in VSED the person acts on his choice himself, whereas in SED by AD, a surrogate must exercise his choice for him. While vulnerable individuals often need extra protections, the accepted view in American law and ethics is that people do not lose their right to make medical decisions when they become incapacitated. See Quill, T, *Palliative Care and Ethics*, Oxford University Press, 2014, p. 195. Indeed, this is the principle behind advance directives.

5 It should be noted that while many people fear that dying this way would be terribly painful, the available evidence, while limited, is to the contrary. See Suskin, *supra* note 3.

6 See *Bentley*, 2015 BCCA 91, *supra*. The Court of Appeals later affirmed the trial court’s ruling. *Ibid*.

7 *Ibid*.

8 See Menzel, P, and Chandler-Cramer, C, “Advance Directives, Dementia, and Withholding Food and Water by Mouth,” *Hastings Center Report* 44: 3 (May-June 2014): 23-37

9 Span, Paula, *Complexities of Choosing an End-Game for Dementia*, New York Times, January 19, 2014

10 See 18 VSA Chapter 113

11 Menzel, *supra*

12 *Id* at 25

13 *Id* at 29

14 *Id* at 25

15 See Menzel, *supra*

16 Quill, *supra* at 241

17 18 VSA § 9704(b)(2)

18 See Menzel, *supra*

19 At the seventh and final stage of dementia, typically “the brain appears to no longer be able to tell the body what to do.” Reisberg, B, “Global Deterioration Scale for the Assessment of Primary Dementia,” *American Journal of Psychiatry*, 1982, 139: 1136-1139.

20 Menzel, *supra* at 25

21 Center for Medicare & Medicaid Services, *State Operations Manual*, App. Q, “Guidelines for Determining Immediate Jeopardy,” rev. 1, 5/21/04, section IV, issue E, trigger 3

22 *Id* at 25

23 See *Bentley*, 2014 BCSC 165, *supra* note 2

24 18 VSA § 9701(12)

25 18 VSA § 9701(20)

26 See *Christman v. Davis*, 179 Vt. 99 (2005). As the Bentley case shows, however, determining consent in patients with advanced dementia can be extremely difficult.

27 For example, it is highly unlikely that a court would order the enforcement of a “Do-Not-Spoon-Feed” request against a demented person who shows obvious continued pleasure in eating, even if that person is extremely demented.



— Fall Conference presented by Vermont Ethics Network —

# Issues at the Intersection of Law & Medical Ethics

Wednesday – November 11, 2015 • 8:00 AM – 4:30 PM

Lake Morey Resort ~ Fairlee, VT

## Primary Objective

The ethical questions that arise in the clinical setting often overlap with legal issues — resulting in implications for patient care. The primary objective of this event is to provide insight and strategies for navigating ethically and legally complex medical situations.

## Featured Presenters



**Arthur Derse, MD, JD, FACEP** – Dr. Derse is the Director of the Center for Bioethics and Medical Humanities and

Professor of Bioethics and Emergency Medicine at the Medical College of Wisconsin. He is a past president of the American Society for Bioethics and Humanities (ASBH), chair of the National Ethics Committee of the Veterans Health Administration, and member and past chair of the Ethics Committee of the American College of Emergency Physicians (ACEP). He is a member of the board of the American Society of Law, Medicine and Ethics (ASLME). He served as Senior Consultant for Academic Affairs at the American Medical Association's Institute for Ethics and as a member of the American Bar Association's Commission on Law and Aging. His publication and research has focused on emergency medicine and ethics, confidentiality, informed consent, end-of-life decision making, the doctor-patient relationship and the use of the internet in academic bioethics and medicine.



**Stephen Latham, JD, PhD** – Stephen R. Latham became Director of the Yale Interdisciplinary Center for Bioethics in 2011, having

been Deputy Director since 2008. For the previous nine years, he had been Professor of Law and Director of the Center for Health Law & Policy at Quinnipiac University School of Law; during that time, he also taught business ethics at the Yale School of Management each year. Before entering academia full-time, Latham served as Director of Ethics Standards at the American Medical Association, and as secretary to its Council on Ethical and Judicial Affairs. His research deals broadly with the intersections of bioethics with law.

## Local Experts

**Hon. Ernest Tobias (Toby) Balivet** – Attorney and Caledonia County Probate Judge since 1999.

**Tim Lahey, MD** – Chair of the Clinical Ethics Committee, and a member of the research ethics and organizational ethics committees at Dartmouth-Hitchcock Medical Center.

**Robert Macauley, MD** – Directs the Clinical Ethics Consultation Service at the UVM Medical Center as well as the ethics curriculum at the UVM College of Medicine.

**John Saroyan, MD** – Hospice Medical Director for BAYADA Hospice.

For questions, please call:  
802-828-2909 or e-mail:

[kcarrier@vtethicsnetwork.org](mailto:kcarrier@vtethicsnetwork.org)

## Agenda

7:45 Arrival, Registration & Breakfast

8:50 Welcome & Overview of Day

### 9:00 *Plenary Session I*

Professional Standards: Between Law and Ethics. **Presented by Stephen Latham, JD, PhD**

10:15 BREAK

### 10:45 *Plenary Session II*

The Interrelation of Law & Ethics in Clinical Practice: Informed Consent & Refusal, Decision-Making Capacity and End-of-Life Care. **Presented by Arthur Derse, MD, JD**

12:00 LUNCH (included)

### 1:00 *Breakout Session 1* (choose one)

A. Honoring Do Not Spoon Feed Requests: Clinical, Ethical & Regulatory Considerations. **Presented by John Saroyan, MD**

B. When Good Patients Make Bad Decisions: Challenges in Informed Consent. **Presented by Tim Lahey, MD**

C. The Ethics of Covert Medications. **Presented by Robert Macauley, MD**

D. Medical Decision-Making, Guardianship & Advance Directives. **Presented by Hon. Ernest Tobias (Toby) Balivet**

2:00 BREAK

### 2:15 *Breakout Session 2* (choose one)

Same offerings as Breakout Session 1

3:15 BREAK

3:30 Closing Panel with Stephen Latham and Arthur Derse. **Facilitated by William Nelson, PhD**

4:15 Evaluations & Pick up CME/CEU's

## VEN Welcomes New Board Members

**Allen Hutcheson, MD**, is the Director of Supportive Care Services at Southwestern Medical Center where he provides consultation, education and palliative care coordination. He is also the Medical Director for the Visiting Nurse Association and Hospice of SVMC. A graduate of the Medical University of South Carolina, Allen completed his residency in urban family practice and a fellowship in pain and palliative care at Beth Israel Medical Center in New York. He is board certified in Family Practice and in Hospice and Palliative Medicine and has a certificate in Bioethics and Humanities from the Cardozo School of Law.

**Molly Kittridge, RN**, is currently employed by the University of Vermont Health Network at Central Vermont Medical Center as the Assistant Director of Nursing for the Medical Group Practices. She earned her Associates degree in Nursing from Vermont Technical College in 2009 and her Master's degree in Nursing Leadership and Management from Walden University in 2014. She lives in Woodbury, Vermont on a small hobby farm with her husband and two young children.

**Tim Lahey, MD, MMSc**, is an HIV doctor and researcher and associate professor at Dartmouth's Geisel School of Medicine. A graduate of Georgetown, Duke University School of Medicine and Harvard Medical School, Tim is chair of the Clinical Ethics Committee, and a member of the research ethics and organizational ethics committees at Dartmouth-Hitchcock Medical Center. Tim has led ethics-related curricular development at Geisel with Bill Nelson, and is an award winning teacher at Geisel and elsewhere. He is the Director of Education at The Dartmouth Institute for Health Policy & Clinical Practice, faculty advisor for the Dartmouth College Health Professions Program,

and 2015 chair of the Geisel Academy of Master Educators. Tim publishes in scholarly journals and the popular press; the latter are available at medmurmurs.com.

**Prema R. Menon, MD**, is a Pulmonary/Critical Care Medicine physician at the University of Vermont Medical Center (UVMMC). She has been living in Vermont since 2008. Prema's primary area of interest is difficult conversations in the ICU. She has taken several graduate level courses in clinical ethics as a part of her PhD coursework. She studies end of life (EOL) communication with family members of critically ill patients and patient- and family- centered com-

munication in the ICU setting and is currently conducting two clinical trials at the UVMMC surrounding these two topics.

In addition to research, Prema works clinically in the adult Medical Intensive Care Unit and in the out-patient Pulmonary Ambulatory Clinic at the UVMMC. She is a member of the UVMMC Ethics Committee and Subcommittee where she participates in the discussion and resolution of hospital-based ethical dilemmas. Originally from Florida and an avid adorer of hot, humid days, Prema lives in South Burlington with her husband, 3 daughters (ages 7, 18 months and 3 months) and 3 dogs.

### Advance Care Planning is for Everyone

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- STEP 2: Complete a comprehensive Advance Directive with detailed information about treatment goals and health care priorities (for adults with chronic illness or those seeking to give more specific information about their preferences).
- STEP 3: Develop a DNR/COLST order with your clinician to ensure that any limitation of treatment will be respected across care settings (for individuals who are seriously ill or dying, or who are certain they would not want life-prolonging interventions).
- REGISTER your Advance Directive with the Vermont Advance Directive Registry.

For more information about advance care planning, the Vermont Ethics Network, or to order Taking Steps Booklets, call us at (802) 828-2909 or visit us online at [www.vtethicsnetwork.org](http://www.vtethicsnetwork.org).