

**GIVE ME LIBERTY TO CHOOSE (A BETTER) DEATH:
RESPECTING AUTONOMY MORE FULLY IN ADVANCE
DIRECTIVE STATUTES**

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ABSTRACT

In the name of state interests, advance directive statutes almost universally include language requiring that a patient be in a particular physical state as a condition precedent to operation of a directive. This article urges state legislatures to recognize and rectify the conflict they have created by imposing such triggering conditions. First, it examines states' efforts to facilitate autonomous end-of-life decision making through advance directive statutes. Then it proposes amending those statutes to align the law with medical ethics by eliminating specified physical triggering conditions burdening the exercise of patients' rights to refuse life-sustaining treatment. Such amendment will improve end-of-life care and serve as an expression of a more caring medical and legal culture.

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I. INTRODUCTION

Death affects us all. Barring medical miracles, none of us will escape it, and most of us will witness the passing of numerous relatives, friends, and acquaintances over our lifetimes. Perhaps an elderly grandfather will pass away after years of slow decline into and endurance through Alzheimer's Disease, requiring medically supplied nutrition and hydration.¹ Perhaps a neighbor, a Jehovah's Witness, will pass away after refusing a blood transfusion, acceptance of which is against his faith.² A good friend's mother-in-law may exist in a vegetative state, non-communicative and non-cognitive,³ yet sustained by medically-supplied nutrition and hydration for years before dying.⁴

Just as the medical conditions of all those people will vary, so too may their preferences for treatment near the end of life. All of them have the right to refuse even life-sustaining treatment, not just under the common law but also under state and federal constitutional law.⁵ If they are able to understand and appreciate the situation and voice their own preferences at the time such refusal becomes an issue, they have nearly *carte blanche* liberty to exercise their autonomy to refuse it.⁶ Yet if they depend on documents executed in accordance with state advance directive statutes to ensure that their wishes are followed when they are unable to do so, they risk having their wishes ignored,

1. See Lou Cannon, *Foreword* to CRAIG SHIRLEY, *LAST ACT: THE FINAL YEARS AND EMERGING LEGACY OF RONALD REAGAN* xiv (2015) (noting former President Ronald Reagan, for example, revealed his diagnosis with Alzheimer's Disease to the public in a letter dated November 5, 1994. It was more than nine years later, on June 5, 2004, that he passed away. The time in between, according to former First Lady of the United States, Nancy Reagan, "taught her a crash course in patience."). See also ALAN MEISEL ET AL., *THE RIGHT TO DIE: THE END OF LIFE DECISION MAKING* § 6.04(E)(2) at 6-121 (Wolters Kluwer, 3d. ed. 2015) (explaining many patients with late-stage Alzheimer's Disease require feeding through medical means, known casually but misleadingly as tube-feeding).

2. See *Lozada Tirado v. Flecha*, 2010 WL 446020, at *2 (P.R. Offic. Trans. 2010).

3. See Kathy L. Cerminara, *Law, Perception and Cultural Cognition*, 55 WASHBURN L. J. 597, 607 (2016) (discussing recent research investigating just what level of awareness persons in vegetative state and the closely related minimally conscious state may possess).

4. See generally *In re Browning v. Herbert*, 568 So. 2d 4 (Fla. 1990) (involving an elderly woman receiving nutrition and hydration for years after a stroke). The *Browning* court used, and the applicable Florida statute uses, the term persistent vegetative state, but medical personnel use the term persistent vegetative state differently from legal sources in many circumstances. *Id.* Technically, a *persistent vegetative state* is a precursor to the irreversible *permanent vegetative state*, but the law generally uses *persistent vegetative state* to refer to both. See Cerminara, *supra* note 3, at 602 n. 29. This article will use the more general term *vegetative state* throughout, with the understanding that whatever term the law uses, it is likely that the person in a vegetative state in any given case has been deemed to be in an irreversible condition. See generally *id.*

5. Compare U.S. CONST. amend. XIV, § 1, with FLA. CONST. art 1, § 2. See *infra* Part III.A.1.

6. See *infra* Part III.A.1.

even if they properly executed the documents.⁷ While protecting autonomous, anticipatory medical decision making, the statutes also impose limitations on complying with patients' instructions in the name of safeguarding state interests.

This article demonstrates that state legislatures must recognize and rectify the conflict they have created by imposing such triggering conditions. First, it examines states' efforts to facilitate autonomous end-of-life decision making through advance directive statutes. Then it proposes amending those statutes to align the law with medical ethics by eliminating specified physical triggering conditions burdening the exercise of patients' rights to refuse life-sustaining treatment.

II. ADVANCE DIRECTIVE STATUTES: MEMORIALIZING PATIENT DECISIONS FOR FUTURE IMPLEMENTATION

State legislatures enact advance directive statutes to regulate the exercise of citizens' pre-existing common-law and constitutional rights to make their own medical decisions. The statutes are not sources of rights; instead, they codify and regulate the exercise of citizens' liberty to control their own bodies and shape their own destinies.⁸ California enacted the first advance directive statute in 1976; now all states have enacted them in a variety of forms.⁹ Many incorporate physical triggering conditions, which can thwart patients' wishes.¹⁰

A. *The Advance Directive Spectrum*

Advance directives vary greatly, but they have one common distinctive feature: They become effective only if and when patients cannot make medical

7. See, e.g., J. Clint Parker & Daniel S. Goldberg, *A Legal and Ethical Analysis of the Effects of Triggering Conditions on Surrogate Decision-Making in End-of-Life Care in the US*, 28 HEC F. 11, 13–14 (2016) (describing a case in which a child did not meet the triggering conditions of the North Carolina advance directive. Her parents and medical team all agreed that withdrawal of ventilator support was ethically and morally appropriate, but hospital risk management personnel argued that withdrawal would violate North Carolina law because the child did not meet either of that state's statutory physical triggering conditions). That case differs from those at issue in this article because the child in that case did not, and indeed could not have, executed a valid written advance directive. Written advance directives are not required for withdrawing treatment, but the case for withdrawal regardless of whether the triggering conditions are met is even stronger in a case in which a patient has executed a written advance directive.

8. See MEISEL ET AL., *supra* note 1 § 7.03[A], at 7-31, § 7.03[B], at 7-33; see also *id.* § 7.03[B], at 7-33–34 (explaining most, if not all, advance directive statutes themselves state that they are not the sources of the rights, but are merely the path to exercise those rights; a citizen's rights are far broader than those stated within the statutes).

9. See *id.* § 7.01[A], at 7-7; see also *id.* § 7.13 (noting advance directive statutes and tables).

10. See Parker & Goldberg, *supra* note 7, at 15–16 tbl. 1.

decisions themselves.¹¹ Until that point, patients speak for themselves. It is only when patients can no longer do so that caregivers and health care providers should follow the wishes set forth in their patients' advance directives.¹²

Advance directives can be either oral or written,¹³ but most people think of written documents when hearing the term. Indeed, there is some advantage to putting wishes in writing. In some states, for example, doing so will establish a presumption that those wishes are to be followed.¹⁴ There are also drawbacks, however, to writing lengthy instructions about numerous treatments, diseases, and conditions; being too specific about which treatments should be withheld or withdrawn, for example, can improperly imply that a treatment omitted from the document must be started or continued.¹⁵

A common way to categorize advance directives is to consider them as giving instructions or appointing a person to speak after the declarant cannot.¹⁶ Among written documents, an instructional advance directive is the type of document commonly known as a living will: a document in which a person sets forth her wishes to guide end-of-life medical treatment after she has lost decision-making capacity.¹⁷ In a proxy directive—variously called a durable health care power of attorney, a health care surrogate designation, or a proxy designation, among other names—the patient appoints a trusted person to speak on her behalf when she has lost the capacity to do so.¹⁸ Without drafting documents, a person instead could verbally instruct her family or friends about those treatment preferences, appoint one or more of them to carry out her wishes, or both. This article focuses specifically on patients who have executed written advance directives, leaving similar issues faced by those who have not done so for another day.¹⁹

11. MEISEL ET AL., *supra* note 1 § 7.02[B], at 7-22.

12. *Id.* (“An advance directive goes into effect not only at a future time . . . but also only if the patient has lost the capacity to make a decision about treatment at that time”); *see also id.* § 7.06[A][1]. *But see* FLA. STAT. § 765.202(6) (permitting patient to assign power to a surrogate to exercise while patient still retains capacity).

13. MEISEL ET AL., *supra* note 1 § 7.01[B][1], at 7-8.

14. *See In re Browning v. Herbert*, 568 So. 2d 4, 16 (Fla. 1990) (“[A] written declaration or designation of proxy, in the absence of any evidence of intent to the contrary, establishes a rebuttable presumption that constitutes clear and convincing evidence of the patient’s wishes”).

15. Kathy L. Cerminara, *An Analysis of H.701*, University of Miami Ethics Programs 4 (Feb. 25, 2005), <https://umshare.miami.edu/web/wda/ethics/documents/schivao/030805-HB701-Legal Analysis.pdf>.

16. *See, e.g.*, MEISEL ET AL., *supra* note 1 § 7.01[B][3]–[4]. It is also possible to combine both types of advance directives into one document. *Id.* § 7.01[B][7].

17. *Id.* § 7.01[B][3].

18. *Id.* § 7.01[B][4].

19. Those people who have executed written advance directives, after all, have done all that medical providers and lawyers can suggest to assure that their future care proceeds in accordance

B. Statutory Limitations and Their Purposes

Importantly for purposes of this article, in addition to requiring incapacity before advance directives become effective, many state statutes include language requiring that a patient be in a particular physical state as a condition precedent to operation of an advance directive.²⁰ For example, Missouri statutes provide that a living will becomes operative only when the patient is in a “terminal condition.”²¹ The Pennsylvania statute states that a living will is effective when a patient is in an “end-stage medical condition” or “permanently unconscious.”²² The Florida Legislature has specified three physical triggering conditions: (1) “terminal condition,” (2) “end-stage condition,” and (3) “persistent vegetative state.”²³

with their wishes. A written advance directive is not required to refuse treatment, and in fact those with written advance directives are far from a majority of Americans. Jaya K. Rao et al., *Completion of Advance Directives Among U.S. Consumers*, 46(1) AM. J. PREV. MED. 65, 68 (2014) (reporting that only 26.3 percent of almost 8,000 U.S. adults surveyed nationwide in 2009 and 2010 had advance directives). The group of individuals not likely to have an advance directive, however, is the population most disadvantaged by faulty drafting of advance directive statutes. *See id.* at 68–69.

20. *See generally* MEISEL ET AL., *supra* note 1 § 7.02[C] (“Under many statutes, advance directives are not effective unless the patient is in a terminal condition or permanently unconscious . . .”). *See also* Parker & Goldberg, *supra* note 7, at 15–16.

21. MO. REV. STAT. § 459.025 (2000). Missouri defines a “terminal condition” as being “an incurable or irreversible condition which, in the opinion of the attending physician, is such that death will occur within a short time regardless of the application of medical procedures.” *Id.* § 459.010(6).

22. 20 PA. CONS. STAT. § 5443(a) (2012). In Pennsylvania, an “end-stage medical condition” is:

An incurable and irreversible medical condition in an advanced state caused by injury, disease or physical illness that will, in the opinion of the attending physician to a reasonable degree of medical certainty, result in death, despite the introduction or continuation of medical treatment. Except as specifically set forth in an advance health care directive, the term is not intended to preclude treatment of a disease, illness or physical, mental, cognitive or intellectual condition, even if incurable and irreversible and regardless of severity, if both of the following apply:

- (1) The patient would benefit from the medical treatment, including palliative care.
- (2) Such treatment would not merely prolong the process of dying.

Id. § 5422. A patient is “permanently unconscious” when:

A medical condition that has been diagnosed in accordance with currently accepted medical standards and with reasonable medical certainty as total and irreversible loss of consciousness and capacity for interaction with the environment. The term includes, without limitation, an irreversible vegetative state or irreversible coma. *Id.*

23. FLA. STAT. § 765.302(1) (2016). Florida defines a “terminal condition” as “a condition caused by injury, disease, or illness from which there is no reasonable medical probability of recovery and which, without treatment, can be expected to cause death;” an “end-stage condition” as “an irreversible condition that is caused by injury, disease, or illness which has resulted in progressively severe and permanent deterioration, and which, to a reasonable degree of medical

Such statutory physical triggering conditions can add an extra layer of complexity to some patients' end-of-life care. On one hand, statutory forms incorporating those physical triggering conditions restrict application to only some patients.²⁴ On the other hand, a patient's advance directive can differ from the terms of her state's statute; such differences are common and the advance directive perfectly valid in some, if not all, states because advance directive statutes are not the source of the right to refuse treatment. They merely facilitate the exercise of pre-existing common-law and constitutional rights to do so.²⁵ Some state statutes even explicitly remind citizens of the validity of advance directives other than those created by completing statutory advance directive forms.²⁶ Some non-statutory directives incorporate different physical triggering conditions, while others do not name particular physical conditions at all. Some may include physical triggering conditions but internally define those triggering conditions differently from the way the applicable statute defines them. In such a case, the issue becomes whether medical professionals should follow the patient's stated wishes or still should require that the patient meet the legal definition of one of the state's physical triggering conditions because the statute requires that condition be present for the statutory advance directive to take effect.²⁷

As a result, it is possible for a patient in Florida to have a valid living will that simply provides that she wants "to refuse any and all efforts to artificially prolong her life," without including any physical triggering conditions at all.²⁸ It is also possible for a Jehovah's Witness to have a valid living will saying

probability, treatment of the condition would be ineffective;" and a "persistent vegetative state" "a permanent and irreversible condition of unconsciousness in which there is: (a) the absence of voluntary action or cognitive behavior of any kind; [and] (b) an inability to communicate or interact purposefully with the environment." *Id.* § 765.101(22), (4), (15).

24. *See, e.g.,* LOIS SHEPHERD, IF THAT EVER HAPPENS TO ME: MAKING LIFE AND DEATH DECISIONS AFTER TERRI SCHIAVO 135 (2009) ("The Florida form would not cover a person in a minimally conscious state or a person who was profoundly disabled.").

25. *See* MEISEL ET AL., *supra* note 1 § 7.01[B][8], at 7–15 ("An advance directive need not necessarily be drafted in accordance with a statute."). MEISEL ET AL., *supra* note 1, § 7.03[B][2]–[3] (such "[n]onstatutory advance directives should be presumed to be valid even in a jurisdiction that has enacted advance directive legislation").

26. *See, e.g.,* FLA. STAT. §§ 765.203, 765.303 (2016) (both stating that the statute's forms "may, but need not," be used).

27. *See* Parker & Goldberg, *supra* note 7, at 28, 29 (terming this a conflict between bioethics and risk management).

28. *Cf. In re Browning v. Herbert*, 568 So. 2d 4, 16 (Fla. 1990). In *Browning*, the Florida Supreme Court explained that under the Florida Constitution, the only "viable challenges to her guardian's decision to implement those wishes would have included:" she changed her mind; she executed the document under conditions that invalidated it; or she reasonably could regain competency. Other evidence, including evidence that she did not meet a statutory physical triggering condition "generally would have been irrelevant to the only issue to be decided—the patient's wishes." *Id.* at 16–17.

that he “absolutely, unequivocally, and vehemently” refuses blood transfusions “under any circumstances, regardless of [his] health condition,”²⁹ although the applicable statute includes two physical triggering conditions.³⁰ In these circumstances, the bioethics response to the question of whether caregivers should forego treatment in accordance with the patients’ wishes would be affirmative, but risk management’s response likely would be resoundingly negative.³¹

In other words, the very statutes intended to facilitate patients’ obtaining the care they wish, and no more care than they wish, thwart the efforts of those who have done all that their lawyers and doctors have advised them to do to memorialize instructions for end-of-life care after their incapacity.

III. INCORPORATING ETHICS TERMINOLOGY INSTEAD OF PHYSICAL TRIGGERING CONDITIONS INTO STATE STATUTES TO BETTER EFFECTUATE PATIENT WISHES

Such physical triggering conditions have multiple purposes. The presence of a written advance directive with a patient who satisfies at least one of the statutory physical triggering conditions incorporated within it serves as an assurance of legality when satisfied.³² If a patient exists in a condition specified in the statute, then physicians and other health care professionals involved in withholding or withdrawing care at the end of life have a shield against liability and potential administrative sanction.³³ Going one step further, one could view statutory physical triggering conditions as “demarcat[ing] a line between legal and illegal activities,”³⁴ thus similarly providing a shield against liability, this time criminal rather than civil.

Importantly, a patient’s failure to exist in one of the statutory physical triggering conditions does not imply that treatment must begin or be continued.

Because most statutes state that they are not intended to preempt common law rights, the failure of a particular patient to fit these definitions does not necessarily mean that life-sustaining treatment may not be forgone, but only that it may not be forgone pursuant to an advance directive drafted in conformance with the statute.³⁵

29. See *Lozada Tirado v. Flecha*, 2010 WL 446020, at *1 (P.R. Offic. Trans. 2010).

30. Puerto Rico’s statute provides that a living will is enforceable only when the patient is in a terminal health condition (also referred to as a *terminal illness* or a *persistent vegetative state*). *Lozada*, 2010 WL 446020, at *3 (recapping the holding of the Puerto Rican Court of Appeals).

31. See generally *Parker & Goldberg*, *supra* note 7, at 19–20; see also Samuel W. Wardle, *The Advance Directive Statute Revisited*, 67 U. MIAMI L. REV. 861, 889 (2013).

32. See MEISEL ET AL., *supra* note 1 § 7.02, at 7-27.

33. See *id.*

34. *Parker & Goldberg*, *supra* note 7, at 12 n.1.

35. MEISEL ET AL., *supra* note 1 § 7.06[A][4], at 7-90.

Such a patient's failure to meet one of the triggering conditions, however, does mean that withholding or withdrawal of treatment is problematic for facility risk-management personnel and some risk-adverse physicians.³⁶

Underlying the inclusion of physical triggering conditions in statutes are valid and important state interests in preserving life and protecting the vulnerable.³⁷ It is easy to understand the perceived threat of a slippery slope if a legislature overtly approves withholding or withdrawing of life-sustaining treatment from incapacitated patients in any physical condition.³⁸ Some persons with disabilities, given historical discrimination against and lack of understanding of that state of being, would be especially concerned.³⁹ Some elderly persons and members of some racial and ethnic minority groups may have similar concerns.⁴⁰

36. See generally Parker & Goldberg, *supra* note 7, at 28 (terming this a conflict between ethics and risk management). Until recently, the American Medical Association (AMA) Council on Ethics and Judicial Affairs (CEJA) explicitly advised AMA members that while other documentation of end-of-life wishes can be legally valid, “[s]tatutory documents give physicians immunity from malpractice for following a patient’s wishes.” AM. MED. ASS’N COUNCIL ON ETHICAL & JUD. AFFS., CODE OF MED. ETHICS: CURRENT OPINIONS WITH ANNOTATIONS 96 (2002). As of June 2016, the AMA CEJA revised that opinion to omit references to obtaining immunity through statutory advance directive documents. Compare *id.*, with AM. MED. ASS’N COUNCIL ON ETHICAL & JUD. AFFS., CODE OF MED. ETHICS: CURRENT OPINIONS WITH ANNOTATIONS § 5.2 (2016). The revision, however, was intended to “comprehensively review, update and re-organize guidance to ensure that the Code remains a timely, easy to use resource,” rather than to memorialize major substantive change. *Am. Med. Ass’n Code of Medical Ethics*, AM. MED. ASS’N, <http://www.ama-assn.org/ama/pub/physician-resources/medical-ethics/code-medical-ethics.page> (last visited Aug. 30, 2016). Some physicians may not realize for quite a while that the CEJA’s opinions no longer reference immunity from malpractice stemming from compliance with statutory advance directive documents. See also Wardle, *supra* note 31, at 873.

37. See Parker & Goldberg, *supra* note 7, at 13 (arguing that the varying triggering conditions in different states in part reflect the underlying values of the state).

38. U.S. DEP’T OF HEALTH AND HUMAN SERVS., OFFICE OF DISABILITY, AGING, AND LONG-TERM CARE POL’Y, ADVANCE DIRECTIVES AND ADVANCE CARE PLANNING FOR PEOPLE WITH INTELLECTUAL DISABILITIES 9–10 (2007) (quoting advocacy groups arguing that “[t]he courts, the political system and the general public must not allow policy to develop that will devalue any individual, no matter what the extent of that individual’s disability or incapacity”).

39. See *id.* at 7–10 (recounting data regarding discrimination and lack of understanding). See also *id.* at 17 (referencing that there are:

- overriding concerns about under-treatment for serious medical conditions due to:
 - devaluation of and lack of respect for the lives of people with disabilities;
 - negative attitudes of health care professionals and the public, including overly pessimistic perceptions of quality of life and misconceptions about life satisfaction; and
 - lack of access to care and services based on discrimination, cost concerns, and environmental barriers.)

40. Both the elderly and African Americans can point to such a history of discrimination. In the 1980s, then-Governor Richard D. Lamm of Colorado famously stated that elderly people with terminal illnesses had a “duty to die and get out of the way” rather than undergo life-prolonging treatment. See *Gov. Lamm Asserts Elderly, if Very Ill, Have ‘Duty to Die,’* N.Y. TIMES (Mar. 29,

Despite the validity of such concerns, states can do much better in terms of honoring the autonomous decisions of those who have executed advance directives. People who have done what they believed necessary to ensure that their wishes govern once they are incapacitated should be able to rely on their wishes governing. Instead, advance directive statutes that incorporate one or more physical states as conditions precedent to the documents' taking effect can undermine patient autonomy. Legislatures may impose conditions as reflections of their states' values⁴¹ and in the service of their states' interests,⁴² but they should use ethics terminology instead of diagnostic or prognostic terms to do so because the intended limitation of advance directives to persons in certain physical conditions is unconstitutional.⁴³ Moreover, using physical triggering conditions to represent the edge of the slippery slope is unrealistic, ethically problematic, and vague. States should eliminate them, substituting language focusing on patient goals and values to better reconcile the law with medical ethics.

A. *The Unconstitutionality of Specified Physical Triggering Conditions as Limitations on the Exercise of the Right to Refuse Life-Sustaining Treatment*

Any discussion of unconstitutionality must, of course, begin with the identification of a constitutional right. Thereafter, depending on the strength of the right in question, the argument must switch to consideration of the strength of the interests the state is seeking to advance with its regulation of that right.

1. Fundamental Constitutional Rights Are at Stake

A competent person—a person with decision-making capacity⁴⁴—has a liberty interest in directing withholding or withdrawing life-sustaining care

1984), <http://www.nytimes.com/1984/03/29/us/gov-lamm-asserts-elderly-if-very-ill-have-duty-to-die.html>. Medical exploitation of African Americans began long before the famed Tuskegee Syphilis Study. See generally Vanessa Northington Gamble, *Under the Shadow of Tuskegee: African Americans and Health Care*, 87 AM. J. PUB. HEALTH 1773, 1773–78 (1997).

41. Parker & Goldberg, *supra* note 7, at 13.

42. See Wardle, *supra* note 31, at 881.

43. MEISEL ET AL., *supra* note 1 § 7.06[A][4], providing:

Because most statutes state that they are not intended to preempt common law rights, the failure of a particular patient to fit these definitions does not necessarily mean that life-sustaining treatment may not be forgone but only that it may not be forgone pursuant to an advance directive drafted in accordance with the statute. Careful drafting of advance directives might avoid these statutory limitations.

44. Although some contexts require specification of whether a patient merely lacks some capacity or is fully incompetent, in this setting, both terms are used to describe “those individuals unable to make medical decisions on their own behalf.” Kathy L. Cerminara, *The Law and Its Interaction with Medical Ethics in End-of-Life Decision Making*, 140 CHEST 775, 778 (2011); *In re Browning v. Herbert*, 568 So. 2d 4, 12 n. 9 (Fla. 1990).

under the Federal Constitution.⁴⁵ The United States (U.S.) Supreme Court in *Cruzan v. Director, Missouri Department of Health* acknowledged that “[t]he principle that a competent person has a constitutionally protected liberty interest in refusing unwanted medical treatment may be inferred from our prior decisions.”⁴⁶ Justice O’Connor, concurring, agreed and expanded upon that statement: “Because our notions of liberty are inextricably entwined with our idea of physical freedom and self-determination, the Court has often deemed state incursions into the body repugnant to the interests protected by the Due Process Clause.”⁴⁷

Crucially, *Cruzan* did not involve a patient with decision-making capacity (a competent patient). Nancy Beth Cruzan was not competent to make her own medical decisions, as she had lain in a vegetative state for years after an automobile accident that left her without oxygen for at least twelve minutes.⁴⁸ Against that backdrop, having assumed the existence of a competent patient’s constitutional right, the Court in *Cruzan* addressed petitioners’ argument that “an incompetent person [Nancy] should have the same right [to refuse life-sustaining treatment] as is possessed by a competent person.”⁴⁹ The Court neither agreed nor disagreed. Instead, it conflated the existence of the right with the ability to exercise the right, saying:

The difficulty with petitioners’ claim is that in a sense it begs the question: An incompetent person is not able *to make an informed and voluntary choice* to exercise a hypothetical right to refuse treatment or any other right. Such a ‘right’ must be exercised for her, if at all, by some sort of surrogate.⁵⁰

45. *Cruzan v. Dir., Mo. Dep’t of Health*, 497 U.S. 261, 279 n. 7 (1990) (distinguishing liberty interest from the right of privacy).

46. *Id.* at 279. The Court then said:

Although we think the logic of the cases discussed above would embrace such a liberty interest, the dramatic consequences involved in refusal of such treatment would inform the inquiry as to whether the deprivation of that interest is constitutionally permissible. But for purposes of this case, we assume that the United States Constitution would grant a *competent* person a constitutionally protected right to refuse life-saving hydration and nutrition.

Id. (emphasis added). The Court in *Glucksberg* later described this statement as “assum[ing] and strongly suggest[ing]” the existence of such a right. *Washington v. Glucksberg*, 521 U.S. 702, 720 (1997).

47. *Cruzan*, 497 U.S. at 287 (O’Connor, J., concurring). After explaining that medically supplied nutrition and hydration implicated “identical concerns” as other forms of medical treatment, O’Connor added that “the liberty guaranteed by the Due Process Clause must protect, if it protects anything, an individual’s deeply personal decision to reject medical treatment, including the artificial delivery of food and water.” *Id.* at 288–89.

48. *Id.* at 266 (majority opinion).

49. *Id.* at 279.

50. *Id.* at 280 (emphasis added).

Dissecting the Court's conflation is important, for it demonstrates the difference between the facts at issue in *Cruzan* and the focus of this article. It was inaccurate to see Nancy Cruzan as not having made a choice because she had left behind oral advance directives, which her parents were attempting to honor.⁵¹ But thinking carefully about the emphasized language leads to the conclusion that the Court believed that a person without a written advance directive (like Nancy) had in fact not yet made a choice regarding end-of-life treatment. To maintain its focus on those who have executed written advance directives, this article will not challenge that belief, although it seems inconceivable that all of the millions of Americans lacking written advance directives have failed to make decisions about their end-of-life preferences.⁵²

Rather, the importance of the assumption reflected in the emphasized language is that in contrast to the class of incompetent patients before the Court in *Cruzan*, there exists no rational argument that the class of incompetent patients at issue in this article, those who have written advance directives, have failed to make their own choices regarding end-of-life care. As noted earlier, advance directives are intended to memorialize a choice a patient *has already made* to facilitate the fulfillment of her previously determined wishes.⁵³ Patients with written advance directives, who are the only patients at issue in this article, have already chosen when they were competent, and they have memorialized their decisions for others to implement.⁵⁴ Such a patient had the constitutional right to make the anticipatory choice when she made it, and now the surrogate decision maker's job is to implement the patient's decision.

Indeed, the *Cruzan* Court noted that it did not face "the question whether a [s]tate might be required to defer to the decision of a surrogate if competent and probative evidence established that the patient herself had expressed a desire that the decision to terminate life-sustaining treatment be made for her by that individual."⁵⁵ Justice O'Connor, in concurrence, went one step further,

51. *Cruzan*, 497 U.S. at 268.

52. See INST. OF MED. OF THE NAT'L ACADS., DYING IN AMERICA: IMPROVING QUALITY AND HONORING INDIVIDUAL PREFERENCES NEAR THE END OF LIFE 125, 126 (2014). The data set forth in that groundbreaking report, in fact, demonstrated that many more Americans had discussed care preferences with loved ones than had executed advance directives. *Id.* at 127 tbl. 3-1; see also *Lozada Tirado v. Flecha*, 2010 WL 446020, at *11 (P.R. Offic. Trans. 2010) (a surrogate is "an *additional* instrument to guarantee that a patient's wish to accept or refuse medical treatment is respected even when he or she is unconscious") (emphasis added).

53. See *supra* Part I.

54. The question is not about whether a right exists, but about "who will exercise this right and what parameters will limit them in the exercise of this right." *In re Browning v. Herbert*, 568 So. 2d 4, 12 (Fla. 1990); see also *id.* at 13 (holding that because Mrs. Browning was unable to exercise her constitutional right, her guardian could do that for her).

55. *Cruzan*, 497 U.S. at 287 n. 12. The Court later explained:

In this Court, the question is simply and starkly whether the United States Constitution prohibits Missouri from choosing the rule of decision which it did. This is

explaining: “I . . . write separately to emphasize that the Court does not today decide the issue whether a [s]tate must also give effect to the decisions of a surrogate decisionmaker. In my view, such a duty may well be constitutionally required to protect the patient’s liberty interest in refusing medical treatment.”⁵⁶ Thus, she said, *Cruzan* “does not preclude a future determination that the Constitution requires the States to implement the decisions of a patient’s duly appointed surrogate.”⁵⁷

Justice O’Connor and the Court appear to be discussing proxy directives in these quotations. Recall that advance directives can either leave instructions, appoint someone to act for the patient after she has lost decision-making capacity, or both.⁵⁸ Either way, the patient with an advance directive has already made a decision about her end-of-life treatment choices; she may have decided what she wanted and did not want and left instructions to that effect, or she may have decided whom she trusted to speak for her after she lost capacity and provided that person’s name for others. She also may have done both in one document.⁵⁹ She has already made important end-of-life choices, choices she had a constitutional liberty interest in making and having carried out.

Moreover, the patient’s right to so decide is fundamental. Since addressing the liberty interest in end-of-life decision making in two important cases in the 1990s,⁶⁰ the U.S. Supreme Court has interpreted the same right, the Due Process interest in liberty, in an expansive way in a series of decisions relating to sexual relationships and marriage.⁶¹ A patient’s interests in bodily control and the ability to safeguard her dignity through end-of-life decision making are at least as important as the decision to marry. These interests closely resemble decision making about “procreation, contraception, family relationships, child rearing, and education.”⁶² Like those matters, the question of when a patient believes her life support should be withheld or withdrawn

the first case in which we have been squarely presented with the issue whether the United States Constitution grants what is in common parlance referred to as a “right to die.” *We follow the judicious counsel of our decision [citation omitted], where we said that in deciding “a question of such magnitude and importance . . . it is the [better] part of wisdom not to attempt, by any general statement, to cover every possible phase of the subject.”*

Id. at 277–78 (emphasis added).

56. *Id.* at 289 (O’Connor, J., concurring) (citation omitted).

57. *Id.* at 292.

58. *See supra* Part I.A.

59. *See id.*

60. *See generally* *Glucksberg v. Washington*, 521 U.S. 702 (1997); *Cruzan*, 497 U.S. at 266 (majority opinion).

61. *See generally* *Obergefell v. Hodges*, No. 14-556, slip op. at 2 (2015) (gay marriage); *U.S. v. Windsor*, No. 12-307, slip op. at 1 (2013) (sexual relations between persons of the same gender).

62. *Planned Parenthood of Se. Penn. v. Casey*, 505 U.S. 833, 851 (1992).

involve[es] the most intimate and personal choices a person may make in a lifetime, choices central to personal dignity and autonomy, are central to the liberty protected by the Fourteenth Amendment. At the heart of liberty is the right to define one's own concept of existence, of meaning, of the universe, and of the mystery of human life. Beliefs about these matters could not define the attributes of personhood were they formed under compulsion of the State.⁶³

Moreover, "as patients are likely to select a family member as a surrogate, . . . giving effect to a proxy's decisions may also protect the 'freedom of personal choice in matters of . . . family life.'"⁶⁴ As the Court recently explained in *Obergefell v. Hodges*, the Constitution extends beyond the enumerated rights in the Bill of Rights to guarantee these types of choices: "personal choices central to individual dignity and autonomy, including intimate choices that define personal identity and beliefs."⁶⁵ Thus, liberty is more than mere freedom from physical restraint, although that freedom certainly is an important part of the interest.⁶⁶ Both the liberty of choice and the liberty of avoiding physical restraint play important roles in the end-of-life care of those stricken with serious illness.

One may argue that the Constitution protects warring rights in these situations—that due process seems to be at odds with itself in these cases because the liberty to refuse treatment will ultimately result in loss of life. At the root of liberty, however, is "the right to define one's own concept of existence, of meaning, of the universe, and of the mystery of human life."⁶⁷ The refusal of life-prolonging treatment, which intrudes upon a patient's bodily integrity, permits a patient to both determine the boundaries of her existence and free herself from physical restraint in the form of that treatment. In that setting, an unduly expansive view of the right to life can diminish the right to liberty to a level below that which is constitutionally guaranteed.

63. *Id.*

64. *Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261, 292 (1990) (O'Connor, J., concurring) (citation omitted); *see also id.* at 341 (Stevens, J., dissenting) (noting that dying traditionally takes place at home, as part of a fundamental and "private realm of family life which the state cannot enter," and as an incident of "liberty to make the decisions and choices constitutive of private life"); *id.* at 341 n. 12, 344 (referencing a "special relationship between the patient and the physician" and an interest in how others will think of oneself after death).

65. *Obergefell*, No. 14-556, slip op. at 10.

66. Charles E. Shattuck, *The True Meaning of the Term "Liberty" in Those Clauses in the Federal and State Constitutions Which Protect "Life, Liberty, and Property,"* 4 HARV. L. REV. 365, 382 (1890).

67. *Planned Parenthood v. Casey*, 505 U.S. 833, 851 (1992). *Cf. Lawrence v. Texas*, 539 U.S. 244, 278 (2003) (holding that "[t]he State cannot demean [gays' and lesbians'] existence or control their destiny by making their private sexual conduct a crime"), relied upon in *Obergefell*, No. 14-556, slip op. at 22.

The *Obergefell* Court instructed:

The identification and protection of fundamental rights is an enduring part of the judicial duty to interpret the Constitution. That responsibility, however, ‘has not been reduced to any formula.’ Rather, it requires courts to exercise reasoned judgment in identifying interests of the person so fundamental that the State must accord them its respect . . . History and tradition guide and discipline this inquiry but do not set its outer boundaries.⁶⁸

The depth and breadth of liberty protected by *Obergefell* and the approach the Court used to identify a fundamental right in that case demonstrate that the right to refuse life-sustaining medical treatment is located firmly within the range of “interests of the person so fundamental that the State must accord them its respect.”⁶⁹ Not only does that right have a strong and long history of respect,⁷⁰ but it also displays “essential attributes . . . based in history, tradition, and other constitutional liberties inherent” within it.⁷¹

Part of the history and tradition of the fundamental federal constitutional right to refuse life-prolonging treatment is a long legal history of state constitutional protection of that same right. While not the focus of this article, state constitutional law, in addition to revealing a historical basis for the federal constitutional right, separately provides a strong weapon to use in guarding against the use of physical triggering conditions in state advance directive statutes to thwart patients’ wishes. Some state constitutions are more clear and expansive in their constitutional protection of liberty interests as a substantive due process matter than the U.S. Supreme Court has interpreted the Federal Constitution to be.

In 2010, for example, the Supreme Court of Puerto Rico ruled that physical triggering conditions in Puerto Rico’s living will statute were unconstitutional under the Puerto Rican and the U.S. Constitutions.⁷² The Puerto Rican Constitution, according to that court, “enshrines the cardinal principle of the inviolability of human dignity.”⁷³ It also “recognizes the right to privacy and the right to the protection of law against abusive attacks on the honor,

68. *Obergefell*, No. 14-556, slip op. at 10 (citation omitted).

69. *Id.* at 10–11.

70. See *Cruzan v. Dir., Mo. Dep’t of Health*, 497 U.S. 261, 269–77 (1990) (discussing lengthy legal history of support for the right to refuse treatment).

71. *Obergefell*, No. 14-556, slip op. at 12.

72. See *Lozada Tirado v. Flecha*, 2010 WL 446020, at *5 (P.R. Offic. Trans. 2010). Although technically not a state, Puerto Rico is analogous to a state in the sense of the relationship between its constitution and the Federal Constitution. T. Alexander Aleinikoff, *Puerto Rico and the Constitution: Conundrums and Prospects*, 11 CONST. COMMENT. 15, 24–27 (1994).

73. See *Lozada*, 2010 WL 446020, at *2 (describing article II, section I of the Puerto Rican Constitution).

reputation, and private or family life as fundamental rights.”⁷⁴ State action is not required; “the right to privacy imposes on every person the duty to refrain from interfering with the private or family life of other human beings.”⁷⁵ The Puerto Rican Constitution is also infringed “when, among other circumstances, limitations are placed on an individual’s faculty to make personal, family, or private decisions.”⁷⁶

Those rights are so strong in the Puerto Rican Constitution that the Puerto Rican Supreme Court has held they not only prevent the state “from acting in a manner that violates the scope of individual freedom and privacy” but also require the state to “take positive action in [sic] behalf of the individual.”⁷⁷ This may be due to civil law influence in Puerto Rico’s history,⁷⁸ but it is also another example of the general proposition that state constitutional rights can be broader than federal constitutional rights.⁷⁹

States without civil law traditions also have constitutions that are broader than the Federal Constitution with respect to decisional privacy or liberty. Article I, Section 23 of the Florida Constitution, for example, provides: “Every natural person has the right to be let alone and free from governmental intrusion into [the person’s] private life except as otherwise provided herein.”⁸⁰ The Florida Supreme Court has explained:

[T]he concept of privacy encompasses much more than the right to control the disclosure of information about oneself. “Privacy” has been used interchangeably with the common understanding of the notion of “liberty, and both imply a fundamental right to self-determination subject only to the state’s compelling and overriding interest.”⁸¹

Recognizing that individuals’ rights to physical and psychological freedom from coercion in decision making are “deeply rooted in our nation’s philosophical and political heritage,”⁸² that court has held: “We can conceive of few more personal or private decisions concerning one’s body that one can

74. *Id.* at *5.

75. *Id.*

76. *Id.*

77. *Id.*

78. See Helen Hershkoff & Stephen Loffredo, *State Courts and Constitutional Socio-Economic Rights: Exploring the Underutilization Thesis*, 115 PENN ST. L. REV. 923 (2011) (addressing the implications of jurisdictions strongly influenced by civil law such as Puerto Rico).

79. See *id.* at 927–30 (addressing states’ incorporation of socio-economic rights that are not traditionally provided at the federal level, thus indicating states’ constitutions providing broader rights than that of the Federal Constitution).

80. FLA. CONST. art. I, § 23.

81. *In re Browning v. Herbert*, 568 So. 2d 4, 9–10 (Fla. 1990).

82. *Id.* at 10.

make in the course of a lifetime . . . [than] the decision of the terminally ill in their choice of whether to discontinue necessary medical treatment.”⁸³

2. State Interests Underlying the Specification of Physical Triggering Conditions

A state may, of course, only limit the exercise of a fundamental constitutional right if the limitations it imposes serve one or more compelling state interests and are “narrowly tailored” to serve that interest or those interests.⁸⁴ In *Cruzan*, only one state interest was at issue: the state’s interest in the preservation of life.⁸⁵ By announcing that Missouri could rightfully assert an “unqualified interest” in protecting life, not just an interest in protecting life of a certain sapience, the *Cruzan* Court implied that the state interest in preservation of life can be compelling even if the life of the patient in question consists of only heartbeat and respiration.⁸⁶ Yet, while a state interest can be compelling, it cannot be absolute. Life and liberty must ultimately balance, without reducing decision-making freedom to an unacceptably low level.

The *Cruzan* Court viewed the requirement that the petitioners produce clear and convincing evidence of the patient’s stated desire to refuse that particular treatment under those particular circumstances as “a procedural safeguard to assure that the action of the surrogate conforms as best it may to the wishes expressed by the patient while competent.”⁸⁷ It decided that Missouri had not violated the Constitution by imposing a heavy burden of proof because “[t]he choice between life and death is a deeply personal decision of obvious and overwhelming finality. We believe Missouri may legitimately seek to safeguard the personal element of this choice through the imposition of heightened evidentiary requirements.”⁸⁸ In other words, Missouri could impose evidentiary hurdles in the name of ensuring that the decision to withhold or withdraw treatment was in fact the patient’s own decision, in a

83. *Id.* (quoting *In re T.W.*, 551 So. 2d 1186, 1192 (Fla. 1989)).

84. *Id.* at 14.

85. *Cruzan v. Dir., Mo. Dep’t of Health*, 497 U.S. 261, 313 (1990)

86. Compare *Cruzan*, 497 U.S. at 282 (stating that the state interest in life can be compelling in patient’s in any health) with *In re Quinlan*, 355 A.2d 647, 664 (N.J. 1976) (ruling that the state’s interest waned “as the degree of bodily invasion increases and the prognosis dims”).

87. *Cruzan*, 497 U.S. at 280.

88. *Id.* at 281. Specifically, the court held that Missouri could decide such protections were necessary to: (1) ensure that patients are being abused by the decision-maker through removal or withholding of treatment, (2) make up for the fact that the judicial proceeding approving the withdrawal/withholding might not be adversarial, and (3) preserve life, in which it could assert an “unqualified interest,” not one that wanes when the patient gets sicker and the bodily invasion grows. *Id.* at 281–82. These are all state choices, within the state’s power. But they are not required; they are merely permissible. *Id.*; see also *id.* at 309 (Brennan, J., dissenting) (“As the majority recognizes, [citation omitted], the question is not whether an incompetent has constitutional rights, but how such rights may be exercised.”).

case in which the patient had not appointed her own surrogate. If a patient with capacity makes the decision before losing capacity, however, fewer safeguards are necessary. Physical triggering conditions are not necessary; what is necessary is an inquiry into whether there is evidence that the patient's previous choice should not apply to the facts at hand. As the Florida Supreme Court has stated regarding that state's constitutional right: "A competent individual has the constitutional right to refuse medical treatment regardless of his or her medical condition."⁸⁹

States also have interests in protecting vulnerable populations.⁹⁰ The *Cruzan* Court did not discuss such populations specifically as it acknowledged a state interest in "legitimately seek[ing] to safeguard the personal element of this choice."⁹¹ It did, however, explicitly recognize a state interest in protecting patients with no family members or friends to speak for them and those with family members who do not have their best interests at heart, especially in the medical decision-making setting, which is not always (or even often) adversarial.⁹² A few years later, in a different end-of-life decision-making context, the Court more specifically described populations that states may wish to protect as "including the poor, the elderly, and disabled persons."⁹³ There, it agreed that a state statute prohibiting physician aid in dying⁹⁴ could serve an interest in protecting such "disadvantaged persons" from being coerced into making certain end-of-life decisions.⁹⁵ For the sake of completeness, although criminal statutes prohibiting physician aid in dying differ greatly from civil statutes permitting citizens to memorialize their end-of-life treatment wishes, this article will consider all of those groups because both types of statutes relate to medical decisions about the end of life.

In advance directive statutes, physical triggering conditions are intended to serve as fences, preventing a tumble down the slippery slope. If only those who satisfy the triggering conditions may have life-sustaining treatment withheld or withdrawn, then the reasoning goes that there is no risk that persons in other

89. *In re Browning*, 568 So. 2d at 10; see also Wardle, *supra* note 31, at 869 n. 7 (arguing that Florida's statute is unconstitutional under *Browning* for this reason).

90. Cf. *Washington v. Glucksberg*, 521 U.S. 702, 721 (discussing a different context, physician aid-in-dying).

91. *Cruzan*, 497 U.S. at 281.

92. *Id.*

93. *Glucksberg*, 521 U.S. at 731. Deciding a withholding/withdrawal case, the Florida Supreme Court in *Browning* seemed to address this interest when it addressed the "'very legitimate concern' that the 'right to die' could become a license to kill." *In re Browning*, 568 So. 2d at 13 (quoting the District Court of Appeals, 543 So.2d 258, 269 (1989)).

94. "With aid in dying, a physician writes a prescription for life-ending medication for an eligible patient." David Orentlicher et al., *The Changing Legal Landscape of Aid in Dying*, 311 JAMA 1961, 1961 (2014). The American Public Health Association recommends use of the term *aid in dying* rather than the term "assisted suicide." *Id.*

95. *Glucksberg*, 521 U.S. at 731–32.

conditions, especially those society undervalues, will have their life-sustaining treatment withheld or withdrawn against their wishes.⁹⁶

Concern about the slippery slope is especially important in light of the disability critique of mainstream bioethics and law.⁹⁷ History provides ample evidence that persons with disabilities, like those of other minority groups, have experienced discrimination. Just as African Americans may respond, even if subconsciously, to a collective memory of Tuskegee with present-day mistrust of the medical system,⁹⁸ so too may persons with disabilities feel the legacy of past mistreatment in Nazi Germany's Action T4 when anticipating how today's medical decision-making laws will affect them.⁹⁹ (The concerns do not differ fundamentally from those motivating federal regulations governing treatment of infants born under a certain weight (the so-called "Baby Doe" regulations).¹⁰⁰ To the extent that persons with disabilities perceive mainstream bioethics and most lawmakers as harboring such prejudices against them, the presence of physical triggering conditions—requiring that a patient be in one of a few physical states—is assurance that

96. Cf. Orentlicher et al., *supra* note 94, at 1962 (explaining that the term "grim prognosis" in the Karen Ann Quinlan case was not specific enough to quell fears that assumptions would be made about a person's quality of life in making end-of-life decisions).

97. Parker & Goldberg, *supra* note 7, at 26; see also ALICIA OUELLETTE, *BIOETHICS AND DISABILITY: TOWARD A DISABILITY-CONSCIOUS BIOETHICS* 297–98 (2011); *A Statement of Common Principles on Life-Sustaining Care and Treatment of People with Disabilities*, SYRACUSE UNIV. CTR. ON HUM. POL'Y, <http://thechp.syr.edu/resources/position-statements/life-sustaining-care/> (last visited Aug. 26, 2016); cf. Paul K. Longmore, *Elizabeth Bouvia, Assisted Suicide and Social Prejudice*, 3 *ISSUES IN L. & MED.* 141, 167 (1987).

98. In the Tuskegee Syphilis Study, United States governmental public health researchers followed the course of syphilis among a population of African American men without providing treatment even after effective treatment was available, and under the guise of providing treatment. See FRED D. GRAY, *THE TUSKEGEE SYPHILIS STUDY: THE REAL STORY AND BEYOND* 24 (1998); STEPHEN B. THOMAS & SANDRA CROUSE, *TUSKEGEE'S TRUTH: RETHINKING THE TUSKEGEE SYPHILIS STUDY* 405 (Susan R. Reverby ed., 2000). It bears noting, however, that the history of medical exploitation of African Americans reaches much further back than Tuskegee. See Gamble, *supra* note 40, at 1773; Catherine M. Waters, *Understanding and Supporting African Americans' Perspectives of End-of-Life Care Planning and Decision Making*, 11 *QUALITY HEALTH RES.* 385, 386 (2001).

99. See Parker & Goldberg, *supra* note 7, at 26 (discussing the "Third Reich's T4 euthanasia program"); Lee Hudson, *From Small Beginnings: The Euthanasia of Children With Disabilities in Nazi Germany*, 47 *J. PEDIATRICS & CHILD HEALTH* 508, 509, 511 (2011) (describing the beginnings of the program, with severely disabled children); Kristen Iannuzzi, *Nazi Euthanasia and Action T4: Effects on the Ethical Treatment of Individuals With Disabilities* 25 (Apr. 4, 2014) (unpublished student paper, Grand Valley State University) (on file with Grand Valley State University's "ScholarWorks@GVSU" program).

100. See generally Michael White, *The End at the Beginning*, 11 *OSCHNER J.* 309, 309 (2011) (describing concern about discriminatory motive underling decision not to treat newborn with disabilities).

life-sustaining treatment will not be withheld or withdrawn from them because of their disabilities.

Persons with disabilities point out, accurately, that persons without disabilities tend to underestimate the quality of life persons with disabilities ascribe to their own lives.¹⁰¹ The use of the unfortunate label “vegetative” to describe a lack of cognition has led at least one person with disabilities to protest that she was not “a cabbage, an onion, . . . a cob of corn.”¹⁰² Some argue that it is difficult to predict one’s own beliefs when in a future state of disability because the capacitated person who executes an advance directive is not the same person who lies incapacitated at the time that advance directive is operationalized.¹⁰³

Countering that evidence and argument, however, is evidence indicating otherwise. For example, a recent major study of cancer patients and their caregivers reveals that, if anything, caregivers want to give more aggressive treatment than patients would choose (other than pain control).¹⁰⁴ A person who is in a vegetative state may present a more troubling case than a cancer patient because the vegetative-state patient is not necessarily near the end of life and does not experience the severe, untreatable pain many cancer patients experience. But recall also that this article is only considering people who have

101. SHEPHERD, *supra* note 24, at 130 (“Studies show that ‘more abled’ people repeatedly express their belief that life with certain kinds of disabilities are not worth living.”). This is true of both people in general and health care professionals. *Id.* See also Parker & Goldberg, *supra* note 7, at 26. Dean Ouellette describes Paul Longmore’s discussion of “rampant prejudice” against those with disabilities: “Disability is often equated with terminal illness and even viewed as ‘living death.’” OUELLETTE, *supra* note 97, at 294 (quoting PAUL K. LONGMORE, *THE DISABILITY RIGHTS OPPOSITION TO ASSISTED SUICIDE EXPLAINED AND CRITIQUED* 151 (Timothy Lillie & James L. Werth eds., 2007)).

102. Kathy L. Cerminara, *Critical Essay: Musings on the Need to Convince Some People with Disabilities that End-of-Life Decision-Making Advocates are Not Out to Get Them*, 37 *LOY. U. CHI. L. J.* 343, 343 (2006).

103. See generally SHEPHERD, *supra* note 24, at 180 (asking, “Should the fact that I would no longer be ‘myself’ mean that the ‘altered self’ I had become should not live?”). See also, e.g., Rebecca Dresser, *Toward a Humane Death with Dementia*, 44 *HASTINGS CTR. REP.* 38, 39 (2014) (describing one advance directive proposal as “empower[ing] [a] competent person[] to impose potential discomfort and distress on a later self who will be unable to understand the reasoning for that choice”); Jeffrey Blustein, *Choosing for Others as a Continuing Life Story: The Problem of Personal Identity Revisited*, 27 *J. L. MED. & ETHICS* 20, 20 (1999) (proposing that surrogates making end-of-life decisions are “continuers of the life stories of those who have lost narrative capacity”). See also generally Norman Cantor, *Prospective Autonomy: On the Limits of Shaping One’s Postcompetence Medical Fate*, 8 *J. CONTEMP. HEALTH L. & POL’Y* 13 (1992) (discussing the competent person and the incompetent person while distinguishing between “prospective autonomy” and “contemporaneous personal choice”).

104. Chetna Malhotra et al., *Comparison of Preferences for End-of-Life Care Among Patients with Advanced Cancer and Their Caregivers: A Discrete Choice Experiment*, 29 *PALLIATIVE MED.* 842, 846 (2015).

previously expressed their own wishes in written advance directives. Persons who have not done so similarly are entitled to have their wishes respected, but they are not at issue in this article. As Alicia Ouellette has said referring to both populations: “A person with disabilities should no more be denied access to treatment refusal than a person without disabilities.”¹⁰⁵ She explains, “Protecting people with disabilities from unscrupulous surrogates, outright discrimination, and negative social attitudes should be central concerns of a just medical system. [But] [e]nsuring equal opportunity [of choice], providing adequate pain relief, and preventing physical suffering are no less important goals.”¹⁰⁶

Similar reasoning applies to the poor and the elderly, two other vulnerable populations the Supreme Court has addressed in the context of end-of-life decision making. History may counsel that society be on guard against exploitation and discrimination,¹⁰⁷ but that does not justify denying persons within those populations the right to refuse life-sustaining treatment even if they are not in precisely the physical condition(s) a legislature envisioned in its advance directive statute. Given that this article addresses only persons who have executed written advance directives, persons who feel vulnerable due to disability, old age, racial or ethnic minority status, or poor economic circumstances can be as specific as they like about the physical triggering conditions they wish to put in place to protect themselves. The choice is theirs, to be expressed in their own advance directives if they wish to and are able to execute a written advance directive; it is not the state’s choice to apply to everyone by inclusion in a statute.

Other answers to these dilemmas lie partly in existing law and partly in the proposal at hand. First, as to existing law, heightened evidentiary standards and third-party (judicial) review serve as safeguards against decisions being made inconsistently with patient desires.¹⁰⁸ Second, this article does not suggest that the law should dispose of all triggering conditions. Rather, as discussed below, it suggests that the law should cease focusing simplistically on specified physical triggering conditions and instead should spotlight the real matter in question: patient intent.¹⁰⁹

Before reaching that point, however, a recap is in order. Under the Federal Constitution, the liberty interest in refusing life-sustaining treatment is

105. OUELLETTE, *supra* note 97, at 311.

106. *Id.* at 314.

107. In the 1980s, then-Governor Richard D. Lamm of Colorado famously stated that elderly people with terminal illnesses had a “duty to die and get out of the way.” See N.Y. TIMES, *supra* note 40. Additionally, it bears mention that medical exploitation of African Americans began long before the famed Tuskegee Syphilis Study. See Gamble, *supra* note 40, at 1173–74.

108. OUELLETTE, *supra* note 97 (discussing Norman Cantor’s work).

109. See Wardle, *supra* note 31, at 862; *In re Browning v. Herbert*, 568 So. 2d 4, 17 (Fla. 1990) (the “only issue to be decided” was “the patient’s wishes”).

fundamental. Limiting the exercise of that right to instances in which incompetent patients lie in certain specified physical triggering conditions neither serves a compelling state interest nor is sufficiently narrowly tailored to withstand scrutiny. Even on the facts of *Cruzan*, with an incompetent patient lacking a written advance directive, four Justices would have invalidated as unconstitutional the high burden of proof Missouri had imposed to protect the patient.¹¹⁰ When the patient in question has expressed her wishes in an advance directive, the presence of the advance directive is “significant”¹¹¹ and serves itself to protect the patient. In that situation, efforts to uphold state interests by limiting exercise of the right to patients in particular, simplistically expressed, physical conditions are unnecessary and unconstitutional.

B. Additional Support for the Substitution of Ethics Language for Physical Triggering Conditions in Advance Directive Statutes

The above analysis demonstrates that incorporating specified physical triggering conditions into advance directive statutes is unconstitutional. No one intends to authorize withholding or withdrawal of life-sustaining treatment in a setting in which a patient would not want that withholding or withdrawal. At the same time, however, a legislature may not limit the right to refuse to cases in which patients suffer from particular physical triggering conditions. Rather, the key inquiry is whether the patient lies in a condition in which that patient did not want treatment. Specifying physical triggering conditions for advance directive operation is a poor proxy for an investigation into patient intent.

Substituting patient-intent focused language for the current specification of physical triggering conditions will reframe the inquiry to consider patient concerns as a focal point. Reframing the inquiry in that fashion will encourage debates about more meaningful matters than the physical condition(s) that particular state believes justify withholding or withdrawal of life-sustaining treatment.

Such substitution of focus on patient intent for a focus on a state’s chosen physical conditions enhances the involvement of a previously unmentioned safeguard against going down the slippery slope: the medical profession. Physicians’ ethical codes obligate them to concentrate on patient intent rather than statutory physical triggering conditions.¹¹² The Council on Ethical and Judicial Affairs (CEJA) of the American Medical Association (AMA) advises its members that in considering—along with a surrogate—whether to carry out the wishes expressed in a patient’s advance directive, the first task is not to

110. *See Cruzan v. Dir., Mo. Dep’t of Health*, 497 U.S. 261, 301–57 (1990) (Brennan, J., dissenting & Stevens, J., dissenting).

111. *See In re Browning*, 568 So. 2d at 13. “Significantly, the patients in both cases, while competent, had executed written documents expressing their wishes.” *Id.*

112. Parker & Goldberg, *supra* note 7, at 23.

determine whether the patient's condition meets any statutory physical triggering condition. Instead, the task is to determine whether the patient is in a physical condition specified in that advance directive, if any is specified.¹¹³ In the absence of a stated physical condition in the advance directive, AMA member physicians are to rely on evidence of "the patient's values, goals for care, and treatment preferences."¹¹⁴ There are only three situations in which the CEJA advises AMA member physicians that they should seek an ethics consult: (1) when the surrogate and the health care team cannot agree; (2) in the absence of a ready, willing, and able surrogate; and (3) if the surrogate's decision "clearly violates the patient's previously expressed values, goals for care, or treatment preferences, or is not in the patient's medical interest."¹¹⁵ This, as J. Clint Parker and Daniel Goldberg indicate,¹¹⁶ is equivalent to the legal search for evidence of the patient's subjective wishes, then evidence supporting a substituted judgment, and then, only if necessary, evidence of what course of action would be in the patient's best interests.¹¹⁷ Statutory physical triggering conditions are not part of the equation.

The American Osteopathic Association echoes these principles, advising its members, without referring to patients' physical conditions, that they should inquire: "If the patient were to awaken and be able to fully understand the circumstances, what decisions would the patient make? If the answer is clear, it is unethical, except in extraordinary circumstances, not to follow the patient's wishes."¹¹⁸ There is no intervening step requiring reference to the law to decide whether the patient meets a statutory physical triggering condition. Care of a patient nearing the end of life involves many physicians and other health

113. See AM. MED. ASS'N COUNCIL ON ETHICAL & JUD. AFFS. (2016), *supra* note 36 § 5.2(b) ("Determine whether the patient's current clinical circumstances meet relevant thresholds set out in the directive."). *Id.* § 5.2(e) ("[H]elp the surrogate understand how to carry out the patient's wishes in keeping with the advance directive (when available), including whether the directive applies in the patient's current clinical circumstances . . .").

114. *Id.* § 5.3. See also *id.* § 2.20 (advising that the physician examine evidence about "the patient's preferences and values" before dropping to a purely objective, best interests test). Importantly, the AMA CEJA's earlier version of these opinions explicitly advised: "Even if the patient is not terminally ill or permanently unconscious, it is not unethical to discontinue all means of life-sustaining medical treatment in accordance with a proper substituted judgment or best interests analysis." AM. MED. ASS'N, *The Code Says: Opinions on Care at the End of Life*, 15 AMA J. ETHICS 1038, 1039 (2013). As noted previously, the newer version was not intended to make substantive changes but to update. *Am. Med. Ass'n Code of Medical Ethics*, *supra* note 36.

115. AM. MED. ASS'N COUNCIL ON ETHICAL & JUD. AFFS. (2016), *supra* note 36 § 5.3(g).

116. Parker & Goldberg, *supra* note 7, at 25.

117. See generally MEISEL ET AL., *supra* note 1.

118. AM. OSTEOPATHIC ASS'N, H431-A/15, POL'Y STATEMENT ON END OF LIFE CARE (2015).

care professionals, and their ethical codes generally are similar in purpose and effect.

What is ethical may not be legal, and *vice versa*, but in this case, the law's addition of specific triggering conditions on top of the medical profession's ethical obligation to honor patient wishes is not only contrary to medical ethics but also contrary to the patient's constitutional right to have her wishes prevail. Parker and Goldberg even argue that imposing triggering conditions is "an intrusion by the state into the patient–physician relationship."¹¹⁹ Those two physicians note:

The medical profession has an interest in preventing the premature death of patients—an interest at least as strong as the state's since preventing the premature death of patients is arguably one of the fundamental, defining goals of the medical profession. Acting in the best interest of patients is a defining characteristic of what it means to be a medical professional¹²⁰

Some statutory triggering conditions do not even properly reflect the medical judgments being applied at the bedside now (as opposed, perhaps, to when they were drafted). Most, if not all, states that incorporate a vegetative state triggering condition use the term *persistent vegetative state*, but it is likely that none of them actually mean the state should be *persistent*. They mean the state should be *permanent*.¹²¹ The neurological definitions of the terms persistent vegetative state and permanent vegetative state rely on temporality; a person in a persistent vegetative state cannot be said to be in a permanent vegetative state until either three months or a year has passed, depending on the cause of injury.¹²² As another example, under the terms of the Tennessee statute, persons with terminal illnesses include those in persistent vegetative states.¹²³ Yet, because persons in vegetative states can live for decades, neurologists do not consider them to be terminally ill.¹²⁴

In addition, scientific advances are teaching us that terms that seem definitive and exact may not be so clear. Recent research with functional magnetic resonance imaging, for example, shows us that a vegetative state diagnosis may not reflect the condition state legislatures envisioned.¹²⁵ That research is in early stages, but the overall point is that as technology advances,

119. Parker & Goldberg, *supra* note 7, at 27.

120. *Id.*

121. See, e.g., FLA. STAT. § 765.101(15) (2015) (defining "persistent vegetative state" as "a permanent and irreversible condition of unconsciousness . . .").

122. JOSEPH J. FINS, RIGHTS COME TO MIND: BRAIN INJURY, ETHICS, AND THE STRUGGLE FOR CONSCIOUSNESS 69, 79 (2015); Cerminara, *supra* note 3, at 614.

123. TENN. CODE ANN. § 32-11-103(9) (2016).

124. See FINS, *supra* note 122, at 39 (explaining that "the vegetative state need not be terminal absent a withdrawal of life-sustaining therapy").

125. See Cerminara, *supra* note 3, at 611; see also Damian Cruse et al., *Bedside Detection of Awareness in the Vegetative State: A Cohort Study*, 378 LANCET 2088, 2088, 2091 (2011).

the precise meaning of certain labels may change, yet patients' views of when they know "it's the end" probably do not change, whatever "it" is called.¹²⁶

Other options that better honor both patient rights and medical ethics could include eliminating specified physical triggering conditions in favor of language such as "a condition from which there can be no recovery" to preserve the edge of the slippery slope. A person may choose to state simply that she wishes to refuse life-sustaining treatment when she "would find continued existence unbearable if she were able to experience it," and then trust a surrogate to know when that point is. Statutory language could read something like this example, adapted from a portion of the Pennsylvania statute:

Except as specifically set forth in an advance health care directive, [the document] is not intended to preclude treatment of a disease, illness or physical, mental, cognitive or intellectual condition, even if incurable and irreversible and regardless of severity, if both of the following apply: (1) The patient would benefit from the medical treatment, including palliative care. (2) Such treatment would not merely prolong the process of dying.¹²⁷

States alternatively may wish to protect those with intellectual or cognitive disabilities by including statutory language specifically prohibiting the operation of advance directives for withholding or withdrawal of life-sustaining treatment from patients "who are mentally incapacitated but physically are in good health."¹²⁸

The final suggestion this article will offer is that instead of relying on physical triggering conditions, a state could require as part of its advance directive completion process that the person executing the directive complete and attach one of a variety of validated advisory documents. These documents are worksheets created to facilitate advance care planning by presenting scenarios and seeking information about the patient's goals and values.¹²⁹ Physicians are urged to use these sorts of worksheets in counseling patients on end-of-life decision making; until recently, the AMA CEJA recommended that its members, when engaging in advance care planning with their patients, "make use of advisory as well as statutory documents Advisory documents should be based on validated worksheets, thus ensuring reasonable confidence that preferences for end-of-life treatment can be fairly and

126. For example, being in a minimally conscious state may be "horrifying" to some people, while "[o]thers [may see] it as a step toward to more fruitful recovery" if recovery is possible. FINS, *supra* note 122, at 125.

127. 20 PA. CONS. STAT. ANN. § 5422 (2016) (defining "end-stage medical condition").

128. *In re Browning v. Herbert*, 568 So. 2d 4, 12 n.10 (Fla. 1990).

129. Linda L. Emanuel, et al., *Advance Care Planning*, 9 ARCHIVES FAM. MED. 1181, 1184 (2000); *see also* Charles P. Sabatino, *Six Key Steps to Advance Care Planning*, 36 BIFOCAL 87, 88 (2015).

effectively elicited and recorded, and that they are applicable to medical decisions.”¹³⁰

In sum, rather than serving state interests in shorthand fashion through reference to physical triggering conditions instead of patient intent, statutory advance directive language should more closely match the fruits of clinicians’ advance care planning efforts.

This approach to statutory drafting, although perhaps seeming less certain than use of specified medical conditions, is more descriptive and thus more precisely targeted. Such language is clearer than the specification of physical triggering conditions because those conditions often are not as definitive as they sound. Florida’s definition of *terminal condition* is “a condition caused by injury, disease, or illness from which there is no reasonable medical probability of recovery and which without treatment, can be expected to cause death.”¹³¹ In Missouri, a *terminal condition* is “an incurable or irreversible condition which, in the opinion of the attending physician, is such that death will occur within a short time regardless of the application of medical procedures.”¹³² A patient in either of those conditions, however, is terminally ill so as to obtain Medicare payment for hospice services when he or she “has a medical prognosis that his or her life expectancy is [six] months or less if the illness runs its normal course.”¹³³ The question is what the person executing an advance directive thinks terminal illness is, and she probably does not examine statutory definitions. The situation in which patients wish to refuse continued treatment is a matter of “I know it when I see it,” and each person knows it when she sees it for herself.

This approach also would account for the reality of conversational English. Rather than categorizing specific physical conditions as acceptable or unacceptable, persons expressing their end-of-life wishes make statements like they “never want[] to be that way,”¹³⁴ “[d]on’t do to me what you did to your mother,”¹³⁵ or I don’t “want to spend [my] life lying in bed and looking at the wall.”¹³⁶ “The right to be free from unwanted medical attention is a right to evaluate the potential benefit of treatment and its possible consequences according to one’s own values and to make a personal decision whether to subject oneself to the intrusion.”¹³⁷ When a patient has taken the time and trouble to do that, and to memorialize the decision in writing, the state should

130. AMA COUNCIL ON ETHICAL & JUD. AFFS. (2002), *supra* note 36 § 2.225, at 96.

131. FLA. STAT. § 765.101(22) (2015).

132. MO. REV. STAT. § 459.010(6) (2000).

133. 42 C.F.R. § 418.3 (2014).

134. *In re Browning v. Herbert*, 568 So. 2d 4, 9 (Fla. 1990).

135. Susan Shapiro, *Do Advance Directives Direct?*, 40 J. HEALTH POLS. POL’Y & L. 487, 502 (2015).

136. *Id.*

137. *Cruzan v. Dir., Mo. Dep’t of Health*, 497 U.S. 261, 309 (Brennan, J., dissenting).

not impose its views of whether the patient is in a condition meriting withholding or withdrawal of treatment by specifying physical conditions that must be satisfied to give effect to the patient's advance directive.

IV. CONCLUSION

Advance directives are instruments of personal preference regarding end-of-life medical treatment. Both persons who have and those who have not set forth their preferences in writing are entitled to have their wishes govern their end-of-life medical care. Especially when they have done so, however, the state has no role in determining when they can refuse treatment. State determinations that only persons in one or more physical triggering conditions may refuse life-prolonging treatment are inconsistent with the U.S. Constitution and unwise for a variety of reasons.

Rather than continue this poor policy practice, states should amend their advance directive statutes to more closely reflect the result of clinicians' advance care planning processes. As many already have with Physician Orders for Life-Sustaining Treatment,¹³⁸ states should recognize and honor the foundation of all end-of-life medical decision-making law: patient wishes. Doing so is natural and appropriate because one of the state interests in play—one that has received less and less attention in the area of withholding or withdrawing treatment over the years—is maintenance of the integrity of medical ethics. It is difficult to imagine a better way to honor and ensure the integrity of medical ethics in this area than by using medical ethical constructs to focus on patient intent rather than determinations of the presence of a particular physical triggering condition. Just as the earliest reported appellate court decision regarding withdrawal of life-sustaining treatment looked to medical ethics as a guide,¹³⁹ so should the law now, a few generations into the development of written advance directives. Doing so will improve end-of-life care and serve as an expression of a more caring medical and legal culture.¹⁴⁰

138. States have legislatively and regulatorily approved such documentary tools for physicians to use in operationalizing patients' end-of-life wishes on patient charts. *See generally* MEISEL ET AL., *supra* note 1 § 7.10(A).

139. *See In re Quinlan*, 355 A.2d. 647, 667 (N.J. 1976).

140. SHEPHERD, *supra* note 24, at 179 (recommending a focus on respect and care in end-of-life decision-making).