Voluntarily Stopping Eating and Drinking: A Normative Comparison with Refusing Lifesaving Treatment and Advance Directives

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An informed and competent patient’s refusal of lifesaving medical treatment (LSMT) is widely seen as having strong protection. It is a person’s moral right, and typically a legal right. The right applies no matter how vital the treatment refused is to the preservation of life. It applies no matter how deliberate, intentional, and assured the death that results from refusal is, and whether or not the illness addressed by the treatment is terminal. The scope of the care that patients may knowledgeably refuse includes both acute lifesaving treatment and continuing life-sustaining care (medical “life support”). It includes withdrawing care midstream as well as initially withholding it. It is a very robust right.

Advance directives (ADs) are generally accepted as a legitimate extension of this fundamental right for times when patients no longer have decision making capacity. To be sure, refusing LSMT by AD is more problematic than refusal by a contemporaneously competent patient. The directive must be valid: the person writing must have been competent, not coerced, and minimally knowledgeable about the relevant conditions. And come time of implementation, the AD must be applicable: the conditions envisioned must now obtain. To make the discriminating judgments often needed to fill in the details of what the person wanted, appointment of a trusted proxy is often advised as a supplement.

Voluntarily stopping eating and drinking (VSED) is another, less recognized option by which people can control how and when they die.\(^1\) In ethical and legal justification, how does it compare with the two much more established forms of control? What extra justification, if any, is required to extend the right to refuse LSMT to refusing to eat and drink? To some the step is a small, easy one; to others it is large and problematic, in which VSED crosses a line. And how does the move from refusing LSMT to refusing food and water by mouth compare with the move from a competent patient refusing lifesaving treatment to the use of an advance directive to refuse such treatment?

I choose to compare VSED with refusing lifesaving treatment and with advance directives to refuse such treatment, and not with either aid-in-dying\(^2\) or voluntary euthanasia.\(^3\) In no U.S. jurisdiction is voluntary euthanasia legally permitted, and in only six states and the District of Columbia is aid-in-dying.\(^4\) By contrast, VSED is arguably already legal by judicial precedent in all of the United States. Comparing its ethical and legal justification with the justification of the already established rights to refuse lifesaving treatment and use advance directives to refuse such treatment may yield a conclusion of more immediate practical benefit than comparing VSED with aid-in-dying or euthanasia.

Though the moral perspective I employ is not exclusively respect for patient autonomy, I pay special attention to that value. I also pay particular attention to the complications for VSED posed by its characterization as suicide and by the possibility that the support given for it by palliative care providers may constitute assisting a suicide. Both aspects pose significant legal and ethical challenges.
Preliminary Considerations

**Voluntarily Stopping Eating and Drinking**

When paced well and managed with appropriate palliative care, dying by VSED is usually relatively peaceful and comfortable. With such care there is little reason to think death by VSED is any less peaceful and comfortable than typical deaths that result from optimally supported refusal of lifesaving treatment, and it may often be more so.

When paired with the right to refuse any medically delivered food and water that might be urged in response, however, refusing food and water by mouth ensures death. In this respect it differs from refusing lifesaving treatment. Even when the treatment that is refused is correctly seen as “lifesaving,” one does not know with absolute certainty that death will ensue. VSED also unquestionably causes death. It does not merely “allow death to come” or “let nature take its course,” as the refusal of LSMT is commonly seen to do.

Though the moral relevance of these differences in certainty and causal role is debatable, they make any alleged right to VSED more problematic than the right to refuse treatment. Additional justification is required.

**Advance Directives**

Similarly, the step from competent persons refusing LSMT to others refusing it for them pursuant to an AD requires additional justification. Respect for patient autonomy may justify refusing LSMT, but with an incompetent patient, arguably, autonomy is no longer at stake. An incompetent patient usually doesn’t understand autonomy and does not care about it. What, then, gives the choices of the previously competent patient (the “then-self”) authority over the best interest of the currently incompetent patient (the “now-self”), especially if the competent persona is never going to re-emerge? We may initially think this has an easy answer — it’s still the patient’s life, so why should not her choices, expressed in her AD, control what happens to her? Ultimately that point may carry the day, but, as we shall see, not without intermediate and qualifying considerations.

**Autonomy**

A central role in my analysis is played by the value (or normative principle) of patient autonomy. I will usually speak of “respect for autonomy,” often adding “... personal autonomy” to make clear that the decisions the principle protects are predominantly self-regarding.

Definitions of normative autonomy vary greatly. A widely used textbook refers to it as the principle that bids us to “respect the capacity of individuals to choose their own vision of the good life and act accordingly” and to engage “the patient’s own powers of deliberation, choice, and agency.” I shall regard autonomy in the medical context as self-determination that reflects the wider notion of respect for persons. Normative autonomy does not bid us to abide by all patient choices, only the choices of patients about their own lives (i.e., self-determination).

Why should such autonomy have moral weight? Preferences and desires may be volatile, fragile, and superficial, a function of serendipitous and questionable factors in individuals and their environments. Respecting “consumerist” preferences provides only a veneer of normative weight. A better understanding focuses on respect for persons. Two of the first things such respect pushes against are deception and coercion. If deception were routinely legitimate and did not require special justification, how could individu-
enslaved, for example, is fundamental. Others’ inevitably do and may influence my mind and body, but they may not simply control them without my consent unless I am adversely affecting others. The title of the film Whose Life Is It Anyway? (1981) captures this fundamental reason for patient self-determination. I refer to it as “self-ownership.” It is utterly basic to persons — beings with the kind of consciousness by which they can think in terms of their own bodies.

Self-determination, respect for persons, and self-ownership are complementary and tightly connected elements in the normative principle of patient autonomy.

Refusing Lifesaving Medical Treatment

The justification of the basic, anchoring right in this comparative analysis, the right to refuse LSMT, is apparent when patient autonomy and respect for persons are understood in this way.

In legal terms, administering medical treatment to competent persons without their informed consent is battery — the unauthorized harmful or offensive invasion of the body or contact with it. Right away we encounter a question: why does it hold for merely “offensive” invasions when there is no reason to think the treatment would be harmful, and every reason to think it would be helpful? Why in such cases is it still offensive to administer treatment without patient consent? In the law there are at least two reasons, reasons that are also ethical.

First, bodily integrity: treatment is typically an invasion of the body, and if anything should be within persons’ province of control, their own bodies should be. Here the self-ownership element is doing the work. Second, patient decision-making capacity: patients can be asked, they are capable of responding if they are asked, and therefore they should be asked.

A basic, stubborn moral judgment is involved here: beings with the capacity to consent should be asked, and their autonomous choice should be respected. If we do not ask, we do not treat them as persons — as the beings with agency and the capacity to consent and refuse consent that they are. And clearly, asking is not genuine if the patient’s response does not matter. The right of “informed consent” to treatment must mean the right to refuse treatment.

Contingent empirical claims are less central, though they bolster the right. Treatments may be more effective if the patient is involved as a decision maker. Treatments often involve risks, and those should be evaluated by the person who is taking the risk. Given the fact that it is inevitable that treatment will sometimes harm, trust of patients in their physicians and caregivers will erode if the responsibility for treatment decisions is not shared.

The legal right to refuse medical treatment thus has a firm ethical foundation. In the U.S. in the late 1970’s and 1980’s, the right expanded to include refusing lifesaving treatment. That said, other questions arise about how far the right should extend.

Non-terminal Illness

The right has its strongest justification in situations of terminal illness and continual pain, for who better to discern the value of the remaining life with suffering than the person experiencing it? How much of this point changes when the person is not terminally ill?

On the one hand, very little. If anything, suffering in non-terminal illness may be longer and all the worse. Moreover, while an illness may not be “terminal” in the sense of death being likely within six months, life may still be on a steady downhill progression in which the patient is losing the things she most associates with being “alive” (in progressive dementia, for example). On the other hand, what if the refusal occurs in a situation that is not terminal at all — an anorexic 25-year-old refuses tube feeding, for example? May we impose an exceedingly non-invasive treatment, for example, adding a tasteless, appetite reviving supplement to the patient’s drink?

Two factors affect how likely we are to stick strictly to a right of refusal in non-terminal situations: degree of bodily invasion and potential for later retrospective consent. A tasteless pill or food additive are different than surgery or tube feeding (though perhaps still not different enough). With highly invasive treatments it is especially objectionable to treat in face of the patient’s refusal. The prospect of retrospective consent may also make a difference. If providers have very good reason to think that a burn patient, for example, will end up saying, after recovery, that it was right to give him lifesaving treatment though at the time he refused because of his horrendous pain, we may think treating him despite his current refusal is justified. Such a justification need not claim that patient benefit overrides autonomy. In appealing to the patient’s eventual consent, it still invokes autonomy. Moreover, it has a natural check: whether the patient will actually validate the override.

Inherent Limitations

Even if low degree of bodily invasion and likelihood of retrospective consent can justify treatment despite a patient’s refusal, however, the default rule remains the right to refuse. The burden of proof falls on the provider or family who wants to treat to show that the patient’s refusal should be rejected because degree
of bodily invasion is unusually minor or likelihood of retrospective consent high. Neither consideration betrays any weakness in, or compromise with, the basic right to refuse treatment. Both are inherent in the right's logic. Degree of bodily invasion matters because of self-ownership, and retrospective consent is relevant because the agent of consent, a person, is not a momentary entity but a being who lives across time.

There is another more frequent legitimate reason for treating patients despite refusal — doubts about a person's capacity to refuse. This "exception," too, is not really an exception, but part of the very nature of the right to refuse. As long as we do not assess the patient's capacity on the basis of our own normative judgment about the treatment, we can still respect the right to refuse when we do not follow the choice of a patient who lacks capacity.

The robust moral right to refuse lifesaving treatment thus holds in non-terminal as well as terminal illness situations, though it has natural limitations that are part of its very logic: when there is insufficient decision making capacity, high probability of retrospective consent, or (more debatably) little bodily invasion in delivering treatment. These are inherent limitations of the right, not compromising exceptions.

Do these foundations for the legal right to refuse lifesaving treatment also support a right to refuse food and water by mouth? If they do, patients' range of legitimate control over their deaths will be greatly expanded. People can effectively hasten death by refusing lifesaving treatment only if they happen to have a fatal condition that requires treatment. The death hastening capacity of VSED is not similarly limited.

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Basic Justification
In the U.S., people effectively have a legal right to VSED even though the case law may not be definitive. One justification sees VSED as derivative from the right to refuse lifesaving treatment. While the right to refuse treatment is partly based on the fact that treatment typically involves bodily intrusion, and providing food and water by mouth is not an intrusion, a moment's reflection reveals the tight connection between VSED and refusing treatment. The only way to keep alive someone who steadfastly refuses to eat and drink is to insert a feeding tube, using whatever force is necessary. That, surely, would be coercive medical treatment. In practice, then, the right to VSED is a right not to be force-fed by imposed lifesaving treatment. The legal reasoning here is not that food and water by mouth are medical treatment, but that the only effective way to require a resolute patient to ingest is to impose treatment. Then the prospect of physically restraining competent patients to insert feeding tubes against their will is sufficiently demeaning and repugnant that we quickly acknowledge a right to VSED. Another justification is more direct. U.S. Supreme Court Chief Justice Rehnquist surmised it to be a direct manifestation of bodily integrity: "It seems odd that your bodily integrity … [would be] violated by sticking a needle in your arm but not by sticking a spoon in your mouth" (..., case). Without the consent of the patient, neither is a warranted intrusion.

These legal justifications are well grounded ethically. As we have seen, the right to refuse treatment is a moral as well as legal right. In one of its legal justifications VSED is protected by the right to refuse medically delivered food and fluid, and it gains the moral and legal reasoning behind that right. The other, more direct justification based on bodily integrity also expresses a moral judgment, that respect for such integrity is integral to respect for persons and one of their central attributes, self-ownership.

Complications: Suicide and Assisting Suicide
A different position on VSED — on its ethical permissibility, at least — focuses on the fact that the person who voluntarily stops eating and drinking intentionally aims at her own death. In some conventional
frameworks, intentionally and directly causing the death of an innocent person, oneself or others, is absolutely prohibited. This is the traditional view of the Roman Catholic church, among others.

In this view it is not morally permissible to intentionally end life, one of the fundamental natural goods of human existence. One can intentionally end life not only by active killing but by an omission. Usually in a refusal of treatment the purpose of the omission is “to relieve the patient of a particular procedure that was of limited usefulness … or unreasonably burdensome,” and even if it is food and water that are omitted, the omission is then not a decision to kill and should not be equated with suicide. At other times, however, the harsh reality is that … withdrawal of nutrition and hydration … directly intend[s] to bring about a patient’s death … Whether orally administered or medically assisted … [food and fluids] are sometimes withdrawn not because a patient is dying, but precisely because a patient is not dying (or not dying quickly) and someone believes it would be better if he or she did … We must be sure that it is not our intent to cause the patient’s death — either for its own sake or as a means to achieving some other goal.

The view is clear: when people intentionally and with certainty cause their own death by VSED, they are impermissibly committing suicide. To be sure, the larger tradition in which this assessment of it is placed harbors the Rule of Double Effect, a principle that can morally rescue an act that causes a foreknown death if the death is an unintended side-effect. The classic case is administering morphine: the act itself is pain-relieving and not inherently wrong, and the death it eventually causes, though foreseen, is not intended. This excusing effect of the Rule of Double Effect, however, does not hold in the typical case of VSED, where death is clearly intended. Moreover, for an action that causes death to be justified by the Rule of Double Effect, “the action having the bad side effect must be permissible independent of considerations about the bad side effect.” In VSED, typically, it is not. Death is intended, and VSED directly and with certainty causes death.

If VSED is thus sometimes suicide, family who cooperate with it and caregivers who facilitate it with palliative care may also be implicated. Depending on the nature of their support and how important it is to the patient’s decision to stop eating and drinking, they may be assisting a suicide. If they are, their assistance is no more permissible than the VSED itself.

Some may want to challenge this view by claiming that only actions, not omissions, can be causes, and that since VSED is the omission of food and water, it can not be the cause of death and is thus not suicide. But an omission, especially an intentional one, certainly can be a cause. We certainly view omissions as causes whenever we hold people responsible for the ill effects of failing to do what they were obligated to do. VSED, then, even if an omission, still causes death. It may be “suicide by omission,” “passive suicide,” or a “singular form” of suicide, not the typical form of suicide, but it is suicide nonetheless.

Once we move outside an ethical framework where intentional killing of the innocent is inherently and always wrong, however, the descriptive and conceptual fact that VSED may be a form of suicide need not make it objectionable. Why should hastening death intentionally, with certainty ensuring it, and being the primary cause of it, make the act that hastens death morally wrong if what it brings about, death sooner rather than later, is a good thing compared to living with great suffering or in a condition of severe deterioration like advanced dementia? The characteristics of VSED’s relationship to death — intention, certainty, causation — may make VSED suicide, not mere “aid-in-dying” or “letting death come,” but do they make it wrong? Intentionally ensuring and causing a good result would, if anything, be better, one would think. As long as SED is voluntary and not foisted on patients by others, why is it not within their moral prerogative as much as refusing LSMT? Either can be done foolishly or wrongly, but there is no reason to think that mistaken exercise of the right occurs more often with VSED than it does with refusing lifesaving treatment.

These are powerful arguments against the view that VSED is inherently wrong because it is a form of suicide, yet the strongest threat to VSED’s legal and moral acceptability still pivots off its potential character as suicide. In U.S. law suicide is not a crime, in the sense that the person who accomplishes or unsuccessfully attempts it is not punished, but it is not a person’s legal right, either. Others may stop it, and in most jurisdictions no one is legally permitted to assist it. The resulting complication for VSED is clear. For it to be a comfortable path to death, VSED should be medically managed and accompanied by palliative care, but if, descriptively, VSED just is suicide and not letting death come, it will involve a kind of assistance in suicide. This poses no moral difficulty if there is nothing ultimately wrong with assisting suicide, but it threatens to complicate the legal and moral situation.

Further pragmatic considerations, though, can halt these pressures against VSED. The objection to seeing the provision of palliative care for VSED as assisting suicide withers once the real alternatives are noted. To block a person’s choice to stop eating and drinking, we would need to do one of three things: swallow our “revulsion at the prospect of physically overcom-
ing and restraining people” and feed them against their will; engage in the seeming hypocrisy of letting people embark on VSED while then pulling them back once they can no longer resist the imposition of food and water; or live with the apparent callousness of denying them palliative care when they stick to their refusal to eat and drink. None of these are likely to be countenanced by families, caregivers, or courts.

In practice, then, we are likely to end up regarding the medical assistance involved in supporting VSED as permissible even if VSED is suicide and assisting suicide is generally not permissible. The strong case for permissibly providing palliative care is a combination of three points: the competent patient’s act of VSED is itself a protected legal liberty, physicians should respect that liberty even when they might not encourage patients to exercise it, and then they should do what they can do for the best interest of the patient. The result is important: professional acceptance of palliative care is crucial if VSED is to have a significant place in the array of patients’ options for hastening death.

“Suicide” and “Terminal” Illness
In many of its cases, moreover, we may just not see VSED as suicide. “Suicide” can be a highly elastic term even when the technically sufficient elements of intention, certainty, and causation are present. Alan Alberts, e.g., employed VSED to ensure that he would not live years into his relentlessly advancing dementia; his wife, Phyllis Shacter, writes that “it never occurred to either of us” that Alan’s refusal to eat and drink could be suicide. Another contributor to the same collection of essays about the experience of VSED, caregiver Wendy Kohlhase, at first surmised that VSED for her patient was suicide, since eating and drinking are not medical treatments, but then she observed that VSED in a hospital would be protected by the Patient Self-Determination Act (PSDA). Food and liquids offered there are care — part of overall treatment — that the patient has the right to refuse. If we do not regard the refusal of even the most clearly lifesaving and least invasive treatment as suicide (for example, basic antibiotics for pneumonia), why do we have to see the refusal to eat and drink as suicide?

The variable use of “suicide” is starkly visible in efforts to legalize physician-assisted suicide. Advocates of legalization prefer to speak of physician “aid-in-dying” and will often insist that it is not assisted suicide. This is not merely a matter of using language that will be better received on behalf of legalization. When the assistance in hastening death is restricted to persons with a “terminal” condition (typically, six months at most to live), it is perfectly correct to refer to what occurs as “aid in dying.” The patient already is dying. And yet, with its characteristics of intended death, assured death, and directly caused death, the patient’s act is also suicide. Descriptively, the act is simply both.

Perhaps perceptions of VSED as “suicide” or not loop back to the same “terminal” illness dimension that allows people to see lethal medication as aid-in-dying, not physician-assisted suicide. Even where VSED hastens a death much further off than six months, the situation may still be legitimately seen as “terminal.” Progressive dementia that is relentlessly becoming severe, for example, is likely to be experienced personally as a “terminal” condition. It is utterly different than normal old age. One is losing one’s mind. Anyone facing that is likely to see it as their “last stage” as much as any person sees life with a six-month prognosis as last-stage. In the terms that matter to people, if the one is a “terminal” condition, the other is, too.

Outside absolutist frameworks, context is likely to matter. What people generally see as suicide when they regard it as tragic or wrong is intentionally causing one’s own death when one is not in some sense “already dying.” VSED in terminal contexts — the sense of terminal that matters, not just a six-month prognosis — does not have to be seen as suicide. And even if it still is seen as suicide, it does not have to be seen as tragic and impermissible.

In summary, while sufficient justification for a right to VSED is not adequately provided simply by the same reasons for the right to refuse LSMT, the necessary additional considerations are readily available, in various moral frameworks: if suicide is not inherently wrong, if VSED is not suicide, or if, though it is, assisting it is still permissible. As long as refusing food and water by mouth is voluntary and not foisted on patients by others — the very same limitations we put on refusing lifesaving treatment — VSED is a patient’s moral prerogative. Here, too, self-determination and respect for persons are at stake. Any significant slippage in ethical justification that occurs in moving from the right to refuse lifesaving treatment to VSED has to rely on a combination of claims many will reject: that VSED is suicide, that suicide is always ethically impermissible, or that those who provide palliative care for VSED assist in a suicide.

Refusing Lifesaving Medical Treatment by Advance Directive
How does the justification for extending the fundamental right to refuse LSMT when competent to refusing it through an advance directive compare with the justification for extending the fundamental right to refusing food and water? I will argue, surpris-
ingly perhaps, that the extension to refusal by advance directive is no stronger, and likely more problematic, than the extension to VSED.

Precedent Autonomy
Withholding or withdrawing LSMT for patients who lack decision making capacity does not fall automatically within the right to refuse LSMT, for without capacity at that point there is no autonomous agent. If, though, the patient previously had capacity and left knowledgeable preferences for the current circumstance, autonomous choice arguably comes back into the picture. “The prevalent legal standard for surrogate medical decision making — substituted judgment — dictates adherence to prior instructions and thus secures for an incompetent patient ‘the same panoply of rights and choices’ as accorded to competent persons.”

The justification for the prerogative of a no longer competent patient to refuse lifesaving treatment may then seem to be the same normative self-determination and respect for persons that justify the right to refuse LSMT in the first place. We tend to look past the current incapacity and regard the patient’s previous directive as still her decision in the current situation. The life that will be affected, after all, is still her life, so the full moral weight of self-determination and self-ownership are still in play. This is the precedent autonomy view of ADs.

To constitute precedent autonomy, the moral force of any substantive AD must track the same basic considerations that give force to a contemporaneously competent patient’s choice. How informed was the person about the medical condition to which the treatment now applies, about the prognosis with and without such treatment, about its risks, etc.? When a person in an AD has refused a kind of treatment, to what conditions, with what range of prognoses, did she understand this refusal to apply? How adequate was the patient’s mental capacity to absorb such information and make decisions based on it? How voluntary and free from pressure and coercion was the choice? The clearer, more knowledgeable, and more unquestionably voluntary a directive is, the greater is its moral force for later caregivers.

The notions of validity and applicability summarize these considerations. A directive has normative force in a given situation if it is valid — made voluntarily and with sufficient understanding of the things to which it speaks. It must also, at the time of implementation, be applicable — the conditions to which the person intended it to apply must now in fact obtain.

It is crucial for a good directive that it be clear and substantive enough to later be applicable. Many directives, undoubtedly, are not. A practical way to help overcome this common deficiency is to supplement the AD with another directive appointing a personal proxy, and for the patient to have substantial communication with this proxy about the matters addressed in the directive.

The difficulties in meeting a reasonably high standard of validity and applicability are ongoing everyday challenges to the legal and moral authority of ADs in a precedent autonomy framework, but most people are inclined not to be very demanding on these scores. We probably, after all, hold two moral beliefs quite stubbornly: a person does not lose her rights when she becomes incompetent; they just have to be exercised for her by others. And the life she lives after becoming incompetent is still her life. We thus tend to see an incompetent person’s right to refuse LSMT by AD as resting on the same values of self-determination and respect for persons that justify the currently competent person’s right.

The Then-Self/Now-Self Problem
The matter, however, is not so simple. A fundamental difficulty intrudes, the “then-self” vs. “now-self” problem. The directive’s competent writer (the “then-self”) may request, for example, that no treatment which would prolong life in a significantly diminished or painful condition be provided because she does not want to live if she has to “live like that.” Yet precisely the situation that motivates writing an AD and which brings it into operation — incompetence — may also affect the person’s values, attitudes, and desires. The now incompetent individual (the “now-self”) may not regard “life like that” as unbearable. She is now not autonomous, does not care about autonomy, is not aware of the directive she wrote, and may no longer value many of the things about life that were the basis for writing her directive. So why should her directive be followed?

Some critics — notably Rebecca Dresser and John Robertson — conclude that the directive is irrel-
evant. We should treat the now incompetent patient solely on the basis of his current best interest, not his previous wishes, even if clearly expressed. “Precedent autonomy” is a misnomer: the moral force of autonomy is simply lost when autonomy is no longer present. To respond that this fails to respect the autonomy manifest in the person’s directive is hardly persuasive, for what Dresser and Robertson are disputing is the very relevance to the current patient of that autonomy.

Nonetheless, there are powerful responses to this rejection of any weight for ADs based on autonomy. One has been articulated by Nancy Rhoden: Dresser and Robertson’s position amounts to treating previously competent patients no differently than patients who have never been competent; both are to be treated only on the basis of best interest. But should we ever treat someone who has had a long life as a competent, vital person as if she had never been competent? Hardly. To do so would be to say that she deserves no consideration for having been an autonomous person. “Someone who makes a prior directive sees herself as the unified subject of a human life. She sees her concern for her body, her goals, or her family as transcending her incapacity.... One...component of treating persons with respect [is] that we view them as they view themselves. If we are to do this, we must not ignore their prior choices and values.”

If this is correct, ADs must have some authority. Dresser and Robertson are factually right in noting that the patients incapacitated at the time when we would act on their directives do not understand autonomy, exemplify it, or care about it, but it does not follow that we may ignore previous wishes. If it is not autonomy per se that we are dealing with here in the incompetent patient, it is something close: the narrative-self sense of self-ownership. “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.” Call this, if you will, the continuing-narrative-self sense of self-ownership.

Ronald Dworkin has made the same sort of claim, though by a notion of “critical interests” that falls within the very category of best interest Dresser and Robertson use to reject the authority of ADs. “Experiential” interests may change significantly with one’s incompetence, but the person’s overall best interest, Dworkin claims, is still connected with previous choices. Autonomous persons have beliefs, desires, and values that form something beyond experiential interests — “critical” interests in satisfying second-order desires that emerge when people reflect on events in their life and on the first-order desires they just have. Critical interests reflect evaluations, not mere preferences — convictions, for example, about “what helps to make ... [one’s] life good on the whole.” For some, those evaluations involve how one’s life should end.

Unlike experiential interests, critical interests can exist even after one no longer experiences them. If someone cares about what happens to his property, his family, or his reputation after he dies, for example, he has critical interests in these things even after he has died, when he will have no experience of whether his interest is thwarted or satisfied. This is also true for any conviction a person might have that his life as a whole would be better if it did not extend into years with a progressively degenerative and eventually fatal disease. Refusing to implement his directive would harm him just as unfairly tarnishing his reputation would.

Formally, the notion of critical interests puts the defense of ADs back into the framework of patient best interest, though, arguably, it is ultimately autonomy as self-determination about one’s whole life that is still the underlying justification. Whether we express the matter in Rhoden’s directly autonomy-focused terms, in Cantor’s language of owning a life narrative, or through Dworkin’s notion of continuing critical interests, self-determination and respect for persons are the fundamental basis of the normative force in ADs.

This sounds like the same justification for ADs as for the original right to refuse treatment, and in a way it is. But because of the then-self/now-self problem, autonomy’s normative power can weaken in actual situations where we would implement someone’s directive. The reason: contrary experiential interests. When they are present, why should we think that the critical interest in dying sooner rather than later that is represented through a person’s directive must always outweighs a contrary experiential interest in survival?

To see this, imagine the following.

A Case
For years, James, 90, has gradually declined physically and mentally. He recently had a series of strokes. In his recovery he has regained enough control to walk short distances with a walker and very slowly feed himself. With his stroke induced dementia he can carry on no conversation, and he can no longer occupy himself with TV or any other simple activity. He seems to recognize his wife and son as his wife and son. He is nonetheless consistently good-natured and smiles when someone looks at him directly and speaks kindly.

James’ AD specifies that once he cannot recognize his closest friends and loved ones, converse with them as
specific individuals, or occupy himself with even simple activities, he should receive no lifesaving treatment of any sort, including antibiotics. Now he has contracted pneumonia, readily curable with an antibiotic but otherwise almost certainly fatal. His directive applies to the situation and clearly tells us not to provide such treatment; he has a critical interest in the pneumonia not being treated. Yet he is not suffering or in pain, and he experiences some real though modest enjoyment of life; he still has an experiential interest in surviving.46

This difficult case would be much easier (in favor of not treating the pneumonia) if the full weight of autonomy carried into the current situation of James’ incompetence through his directive. Rhoden’s, Cantor’s, and Dworkin’s arguments show that his directive’s earlier wishes must be accorded significant weight if we are to respect him as a person, but it is indisputable that in his current state he has some experiential interest in continuing to live.47 Furthermore, if we do not now follow the directive, James will not know that we have not and will experience no consternation, a situation very different than if he were either competent now and given the antibiotic against his wishes or, though not now competent, he could again become competent and judge what we had done.

Thus, though James’ autonomy and respect for him as a person still applies when he is “speaking” only through his AD, it does not have the same force. First, any contrary experiential interest that we are convinced he has in being given lifesaving treatment pulls us much more strongly toward not abiding by his directive than we would be pulled by such an interest that we would observe him to have if he were competent and refusing the lifesaving treatment. In the competence situation, we would likely abide by his refusal. Legally we would probably have to. The desire of others to save his life for his own sake provides little room for maneuver when James is currently competent and his refusal clear and persistent.

Second, the legal sanctions on caregivers are likely to be different in the two situations. With an incompetent James, courts are not likely to punish caregivers or surrogate decision makers “for failure to facilitate the death of a non-suffering patient who no longer recalls his or her dignity-based instructions.”48 By contrast, if caregivers were to treat a competent James against his will, they would very likely be liable. They may even be stopped by court order.

Note, by contrast, that there is no such difference in legal obligations and liability between a competent person’s right to refuse lifesaving treatment and a competent person’s right to pursue VSED. With VSED, autonomy, bodily integrity, and respect for persons apply with virtually the same normative force that they do in the case of a competent person’s refusal of lifesaving treatment.

Comparatively, VSED is a less problematic extension of the basic legal and moral right to refuse LSMT than refusing lifesaving treatment by AD. If refusing lifesaving treatment by advance directive is accepted as a person’s ethical and legal prerogative, refusal to eat and drink by a competent person should be also. There is ample ethical and legal reason to regard VSED as ready for prime time in the array of legitimate options for hastening death.

Conclusion: Comparing the Justifications
Advance directives and the patient autonomy that lies behind them very much count when a person loses competence, but they do not transmit decisions with the same full force of autonomy that a currently competent person’s decisions have. When an important segment of the incompetent person’s interests stand in conflict with the earlier directive, a stronger case can be made for going against prior wishes to refuse LSMT than could ever be made for going against the contemporaneous wishes of a competent person. To be sure, the critical interests defined by a person’s directive still carry over as a crucial ingredient in determining the overall best-interest of the current, incompetent person, but there is little reason to think such critical interests should always outweigh contrary experiential interests in continuing to live. Thus, ADs are compelling but problematic vehicles for self-determination. They command attention and general support, but their discerning application is complex.

Compare this justification of ADs with that of VSED, keeping in mind the right to refuse LSMT as one’s reference point. (1) Denying a right to VSED by forcibly feeding a competent person, whether by oral feeding or imposition of a feeding tube, seems as grave
a violation of bodily integrity and self-determination as forcing someone to have life-extending treatment against her wishes. (2) The prospect of later retrospective consent to the forced feeding of someone who embarks on VSED is no more — and probably less — likely than later retrospective consent by a person who refuses lifesaving treatment. (3) In intention, certainty of death, and direct causal role, VSED can more often be correctly described as suicide than refusing LSMT can be, but the differences are slim. Some people who refuse LSMT, too, do it in order to hasten death, and they know with virtual certainty that their refusal will hasten it, yet they are not for a moment denied the right to refuse treatment. (4) The moral framework in which suicide and assisting it are always wrong, and in which the VSED that qualifies as suicide is therefore wrong, is only one moral framework. Self-determination and respect for persons lean strongly against letting any one univocal moral view dominate when others are eminently reasonable.

Comparatively, VSED is a less problematic extension of the basic legal and moral right to refuse LSMT than refusing lifesaving treatment by AD. If refusing lifesaving treatment by advance directive is accepted as a person’s ethical and legal prerogative, refusal to eat and drink by a competent person should be also. There is ample ethical and legal reason to regard VSED as ready for prime time in the array of legitimate options for hastening death.

References
2. Alternately known as physician-assisted suicide. By either term the act referred to is the same: a physician authorizes a lethal agent that the patient self-administers.
3. In this paper I do not address another question that will be important to some in considering VSED: withholding food and water by mouth in accordance with a patient’s advance directive to do so. Though legally and ethically problematic, this combination of VSED and advance directive has been explored and cautiously defended by some. For sources and further discussion, see note 49.
4. Physician assistance in a suicide is legal in Oregon, Washington, Vermont, Montana, California, and Colorado, as well as the District of Columbia. Outside the U.S. it is legal in Switzerland, Belgium, and The Netherlands. In those jurisdictions it is typically allowed only in restricted circumstances such as terminal illness (the U.S. states) or unbearable suffering (Belgium and the Netherlands). The exception is Switzerland, where neither terminal illness nor a minimum level of suffering are required, though the person assisting must be acting unselfishly. See P. Lewis, “Assisted Dying: What Does the Law in Different Countries Say?” BBC World report (2015), available at <http://www.bbc.com/news/world-34445715?sthisFB> (last visited November 17, 2017).
13. Expressed by Justice Cardozo in *Schloendorff v. New York Hospital* 211 NY 125 (1914) at 129: “Every human being of adult years and sound mind has a right to determine what shall be done with his own body.”
14. T.M. Pope, “Clinicians May Not Administer Life-Sustaining Treatment Without Consent: Civil, Criminal, and Disciplinary Sanctions,” *Journal of Health and Biomedical Law* 9 (2015): 213-216; A. Meisel, K. Cermiina, and T.M. Pope, *The Right to Die: The Law of End-of-Life Decisionmaking*, 3rd ed. (New York: Wolters Kluver Law & Business, 2017): loose-leaf publication from 2004, with annual supplements). From Meisel et al., a short historical sketch running up to the inclusion by 1990 of lifesaving treatment in even non-terminal situations can be constructed. Initial steps were to define “life-sustaining treatment” as treatment that “will serve only to prolong the process of dying” (para. 7.06[A-1]) and to dispense with the usefulness of “the purported distinction between ordinary and extraordinary treatments... Antibiotics [for example] may be forgone on the same basis and pursuant to the same standards of decisionmaking as any other therapy” (para. 6.09[F]). In 1978, *Sats v. Pernment* 362 So. 2d 160 (Fla. Ct. App. 1979) affirmed 379 So. 2d 359 (Fla., 1980), ruled that an exercise of the right to refuse lifesav-
ing treatment that leads to death is not attempted suicide if the patient’s affliction is not self-induced (para. 12.02[C-4]). Beginning in 1985, “courts in a ... growing number of cases have not only recognized, but also have ceased trying to circumvent, the right of competent patients to refuse treatment when refusal would almost certainly result in their deaths but treatment was almost certain to restore their health to the status quo ante” (para. 5.01[A]). By 1990, in In re Browning: 568 So. 2d 4.10 (Fla. 1990), the right of a competent patient to refuse treatment had expanded further to be virtually absolute, encompassing the right to refuse “regardless of his or her medical condition” (para. 5.01[A]), including not being limited to terminal illness.

As reflected in one of the most expansive statements of the scope of the right, In re Browning: 568 So. 2d 4.10 (Fla. 1990), supra note 14: the patient’s right to refuse treatment holds “regardless of his or her medical condition.”


20. This close connection of VSED with the right to refuse lifesaving treatment may not similarly obtain between the right to refuse treatment and physician-assisted death (euthanasia and aid-in-dying). If it does not, fewer pressures of consistency push toward legalizing aid-in-dying or euthanasia when the society accepts VSED.


23. Id., at 393 (emphasis added).

24. Some may argue that the doctrinal Roman Catholic position should not reach this conclusion. The elements in Catholic moral theology that may provide grounds for regarding VSED as permissible include a fuller understanding of the “extraordinary” care that may be refused as involving “disproportionate” or “excessive burden,” a strong emphasis on “hope of benefit” and “friendship with God” as the ultimate goods that extended life can often bring but sometimes threatens, and wariness about a too exclusive focus on the slippery notion of intention. On these important nuances in Catholic moral tradition, see K.D. O’Rourke, “The Catholic Tradition on Forgoing Life Support,” The National Catholic Bioethics Quarterly 5, no. 3 (2005): 537-553. I only call attention to these elements; O’Rourke himself does not attempt to draw from them any conclusion about the permissibility of VSED.

25. Boyle, supra note 21, at 262. Boyle clarifies the relationship further at 272: “...The justification of the prohibition against intentional killing is not achieved by the Rule of Double Effect; that is a distinct and prior matter.” See also the discussion of the role of double effect and suicide in the assessment of VSED in L.A. Jansen and D.P. Sulsms, “Sedation, Alimentation, Hydration, and Equivocation: Careful Conversation about Care at the End of Life,” Annals of Internal Medicine 136, no. 11 (June 2002): 845-849, at 846 and 848.

26. One might try to rescue VSED, using the framework of the Rule of Double Effect, by claiming that stopping eating and drinking does not directly cause death — the dehydration that flows from VSED does, not VSED itself. This reasoning will not work. The Rule of Double Effect does not permit treating the causation per se but on whether one directly and intentionally causes the death. “Directly,” however, is sufficiently problematic that it likely has little substantive role in the formulation except to accentuate the importance of not intentionally causing death. It cannot mean that there are no intermediate processes between the action and the final result, for that would mean that a fatal stabbing directly caused only the bleeding, and the bleeding, not the stabbing, is what caused death. Since we do not accept that sophistry, we have to allow intermediate elements into a causal chain to death without canceling the initial act’s status as causing death. Some meaning other than “without intermediate effects” will have to be found for what the prohibited “directly causing” means.

One plausible candidate is that it calls attention to the certainty with which the causation will proceed. Refusal of lifesaving treatment, for example, could then qualify as an act that did not directly and intentionally cause death, for the perils thereof. Another candidate is that it is “not directly” just means, or emphasizes, “not intentionally.” Note that under neither interpretation will VSED be excused. In many cases the patient employs VSED precisely with the intention to die, and in all cases in which the patient follows through with it, it is with certainty that ceasing the intake of food and fluids will cause death. VSED does cause dehydration, and dehydration is the immediate cause of death, but VSED, too, still causes death, intentionally and with certainty.


28. A slightly different analysis of how VSED qualifies as suicide is given by Jox et al., supra note 27. Jox et al. focus on action rather than causation: suicide involves an explicit element of
deliberate action, and actions are sometimes performed by omissions.
29. See supra note 4.
30. Jox et al., supra note 27, argue that different circumstances should determine whether the palliative care used with the VSED that is suicide constitutes assistance with a suicide or only comfort enhancing care. If patients would choose VSED only when assured that they will receive palliative care as needed throughout the process, or if the patient has already begun VSED but would resume eating and drinking were palliative care not provided, then providing such care is assisting in a suicide. On the other hand, if VSED has been begun and the patient will continue its course even if palliative care is not provided, then providing it is not assisting the suicide. These distinctions may or may not be coherent and relevant. I do not pursue them because in my analysis, the more important question is whether the suicide and suicide assistance that VSED may involve make it wrong. That is not an option for Jox et al., who are concerned with whether palliative care organizations and legal scholars can defend the provision of medical support for VSED when they are already professionally committed to opposing suicide and its assistance.
32. The Supreme Court of South Australia in H Ltd v J, supra note 19, made a slightly different move to avoid the conclusion that assisting with VSED is the criminal offence of assisting a suicide. The court concluded that if the VSED was not suicide, but stated that even if he was wrong and it was suicide, “merely respecting a competent refusal falls short of the required encouragement to constitute aiding and abetting.” See White, Willmott, and Savulescu, supra note 5, at 382-384. (The quotation is White, Willmott, and Savulescu’s description of the judge’s position, not the judge’s own words.) This point will not hold if providing the palliative care is significantly more by way of assistance than merely respecting the patient’s choice to use VSED.
33. Span, supra note 6, conveying the remarks of Dr. Timothy Quill and other caregivers at the conference, “Hastening Death by Voluntarily Stopping Eating and Drinking,” Seattle University School of Law, October 14-15, 2016.
34. P.R. Shacter, “Not Here by Choice: My Husband’s Choice About How and When to Die,” Narrative Inquiry in Bioethics 6, no. 2 (2016): 94-96, at 95. For a fuller account of Shacter’s husband’s death by VSED, see P.R. Shacter, Choosing to Die, A Personal Story of Euphoric Death by VSED in the Face of Degenerative Disease (self-published, 2017, information at info@PhyllisShacter.com).
37. Some authors approach the question of whether VSED is suicide from a somewhat different pragmatic perspective: since VSED and its assistance are legally permissible, they do not warrant the label “suicide,” especially not when they are pursued in the context of suffering at the end of life. Two substantial discussions by Judith Schwarz of the relationship of VSED to suicide might be interpreted to take such an approach. See J. Schwarz, “Exploring the Option of Voluntarily Stopping Eating and Drinking within the Context of a Suffering Patient’s Request for a Hastened Death,” Journal of Palliative Medicine 10, no. 6 (2007): 1288-1297; J. K. Schwarz, “Death by Voluntary Dehydration: Suicide or the Right to Refuse a Life-Prolonging Measure?” Widener Law Review 17, no. 2 (2011): 351-361.
39. Articulated in many cases, including Brophy v. N. Eng. Sinai Hospital, 497 N.E.2d 626 (Mass. 1986), at 634.
42. In speaking of the “authority” of ADs I do not claim for them anything like final control. The term only means that they have normative force and should be respected as having a substantial role.
46. Sometimes the new situation that poses the dilemma about whether to follow the previous directive is more accurately described as a “change of mind” situation than a conflict between the patient’s directive and her current best interest. A legitimate change of mind about one’s directive changes the directive itself and may thus remove the conflict. What changes in mental attitude constitute a real change of mind about one’s directive is itself a complex matter. I have attempted to sort out this issue in P. Menzel, “Change of Mind: An Issue for Advance Directives,” in J.K. Davis (ed.), Ethics at the End of Life: New Issues and Arguments (New York: Routledge, 2008): 126-137.
47. We must be careful here. Admitting into the moral equation James’ experiential interest in surviving does not dictate the conclusion that we should administer the lifesaving treatment. It only means that the AD does not have exclusive authority. Were James to slide further into dementia, for example, to a point where he could not anticipate tomorrow or appreciate having survived from yesterday, for example, a decision to follow his directive could be justified on the basis of what would appear to be a compelling judgment about his current overall best interest. The subjective value to him of survival will have diminished to a point that it can readily be outweighed by his strong critical interest in not being treated. If we did not at some point allow the critical interests conveyed in James’ AD to tip the balance as his experiential interest in survival declines, we would be treating him the same as a never-competent person. That would expose us to Rhoden’s compelling objection that previously competent persons never be treated simply as if they had never been competent. With co-authors I have referred to this way of handling the tension between then-self and now-self — weighing up together a person’s experiential and critical interests — as a “balancing” or “sliding scale” model. See Menzel and Steinbock, supra note 45, at 495-496, and Menzel and Chandler-Cramer, note 49, at 28-29.
48. Cantor (2017), supra note 38, at the last (unnumbered) page before Cantor presents his own advance directive (emphasis added). One can also observe more generally about ADs...
that clinicians’ actual incentives to follow them may be weak. Even if ADs are seen by clinical caregivers to have significant ethical and legal authority, their perceptions of legal vulnerability can easily lead them not to follow an AD. They may, not unreasonably, have greater fear of legal vulnerability if they follow a directive and the patient dies than they do if they fail to follow the directive. This situation in the world of practice may be changing, however, as more judicial decisions come forth that hold providers accountable for not following a valid, applicable directive. See T.M. Pope, “Legal Briefing: New Penalties for Disregarding Advance Directives and Do-Not-Resuscitate Orders,” Journal of Clinical Ethics 28, no. 1 (2017): 74-78.

49. If VSED is at least as firmly established legally and ethically as advance directives to refuse lifesaving treatment, one might ask whether a next logical step isn’t their combination: advance directives for stopping eating and drinking (SED by AD). Such directives, assuming they could be implemented, would be of particular interest to persons who strongly desire not to live into years of severe dementia but who do not want to forego what they regard as the still valuable life they would give up if they employed VSED pre-emptively while they were still competent and decisive. After all, they cannot count on ADs for refusing lifesaving treatment to rescue them from years of severe dementia; those years may unfold without need of such treatment. And with medical aid-in-dying legalized in only a few states, and even then, only for patients who are currently competent, SED by AD becomes the only possibly legal way by which people can ensure that they will not end their lives in extended years of severe dementia.


Two of the barriers pursued in Menzel’s paper are the willingness of some severely demented patients to accept food when provided with adequate assistance, which some will see as a change of mind about their directive, and the perception of oral feeding as basic personal care that, unlike medical care, caregivers allegedly have an obligation to provide regardless of previous directive.