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Three Barriers to VSED by Advance Directive: A Critical Assessment

Paul T. Menzel, PhD*

ABSTRACT

Competent persons have the right to voluntarily stop eating and drinking as a means of hastening death, just as they have the right to refuse lifesaving medical treatment. If people do not lose their rights merely by becoming incompetent, then arguably their right to stop eating and drinking is not lost when they become incompetent. Such a right could be exercised on their behalf pursuant to an advance directive.

However, such directives to withhold food and fluids by mouth face significant legal and moral barriers. Among them are that *consent is no defense* to a charge of criminal homicide for failure to feed, that an incompetent person's *willingness to eat constitutes a change of mind* revoking her directive, and that oral feeding is *basic personal care that falls outside the legitimate scope of advance directives*. None of these three objections is persuasive. Strong reasons for rejecting them bolster the case for permitting the implementation of adequately clear directives to withhold food and fluids by mouth.

I. INTRODUCTION

Voluntarily stopping eating and drinking (VSED) is one way in which people afflicted with painful or debilitating conditions can hasten their deaths. When paced and managed with the appropriate palliative care, dying by VSED is usually a relatively peaceful and comfortable death.¹ It is

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¹ Ira Byock, *Patient Refusal of Nutrition and Hydration: Walking the Ever-Finer Line*, 12 AM. J. HOSPICE & PALLIATIVE CARE 8, 8-13 (1995); Judith K. Schwarz, *Hospice Care for Patients Who Choose to Hasten Death by Voluntarily Stopping Eating and*

attractive to patients for that and various other reasons, including the fact that, unlike the refusal of lifesaving treatment, VSED expedites death even when no lifesaving care is needed that could be refused.² As an option for hastening death, VSED also ensures that death will come within a few weeks.

An elegant, logical sequence forms the initial argument for the use of advance directives (ADs) to exercise VSED in situations where the patient is not competent. In what I will refer to as “the basic argument,” two legal and moral realities, one about VSED and the other about ADs, create a third claim:

1. Competent persons have a right to VSED.³
2. Competent persons can also write ADs for future situations when they will lack decision-making capacity, including instructions to refuse lifesaving medical treatment.⁴ If those directives are clear and

Drinking, 16 J. HOSPICE & PALLIATIVE CARE NURSING 126, 126-31 (2014); Paula Span, *The VSED Exit: A Way to Speed Up Dying, Without Asking Permission*, N.Y. TIMES, Oct. 25, 2016, at D5. Numerous other sources are provided in Paul T. Menzel & M. Colette Chandler-Cramer, *Advance Directives, Dementia, and Withholding Food and Water by Mouth*, 44 HASTINGS CTR. REP. 23, 23-37 n.14-22 (2014).

² Span, *supra* note 1; Paul T. Menzel, *Merits, Demands, and Challenges of VSED*, 6 NARRATIVE INQUIRY BIOETHICS 120, 121-26 (2016).

³ Concerning the legal right, *see generally* Thaddeus M. Pope & Lisa E. Anderson, *Voluntarily Stopping Eating and Drinking: A Legal Treatment Option at the End of Life*, 17 WIDENER L. REV. 363 (2011); Norman L. Cantor, *Honing the Emerging Right to Stop Eating and Drinking*, BILL OF HEALTH (Nov. 18, 2016), <http://blogs.harvard.edu/billofhealth/2016/11/18/patients-right-to-stop-eating-and-drinking/>, hereinafter referred to as Cantor, BILL OF HEALTH (2016). (I add to this claim that VSED is a legal right that people have a moral right to VSED as well, in the sense of a “moral liberty”—others are doing something morally wrong if they forcibly interfere with a person’s pursuit of VSED.)

⁴ The development of the legal view that a person’s common law and constitutional liberty based right to control medical choices does not vanish upon incompetence was led by state courts in the 1980s and 1990s. *See* Norman R. Cantor, *Can the Right to Stop Eating and Drinking be Exercised via a Surrogate Acting Pursuant to an Advance Instruction?* BILL OF HEALTH (Jan. 23, 2017), <http://blogs.harvard.edu/billofhealth/2017/01/23/can-the-right-to-sed-be-exercised-via-a-surrogate-acting-pursuant-to-an-advance-instruction/#more-20582> (blogsite of Petrie-Flom Center, Harvard Law School), hereinafter referred to as Cantor, BILL OF

substantive enough for later decision-makers to know when to apply them, they have considerable normative weight, exemplifying the underlying principle that a person's basic rights are not lost with incompetence.

It would then seem to follow:

3. By sufficiently clear ADs, people should be able to have food and fluids as well as lifesaving medical treatment withheld.

I will refer to the directives that emerge from this basic argument as “ADs for Stopping Eating and Drinking” (“ADs for SED”) and what happens when they are implemented as “Stopping Eating and Drinking by ADs” (“SED by AD”). If such directives can be implemented, one's control over the end of life will be significantly enhanced. Short of preemptive suicide or stopping eating and drinking when one is still competent and decisive, ADs for SED are arguably the only way of ensuring, for example, that one will not live into long years of severe dementia. Some find such a fate at least as objectionable as the weeks and months of suffering that they can avoid by aid-in-dying or refusing lifesaving treatment.⁵ To them, ADs for SED provide a vital end-of-life option.

HEALTH (2017). Influential cases in the development of common law about advance directives include *In re Browning*, 568 So.2d 4 (Fla. 1990) and *In re Jobes*, 529 A.2d 434, 451 (N.J. 1987). See also the comprehensive book-length treatment by NORMAN R. CANTOR, *ADVANCE DIRECTIVES AND THE PURSUIT OF DEATH WITH DIGNITY* (1990).

⁵ The author knows of no studies directly of the prevalence of this view in a population. However, many individual cases have been described in the literature, including (1) Margot Bentley, see Katherine Hammond, *Kept Alive – The Enduring Tragedy of Margot Bentley*, 6 NARRATIVE INQUIRY BIOETHICS 80, 80-82 (2016) (the legal cases involving Mrs. Bentley are *infra* note 7); (2) Alan Alberts, see Phyllis Shacter, *Not Here by Choice: My Husband's Choice About How and When to Die*, 6 NARRATIVE INQUIRY BIOETHICS 94, 94-96 (2016); (3) Jephtha Carrell, see Paul T. Menzel, *Carpe Diem: the Death of Jephtha Carrell* (2010), <https://docs.google.com/a/plu.edu/viewer?a=v&pid=sites&srcid=cGx1LmVkdXxtZW56ZWxwdHxneDphM2FmY2F1MWMwMzIwOGY> (also available at <https://sites.google.com/a/plu.edu/menzelpt/selected-unpublished-documents>). An intensive study by Volicer and Stets, while not a population study, is also revealing. Volicer & Stets, *infra* note 39 (from two focus groups of relatives of persons who had died with dementia, the authors found generally positive attitudes toward using advance

Since the basic legal elements that generate such directives—the first two propositions in the basic argument above, the right of competent persons to VSED and the principle that people do not lose their rights when they become incompetent—already exist by common law, not statutory law, ADs for SED would also arguably be legal without legislative authorization.⁶ Moreover, since the initial right to VSED is not limited to situations of terminal illness, SED by AD would also not be limited to such situations.

As a matter of propositional logic, the inference in the basic argument to the legitimacy of ADs for SED may be sound, but as a matter of moral and legal reasoning, it is simplistic. Various legal, moral, and clinical considerations intrude. This paper will address three legal and ethical objections that constitute barriers to implementing ADs for SED.

A. Consent Is No Defense to Criminal Homicide

A valid directive has to be implemented by someone. Nursing home staff, for example, will have to stop providing food and fluids by mouth. But if failing to provide such a basic need can constitute culpable homicide, and the victim's consent is legally no defense to a homicide, then a person's consent that is carried forward to the time of incompetence by an AD will not provide a defense for anyone who implements a directive.

B. Willingness to Eat Is a Change of Mind

In a later state of incompetence like severe dementia, a person with an AD for SED may still accept food and fluids by mouth. Does such acceptance constitute a change of mind about the directive, effectively revoking it? If it does, it removes the directive's normative force.⁷ Even if

directives to refuse various forms of life-sustaining care, including oral feeding, implying a preference that life not extend into years of severe dementia).

⁶ See Cantor, BILL HEALTH (2017), *supra* note 4, at 2 and accompanying cases.

⁷ This was one of several key issues in *Bentley v. Maplewood Seniors Care Society*, 2015 BCCA 91 (Mar. 5th, 2015) (on appeal of *Bentley v. Maplewood Seniors Care*

acceptance of food is not the kind of change of mind that revokes a directive, it still may constitute the patient's consent and will, which caregivers would be obliged to respect.

C. Food and Fluids Is Basic Personal Care

Providing food and fluids arguably constitutes basic personal care, not medical treatment. Even if acceptance of food and fluids does not constitute adequate consent or the change of mind that revokes an AD, food and fluids are different than medical treatment. As basic personal care, provision of food and fluids by mouth is not properly amenable to control by AD.⁸ Caregivers' obligations to provide basic personal care are not restricted by ADs in the same way their obligations to provide medical care are restricted.

While each of these objections is cogent, I will argue that morally and legally none constitutes a persuasive reason for refusing to implement an AD for SED. As we shall see, the first objection disintegrates upon analysis of when not providing a basic need is culpable homicide. The second objection can be correct—sometimes physically accepting food and fluids does constitute a relevant change of mind, but in many situations the mere acceptance of food will not. The third objection fails once we examine the fundamental reasons that ADs have normative force.

Society 2014 BCSC 165 (Feb. 3, 2014)). The Court of Appeal, as had the B.C. Supreme Court, decided that Ms. Bentley's acceptance of certain foods by opening her mouth and swallowing constituted the relevant consent to eat. For a longer elaboration of a wider array of change-of-mind issues for ADs, see Paul T. Menzel, *Change of Mind: An Issue for Advance Directives*, in *ETHICS AT THE END OF LIFE: NEW ISSUES AND ARGUMENTS* 126-37 (John K. Davis ed., 2017).

⁸ On this issue too, the 2014 Bentley court came out against implementing Mrs. Bentley's prior wishes. *Bentley*, 2014 BCSC at paras. 62-84, 153.

II. MORAL AND LEGAL ANALYSIS

My ethical-legal analysis of each of these three objections will discern the moral underpinnings of the law and what the law should be. I will not rely heavily on judicial decisions, although I will engage various arguments and principles highlighted in some decisions and in the legal literature. Even if I am correct that the reasoning behind these three objections to ADs for SED is weak, one can therefore not conclude from my argument that implementing such directives is actually legally permissible. My analysis is most convincing as a *moral* argument against these three barriers, and as the legal *reasoning* that can be brought to bear against them. Actual judicial rulings may not follow this reasoning if and when an appropriate case comes to trial. Moreover, in some jurisdictions, the legal force of ADs may be contingent on legislation and therefore relatively immune to my argument.⁹

My assessment is thus best taken as an argument that none of these three objections should stand as a barrier to using ADs for withholding food and fluids by mouth. Such an argument can contribute to the larger societal process of determining whether such directives should have normative force in clinical decisions.

A. Consent Is No Defense to Criminal Homicide

In the criminal law generally, victim consent provides no defense for a crime's perpetrator. Against a charge of murder, for example, the victim's consent to be killed provides no defense. At most, consent may justify

⁹ Also relevant to the predictive legality of implementing an AD for SED may be the distinction between criminal and civil cases. The legal risk for a surrogate decision maker or health care provider would likely be less in the context of a civil case for guardianship, which could be brought before the withholding of food and fluids, than in a criminal case brought after withholding had already been started or completed. Perhaps the law could be tested in a civil context without someone taking the risk of becoming a criminal law martyr. E-mail correspondence with Terry J. Barnett, JD, of Tacoma, WA (Jan. 26, 2015) (e-mail on file with author).

reducing the wrong that society sees in the killing to a lesser degree of criminal homicide.¹⁰

In the current context of SED by AD, a proxy decision maker and caregiver do not provide food and feeding assistance to the person who lacks the capacity to obtain food and feed himself. Not providing the food would constitute “starving” the person, causing his death, and the person deemed responsible could then be charged with criminal homicide. If the defendant claims that the person’s AD constitutes his consent to not being fed, that claim may be accepted but the acknowledged consent will provide no legal remedy for the defendant.

The analysis in the previous paragraph, however, is incomplete and misleading. A “passive act” or omission, like the failure to feed, can appropriately lead to a charge of criminal homicide, but this is only the case when the caregiver/decisionmaker is seen to have a duty to do what she did not do (here, to feed). One does not even reach the question of whether consent can provide a defense *if* there is no duty to feed that can ground a charge of homicide. But the precise question at issue when a person has an AD for SED is whether, in *that* circumstance, caregivers do have a duty to feed. Whether the AD releases caregivers from their normal duty to feed has to be determined *before* we know whether a charge of criminal homicide is appropriate.

If, on the one hand, the AD does release caregivers from their normal duty, then there is no duty to feed, there can be no charge of homicide, and the question of what defenses are available does not arise. The consent that resides in a patient’s directive is not asked to do its normative work by providing the defendant with a defense; it does its work at a logically prior

¹⁰ John Kleinig & North Ryde, *Consent as a Defence in Criminal Law*, 65 ARCHIVES FOR PHIL. L. & SOC. PHIL. 329, 330 (1979). The legal maxim *volenti non fit injuria*—to the one who consents, no wrong is done—is longstanding in the criminal law but has many equally established exceptions: murder, castration, and dueling, among them. Sayings have formed for some of the exceptions, e.g., “consent is no defense to murder.”

point by determining whether there is a duty to feed, a requisite element if failure to feed is homicide. If, on the other hand, providers and proxies still have a duty to feed despite a person's directive, then homicide may indeed be an appropriate charge, but the consent residing in the AD has already been determined impotent. It cannot come back into play to provide a criminal defense; it has already failed to alter caregivers' normal duty to provide food and fluids.

Indeed, the consent of the person who wrote the AD provides no defense against a charge of criminal homicide, but the normative work that the consent present in a person's AD may play is located elsewhere—in the logically prior question of whether caregivers have a duty to feed.

This analysis of why “consent is no defense” does not settle the primary substantive question of whether SED by AD is permissible. The analysis is only a point within the internal logic of homicide charges for a failure to perform an obligatory act. The primary question remains whether caregivers' normal duties to feed are still in fact duties when the person has a clear AD for SED.

B. Willingness to Eat Is a Change of Mind¹¹

Assume that ADs have normative power to preserve patient choice that ought to be respected. Assume also that a person has a directive to withhold food and fluids by mouth, especially assistance with eating and drinking, and that the AD is both valid and applicable—valid because it was not coerced and was adequately informed, and applicable because the patient now lacks mental capacity, the directive was clear about the future conditions in which food and fluids is to be withheld, and those conditions now obtain. As is quite common in severe cognitive decline, however, the

¹¹ See Menzel, *supra* note 7. In the current paper, I apply to eating behavior specifically the general framework worked out in the previous paper for determining whether something new in a person's desires, beliefs, or values constitutes a relevant change of mind that should be seen as revoking a directive.

person may still willingly eat when offered food. Does such willingness constitute a change of mind that revokes the directive?

Relevant change of mind by a patient that would revoke a directive has a critical role in the moral and legal architecture of directives. It is always important to be on the lookout for any change of mind if we are to be justifiably confident that a directive really does still represent the expressed will of the patient when it is implemented. The same concern that the document still represents the will of the patient is reflected in our presumption that a directive's authority is stronger the more recently it was written or reiterated.¹² Above all, a subsequent valid directive replaces any element that it conflicts with in an earlier directive.

Despite the importance of change of mind, such situations are improbable in cases of chronic cognitive impairment. The very state of diminished capacity for which an AD is written makes it unlikely that, as the time for the directive's implementation approaches, its author is capable of changing it. As Ron Berghmans states, in the case of dementia the irony is that "at the time you would most likely 'change your mind,' you do not have enough mind left to change."¹³ Many will then conclude that in most typical cases, a

¹² In our moral and legal culture, we do not carry this concern that people might have changed their mind without bothering to express it to an extreme. If we did, we would dispense with ADs altogether, along these lines: "It is always possible that someone changed her mind. Now, precisely because she is incompetent and unable to express herself, *we do not know* that she has *not* changed her mind. Therefore, without knowing that a person has not changed her mind, we can never regard a directive as having authority once the time of incompetence to which it was meant to apply has arrived. So ADs are out of order generally." I owe recognition of this substantive line of thinking (not the precise words used here) to Lawrence Nelson of Santa Clara University. The general acceptance of ADs in the last half century implies that we reject this line of argument. Hidden change of mind is always possible, but its *mere possibility* is no reason to discount directives. According ADs any authority at all does run some risk that unbeknownst to us, the person has had a change of mind. According directives no authority, however, runs a much greater risk of not respecting patient choice. We generally think that for change of mind to justify not following a directive, there must be evidence it has actually occurred.

¹³ Ron L.P. Berghmans, *Advance Directives and Dementia*, 913 ANNALS N.Y. ACAD. SCI. 105, 106 (2000).

change of mind *about one's directive* is no longer possible. No matter how much the person is now willing to eat, for example, she does not have the cognitive capacity to revise or revoke a directive.

This, however, excessively narrows what qualifies as a relevant change of mind. Even if the person is well past the time when she still has capacity to revise the directive, if certain attitudes and desires change that were significant reasons for the person's choice to write her directive the way she did, then a relevant change of mind can still occur. To see this, imagine two versions of the directive of a person I shall refer to as Andrew,¹⁴ and then consider a third, real case, Margot Bentley.

1. Andrew

Andrew's directive says that he is to receive no life-extending care, including food and fluids by mouth, when he is irreversibly in a cognitive state where he no longer recognizes his closest friends and loved ones. Now he is in that state. He amply conveyed to his family his reasons for writing this kind of directive, and he stated some of them in the AD itself: that life without the capacity for such recognition is not the kind he has always lived for and encouraged others to appreciate, that he prefers resources to go to things he cares about much more strongly than he cares about having his life extend into such a condition, and that he wants loved ones not to have to care for him for years on end with little if any communication back from him, with the likely result that they will remember him less clearly and fondly. (This reasoning will change in the ensuing "Andrew Revised" case.)

Now Andrew is in need of the feeding assistance, assistance he said in his directive he wanted withheld, and he apparently wants to be fed. He will accept careful spoon feeding, especially of certain foods he apparently likes more than others. Occasionally, if he smells food nearby that is not offered

¹⁴ These two versions of Andrew parallel the contrasts between "Richard" and "Revised Richard" and between "Margo" and "Complex Margo" pursued at length in Menzel, *supra* note 7.

to him, he will look at it and make soft sounds. Yet not only is he incapable of rewriting his directive to say that feeding assistance should not be withheld, but he no longer has the mental capacity to change the attitudes about vitality in life, judicious use of resources, and others' memories of him after he dies that were the important reasons for his directive. In fact, it is doubtful that he can now hold attitudes of any sort about those things. He has never changed the values and attitudes that led him to write his directive, and now, he can no longer change them.

2. Andrew Revised

Contrast this with a similar Andrew with a slightly but crucially different directive. His directive stipulates withholding the very same things as in his directive stated previously, and under the same circumstances. Andrew Revised's reasoning, though, is different. Both orally and briefly in his written directive, he expressed his view that life without being able to recognize anyone was a condition he could not enjoy. His belief and attitude in this respect was not irrational, for he was a very social person. Contrary to what he anticipated, however, he now seems to experience some enjoyment in a non-recognizing life. He is not distressed, he smiles often, and he usually responds with a few isolated words or positive sounds when someone looks him in the eye and gently strokes his arm.

Andrew Revised has reversed some of his previous attitudes that were major reasons for writing his AD—this is important. The fundamental rationale for looking to a person's AD when he is no longer competent, no longer remembers having an AD, and no longer cares about the personal autonomy that a directive is intended to preserve, is that the values and attitudes that were important enough to him to write an AD are still thought of as his. However, sometimes those attitudes, not just his mental competence, change. Why should we demand the fuller capacity to change the directive itself in order to see the person's altered state of mind as effectively revoking his directive? Respect for persons involves, if anything,

appreciating the fact that people have their own reasons for their decisions. But then, if some of the attitudes that were important reasons for a person to write an AD do in fact change, we can hardly still claim that we must follow the directive in order to respect the person. Andrew Revised is an example: we respect him more by interpreting his directive in light of new developments directly related to his reasoning in writing his directive than if we implement the directive as it was written.

Thus, the fact that a person is past the point where he or she can revise a directive does not close the door to a relevant change of mind. Changes in attitudes that were among the very reasons the person had for writing the directive may still be possible. If they occur, they effectively revise the directive. Let us apply this now to the most important case, an actual one.

3. The Bentley Case

Margot Bentley, an 85-year-old former nurse, was diagnosed with Alzheimer's 17 years before she died in November 2016. Mrs. Bentley lived her last 12 years in a residential care facility, the last four with the most severe Alzheimer's. She did not recognize or respond to any of her friends or family, did not speak, and could make only very limited movements. She spent her days motionless in bed or slumped in a wheelchair with her eyes closed and required spoon feeding. She would usually open her mouth when food was held to it, though that varied, and sometimes caregivers had to offer it several times. She accepted different types and amounts of food on different days, seeming to prefer certain flavors, and she would stop opening her mouth when she apparently felt full.¹⁵

¹⁵ The facts about Mrs. Bentley in this paragraph are compiled from the descriptions in *Bentley v. Maplewood Seniors Care Society*, 2015 BCCA 91 at paras. 1-3 (Mar. 5th, 2015); *Bentley v. Maplewood Seniors Care Society*, 2014 BCSC 165 at paras. 18-20, 23-24 (Feb. 3, 2014); Hammond, *supra* note 5. Her death on November 9, 2016, was reported in Pamela Fayerman, *Margot Bentley Dies, A Finality that Couldn't Come Too Soon for Anguished Family*, VANCOUVER SUN (Nov. 11, 2016),

Mrs. Bentley first executed a directive in 1991, requesting that “If . . . there is ‘no reasonable expectation of my recovery from extreme physical or mental disability,’ she be ‘allowed to die and not be kept alive by artificial means or heroic measures.’”¹⁶ She listed specific instructions, including “no nourishment or liquids,” and designated her husband and daughter as proxy decision makers.¹⁷ In 2000, shortly after the diagnosis of her Alzheimer’s and consistent with her earlier directive, she “repeatedly told her family that she wished to be allowed to die when she reached a stage of advanced dementia,” a stage she reached in 2012.¹⁸ Did Mrs. Bentley’s apparent willingness to accept food even after she was in severe dementia constitute a change of mind about what she requested in her directive?¹⁹

<http://vancouver.sun.com/health/seniors/margot-bentley-dies-a-finality-that-couldnt-come-too-soon-for-anguished-family>.

¹⁶ *Bentley*, 2015 BCCA at para. 2 (the quotation is from the Court of Appeal decision, describing Mrs. Bentley’s advance directive and in turn quoting it).

¹⁷ *Bentley v. Maplewood Seniors Care Society*, 2014 BCSC 165 at paras. 103-113; *Bentley*, 2015 BCCA at para. 7. The representatives of the Fraser Health Authority and both courts read these passages as Mrs. Bentley not clearly conveying that she to the end wanted oral feeding to be stopped in the specified circumstances, but only medically delivered nutrition and hydration. See also Thaddeus M. Pope & Amanda West, *Legal Briefing: Voluntarily Stopping Eating and Drinking*, 25 J. CLINICAL ETHICS 68, 68-80 (2014); Thaddeus M. Pope, *Prospective Autonomy and Ulysses Contracts for VSED*, one of two sections of Thaddeus M. Pope & Bernadette J. Richards, *Decision-Making: At the End of Life and the Provision of Pretreatment Advice*, 12 J. BIOETHICAL INQUIRY 389, 391 (2015), hereinafter Pope, *Decision-Making*. As the court record and these two articles note, various other particular considerations about Mrs. Bentley’s directive were influential in the B.C. courts’ decisions not to see her directive as authoritative.

¹⁸ Pope, *Decision-Making*, *supra* note 17, at 389.

¹⁹ This is not precisely the question the British Columbia courts addressed. They addressed whether Mrs. Bentley had the capacity to consent to eat and whether her behavior of sometimes accepting food constituted that consent. They answered both questions in the affirmative and then determined that her previous wishes could not control. *Bentley*, 2014 BCSC at paras. 43-61, 153; *Bentley*, 2015 BCCA at paras. 11-16; Pope, *Decision-Making*, *supra* note 17, at 390,391. The 2014 court also found that providing food and fluids by mouth was “basic personal care,” not medical care, and, as such, not within the purview of any AD. *Bentley*, 2014 BCSC at paras. 77-84. Other nuances not noted here were also important to the two decisions.

Especially with her experience as a nurse, Mrs. Bentley could be presumed to be knowledgeable in writing her directive. The directive later became clearly applicable: she had been in advanced dementia for several years, one of the conditions explicitly stated in her directive for not being given life-extending measures, including nourishment and liquids. During this time, she selectively opened her mouth to accept food, appearing to discriminate between foods she liked and those she did not, and between eating when hungry and not when she felt full.

a) Consensual Behavior and Change of Mind

Did Mrs. Bentley's discriminating acceptance of food constitute a relevant change of mind about her directive?

We might first ask whether we should deem Mrs. Bentley's discriminating acceptance of food to be "consenting behavior" and not a non-voluntary reflex.²⁰ It may be reasonable to see her behavior as consent to eat. The capacity required for any given consent is relative to what the person is consenting to. For an elemental activity such as eating, the cognitive capacity required for it to be a consenting behavior is minimal; it is a basic, simple activity that the person has been doing his or her whole life.

Concluding that the activity is consensual, though, does not settle the question of whether it constitutes a change of mind that revokes the person's directive. For a relevant change of mind, Mrs. Bentley does not

²⁰ Two different assessments ought to be distinguished, between *making a choice* about eating and *consenting* to eat. The former is the more minimal claim. In the *Bentley v. Maplewood* court record, some of the claims discussed are put in terms of "choice"; some of the Fraser Health Authority's staff, for example, argued 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." *Bentley*, 2014 BCSC 165 at paras. 31-32, exhibit L (emphasis added). The conclusion of the court went further, into consent: she showed "current consent," she had capacity to consent to being fed, and she continued to give her consent. *Bentley*, 2014 BCSC *Id.* at para. 54. For further detail and analysis, see Pope and West, *supra* note 17, at 74-77.

have to be capable of considering her directive, but if she is not capable of that, her eating behavior would have to convey *a new attitude toward something that was part of her reasoning* in writing her directive. It is theoretically possible that her reason for stipulating no nourishment and liquids upon becoming extremely disabled, physically or mentally, was that she thought eating or drinking would be uncomfortable, but that is hardly plausible. If that was her reason, why would she have stipulated all the other interventions that she wanted to have withheld? The plausible reasons are much more likely to have something to do with her beliefs that her whole life should not conclude with years of advanced dementia, rather than any anticipation that she would not be willing to eat. In her later years, Mrs. Bentley was no longer capable of any change of mind in regard to those reasons. Therefore, her acceptance of food, even if it did constitute consent to eat, did not constitute a relevant change of mind. She never revoked her directive.

Mrs. Bentley's directive, therefore, was still valid, despite her willingness to eat. Her willingness may well have constituted consenting to eat, and when she ate, she may well have been making a choice. Yet, such consent and choice did not constitute a relevant change of mind about her directive unless they related to the substance of her reasons for writing it.

Nonetheless, one might still regard her willingness to eat as reason not to implement her directive. It certainly pulls one toward feeding her despite her directive. This pull may be justified, but for reasons quite different than a change of mind. Even when ADs are fully intact, with no hint of revocation, they can confront other problems that complicate their authority, including the basic "then-self, now-self" problem.

b) The Then-Self vs. Now-Self Problem—Beyond Change of Mind

Despite the conclusion that consensual willingness to eat did not constitute a change of mind for Mrs. Bentley, the most fundamental problem afflicting advance directives still remains a challenge: the so-called

“then-self, now-self” problem. In a nutshell, the problem is that the current incompetent self is different than the self who wrote the directive.²¹ The now-self doesn’t remember writing the AD, doesn’t care about autonomy, and may not find unbearable the diminished condition into which the person insisted he or she did not want his or her life to extend. So what gives the then-self any prerogative to determine how the now-self is treated? Why not ignore any AD and just treat the current patient according to his or her own best interest?

Though this is a powerful objection to the relevance of ADs, it only complicates rather than destroys their normative force. ADs tend to retain normative weight because even the current self still has interests shaped by the life that the person developed and the values he or she held through all the years of competent deliberation and decision making. To say that one should treat the current person only according to the interests that he or she is now experiencing *would be to treat the person as if he or she had never been competent*.²² Most people do not have to think about this possibility very long to express a strong opinion: of course we do not want ourselves to be treated as if we had never been competent! Even later, when we lose our competence to make medical treatment decisions, a never-competent person is not who we become, for at one time we were competent. Our identities, our lives, extend over time. Our narrative identity does not end with incompetence.

If that is the case, we have to include in what constitutes Mrs. Bentley’s *current* best interest in her advanced dementia the overarching concerns she

²¹ An originating and formative statement of the problem is in Rebecca Dresser & John S. Robertson, *Quality of Life and Non-Treatment Decisions for Incompetent Patients*, 17 L. Med. & Health Care 234 (1989). A fuller discussion of the problem, of some important literature about it, and of the most persuasive resolutions of it is provided in Menzel & Chandler-Cramer, *supra* note 1, at 27-29; Paul T. Menzel & Bonnie Steinbock, *Advance Directives, Dementia, and Physician-Assisted Death*, 41 J. L., MED., & ETHICS 484, 488-493 (2013).

²² Nancy Rhoden, *The Limits of Legal Objectivity*, 68 N.C. L. REV. 845, 860 (1990).

had about the shape of her whole life, some of which she conveyed in her directive. Moreover, with the severe dementia that is Mrs. Bentley's condition, one's current subjective interest in survival is much lower than it is for a less impaired person. *With very little capacity for memory or anticipation*, surviving until tomorrow cannot mean much, and when we get to tomorrow, our having survived from a yesterday that we do not remember won't mean much either.²³ If that is the case, and if people's insistent self-identification as persons who have long lives of competence before losing competence, then we cannot show adequate respect for them if we count the minimal current subjective value of survival for a severely demented person, like Mrs. Bentley, as outweighing the value of respecting the person who has a whole life.

Thus, it is difficult to conclude that in her last half decade, Mrs. Bentley's *overall* interests were best served by continuing to provide the feeding assistance that she objected to in her directive, even if the correct interpretation of her later behavior was that she willingly ate, consented to eat, and chose to eat. The seriousness of the now-self versus then-self-challenge, however, does explain why it is not irrational for someone to feel pulled to continue to feed her. Imagine that Mrs. Bentley were less demented and could still anticipate her own survival and appreciatively remember having survived. The balance of the conflicting factors between her directive and her current experience and appreciation of life might then justify saying "not yet" to implementing her directive.²⁴ If that is the reason we decide not to follow a person's directive, it is not because we see her willingness to eat as a change of mind revoking the directive. It is because

²³ Two co-authors and I have termed this the "sliding scale" or "balancing" model for discerning the subjective value of life for a person in dementia. See Menzel & Steinbock, *supra* note 21, at 492-93; Menzel & Colette-Chandler, *supra* note 1, at 28.

²⁴ Menzel & Steinbock, *supra* note 21, at 497; Menzel & Colette-Chandler, *supra* note 1, at 34.

we see the person's overall best interest as at that point in time still conflicting with the directive.

In summary, a change of mind that effectively revokes a directive does not require decision-making capacity to write a revised directive; it can occur with changes in attitudes that were among the reasons the person had for writing the directive she did. Sometimes those changes occur in a person with significant dementia. However, willingness to accept food in a case like Mrs. Bentley's does not constitute such change. It leaves intact the normative force of the directive with the reasons she had for writing it, even if other ethical complications inherent in ADs justify delaying its implementation.²⁵

C. Basic Personal Care and the Range of Directives' Authority

If we are generally going to reject ADs for SED, then it will have to be for some reason other than that a person's current willingness to eat constitutes a change of mind about the directive, because in many cases, such as Mrs. Bentley's, it will not. Such another reason was found by the British Columbia courts that ruled on Mrs. Bentley's case: providing food and fluids and assistance with eating and drinking is *basic personal care* and not medical care, and refusing basic personal care falls outside the legitimate scope of any person's AD.²⁶ The B.C. courts based this element of their decision on a variety of factors, including statutes about directives

²⁵ Whether courts will follow this reasoning and make rulings about actual legal permission consonant with it is an open question. See *infra* Part III.

²⁶ *Bentley v. Maplewood Seniors Care Society*, 2014 BCSC 165 at paras. 62-84, 153 (Feb. 3, 2014). The 2015 B.C. Court of Appeals decision did not specifically address the personal care matter because this aspect of the 2014 B.C. Supreme Court's decision was not one of the grounds for the plaintiffs' appeal. *Bentley v. Maplewood Seniors Care Society*, 2015 BCCA 91 at para. 10 (Mar. 5th, 2015). Since it did not overturn the 2014 British Columbia Supreme Court's reasoning about basic personal care, *Id.*, however, I speak of both courts as having the view that the personal care character of oral feeding is relevant to its proper place in advance directives.

and agency guidelines about abuse.²⁷ Beyond these two courts' particular reasons for invoking the distinction between medical treatment and basic personal care, the essential argument can be expressed by focusing on the orientation of caregivers: it is their duty to provide basic personal care, which will always include oral feeding when it is not distressing or medically complicating.²⁸

One might, of course, contest the premise that oral feeding is basic personal care. In many patient circumstances, caregivers have to be experienced if they are to effectively feed a person. In such cases, oral feeding is essentially professional care. Why is it not therefore "health care," even if we hesitate to call it "medical care"? I note these reasons for claiming that oral feeding should be classified as health care, not basic personal care, but I will not employ them in developing my argument. I will assume that oral feeding is basic personal care, but then ask, why should we think that the usual normative force of a person's AD dissipates when it addresses basic personal care, and why should those who provide personal care be insulated from a person's directive any more than those who provide health care?

To answer these questions, one first needs to discern the fundamental reasons ADs have moral weight regarding medical treatment. Then one can assess the extent to which those reasons apply to basic personal care. The closest comparison to withholding oral feeding will be provided by directives to withhold *lifesaving* medical treatment, an act that like VSED is expected to be fatal. Therefore, in articulating the fundamental reasons for ADs' normative force, I will have in mind directives to refuse lifesaving care.

²⁷ Bentley, 2015 BCCA at paras. 17, 18; Bentley, 2014 BCSC at 85-102, 114-120, 129-152.

²⁸ Some of the arguments of Cynthia Meier and Thuang Ong take this form. See Cynthia A. Meier & Thuan D. Ong, *To Feed or Not to Feed? A Case Report and Ethical Analysis of Withholding Food and Drink in a Patient with Advanced Dementia*, 50 J. PAIN & SYMPTOM MGMT. 887, 888-89 (2015).

1. Fundamental Reasons for Advance Directives' Normative Weight

I shall discuss three key reasons for thinking advance directives have normative power.²⁹ Together they address the difficult then-self/now-self problem that ADs must face.³⁰

a) *Respect for Persons*

One reason is the importance of previous competence and the fact that even a current incompetent person is not a never-competent person.³¹ Ignoring a person's AD amounts to treating her in exactly the same way we would be treating her as if she had never been competent. But how can doing that *respect the person* who the patient currently is, for even now, that person is not a never-competent person.

b) *Continuity of Self*

A second reason pivots off the basic element of narrative identity. Norman Cantor states it this way: "A person, by nurturing and developing a body, character, and relationships has earned a prerogative to shape a life narrative – including the medical fate of a succeeding incompetent persona."³² I refer to this as *continuity of self* across a life. The narrative by and about oneself continues into incompetence. Mrs. Bentley, for example, even in her most severe dementia, is still her daughter's mother, and she is still Mrs. Bentley. She undoubtedly would have said that she would still be Mrs. Bentley, and Mother, if she had been asked about it when she was still

²⁹ I articulate essentially similar reasons for advance directives in Paul T. Menzel, *Respect for Personal Autonomy in the Justification of Death Hastening Choices*, in EUTHANASIA AND ASSISTED SUICIDE: GLOBAL VIEWS ON CHOOSING TO END LIFE 231, 239-44 (Michael Cholbi ed., 2017).

³⁰ *Supra* section II, B, 3, b.

³¹ Rhoden, *supra* note 22, at 860.

³² Norman L. Cantor, *Is It Immoral for Me to Dictate an Accelerated Death for My Future Demented Self?*, at 5 (Dec. 2, 2015), <http://blogs.harvard.edu/billofhealthj/2015/12/02/is-it-immoral-for-me-to-dictate-an-accelerated-death-for-my-future-demented-self/>.

competent, and people now around her still assume that she is. A person's life narrative does not stop when she becomes severely demented.³³

c) Self-Ownership

A third, closely related reason is *self-ownership*. One of the basic reasons a competent person has the right to refuse lifesaving medical treatment is that such decisions are about *his life*, not about anyone else's life, and certainly not about no one's life. That life is the life of the person with his narrative history, a history that includes the AD he wrote. This sense of ownership of the self by the self that has narrative continuity is so basic to our notion of personhood that we rarely think about it. In being a person with consciousness about our bodies, many of our thoughts, and our own lives over time and into the future, we implicitly see the lives we have as *our* lives. We readily use ADs to extend the right to refuse lifesaving treatment deriving from self-ownership into the time of a person's incompetence because the life at stake at that later time is still *that person's* life.

These three fundamental points about distinguishing previously competent persons from never-competent persons, about continuity of narrative self, and about self-ownership explain why ADs have moral and legal force for medical treatment. That force is not limited to non-lifesaving treatment—it can include even the most basic and common lifesaving treatments, such as antibiotics for pneumonia.³⁴

³³ Menzel & Steinbock, *supra* note 21, at 488-89 (discussing in part various other authors' views of personal identity).

³⁴ This is assumed to hold, of course, only if the directive is sufficiently clear: for example, for what illnesses, in what conditions and with what prognoses for recovery, etc., is the lifesaving treatment to be withheld?

2. Application of These Reasons to Basic Personal Care

Do these three fundamental reasons for ADs' moral weight in the case of lifesaving treatment apply also to basic personal care? In particular, do they apply to oral feeding?

All three reasons do apply. In order to understand why, it is important to note the context in which a directive to curtail oral feeding is likely to arise. Any person who would write such a directive to withhold oral feeding upon specified circumstances like severe dementia, for example, strongly desires to control eating and drinking in those circumstances just as he or she desires to control lifesaving medical treatment, for why else would the person write such a directive? The prospect of living years into severe dementia can be as daunting as enduring months of physical suffering at the end of life. Those who would write a directive to curtail oral feeding are intent on not having their lives extend into years of severe dementia. They may be concerned about the effect on their loved ones, on how they themselves will be remembered, or the disappointing shape of a whole life that comes to a close in that unfortunate way. Their beliefs, values, and attitudes on these scores are not incidental or shallow, and as they live into their early- and mid-stage progressive dementia, these beliefs may be among their most important convictions. For writers of ADs for SED, such directives are a crucial part of how to accomplish their aim; they know they may well not have the fortune of procuring an illness requiring lifesaving care that can be refused pursuant to more conventional parts of their AD.

In this context, all three of the fundamental reasons for following advance directives to refuse lifesaving treatment also apply to oral feeding. *Not treating a person as if she had never been competent* is as important to who the person still is—a previously competent person—as it is with medical treatment. *Continuity of narrative self* is just as present, perhaps even more so given the insistence the person conveys in her directive about wanting not to live into years of severe dementia. And it is still *her life* that is at stake as much as it ever is in a lifesaving treatment decision.

An additional legal consideration is that for many “personal” matters, “mental health directives” can be written for a variety of considerations about dementia that go far beyond medical care—for example, financial matters and interpersonal behavior such as sexual relations.³⁵ The degree of bodily intrusion involved in these matters and in oral feeding may be less than in most medical care, but the right to refuse medical treatment is not based solely on an intervention’s bodily intrusiveness (e.g., witness oral medication).

3. What Caregiver Obligations Are Altered by Advance Directives?

The question about caregiver obligations that needs to be addressed for oral feeding is the same as the question for lifesaving treatment: what normal obligations to provide care are altered by a clear advance directive? With lifesaving treatment, the normal obligation of a caregiver in the absence of a directive refusing care is to provide the treatment. Perhaps when directives first came into prominence, caregivers resisted following a directive to refuse ordinary basic lifesaving care. They rather quickly, however, came to see that their normal obligations to provide care were modified when an AD refusing such care was present. If someone’s directive clearly says that certain lifesaving medical care is to be withheld, not only are caregivers not obligated to provide it, they may even be obligated not to provide it.

Why should caregivers’ obligations about oral feeding be altered any less by ADs if the fundamental moral and legal reasons behind ADs’ moral and legal force apply as much to life-extending oral feeding as they do to

³⁵ Lisa Brodoff, *Planning for Alzheimer’s Disease with Mental Health Advance Directives*, 17 ELDER L.J. 239, 281 (2010); Lisa Brodoff, *Alzheimer’s Disease and Dementia Mental Health Advance Directive*, END OF LIFE WASHINGTON 7 (2015), http://endoflifewa.org/wp-content/uploads/2014/07/Alzheimers.Disease.and_.Dementia.Mental.Health.Advance.Directive.10.2015.pdf.

lifesaving treatment? Caregivers are indeed obligated to provide food, water, and any necessary feeding assistance if no directive from the patient says otherwise. But when there is a sufficiently clear directive, caregivers' obligations to feed change, just as their obligations to provide lifesaving treatment change when a directive enters the situation.

Critics may object because food, the most basic of necessities, is involved. So too, though, is air a most basic necessity; when one cannot breathe without a ventilator, a ventilator becomes a necessity. Yet we respect a competent person's decision to withhold or withdraw a ventilator. Similarly, we respect a person's competent decision to stop eating and drinking, and if a competent patient needs physical feeding assistance, we respect her decision to reject that assistance. If we extend a patient's right to refuse a ventilator to times of incompetence by a clear and applicable AD despite the utter necessity of respiration, why would the utter necessity of nutrition and hydration block us from extending the right to VSED to times of incompetence by a clear and applicable AD? If no differences in actual necessity provide the moral difference, why would the mere fact of food?

I conclude, then, that the difference between basic personal care and medical treatment does not justify excluding oral feeding from the legitimate scope of an AD.

4. Complicating Factors That an AD for SED Should Address

This conclusion does not mean that there are no other moral and legal difficulties in SED by AD. Complicating factors are likely to make writing and implementing such directives more challenging than directives to withhold most medical treatments. A good AD for SED needs not only to state clearly the circumstances in which oral feeding is to be stopped. It will also need to address other issues that may arise for one's caregivers.

One issue occurs if and when the incapacitated person wants to eat. In the most advanced stages of progressive dementia, a person may not express any desire to eat when food is withheld, but in somewhat earlier stages, still

severe, desire for food may be expressed by a grimace, gesture, or sound of apparent need. Unless oral feeding runs a significant risk of aspiration with all of its attendant distress and risk of infection, an expression of desire to eat creates a conflict between the directive and the person's current experience-based interest in eating and surviving. In the overall picture, as a previously competent person with a strongly stated AD, she has a larger shape-of-her-life interest in not being kept alive with continued feeding.³⁶ However, the tension between that larger interest and the current apparent desire to eat makes it understandably difficult for caregivers to withhold food.

ADs should address these kinds of prospective situations. Otherwise caregivers will be left not knowing whether the person meant to proceed with withholding oral feeding in this kind of situation. In the AD, one might stipulate, for example, that in such a circumstance feeding should still be stopped, but with coordinated use of distress-relieving and appetite-suppressing drugs. The directive might also include a reminder that most deaths by SED can be made peaceful and comfortable by appropriate mouth care for the discomfort of dehydration and by the employment of any anti-delirium drugs that may be called for.³⁷ If the directive addresses such considerations, it will speak directly to later caregivers and their obligations. Caregivers will more readily see that their normal obligations concerning food and fluids are altered by a person's AD.³⁸

³⁶ See generally Ronald Dworkin, LIFE'S DOMINION: AN ARGUMENT ABOUT ABORTION, EUTHANASIA, AND INDIVIDUAL FREEDOM 200-32 (1993). The notion of "critical interests" is analyzed and applied to situations of persons in severe dementia by Menzel & Chandler-Cramer, *supra* note 1, at 27-28; Menzel & Steinbock, *supra* note 21, at 489-96.

³⁷ It should not be necessary to mention such particular ameliorative measures in a directive, for they are simply good palliative care that should be available in any dying by SED. Palliative care, however, does not always get the attention it deserves, and many providers may not be sufficiently familiar with VSED and death from lack of food and fluids to know the important role that palliative care can play in it.

³⁸ These are not the only important elements of a good directive for SED. Additional ones are detailed in Menzel & Chandler-Cramer, *supra* note 1, at 34-35.

A second issue that a complete AD for SED will address is the continuum between simply offering adequately prepared food and providing sustained manual feeding *assistance*. The directive should be reasonably specific where on this continuum oral feeding should stop. If the person wants persistent manual assistance with feeding to be withheld, though not the mere offering of prepared food, then she should state that clearly in her AD. If this matter is not spoken to in the directive, caregivers will be left hanging without knowing just what the directive means.³⁹

The more clearly the AD addresses these issues and the more explicitly they are discussed with a person's designated representatives when the person is still competent, the more persuasive the directive can be to loved ones and caregivers. Proceeding to withhold oral feeding is a very difficult decision for representatives and caregivers even when it is justified by a strong directive. The person writing the directive should do what is possible to ease the burden of these difficult decisions on loved ones and caregivers.

III. CONCLUSION

VSED is a legal option in the United States for hastening one's death.⁴⁰ It is not restricted by the eligibility limits such as terminal illness (six-month-prognosis) that have characterized physician aid-in-dying in the US jurisdictions where aid-in-dying has been legalized. In this respect, VSED is the first legally realistic option for people who want not to have their lives extend into years of chronic disease such as progressive dementia. VSED,

³⁹ For empirical studies and discussion of physicians' and family members' views on how to regard a current desire to eat in relation to the person's directive to withhold food and fluids by mouth and where on the continuum from making food available to providing manual assistance in ingesting it, see generally Ladislav Volicer & Karen Stets, *Acceptability of an Advance Directive That Limits Food and Liquids in Advanced Dementia*, 33 AM. J. HOSPICE & PALLIATIVE MED. 55 (2016); Ladislav Volicer, *Fear of Dementia*, 17 J. AM. MED. DIRECTORS ASS'N 875 (2016). Volicer's and Stets' findings are more complex than can be summarized here, though generally they point to a notable openness of many providers and family members to cease oral feeding for someone in severe dementia with a pertinent AD.

⁴⁰ Pope & Anderson, *supra* note 3; Cantor, *supra* note 3.

however, requires that a person be decisive and have a mental capacity that is no longer likely to be present in late to moderate dementia patients and disappears completely in severe dementia. To be sure, “pre-emptive VSED,” performed when a person is still competent and decisive, remains a legal option by which one can avoid eventual prolonged deterioration, but that option will usually involve the sacrifice of valuable time in life between the time of action and the stage of debilitation that the person wants to avoid. SED by AD is the only remaining option that has an existing legal basis.⁴¹

To become a truly viable legal option, however, SED by AD will need to overcome numerous objections. The three considered in this paper may seem too many to be definitive ethical and legal barriers to implementing any AD for SED. Careful moral and legal analysis, however, does not support these objections. The objection that consent is no defense to criminal homicide does not even arise if an AD has already altered the obligation of a caregiver to provide food and fluids. Mere willingness of the incompetent person to eat will not typically constitute a change of mind about the directive to withhold oral feeding. And the fact that oral feeding is basic personal care does not put it outside the scope of a directive’s normative power because the fundamental reasons that ADs have any normative power at all apply as much to persons’ desire to have food and fluids withheld as they do to their desire to have prospective lifesaving treatment withheld. Caregivers’ obligations for oral feeding should be as amenable to alteration by AD as are their obligations to provide basic lifesaving medical care.

This conclusion emerges from moral and legal reasoning; it is not a claim based on actual judicial rulings, which on this issue (at least in the United States) barely exist. Cultural and institutional barriers will also make the path to persuading caregivers that they are permitted to implement ADs for

⁴¹ Cantor, BILL OF HEALTH, *supra* note 4.

SED less than smooth.⁴² Arguably, however, it is likely that VSED itself will become more accepted, in part because it increasingly and dependably gets accompanied by good palliative care; that the incidence and toll of extended years in severe dementia will grow, as will the determination not to live long into such years; and that ADs for SED will increasingly get written with the clarity needed to speak to the real difficulties representatives and caregivers often experience in sensing their obligations about oral feeding. Then implementing ADs for SED may become increasingly feasible. The three objections discussed at length in this paper should not stand in the way.

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⁴² See generally, David A. Gruenewald, *Voluntarily Stopping Eating and Drinking: Institutional Considerations* (Submitted for publication, manuscript available from author). This paper is an outgrowth of, though not a presentation at, a session of the same title at the conference, "Hastening Death by VSED," Seattle University School of Law, Oct. 14-15, 2016.