RULES FOR DYING FIFTY YEARS AFTER *QUINLAN*: PUTTING PATIENTS AND FAMILIES FIRST

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ABSTRACT

March 31, 2026, marked fifty years since the landmark New Jersey Supreme Court decision in the case of Karen Ann Quinlan,

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Before taking the bench, Judge Armstrong was a pioneer of patients' rights, having argued landmark cases before the New Jersey Supreme Court in *In re Quinlan* and *Matter of Jobes* as Counsel to the families of Karen Ann Quinlan and Nancy Ellen Jobes. He also appeared as Counsel of Record to the *amici curiae* the American Hospital Association in *Cruzan v. Director, Missouri Department of Health Department*, and the Medical Society of New Jersey in *Vacco v. Quill*, in these landmark cases before the United States Supreme Court. He has served as Chairman of the New Jersey Bioethics Commission (formally the New Jersey Commission on Legal and Ethical Problems in the Delivery of Health Care), the New Jersey Governor's Advisory Council on AIDS, and as a member of the New Jersey Health Commissioner's COVID Resource Committee.

As a New Jersey Superior Court Judge for approximately two decades, Judge Armstrong performed judicial duties in the Civil, Criminal and Family Divisions and sat in the historic courthouses of Somerset, Hunterdon, Warren and Morris counties. He served as Chairman of the Conference of Drug Court Judges and Vice-Chair of the New Jersey

holding for the first time that patients have a constitutional right to refuse unwanted medical interventions, including life-sustaining treatment. In re Quinlan*'s sound reasoning, grounded in principles of constitutional law, respect for patient autonomy and self-determination, and the rights of families to act on behalf of incompetent loved ones, with appropriate safeguards and due consideration of countervailing state interests and commitments of the medical profession, became the model for the nation.*

Over the next fifteen years, a judicial consensus emerged as courts in state after state embraced the core principles of Quinlan*, ruling that patients who are terminally ill or in persistent vegetative state have a constitutional and common law right to refuse life-sustaining treatment, and that when the ravages of illness, disease or accident take our ability to decide for ourselves, families may decide in the exercise of substituted judgment, positions that were cemented in the U.S. Supreme Court's decision in* Cruzan.

Parallel to the courts, state legislatures nationwide enacted advance directive laws to establish the right to assert personal autonomy over the dying process in the event of future incompetence by putting our wishes in writing. This article discusses and critically appraises the history and status of this consensus, from its foundations in Quinlan *to the present day, and the impact of* Dobbs*. The end-of-life consensus answers the critical question, how do we know what the patient wants under the circumstances, and embodies a settled commitment to putting patients and families first in the pursuit of death with dignity.*

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Supreme Court Committee on Judicial Education and the Judiciary Advisory Group on the Americans with Disabilities Act. One of his many notable cases includes presiding over the infamous criminal matter of *State of New Jersey v. Charles Cullen*, which involved an odious serial killer nurse.

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INTRODUCTION

March 31, 2026, marked fifty years since the landmark case of Karen Ann Quinlan. In *In re Quinlan,* the New Jersey Supreme Court held, for the first time, that patients have a constitutional right to refuse unwanted medical interventions, including life-sustaining treatment, and that families may exercise this right on behalf of incompetent loved ones.[1] Although the decision set precedent only for New Jersey, its sound

1. *In re* Quinlan, 355 A.2d 647, 663–64 (N.J. 1976), *cert. denied sub nom.*, Garger v. New Jersey, 429 U.S. 922 (1976).

reasoning—grounded in principles of constitutional law, respect for patient autonomy and self-determination, and the rights of families to act on behalf of incompetent loved ones, with appropriate safeguards and due consideration of countervailing state interests and commitments of the medical profession became the model for the nation.[2] By 1990, a judicial and legislative consensus on approaches to end-of-life decisions built on *Quinlan*'s foundations had taken hold.[3]

Over the years, *Quinlan* has been the most-cited legal case in bioethics scholarship and the most-taught in legal, medical, and undergraduate bioethics education.[4] *Quinlan*'s impact on the jurisprudence of decisions near the end of life has been compared to that of *Brown v. Board of Education* on public education.[5] *Quinlan* has been lauded as one of the trials of the twentieth century for its profound impact on the role of law and the courts in reconciling progress in science and technology with extant and changing ethical norms and values.[6] As part of the commemoration of the seventy-fifth anniversary of the New Jersey Constitution, adopted in 1947, ratified in 1948, the New Jersey Supreme Court Historical Society selected *Quinlan* as a landmark opinion for its application of the state constitution's core principles to the development of healthcare, bioethics, and law.[7]

The *Quinlan* saga's impact on practice and culture beyond the courtroom and the state house cannot be gainsaid. The case made the covers and front pages of numerous magazines and newspapers. Her story was front-page news in *The New York Times*, and of course, the

2. *See id.*; *see also* Norman L. Cantor, *Marking the 40th Anniversary of In re Quinlan's Landmark Contribution to Death & Dying Jurisprudence*, PETRIE-FLOM CTR. (July 26, 2016), https://petrieflom.law.harvard.edu/2016/07/26/marking-quinlans-landmark-contribution/ [https://perma.cc/X959-6G2T] (describing *Quinlan* as the model for subsequent right-to-die jurisprudence).

3. *See* Cruzan v. Missouri Dep't of Health, 497 U.S. 261, 270–78 (1990).

4. *See* Robert S. Olick & Paul W. Armstrong, *In Re Karen Ann Quinlan (1976): Establishing a Patient's Right to Die in Dignity*, *in* COURTING JUSTICE: 10 NEW JERSEY CASES THAT SHOOK THE NATION 78 (Paul L. Tractenberg ed. 2013) (portions used with permission of the authors).

5. Cantor, *supra* note 2.

6. Debra Baker, *Trials of the Century: In a Nation Obsessed with Lists, the Trials That Have Shaped the Law Are More Patterns for the Future than Rankings of the Past*, 85 A.B.A. J. 42, 46–47 (1999).

7. In celebration of seventy-five years since the amendment of the New Jersey Constitution, the New Jersey Supreme Court Historical Society recognized the *Quinlan* case as one of the landmark applications of the amended constitution. As part of this event, the Historical Society conducted videotaped interviews with three of the attorneys involved in the case—the prosecutor, the guardian, and counsel for the Quinlan family. (on file with the authors). *See generally* ROBERT F. WILLIAMS & RONALD K. CHEN, THE NEW JERSEY STATE CONSTITUTION 6–42 (3d ed. 2023) (providing a detailed history of the New Jersey Constitution).

Newark Star-Ledger, both at the time of the court decision[8] and when she died nine years later.[9] Karen's high school picture appeared on the cover of *Newsweek*[10] and France's *Le Monde*.[11] The story of Karen Ann Quinlan was instrumental in advancing our national dialogue about death and dying, including interest in the hospice movement and compassionate care near the end of life.[12] The Karen Ann Quinlan Hospice was founded in 1980, a pioneering achievement in palliative care and a pillar of what has become a national fixture in the care of dying patients.[13] The Quinlan Hospice continues to provide care and support to patients and families to this day.[14]

This article discusses the history and status of today's end-of-life consensus, beginning with the foundations that took root in *Quinlan*. We conclude by asking whether the *Dobbs*[15] decision, which undermined the federal constitutional right to privacy, poses a risk to the consensus.

8. Joseph F. Sullivan, *Court Rules Karen Quinlan's Father Can Let Her Die by Disconnecting Respirator if Doctors See No Hope*, N.Y. TIMES (Apr. 1, 1976), https://www.nytimes.com/1976/04/01/archives/court-rules-karen-quinlans-father-can-let-her-die-by-disconnecting.html [https://perma.cc/CWE3-ACYF]; Robert Cohen, *Court: Karen Can Die: Justices*, STAR-LEDGER (Newark, N.J.), Apr. 1, 1976, at 1, 8–10.

9. Karen Ann Quinlan died on June 11, 1985. Robert D. McFadden, *Karen Ann Quinlan, 31, Dies; Focus of '76 Right to Die Case*, N.Y. TIMES (June 12, 1985), https://www.nytimes.com/1985/06/12/nyregion/karen-ann-quinlan-31-dies-focus-of-76-right-to-die-case.html [https://perma.cc/V254-G4A4].

10. Photograph of Karen Ann Quinlan, *in* NEWSWEEK (Nov. 3, 1975).

11. Photograph of Karen Ann Quinlan, *in* LE MONDE (Apr. 5, 1976). The case garnered international interest in the ethical and legal issues surrounding the use of life-sustaining medical technologies. *See* Colette Porlier, POUR OU CONTRE L'EUTHANASIE? [For or Against Euthanasia?], PARIS MATCH, Nov. 22, 1975, at 45.

12. *See* PETER G. FILENE, IN THE ARMS OF OTHERS: A CULTURAL HISTORY OF THE RIGHT-TO-DIE IN AMERICA 1 *passim* (1998) (discussing how *Quinlan* helped spark national dialogue about death, dying, and compassionate end-of-life care).

13. *See History*, KAREN ANN QUINLAN HOSPICE, https://karenannquinlanhospice.org/about/history/ [https://perma.cc/2UBJ-E6CC] (last visited June 13, 2026); *About*, KAREN ANN QUINLAN HOSPICE, https://karenannquinlanhospice.org/about/ [https://perma.cc/2PWB-PTLE] (last visited June 13, 2026).

14. This article is dedicated to Karen's parents, Joseph and Julia Quinlan, whose compassion, devotion, and faith inspired a movement and changed history. We also wish to acknowledge the preeminent legal and scholarly contributions of James M. Crowley, Esq., co-counsel in *In re Quinlan*, the shared wisdom and compassion of Joseph F. Fennelly, M.D., who cared for Karen Ann through part of her journey, and the exemplary work of our former colleague Michael Vollen. We are all indebted to the families of Nancy Ellen Jobes, Nancy Beth Cruzan, and so many others who fought for their loved ones' right to die with dignity according to their own wishes.

15. *See generally* Dobbs v. Jackson Women's Health Org., 597 U.S. 215 (2022) (overruling *Roe v. Wade* and *Planned Parenthood v. Casey* to hold that the U.S. Constitution does not confer a right to abortion, thereby returning the authority to regulate or prohibit abortion to individual states and their elected representatives).

Section I presents the *Quinlan* case itself in some detail, placing the story of Karen Ann Quinlan in its personal, social, and legal context. We focus on four central holdings: 1) the patient's constitutional and common law right to refuse life-sustaining treatment; 2) the family's right to decide on behalf of incompetent loved ones; 3) the doctrine of substituted judgment; and 4) process and safeguards, in particular, the role of ethics committees in resolving ethical dilemmas in patient care. These principles establish a commitment and approach to putting patients and families first when confronting the burdens of end-of-life decisions.

Section II presents the judicial consensus that emerged in the aftermath of *Quinlan*, including the 1990 case of Nancy Beth Cruzan, the only case addressing refusal of life-sustaining treatment to reach the U.S. Supreme Court to date.[16] Parallel to the emerging judicial consensus, the nation saw the rapid enactment of legislation recognizing advance directives for health care as the best means of ensuring respect for patients' wishes after they had lost contemporaneous decisional capacity.

Section III presents this body of statutory law, with particular focus on the scope and limits of treatment refusal and key issues that affect respect for patient directives at the bedside. Sections IV and V turn to two of the most significant and recent developments that strengthen and extend patients' rights: Physician Orders for Life-Sustaining Treatment (POLST) and the role of hospital ethics committees and consultants as participants in resolving conflicts. Section VI offers a bullet summary of key principles of the end-of-life consensus.

Lastly, Section VII addresses current challenges and future prospects for the end-of-life consensus fifty years on from this landmark decision in light of the potential impact of the Supreme Court's decision in *Dobbs*. While the article presents the end-of-life consensus in the voice of the law, including its development and contributions, it is essential to understand that the legal consensus also reflects the ethical, medical, and societal consensus.

It is useful to first set some context for thinking about end-of-life decisions. Approximately three million Americans die each year.[17] More than 700,000 of those deaths occur in hospitals.[18] About three-quarters

16. *See generally* Cruzan v. Missouri Dep't of Health, 497 U.S. 261 (1990).

17. Farida B. Ahmad et al., *Provisional Mortality Data — United States, 2022*, 72 MORBIDITY & MORTALITY WKLY. REP. 488, 488–92 (2023), https://www.cdc.gov/mmwr/volumes/72/wr/pdfs/mm7218a3-H.pdf [https://perma.cc/AGE3-N8U8].

18. MARGARET JEAN HALL, SHALEAH LEVANT & CAROL J. DEFRANCES, NAT'L CTR. FOR HEALTH STATS., TRENDS IN INPATIENT HOSPITAL DEATHS: NATIONAL HOSPITAL DISCHARGE SURVEY, 2000–2010, NCHS DATA BRIEF NO. 118, at 1 (Mar. 2013), https://cdc.gov/nchs/data/databriefs/db118.pdf [https://perma.cc/LGJ9-LHYT].

of all hospital deaths come after a decision to withhold or withdraw life-sustaining treatment.[19] In only a comparatively small number of instances over the past fifty years—perhaps hundreds of times—have disagreements and controversies reached an American courtroom.[20] We need to have rules for dying that enable decisions at the bedside among patients, families, physicians, and all those caring for dying patients. It matters what those rules are, and that they work to allow these difficult choices to be made within the private confines of the patient-family-physician relationship, away from the probing eyes of the fourth estate and the American courtroom.

19. *See* Bruce Jennings, *Preface* to IMPROVING END OF LIFE CARE: WHY HAS IT BEEN SO DIFFICULT?, 35 HASTINGS CTR. REP. (SPECIAL REPORT) S2 (2005) ("Over 700,000 people who die each year receive hospice services for at least a short period of time before death; and roughly three-quarters of all deaths in hospitals now come after some explicit decision has been made to forgo the use of some type of potentially life-prolonging intervention."). *See generally* Hall et al., *supra* note 18 (examining death rates of admitted patients between 2000 to 2010); Ahmad et al., *supra* note 17 (examining underlying causes of death in 2022); *see also* Suzana M. Lobo et al., *Decision-Making on Withholding or Withdrawing Life Support in the ICU: A Worldwide Perspective*, 152 CHEST J. 321, 326–29 (2017) (finding significant variation in frequency of requests to withhold or withdraw life-sustaining treatments among ICU patients in 730 ICUs across 84 countries). It also matters where we die. Over the past twenty or so years, there has been a trend toward fewer deaths in the hospital, with more dying in nursing homes or choosing to die at home. *See* R. Henry Olaisen, *Percentage of Deaths, by Place of Death — National Vital Statistics System, United States, 2000–2018*, 69 MORBIDITY & MORTALITY WKLY. REP. 611, 611 (2020), https://www.cdc.gov/mmwr/volumes/69/wr/pdfs/mm6919a4-H.pdf [https://perma.cc/F89U-3QTZ]. The rules for dying that comprise the end-of-life consensus, in particular the right of patients and families to decide when enough is enough, apply with equal force in these settings, with some variations in practice; for example, when patients opt for home hospice care committed to easing the dying process, the decision against high-tech mechanical interventions has already been made. Note that the provisional mortality data through 2022 accounts for the tragic death toll during the early years of the COVID pandemic. *See* Ahmad et al., *supra* note 17, at 488. Data regarding place of death precedes the pandemic. *See id.*; R. Henry Olaisen, *Percentage of Deaths, by Place of Death — National Vital Statistics System, United States, 2000–2018*, 69 MORBIDITY & MORTALITY WKLY. REP. 611, 611 (2020).

20. Alan Meisel, *Legal Myths About Terminating Life Support*, 151 ARCH. INTERN. MED. 1497, 1500 (1991) (stating that "only rarely do health care professionals actually go to court to obtain permission to terminate life support. There have been only about 60 reported appellate cases involving the forgoing of life-sustaining treatment"); *see also* John M. Luce, *A History of Resolving Conflicts over End-of-Life Care in Intensive Care Units in the United States*, 38 CRIT. CARE MED. 1623, 1624–25 (2010) (finding that conflict at the end of life is relatively rare in ICUs and that mediation between families and physicians usually resolves conflicts, based on a sample of published studies).

I. THE CASE OF KAREN ANN QUINLAN[21]

Karen had been rushed to the emergency room of Newton Memorial Hospital after suffering a cardiac arrest at a party, being deprived of oxygen to the brain (anoxia), and falling into a coma. Soon thereafter, Karen's care was transferred to St. Claire's Hospital, a larger and better-equipped facility known to the Quinlans. She required a respirator to assist her breathing and a nasogastric tube to provide her with artificial fluids and nutrition. At the age of twenty-one, Karen was diagnosed with a persistent vegetative state (PVS), a condition in which all cognitive functions of the brain have been lost, resulting in complete unawareness of self and the environment.

At the same time, PVS patients retain some brainstem functions that regulate autonomic, involuntary activities of the body, such as heart rate, blood pressure, digestion, and breathing.[22] PVS patients may exhibit very limited movement, react to light or sound, blink, and make sounds that appear to be grimaces or cries.[23] These reactions can be interpreted by families as signs of cognitive interactions, but they are in fact merely reflexive and not signs of thought or awareness of their surroundings.[24] When properly diagnosed, there is virtually no hope of recovery from PVS to a cognitive sapient state. With medical interventions, PVS patients may live for several years to a decade; in rare cases, patients have been known to survive in this condition for more than three decades.[25]

After much private and public agonizing, including numerous consultations with their parish priest Father Trapasso, the Quinlans resolved that their twenty-one-year-old daughter would not want to have her biological life prolonged indefinitely in this "unblessed" condition. Nor was it in her best interests to be continuously tethered to the

21. This discussion of the Quinlan story is adapted in part from Robert S. Olick & Paul W. Armstrong, *In re Karen Ann Quinlan (1976): Establishing a Patient's Right to Die in Dignity*, *in* COURTING JUSTICE: 10 NEW JERSEY CASES THAT SHOOK THE NATION 77, 78 (Paul L. Tractenberg ed. 2013) (with permission of the authors).

22. *See* Kenneth Maiese, *Vegetative State*, MERCK MANUAL CONSUMER VERSION, https://www.merckmanuals.com/home/brain-spinal-cord-and-nerve-disorders/coma-and-impaired-consciousness/vegetative-state [https://perma.cc/D4QN-UC2B] (last visited June 13, 2026).

23. *Id.*

24. *See id.*

25. Hannah C. Kinney et al., *Neuropathological Findings in the Brain of Karen Ann Quinlan: The Role of the Thalamus in the Persistent Vegetative State*, 330 NEJM 1469, 1469 (1994); *see also* Multi-Soc'y Task Force on PVS, *Medical Aspects of the Persistent Vegetative State (1)*, 330 NEJM 1499, 1499 (1994) (stating that the course and outcome for PVS patients depends on the cause of the condition, and that "[r]ecovery from a nontraumatic persistent vegetative state after three months is exceedingly rare in both adults and children").

respirator, forcing her to breathe. Initially, Karen's physician, Dr. Morse, suggested the removal of the respirator, allowing her to die. The Quinlans accepted this recommendation and asked that this be done. St. Claire's hospital agreed and asked the Quinlans to sign a consent and release form directing the physician to "discontinue all extraordinary measures, including the use of a respirator."[26] The physician and hospital would be released from liability for carrying out the parents' wishes.[27]

But the hospital quickly changed its mind, forcing the Quinlans to go to court on behalf of their daughter. Most likely, two factors moved St. Claire's to reverse course. Without legal precedent to rely on, hospital counsel and the treating physicians may well have feared exposure to legal liability for removing the respirator.[28] Inferentially, counsel may have felt that if withdrawal of the respirator was not clearly permitted, it was therefore prohibited.[29] There was no reliable precedent that withdrawing life support met the medical or legal standard of care.[30] This was a time when rapid advances in medicine had provided the tools of respirators, feeding tubes, dialysis, cardiac resuscitation, blood transfusion, and other interventions to prolong life and forestall death. Yet in the mid-1970s, the ethical imperative of the medical profession was still thought to be the preservation of life, perhaps at all costs, as it had been throughout the history of medicine.[31] Karen's physician testified that "to terminate the respirator would be a substantial

26. As quoted in the trial court opinion, the text of the authorization and release read: We authorize and direct Doctor Morse to discontinue all extraordinary measures, including the use of a respirator for our daughter Karen Quinlan. We acknowledge that the above named physician has thoroughly discussed the above with us and that the consequences have been fully explained to us. Therefore, we hereby RELEASE from any and all liability the above named physician, associates and assistants of his choice, Saint Claire's Hospital and its agents and employees.

In re Quinlan, 348 A.2d 801, 813–14 (N.J. Super. Ct. Ch. Div. 1975) (emphasis in original).

27. *Id.*

28. The physicians denied being motivated by legal risks. *In re* Quinlan, 355 A.2d 647, 666–67 (N.J. 1976). The county prosecutor who later became involved in the case argued that withdrawal of the respirator could be a criminal act. *Id.* at 669. It is unclear whether fears of criminal liability played a role in the hospital's sudden reversal, but the specter of criminal law was likely relevant to maintaining their position at trial in opposition to withdrawal of the respirator.

29. *See generally* Meisel, *supra* note 20 (explaining that the absence of a specific statute does not necessarily render the termination of life support illegal and debunking common legal misconceptions held by medical professionals).

30. *See Quinlan*, 348 A.2d at 815.

31. *See generally* John M. Luce & Douglas B. White, *A History of Ethics and Law in the Intensive Care Unit*, 25 CRIT. CARE CLIN. 221 (2009) (discussing beneficence and non-maleficence as the oldest ethical principles guiding the practice of medicine and noting that patient autonomy did not make its way into American medicine as a "compelling ethical principle" until the mid-twentieth century).

deviation from medical tradition," and that it required judgment about her quality of life.[32] Official pronouncements of the medical profession offered no affirmative support for complying with the Quinlans' request. The American Medical Association (AMA) did not officially embrace the removal of life support from dying patients until several years later.[33]

A. The Quinlans Go to Court

On September 10, 1975, approximately six months after Karen's emergency admission to Newton Memorial, Joseph and Julia Quinlan petitioned the court in Morris County, New Jersey, for legal guardianship with permission to direct removal of the respirator sustaining her life.[34] The petition for relief asserted that, as a patient, Karen had the right to refuse life-sustaining treatment. Her father, as guardian, should have the authority to exercise that right on her behalf, and, in so doing, to direct "the discontinuance of all extraordinary means of sustaining the vital processes of his daughter."[35] The patient's right to refuse treatment was premised on several grounds, most significantly the federal and state constitutional right to privacy in making decisions about one's own body and to be free from unwanted medical interventions.

Opposing the petition were her physicians, the hospital, the county prosecutor, the Attorney General of New Jersey, and the guardian *ad litem* appointed by the court to impartially represent Karen's best interests. In summary, the arguments in opposition contended that there is no constitutional "right to die"; there is a compelling state interest in favor of preserving human life; and to remove the respirator would be homicide and an act of euthanasia.[36] The physicians argued that whether to continue the respirator was for the medical profession to decide—not the patient or family—and that accepted norms of medical practice

32. *Quinlan*, 348 A.2d at 813–14.

33. *See* AMA Council on Ethical & Jud. Affs., *The Code Says: AMA Code of Medical Ethics' Opinions on Care at the End of Life*, 15 AMA J. ETHICS 1038, 1038–39 (2013) (noting the history and evolution of AMA opinions on withholding and withdrawing life support). According to one leading scholar, removing a respirator from PVS patients was not in fact contrary to prevailing medical practice at the time. *See* ROBERT M. VEATCH, DEATH, DYING AND THE BIOLOGICAL REVOLUTION: OUR LAST QUEST FOR RESPONSIBILITY 119–21 (rev. ed. 1989); s*ee also* M.L. Tina Stevens, *The Quinlan Case Revisited: A History of the Cultural Politics of Medicine and the Law*, 21 J. HEALTH POL. POL'Y & L. 347, 357 (1996) (claiming that withdrawal of life support for PVS patients was "customary"). This view is refuted in Joel Frader, Commentary, *The Quinlan Case Revisited*, 21 J. HEALTH POL. POL'Y & L. 367, 368 (1996) (discussing how medical practice changes, often "unevenly").

34. Olick & Armstrong, *supra* note 21, at 77.

35. *See Quinlan*, 348 A.2d at 806.

36. *See id.* at 814–15.

required aggressive efforts to sustain life.[37] It was further contended that removing the respirator involved judgments about Karen's quality of life, a morally objectionable precedent for future cases.[38]

Over six days, the trial judge received testimony from Joseph and Julia Quinlan, Karen's sister and a good friend, and also from medical experts and theologians. At the conclusion of the trial, Judge Muir adopted the position of the medical profession and the state. Protective of the medical profession's traditional prerogatives, the court ruled that "[t]here [*i*]*s* a duty to continue the life-assisting apparatus, if, within the treating physician's opinion, it should be done."[39] Striking an extra blow at the family, the judge kept the court-appointed attorney as guardian *ad litem* of the person and refused to appoint Joseph Quinlan as guardian over her property.[40] That the trial court declined to find a "new" constitutional right was not surprising. But this set the stage for consideration on appeal of novel questions of profound personal and constitutional rights. Disheartened but resolute, the Quinlans quickly filed and were granted an expedited appeal to the New Jersey Supreme Court.[41]

B. The New Jersey Supreme Court's Landmark Decision

1. The Constitutional Right to Refuse Treatment

In the first judicial ruling of its kind, the New Jersey Supreme Court held that Karen Quinlan, an incompetent patient in a persistent vegetative state, had the right to refuse the respirator that artificially sustained her life, and appointed her father legal guardian with authority to exercise this right on his daughter's behalf.[42] Reversing the ruling below,[43] a unanimous court held that a patient has a fundamental constitutional right to refuse life-sustaining treatment, grounded in the right of privacy under the federal and state constitutions.[44] Finding the legal underpinnings for the right of privacy in the U.S. Supreme Court's

37. *Id.* at 814.
38. *Id.* at 814 (testimony of Dr. Morse).
39. *Id.* at 819 (emphasis added).
40. *Id.* at 824.
41. *See In re* Quinlan, 355 A.2d 647, 651 (N.J. 1976). The family's reaction to the trial court's ruling is chronicled in their book, *Karen Ann: The Quinlans Tell Their Story*. *See* JOSEPH QUINLAN, JULIA QUINLAN & PHYLLIS BATTELLE, KAREN ANN: THE QUINLANS TELL THEIR STORY 217–19 (1977).
42. *See Quinlan*, 355 A.2d at 662–64, 671.
43. *See id.* at 671–72.
44. *See id.* at 662–64, 671–72.

decisions in the area of procreation, in particular *Roe v. Wade*,[45] the court held that "this right is broad enough to encompass a patient's decision to decline medical treatment under certain circumstances, in much the same way as it is broad enough to encompass a woman's decision to terminate pregnancy under certain conditions."[46] The New Jersey Constitution also protects individual privacy and encompasses the patient's right to refuse life-sustaining treatment.[47] If the patient has a right of privacy as a competent adult to refuse life support, as she does, then "[t]he only practical way to prevent destruction of the right is to permit the guardian and family of Karen to render their best judgment [on her behalf]."[48] Put another way, a patient's right to refuse treatment is not lost when the patient loses the capacity to decide for themselves; there must be a way for that right to be exercised on the patient's behalf.

Like other constitutional rights, the right to refuse treatment is not absolute.[49] There are four countervailing state (societal) interests that must be balanced against a patient's right to refuse life-sustaining treatment: the state's interests in preserving life, in preventing suicide, protecting vulnerable citizens, and in safeguarding the integrity of the medical profession.[50] In an oft-quoted passage, *Quinlan* held that "the State's interest *contra* weakens and the individual's right to privacy

45. 410 U.S. 113, 154 (1973) (holding "that the right of personal privacy includes the abortion decision"), *overruled by* Dobbs v. Jackson Women's Health Org., 597 U.S. 215 (2022).

46. *Quinlan*, 355 A.2d at 663 (citing Roe v. Wade, 410 U.S. 113, 153 (1973)). The court also relied on *Griswold v. Connecticut*, which held that there is a federal constitutional privacy right to have and use contraception. *See id.*; Griswold v. Connecticut, 381 U.S. 479, 484 (1965). "The Court in Griswold found the unwritten constitutional right of privacy to exist in the penumbra of specific guarantees of the Bill of Rights 'formed by emanations from those guarantees that help give them life and substance.'" *Quinlan*, 355 A.2d at 663 (quoting *Griswold*, 381 U.S. at 484).

47. N.J. CONST. art. I, § 1. Like the U.S. Constitution, the New Jersey Constitution does not contain the word "privacy." *See id.* The first paragraph of Article I, "Natural and unalienable rights," states: "All persons are by nature free and independent, and have certain natural and unalienable rights, among which are those of enjoying and defending life and liberty, of acquiring, possessing, and protecting property, and of pursuing and obtaining safety and happiness." *Id.* The court did not explain its reasoning as to the right of privacy found in this text, but it may be inferred that, as in *Roe*, privacy rights exist in the penumbras of the state constitution. *See Quinlan*, 355 A.2d at 664.

48. *Id.*

49. A prominent example of a fundamental right that is sometimes limited by important public interests and hence is not absolute is the First Amendment right to free speech. *See, e.g.*, Grayned v. City of Rockford, 408 U.S. 104, 116 (1972) (upholding reasonable regulation of time, place and manner for picketing and protesting); Brandenburg v. Ohio, 395 U.S. 444, 447 (1969) (stating that speech likely to incite or produce imminent unlawful action is not protected speech).

50. *See Quinlan*, 355 A.2d at 663–64.

grows as the degree of bodily invasion increases and the prognosis dims."[51] Society's interest in preserving the life of a vegetative patient with no hope of recovery must be subordinated to the contrary assertion of the patient's right to refuse unwanted life support. Further, rejection of life support in these circumstances is an exercise of self-determination, not an act of purposeful self-destruction that defines suicide.[52] It follows that forgoing life support in compliance with the patient's and family's request is not assisting suicide, homicide, or euthanasia (mercy killing). The grant of judicial immunity for compliance with the family's request removed any doubt about legal consequences.[53]

Finally, the court went to some length to reconcile medicine's standards with the family's refusal of the respirator.[54] Though Karen's physicians opposed withdrawal of the respirator, other testimony and sources of medical ethics authority supported the family's request and the physician's duty to comply.[55] Many physicians felt compelled to continue life support for a dying patient, but many others refused to prolong an unwanted dying process for a patient whose condition was irreversible with no hope of cure or recovery.[56] Again, at the time, there was no definitive statement on the issue from the AMA or other leading medical organizations.[57] In sum, because there was no established practice standard, allowing Karen to die was *not contrary* to accepted medical standards.[58] The court's strongly worded conclusion was that "no external compelling interest of the State could compel Karen to endure the unendurable, only to vegetate a few measurable months with no realistic possibility of returning to any semblance of cognitive or sapient life."[59]

51. *Id.* at 664.

52. *Compare id.* at 662–64 (discussing the right to privacy and self-determination), *with id.* at 669–70 (discussing the criminal exposure under New Jersey's then-existing law on assisted suicide).

53. *See id.* at 669–71 (discussing the rationale and process to be followed for immunity from criminal and civil liability for all participants in the decision).

54. *See id.* at 664–69.

55. *See id.* at 656–57 (doctors' testimony); *id.* at 668–69 (discussion of medical ethics).

56. *See id.* at 669.

57. *See id.* at 665 (noting the rising medical dilemma presented by "the dramatic advance of medical technology"); *see also supra* note 33 and accompanying text (discussing the state of medical ethics at the time).

58. *See Quinlan*, 335 A.2d at 666–67.

59. *Id.* at 663. Five years earlier in *John F. Kennedy Memorial Hospital v. Heston*, this same court held that a hospital could overrule a mother's refusal of a lifesaving blood transfusion for her now-incompetent adult daughter that was based on their shared commitment to the Jehovah's Witness faith. *See* 279 A.2d 670, 674 (N.J. 1971). There, however, the state's interest was far weightier as the intervention was lifesaving and would likely restore the patient's health and well-being. *See id.*

Finding no conflict between the Quinlans' request and principles of medical ethics, the opinion issued a clarion call that the ultimate decisional authority rests with the patient and family, not with the physician.[60] "[T]he interests of the patient, as seen by her surrogate, the guardian, must be evaluated by the court as predominant, even in the face of an opinion Contra by the present attending physicians."[61] More broadly: "Determinations as to [who decides] must, in the ultimate, be responsive not only to the concepts of medicine but also to the common moral judgment of the community at large."[62] Thus, *Quinlan* rejects the time-honored view that law and society had ceded responsibility for medical-ethical decisions to physicians. Rather, principles of medical ethics must be responsive to society's legal and moral rules and values. Medicine would no longer be an insular profession that sets its own ethical standards.

By the mid-1980s, the AMA Council on Ethical and Judicial Affairs would issue a series of official statements and opinions embracing the position that it is ethically permissible to honor the request of an irreversibly dying patient to forgo life-sustaining treatment and to look to appropriate surrogates to make these decisions on the incompetent patient's behalf.[63] More than two centuries of physician paternalism must now yield to the new era of patient autonomy, where patients, families, physicians, and societal values are all moral players in decisions near the end of life. Ultimately, the patient's voice controls.[64]

60. *See Quinlan*, 355 A.2d at 664.

61. *Id.* at 663–64.

62. *Id.* at 665. The court made the following perhaps prescient statement: "this decision should be accepted by a society the overwhelming majority of whose members would, we think, in similar circumstances, exercise such a choice in the same way for themselves or for those closest to them." *Id.* at 664. This is another indication of the court's commitment to the principle that norms of the medical profession must yield to those of society and the values of patients and families. The court also expressly asserted the judiciary's role in resolving disputes and doing justice in particular cases, and its duty not to simply defer to medical judgment. *See id.*

63. *See* AMA Council on Ethical & Jud. Affs., *supra* note 33, at 1038.

64. Other developments in law and ethics in that period contributed significantly to the sea change from the long era of physician paternalism to the age of patient autonomy. For example, *The Belmont Report* from the U.S. Department of Health, Education, and Welfare gave the principle of respect for autonomy philosophical and policy credibility. *See generally* NAT'L COMM'N FOR THE PROT. OF HUM. SUBJECTS OF BIOMEDICAL & BEHAV. RSCH., THE BELMONT REP.: ETHICAL PRINCIPLES AND GUIDELINES FOR THE PROT. OF HUM. SUBJECTS OF RSCH. (1979) (outlining the foundational ethical principles of respect for persons, beneficence, and justice that govern the conduct of research involving human subjects). The reports of the President's Commission for the Study of Ethical Problems in Medical and Biomedical and Behavioral Research were extremely influential. *See generally* PRESIDENT'S COMM'N FOR THE STUDY OF ETHICAL PROBS. IN MED. & BIOMEDICAL & BEHAV. RSCH., MAKING HEALTH CARE DECISIONS (1982) (examining the ethical and legal foundations of

2. The Right of Religious Freedom

It was further argued that the First Amendment's free exercise of religion clause supports a right to refuse treatment, so long as the refusal of life-sustaining treatment is grounded in Karen's and her family's religious beliefs.[65] However, the court found no constitutional issue here.[66] This was a secular constitutional question and a religiously neutral one, a right that belongs to all, whether Catholic, Protestant, Jewish, Muslim, Buddhist, or Atheist; as such, the public interest was "paramount" and the case would be decided "without essential dissolution of respect for religious beliefs," and without privileging one religion or another.[67] Further, there is no independent right of parental religious freedom to make this decision.[68] The family's Catholic faith played a different role; it established that the removal of the respirator was consistent with Karen's and her family's values and wishes, was ethically permissible, and morally licit.[69] It also placed Joseph Quinlan's character beyond reproach in bearing this extraordinary burden.[70]

informed consent and recommending that patients and practitioners engage in a collaborative decision-making process); PRESIDENT'S COMM'N FOR THE STUDY OF ETHICAL PROBS. IN MED. & BIOMEDICAL & BEHAV. RSCH., DECIDING TO FOREGO LIFE-SUSTAINING TREATMENT (1983) (providing a comprehensive analysis of the ethical and legal frameworks governing decisions to halt life-sustaining medical interventions). In the 1970s, courts began to seriously examine the legal doctrine of informed consent. *See* Canterbury v. Spence, 464 F.2d 772, 786 (D.C. Cir. 1972) ("[T]he patient's right of self-decision . . . can be effectively exercised only if the patient possesses enough information to enable an intelligent choice."). While recognizing the patient's right to consent to or refuse treatment, many courts also took a more patient-centered approach to the physician's duty to provide patients with relevant information necessary to make informed decisions. *See* JESSICA W. BERG ET AL., INFORMED CONSENT: LEGAL THEORY AND CLINICAL PRACTICE 48–52 (2d ed. 2001) (discussing legal standards of disclosure and the emergence of the patient-oriented standard beginning in the 1970s); TOM L. BEAUCHAMP, STANDING ON PRINCIPLES: COLLECTED ESSAYS 50–78 (2010) (discussing the history and meaning of informed consent both in law and ethics). *Quinlan* stands out as the seminal case establishing the patient's right to refuse life-sustaining interventions. For a collection of short essays looking back on the first twenty-five years of bioethics, see generally Albert R. Jonsen et al., *The Birth of Bioethics*, 23 HASTINGS CTR. REP. (SPECIAL SUPP.) S1 (1993) (discussing the history of bioethics).

65. *See Quinlan*, 355 A.2d at 653, 661–62.

66. *See id.* at 661–62.

67. *Id.* at 661.

68. *Id.* at 661–62. The court also rejected the argument that mandating continued life support for a PVS patient violated the constitutional prohibition against cruel and unusual punishment. *Id.* at 662. In doing so, it held that this Eighth Amendment prohibition applies to penal sanctions and was thus irrelevant here. *Id.* Continued truncated life in PVS may be cruel and "most unusual," but it is not criminal. *Id.*

69. *See id.* at 657–59.

70. Though "the right to religious beliefs is absolute[,] . . . conduct in pursuance thereof is not wholly immune from governmental restraint." *Id.* at 661. Basing treatment refusal on religious grounds does not insulate such decisions from legal rules and restrictions. *See id.*

3. The Doctrine of Substituted Judgment

The opinion signaled a radical transformation of the way we understand the patient-family-physician relationship and the place of personal and societal values in shaping that relationship. The pivotal issue at the bedside is, whose wishes and values take precedence when patients and physicians disagree? In order to grant the requested relief, the court had to find both that a patient's constitutional and common law rights to privacy, autonomy, and self-determination are not lost when they become incapacitated, *and* that the right to refuse treatment may be exercised on their behalf by others.[71] Appointment of Joseph Quinlan as legal guardian with authority to make decisions on his daughter's behalf answered the question of *who* should exercise Karen's rights.[72] This reversed the trial court's ill-considered choice to continue the guardian *ad litem* as guardian of the person in place of Karen's father.[73]

How this decision should be made was a more challenging question. Not surprisingly, a young woman barely twenty-one years old had not given much thought to what she would want under the circumstances.[74] Trial testimony from friends and family asserted that Karen had said she "never wanted to be kept alive by extraordinary means," statements made in relation to close friends or relatives struggling with terminal illness.[75] But a handful of previous conversations was not enough evidence to conclude that Karen would refuse the respirator—the trial and appellate courts agreed on this point.[76] Joseph Quinlan was authorized to use his "best judgment" to effectuate Karen's interests and wishes, a decision he would make in consultation with his family.[77]

This has come to be known as the "substituted judgment" standard. Substituted judgment literally means that the decisionmaker is substituted for the decisionally-incapable patient, charged with

But personal religious beliefs are always relevant to determining the patient's wishes for end-of-life care. *See id.* at 657–69. Religious doctrine would later come to play an important role in policy debates about the scope and limits of treatment refusal, in particular regarding refusal of feeding tubes, and assertions of professional and institutional conscience in opposition to compliance with patient and family wishes. *See generally* The Ad-Hoc PEG Tube Study Grp., *When to Recommend a PEG Tube: A Decision Tree for Clinicians from a Catholic Perspective*, 79 LINACRE Q. 25 (2012) (discussing the moral and religious questions of the feeding tube presented to the Catholic faith).

71. *See Quinlan*, 355 A.2d at 664.
72. *See id.*
73. *See id.* at 670–71.
74. *See id.* at 663–64.
75. *In re* Quinlan, 348 A.2d 801, 814 (N.J. Super. Ct. Ch. Div. 1975).
76. *See Quinlan*, 355 A.2d at 664.
77. *Id.*

responsibility to make the decision the patient would make for herself if competent to do so.[78] A surrogate's (guardian's) primary task is to ascertain and effectuate what the patient would want.[79] In theory and practice, however, the decision to forgo life support also involves assessment of the patient's objective best interests. Families commonly consider a mix of subjective (patient's wishes) and objective (best interests) factors in making substituted judgments.[80] Karen's family and friends knew she had made prior statements disapproving of the use of extraordinary medical procedures to sustain life in circumstances like hers.[81] And they knew that "living" indefinitely in a vegetative state offended her personal values; thus, in exercising their best judgment, the Quinlans also considered what would be best for Karen.[82]

As devout Catholics, the Quinlans could not in good conscience direct withdrawal of the ventilator unless they could place this decision squarely within the teachings and tenets of their faith.[83] Traditional Judeo-Christian teaching holds that *extraordinary* medical treatment may be withheld or withdrawn based on the patient's wishes.[84] A widely accepted definition of this concept is that an intervention is extraordinary when it would impose excessive pain, suffering, expense, or inconvenience and offers no reasonable prospect of benefit for the patient.[85] By contrast, *ordinary* treatment offers a reasonable hope of benefit to the patient and does not impose excessive pain, suffering, expense, or inconvenience.[86] On this view of Catholic teaching, interventions considered ordinary are often deemed obligatory; those considered extraordinary are deemed optional and may be withheld or withdrawn.[87] The more nuanced view holds that

78. N.J. ADMIN. OFF. OF THE CTS., GUARDIANSHIP OF THE PERSON: DUTIES & RESPONSIBILITIES (2017), https://www.njcourts.gov/sites/default/files/courts/guardianship/guardianshippersonweb.pdf [https://perma.cc/L4J5-8587].

79. Norman L. Cantor, *Twenty-Five Years After* Quinlan*: A Review of the Jurisprudence of Death and Dying*, 29 J.L. MED. & ETHICS 182, 191 (2001) [hereinafter *Twenty-Five Years After* Quinlan]; Thaddeus Mason Pope, *Legal Fundamentals of Surrogate Decision Mak*ing, 141 CHEST J. 1074, 1077 (2012).

80. *See Twenty-Five Years After* Quinlan, *supra* note 79, at 191; Stewart G. Pollock, *Life and Death Decisions: Who Makes Them and By What Standards?*, 41 RUTGERS L. REV. 505, 518–25 (1989). Substituted judgment is discussed at greater length in Section II.B.2 below.

81. *See Quinlan*, 355 A.2d at 653.

82. *See id.* at 664.

83. *See id.* at 657–58.

84. *See* William B. Smith, *Judeo-Christian Teaching on Euthanasia: Definitions, Distinctions and Decisions*, 54 LINACRE Q. 27, 27–28 (1987).

85. *Id.* at 28.

86. *Id.*

87. For a succinct statement of this view, see Joseph Meaney, *Discerning Ordinary vs. Extraordinary Means in Catholic Bioethics*, NAT'L CATH. BIOETHICS CTR. (Oct. 30, 2020),

applying these concepts to particular cases involves asking whether the benefits of the treatment are proportional to its risks and burdens for the patient.[88] In consultation with Father Trapasso and aided by scholarly commentary, official Church pronouncements, and other experts, the Quinlans concluded that the ventilator sustaining Karen's biological life was an extraordinary intervention that imposed an extraordinary burden with no meaningful benefit, and that it was permissible to withdraw it to allow a natural dying process to take its course.[89] Focus on the concept of extraordinary means also mirrored Karen's own statements in the past.[90] The petition for authority to direct discontinuance of "all extraordinary medical procedures" sustaining Karen's life was carefully crafted in conformity with the family's values and best judgment.[91]

The court's opinion did not clearly define the concept of substituted judgment.[92] Since *Quinlan*, the doctrine of substituted judgment has become a core concept in decisions near the end of life.[93] As examined in Section II, the meaning, scope, and limits of surrogate decision-making have been among the most discussed issues in end-of-life law and practice. Of particular note, the proper standard of evidence would become a matter of controversy in the years to come. It was a central issue in the *Cruzan* case some fourteen years later.[94]

https://www.ncbcenter.org/messages-from-presidents/catholicbioethicsandvoting-rk6j5 [https://perma.cc/4NL8-MJRZ].

88. *See Quinlan*, 355 A.2d at 658–60 (discussing both interpretations of the Catholic position). *See generally* Richard A. McCormick, *'Moral Considerations' Ill Considered*, 166 AM. 210 (1992) (criticizing a statement from the bishops of Pennsylvania released in the aftermath of *Cruzan*). For broader discussion of the Catholic position, see AARON L. MACKLER, INTRODUCTION TO JEWISH AND CATHOLIC BIOETHICS: A COMPARATIVE ANALYSIS 85 *passim* (2003), and sources cited therein.

89. In review of Catholic doctrine, the court allowed an amicus curiae brief filed by the New Jersey Catholic Conference and reviewed the "allocutio" (address) of Pope Pius XII, in addition to the testimony at trial from a number of theologians. After a fashion, the teachings of the Church and the testimony of theologians played the part of moral and spiritual advisor. The stated purpose of the court's doctrinal exploration was to examine and confirm Joseph Quinlan's character, conscience, motivation, and commitment as guardian. Again, in the final analysis the court's decision is decidedly secular; no precedent concerning the role of religion in the civil law was intended, nor has the case been interpreted in this way.

90. *See In re* Quinlan, 355 A.2d 647, 653 (N.J. 1976).

91. *See id.* at 651.

92. *See id.* at 666–69.

93. *See, e.g.*, *In re* Jobes, 529 A.2d 434, 443–45 (N.J. 1987).

94. *See* Cruzan v. Missouri Dep't of Health, 497 U.S. 261, 280–85 (1990); *see also* discussion *infra* Section II.B (discussing evidentiary standards courts have applied for the exercise of substituted judgment).

4. Procedure and Safeguards

It had been some time since Karen's medical condition had been confirmed.[95] Even after the court's ruling, her treating physicians might still harbor concerns about criminal charges or civil suits. Her parents were free to transfer their daughter's care to other physicians, but they, too, might have had legal concerns.[96] To facilitate implementation of its decision, the court designed a process and safeguards for this and future similar cases.[97] In sum, if a current medical evaluation confirmed that her condition was irreversible with no reasonable prospect of recovery to a cognitive, sapient state, and the family maintained its request for withdrawal of the ventilator, an "ethics committee" of the hospital should be established and consulted.[98] If that committee agreed that Karen was still in PVS, the respirator could be withdrawn.[99] The family, physicians,

95. Often overlooked is the court's attention to establishing that Karen was a living patient in PVS for whom treatment decisions must be made, and that she was not "brain dead." The trial court received extensive testimony on this question from medical experts; much of which was reviewed and recited in the New Jersey Supreme Court's opinion. *See In re* Quinlan, 355 A.2d 647 *passim* (N.J. 1976). Looking back, this may seem an odd detour in the opinion. But at the time, New Jersey had not yet recognized the "irreversible cessation of all functions of the entire brain, including the brain stem," also known as neurological death or "whole brain death," as a legal standard of death. This language was promulgated in the Uniform Determination of Death Act. *See* UNIF. DETERMINATION OF DEATH ACT § 1, 12A U.L.A. 781 (1980). The Act has been adopted verbatim, or nearly so, in all fifty states and D.C. and is universally accepted in law, medicine, and society. *See* Nikolas T. Nikas, Dorinda C. Bordlee & Madeline Moreira, *Determination of Death and the Dead Donor Rule: A Survey of the Current Law on Brain Death*, 41 J. MED. & PHIL. 237, 237–43 (2016). For discussion of development of the whole brain death standard, see PRESIDENT'S COMM'N FOR THE STUDY OF ETHICAL PROBS. IN MED. & BIOMEDICAL & BEHAV. RSCH., DEFINING DEATH: A REPORT ON THE MEDICAL, LEGAL AND ETHICAL ISSUES IN THE DETERMINATION OF DEATH *passim* (1981). New Jersey is among the last states to legislate the definition of death. *See* N.J. STAT. ANN. § 26:6A-1 (West 1991). But New Jersey was the *first* state to include a religious exemption from a determination of neurological death. *See* Robert S. Olick, *Brain Death, Religious Freedom, and Public Policy: New Jersey's Landmark Legislative Initiative*, 1 KENNEDY INST. ETHICS J. 275, 275–77 (1991). The religious exemption, also recognized in some form in three other states—California, Illinois and New York—is another example of respect for patients' religious beliefs at the bedside. *See* Thaddeus Mason Pope, *Brain Death Rejected: Expanding Legal Duties to Accommodate Religious Objections*, *in* LAW, RELIGION, AND HEALTH IN THE UNITED STATES 293, 296–301 (Holly Fernandez Lynch, I. Glenn Cohen & Elizabeth Sepper eds., 2017) (discussing the states with religious exemptions). For more on death by neurological criteria, current controversies and religious exemptions, see Ariane Lewis et al., *Determination of Death by Neurologic Criteria in the United States: The Case for Revising the Uniform Determination of Death Act*, 47 J.L. MED. & ETHICS 9 *passim* (2019).

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

97. *See id.* at 671–72.

98. *See id.*

99. *See id.*

hospital, and others involved in implementing this decision would be immune from civil or criminal liability.[100] This grant of judicial immunity gave the health care professionals a safe harbor intended to ensure compliance with the family's wishes.[101] It also served to free physicians to exercise independent medical judgment in the best interests of dying patients in future cases.[102]

The ethics committee directive is the only part of Chief Justice Hughes' opinion to draw serious criticism. First, although the court used the term "Ethics Committee," it assigned to the committee the narrow medical task of confirming Karen's condition.[103] The court had itself resolved the legal and ethical issues, and they were not to be revisited or second-guessed by the committee. This made sense as a way to bring closure to the family's dilemma. But in the aftermath of *Quinlan*, some have found it more accurate to refer to the Quinlan committee as a "prognosis committee" that was concerned with clinical, not ethical, issues.[104] Second, this approach arguably ceded back to the medical profession some of the family's decisional authority, as a committee with a number of physician members would have a "final" say. Going a step further, *Quinlan* extended a grant of judicial immunity from civil and criminal liability for future cases in which the so-called *Quinlan* procedures are followed.[105]

As later interpreted by New Jersey hospitals, other courts, and the New Jersey Supreme Court itself, the so-called *Quinlan* procedure mandates prognosis confirmation for PVS patients by a "prognosis

100. *See id.*

101. *See id.*

102. *See id.* The concept of ethics committees was not advanced by any of the parties. It emerged from the justices themselves sua sponte, drawn from a 1975 law review article authored by pediatrician Karen Teel. *See* Karen Teel, *The Physician's Dilemma - A Doctor's View: What the Law Should Be*, 27 BAYLOR L. REV. 6 *passim* (1975). Teel envisioned a multidisciplinary ethics committee that shares responsibility for decisions and thereby diffuses the personal responsibility of the physician. *See id.* In the court's opinion, this diffusion of responsibility that would also be protective of the hospital and physicians was the most appealing feature of Teel's proposal. *See Quinlan*, 355 A.2d at 668–69. Most hospitals today have ethics consultants who serve this function rather than more cumbersome committees. *See infra* Section V. The participation of consultants, and sometimes committees, in the decision-making process typically helps to resolve disagreements. In that sense, it is protective of hospitals and physicians, but this does not confer any formal immunity from liability when conflicts do go to court.

103. *See Quinlan*, 355 A.2d at 671.

104. *See* Janet E. Fleetwood, Robert M. Arnold & Richard J. Baron, *Giving Answers or Raising Questions?: The Problematic Role of Institutional Ethics Committees*, 15 J. MED. ETHICS 137, 137 (1989); Susan M. Wolf, *Ethics Committees and Due Process: Nesting Rights in a Community of Caring*, 50 MD. L. REV. 798, 827 (1991).

105. *See Quinlan*, 355 A.2d at 668–71.

committee" comprised of physicians—or by qualified physicians in the absence of a committee—not a review of the ethical issues by a multidisciplinary ethics committee.[106] Hence, follows a third critique of the *Quinlan* procedures. Although the case is notable for its introduction of institutional ethics committees as participants in end-of-life decisions, the growth of ethics committees in hospitals and beyond was initially accompanied by confusion about their functions and those of prognosis committees.[107] As discussed in Section V, in subsequent years, multidisciplinary ethics committees and the involvement of individual ethics consultants would emerge as an important vehicle for shielding the privacy of end-of-life decisions, and for the embrace of a patient-centered ethic that empowers patients and families facing conflicts with physicians or other health care professionals.[108] Committees and consultants have contributed in major ways to the aspiration of *Quinlan* that these very personal decisions can be made privately, away from the public glare of the courtroom.[109] Their salutary and lasting contribution has been to serve as a local institutional process that allows disagreements to be resolved and controversial decisions to be made privately at the bedside in the vast majority of instances.[110]

C. After the Decision

As we would expect, the Quinlan family experienced a flood of emotions. They held in both heart and mind profound gratitude for the courage and compassion of Chief Justice Hughes and the entire court, alongside the somber expectation of transition to rites of passage. Shortly after the opinion was rendered, the family again asked that the respirator be removed and that St. Clare's Hospital convene an ethics

106. *See, e.g.*, Joseph C. d'Oronzio, Dorothea Dunn & John J. Gregory, *A Survey of New Jersey Hospital Ethics Committees*, 3 HEC F. 255, 255–56 (1991); *In re* Welfare of Colyer, 660 P.2d 738, 749 (Wash. 1983); *In re* Peter, 529 A.2d 419, 425 (N.J. 1987).

107. *See* Norman L. Cantor, Quinlan, *Privacy, and the Handling of Incompetent Dying Patients*, 30 RUTGERS L. REV. 243, 253–54 (1977) ("The New Jersey Supreme Court significantly circumscribed the prerogatives of an incompetent patient's guardian by injecting a hospital ethics committee, with ostensible veto power, into the decisionmaking process."); VEATCH, *supra* note 33, at 122–23 (noting confusion about the nature of ethics committees and stating that a close reading of *Quinlan* suggests a return of authority to physicians to decide whether to discontinue treatment).

108. *See infra* Section V.

109. *See, e.g.*, Andrew H. Malcolm, *The End of the Quinlan Case, but not the Issue it Raised*, N.Y. TIMES (June 16, 1985), https://www.nytimes.com/1985/06/16/weekinreview/the-end-of-the-quinlan-case-but-not-the-issue-it-raised.html [https://perma.cc/K243-YCQT].

110. *See Quinlan*, 355 A.2d at 669 ("Decision-making within health care . . . should be controlled primarily within the patient-doctor-family relationship . . . .").

(prognosis) committee pursuant to the court order.[111] This should have marked release from their tragedy, a final chapter in their long journey, and a return to a private life away from public scrutiny. Unfortunately, the attending physician in charge of Karen's care did not fully accept the decision and continued to maintain that he could not, in good conscience, simply remove the respirator.[112] Instead, the physicians chose to wean her from the respirator, removing it and then re-attaching it on a number of occasions when she failed to breathe on her own.[113]

Remarkably, after a time, Karen did have the strength to breathe on her own.[114] A short while later, she was transferred to Morris View Nursing Home, where she lived for another nine years until her death from pneumonia on June 11, 1985.[115] During these years, she received daily artificial nutrition and hydration through a nasogastric tube and, from time to time, antibiotics for infections. True to their Catholic faith, the Quinlans believed that the feeding tube and antibiotics were ordinary care and an expression of basic human caring.[116] They never requested that these treatments be stopped.[117]

II. EMERGENCE OF THE JUDICIAL CONSENSUS

The period from 1976 to 1990 was an exceptionally active period for the development of bioethics and law from the courthouse to the statehouse. State after state had its own highly publicized case that compelled the courts to confront the rights of patients and families nearing the end of life.[118] With rare exception, court after court followed the core approach of *Quinlan*, holding that incompetent patients retain

111. *See* McFadden, *supra* note 9.

112. *See* Joseph F. Sullivan, *Miss Quinlan Taken off Respirator Temporarily*, N.Y. TIMES (May 24, 1976), https://www.nytimes.com/1976/05/24/archives/miss-quinlan-taken-off-respirator-temporarily-miss-quinlan-reported.html [https://perma.cc/BG24-XDGN].

113. *See id.*

114. *See id.*

115. *See Chronology of Karen Ann Quinlan's Life*, UNITED PRESS INT'L (June 12, 1985), https://www.upi.com/Archives/1985/06/12/Chronology-of-Karen-Ann-Quinlans-life/2454487396800/ [https://perma.cc/TC5N-KB8K]; McFadden, *supra* note 9.

116. *See id.*

117. *See id.* Though press coverage of the Quinlan story abated during her years in the nursing home, the Quinlans' saga never left our national consciousness. On the occasion of Karen's 28th birthday the Quinlans received a letter from President Ronald Reagan extending the first couple's prayers and expressing that the family's love and devotion to their daughter was "inspiring to all of us." Letter from President Ronald Reagan to the Quinlans (on file with the authors).

118. Alan Meisel, *The Legal Consensus About Forgoing Life-Sustaining Treatment: Its Status and Prospects*, 2 KENNEDY INST. ETHICS J. 309, 309–10 (1993) [hereinafter Meisel, *Legal Consensus*].

the right to refuse unwanted life support and that family members may exercise this right on the patient's behalf under the rubric of substituted judgment.[119] While *Quinlan* spoke with extraordinary breadth, it was also limited by the primary task of resolving the dispute before it. A number of further significant issues were presented to other courts. Our discussion of the post-*Quinlan* judicial consensus centers on three of the most significant questions that courts and legislatures have repeatedly considered: 1) whether the right to refuse treatment applies equally to terminal illness, PVS and other serious life-threatening conditions; 2) whether patients have the same right to refuse artificially-provided nutrition and hydration as they do other medical modalities; and 3) defining the proper evidentiary standard for surrogate decision makers in the exercise of substituted judgment. We begin with the foundational rights of competent patients that ground the rights of incompetent patients. This Section concludes with *Cruzan*, the first and only refusal of life-sustaining treatment case to reach the U.S. Supreme Court.

Much of the debate has been framed under the banner of "Death with Dignity," an idiom that is still used to this day.[120] The phrase death with dignity implies that there are ways to die that are undignified, even inhumane—among them, prolonged pain and suffering, loss of ability to meaningfully interact with others, dependence on the armamentarium of medicine, reliance on the care and support of others for basic needs, loss of freedom due to physical disability or confinement to hospital or nursing home, and imposition of emotional and financial burdens on loved ones. To avoid or limit an undignified dying process and allow a natural dying process with supportive comfort measures to take its course is to die with dignity. Death with (in)dignity means different things to different people. The universal essential meaning of "death with dignity" is the right to die on one's own terms according to one's wishes and values.[121]

119. *See id.* (explaining that the judicial end-of-life consensus is established by "close to 75 similar cases" decided by courts across the country since *Quinlan*); *Twenty-Five Years After* Quinlan, *supra* note 79, at 189 ("Most jurisdictions have followed the pattern fixed by *Quinlan*."). Many of these cases are discussed in this section.

120. *See generally* NORMAN L. CANTOR, ADVANCE DIRECTIVES AND THE PURSUIT OF DEATH WITH DIGNITY (1993) (explaining that while contemporaneous and prospective autonomy differ, both are rooted in the common law principle of self-determination).

121. *Id.* at 54–55 (describing the various ways death with dignity is understood and emphasizing the importance of asserting control over the dying process); *see also* Timothy E. Quill, *Death and Dignity: A Case of Individualized Decision Making*, 324 NEJM 691 (1991) (providing a physician's account of his journey with a dying patient and the central importance of patient control over the dying process).

A. Patients and Families in the Courts: Competent Patients

In the absence of clear rules for dying, patients and families repeatedly found that the pursuit of death with dignity for themselves and their loved ones led to the courthouse, often cases of first impression for the state.[122] As courts across the country were called to resolve disputes between patients, families, physicians, and hospitals, judicial analysis turned first to the rights of competent patients to refuse unwanted interventions upon bodily integrity. As in *Quinlan*, the rights of competent patients ground those of incompetent patients.[123]

Treatment refusal by competent patients starts with the rights of self-determination and bodily integrity that ground the doctrine of informed consent.[124] The two core components of the doctrine are that intrusions upon the body, in the form of medical diagnosis or treatment, require the patient's voluntary consent, and that patients must be provided with appropriate information to make informed decisions.[125] The corollary of the right to consent is the right to say no to unwanted medical interventions, including life-sustaining treatment.[126]

A common formulation of informed consent describes it as a process in which patients voluntarily exercise their capacity to understand and reason about relevant information to decide whether to consent to or refuse a proposed treatment or intervention.[127] While patients possess rights of informed consent, physicians have corresponding obligations to disclose relevant information to their patients, including: 1) the nature of their medical condition, including diagnosis and prognosis; 2) the risks, benefits, and burdens of the recommended treatment or procedure; and 3) the risks, benefits, and burdens of reasonable alternatives, including

122. *See generally Legal Consensus About Forgoing Life-Threatening Treatment*, *supra* note 118 (discussing the seminal state cases that formed the judicial consensus).

123. *See generally* George J. Annas, *The Right to Die in America: Sloganeering from Quinlan and Cruzan to Quill and Kevorkian*, 34 DUQ. L. REV. 875 (1996) (providing a detailed discussion comparing the rights of competent patients with those of incompetent patients).

124. *See Twenty-Five Years After* Quinlan, *supra* note 79, at 183–85; *In re* Conroy, 486 A.2d 1209, 1221 (N.J. 1985) ("The starting point in analyzing whether life-sustaining treatment may be withheld or withdrawn from an incompetent patient is to determine what rights a competent patient has to accept or reject medical care.").

125. *See Twenty-Five Years After* Quinlan, *supra* note 79, at 183–85.

126. *See* BERG ET AL., *supra* note 64, at 44–52.

127. *See Informed Consent FAQs: What Is Informed Consent and When, Why, and How Must It Be Obtained?*, U.S. DEP'T OF HEALTH & HUM. SERVS., https://www.hhs.gov/ohrp/regulations-and-policy/guidance/faq/informed-consent/index.html [https://perma.cc/4L8N-8K3Q] (last visited June 13, 2026).

the option of no treatment.[128] Reasoning toward a treatment decision requires that the patient possess a set of values that shape their treatment goals.[129]

Courts have consistently ruled in favor of the competent patient's right to refuse life-sustaining treatment. Several well-known cases tested the limits of treatment refusal. A California appellate court upheld the right of Elizabeth Bouvia, a young woman with severe cerebral palsy and quadriplegia, to refuse a nasogastric tube.[130] A Georgia case upheld the right of Larry McAfee, who became quadriplegic following a motorcycle accident, to be disconnected from the ventilator sustaining his life.[131] Courts have upheld treatment refusals made on religious grounds, for example, the refusal of a blood transfusion by a Jehovah's Witness when facing life-saving surgery, even when treatment could restore the patient's health.[132] These cases are representative of a judicial consensus that the patient's right to refuse is not limited to any particular medical condition, is not dependent on the severity of illness or disease, and is not predicated on the type of medical intervention. The patient's view that continued medical interventions would mean an intolerable quality of life, together with the informed choice to allow a natural dying process to run its course, takes precedence over the contrary view of the patient's longevity and quality of life with treatment that may be held by the physician, hospital, or family.[133]

The right of competent patients to refuse unwanted life-sustaining interventions is so well-established that today, serious disagreements are rare, and going to court is even more unusual. A recent New Jersey case involved the rare circumstance of a thirty-year-old patient who had struggled with an eating disorder for more than ten years.[134] After ruling that she had a terminal condition and that she was competent to refuse artificial nutrition and hydration—a diagnosis and conclusion disputed by some psychiatrists—the court went on to hold that her refusal should

128. *See* RUTH R. FADEN, TOM L. BEAUCHAMP & NANCY M. P. KING, A HISTORY AND THEORY OF INFORMED CONSENT 30–35 (1986).

129. *See id.* at 242–47 (discussing how intentional actions are willed in accordance with a plan to achieve an outcome).

130. Bouvia v. Superior Ct., 225 Cal. Rptr. 297, 298–300 (Cal. Ct. App. 1986).

131. State v. McAfee, 385 S.E.2d 651, 651–53 (Ga. 1989).

132. *See, e.g.*, *In re* Osborne, 294 A.2d 372, 374–75 (D.C. 1972); *In re* Boyd, 403 A.2d 744, 748–49 (D.C. 1979) (upholding the right of a Christian Scientist to refuse medication).

133. *See generally* cases cited *supra* notes 130–32 (representing the judicial consensus of patient's right to refuse).

134. *In re* A.G., No. MRS-P-1448-2016 (N.J. Super. Ct. Ch. Div., Nov. 21, 2016). *See* Tom Davis, *N.J. Woman Didn't Want Food and Fought Until She Died*, PATCH (Mar. 1, 2017, at 16:54 ET), https://patch.com/new-jersey/morristown/n-j-woman-didnt-want-food-fought-until-she-died [https://perma.cc/32Z2-UBYB].

also be honored because her supportive family agreed and alternatively could make that decision on her behalf.[135]

Stepping back, we can take two enduring lessons from these cases. First, the rights of competent patients to say yea or nay to medical treatments are near absolute. This means that clinicians have a clear and firm obligation to respect the competent patient's informed decision to refuse life-sustaining treatment. Society's interest in preserving life must yield to the patient's own judgment as to whether their quality of life, characterized by disability and dependence on medical interventions, is worth continuing.[136] Second, when medical interventions could afford the patient a longer life with a different but perhaps desirable quality of life, there is reason to be more certain that the patient is making a truly informed choice to accept an earlier death. In the case of Larry McAfee, some disability advocates argued forcefully that refusal of the respirator could not be considered informed unless he was exposed to and educated about what life would be like as a quadriplegic, including talking to others similarly situated.[137] This did happen, and as a result, Mr. McAfee outfitted his home with assistive technologies and chose to delay exercise

135. *See A.G.*, No. MRS-P-1448-2016; Davis, *supra* note 134.

136. Protection of others from harm sometimes justifies exceptions to competent patients' rights to refuse any and all treatments. The U.S. Supreme Court in *Jacobson v. Massachusetts* upheld compulsory vaccination against smallpox, establishing a public health exception to treatment refusal. 197 U.S. 11, 39 (1905). Compulsory vaccination received considerable attention during the COVID pandemic. The core principle of *Jacobson* has been upheld in subsequent cases and remains good law more than a century later. *See generally* Ross D. Silverman, *The Role of Law and Ethics in Recent Preparedness and Response for Vaccine-Preventable Illness*, 135 PUB. HEALTH REPS. 851 (2020) (discussing the historical application of state police power to mandate public health interventions). Treatment may be ordered over the patient's objection to protect dependent children from harm. *See In re* President & Dirs. of Georgetown Coll., 331 F.2d 1000, 1008 (D.C. Cir. 1964), *cert. denied*, 377 U.S. 978 (1964) (involving a mother's blood transfusion, which was ordered because of her "responsibility to the community to care for her infant"). *Georgetown College* is cited with approval of this principle in *Tune v. Walter Reed Army Medical Hospital*. *See* 602 F. Supp. 1452, 1454 n.5 (D.D.C. 1985); *see also* Raleigh Fitkin-Paul Morgan Mem'l Hosp. v. Anderson, 201 A.2d 537, 538 (N.J. 1964), *cert. denied*, 377 U.S. 985 (1964) (reasoning that the interests of an unborn infant were sufficiently compelling to order a life-saving blood transfusion for a pregnant woman). As discussed in Section VII.C, we have already seen violations of patients' rights that privilege the interests of the unborn fetus post-*Dobbs*.

137. *See generally* Associated Press, *Larry McAfee, 39; Sought Right to Die*, N.Y. TIMES (Oct. 5, 1995), https://www.nytimes.com/1995/10/05/obituaries/larry-mcafee-39-sought-right-to-die.html [https://perma.cc/5T43-ZYBF] (obituary for Larry McAfee). *Cf.* Eleanor Smith, *Southern Voices: Killing Us Softly*, FACING SOUTH (Dec. 1, 1989), https://www.facingsouth.org/1989/12/southern-voices-killing-us-softly [https://perma.cc/ZLH6-Z8AA] (discussing backlash from disability activists following the case).

of his right to refuse until sometime later.[138] Such cases are uncommon, but they test the limits of treatment refusal by competent patients.

B. Patients and Families in the Courts: Incompetent Patients

The principle that incompetent patients have the same rights as competent patients and that these rights should not be lost due to incapacity is commonly recited and readily accepted in some form in judicial opinions, legislation, and legal commentary.[139] To hold otherwise would be to "permit obliteration of an incompetent's panoply of rights merely because the patient could no longer sense the violation of those rights."[140] Yet, it is not literally true that competent and incompetent patients enjoy the same rights.[141] The chief difference is that the incompetent patient's right to refuse life-sustaining treatment depends on their medical condition in ways that the competent patient's refusal does not.[142] In addition, because substituted judgments can be imperfect and less reliable than first-person consent, the surrogates' decisions are more open to question than those of the competent patient.[143] After summarizing the judicial consensus that establishes the incompetent patient's right to refuse life-sustaining treatment, this Section looks more closely at the scope and limits of this right, and at the doctrine of substituted judgment.

It is well-established that incompetent patients who are terminally ill or in PVS have the right to refuse life-sustaining treatment. Some courts have grounded the right to refuse treatment in a federal constitutional right of privacy, others in their own state constitutions, or both.[144] Most have chosen not to rely on constitutional rights and have looked instead to the common law.[145] As discussed above, the common law has long recognized the individual's right to control one's own body and to be free from nonconsensual bodily invasions.[146] The right to make

138. *See* Associated Press, *supra* note 137.
139. *See* discussion *infra* Section II.B.1.
140. Cantor, *supra* note 107, at 252.
141. *See* discussion *infra* Section II.B.1.
142. *See id.*
143. *See* discussion *infra* Section II.B.2.
144. *See, e.g.*, Gray v. Romeo, 697 F. Supp. 580, 586 (D.R.I. 1988); Rasmussen v. Fleming, 741 P.2d 674, 682 (Ariz. 1987); Corbett v. D'Alessandro, 487 So. 2d 368, 370–71 (Fla. Dist. Ct. App. 1986), *review denied*, 492 So. 2d 1331 (Fla. 1986).
145. *See, e.g.*, *In re* Fiori, 673 A.2d 905, 913 (Pa. 1996); Conservatorship of Drabick, 245 Cal. Rptr. 840, 845–46 (Cal. Ct. App. 1988); *In re* Est. of Longeway, 549 N.E.2d 292, 301–02 (Ill. 1989); *In re* Gardner, 534 A.2d 947, 952–53 (Me. 1987); *In re* Westchester Cnty. Med. Ctr. *ex rel.* O'Connor, 531 N.E.2d 607, 614–15 (N.Y. 1988).
146. *See* cases cited *supra* notes 144–45.

choices about one's own health care—both to accept and refuse treatment—is protected by the doctrine of informed consent.[147] Refusal of life-sustaining treatment is a logical application of this time-honored canon.[148]

Whether grounded in common law or constitutional law, the judiciary has consistently embraced the fundamental nature of the right, holding that it should not be lost when the ravages of illness, disease, or accident render us incompetent to exercise that autonomy.[149] Further, patients may request that treatment be withheld or withdrawn.[150] For legal purposes, this is a distinction without a difference.[151] To hold otherwise—that treatment could not be stopped once started—would discourage trials of potentially beneficial treatments.[152] It is settled law that "[a]ll patients, competent or incompetent, with some limited cognitive ability or in a persistent vegetative state, terminally ill or not terminally ill, are entitled to choose whether or not they want life-sustaining medical treatment."[153]

When balancing patients' rights with the state's potentially countervailing interests, patients' rights have almost invariably prevailed. The most significant of these interests is of course the preservation of life, understood to embrace "an interest in preserving the life of the particular patient, and an interest in preserving the sanctity of all life."[154] The judiciary has repeatedly stated that society's indirect and abstract interest in preserving life must yield to the individual's much stronger, direct, and personal claim to control over the course of his or

147. *See supra* note 127 and accompanying text (discussing core elements of the doctrine of informed consent); *In re* Conroy, 486 A.2d 1209, 1222 (N.J. 1985) (discussing the doctrine of informed consent as the foundation for the right to refuse treatment).

148. *See* discussion *supra* Section II.A.

149. *See Twenty-Five Years After* Quinlan, *supra* note 79, at 183–84.

150. *See In re* Peter, 529 A.2d 419, 423 (N.J. 1987).

151. *Id.* at 428.

152. *See* Jean-Louis Vincent, Commentary, *Withdrawing May Be Preferable to Withholding*, 9 CRIT. CARE 226, 227 (2005) (stating that refusal to permit withdrawal may introduce a degree of hesitation into decisions regarding treatments).

153. *Peter*, 529 A.2d at 423. For a cogent and insightful account of the bases for the right and end-of-life jurisprudence, see Pollock, *supra* note 80. Writing of New Jersey's rich history in this area, Justice Pollock explains that the right to refuse treatment is protected by the common law right of self-determination and the federal and state constitutions. *See id.* Justice Pollock's distinguished career as a member of the New Jersey Supreme Court spanned twenty years, from 1979 to1999. *See Associate Justice Stewart G. Pollock*, N.J. CTS., https://www.njcourts.gov/public/museum/meet-the-justices/associate-justice-stewart-g-pollock [https://perma.cc/VR7B-MACU] (last visited June 13, 2026). He was a true champion of patient and family rights.

154. *In re* Farrell, 529 A.2d 404, 411 (N.J. 1987) (quoting *In re* Conroy, 486 A.2d 1209, 1223 (N.J. 1985)).

her own life.[155] When patients refuse treatment in the face of an inexorable dying process, it is the underlying disease or condition that is the cause of death, not the forgoing of unwanted interventions.[156] Although identified as a distinct concern, the state's interest in preventing suicide is encompassed within the state's interest in preserving life.[157] A patient's choice of a personally preferred dying process is not an act of purposeful self-destruction that defines suicide.[158] Nor is withholding or withdrawing treatment assisting suicide.[159] This view is reaffirmed in *Glucksberg* where the Supreme Court drew a bright line between refusal of treatment and requests for physician-assisted dying.[160]

With respect to the state's interest in maintaining the integrity of the medical profession, courts have asked the same question posed in *Quinlan*, namely, whether the patient's refusal of life-sustaining treatment is consonant with existing norms of medical ethics promulgated by the profession.[161] This became an easy question in the post-*Quinlan* years. Judge after judge found that leading medical authorities—official policy statements from the state's professional and regulatory bodies, the AMA and many other national organizations, as well as medical testimony—strongly support the physician's professional obligation to respect a patient's right to self-determination, including refusal of life support, and the proper role of family, proxy, and guardians to exercise this right on the

155. *See* CANTOR, *supra* note 120, at 8–10.

156. *See id.* at 15–16.

157. *But see Farrell*, 529 A.2d at 411 (finding that "preserving life, preventing suicide, safeguarding the integrity of the medical profession and protecting innocent third parties" to be separate interests).

158. *See id.*; Bartling v. Superior Ct., 209 Cal. Rptr. 220, 225–26 (Cal. Ct. App. 1984); *In re* Gardner, 534 A.2d 947, 955–56 (Me. 1987); Foody v. Manchester Mem'l Hosp., 482 A.2d 713, 720 (Conn. Super. Ct. 1984).

159. *See* cases cited *supra* note 158.

160. In *Washington v. Glucksberg*, the United States Supreme Court held that there is no constitutionally protected right to physician-assisted suicide (also called physician-assisted dying or medical aid in dying (MAID)). 521 U.S. 702, 751 (1997). Writing for the majority, Chief Justice Rehnquist went to some lengths to distinguish the Court's prior ruling in *Cruzan* that the right to refuse treatment enjoys constitutional protection, stating that "the decision to commit suicide with the assistance of another . . . [is] widely and reasonably regarded as quite distinct." *Id.* at 725; *see also* Vacco v. Quill, 521 U.S. 793, 800–01 (1997) ("[T]he distinction between assisting suicide and withdrawing life-sustaining treatment, a distinction widely recognized and endorsed in the medical profession and in our legal traditions, is both important and logical; it is certainly rational."). Without constitutional protection, debates about MAID returned to the states. At present, thirteen states and D.C. have legalized the practice. *See End-of-Life Choice in Your State* (map), *in* COMPASSION & CHOICES, https://compassionandchoices.org [https://perma.cc/P6H3-CMPS] (last visited June 13, 2026).

161. *See In re* Quinlan, 355 A.2d 647, 664–69 (N.J. 1976).

incompetent patient's behalf.[162] The contention that decisions to terminate life support belong exclusively to the medical profession, a claim that so occupied the *Quinlan* court, quickly faded away.[163] Whether individual physicians may decline to comply with the patient's wishes as a matter of professional conscience is an important feature of bedside decision-making, one that has been addressed more often and more comprehensively by legislation than by case law. We discuss professional conscience separately in Section III.D.[164]

1. Scope and Limits of the Right to Refuse Treatment

The majority of reported cases have involved incompetent patients who were either terminally ill or in a persistent vegetative state.[165] As a consequence, it is widely accepted that treatment may be foregone when the patient is in one of these two conditions (categories).[166] Most of us think of terminal illness as meaning a condition that is irreversible and will unavoidably cause death. The concept of irreversibility is central to the legal definition as well; however, the formal legal definition of terminal illness (terminal condition) often focuses on prognosis for length of life remaining and can vary from state to state.[167] Following the rules

162. A clear statement of the AMA's position, with commentary, can be found in AMA COUNCIL ON ETHICAL & JUD. AFFS., CODE OF MEDICAL ETHICS: CURRENT OPINIONS WITH ANNOTATIONS 45 (1998–99 ed.). The commentary to this section includes an annotated listing of the many court decisions in which this section of the AMA Code has been cited by the courts. *See, e.g.*, Rasmussen v. Fleming, 741 P.2d 674, 685 (Ariz. 1987); Conservatorship of Drabick, 245 Cal. Rptr. 840, 845 (Cal. Ct. App. 1988); McConnell v. Beverly Enters.-Conn., 553 A.2d 596, 603 n.13 (Conn. 1989).

163. *See, e.g.*, Bouvia v. Superior Ct., 225 Cal. Rptr. 297, 301 (Cal. Ct. App. 1986) ("The right to refuse medical treatment is basic and fundamental . . . . It is not merely one vote subject to being overridden by medical opinion.").

164. As for the fourth state interest, the interests of others have not been found sufficient ground to override an incompetent dying patient's refusal of treatment. *See, e.g.*, *In re* Storar, 420 N.E.2d 64, 73 (N.Y. 1981) ("[A] court should not in the circumstances of this case allow an incompetent patient to bleed to death because someone, even someone as close as a parent or sibling, feels that this is best for one with an incurable disease."). A notable exception is sustaining the biological life of a pregnant woman for benefit of the fetus. *See infra* Section VII.C.

165. More of the cases have involved PVS patients. However, a number of courts characterized PVS as a terminal condition; this contributed to emergence of a consensus around treatment refusal when terminally ill. *See* ALAN MEISEL, THE RIGHT TO DIE 634–42 (2d ed. 1995) (listing cases). As discussed in Section III, this consensus is cemented by advance directive laws nationally that uniformly recognize the right to refuse life-sustaining treatment when terminally ill or in PVS. *See infra* Section III.

166. *See* MEISEL, *supra* note 165, at 641.

167. *See, e.g.*, Medical Aid in Dying for the Terminally Ill Act (MAID), N.J. STAT. ANN. § 26: 16-3 (West 2025) ("'Terminally ill' means that the patient is in the terminal stage of an irreversibly fatal illness, disease, or condition with a prognosis, based upon reasonable

for hospice care eligibility, common guidelines in clinical practice define a terminal condition as a prognosis of six months of life or less remaining.[168] As for other terms indicating the length of life remaining, some states consider likely death within a year to be terminal,[169] while others state that a terminal condition means death is imminent or will occur within a short time.[170] It is commonly understood that a terminal condition is determined regardless of whether life-sustaining treatment is provided.[171] Predicting how much longer the patient will live is not an exact science. When the choice of whether to continue life-sustaining treatment arises, physicians use their best considered judgment to answer the question of how long the patient has left.[172]

Trial courts look to testimony from the treating physician(s) to establish the patient's medical condition and prognosis.[173] Where this issue has been contested, courts have resolved a *battle of the experts* by reviewing the medical record and assessing the credibility of the testimony.[174] A handful of reported cases have involved patients in a minimally conscious state, and incompetent patients with substantial cognitive impairment and extremely limited capacity for interaction, but who are neither terminally ill nor clinically in PVS. Decisions in California[175] and Michigan[176]—both involving severe brain damage following a motor vehicle accident—and Wisconsin, involving Alzheimer's dementia,[177] all ruled against a family member's petition for

medical certainty, of a life expectancy of six months or less."); Rights of the Terminally Ill Act, NEB. REV. STAT. § 20-403 (2026) ("Terminal condition shall mean an incurable and irreversible condition that, without the administration of life-sustaining treatment, will, in the opinion of the attending physician, result in death within a relatively short time.").

168. *See, e.g.*, *Hospice Care*, MEDICARE.GOV, https://www.medicare.gov/coverage/hospice-care [https://perma.cc/A45L-PFPG] (last visited June 13, 2026).

169. *See, e.g.*, FLA. STAT. § 400.601 (1979) (""Terminally ill' means that the patient has a medical prognosis that his or her life expectancy is 1 year or less if the illness runs its normal course.").

170. *See, e.g.*, NEB. REV. STAT. § 20-403 (1992).

171. *See generally* David Crippen et al., Commentary, *Debate: What Constitutes 'Terminality' and How Does It Relate to a Living Will*, 4 CRIT. CARE 333 (2000) (providing insight on "terminality" from five physicians).

172. *Id.*; *see infra* notes 304–08 and accompanying text.

173. *See, e.g.*, *In re* Jobes, 529 A.2d 434, 438–40 (N.J. 1987).

174. *See, e.g.*, *id.* at 441.

175. Conservatorship of Wendland, 28 P.3d 151, 154 (Cal. 2001). The California Supreme Court limited its ruling to patients who are conscious and incompetent and have not put their wishes in writing or shared information about their preferences with a surrogate. *Id.* The preponderance of the evidence standard would apply for PVS patients and those who have a health care proxy or whose wishes are otherwise known to a surrogate by substituted judgment. *See id.* at 171.

176. *In re* Martin, 538 N.W.2d 399, 413 (Mich. 1995).

177. *In re* Edna M.F., 563 N.W.2d 485, 491–92 (Wis. 1997).

authorization to direct the forgoing of life support. These cases suggest a limitation on the right to refuse treatment based on the patient's medical condition. A better interpretation is that courts may demand more substantial evidence of the patient's intent to forgo treatment when their condition is not terminal, and they have some capacity for interaction, but that patients nonetheless retain the right to refuse.

These cases deciding "the other way" suggest that the irreversibility of the patient's medical condition will remain an important factor in balancing the right to refuse treatment with competing principles, especially as medicine's ability to prolong life and restore function continues to progress.[178] Recent progress in the treatment of patients with this or similar disorders of consciousness shows that some may be able to regain significant cognitive ability.[179] This could strengthen the argument for treatment in the patient's best interests despite prior refusal, at least on a trial basis, in future cases.[180]

Courts are unanimous in finding that the patient's right to refuse life-sustaining treatment is not dependent upon or limited by the nature of the *medical treatment* in question.[181] Of particular concern has been whether artificially provided fluids and nutrition constitute medical treatment, which a patient is entitled to refuse on the same basis as other forms of treatment, such as a respirator.[182]

In *In re Conroy*, the patient's nephew, acting as guardian of an eighty-four-year-old nursing-home patient with serious, irreversible physical and mental impairments, and a life expectancy of one year or less,

178. For another analysis of these cases, see Lawrence J. Nelson & Ronald E. Cranford, *Michael Martin and Robert Wendland: Beyond the Vegetative State*, 15 J. CONTEMP. HEALTH L. & POL'Y 427, 443–48 (1999) (criticizing the *Wendland* and *Martin* decisions for sharply distinguishing minimally conscious patients from PVS patients on policy grounds and being "far more concerned about projected social consequences to anonymous persons than the interests and rights of the particular injured individuals and their close family members").

179. *See* Megan S. Wright, Michael R. Ulrich & Joseph J. Fins, *Guardianship and Clinical Research Participation: The Case of Wards with Disorders of Consciousness*, 27 KENNEDY INST. ETHICS J. 43, 57–58 (2017) (reviewing guardianship law and arguing that guardians should be authorized to consent to research for those who might be able to regain cognitive capacity).

180. In the discussion below of whether advance directives are binding, we propose that it can be justified for a proxy acting in the patient's best interests to consent to a promising treatment that was not available when the patient authored their prior directive.

181. Meisel, *Legal Consensus*, *supra* note 118, at 315–16, 325 (stating that one of the key points of the consensus is that "[a]rtificial nutrition and hydration is a medical treatment and may be withheld or withdrawn under the same conditions as any other form of medical treatment").

182. *Id.* at 325. *See infra* notes 314–20 and accompanying text for discussion on forgoing of artificial nutrition and hydration.

requested withdrawal of her nasogastric feeding tube.[183] Although Ms. Conroy died during the pendency of the appeal, the court went on to discuss the issues at length and to set forth rules for future cases.[184] *Conroy* states that "artificial feedings such as nasogastric tubes, gastrostomies, and intravenous infusions . . . are medical procedures . . . equivalent to artificial breathing by means of a respirator. Both prolong life through mechanical means when the body is no longer able to perform a vital bodily function on its own."[185] The opinion accepts that, for some, including some healthcare professionals, artificial feeding may have symbolic and psychological significance as an expression of basic human caring, and be viewed as ordinary and obligatory, but rejects the argument that these positions should have legal significance.[186]

In sum, a "competent patient has the right to decline any medical treatment, including artificial feeding, and should retain that right when and if he becomes incompetent."[187] Following *Conroy*'s lead, courts nationwide have reached the same conclusion and have drawn no distinction between artificially-provided fluids and nutrition and other forms of life-sustaining interventions.[188] This position was reaffirmed by the U.S. Supreme Court in *Cruzan,* discussed separately below.[189]

While the judicial position here is clear and consistent, disagreement over artificially-provided fluids and nutrition has taken a different path in some state legislatures. In a handful of states, forgoing a feeding tube requires some specific evidence of the patient's intent. Advance directive laws have also given voice to health care provider objections to forgoing feeding tubes, couched as claims of professional or institutional conscience. We discuss each separately below.

183. *In re* Conroy, 486 A.2d 1209, 1216 (N.J. 1985).

184. *Id.* at 1219.

185. *Id.* at 1236.

186. *See id.* at 1235–37.

187. *Id.* at 1236.

188. *See, e.g.*, Rasmussen v. Fleming, 741 P.2d 674, 684 (Ariz. 1987); Conservatorship of Drabick, 245 Cal. Rptr. 840, 841 (Cal. Ct. App. 1988); Corbett v. D'Alessandro, 487 So. 2d 368, 371 (Fla. Dist. Ct. App. 1986), *review denied*, 492 So. 2d 1331 (Fla. 1986); Gray v. Romeo, 697 F. Supp. 580, 587 (D.R.I. 1988); McConnell v. Beverly Enters.-Conn., 553 A.2d 596, 602–03 (Conn. 1989).

189. *See infra* Section II.B.3. In a departure from this position, the trial court in the case of Paul Brophy, a Massachusetts fireman and medical technician in PVS, denied his wife's request to withdraw his feeding tube, ruling that feeding tubes are categorically different than other forms of life support. Brophy v. New Eng. Sinai Hosp., 497 N.E.2d 626, 637–38 (Mass. 1986). The Supreme Judicial Court of Massachusetts reversed, joining the national consensus. *See id.* The trial court opinion is discussed in George J. Annas, Patrick G. Derr & John J. Paris, *At Law: Do Feeding Tubes Have More Rights than Patients?*, 16 HASTINGS CTR. REP. 26, 26–28 (1986) [hereinafter Annas et al., *At Law*].

2. Substituted Judgment and the Evidentiary Standard

Like-minded courts have adopted the substituted judgment standard.[190] Time and again, a surrogate decisionmaker—most often a close and caring family member—has been charged with the responsibility to choose as the patient would for themselves under the circumstances if able to do so.[191] Substituted judgment is the vehicle for honoring the autonomy-based rights of incompetent patients on a par with those of competent patients.[192] Law has readily accepted the basic premise that "[a]lmost invariably the patient's family has an intimate understanding of the patient's medical attitudes and general world view and therefore is in the best position to know the motives and considerations that would control the patient's medical decisions."[193]

It is important to distinguish the doctrine of substituted judgment—a substantive standard and a practical mechanism—from the evidentiary standard surrogates must satisfy in the exercise of substituted judgment.[194] The appropriate evidentiary standard for the exercise of substituted judgment has been one of the most controverted and troublesome aspects of life and death litigation.[195] As courts have received testimony from family, friends, religious advisors, physicians, and others attesting the patient's prior statements, preferences, and values, they have repeatedly struggled with the probative value and reliability of the evidence presented, weighing such factors as specificity, consistency, remoteness in time, the thoughtfulness of prior statements and actions, and any contrary indications suggesting the patient would want to continue with life support.[196]

190. *See, e.g.*, *In re* Martin, 538 N.W.2d 399, 407–08 (Mich. 1995); *In re* Fiori, 673 A.2d 905, 911–12 (Pa. 1996).

191. *See Martin*, 538 N.W.2d at 407–08 (describing substituted judgment doctrine).

192. *Twenty-Five Years After* Quinlan, *supra* note 79, at 191; *see* Pope, *supra* note 79, at 1077.

193. *In re* Jobes, 529 A.2d 434, 445 (N.J. 1987).

194. The substituted judgment doctrine has its origins in estate administration and can be traced as far back as the early 1800's in English law. Thomas G. Gutheil & Paul S. Appelbaum, *Substituted Judgment: Best Interests in Disguise*, 13 HASTINGS CTR. REP. 8, 8 (1983). An early application of the doctrine in U.S. health care involved organ transplantation. *See* Strunk v. Strunk, 445 S.W.2d 145, 148–49 (Ky. 1969) (authorizing removal of a kidney from an incompetent adult "donor" for transplantation into his brother on the ground that both parties would benefit and that the donor would consent to the procedure if competent).

195. *See Martin*, 538 N.W.2d at 405–08 (recounting development of evidentiary standard of substituted judgment doctrine in sister states).

196. *See, e.g.*, *Jobes*, 529 A.2d. at 442–43 (citing *In re* Conroy, 486 A.2d 1209, 1230 (N.J. 1985)).

Courts have consistently found that in the exercise of substituted judgment, families have shown evidence sufficient to overcome the presumption in favor of continued life. Some have reached this conclusion without stating a formal evidentiary standard, have found a preponderance of the evidence or "some trustworthy evidence" interpreted by a surrogate in good faith to be sufficient, or have expressly rejected the clear and convincing evidence standard of proof as too demanding.[197]

The clear and convincing evidence test, applied in a minority of states, requires that there be "proof sufficient to persuade the trier of fact that the patient held a firm and settled commitment to the termination of life supports under the circumstances like those presented."[198] Some courts applying this standard require evidence of the patient's specific intent, finding that only the patient's prior statements count and setting aside family judgment of what is best for their loved ones,[199] but other courts have been less rigid.[200] Courts applying the clear and convincing evidence standard have less often ruled in favor of surrogate requests to terminate life support.[201]

Critics of substituted judgment have argued that it is a "legal fiction" to claim that substituted judgment is a subjective standard that

197. *E.g.*, *In re* Fiori, 673 A.2d 905, 912 (Pa. 1996) ("[W]e find the clear and convincing evidence test to be overly restrictive . . . ."); *Jobes*, 529 A.2d at 443 (involving some trustworthy evidence); *see* Conservatorship of Wendland, 28 P.3d 151, 175 (Cal. 2001) (affirming that preponderance of evidence test applies when there is some evidence of patient's wishes).

198. Cruzan v. Missouri Dep't of Health, 497 U.S. 261, 285 n.11 (1990) (quoting *In re* Westchester Cnty. Med. Ctr. *ex rel.* O'Connor, 531 N.E.2d 607, 613 (N.Y. 1988)); *see In re* Storar, 420 N.E.2d 64, 72 (N.Y. 1981), *cert. denied*, 454 U.S. 858 (1981); George J. Annas, *The Long Dying of Nancy Cruzan*, 19 L. MED. & HEALTH CARE 52, 58 (1991) [hereinafter Annas, *Long Dying*]. At least two states provide by statute that courts should adopt a clear and convincing standard in some circumstances. *See* CONN. GEN. STAT. ANN. § 19a-580c(a) (West 2026) (establishing that when evidence of the patient's wishes is not in writing "the court shall consider whether there is clear and convincing evidence of such communication"); MD. CODE ANN., EST. & TRUSTS § 13-712(b) (West 2026) (requiring that the court may make a substituted judgement to forego life-sustaining treatment for a disabled person "only on the basis of clear and convincing evidence" of what the disabled person would decide under the circumstances, if competent).

199. *E.g.*, Cruzan v. Harmon, 760 S.W.2d 408, 419–20 (Mo. 1988) (en banc). The *Cruzan* case is discussed *infra* Section II.B.3.

200. *See* Mack v. Mack, 618 A.2d 744, 758–61 (Md. 1993).

201. *See, e.g.*, *id.* at 760–61; *In re* Tavel, 661 A.2d 1061, 1069–71 (Del. 1995); *In re* Estate of Longeway, 549 N.E.2d 292, 300–02 (Ill. 1989). For many years New York also imposed the clear and convincing evidence standard. *E.g.*, *In re* Westchester Cnty. Med. Ctr. *ex rel.* O'Connor, 531 N.E.2d 607, 608 (N.Y. 1988). This standard was effectively overruled with the 2010 enactment of the Family Health Care Decisions Act, N.Y. PUB. HEALTH LAW § 2994-d(3)(a)(i) (McKinney 2020).

implements the intentions and preferences of the patient. Review of the caselaw of the 1980s led some legal scholars to conclude that the result reached to authorize termination of life support was rarely justified by the court's reasoning.

Law professor Nancy Rhoden concluded that "courts require a higher quantum of justification than is typically available, and are led to write opinions that misleadingly imply that such a justification is possible."[202] In her view, the cases wrongly equated decisions based on past expressions and probable preferences with the implementation of the patient's wishes.[203] In reality, the underlying rationale shows deference to families as the appropriate decision-makers and the implicit acknowledgment that substituted judgment properly promotes the dual values of respecting patient self-determination and promoting patient well-being.[204]

Law professor Rebecca Dresser concurs, stating that there is an inherent flaw in substituted judgment; it is an imaginative exercise and a "legal fiction" to claim this is a subjective standard.[205] She is highly critical of substituted judgment for this reason.[206] Dresser argues further that these conceptual infirmities mask courts' hidden resistance to taking responsibility for the quality of life judgments involved in deciding when the patient should be allowed to die.[207]

Others question the accuracy of substituted judgments with empirical data. A number of studies have found that family predictions of their loved ones' wishes are sometimes inaccurate.[208] One systematic literature review found that surrogates accurately predicted patients'

202. Nancy K. Rhoden, *Litigating Life and Death*, 102 HARV. L. REV. 375, 390 (1988).

203. *See id.* at 394–96.

204. *See id.* at 390–93. Rhoden contends that the remedy for this conceptual inconsistency would be to simply recognize a presumption in favor of family authority. *See id.* at 393–94. Those opposed to discontinuing treatment should bear the burden of proof to overcome this presumption. *Id.* at 441.

205. *See* Rebecca Dresser, *Life, Death, and Incompetent Patients: Conceptual Infirmities and Hidden Values in the Law*, 28 ARIZ. L. REV. 373, 383–88 (1986).

206. *See id.* at 404–05.

207. *Id.* at 399–404. In contrast to Rhoden, Dresser believes the law should abandon substituted judgment altogether in favor of an outright best interests analysis for incompetent patients. *See* Rebecca S. Dresser & John A. Robertson, *Quality of Life and Non-Treatment Decisions for Incompetent Patients: A Critique of the Orthodox Approach*, 17 L. MED. & HEALTH CARE 234, 240–41 (1989). Consistent with this position, Dresser also challenges the notion that prior expressions are the appropriate measure of the incompetent patient's current interests. *Id.* at 236–37.

208. *See* David I. Shalowitz, Elizabeth Garrett-Mayer & David Wendler, *The Accuracy of Surrogate Decision Makers: A Systematic Review*, 166 ARCH. INTERN. MED. 493, 494–96 (2006). This review included sixteen eligible studies. *See id.* at 493.

treatment preferences only 68% of the time.[209] The authors suggest that this data undermines the rationale that family members—or other trusted surrogates—are able to know and faithfully implement the wishes of seriously ill, dying patients.[210] Family predictions of how patients want their family to decide, for example whether to rely on the patient's prior expressions or their own view of best interests, can also be less accurate than we would hope.[211]

These are valid criticisms, but taken collectively, they hardly make the case to abandon the doctrine. To be sure, substituted judgments should accurately reflect the patient's wishes and values as often as possible. But these critiques mistakenly insist that substituted judgment is or must be a purely subjective standard—admittedly, this is the law's doctrinal definition.[212] In reality, families acting as surrogates typically look to a mix of subjective (patient's wishes) and objective (best interests) factors.[213] Loving family members are almost invariably the best-positioned not only to know the patient, but also to act in the patient's best interests—and not their own interests.

To reject substituted judgment is to repudiate the fundamental principle of end-of-life decisions for incompetent patients—that this very personal right to refuse treatment should not be lost when illness, disease, or accident rob us of our contemporaneous autonomy, and that it matters that the dying process be shaped by our own wishes and values. Strong objection reveals a distrust and rejection of the family's rightful place at the bedside. Moreover, if patients' wishes and family wisdom are set aside—if they do not come first—the default position is to look to the best interest judgments of physicians, hospitals, or judges, which are all unacceptable alternatives.[214] It is noteworthy that

209. *Id.* at 495.

210. *Id.*

211. Rashmi K. Sharma et al., *Family Understanding of Seriously Ill Patient Preferences for Family Involvement in Healthcare Decision Making*, 26 J. GEN. INTERN. MED. 881, 885 (2011).

212. *See* Dresser, *supra* note 205, at 376–79.

213. *See generally id.* (discussing that surrogates consider patient's preferences and best interests); Rhoden, *supra* note 202; Pollock, *supra* note 80. This has been our common experience consulting with patients, families and physicians over more than four decades. The family's decision-making process can also be described as seeking to ascertain the patient's probable wishes if clear and reliable evidence of the patient's actual, stated wishes cannot be ascertained. *See* Alan Meisel, *Suppose the Schindlers Had Won the* Schiavo *Case*, 61 U. MIA. L. REV. 733, 744–45 (2007).

214. *See* Scott J. Schweikart, *Who Makes Decisions for Incapacitated Patients Who Have No Surrogate or Advance Directive?*, 21 AMA J. ETHICS 587, 588 (2019).

physicians are worse at predicting their patients' wishes than are families, even when patients have written advance directives.[215]

A state's legal standard can have a significant impact on patient care decisions. The more stringent clear and convincing evidence test (the Delaware rule) can have a chilling effect on respect for patients' previously expressed wishes and on the authority of families to decide.[216] Holding families to a less rigorous standard, such as having some trustworthy evidence (the New Jersey rule), encourages greater deference to the special role of loving family members.[217] The small but significant number of courts to have denied a surrogate's authority to direct withholding or withdrawal of life support found that the patient's surrogate (most often a spouse) did not show by clear and convincing evidence that foregoing of life support was grounded in the patient's own wishes and not the family's view of their loved one's best interests.[218]

In practice, however, the law's evidentiary bar offers little guidance to those who must daily weigh and balance what is known of the patient's prior expressions. A preponderance of trustworthy evidence, or simply "sufficient evidence," approaches embraced by most courts, however phrased, is closer to bedside reality for patients and families, and expresses appropriate trust in the judgment of surrogates.[219] Yet, attaching a legal label to the degree of certainty needed to warrant termination of life support does little to assist family and physicians to decide when to take comfort in the belief that this is what the patient would want. At the bedside, recitation of the legal standard rarely enters the conversation.[220]

215. *See* Kristen M. Coppola et al., *Accuracy of Primary Care and Hospital-Based Physicians' Predictions of Elderly Outpatients' Treatment Preferences with and Without Advance Directives*, 161 ARCH. INTERN. MED. 431, 437 (2001).

216. *See* Cruzan v. Missouri Dep't of Health, 497 U.S. 261, 319–20 (1990) (Brennan, J., dissenting) (arguing that the clear and convincing evidence standard imposes an "obstacle to the exercise of a fundamental right"); *In re* Fiori, 673 A.2d 905, 912 (Pa. 1996) (rejecting the clear and convincing evidence standard as being "overly restrictive"); *see also In re* Tavel, 661 A.2d 1061, 1070–71 (Del. 1995) (describing the Delaware rule of clear and convincing standard).

217. *See, e.g.*, *In re* Jobes, 529 A.2d 434, 443 (N.J. 1987).

218. The best-known case is *Cruzan*, 497 U.S. at 284–87. *See* discussion *infra* Section II.B.3.

219. *See* Mark R. Tonelli, *Substituted Judgment in Medical Practice: Evidentiary Standards on a Sliding Scale*, 25 J.L. MED. & ETHICS 22, 23–25 (1997). *See, e.g.*, *In re* Conroy, 486 A.2d 1209, 1229–30 (N.J. 1985).

220. *Conroy* characterized the task of deciding for incompetent patients as consisting of three tests, each reflecting a place on "a continuum of subjective and objective information about the patient that will support a reliable decision." Pollock, *supra* note 80, at 518. As evidence of what the patient would want becomes weaker, other objective measures of the patient's interests take on greater significance and the standard begins to shade into a best

3. Treatment Refusal at the Supreme Court: *Cruzan*

When the U.S. Supreme Court agreed to hear the case of Nancy Beth Cruzan (1990), many feared the end-of-life consensus was in jeopardy. The Missouri decision to be reviewed was aberrational, out of keeping with the established national consensus.[221] For the Court, with five conservative appointees widely viewed as unfriendly toward the constitutional right of privacy,[222] this was a case of first impression.[223] These concerns proved largely, but not entirely, unfounded.

The bare facts of *Cruzan*[224] are similar to those of *Quinlan*. Nancy Beth Cruzan was a young Missouri woman who was seriously injured in a car accident.[225] After a period of time she was diagnosed as being in PVS, her life sustained by a gastronomy tube.[226] Nancy was able to breathe on her own without a respirator.[227] After several agonizing years, her parents, Joe and Joyce Cruzan, sought to discontinue the feeding tube sustaining her in this condition.[228] The hospital's refusal to comply with their request led to extended litigation through the Missouri courts to the U.S. Supreme Court.[229]

interests analysis. In some cases, the patient's wishes are sufficiently clear (the subjective test) to warrant termination of treatment. Under the limited-objective test, life support may be withheld or withdrawn "when there is some trustworthy evidence that the patient would have refused the treatment, and the decision-maker is satisfied that it is clear that the burdens of the patient's continued life with the treatment outweigh the benefits of that life for him." *Conroy*, 486 A.2d at 1232. Where trustworthy evidence is insufficient, or simply absent, the pure-objective test (objective best interests) may be applied to determine whether the burdens of continued life "clearly and markedly outweigh the benefits that the patient derives from life." *Id.* Under *Conroy* the objective best interests test also requires that the pain associated with continued treatment "would be inhumane." *Id.* This test would not apply for PVS patients, who do not experience pain, but treatment may be terminated on best-interests grounds for PVS patients without this added requirement. *See id.* at 1233. *Conroy*'s limited-objective test captures the process that often occurs informally for families and within the private confines of the physician-patient-family relationship at the bedside. *See id.* This offers a useful analytical frame, though much of the end-of-life jurisprudence does not use this term.

221. *See* Cruzan v. Harmon, 760 S.W.2d 408, 416–19 (Mo. 1988) (en banc); George J. Annas, *Nancy Cruzan and the Right to Die*, 323 NEJM 670, 671 (1990).

222. *See Justices Serving on the Court 1990–2009*, OR. STATE U., https://open.oregonstate.education/governmentpowers/back-matter/justices-1990-2009/ [https://perma.cc/9Z99-S4GN] (last visited June 13, 2026).

223. Cruzan v. Harmon, 760 S.W.2d 408, 412 (Mo. 1988) (en banc).

224. Cruzan v. Missouri Dep't of Health, 497 U.S. 261, 270–72 (1990).

225. *Id.* at 265–66.

226. *Id.* at 266.

227. *Id.*

228. *Id.* at 267.

229. *Id.* at 268. *See generally* WILLIAM H. COLBY, LONG GOODBYE: THE DEATHS OF NANCY CRUZAN (2002) (providing a first-hand account of the Cruzan family's struggles and

Initially, the Missouri trial court joined the chorus of judicial voices in support of the family's right to decide and appointed Nancy's parents as co-guardians with authority to direct the discontinuance of the feeding tube.[230] However, the Missouri Supreme Court disagreed.[231] Adopting a vitalist posture toward the state's interests, Missouri's highest court rejected the asserted right to refuse treatment, finding that "[t]he state's concern with the sanctity of life rests on the principle that life is precious and worthy of preservation without regard to its quality."[232]

Swimming against the tide, the court also refused to equate the rights of competent patients with those of incompetent patients, stating that "[i]t is logically inconsistent to claim that [fundamental rights to] personal autonomy can be exercised by another absent the most rigid of formalities."[233] The Missouri court took a dim view of substituted judgment, concluding that "it is definitionally impossible for a person to make an informed decision—either to consent or to refuse—under hypothetical circumstances."[234] In what would become the most-discussed part of the opinion, the court adopted the clear and convincing evidence standard, concluding that even assuming that Nancy's wishes could be implemented by her family,[235] her prior statements failed—in the court's view—to satisfy the standard of being "clear and convincing, inherently reliable evidence."[236] The Cruzans petitioned for certiorari to the U.S. Supreme Court.[237]

The High Court's decision reaffirmed the constitutional basis of the right to refuse treatment**.** Writing for the 5-4 majority, Chief Justice Rehnquist states that the "liberty interest in refusing unwanted medical

their courage in pursuit of a death with dignity for their daughter). Bill Colby served as the Cruzans' attorney throughout the protracted litigation. The book's title is poignant. Like many who have lost a loved one to PVS, loss of the person is felt long before death occurs. During the Cruzans' long struggle, which included significant media exposure, they befriended and received counsel from the Quinlans. The same was true of the attorneys for the two families.

230. Cruzan v. Harmon, 760 S.W.2d 408, 411–12 (Mo. 1988) (en banc).

231. *Id.* at 426–27.

232. *Id.* at 419.

233. *Id.* at 425.

234. *Id.* at 417.

235. *Id.* at 415.

236. *Id.* at 425, 427.

237. Cruzan v. Missouri Dep't of Health, 492 U.S. 917 (1989) (granting certiorari). The Missouri Supreme Court's ruling was issued by a seven-member panel with a vote of four to three. *See Cruzan*, 760 S.W.2d at 427. After the case was filed there was a vacancy on the court. *See id.* (noting concurrence of Special Judge Reinhard in the majority opinion); *Missouri History: Judges of the Supreme Court of Missouri 1820–2011*, MO. SEC'Y OF STATE, https://www.sos.mo.gov/archives/history/historicallistings/judges [https://perma.cc/8RDY-JGZX] (last visited June 13, 2026).

treatment may be inferred from our prior decisions."[238] The Court goes on to state that "for purposes of this case, we assume that the United States Constitution would grant a competent person a constitutionally protected right to refuse lifesaving hydration and nutrition."[239] Taken together, the majority and concurring opinions—eight of the nine justices, excluding Justice Scalia—agreed that the right to refuse life-sustaining treatment, including artificially provided fluids and nutrition, enjoys constitutional protections.[240] This position is most forcefully stated in Justice O'Connor's concurrence: "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."[241] Justice O'Connor's concurrence even suggests that implementing the decisions of a duly appointed health care agent "may well be constitutionally required."[242]

But the Cruzans did not get the relief they sought. Under *Cruzan*, it is constitutionally permissible, but not constitutionally required, for a state to impose appropriate procedural guidelines for treatment decisions on behalf of incompetent patients.[243] States retain authority to establish rules for dying patients, provided these rules do not unduly impinge on their protected rights.[244] Per the majority, the ultimate issue to be decided was whether the U.S. Constitution forbids the State's establishment of the procedural requirement of proof of the patient's wishes by clear and convincing evidence.[245] Holding that it does not, the majority upheld Missouri's clear and convincing evidence standard.[246]

Bolstering this conclusion, the majority endorsed the finding below that the evidence of Nancy's wishes did not meet this test.[247] It also showed a disturbing skepticism toward the family's position, stating that the State may choose to accept only evidence of the patient's wishes, "rather than

238. Cruzan v. Missouri Dep't of Health, 497 U.S. 261, 278 (1990).
239. *Id.* at 279.
240. *See* Annas, *supra* note 221, at 671.
241. *Cruzan*, 497 U.S. at 289 (O'Connor, J., concurring).
242. *Id.* Four dissenting Justices seem to agree with Justice O'Connor on the constitutional deference to be afforded advance directives. *Id.* at 302, 356 (Brennan, J., dissenting) (stating that the patient's right to refuse treatment is fundamental and the state's role is to limit procedural requirements to enhancing accurate determinations of the patient's wishes, not to impose "improperly biased procedural obstacles" that burden the right to refuse); *id.* at 356 (Stevens, J., dissenting) (arguing that decisions "should be controlled by persons who have her best interests at heart-not by a state legislature concerned only with the 'preservation of human life'").
243. *Id.* at 282, 284.
244. *See id.* at 273–79.
245. *Id.* at 280.
246. *Id.* at 285–87.
247. *See id.* at 285.

confide the decision to close family members."[248] Ultimately, the Cruzans were forced to return to the same Missouri trial court that had ruled in their favor years before for another hearing at which new—though limited—evidence of their daughter's wishes was presented.[249] Finally, nearly eight years after Nancy's tragic accident, the Cruzans got the relief they had long ago requested—authority to direct removal of the feeding tube.[250]

In its immediate aftermath, patient-rights proponents critiqued *Cruzan* on several grounds. Two leading scholars noted that the liberty interest in the Constitution does not require the heightened strict scrutiny standard for review of state actions and that the Court avoided calling the right to refuse treatment "fundamental."[251] Consequently, *Cruzan* "provides uncertain protection" of patients' rights.[252] Further, the clear and convincing evidence standard—and the Court—are out of touch with the fact that most people do not spend much time contemplating how they want to die and making plans. By insisting on this unreasonable level of proof, *Cruzan* discounts reliable information of the patient's wishes and distrusts the family; taken together, this effectively creates a presumption in favor of continued treatment.[253]

We agree with these criticisms, but view *Cruzan* more favorably with the benefit of hindsight, largely because it did little to alter patients' rights near the end of life. After a fashion, *Cruzan* was two steps forward, one step back. *Cruzan* disappoints by allowing states to demand the higher clear and convincing standard for the exercise of substituted judgment.[254] Far more importantly, it cemented the foundational right to refuse treatment and the family's right to decide on behalf of incompetent loved ones.[255] It put to rest controversies over whether withholding and withdrawing treatment are legally distinct, while affirming that patients have the same rights to refuse artificial nutrition and hydration as they do

248. *Id.* at 287.

249. *See generally* Annas, *Long Dying*, *supra* note 198 (discussing the standard of clear and convincing evidence regarding previous decisions and hearings that considered new evidentiary testimony supporting Cruzan's wishes).

250. *Id.* at 56.

251. *See* Larry Gostin & Robert F. Weir, *Life and Death Choices After Cruzan: Case Law and Standards of Professional Conduct*, 69 MILBANK Q. 143, 145 (1991).

252. *Id.*

253. *See id.* at 145, 168. These criticisms track Justice Brennan's dissent in which Justices Marshall and Blackmun joined. *See* Cruzan v. Missouri Dep't of Health, 497 U.S. 261, 301–30 (1990).

254. *See Cruzan*, 497 U.S. at 282–83.

255. *See id.* at 277–80.

any other medical modality.[256] It did not change any state laws.[257] From another vantage point, a salutary effect of *Cruzan* may be to have ingrained in the collective consciousness the potential evidentiary concerns that can arise with surrogate decisions, and the importance of conversations with one's family, proxy, and physician. *Cruzan* reminds us that one of the first questions to be asked at the bedside is, "How do we know what the patient would want?" The proliferation of advance directives offers an answer.

III. AT THE STATE HOUSE: ADVANCE DIRECTIVES SWEEP THE NATION

On the heels of *Quinlan*, in 1976, California became the first state to enact an advance directive law, titled the "Natural Death Act."[258] Parallel to the accretion of judicial rulings, over the next fifteen years, state after state enacted advance directive laws to empower patients to control how they die.[259] Today, all fifty states and Washington D.C. have advance directive laws that recognize the right of competent adults eighteen and older to put their wishes in writing and to have those wishes respected by others when illness, disease, disability, or accident deprive us of capacity for first-person consent.[260]

The critical role of state legislatures cannot be overstated. Litigation frames the issues around the facts and circumstances of the particular dying patient; the judiciary's ultimate responsibility is to resolve the dispute before it. Although many decisions have gone to further lengths to set forth rules and guidance for future cases, as did *Quinlan*, courts are not in the position to craft comprehensive prospective guidance across the range of issues and concerns that arise near the end of life. Fully aware of the limitations of their role, courts called upon their state lawmakers to develop more comprehensive approaches to decisions near

256. *See id.*

257. George J. Annas et al., *Bioethicists' Statement on the U.S. Supreme Court's Cruzan Decision*, 323 NEJM 686, 686 (1990) ("[T]he *Cruzan* decision does not alter the laws, ethical standards, or clinical practices permitting the forgoing of life-sustaining treatment that have evolved in the United States since the *Quinlan* case in 1976."); *see also* Meisel, *supra* note 213, at 739 ("[*Cruzan*] was largely a reflection of the consensus that was already in place. On substantive end-of-life decisionmaking issues, *Cruzan* broke no new ground.").

258. *See* CAL. HEALTH & SAFETY CODE §§ 7185–95 (repealed 2000). The germinal idea of advance directives can be traced to living wills in 1969. *See generally* Luis Kutner, *Due Process of Euthanasia: The Living Will, a Proposal*, 44 IND. L.J. 539 (1969) (discussing the legalities involved with living wills and a patient's contingencies contained therein).

259. *See* CANTOR, *supra* note 120, at 33–35.

260. *See generally id.* (providing an in-depth analysis of the advance directive consensus that developed between Quinlan and Cruzan, and how it mobilized state legislation).

the end of life.[261] The beck and call of the courts added to the clarion call of shifting societal norms and rising public opinion in support of patients' rights. All served to amass momentum behind legislative action.[262] The animating purpose of advance directive laws was to affirm the right of self-determination to accept or reject medical treatment, particularly life-sustaining treatment, and to establish a means for competent adults to ensure their wishes will be counted in shaping their post-competence treatment in pursuit of death with dignity.[263] It was thought that "putting it in writing" would solve the problem that plagued substituted judgment by providing clear and reliable documented evidence of the patient's wishes and instructions for end-of-life treatment, thereby putting patients in charge.[264]

After an overview of some of the basic features of the law, we continue the theme of putting patients and families first at the bedside with a closer look at three issues: the scope and limits of the right to refuse

261. *See, e.g.*, *In re* Jobes, 529 A.2d 434, 450 (N.J. 1987) ("[T]he Legislature is better equipped than we to develop and frame a comprehensive plan for resolving these problems."); *In re* Tavel, 661 A.2d 1061, 1067 (Del. 1995) (enactment of Delaware's Death With Dignity Act was a direct response to a prior Delaware case on the right to refuse treatment); Rasmussen v. Fleming, 741 P.2d 674, 692 (Ariz. 1987) ("[W]e urge our Legislature to respond to these matters within permissible constitutional limits.").

262. In two states a bioethics study commission drafted the bills that became law: The New Jersey Bioethics Commission, and The New York State Task Force on Life and the Law. *See* N.J. BIOETHICS COMM'N, THE NEW JERSEY ADVANCE DIRECTIVE FOR HEALTH CARE AND DECLARATION OF DEATH ACTS: STATUTES, COMMENTARIES AND ANALYSES 3 (1991); N.Y. TASK FORCE ON LIFE & THE L., LIFE SUSTAINING TREATMENT: MAKING DECISIONS AND APPOINTING A HEALTH CARE AGENT 94–101 (1987); N.Y. TASK FORCE ON LIFE & THE L., WHEN OTHERS MUST CHOOSE: DECIDING FOR PATIENTS WITHOUT CAPACITY, at vii.

263. These principles are recited in the legislative findings and preambles of most advance directive statutes. *See, e.g.*, COLO. REV. STAT. ANN. § 15-18.5-101(1) (West 2026); FLA. STAT. ANN. § 765.102(1)–(2) (West 2026); N.J. STAT. ANN. § 26:2H-54(a)–(c) (West 2026).

264. *See, e.g.*, COORDINATING COUNCIL ON LIFE-SUSTAINING MEDICAL TREATMENT DECISION MAKING BY THE COURTS, GUIDELINES FOR STATE COURT DECISION MAKING IN LIFE-SUSTAINING MEDICAL TREATMENT CASES 13–15 (2d ed., rev. 1993) (discussing a survey of 384 state trial judges nationally in which, although only 1% of judges indicated they had actually heard a case in which an advance directive was at issue, 82% believed "that a properly executed document representing the patient's wishes should be dispositive where the patient is not currently competent to express such wishes"). Among the few reported cases to involve an advance directive, at least two confirm this view. In *John F. Kennedy Memorial Hospital, Inc. v. Bludworth*, the high court of Florida declared that a comatose terminally ill patient's surrogate can implement an advance directive refusing continued life support without the need for court approval, finding that "a so-called 'living' or 'mercy' will . . . [is] persuasive evidence of [the] incompetent person's intention and it should be given great weight." 452 So. 2d 921, 926 (Fla. 1984). *Saunders v. State* characterized a living will as "evidence of the most persuasive quality" and a "clear and convincing demonstration" that the patient would refuse treatment if terminally ill. 492 N.Y.S.2d 510, 517 (N.Y. Sup. Ct. 1985).

treatment, whether advance directives are always binding in practice, and the role of professional and institutional conscience when in conflict with patient rights.

A. Overview of Advance Directive Laws

There are three approaches to planning ahead with advance directives. Proxy directives designate and empower a trusted family member, friend, or advisor to engage with the physician and healthcare team in the informed consent process and make decisions in accordance with the patient's wishes.[265] Living wills—also known as "instruction directives"—state the patient's wishes and directions to those responsible for the patient's care with some specificity, but do not designate a proxy.[266] A combined directive merges these two approaches into a single document.[267] Nearly all states recognize all three of these approaches to advance care planning.[268] New York,[269] Massachusetts,[270] and Michigan[271] laws formally recognize only the health care proxy by statute; however, individuals can still use combined forms in these states.[272] And living wills alone are still important evidence of the

265. *See* CANTOR, *supra* note 120, at 33, 41.

266. *See id.* at 33, 43.

267. This is a widely used description of the three basic approaches to advance care planning, found in numerous discussions of advance directives. *See, e.g.*, *id.* at 33–43 (describing these three approaches). National organizations that provide education about advance care planning, such as AARP and CaringInfo, discuss all three approaches and provide advance directive forms, typically a version of a combined form. *See, e.g.*, *Find Advance Directive Forms by State*, AARP, https://www.aarp.org/caregiving/financial-legal/free-printable-advance-directives/ [https://perma.cc/3U6N-6Z9B] (last visited June 13, 2026); CARINGINFO, https://www.caringinfo.org [https://perma.cc/9UUB-7PAB] (last visited June 13, 2026).

268. *See, e.g.*, N.M. STAT. ANN. § 24-7A-2 (A)–(B) (West 2026); N.J. STAT. ANN. § 26:2H-55 (West 2025); VA. CODE ANN. § 54.1-2983 (West 2026).

269. *See* N.Y. PUB. HEALTH LAW § 2980(8) (McKinney 2026).

270. *See* MASS. GEN. LAWS ANN. ch. 201D, § 2 (West 2026).

271. *See* MICH. COMP. LAWS ANN. § 700.5506(1) (West 2026) (using the term "patient advocate"); MICH. COMP. LAWS ANN. §§ 700.5507(1)-(2) (West 2025) (stating that the patient advocate designation may include express statements of the patient's wishes).

272. *See New York Advance Directive Planning for Important Healthcare Decisions*, CARINGINFO, [hereinafter *N.Y. Advance Directive Planning*], https://www.caringinfo.org/wp-content/uploads/New_York.pdf [https://perma.cc/QM7A-FUZ3] (last visited June 13, 2026); *Massachusetts Advance Directive Planning for Important Healthcare Decisions*, CARINGINFO, https://www.caringinfo.org/wp-content/uploads/Massachusetts.pdf [https://perma.cc/Z9BN-4KWG] (last visited June 13, 2026); *Michigan Advance Directive Planning for Important Healthcare Decisions*, CARINGINFO, https://www.caringinfo.org/wp-content/uploads/Michigan.pdf [https://perma.cc/MC7N-W57J] (last visited June 13, 2026).

patient's wishes in these states that should not be ignored.[273] Advance directives often provide the best and most reliable information about the patient's wishes.[274] Here, we focus on the role of the proxy, as designation of a proxy in a combined, integrated form is the preferred and most prevalent use of advance directives today.[275]

Advance directives take effect—i.e., are triggered—when the patient is determined to lack decisional capacity; that is, the ability to understand and appreciate the nature of his or her medical condition and the risks, benefits and consequences of the treatment options, including refusal of life-sustaining treatment, and to reach an informed decision.[276] This determination is made by the patient's attending physician or sometimes another qualified professional such as a nurse practitioner, and is documented in the medical record,[277] and must sometimes be confirmed by a second consulting physician.[278] It bears emphasis that these judgments are made by physicians daily in hospitals across the

273. *See* CANTOR, *supra* note 120, at 46–48.

274. *See id.*

275. *See* U.S. DEP'T OF HEALTH & HUM. SERVS., ADVANCE DIRECTIVES AND ADVANCE CARE PLANNING: LEGAL AND POLICY ISSUES 12–13 (2007), https://aspe.hhs.gov/sites/default/files/private/pdf/75366/adacplpi.pdf [https://perma.cc/G5CX-CQGG]. Other terms for the proxy or proxy directive are healthcare power of attorney, durable power of attorney for health care, attorney in fact and healthcare directive. *See State Health Care Power of Attorney Statutes: Selected Characteristics*, A.B.A. COMM'N ON L. & AGING, 1–2, 6, 9 [hereinafter *State Healthcare P.O.A. Statutes*], https://www.americanbar.org/content/dam/aba/administrative/law_aging/2019-sept-state-health-care-power-of-attorney-statutes.pdf [https://perma.cc/5SX2-65Y6] (last visited June 13, 2026). The proxy is formally known as the agent in New York, and as the health care representative in New Jersey. N.Y. PUB. HEALTH LAW § 2980(5) (McKinney 2026); N.J. STAT. ANN. § 26:2H-55 (West 2025).

276. *See* 2 MEISEL, *supra* note 165, at 153. By definition, advance directives are intended to take effect only when the patient has lost capacity for first-person informed consent. State laws make this explicit. Decisional capacity is often defined in terms very similar to the formulation above, though the precise language varies. *See, e.g.*, MD. CODE ANN., HEALTH-GEN. § 5-601(o)(1) (West 2026); N.H. REV. STAT. ANN. § 137-J:2(VI) (2026); WASH. REV. CODE ANN. § 71.32.020(8) (West 2026).

277. Advance directive laws uniformly assign the task of assessing patient capacity to physicians. *See* 2 MEISEL, *supra* note 165, at 153 ("The common statutory approach is to specify that one or two physicians must certify that the patient has lost decisionmaking capacity."). Some states have amended their statutes to authorize qualified nurse practitioners and physician assistants to assess capacity. *See infra* note 434 and accompanying text.

278. *See, e.g.*, N.Y. PUB. HEALTH LAW § 2983(1) (McKinney 2025) (requiring a second confirming opinion for decisions to withhold or withdraw life-sustaining treatment, and by a physician with relevant expertise for patients with diagnosed mental illness or a history of intellectual or developmental disability).

country.[279] Ordinarily there is no need to go to court for this purpose.[280] At the bedside, capacity assessments should be on a decision-specific basis. Patients may be able to make some decisions—i.e., choosing a proxy—but not others—i.e., weighing the risks and benefits of complex heart surgery, or may be able to make treatment decisions when lucid and in less pain though they were confused the day before. Patients should not be assumed to be incapable based on age or disability status. Respect for patient autonomy means facilitating opportunities for patients to give first-person consent, and to otherwise participate in decisions about their own treatment to the extent reasonable. With patients who retain some interactive abilities, it is a best practice for proxy and physician to engage the patient in a shared decision-making process.[281] While all states establish legal definitions of capacity and the physician's responsibility, some, but not all, states make these further nuances of capacity assessments explicit.[282] Upon a determination of incapacity, the locus of decision-making authority is reposed in the proxy.

In general, an individual can choose whomever they trust to serve as proxy—spouse, adult child, close friend, religious advisor—but, out of concern for conflicts of interest, most states prohibit the patient's physician or a long-term care provider from also serving as proxy.[283] Both law and ethics firmly establish that the proxy's first obligation is to make decisions in accord with the patient's wishes and values.[284] Secondarily, the proxy should also act in the patient's best interests.[285] This fiduciary

279. *See* 1 MEISEL, *supra* note 165, at 180 ("The customary practice of physicians in making determinations of incompetence in ordinary medical decision making has gradually become the accepted norm in right-to-die cases too.").

280. *See* Paul S. Appelbaum, *Assessment of Patients' Competence to Consent to Treatment*, 357 NEJM 1834 (2007).

281. *See* Linda Ganzini et al., *Ten Myths About Decision-Making Capacity*, 5 J. AM. MED. DIRS. ASS'N 263, 264–65 (2004); *see also* Appelbaum, *supra* note 280 (discussing and applying criteria of decisional capacity to a case study of an elderly, depressed and confused patient with diabetes mellitus refusing recommended amputation for a gangrenous foot).

282. For a more comprehensive approach to decisional capacity, see, e.g., N.J. STAT. ANN. §§ 26:2H-60 to -63 (West 2025); N.Y. PUB. HEALTH LAW § 2983(1) (McKinney 2026).

283. *See Choosing a Health Care Proxy*, NAT'L INST. ON AGING (Oct. 31, 2022), https://www.nia.nih.gov/health/advance-care-planning/choosing-health-care-proxy [https://perma.cc/N4NY-KGXS]; *Who Will Speak for You? A Guide to Choosing a Health Care Proxy*, COMPASSION & CHOICES (Apr. 25, 2025), https://compassionandchoices.org/news/who-will-speak-for-you-a-guide-to-choosing-a-healthcare-proxy/ [https://perma.cc/NQM9-KAD9].

284. *See, e.g.*, N.J. STAT. ANN. § 26:2H-61(f) (West 2025).

285. *See id.* ("[T]he health care representative shall seek to make the health care decision the patient would have made had he possessed decision making capacity under the circumstances, or, when the patient's wishes cannot adequately be determined, shall make a health care decision in the best interests of the patient."). A clear articulation of the proxy's dual authority is Rose Mary Bailly, *Healthcare Proxies: Appointing People with the*

responsibility and its dual nature are recited in statutory law defining the proxy's responsibilities and in the standard text of proxy/advance directive forms.[286] Physicians, hospitals, and all healthcare professionals caring for the patient are obligated to respect the rights and authority of proxies and to honor the patient's wishes.[287] Seeking to encourage respect for advance directives at the bedside, statutory immunity from civil and criminal liability and professional discipline attaches when clinicians and health care facilities act in good faith to respect the patient's wishes (at the proxy's direction) to forgo treatment in accordance with accepted medical standards.[288] The full import of these immunity provisions has not been tested in court.[289]

Power to Make Healthcare Decisions for Others, ALB. L. SCH. (Jan. 27, 2020), https://www.albanylaw.edu/media/9806 [https://perma.cc/TKX5-QZ6T]. This "explainer" from the Government Law Center at Albany Law School discusses the New York proxy law. *Id.* ("The agent must make decisions in accordance with the principal's wishes, including their religious and moral beliefs. If the principal's wishes are not reasonably known, and cannot be ascertained with reasonable diligence, the agent must act in accordance with the principal's best interests."). *Id.*

286. *See* N.J. STAT. ANN. § 26:2H-61(f) (West 2025). There is a multiplicity of forms available for advance health care planning, including state-specific forms available from state agencies, local hospitals, and other various organizations. Among the many resources for advance directive forms is *Find Advance Directive Forms by State*, *supra* note 267. Several states include model forms in their statutory law, but it is not required that individuals use this or any other specific form. Legal formalities—e.g., signing, witnessing, revocation—for valid execution of directives are highly uniform across the states. Documents executed in one state are recognized in another if valid under the law of either state (reciprocity). *See* Charles Sabatino, *Can My Advance Directives Travel Across State Lines?: An Essay on Portability*, 38 BIFOCAL 3, 3–4 (2016) (noting that "most . . . states have provisions explicitly validating out-of-state advance directives"). For a fifty-state table that lists some of the formalities and core features, see *State Healthcare P.O.A. Statutes*, *supra* note 275, at 1–2, 6, 9.

287. For discussion of whether advance directives must always be followed, see discussion *infra* Section III.C. For the physician's perspective on the general obligation to respect patient autonomy, proxies and directives, see *Advance Directives*, AMA CODE OF MED. ETHICS, https://code-medical-ethics.ama-assn.org/ethics-opinions/advance-directives [https://perma.cc/GX34-M48H] (last visited June 13, 2026).

288. *See* Charles P. Sabatino, *The Evolution of Health Care Advance Planning Law and Policy*, 88 MILBANK Q. 211, 213 (2010) [hereinafter Sabatino, *Evolution*] (discussing the rationale for immunity provisions). Statutory immunity for good faith compliance with patient/proxy wishes typically applies to criminal and civil liability and to discipline for unprofessional conduct. For examples of statutory language, see, e.g., GA. CODE ANN. § 31-32-10 (West 2026); MD. CODE ANN., HEALTH–GEN. § 5-609(a)(1) (West 2026); 20 PA. CONS. STAT. § 5431(a)(1)–(2) (2026).

289. In a handful of cases, healthcare provider refusal to honor the patient's wishes has resulted in lawsuits known as "wrongful life suits" alleging that life-sustaining treatment was wrongfully continued. These cases have seen mixed results. Some legal experts see a growing threat of litigation when patients' directives are disregarded. *See* Samuel D. Hodge, Jr., *Wrongful Prolongation of Life – A Cause of Action That May Have Finally Moved into the Mainstream*, 37 QUINNIPIAC L. REV. 167, 183–98 (2019) (discussing wrongful

The role and responsibilities of the health care proxy reflect the same conceptual structure as the doctrine of substituted judgment. The proxy's charge is to form a coherent narrative of what the patient would want under the circumstances and to reach an informed decision on this basis.[290] Terms of the directive are the foundation for this undertaking, but fidelity to the patient's wishes also means looking beyond the four corners of the document to what the proxy, as well as close family and others, know about the patient's intentions, values, preferences, and interests.[291]

This picture serves to inform and authenticate the interpretation and implementation of the patient's directive, and most often affirms its authenticity and accuracy.[292] On occasion, it reveals evidence contrary to the patient's wishes that must be reconciled. The written document, formalized by its valid execution, suggests the patient has given careful thought to their treatment choices. Combined directives prompt individuals to consider not only which anticipated medical conditions may be unacceptable, but also which medical interventions—e.g., chemotherapy, resuscitation, ventilator support, dialysis, surgery, feeding tubes, etc.—are to be withheld or withdrawn.[293] While the primary intent of directives is to refuse treatment near the end of life, they may also direct that medical interventions to sustain life be provided.[294]

The proxy may also be empowered to refuse nursing home placement or request home hospice care, palliative care, consent to organ donation, or be directed to consult with other family members.[295] Treatment refusal

prolongation of life cases); *Hospitals Sued for Wrongful Prolongation of Life: Ethicists Offer Unique Expertise*, CLINICIAN.COM: MED. ETHICS ADVISOR (Apr. 1, 2021), https://www.clinician.com/articles/147766-hospitals-sued-for-wrongful-prolongation-of-life-ethicists-offer-unique-expertise [https://perma.cc/6KBG-W926].

290. *See* CANTOR, *supra* note 120, at 74–75.

291. *See id.* at 74–77.

292. *See id.*

293. The many advance directive forms available for use are designed to comply with their respective state laws. Any of the forms available through AARP & CaringInfo, for example, see *Find Advance Directive Forms by State*, *supra* note 267; *see also N.Y. Advance Directive Planning*, *supra* note 272, will prompt individuals to consider both anticipated medical conditions and specific medical modalities. The precise language may vary from one state to the next, as will the list of medical modalities in the printed form. It is common for advance directive forms to allow individuals to write in additional personal preferences for end-of-life care.

294. *See Advance Directives*, *supra* note 287.

295. Forms typically provide space for individuals to express their personal preferences regarding any of these matters. Standard form language commonly prompts individuals to choose whether to be an organ donor. State forms are available from a number of sources.

is always accompanied by pain relief and comfort measures to ease the dying process.[296] This is commonly recited in the directive's standard form language and is also considered a professional obligation.[297] Consistent with the right to give informed consent or refusal, the proxy controls access to the patient's otherwise confidential health information.[298]

Specificity of the document suggests that the directive is controlling; to follow its terms is to honor the patient's wishes. This is most often, but not always, true. Advance directives do not answer all questions about what the patient would want; they do not always satisfy the subjective test for surrogate decisions.[299] And, as discussed below, they are not absolutely binding. There are times when the directive fails to provide sufficient guidance or should be overridden in the patient's best interests.

B. Scope and Limits of the Right to Refuse Treatment

Statutory language often declares that the proxy can make any and all treatment decisions the patient could make if competent; the same

See Find Advance Directive Forms by State, *supra* note 267; *see also N.Y. Advance Directive Planning*, *supra* note 272.

296. *See* AMA, *The Code Says: AMA Code of Medical Ethics' Opinions on Care at the End of Life*, 15 AMA J. ETHICS 1038, 1039 (2013).

297. *Id.* ("Physicians have an obligation to relieve pain and suffering and to promote the dignity and autonomy of dying patients in their care."); *see also* John M. Luce & Ann Alpers, *End-of-life Care: What Do the American Courts Say?*, 29 CRIT. CARE MED. N40, N40 (2001) ("End-of-life care of critically ill patients generally consists of two closely related practices: the withholding and withdrawal of life support, and the administration of palliative care."). While both palliative care and hospice care focus on relief of pain and symptoms, palliative care refers to specialty care for patients with life-threatening illness "without regard for life expectancy," while hospice care focuses more narrowly on symptom management, quality of life and comfort through the dying process for patients with a prognosis of six months or less. *See The Difference Between Hospice Care and Palliative Care*, HOSPICE FOUND. AM. (Nov. 20, 2024), https://hospicefoundation.org/the-difference-between-hospice-care-and-palliative-care/ [https://perma.cc/EN97-HJS9]. For a basic description of pain and symptom management and of hospice care, see *End-of-Life Options for Care and* Choice, COMPASSION & CHOICES, https://compassionandchoices.org/resource/end-of-life-options-for-care-and-choice/ [https://perma.cc/EDQ2-54DW] (last visited June 13, 2026).

298. *See generally* Linda Farber Post, Jeffrey Blustein & Nancy Neveloff Dubler, *Introduction: The Doctor-Proxy Relationship: An Untapped Resource*, 27 J.L. MED. & ETHICS 5 (1999) (discussing the nature of the physician-proxy relationship and the ways the proxy "stands in the shoes" of the patient to exercise the patient's rights of informed consent). A number of states make explicit that the proxy has the same rights of informed consent as the patient, including to access and manage information. *See, e.g.*, N.Y. PUB. HEALTH LAW § 2982(3) (McKinney 2026); 20 PA. CONS. STAT. § 5456(a) (2026).

299. *See Advance Care Planning: Advance Directives for Health Care*, NAT'L INST. ON AGING, https://www.nia.nih.gov/health/advance-care-planning/advance-care-planning-advance-directives-health-care [https://perma.cc/Q4R4-FE7N] (last visited June 13, 2026).

principle was embraced by courts as a foundational principle for substituted judgments.[300] However, the statutory rules do not live up to this promise. Mirroring the caselaw, advance directive laws uniformly permit refusal of life-sustaining treatment when the patient is either terminally ill or permanently unconscious (including but not limited to PVS).[301] That the patient is terminally ill or permanently unconscious typically requires the determination of the attending and a second concurring physician or qualified clinician.[302] While there are well-established clinical criteria for the diagnosis of PVS,[303] terminal illness is as much a concept as a medical condition.[304]

An important consideration is that the definition of "terminal condition" varies among the states. "Terminal" may be defined as death within one year or "in a relatively short time," or a condition where continued life support will only "prolong the process of dying."[305] A common guideline is that death is reasonably likely to occur within six months—again, tracking hospice rules.[306] It is understood in clinical practice that terminal prognoses can be uncertain; dying is a process, not an event, the course and timing are often stated in terms of days, weeks, or even months, and sometimes predictions of life expectancy can be wrong.[307] Medicine is often as much art as science. Given uncertainty,

300. *See, e.g.*, N.Y. PUB. HEALTH LAW § 2982(1) (McKinney 2026) ("Subject to any express limitations in the health care proxy, an agent shall have the authority to make any and all health care decisions on the principal's behalf that the principal could make."); *see also In re* Jobes, 529 A.2d 434, 444 (N.J. 1987) (noting that the substituted judgments doctrine "is intended to ensure that the surrogate decisionmaker effectuates as much as possible the decision that the incompetent patient would make if he or she were competent").

301. *See Twenty-Five Years After* Quinlan, *supra* note 79, at 182–83; *see also, e.g.*, N.J. STAT. ANN. §§ 26:2H-67(a)(2), (3) (West 2025) (stating that "life-sustaining treatment may be withheld or withdrawn from a patient" where "the patient is permanently unconscious" or "the patient is in a terminal condition").

302. *See, e.g.*, N.J. STAT. ANN. § 26:2H-67(a) (West 2025).

303. *See* The Multi-Soc'y Task Force on PVS, *supra* note 25, at 1501 (1994); Eelco F. M. Wijdicks & Ronald E. Cranford, *Clinical Diagnosis of Prolonged States of Impaired Consciousness in Adults*, 80 MAYO CLINIC PROC. 1037, 1040 (2005).

304. *See* David Hui et al., *Concepts and Definitions for "Actively Dying," "End of Life," "Terminally Ill," "Terminal Care," and "Transition of Care": A Systematic Review*, 47 J. PAIN & SYMPTOM MGMT. 77, 77–78 (2014); *see also supra* notes 167–74 and accompanying text.

305. *See* MEISEL, *supra* note 165, at 96–99.

306. *See, e.g.*, N.J. STAT. ANN. § 26:2H-55 (West 2025) ("[A] prognosis of a life expectancy of six months or less, with or without the provision of life-sustaining treatment, based upon reasonable medical certainty, shall be deemed to constitute a terminal condition."); *see also* Abigail M. Lowin, *Changing the Means to Justify the End: Recommendations for the New York Palliative Care Information Act*, 49 COLUM. J.L. & SOC. PROBS. 167, 187–88, 196–98 (2015) (discussing definitions and meanings of terminal illness diagnosis in four states with statutes addressing "right to information" about palliative care options).

307. Alan B. Astrow & Beth Popp, *The Palliative Care Information Act in Real Life*, 364 NEJM 1885, 1885 (2011) ("Whereas the prognosis of patients with advanced cancer can

criteria, and life expectancy may be interpreted flexibly at the bedside to honor the patient's wishes for comfort through the dying process.[308] However, the law's definition of a terminal condition shapes the boundaries for permissible refusal of treatment.

This *medical condition limitation* is an unwelcome restriction for many patients. The cases involving minimally conscious, severely debilitated patients noted earlier illustrate the dilemma for patients, families, and proxies.[309] In those cases, notwithstanding patient and family refusal, treatment was ordered to continue because the patient's medical condition did not fall into the categories of PVS or terminal condition.[310] This same obstacle could arise for other patients—consider cardiovascular disease or progressive dementia—who are neither permanently unconscious nor terminally ill, but who may find their quality of life intolerable and prefer to be allowed to die.

Some states allow forgoing of life-sustaining treatment when the patient has a progressive, irreversible condition that does not meet the definition of "terminal," but based on the patient/proxy's wishes, the burdens of continued intervention outweigh the benefits. Florida law uses the term "end-stage condition."[311] Oregon law authorizes forgoing treatment for "progressive, debilitating illness that will be fatal and is in its advanced stages."[312] New Jersey permits forgoing life-sustaining treatment for patients with a non-terminal "serious irreversible illness or condition" where the likely risks and burdens of continued treatment outweigh the benefits, or continued interventions would be inhumane.[313] These states are representative of a more expansive view of qualifying medical conditions found in some states.

Again, mirroring the judicial consensus, advance directives may refuse any and all unwanted medical modalities. However, some states have treated the forgoing of artificially provided fluids and nutrition differently, carving out a *medical treatment limitation*. A number of states require a specific statement in the document to forgo artificially-

often be estimated, 75% of people in the United States die of conditions other than cancer, such as cardiovascular disease, chronic lung disease, Alzheimer's disease, and other illnesses whose timing and course are far less predictable."). The authors describe one of their patients, an eighty-five-year-old man with gastrointestinal cancer spread to his lungs who was on home hospice care but "far outlived his predicted life expectancy." *Id.* at 1886.

308. *See* Melahat Akdeniz, Bulent Yardimci & Ethem Kavukcu, *Ethical Considerations at the End-of-Life Care*, 9 SAGE OPEN MED. 1, 1–4 (2021).

309. *See supra* notes 175–79 and accompanying text (discussing in particular Conservatorship of Wendland, 28 P.3d 151 (Cal. 2001)).

310. *See* discussion *supra* Section II.B.1.

311. FLA. STAT. §§ 765.304(2)(b), 765.305(2)(b) (2026).

312. OR. REV. STAT. § 127.540(5)(b)(D) (2026).

313. N.J. STAT. ANN. § 26:2H-67(a)(4) (West 2025).

provided fluids and nutrition or that the patient's refusal of fluids and nutrition is "reasonably known" or "clearly expressed."[314] If there is no indication of the patient's refusal, the presumption is that fluids and tube nutrition are to be continued.[315]

The early history of enactments into the 1980s tells a different story. A significant number of states associated artificial fluids and nutrition with comfort care and required provision of measures "deemed necessary to provide comfort, [or] care."[316] Other states excluded feeding tubes from the types of interventions patients could refuse.[317] Here, legislatures balanced state interests in preserving life differently from the judiciary.[318] In a number of states, this position was strongly influenced by the contention that artificial fluids and nutrition are basic sustenance akin to food and water, an expression of human caring and hence obligatory—an argument made in some form by conservative religious groups and others who vigorously opposed the forgoing of feeding tubes.[319] Post-*Cruzan*, laws were amended to remove these severe restrictions and restore patients' rights to refuse interventions that provide artificial fluids and nutrition.[320] The requirement of specificity represents a compromise between patients' rights as recognized by the judiciary and those who continued to advocate for a carve-out for feeding tubes before state lawmakers.

It is doubtful that the specificity requirement makes a meaningful difference in practice today. One outcome of singling out feeding tubes is that advance directive forms commonly prompt an express indication—i.e., a check box—of the patient's wish to refuse artificial fluids and nutrition, even in states that do not require this stipulation.[321] The

314. N.Y. PUB. HEALTH LAW § 2982(2)(b) (McKinney 2026) (requiring that the patient's wishes be "reasonably known"); 20 PA. CONS. STAT. § 5456(c)(5)(iii)(B) (2026) (requiring that the patient's wishes be "clearly expressed").

315. N.Y. PUB. HEALTH LAW § 2982(2)(b) (McKinney 2026); 20 PA. CONS. STAT. § 5456(c)(5)(iii)(A) (2026).

316. *See, e.g.*, MO. REV. STAT. § 459.010(3) (2026).

317. *See* SOC'Y FOR THE RIGHT TO DIE, HANDBOOK OF LIVING WILL LAWS 5 (1987). The authors note that forgoing artificial feeding featured prominently in legislative debates in the 1980s, with the period from 1985–86 as an especially active time for lawmakers. *Id.*

318. *See id.* at 5–9.

319. *See generally* Howard Brody et al., *Artificial Nutrition and Hydration: The Evolution of Ethics, Evidence, and Policy*, 26 J. GEN. INTERN. MED. 1053 (2011) (discussing the debate and religious influence over use of artificial nutrition and hydration).

320. *See* Meisel, *supra* note 20, at 1497–99.

321. *Compare Health Care Proxy: Appointing Your Health Care Agent in New York State*, N.Y. STATE DEP'T OF HEALTH, https://www.health.ny.gov/publications/1430.pdf [https://perma.cc/6AED-KD4F] (requiring a specific statement by statute) (last visited June 13, 2026), *with Maryland Advance Directive: Planning for Future Health Care Decisions*,

proxy's statement of the patient's intent to refuse a feeding tube should be considered reasonably known, even if the patient's statement was isolated and remote in time, so long as it is consistent with the patient's overall intent not to prolong the dying process. Moreover, many advance directive laws provide that common law and constitutional rights are preserved and should be seen as cumulative with those recognized by the courts.[322] Arguably, these modest statutory limitations on withholding or withdrawing feeding tubes are largely symbolic and hortatory, and unlikely to be strictly applied.

C. Are Advance Directives Always Binding?[323]

Clinicians and families may believe that proxy authority is absolutely binding; that whatever the proxy says goes, or that the terms of the written document must always be followed literally.[324] There is no room for discretion.[325] The frequent references to advance directives as "legally binding" documents certainly give this impression, as does the expectation that a writing is by definition clear and convincing. But this is a misunderstanding. The better view is that directives are *prima facie* binding. A properly executed document imposes legal and ethical obligations on proxy, family, physician, and other healthcare providers to respect the patient's wishes, but the terms of the directive may be overridden or set aside if there is strong justification for doing so.[326]

There is a good argument for not following a directive in at least four circumstances. For each, the law offers at least some guidance. First, though patients invariably choose someone they trust to serve as a proxy, it is more than a theoretical possibility that a proxy will deliberately disregard their duty to the patient and instead act in their own interests. Perhaps the proxy is of ill motive, thinking "I can't wait to be rid of him," or is desperate for an inheritance, and urges premature cessation of life

MD. OFF. ATT'Y GEN. (2015), https://aging.maryland.gov/documents/adirective.pdf [https://perma.cc/J5TY-U5WL] (lacking requirement for specific statement).

322. *See* Corbett v. D'Alessandro, 487 So. 2d 368, 370–71 (Fla. Dist. Ct. App. 1986), *review denied*, 492 So. 2d 1331 (Fla. 1986) (holding that the statutory limitation does not affect the patient's otherwise existing constitutional right to refuse a feeding tube).

323. For more extensive analysis of this question, including the process for challenging a directive, see generally ROBERT S. OLICK, TAKING ADVANCE DIRECTIVES SERIOUSLY: PROSPECTIVE AUTONOMY AND DECISIONS NEAR THE END OF LIFE 167–97 (2001).

324. *See* Charles P. Sabatino, *Top Ten Myths and Facts About Health Care Advance Directives*, 37 BIFOCAL 6, 7–9 (2015).

325. *See id.*

326. *See* Meisel, *supra* note 20, at 1500–01. Another legal meaning of binding is, of course, enforceability. Court challenges to advance directives are likely to construe the issue as determining the patient's wishes under the circumstances rather than asking whether the directive is an enforceable contract.

support. Or insists on keeping the patient alive in contravention of their wishes to continue collecting social security. These are all examples of the *rebel proxy* who breaches their fiduciary duty. The rebel proxy should be removed from this role altogether. Or a proxy could simply be seriously mistaken, an accusation sometimes made in the throes of serious family disagreement. The proxy still acting in good faith (but clearly wrong) can be denied authority to make the particular decision in question while continuing in the proxy role. To remove a proxy of ill motive most likely requires a court order, though few states have made this explicit.[327]

A second scenario concerns a *significant change in circumstances* from those contemplated at the time the directive was written. Completion of an advance directive is an exercise in prospective autonomy. Directives are often written in times of relative health and involve anticipatory judgments about a future state of affairs.[328] Future-oriented treatment refusals are rooted in today's medicine, including the nature of illness, disease, and disability, and what medicine has to offer to heal, restore function, prolong life, control pain, and relieve suffering. It may be that medical and scientific progress now offers the promise of substantial benefit for the patient that did not previously exist.

Consider the potential of genetic research and precision medicine and developments in pharmacogenomics that have led to new targeted approaches to tumor treatment. One of many examples is ongoing efforts to find more effective treatments for Alzheimer's and other dementias.[329] Acting in the patient's best interests, the proxy may decide that a significant change in circumstances justifies consent to treatment, looking past the patient's prior refusal of treatment. This could be on a trial basis. A trial of potentially beneficial interventions can also respect the patient's desire to keep trying. Some make this explicit in their directive, in effect carving out an exception to their plan for easing the dying process.[330] We would caution, however, that the intervention must treat the very condition that underlies the patient's refusal of treatment and should offer

327. *See, e.g.*, N.Y. PUB. HEALTH LAW § 2982(2) (McKinney 2024) (specifying grounds for challenging a proxy's authority and strongly suggesting getting a court order).

328. *See Advance Care Planning: Advance Directives for Health Care*, *supra* note 299.

329. *Treatments for Alzheimer's*, ALZHEIMER'S ASS'N, https://www.alz.org/alzheimers-dementia/treatments [https://perma.cc/MBL2-AKD2] (last visited June 13, 2026) (providing information on treatment and research for Alzheimer's and dementia).

330. *Law for Older Americans*: *Health Care Advance Directives*, A.B.A. (Sep. 9, 2019), https://www.americanbar.org/groups/public_education/resources/law_issues_for_consumers/directive_writing/ [https://perma.cc/8TQP-4BSZ]; *Geriatrics and Extended Care: Advance Directives*, U.S. DEP'T OF VETERANS AFFS. (Feb. 11, 2025), https://www.va.gov/geriatrics/pages/acp_completing_an_advance_directive.asp [https://perma.cc/5HRF-E2FG].

a return to an acceptable quality of life. Mere prolongation of life of the same undesired quality is not a substantial benefit.[331]

Third, directives can be *hopelessly ambiguous*. Critics of living wills over the years assert that we can be poor forecasters of future illness, disease, and disability, our medical needs, treatment options, and even our life circumstances.[332] It can be difficult for the proxy and family to accurately determine the patient's stable and reliable preferences when written instructions are vague or ambiguous.[333] Problems of ambiguity and reliability most often arise with living wills standing alone, but these same concerns can be raised for combined directives.[334] In short, advance directives are not immune to the familiar problems with substituted judgment.[335] The choice of a trusted proxy is hardly ambiguous, though we may wonder about its wisdom should the proxy turn out to be unwilling, unable, or unavailable to serve, or go rogue.[336]

331. Another issue here is whether the proxy can consent to the patient's participation in research. *See Informed Consent FAQs*, U.S. DEP'T OF HEALTH & HUM. SERVS., https://www.hhs.gov/ohrp/regulations-and-policy/guidance/faq/informed-consent/index.html [https://perma.cc/U5CJ-B24D] (last visited June 13, 2026) (stating that surrogate consent to research is permissible but who qualifies as a surrogate for this purpose is a matter of state law). Most states have not directly addressed this question. Virginia is among the very few states that clearly state a proxy may be authorized to consent to an IRB-approved health care study that offers direct therapeutic benefit. The proxy may also consent to research that has no prospect of direct benefit but "aims to increase scientific understanding of any condition that the [participant] may have or otherwise [] promote[s] human well-being[.]" VA. CODE ANN. § 54.1-2983.1 (2025).

332. *Living Will: Do or Don't?*, AMERICARE HOSPICE & PALLIATIVE CARE (Oct. 11, 2019), https://americarehospice.org/living-will-do-or-dont [https://perma.cc/S9C8-ZHYL]; Laraine Winter, Susan M. Parks & James J. Diamond, *Ask a Different Question, Get a Different Answer: Why Living Wills are Poor Guides to Care Preferences at the End of Life*, 13 J. PALLIAT. MED. 567, 569–70 (2010).

333. Angela Fagerlin et al., *The Use of Advance Directives in End-of-Life Decision Making*, 46 AM. BEHAV. SCI. 268, 270–74 (2002). Based on an extensive review of the empirical literature the authors conclude that there are "significant doubts" that living wills achieve the goal of accurately communicating the patient's wishes. Some of the literature reviewed found that surrogates (family) are not as good at predicting their loved ones' wishes as we might expect. On the other hand, other studies reviewed found that entrusting close family to make decisions is more important than trying to dictate specific treatment choices and that this may extend to allowing a surrogate to override the terms of the document in the patient's best interests.

334. *See* Jordan Potter & Susannah W. Lee, *When Advance Directives Collide*, 35 J. GEN. INTERN. MED. 2191, 2191–92 (2020).

335. It has been argued that advance directives suffer from essentially the same faults as substituted judgment and should be taken to be "nearly irrelevant." Rebecca Dresser, *Confronting the "Near Irrelevance" of Advance Directives*, 5 J. CLIN. ETHICS 1, 1–2 (1994).

336. Naturally the proxy must be willing to assume this responsibility. Some states expressly address how to proceed if the proxy is unable, unwilling or unavailable to serve. *E.g.*, N.Y. PUB. HEALTH LAW § 2992(2) (McKinney 2025); N.J. STAT. ANN. § 26:2H-58(a)(3) (West 2025). To anticipate these eventualities, it is recommended to choose an alternate

Advance care planning and the forms themselves have improved significantly over the years, rendering criticism about ambiguity and reliability less apt. Today's forms no longer use ambiguous phrases like "no heroic measures," which were a common target of critics.[337] Additionally, forms have been tailored to planning for the progression of specific, diagnosed diseases.[338] Still, the document itself, together with what else is known of the patient's wishes and values, can sometimes find the proxy and family struggling to know what to do. Does a series of specific choices among medical modalities to be refused—checking off from a list—mean that other interventions are to be provided, even if they may be harmful or simply contrary to the patient's overall plans for the dying process?[339] The belief that anything not included is therefore excluded is a familiar rule of construction for legal documents.[340] Perhaps information about the patient's past statements and values contradicts the directive's terms. Should a patient's curable pneumonia be treated if this is unrelated to the life-threatening condition contemplated by the directive? Should the patient's request to be DNR/DNI if dying from an irreversible cancer that is not in a terminal stage be honored if resuscitation is needed to recover from a drowning accident?

These and other scenarios are familiar dilemmas both in the delivery of end-of-life care and scholarly commentary.[341] The proxy has been entrusted with resolving any ambiguities, but its interpretation has its limits, and others may strongly disagree.[342] The best option may be to set aside the directive's instructions, at least for now. Uncertainty and

proxy. Some people want decisions to be shared among family members, perhaps adult children. This may make sense for some families, but is generally discouraged, as any requirement for agreement effectively gives a single family member veto power. Individuals are free to update their directive or write a new one at any time so long as they are competent. These are among the points made and issues raised for consideration in various tools for advance care planning. *See, e.g.*, CAL. HEALTH & SAFETY CODE §§ 7185–95 (repealed 2000); Kutner, *supra* note 258, at 539. The problem of the rogue or rebel proxy is discussed, *supra* note 327 and accompanying text.

337. *See* J. Andrew Billings, *The Need for Safeguards in Advance Care Planning*, 27 J. GEN. INTERN. MED. 595, 597 (2012) ("No advance directive should include vague instructions like 'No heroics' or 'No extraordinary care.'").

338. *See* Winter, Parks & Diamond, *supra* note 332, at 567–68; *Treatments for Alzheimer's*, *supra* note 329; *Law for Older Americans: Health Care Advance Directives*, *supra* note 330.

339. *See* Fagerlin et al., *supra* note 333, at 268–69; Muriel R. Gillick, *Advance Care Planning*, 350 NEJM 7, 7–8 (2004) (noting that even detailed instructions cannot anticipate all future conditions and that precision can make directives inflexible).

340. *Understanding Expressio Unius Est Exclusio Alterius in Legal Context*, USLEGAL, https://legal-resources.uslegalforms.com/e/expressio-unius-est-exclusio-alterius [https://perma.cc/4F5U-PWRH] (last visited June 13, 2026).

341. *See* Gillick, *supra* note 339, at 7–8.

342. *Id.*

disagreement about how to interpret and apply advance directives are common reasons to call for an ethics consult.[343]

To construct an argument for the foregoing scenarios, we can appeal to the proxy's inherent duty to the patient's autonomy and best interests, and the authority to consent to treatment such as a clinical trial, if given in the directive. Additionally, much of the same could be said of the families' obligations to their loved ones. A fourth circumstance appeals to the ethical/legal parameters of decisional capacity. Sometimes patients have a *change of mind*—or appear to. For patients who regain capacity, the rules are clear. Competent patients have the right to give first-person contemporaneous consent or refusal.[344] In such cases, if the proxy's authority has already been invoked that authority should be considered suspended. As such, the patient has the right to exclude the proxy or even to choose a different person for this role, but we would expect this to be extremely rare. Ideally, the proxy will function as a partner, continuing to be involved in dialogue with both patient and physician, perhaps on

343. *See* NANCY M. P. KING & JOHN C. MOSKOP, *Advance Care Planning and End-of-Life Decision-Making*, *in* GUIDANCE FOR HEALTHCARE ETHICS COMMITTEES 121, 121–28 (D. Micah Hester & Toby L. Schonfeld eds., 2d ed. 2022). Another oft-discussed issue is when proxy and family insistence that life is valued and must be preserved at all costs conflicts with the physician's view that continued aggressive interventions to sustain life are medically inappropriate or "futile." This scenario typically is not addressed by advance directive laws (Texas is an exception). There have been few cases on point and other laws, such as so-called "unilateral decision statutes," are untested and offer limited guidance. Thaddeus Mason Pope, *Medical Futility Statutes: No Safe Harbor to Unilaterally Refuse Life-Sustaining Treatment*, 75 TENN. L. REV. 1, 3–6 (2007). Questions about medical futility, including the proper definition of the term are complex and unresolved, and have generated an extensive literature. For a book-length treatment of the topic, see generally SUSAN B. RUBIN, WHEN DOCTORS SAY NO: THE BATTLEGROUND OF MEDICAL FUTILITY (1998) (examining debates over medical futility and whether physicians may refuse treatment deemed futile). Among the many helpful articles on the topic include Paul R. Helft, Mark Siegler & John Lantos, *The Rise and Fall of the Futility Movement*, 343 NEJM 293 (2000); Lawrence S. Schneiderman, Nancy S. Jecker & Albert R. Jonsen, *Medical Futility: Its Meaning and Ethical Implications*, 112 ANN. INTERN. MED. 949 (1990).

344. This follows from the right of competent patients to make their own medical decisions and from the fact that, under state laws, incapacity is a precondition for proxy authority. Some states explicitly address circumstances in which patients regain capacity. *See, e.g.*, N.J. STAT. ANN. § 26:2H-61(a) (West 2025) (codifying that a health-care representative may act only after the attending physician has determined that the patient lacks capacity with respect to the particular decision); N.Y. PUB. HEALTH LAW §§ 2983(1), (7) (McKinney 2025) (providing that a health care agent's authority begins upon a determination that the principal lacks capacity to make health care decisions and revives if the principal regains such capacity); *In re* Conroy, 486 A.2d 1209, 1222–23 (N.J. 1985) (recognizing that competent adults have a fundamental right to refuse or consent to treatment and that this right is personal and contemporaneous); Cruzan v. Missouri Dep't of Health, 497 U.S. 261, 278 (1990) (holding that competent individuals possess a constitutionally protected liberty interest in refusing unwanted medical treatment).

the model of supported decision making to facilitate and assist the patient's exercise of autonomy, to speak with rather than for the patient.[345] Continued involvement of the proxy promotes a seamless transition if and when the patient loses capacity and proxy authority resumes.

More challenging issues are present when the incompetent patient who has previously refused life-sustaining interventions communicates a desire to continue living. Such scenarios can be an acute concern with dementia patients. Some argue that this apparent contradiction of prior written instructions should be disregarded.[346] The wishes of the now incompetent patient in favor of treatment should not override the prior autonomous refusal. A further concern is that the incompetent patient will be perceived to be revoking their directive and, in effect, firing the proxy. The better position is to respect the patient's contemporaneous plea for continued life, on the understanding that this will be time-limited. To be clear, contemporaneous expressions, such as responses to pain, discomfort, conversation, and family, are clues to the interpretation of the patient's prior autonomous statements.[347] They can be especially important when proxy and family must weigh the burdens and benefits of treatment in the context of the patient's prior written intentions. But in such instances when a decision to continue dialysis or a feeding tube must be taken the usual standards for decisional capacity should be relaxed; it does not take much capacity to say, "I want to live."[348] At appropriate intervals patients should be asked again for their

345. Supported decision-making has become a popular alternative to traditional guardianship for those with impaired cognitive capacity, such as adults with intellectual disability. It is recognized in law in more than half of states. *See In Your State*, NAT'L RES. CTR. FOR SUPPORTED DECISION-MAKING, https://supporteddecisionmaking.org/in-your-state/ [https://perma.cc/6PP2-J3NW] (last visited June 13, 2026). For analysis of the law governing supported decision making, see Nina A. Kohn, Megan S. Wright & Robert D. Dinerstein, *The Legal Landscape for Supported Decision-Making in the United States and its Application to Clinical Research*, 54 J.L. MED. & ETHICS 4 (supp. 2026) [https://doi.org/10.1017/jme.2025.10202].

346. CANTOR, *supra* note 120, at 112–13.

347. *See generally* Martin Harvey, *Advance Directives and the Severely Demented*, 31 J. MED. & PHIL. 47, 55–59 (2006) (illustrating that a person's prior conduct in creating an advance directive expresses their precedent autonomy when they were capable of making informed choices about future medical care).

348. Law professor Sanford Kadish adopts parts of both positions. He describes a case of Composer Then who previously refused life support and Composer Now who in an agitated state with unclear understanding says she does not want to die. He contends that in principle Composer Now's contemporaneous choice does not take precedence over her prior autonomous treatment refusal, but that life support should be continued because this shows "compassion for the human being before us." Sanford H. Kadish, *Letting Patients Die: Legal and Moral Reflections*, 80 CALIF. L. REV. 857, 871–72, 876 (1992).

preferences. The proxy's authority and the patient's prior treatment refusal should be considered suspended to resume when the patient's request ceases.[349]

D. Professional and Institutional Conscience

An extensive body of federal and state law protects the right of professional conscience in various health care contexts.[350] On occasion, physicians, nurses, or other health care providers believe that to participate in forgoing life-sustaining treatment would violate their sincerely held personal or professional convictions.[351] Advance directive laws provide a well-considered paradigm for balancing the rights and interests of patients and families with the rights and interests of physicians and nurses when there is tension between the two. This same approach to accommodation of conscientious objection has been applied to health care institutions.[352]

349. Is the now incompetent patient the same person they once were? It has been argued that some incompetent patients have become new and different persons, are no longer who they once were, and that prior directives should therefore be ignored or discounted because prior preferences for terminating life support are those of a different and no longer existing person, not those of the patient before us. This is a nutshell summary of a position that draws on the philosophical concept of personal identity often traced to the 17th century British philosopher John Locke who argued that what makes us the same person today as we were in the past is our memories. JOHN LOCKE, ESSAY CONCERNING HUMAN UNDERSTANDING 133–35 (Kenneth P. Winkler ed., 1996). The social meaning of the concept resonates for families who find that their now incompetent loved one is "not who they once were." But the personal identity challenge to advance directives and substituted judgment has found no traction in law or ethics. One logical consequence of this position is that bedside decisions would be made in accord with the best interest judgments of families and physicians, not the prior intentions, values and directives of the patient—they would no longer count. *See* Rebecca S. Dresser & John A. Robertson, *Quality of Life and Non-Treatment Decisions for Incompetent Patients: A Critique of the Orthodox Approach*, 17 L. MED. & HEALTH CARE 234, 236–38 (1989) (pressing this personal identity critique and arguing for a best interests approach for the now incompetent patient before us); ALLEN E. BUCHANAN & DAN W. BROCK, DECIDING FOR OTHERS: THE ETHICS OF SURROGATE DECISION MAKING 152–54 (1989) (discussing the philosophical and ethical implications of personal identity theory for end-of-life decisions); OLICK, *supra* note 323, at 129–30 (defending the advance directives consensus and arguing for the essential place of prospective autonomy and respect for our prior intentions and plans in the moral life and in defining who we are).

350. *See* Dov Fox, *Medical Disobedience*, 136 HARV. L. REV. 1030, 1038–42, 1054–60 (2023) (detailing the development and statutory bases of conscience protections); Thaddeus Mason Pope, *Legal Briefing: Conscience Clauses and Conscientious Refusal*, 21 J. CLIN. ETHICS 163, 163–70 (2010).

351. *Physician Exercise of Conscience: Code of Medical Ethics Opinion 1.1.7*, AMA [hereinafter *Medical Ethics Opinion 1.1.7*], https://code-medical-ethics.ama-assn.org/ethics-opinions/physician-exercise-conscience [https://perma.cc/2GY8-Y5XN] (last visited June 13, 2026).

352. S*ee* CANTOR, *supra* note 120, at 96–97.

Professional conscience. *Quinlan* and other cases were primarily concerned with the integrity of the medical profession writ large as a countervailing state interest.[353] They implicitly recognized that protecting the physician's personal code of conduct is both important in its own right and serves to preserve the ethics of the profession, but did not go further to analyze the place of a physician's personal code of conduct.[354] As stated by the AMA, physicians are bound to the ethical norms of the profession, but are also "moral agents in their own right," not defined solely by professional norms.[355] Physicians may have philosophical, religious, or cultural values and beliefs that occasionally conflict with those of their patients and may also be at odds with established professional norms. Karen Quinlan's physician felt that the removal of her respirator violated his commitment to preserving life, while Paul Brophy's physician considered his feeding tube to be basic and obligatory care.[356] The task for law and practice is to balance the rights and interests of patients and families with those of physicians in a way that respects all parties. Law and ethics also recognize and protect the professional convictions of nurses and other healthcare professionals; we focus here on physicians.

In sum, advance directive laws commonly provide that when, as a matter of conscience, a physician objects to forgoing life-sustaining treatment, they should inform the patient, proxy, and family of their objection and desire to withdraw from the patient's care, and should follow institutional policy for withdrawing and transferring patient care to another physician or facility.[357] There should be a timely and respectful transfer to another clinician willing to follow the patient, proxy, and family's wishes. Pending transfer, care and treatment are to be continued; patients cannot be abandoned. Immunity attaches for following these steps in good faith.[358] This prudential balancing of interests is designed to respect both patient rights and the physician's

353. *See In re* Quinlan, 355 A.2d 647, 664–66 (N.J. 1976) (recognizing the state's interest in maintaining the ethical integrity of the medical profession as a countervailing consideration in right-to-die cases).

354. *See id.* (acknowledging the physician's ethical obligations as part of the state's interest in preserving medical integrity); *Medical Ethics Opinion 1.1.7*, *supra* note 351 (recognizing physicians as moral agents who must balance personal conscience with professional norms).

355. *Medical Ethics Opinion 1.1.7*, *supra* note 351.

356. *See Quinlan*, 355 A.2d at 665–70; Brophy v. New Eng. Sinai Hosp., Inc., 497 N.E.2d 626, 632 (Mass. 1986).

357. *E.g.*, N.J. STAT. ANN. § 26:2H-62(b) (2025); VA. CODE ANN. §§ 54.1-2987, 2990(B) (2025).

358. *See* sources discussed *supra* note 288.

conscience.[359] Who bears responsibility for effectuating a transfer of care is of critical importance. Most states properly place this duty with the physician—or by extension also the hospital—recognizing that safe and appropriate transfers are sometimes complex, and that healthcare professionals are knowledgeable about their colleagues, the medical community, and the healthcare system, while families are relative strangers to the system and burdened by the imminent loss of a loved one.[360]

The concept of conscience and its influence on behavior, and whether acting on conscience is protected, rewarded, or punished, has a long history in religious and secular traditions and in various social and professional contexts.[361] Law Professor Dov Fox has analyzed more than a dozen examples of the law's approach to professional conscience in health care.[362] The principal rationale for conscience protections is that they respect both autonomy and the moral integrity of the physician.[363] In principle, appeals to conscience assert that to comply with the patient's wishes would be a harmful violation of integrity. It follows that to be worthy of accommodation, a claim of conscience should be based on

359. Consistent with the primary purpose of advance directives, the structure of professional conscience protections contemplates patient/proxy refusal of life support. A growing controversy in end-of-life care involves patient/proxy/family insistence on continued aggressive treatment the physician finds inappropriate, medically futile, or violative of the time-honored maxim to do no harm. These same rules for withdrawal from patient care should apply here as well, though they have rarely been the subject of legal scrutiny. So-called medical futility cases have become a familiar issue for the work of ethics consultants. *See* CANTOR, *supra* note 120, at 72–73 (discussing medical futility); Luce, *supra* note 20 (discussing resolution of futility-type cases in the ICU).

360. *Compare* IND. CODE. § 16-36-7-37(a), (b) (2024) (provider shall transfer), *and* N.H. REV. STAT. ANN. § 137-J:7(II) (2025) (provider shall make necessary arrangements), *with* 20 PA. CONS. STAT. § 5424(b) (2024) (physician and provider "shall make every reasonable effort to assist in the transfer"), *and* N.Y. PUB. HEALTH. LAW § 2984(3)(b) (proxy must first try to transfer, but then the hospital should step in).

361. For a concise and informative discussion, see generally PAUL STROHM, CONSCIENCE: A VERY SHORT INTRODUCTION (2011).

362. *See* Fox, *supra* note 350. Fox argues there is a stark asymmetry between the ways the law protects conscience for healthcare professionals who refuse to provide care and the ways the law punishes provision of treatment and services as a matter of conscience when contrary to law. *Id.* He argues that this deep inconsistency shows that "America's medical conscience regime is broken." *Id.* at 1038. MAID illustrates his point. States that have legalized the practice allow physicians to refuse to write a lethal prescription and even to refuse to make a referral. *E.g.*, 18 VT. STAT. ANN. § 5285 (2024). Where it is not legal—i.e., in most states—physicians who feel compelled to write the prescription to ease the pain and suffering of a dying patient face the prospect of criminal prosecution. Fox, *supra* note 350, at 1099–100.

363. Mark R. Wicclair, *Conscientious Objection in Medicine*, 14 BIOETHICS 205, 212–18 (2000). Wicclair also identifies ethical relativism and respect for moral diversity as policy justifications for conscience protections and goes on to criticize both. *Id.* at 210–12.

sincerely held personal or professional convictions. Although law and ethics often recite this understanding of conscientious objection, in practice, there may be no demand for a reasoned explanation nor a probing inquiry into the physician's sincerity. Assertions of religiously-based objections need not be consonant with the teachings and tenets of the physician's faith as long as they are said to be sincerely held.[364] Claims of conscience sometimes assert that to transfer is to be complicit in the decision and is therefore objectionable.[365] Whether felt-complicity justifies refusal to refer in other, more familiar situations, for example, opposition to abortion or medical aid in dying, is controversial.[366] The professional duty to transfer holds that complicity is insufficiently weighty, a minimal, perhaps fleeting injury to integrity, compared to the interests of patients and families.[367]

Institutional conscience. The New Jersey case of Nancy Ellen Jobes illustrates the potential conflict between patient rights and institutional conscience.[368] Nancy Ellen, a young woman in her mid-twenties, was

364. *See generally* CYNTHIA BROUGHER ET AL., CONG. RSCH. SERV., R40722, HEALTH CARE PROVIDERS' RELIGIOUS OBJECTIONS TO MEDICAL TREATMENT: LEGAL ISSUES RELATED TO RELIGIOUS DISCRIMINATION IN EMPLOYMENT AND CONSCIENCE CLAUSE PROVISIONS (July 18, 2011). This report states that under Title VII and First Amendment jurisprudence, religious beliefs need not be "acceptable, logical, consistent, or comprehensible" to others to merit protection, provided they are sincerely held as moral or ethical beliefs. *Id.* at 3; *see also supra*, note 13.

365. *See* Cynthia Jones-Nosacek, *Referral vs Transfer of Care: Ethical Options When Values Differ*, 89 LINACRE Q. 36, 36–37 (2022).

366. *See, e.g.*, Louise P. King, *Tennessee's Inappropriate Reliance on Conscientious Objection*, HASTINGS CTR. FOR BIOETHICS (July 25, 2025), https://www.thehastingscenter.org/tennessees-inappropriate-reliance-on-conscience-objections/ [https://perma.cc/J3S2-JV52]. New Mexico's End of Life Options Act provides that there is no obligation to participate in MAID, but providers who refuse to participate have a duty to refer. N.M. STAT. ANN. § 24-7C-7 (2024). The California End of Life Option Act states that provider participation in MAID is entirely voluntary and provides broad immunity for refusal to offer patients information or make a referral. CAL. HEALTH & SAFETY CODE § 443.14(e) (2024).

367. Conscience protections here are not a license to engage in unlawful discrimination on the basis of race, ethnicity or religion, nor do they shield practitioners from the consequences of other unlawful behavior. Conscience protections are also not intended to shield refusals of care based on inappropriate social or political judgments about patients, as occurred recently in Tennessee where a physician refused to care for a pregnant woman because she was un-married. King, *supra* note 366. Discrimination per se is more likely to arise at the point where the physician-patient relationship is first formed but can become an issue later on. Implicit bias can also play a role in the physician's response to patient/proxy demands. *See generally* DAYNA BOWEN MATTHEW, JUST MEDICINE: A CURE FOR RACIAL INEQUALITY IN AMERICAN HEALTH CARE (2015) (discussing generally implicit bias in medicine).

368. *See In re* Jobes, 529 A.2d 434, 436–37 (N.J. 2021).

treated at a hospital for serious injuries suffered in a car accident.[369] She would come to be diagnosed with PVS resulting from severe oxygen deprivation to her brain.[370] Five months after her accident, she was transferred to Lincoln Park Nursing and Convalescent Home, where she received artificial nutrition and hydration through a jejunostomy tube along with other supportive and comfort measures.[371] After five years of nursing home care with no signs of improvement, her husband and parents asked that the feeding tube sustaining her life be removed to allow her to die.[372] The nursing home, though secular, asserted a faith-based objection to withdrawing the feeding tube and refused to do so.[373] After ruling that Nancy's husband could make this decision in the exercise of substituted judgment, based on sufficient trustworthy evidence of Nancy's own wishes offered by recollections of family and friends, the New Jersey Supreme Court addressed the nursing home's objection.[374]

The *Jobes* court declined to rule on the ultimate question as to whose rights prevail in the face of such a conflict—the patient's or the nursing home's—leaving this question for another day.[375] But it upheld the patient's rights on process grounds, holding that because the family had never been given notice of the nursing home's policy (in fact, a written policy was never provided to them nor introduced as evidence in court), the treatment refusal must be honored.[376] If the Jobes family were to "surrender[] the right to choose among medical alternatives[,]" they must be put on notice and given the opportunity to accept this limitation or seek a different facility for Nancy Ellen's care.[377] The family transferred Nancy Ellen to Morristown Memorial Hospital where she died not long after, following removal of her feeding tube with palliative care.[378]

Many advance directive laws establish a right of health care institutions to assert conscientious objection to compliance with patient/proxy refusal of treatment. A common approach is to limit this

369. *Id.* at 437–38.
370. *Id.*
371. *Id.* at 438.
372. *Id.* at 437.
373. *Id.*
374. *See id.* at 447–48.
375. *Id.* at 449–50.
376. *Id.* at 450.
377. *Id.*
378. William Westhoven, *Remembering Nancy Ellen Jobes, The Center of NJ's Lesser-Known Landmark Right-to-Die Case*, MORRISTOWN DAILY REC. (June 4, 2025, at 10:47 ET), https://www.northjersey.com/story/news/new-jersey/2025/06/04/nancy-ellen-jobes-nj-persistent-vegetative-state-feeding-tube-fight/83385095007/ [https://perma.cc/VDQ9-TY83].

right to private, religiously affiliated institutions—public hospitals and private secular facilities excluded—and to require the adoption of written institutional policies that define the circumstances under which an objection to a patient's wishes to forgo life-sustaining interventions would be made.[379]

Communication of the policy is intended to put patients, families, and proxies on notice, thereby better enabling placement in a facility whose values are compatible with the patient's and avoiding foreseeable conflicts. If conflict arises after admission, most states place the duty to effectuate the transfer on the institution.[380] This approach recognizes that hospitals have the resources to navigate inter-facility transfers, that safe discharge may require complicated coordination, and that it would be unfair to place this responsibility on families. Hospital discharge planners, commonly social workers, should, of course, work with families to find a safe discharge and appropriate placement; "appropriate" here means to place the patient in a facility that will honor the refusal of artificial fluids and nutrition, or sometimes to home hospice care.

Some find the very concept of institutional conscience incoherent. A corporation is not a natural person with an intellect and a will.[381] Others accept the idea and look for evidence of conscience in a hospital's legal structure as expressed in its by-laws, mission statement, and policies, perhaps also to the institution's culture of practice, and whether patient mix and services provided are aligned.[382] The latter view informs these legislative initiatives that recognize the unique values of some healthcare institutions. We find that the statutory approach strikes a reasonable balance, provided the policies and practices at issue reflect shared convictions within the institution—and are not manufactured after the conflict in patient care emerges, as appears to have happened in *Jobes*. When transfer cannot be effectuated within a reasonable time, the balance should tip in favor of the patient and family and require compliance.

379. *E.g.*, N.J. STAT. ANN. § 26:2H-65(6)(b) (West 2025); MASS. GEN. LAWS ch. 201D, § 15 (2025); N.Y. PUB. HEALTH LAW § 2984(3) (McKinney 2025) (respecting also "sincerely held moral convictions" if "central to the facility's operating principles").

380. *See, e.g.*, statutes cited *supra* note 379.

381. Ryan Meade, *The Natural Person as the Limiting Principle for Conscience: Can a Corporation Have a Conscience If It Doesn't Have an Intellect and Will?*, *in* LAW, RELIGION, AND HEALTH IN THE U.S. 103, 104–06 (Holly Fernandez Lynch, I. Glenn Cohen & Elizabeth Sepper eds., 2017).

382. *See* David M. Craig, *Mission Integrity Matters: Balancing Catholic Health Care Values and Public Mandates*, *in* LAW, RELIGION AND HEALTH IN THE U.S. 125, 134–37 (Holly Fernandez Lynch, I. Glenn Cohen & Elizabeth Sepper eds., 2017).

We are, however, chary about the larger systemic implications that may follow from recognition of institutional conscience. According to the Catholic Health Association ("CHA"), there are as many as 650 Catholic hospitals and 1,600 long-term care and other facilities across the country.[383] Recent years have seen more mergers and consolidations of health systems, bringing multiple hospitals under a single corporate umbrella, sometimes including the sole hospital in the community and leaving patients and families with no other reasonable option.[384] The CHA adopts the Directive of the U.S. Conference of Catholic Bishops as its mission statement for its members.[385] The plain terms of the Directive require long-term provision of feeding tubes for PVS patients, and permit the forgoing of feeding tubes for terminally ill patients only when close to death.[386] Both positions are contrary to settled law and secular ethics. As noted earlier, there is no single Catholic position on forgoing feeding tubes.[387] But if large Catholic hospitals and facility chains fully embrace this more conservative position, this could lead to situations where, to quote Law Professor George Annas, writing with his characteristic rhetorical flair, feeding tubes have more rights than patients.[388]

E. Advance Directives After Fifty Years

It is fair to say that fifty years on, advance directives have made a tremendous difference in securing the rights of patients and families near the end of life. This body of law has contributed mightily to shaping culture and practice that are patient-centered and respectful of patient and family rights to control end-of-life decisions. But law and practice

383. *About Us*, CATH. HEALTH ASS'N OF THE U.S., https://www.chausa.org/about [https://perma.cc/8M9L-YAA3] (last visited June 13, 2026).

384. *See generally* Elizabeth Sepper, *Contracting Religion*, *in* LAW, RELIGION, AND HEALTH IN THE U.S. 113, 114–16 (Holly Fernandez Lynch, I. Glenn Cohen & Elizabeth Sepper eds., 2017) (describing the potential consequences of vertical and horizontal integration of health care systems).

385. *See About Us*, *supra* note 383.

386. *See* U.S. CONF. OF CATH. BISHOPS, ETHICAL AND RELIGIOUS DIRECTIVES FOR CATHOLIC HEALTH CARE SERVICES 20–21 (6th ed. 2018). The text of paragraph fifty-eight of the document reads: "In principle, there is an obligation to provide patients with food and water, including medically assisted nutrition and hydration for those who cannot take food orally." *Id.* at 21. This obligation is said to expressly apply to chronic and irreversible conditions like PVS. The text goes on to say that "[m]edically assisted nutrition and hydration become morally optional when they cannot reasonably be expected to prolong life" or become excessively burdensome. *Id.* The illustration of excessive burden is being "close to inevitable death," and such that the intervention would have "limited ability to prolong life or provide comfort." *Id.* Both positions are contrary to settled law and secular ethics.

387. *See supra* notes 83–88 and accompanying text.

388. *See* Annas et al., *At Law*, *supra* note 189, at 26.

have yet to fulfill the more concrete promises that putting it in writing will ensure our personal plans always control the dying process, and that the vast majority of us will use directives to plan ahead for decisions near the end of life. Experience tells us these remain worthy aspirations.

In 1990, Congress became involved in end-of-life decisions with the enactment of the Patient Self-Determination Act ("PSDA").[389] Under this federal law, hospitals and other healthcare facilities are required to provide information about advance care planning to patients and families to inquire about the patient's "advance directive status" and seek to obtain a copy for the patient's record.[390] The law prohibits requiring anyone to write a directive as a condition of receiving care, and it also prohibits insurance companies from requiring directives as a condition of coverage.[391] The PSDA does not create or modify substantive rights to make end-of-life decisions under state law. Rather, the PSDA is about process.[392] Its dual purposes are to encourage more of us to write directives and to ensure that they become known and are honored when we do.[393] Certainly, the PSDA has succeeded in its targeted mission. Advance directive packets are a routine part of the hospital admissions process.[394] Asking who speaks for the incompetent patient after hospital admission is top of mind for the care team, especially social work.[395] And when a legally recognized proxy is identified, this goes a long way to resolving potential family disagreements about who speaks for the patient. Later enactment of Medicare reimbursement for advanced care planning conversations with patients further supports these goals.[396]

389. *See* 42 U.S.C. §§ 1395cc(f)(1), 1396a.

390. *Id.*

391. *See id.*

392. *See* LAWRENCE P. ULRICH, THE PATIENT SELF-DETERMINATION ACT: MEETING THE CHALLENGES IN PATIENT CARE 10, 11 (1999).

393. *See generally id.*

394. *See* Joan M. Teno et al., *The Impact of the Patient Self-Determination Act's Requirement that States Describe Law Concerning Patients' Rights*, 21 J.L. MED. & ETHICS 102, 102 (1993); *Law for Older Americans*, A.B.A. (Sep. 9, 2019), https://www.americanbar.org/groups/public_education/resources/law_issues_for_consumers/patient_self_determination_act/ [https://perma.cc/2JY4-459W].

395. *See* Chong-Wen Wang, Cecilia L.W. Chan & Amy Y.M. Chow, *Social Workers' Involvement in Advance Care Planning: A Systematic Narrative Review*, 17 BMC PALLIATIVE CARE 1, 1, 9–16 (2018); Frances R. Nedjat-Haiem et al., *A National Survey of Social Workers Focusing on Attitudes, Knowledge, and Practice Behaviors for Educating Patients About Advance Directives: Implication During COVID19*, 39 AM. J. HOSPICE & PALLIAT. CARE 737, 743 (2022).

396. *See* Amelia K. Barwise et al., *Ethical Considerations About Clinician Reimbursement for Advance Care Planning*, 95 MAYO CLINIC PROC. 653, 654–55 (2020).

Studies of advance directive use around the time of the PSDA's passage found that only about 20% of people had written a directive.[397] More recently available data confirm that advance directive use has trended upward but still hovers, on average, below 50%.[398] According to this 2015 GAO report, 47% of adults over forty had completed an advance directive, though another earlier national survey found that only 26% of adults over eighteen had done so.[399] The prevalence of use varied by provider type and demographic characteristics.[400] Unsurprisingly, 88% of hospice patients had taken this step, as had 65% of nursing home patients, while hospital patients were least likely to have directives.[401] A 2020 University of Michigan National Poll on Healthy Aging found that among adults ages fifty to eighty, nearly half (46%) reported having completed an advance directive.[402] A greater number (59%) had talked to someone about their treatment preferences; those over sixty-five were more likely (70%) to discuss end-of-life choices.[403] As suggested by the Michigan study, advance directive usage and awareness tend to be higher among the elderly.[404] There is also evidence of greater use of directives among patients with diagnosed chronic conditions.[405] The GAO found that "individuals who were older, white, had higher education or incomes, or were women were more likely to have advance directives than others."[406]

397. *See* John La Puma et al., *Advance Directives on Admission: Clinical Implications and Analysis of the Patient Self-Determination Act of 1990*, 266 JAMA 402, 402 (1991) (summarizing previous studies); Joanne Lynn & Joan M. Teno, *After the Patient Self-Determination Act: The Need for Empirical Research on Formal Advance Directives*, 23 HASTINGS CTR. REP. 20, 21 (1993).

398. *See* U.S. GOV'T ACCOUNTABILITY OFF., GAO-15-416, ADVANCE DIRECTIVES: INFORMATION ON FEDERAL OVERSIGHT, PROVIDER IMPLEMENTATION, AND PREVALENCE 20–21 (2015) [hereinafter GAO REPORT].

399. *Id.* at 21 (quoting a 2013 Institute of Medicine report).

400. *Id.*

401. *Id.* To prepare this report to Congress, the GAO conducted an extensive analysis of peer reviewed articles and government reports issued between 2009 and 2014. See *iId.* at 21–26, for the summary and more detailed analysis and tables.

402. Chithra R. Perumalswami et al., *Older Adults' Experiences with Advance Care Planning*, UNIV. MICH. INST. HEALTHCARE POL'Y & INNOVATION (Apr. 6, 2021), https://ihpi.umich.edu/national-poll-healthy-aging/national-findings/older-adults-experiences-advance-care-planning [https://perma.cc/A8QP-98G3].

403. *Id.*

404. *See id.*

405. *See* Joan Teno et al., *The Use of Formal Prior Directives Among Patients with HIV-related Diseases*, 5 J. GEN. INTERN. MED. 490, 494 (1990); Jean L. Holley et al., *Factors Influencing Dialysis Patients' Completion of Advance Directives*, 30 AM. J. KIDNEY DIS. 356, 356 (1997).

406. *See generally* GAO REPORT, *supra* note 398.

No doubt, increased interest in advance care planning is due in large measure to the ways in which the legal and ethical consensus has shaped culture, practice and public awareness, and to the efforts of dedicated healthcare professionals and end-of-life advocacy organizations. Efforts to educate the public and provide resources for advance care planning have become nationalized. Hospitals and healthcare professionals are keenly aware of advance directives, and many physicians have advance care planning conversations with their patients, particularly for chronically and critically ill patients.[407] We should expect the prevalence of advance care planning to continue to improve. Nonetheless, the fact that fewer than 50% of adults complete this step remains below expectations. The POLST initiative, a complementary approach to documenting patient wishes, discussed below, helps fill some of this gap.[408]

Since the flurry of activity in the 1980s and 1990s that removed major obstacles to patients' refusal of artificial nutrition and hydration, advance directive laws have undergone many revisions. Almost all have been minor changes that leave patient and proxy rights undisturbed.[409] The tone and tenor of many amendments have been to slightly augment the rights of patients and proxies and improve bedside decision making. In recent years, several states have authorized non-physician qualified professionals, such as physician assistants and nurse practitioners, to determine a patient's decisional capacity.[410] Some states made the rules for valid execution more user-friendly including use of e-signatures, while others joined the ranks of states with advance directive

407. *See, e.g.*, *Find Advance Directive Forms by State*, *supra* note 267 (providing resources for education and materials); *State Healthcare P.O.A. Statutes*, *supra* note 275, at 1–28; *Advance Directives*, AM. CANCER SOC'Y (Aug. 1, 2025), https://www.cancer.org/cancer/managing-cancer/making-treatment-decisions/advance-directives.html [https://perma.cc/E6SG-ADXW]; *see also Living Wills and Advance Directives for Medical Decisions*, MAYO CLINIC (Mar. 25, 2025), https://www.mayoclinic.org/healthy-lifestyle/consumer-health/in-depth/living-wills/art-20046303 [https://perma.cc/3JNW-JHP6] (exemplifying patient and community outreach at a hospital level).

408. *See POLST Basics*, NAT'L POLST COLLABORATIVE, https://polst.org/about/ [https://perma.cc/T84T-XRYU] (last visited June 13, 2026).

409. The Maryland Health Care Decisions Act repealed and replaced prior law, bringing the state firmly within the mainstream consensus. For in-depth analysis and an inside look at the legislative process in Maryland, see generally Diane E. Hoffmann, *The Maryland Health Care Decisions Act: Achieving the Right Balance?*, 53 MD. L. REV. 1064 (1994).

410. Katlyn Slough, *Summary of Health Care Decision Statutes Enacted in 2020–2021*, 43 BIFOCAL 1, 5 (July 1, 2021), https://www.americanbar.org/content/dam/aba/administrative/law_aging/2021-hcpa-legis-update.pdf [https://perma.cc/9FYX-W48X].

registries.[411] An interesting amendment in Oregon invokes the doctrine of supported decision making to make explicit the patient's right to a "support person" to assist in making decisions when their capacity is impaired.[412] We encourage lawmakers to follow the lead of states with broader medical condition criteria that recognize the right to refuse treatment when confronting an irreversible and progressive but not terminal condition. This would go a long way toward expanding patient rights near the end of life.

End-of-life laws have not kept up with the times for the growing number of patients with dementia. Many patients diagnosed with Alzheimer's and other dementias foresee an inevitable decline toward physical dependence on family or others for daily needs and inability to communicate rationally with loved ones.[413] For some, a more dignified death is preferable to hanging on with this intolerable quality of life and the burdens it imposes on families.[414] They may wish to refuse food and water by mouth instead of continuing to decline until their disease progresses to the point of terminal illness and dependence on medical interventions that they have the right to refuse.[415]

There is a rising interest in the option of voluntarily stopping eating and drinking ("VSED").[416] Compassion & Choices, a leading organization that advocates for end-of-life options, has published a directive addendum that allows patients to refuse food and fluids, including by spoon-feeding, should they be in an advanced stage of dementia and no longer show interest in eating or drinking, or actively reject efforts to feed them by turning away or clenching the mouth shut.[417] Such directives,

411. *E.g.*, Anne L. Moody, *Summary of Health Care Decision Statutes Enacted in 2019,* A.B.A. COMM'N ON L. & AGING, https://www.americanbar.org/content/dam/aba/administrative/law_aging/2019-hcpa-legis-update.pdf [https://perma.cc/62LA-NULQ] (last visited June 13, 2026).

412. OR. REV. STAT. § 441.049 (2023).

413. Silva Banovic et al., *Communication Difficulties as a Result of Dementia,* 30 MATER SOCIOMED. 221, 222 (2018), https://www.ejmanager.com/mnstemps/16/16-1536861905.pdf?t=1760758803 [https://perma.cc/MB3P-8QPB]; Trent McLaughlin et al., *Dependence as a Unifying Construct in Defining Alzheimer's Disease Severity*, 6 ALZHEIMER'S & DEMENTIA 482, 484 (2010).

414. *See, e.g.*, Terry Gross, *After an Alzheimer's Diagnosis, Her Husband Asked for Help to Die with Dignity*, NPR (Mar. 8, 2022, at 13:12 ET), https://www.npr.org/sections/health-shots/2022/03/08/1084912553/alzheimers-assisted-suicide-amy-bloom-in-love [https://perma.cc/H78P-SB4C].

415. John W. Wax et al., *Voluntary Stopping Eating and Drinking*, 66 J. AM. GERIATR. SOC'Y 441, 441 (2018).

416. Hope Wechkin et al., *Clinical Guidelines for Voluntarily Stopping Eating and Drinking (VSED)*, 66 J. PAIN & SYMPTOM MGMT. 625, 625 (2023).

417. *Dementia Values & Priorities Tool*, COMPASSION & CHOICES 1, https://compassion

however, rest on an uncertain legal footing and have yet to be tested in court. Competent patients have the right to refuse food and water by mouth—spoon or bottle feeding—but a significant number of states provide that the incompetent patient's right to refuse artificially-provided fluids and nutrition in an advance directive does not extend to refusal of food and water by mouth.[418] Other states are simply silent on this question. This area is ripe for law reform. Express recognition of the right to refuse food and water by mouth, on a par with competent patients, would be a significant law reform to the benefit of the large and growing aging population who would choose to avoid the progressive decline and indignity brought by Alzheimer's and other dementias.[419]

IV. STRENGTHENING PATIENT AND FAMILY RIGHTS: POLST

States have continued to strengthen the rights of patients and families to determine their own health care. The most notable initiative now in widespread use is Physician Orders for Life-Sustaining Treatment ("POLST") in the hospital setting.[420] Many hospitals

andchoices.org/dementia-values-tool/ [https://perma.cc/EV6Y-5Q44] (last visited June 13, 2026) (providing additional planning tools).

418. *E.g.*, ALA. CODE § 22-8A-3(2) (2024); GA. CODE ANN. § 31-32-2(12) (2024); IOWA CODE § 144A.2(9)(b) (2024).

419. A related issue concerns the availability of the alternative of medical aid in dying (MAID). In the fourteen jurisdictions with MAID laws patients must be terminally ill (prognosis of six months remaining or less) and when competent must make a repeated informed request two weeks apart (in most of these jurisdictions) for the physician to write a prescription for drugs the patient will self-administer at a time and place of their choosing. *States Where Medical Aid in Dying is Authorized*, COMPASSION & CHOICES, https://compassionandchoices.org/states-where-medical-aid-in-dying-is-authorized/ [https://perma.cc/D96B-KSJE] (last visited June 13, 2026) (providing patient-friendly information about the law in each of these jurisdictions, and links to the state statutes). Notably, patients can face a catch-22 under these rules. Competent patients may not be considered terminal, based on a dementia diagnosis alone absent an underlying life-threatening condition. *See* Thaddeus M. Pope & Lisa Brodoff, *Medical Aid in Dying to Avoid Late-Stage Dementia*, 72 J. AM. GERIATR. SOC'Y 1216, 1221 (2024). But when dementia progresses, they may lose the ability to request MAID within the window of time prescribed by law, or dementia may become so serious that ability to self-administer the drug may be lost. *See id.* Patients can choose VSED to accelerate the path to a terminal condition, but risk delirium and loss of capacity from starvation and dehydration. *See id.* Pope and Brodoff propose that a resolution to this dilemma is to recognize VSED-induced starvation and dehydration as a terminal condition and to shorten the waiting period for repeat consent/requests. *Id.* at 1216, 1221. Some states have shortened their waiting periods, but none have defined VSED as a qualifying terminal condition. *Id.* at 1220–21.

420. *See Issues at a Glance: Provider Orders for Life-Sustaining Treatment (POLST)*, AM. ASS'N OF NURSE PRACTITIONERS [hereinafter *POLST Issues*], https://www.aanp.org/advocacy/advocacy-resource/policy-briefs/issues-at-a-glance-provider-orders-for-life-sustaining-treatment-polst [https://perma.cc/G5YN-QCBW] (last

nationwide use POLST forms, first developed in Oregon in 1994, to document orders for care and treatment near the end of life.[421] POLST is sometimes recognized by statute, in other states it is authorized by department of health regulation, or it may be established through clinical guidelines that have consensus support of professional organizations, institutions and clinicians.[422] Whatever their source of authority, all states have POLST programs.[423] In some states they go by different names; for example, Medical Orders for Life-Sustaining Treatment ("MOLST") in New York,[424] Pennsylvania Orders for Life Sustaining Treatment ("PA POLST") in Pennsylvania,[425] and Medical Orders for Scope of Treatment in Michigan ("MI-POST").[426]

The primary purpose of the POLST paradigm is "to convert patient preferences for life-sustaining treatments into immediately actionable medical orders."[427] The practical goal is to bring together in one place all end-of-life orders, such as do-not-resuscitate ("DNR"), withdrawal of feeding tubes, and comfort care measures, and to communicate a comprehensive plan readily accessible to all members of the care team under the signature of the physician's order.[428] POLST may document the competent patient's oral directives for care and treatment and choice of preferred surrogate, or operationalize the terms of an advance

visited June 13, 2026). There are several other examples of the law's expansion of patient and family rights near the end of life. Many states have laws that establish out-of-hospital DNR orders. These orders direct emergency personnel not to attempt resuscitation and may also instruct family not to call EMS in event of a medical emergency. Charles P. Sabatino, *Survey of State EMS-DNR Laws and Protocols*, 27 J.L. MED. & ETHICS 297, 310–12 (1999). Also, many states recognize advance directives specifically for mental health patients. Maurice S. Fisher, Jr., *Psychiatric Advance Directives and the Right to Be Presumed Competent*, 25 J. CONTEMP. HEALTH L. & POL'Y 386, 387–88 (2009). These laws add to the legal framework supportive of patients' rights.

421. *POLST Issues*, *supra* note 420.

422. *Id.*

423. *See* Kathy L. Cerminara & Seth M. Bogin, *A Paper About a Piece of Paper: Regulatory Action as the Most Effective Way to Promote Use of Physician Orders for Life-Sustaining Treatment*, 29 J. LEGAL MED. 479, 480–81 (2008).

424. *Medical Orders for Life-Sustaining Treatment (MOLST)*, N.Y. DEP'T OF HEALTH (2025), https://www.health.ny.gov/professionals/patients/patient_rights/molst/ [https://perma.cc/4F67-B5NN].

425. *Pennsylvania Orders for Life Sustaining Treatment (PA POLST)*, PA. POLST, papolst.org [https://perma.cc/69TY-FHBN] (last visited June 13, 2026).

426. *Michigan Physician Orders for Scope of Treatment (MI-POST)*, MICH. DEP'T OF HEALTH & HUM. SERVS., https://www.michigan.gov/mdhhs/inside-mdhhs/legislationpolicy/ems/news/mi-post [https://perma.cc/K99W-DYTG] (last visited June 13, 2026).

427. Susan E. Hickman et al., *POLST (Physical Orders for Life-Sustaining Treatment) Paradigm to Improve End-of-Life Care: Potential State Legal Barriers to Implementation*, 36 J.L. MED. & ETHICS 119, 119 (2008).

428. *See id.* at 119–20.

directive and the proxy's decisions.[429] Oftentimes, the treating physician completes this form in consultation with the proxy or family.[430] POLST forms are used mostly, though not exclusively, in hospitals, are portable, and should follow the patient when transferred from one facility to another.[431]

POLST laws and regulations are typically procedural and do not constitute a source of patients' substantive rights.[432] Forms are commonly tailored to reflect and be consistent with the governing state law.[433] It has been noted that clinicians using POLST may have stronger legal protections in states with enabling legislation compared to those who rely on consensus practice in the absence of legislation,[434] but compliance with other extant law governing surrogate decision making and advance directives should largely obviate these concerns.

Charles Sabatino, an expert on the end-of-life legal landscape who headed the ABA Commission on Law and Aging for many years, describes the emergence of POLST as a transition from the "legal transactional approach" of advance directives to a "communications approach" that emphasizes advance care planning.[435] By legal transactional approach is meant a "framework focuse[d] on the formal steps of creating and implementing the legal tools" for controlling health care decisions in the event of future incapacity.[436]

For example, many provisions of advance directive laws model legal formalities for execution of a valid document, such as signing and witnessing, selection of a trusted proxy and alternates, as well as rules for the exercise of proxy authority, after statutes governing testamentary wills and powers of attorney for personal matters, adopting extant law to

429. *See* Cerminara & Bogin, *supra* note 423, at 480.

430. *Id.* at 483–84. POLST, DNR, and advance directives are sometimes confused, mostly because they all express patients' wishes and involve some degree of advance planning. *See* Sabatino, *Evolution*, *supra* note 288, at 16 (discussing the difference between POLST, DNR and advance directives). A key distinction is that do-not-resuscitate (DNR), do-not-intubate (DNI), and DNR/DNI orders are physician orders. *See id.* These orders implement patient/proxy refusal of cardiopulmonary resuscitation or intubation and may be documented in a POLST. *See id.* at 228–30.

431. *See Honoring the Wishes of People with Progressing Serious Illness.*, NAT'L POLST COLLAB., https://polst.org [https://perma.cc/XF4Z-3AN3] (last visited June 13, 2026).

432. *See* Charles P. Sabatino, *Advance Directives and Advance Care Planning: Legal and Policy Issues*, OFF. OF ASS'T SEC'Y FOR PLAN. & EVALUATION (Sep. 30, 2007), https://aspe.hhs.gov/reports/advance-directives-advance-care-planning-legal-policy-issues-0 [https://perma.cc/A3TY-RLXN].

433. *See* Cerminara & Bogin, *supra* note 423, at 485–86.

434. Thaddeus M. Pope & Melinda Hexum, *Legal Briefing: POLST: Physician Orders for Life-Sustaining Treatment*, 23 J. CLIN. ETHICS 353, 357 (2012).

435. Sabatino, *Evolution*, *supra* note 288, at 211.

436. *Id.* at 218.

the domain of health care.[437] Sabatino further notes that formalities that validate a document's legal authority impress upon others their obligations to respect advance directives and hence the patient's and proxy's wishes.[438] These are valuable insights. We should also observe that POLST is a logical extension of the PSDA's requirement to document a patient's advance directive status and is part of a larger movement, spanning decades, that emphasizes communication about end-of-life planning, including education about and preparation of advance directives.[439] It is familiar advice that individuals should discuss their end-of-life plans with both family and their physician, and most importantly, their chosen health care proxy, and alternates.

V. SUPPORTING PATIENTS AND FAMILIES: ETHICS COMMITTEES AND CONSULTANTS

The rapid growth of ethics committees and consultants can be traced to the 1992 Joint Commission on Accreditation of Healthcare Organizations ("JCAHO") accreditation standard that requires facilities to establish and maintain "a mechanism[] for the consideration of ethical issues arising in the care of patients . . . ."[440] Implementation of this quasi-legal mandate has resulted in the presence of ethics committees[441] and consultants[442] in hospitals and other healthcare facilities across the

437. *See id.* at 214, 219–20.

438. *Id.* at 219. Sabatino includes in his account of the legal transactional approach the high degree of uniformity in the conditions under which patients may refuse treatment with an advance directive, i.e., terminal illness and PVS. *Id.* at 220. In one sense the diagnosis of terminal illness or PVS triggers a "transaction" or engagement with the choice whether to continue aggressive interventions. This Article construes these and related provisions as substantive rights rather than legal formalism.

439. *See History of the Movement*, COMPASSION & CHOICES, https://compassionandchoices.org/resource/history-end-life-choice-movement/ [https://perma.cc/AK44-4C23] (last visited June 13, 2026).

440. JOINT COMM'N ON ACCREDITATION OF HEALTHCARE ORGS., ACCREDITATION MANUAL FOR HOSPITALS, STANDARDS RI.1.1.6.1 (1994) [hereinafter JOINT COMM'N].

441. Even before promulgation of the Joint Commission standards, it was estimated that by 1985 "more than sixty percent of American hospitals and nearly ten percent of all nursing homes had established their own ethics committees." Diane E. Hoffmann, *Regulating Ethics Committees in Health Care Institutions – Is it Time?*, 50 MD. L. REV. 746, 746–47 (1991). Ethics committees and consultants are still less prevalent in nursing homes. *See* Gary Glasser et al., *The Ethics Committee in the Nursing Home: Results of a National Survey*, 36 J. AM. GERIATR. SOC'Y 150, 151 (1988). Some nursing homes share a committee with an affiliated hospital or participate in a network that offers access to committee consultation. *Id.*

442. According to one study, in 2007, eighty-one percent of hospitals had ethics consultants. Ellen Fox, Sarah Meyers & Robert A. Pearlman, *Ethics Consultation in United States Hospitals: A National Survey*, 7 AM. J. BIOETH. 13, 15 (2007). For discussion of the

country. The JCAHO initiative resolved any lingering confusion about the difference between ethics committees and prognosis committees. Ethics committees are multidisciplinary bodies that count among their members physicians, nurses, social workers, administrators, bioethicists, clergy, and often at least one community member unaffiliated with the institution.[443] Many include hospital counsel, though some consider it preferable to have an independent lawyer—essentially another community member—as the primary duty of counsel is to protect the hospital.[444] Committees typically engage in the core functions of policy development and institutional education. They may be a resource to consult on a current patient care matter, or discuss cases retrospectively as a form of oversight and quality improvement. [445] Clinical ethics consultants may be physicians, nurses, social workers, philosophers, lawyers or bioethicists by training.[446] Many hospitals look to an individual consultant or a staffed consult service that functions largely independently of the committee to provide on-demand assistance when ethical issues arise.[447] (It's easier to page a consultant than a multidisciplinary committee).

There is very little black-letter law directly applicable to the structure and function of ethics committees or consultants, making committees largely unregulated entities.[448] Guidelines for how ethics committees operate may be set forth in hospital policy or in regulations, implementing the Joint Commission mandate[449] or the few state laws establishing ethics committees. Among the handful of states with relevant statutes, Maryland law stands out. In Maryland, multidisciplinary ethics committees—called "patient care advisory committees"—are to be established with a minimum of four members involved in a case; patients, families and proxies, members of the health

history and growth of ethics consultation, see Elliot B. Tapper, *Consults for Conflict: The History of Ethics Consultation*, 26 BAYLOR U. MED. CTR. PROCS. 417, 418 (2013).

443. Elizabeth Heitman, *Institutional Ethics Committees: Local Perspectives on Ethical Issues in Medicine*, NAT'L CTR. FOR BIOTECH. INFO., https://www.ncbi.nlm.nih.gov/books/NBK231970/ [https://perma.cc/N4KQ-4F28] (last visited June 13, 2026).

444. *See* Suzanne M. Mitchell & Martha S. Swartz, *Is There a Place for Lawyers on Ethics Committees? A View from the Inside*, 20 HASTINGS CTR. REP. 32, 33 (1990) (discussing the pros and cons of attorneys on ethics committees).

445. *See* Fleetwood, Arnold & Baron, *supra* note 104, at 140; Heitman, supra note 443.

446. Heitman, *supra* note 443.

447. *See id.*; Fleetwood, Arnold & Baron, *supra* note 104, at 138.

448. *See* Diane E. Hoffmann & Anita J. Tarzian, *The Role and Legal Status of Health Care Ethics Committees in the United States*, *in* LEGAL PERSPECTIVES IN BIOETHICS: ANNALS OF BIOETHICS SERIES 46, 46 (Ana S. Iltis, Sandra H. Johnson & Barbara A. Hinze eds., 2008).

449. *See* JOINT COMM'N, *supra* note 440, at Standards R1.1.1.6.1.

care team or others with responsibility for making decisions or directly involved in the patient's care are permitted to request a consultation; and notice of committee meetings must be given to patients, families and proxies with opportunity to attend.[450] The consulting committee is directed to give priority to the patient's wishes in its deliberations and is immune from liability for deliberating in good faith.[451] It is stressed that committee advice is just that—advice.[452] The committee's recommendations are not binding.[453] Physicians and others who choose in good faith not to follow the committee's advice are granted immunity.[454] The committee's recommendation becomes part of the patient's medical record.[455]

At least three states repose some decisional authority over treatment decisions in ethics committees, but only in limited circumstances where there is no one to speak for the incompetent dying patient and no reliable evidence of their wishes despite reasonable efforts to identify a surrogate or a directive. In Arizona, the attending physician can make treatment decisions after consulting with and obtaining an ethics committee's recommendations.[456] Alabama provides that in such instances a hospital committee, that includes the primary treating physician, can decide to forego life-sustaining treatment if by unanimous vote.[457] New York also carves out a role for ethics committee review in decisions to terminate treatment for incompetent patients when nothing is known of the patient's wishes and there is no surrogate decision maker.[458]

450. MD. CODE ANN., HEALTH–GEN. §§ 19-370, -372, -374 (West 2025).

451. *Id.* § 19-374.

452. *See id.* §§ 19-373–74 (stating several times that the committee gives advice).

453. *See id.*

454. *Id.* § 19-374 (f).

455. *Id.* § 19-374 (e)(2). New York mandates that hospitals establish ethics committees or participate in a committee that serves more than one hospital. N.Y. PUB. HEALTH LAW § 2994-m(1) (McKinney 2025). The committee is directed to become involved in current patient care issues only in limited circumstances. *Id.* Hawaii establishes legal immunities for consultation with an ethics committee, a strong incentive to have one, but not an actual requirement. *See* HAW. REV. STAT. §§ 663-1.7(b)–(c) (2025).

456. ARIZ. REV. STAT. ANN. § 36-3231(B) (2024).

457. ALA. CODE § 22-8A-11(d)(7) (2024).

458. In New York, in the absence of a family surrogate or designated proxy, or evidence of the patient's wishes, hospital physicians may decide to forgo life-sustaining treatment for an incompetent imminently dying patient when its provision offers "no medical benefit" and would violate accepted medical standards, or they may refer the patient for hospice care, subject to review by an ethics committee. N.Y. PUB. HEALTH LAW § 2994-G (McKinney 2024). Approaches to deciding for those with no one to speak for them, including the recommendations of the New York Task Force on Life and the Law that ethics committees have a role in reviewing treatment decisions, are discussed in Tracy E. Miller, Carl H. Coleman & Anna Maria Cugliari, *Treatment Decisions for Patients Without Surrogates: Rethinking Policies for a Vulnerable Population*, 45 J. AM. GERIATR. SOC'Y 369 (1997).

Texas gives committees a role in overriding patient autonomy in medical futility type cases.[459] Under the Texas advance directives statute, if the physician disagrees with a request for continued life support from a surrogate or pursuant to the patient's directive on grounds that the intervention is "medically inappropriate," resolution of the conflict can be taken to an ethics committee.[460] If the committee agrees with the physician, the treatment need not be provided.[461] The law goes to lengths to prescribe due process and opportunity for proxy and family to be heard, and that transfer of care should be pursued, but ultimately, with the imprimatur of the committee, medically inappropriate treatment need not be provided.[462]

The composition of ethics committees invites questions about who the committee serves. While ethics committees have been praised for their professional and intellectual diversity, in their early development committee structure was also criticized for a perceived lack of independence, because these very same members are employees of the institution, accountable to the hospital at some level.[463] Another consequence of institutional membership is committee groupthink, which reflects a convergence of professional training and institutional culture. Critics do not doubt that hospitals and healthcare professionals are committed to patient welfare; that is a given, but they question whether ethics committees can be truly patient-centered in difficult cases that put patient and hospital interests at odds or when they have divided loyalties.[464] In theory, similar concerns about divided loyalties apply to clinical ethics consultants who are also employed by the hospital in some capacity.

These are important considerations, but their importance is diminished by the tremendous growth of ethics consultation over the past several decades. Consultants are important resources for physicians,

459. TEX. HEALTH & SAFETY CODE ANN. § 166.046 (West 2024).

460. *Id.* §166.046(d-2).

461. *Id.* §166.046(d-2)(1).

462. *Id.* §166.046(e). Regulations require all facilities to establish an ethics committee to be available for consultation with regard to decisions about life-sustaining treatment. 25 TEX. ADMIN. CODE § 405.60 (2009). Similarly, Colorado provides that to forgo nonbeneficial end of life treatment a consensus of a medical ethics committee must agree. COLO. REV. STAT. § 15-18.5-103(6.5) (2024). If the hospital does not have its own ethics committee it must refer the parties to another facility that does. *Id.*

463. Thaddeus M. Pope, *Multi-Institutional Healthcare Ethics Committees: The Procedurally Fair Internal Dispute Resolution Mechanism*, 31 CAMPBELL L. REV. 257, 258 (2009).

464. *See generally* Cynthia B. Cohen, *The Social Transformation of Some American Ethics Committees*, 19 HASTINGS CTR. REP. 21 (1989) (containing a collection of short essays addressing ethics and institutional agendas).

nurses, and social workers, but also for patients and families. In many hospitals, anyone with direct involvement in the patient's care may request an ethics consult. Several conceptual models for ethics consultation have been proposed.[465] All share a commitment to facilitating dialogue among all concerned parties, in particular patient (if able), family, proxy, physician, nurse, social work, and giving due consideration to competing perspectives. The mission of the consultant is to identify ethical issues, clarify misunderstandings and to help resolve disagreements.[466]

For ethics consultants today, the frame is a core set of principles, in particular respect for autonomy and beneficence, that together with relevant law puts patients and families first. In many cases, the consultant's task is to help answer the central question: What would the patient want? And often it is to educate family, physician or others that the patient's preferences, values and directions take priority in the balancing of competing concerns for the patient's best interests or in the effort to resolve family disagreement.[467] This is the end-of-life consensus at work at the local level. Where these models differ is the line between advising and deciding. We believe the better model, and the approach taken by most ethics consultants, maintains that ethics consultants have an advisory role only. The consultant is best seen as a partner, there to assist and advise in the decision-making process (and should never be thought of as the ethics police).[468] The consultant makes recommendations, often formalized by placing a chart note in the patient's record, but ought not to become the judge, jury, and decider.[469] Authority and responsibility for treatment decisions rest in the physician-patient-family relationship.[470]

465. *See* Hoffmann & Tarzian, *supra* note 448, at 54–55. The authors identify four procedural models for consults: case conference, consultation, quasi-judicial and mediation. *Id.* The case conference and quasi-judicial models repose more decisional authority in the consultant. *Id.* at 55.

466. Anita J. Tarzian, *Health Care Ethics Consultation: An Update on Core Competencies and Emerging Standards from the American Society for Bioethics and Humanities' Update Task Force*, 13 AM. J. BIOETH. 3, 5 (2013).

467. The ASBH Core Competencies Task Force favors an "ethics facilitation" approach that emphasizes the knowledge and skills to identify and analyze the issues and points of disagreement and conflict and to facilitate a "principled ethical resolution." *Id.*

468. *See* Robert D. Orr & Wayne Shelton, *A Process and Format for Clinical Ethics Consultation*, 20 J. CLIN. ETHICS 1, 3 (2009).

469. *See id.*

470. In the very few instances when ethics committees or consultants have been sued as named defendants the dispute most often has been about whether continued treatment is futile, and it has sometimes been alleged that the consultant overstepped their bounds and acted in such a way as to strongly influence the decision or arrogated decisional authority to themselves. To our knowledge, none of these cases have resulted in liability for committee

The value of ethics consultation cannot truly be measured. Within a hospital, a high volume of consults evidences an institutional presence for the consult service and awareness of ethical issues at the bedside. On the other hand, fewer consult calls could suggest the opposite, that physicians in particular are comfortable handling ethical concerns themselves, or that hospital education has effectively raised staff competence with ethical concerns. To the extent data can be culled from the records of a consult service, the numbers can be driven significantly by a hospital's patient mix and range of services, with an asterisk to generate comparative data. Quantitative data sheds little light on the quality of consultations. Some quality measures emerge informally from consultant team meetings where peer review of cases occurs.[471] The American Society for Bioethics and Humanities, the leading professional organization in the field, has promulgated a Code of Ethics and Professional Responsibilities for Healthcare Ethics Consultants and sponsors training and certification programs.[472] These initiatives will no

members or consultants. *See* Hoffmann & Tarzian, *supra* note 448, at 61–62; Robert S. Olick, *Ethics Consultation and the Law: What is the Standard of Care?*, *in* MARGIN OF ERROR: THE ETHICS OF MISTAKES IN THE PRACTICE OF MEDICINE 287 (Susan B. Rubin & Laurie Zoloth eds., 2000) (discussing cases and exploring lessons from the medical malpractice model); Stacy Kusterbeck, *Can Ethicists be Sued for Recommendations? Attorneys Warn of Potential Legal Risk*, CLINICIAN.COM: MED. ETHICS ADVISOR (July 1, 2024), https://www.clinician.com/articles/can-ethicists-be-sued-for-recommendations-attorneys-warn-of-potential-legal-risks [https://perma.cc/7HDB-Y8MG] (discussing the risks of liability as clinical ethics consultation has become more professionalized with proposed standards of conduct).

471. *See* Stacy Kusterbeck, *How Is the Ethics Service Doing? Data Are Necessary to Know*, CLINICIAN.COM: MED. ETHICS ADVISOR (July 1, 2024), https://www.clinician.com/articles/how-is-the-ethics-service-doing-data-are-necessary-to-know [https://perma.cc/7WYK-9ZE4]. One small anecdotal study collected narratives from twelve recipients of consult services; while the narratives reported a very positive experience with consults, they also pointed to the need for greater education and awareness among patients, families and healthcare providers. *See* Stacey Kusterbeck, *Ethics Consult Requestors Validate Value of Ethicists, Voice Concerns About Access*, CLINICIAN.COM: MED. ETHICS ADVISOR (Dec. 1, 2024), https://www.clinician.com/articles/ethics-consult-requestors-validate-value-of-ethicists-voice-concerns-about-access [https://perma.cc/SSS7-YJDT].

472. AM. SOC'Y FOR BIOETH. & HUMANIT., https://asbh.org [https://perma.cc/N3MS-JE9G] (last visited June 13, 2026). The ASBH standards are not considered professional standards analogous to those of the AMA. The ASBH offers a voluntary Healthcare Ethics Consultant Certified Program. *Healthcare Ethics Consultant-Certified Program*, AM. SOC'Y FOR BIOETH. & HUMANIT., https://asbh.org/certification/hcec-certification [https://perma.cc/P74S-CS88] (last visited Apr. 14, 2026). Whether it is appropriate to call ethics consultation a profession is an open question. In contrast to other professions, there are no requirements for education, training or licensure as an ethics consultant. *See* Michael D. Bayles, *The Professions*, *in* ETHICAL ISSUES IN PROFESSIONAL LIFE 27 (Joan C. Callahan ed., 1988).

doubt improve the consultation process and bring some standardization to the work of ethics consultants.

That said, the salutary and pervasive impact of ethics committees and consultants has been their contribution to resolving ethical dilemmas in patient care within the private confines of the physician-patient-family relationship, keeping disagreement within the walls of the hospital, away from the media and the public, and from the adversarial spectacle of the courtroom. This was Chief Justice Hughes's grander vision in *Quinlan*.[473]

VI. SUMMARY OF THE END-OF-LIFE CONSENSUS

Chief Justice William Rehnquist wrote in *Glucksberg*, "[t]he primary and most reliable indication of [a national] consensus is . . . the pattern of enacted laws."[474] The story of the right to refuse life-sustaining treatment began in the courts. While caselaw and statutes can be understood and analyzed as proceeding on parallel tracks—as we largely did here—they are also to be read as complementary and interrelated, as a unified body of law despite important differences. Both legislative enactments and judicial opinions shape and reflect culture, norms, and practice.[475]

It is now established beyond peradventure that all patients, competent and incompetent, have the right to refuse treatment near the end of life, and that family members and health care proxies may act on behalf of incompetent patients to effectuate their previously expressed wishes.[476] The consensus that emerged principally in the period from *Quinlan* to *Cruzan* has remained undisturbed and has become more widely accepted, on occasion it has been re-affirmed in the courts.[477] The

473. *In re* Quinlan, 355 A.2d 647, 669 (N.J. 1976) ("Decision-making within health care . . . should be controlled primarily within the patient-doctor-family relationship . . . .").

474. Washington v. Glucksberg, 521 U.S. 702, 710–11 (1997) (quoting Stanford v. Kentucky, 492 U.S. 361, 373 (1989) (alterations in original)).

475. Other laws not discussed here also contribute to the fabric of our legal, ethical and societal consensus, including national recognition of out-of-hospital DNR orders, specific laws for advance mental health directives in many states, and other laws establishing family surrogate decision making (some but not all expressly address end-of-life decisions), and the 50-state network of laws that recognize advance consent and surrogate consent to organ donation, modeled after the Uniform Anatomical Gift Act. Also of great importance, various health care organizations, government commissions, scholars, religious institutions, media and others both adopted and informed the core tenets of the consensus in an iterative relationship with the law. Meisel, *supra* note 213, at 738–39.

476. *Id.*

477. *Id.* at 739–40, 740 n.22 ("[N]o state has repudiated the consensus' main points.").

core principles of the end-of-life consensus, found in extensive bodies of law from courthouse to statehouse, can be summarized as follows:

- Competent patients have the right to refuse unwanted treatment, including life- sustaining treatment, and to have their treatment refusals respected. This right is based on both the federal and a number of state constitutions, and on the common law right of self-determination.
- Incompetent patients have the same right to refuse life-sustaining treatment as competent patients, but the rights of incompetent patients are exercised in a different manner.
- Family members may decide for incompetent loved ones in the exercise of substituted judgment.
- State laws allow and encourage competent adults to execute advance directives to control decisions near the end of life at a future time of decisional incapacity. There are three types of advance directives: health care proxies, living wills, and the combination of both approaches.
- The patient's previously expressed wishes should be respected by proxies, families, physicians and others. Family members or other surrogate decisionmakers should act first and foremost in accordance with the patient's previously expressed wishes, and also in the patient's best interests.
- There is no legal distinction between withholding and withdrawing treatment. When treatment is withheld or withdrawn from a dying patient this allows the patient's underlying disease process to take its course. Implementing this decision does not constitute killing, assisted suicide or suicide.
- Any and all forms of life-sustaining treatment can be refused. There is no legal distinction between respirators, feeding tubes, CPR, chemotherapy, antibiotics or other interventions.
- Forgoing of life-sustaining interventions does not mean cessation of all care. Appropriate pain relief, symptom management and comfort measures should always be provided.
- There are a number of limitations on the rights of incompetent patients to refuse life-sustaining treatment that do not apply for competent patients. Many (but not all) states require that the patient have a terminal condition or be in a state of permanent unconsciousness before forgoing treatment is authorized.
- When legal-ethical dilemmas arise in patient care, ethics consultation can help to clarify ethical issues and to resolve disagreements. This is common practice in hospitals, though it is rarely required by law.

- POLST forms document physician orders that implement patient, family and proxy decisions.
- End-of-life law is very much a matter of state law.[478]

VII. TREATMENT REFUSAL AFTER *DOBBS*

In *Dobbs*,[479] a divided Supreme Court overturned both *Roe*[480] and *Casey*,[481] precedents that first established and then reaffirmed a woman's right to choose to terminate her pregnancy under the U.S. Constitution. In overturning nearly fifty years of precedent, the conservative majority rejected the Court's prior substantive due process analysis that has grounded constitutional protection of the right to choose and other fundamental rights.[482] The majority takes pains to insist that its decision "concerns the constitutional right to abortion and no other right. Nothing in this opinion should be understood to cast doubt on precedents that do not concern abortion."[483] But in the aftermath of *Dobbs*, some legal scholars have raised concerns about whether other rights that rest on privacy and liberty may be in jeopardy.[484] These suspicions are fueled by Justice Thomas' concurrence calling for re-examination of all of the Court's substantive due process cases,[485] and by the dissent's prediction that other precedents protecting profoundly personal choices are in jeopardy.[486] While speculation and concern have focused largely on

478. Earlier formulations of the end-of-life consensus as it pertains to patient and family rights to refuse life-sustaining treatment are consistent with our summary here. *See, e.g.*, Meisel, *supra* note 213, at 738–41; CANTOR, *supra* note 120, *passim*; Gostin & Weir, *supra* note 251, *passim*.

479. Dobbs v. Jackson Women's Health Org., 597 U.S. 215, 229–31 (2022).

480. Roe v. Wade, 410 U.S. 113 (1973), *overruled by*, Dobbs v. Jackson Women's Health Org., 597 U.S. 215 (2022).

481. Planned Parenthood v. Casey, 505 U.S. 833 (1992), *overruled by*, Dobbs v. Jackson Women's Health Org., 597 U.S. 215 (2022).

482. *Dobbs*, 597 U.S. at 229–31.

483. *Id.* at 221.

484. *See* Kenji Yoshino, *After the Supreme Court's Abortion Ruling, What Could Happen to Other Unwritten Rights?*, WASH. POST MAG. (Nov. 30, 2022, at 17:34 ET), https://www.washingtonpost.com/magazine/interactive/2022/substantive-due-process-dobbs/ [https://perma.cc/F3DV-B5TK].

485. Justice Thomas pronounces that "we should reconsider all of the Court's substantive due process precedents," and that "we should eliminate [substantive due process] from our jurisprudence at the earliest opportunity." *Dobbs*, 597 U.S. at 332, 336 (Thomas, J., concurring). *But see id.* at 346 (Kavanaugh, J., concurring) ("I emphasize what the Court today states: Overruling *Roe* does *not* mean the overruling of those precedents, and does *not* threaten or cast doubt on those precedents." (emphasis in original)).

486. *Id.* at 362 (Breyer, J., Sotomayor, J., and Kagan, J., dissenting) ("[N]o one should be confident that this majority is done with its work.").

contraception, same-sex relationships, and marriage,[487] the other rights and precedents cited in *Dobbs*, a few have begun to question whether the decision opens the door for attempts to roll back aspects of the end-of-life consensus.[488] In our view, *Dobbs* does little to disturb patient and family rights because the rationales and foundations of this well-settled, extensive body of law simply do not rely on the U.S. Constitution.[489] However, this does not preclude the possibility of officious political interference, as occurred in the case of Terri Schiavo.[490] This Section starts with a brief summary of *Dobbs*' approach to substantive due process and concludes with the one place where the case has significantly impaired patients' rights near the end of life, the rare but real situation of a dying pregnant woman and the choice between forgoing treatment to ease the dying process or continuing medical interventions for the benefit of fetal life.

A. Substantive Due Process

No one should be deprived of life, liberty, or property without due process of law.[491] This guarantee of due process applies to the federal government under the Fifth Amendment of the Constitution, and is made applicable to the states by the Fourteenth Amendment.[492] The substantive due process doctrine refers to rights that, though not enumerated in the Constitution, can be inferred from its text, meaning,

487. The Supreme Court declined to accept review of the case of Davis v. Ermold, 130 F.4th 553 (6th Cir. 2025), *cert. denied*, 146 S. Ct. 398 (2025). The third question presented in the petition for writ of certiorari asserted that the right to same sex marriage recognized in Obergefell v. Hodges, 576 U.S. 644 (2015), should be overturned and contended that the substantive due process analysis it was based on is a "legal fiction." Petition for Writ of Certiorari at 32, Davis v. Ermold, 146 S. Ct. 398 (2025) (No. 25-125), 2025 WL 2211011; *see also Supreme Court Declines to Hear Case on Constitutionality of Same-Sex Marriage*, SCOTUSBLOG (Nov. 10, 2025), https://www.scotusblog.com/2025/11/supreme-court-declines-to-hear-case-on-constitutionality-of-same-sex-marriage/ [https://perma.cc/A8KF-A6ZB].

488. *See* Rebecca Dresser, Cruzan *After* Dobbs*: What Remains of the Constitutional Right to Refuse Treatment?*, 53 HASTINGS CTR. REP. 9, 9 (2023); Joseph J. Fins, *After Roe, What's Next for End-of-Life Care?*, HASTINGS BIOETHICS F. (June 29, 2022), https://www.thehastingscenter.org/after-roe-whats-next-for-end-of-life-care/ [https://perma.cc/XF9Z-BEZY].

489. *See* Meisel, *supra* note 213, at 740.

490. *See generally* George J. Annas, *'Culture of Life' Politics at the Bedside: The Case of Terri Schiavo*, 352 NEJM 1710 (2005) [hereinafter Annas, *The Case of Terri Schiavo*] (arguing that political intervention in the *Schiavo* case undermined settled legal principles protecting patient autonomy in end-of-life decision making).

491. U.S. CONST. amend. V; U.S. CONST. amend. XIV.

492. U.S. CONST. amend. V; U.S. CONST. amend. XIV, § 1.

and history.[493] *Roe* rests on the position that there is a guaranteed right of privacy, even though the term "privacy" does not appear in the text of the Constitution.[494] Privacy is said to be an unenumerated right, found in the meaning of the Fifth and Fourteenth Amendments to the Constitution, and perhaps other constitutional provisions—*Roe* cited to as many as five constitutional provisions.[495] Substantive due process is also about finding a more concrete definition of the meaning of the rights that are found in the constitutional text, here the rights to "life, liberty, [and] property."[496] *Casey* shifted the basis for the right to abortion to the Constitution's liberty interest and away from privacy.[497] *Dobbs* overrules both and returns the issue to the states.[498]

Law professor Katharine Bartlett identifies several approaches to substantive due process in contemporary Court opinions.[499] Most prevalent and well-known is the contrast between conservative jurists, who look to the past and valorize history and tradition in the name of originalism, and liberal jurists, who favor contemporary norms and reasoned judgment about the present, seeing a more dynamic Constitution for the times we live in.[500] The two approaches have been loosely characterized as the difference between the conservative backward-looking camp and the liberal forward-looking camp.[501] For originalists, the relevant time period for abortion is from the original founding to the second, in 1868, when the Fourteenth Amendment was adopted; earlier common-law history is also salient, but later history is of lesser weight and may be discounted or ignored.[502] For liberals, the past, present, and future all matter, including the full history of Court

493. *See, e.g.*, Roe v. Wade, 410 U.S. 113, 167–68 (1973) (Stewart, J., concurring) (listing cases).

494. *See id.* at 174 (1973) (Rehnquist, J., dissenting) ("To reach its result, the Court necessarily has had to find within the Scope of the Fourteenth Amendment a right that was apparently completely unknown to the drafters of the Amendment.")

495. *Id.* at 152–53 (majority opinion).

496. U.S. CONST. amend. V; U.S. CONST. amend. XIV, § 1.

497. Planned Parenthood v. Casey, 505 U.S. 833, 846 (1992).

498. Dobbs v. Jackson Women's Health Org., 597 U.S. 215, 292 ("[T]he authority to regulate abortion must be returned to the people and their elected representatives.").

499. *See* Katharine T. Bartlett, *Tradition as Past and Present in Substantive Due Process Analysis*, 62 DUKE L.J. 535, 561–72 (2012).

500. *See id.* at 555–56. Bartlett goes on to argue that this familiar either/or dichotomy between these two approaches is flawed. *Id.* Instead, she advocates for "[a]n integrative view of tradition [that] recognizes substantive due process claims cannot be decided either by relying entirely on the past, or by ignoring it." *Id.* at 572.

501. *See* Yoshino, *supra* note 484.

502. *See Dobbs*, 597 U.S. at 248–50.

rulings, and their impact on settled law and societal norms and expectations.[503]

Writing for the conservative majority, Justice Alito states that the proper test of whether an unenumerated right enjoys constitutional protection is that any such right must be "deeply rooted in this Nation's history and tradition" and "implicit in the concept of ordered liberty."[504] According to the majority, the abortion right "does not fall within this category" whether one construes the basis of the right as sounding in privacy or liberty.[505] This formulation of the inquiry follows the Court's 1997 decision in *Glucksberg*, where the conservative, backward-looking test garnered majority support in ruling that the federal Constitution does not protect a right to physician-assisted suicide—now called medical aid in dying.[506]

Applying this standard, Justice Alito engages in a lengthy recitation of the history of the common law and 19th and early 20th century state laws that criminalized abortion (listed in an appendix to the opinion) to establish that the right to choose was not part of our history and tradition.[507] The Court goes on to state that, by the end of the 1950s, most states prohibited abortion unless to save or preserve the life of the mother.[508] "This overwhelming consensus endured until the day *Roe* was decided."[509] According to the majority, "[t]he inescapable conclusion is that a right to abortion is not deeply rooted in the Nation's history and traditions."[510] The past fifty years of precedent since *Roe* and its meaning for culture, society, health care, and women's rights are given little credibility in this analysis.[511] Ironically, when the majority claims it is returning the issue to the states in the name of democracy to allow the people of each state to "address a question of profound moral and social importance[,]"[512] it holds that the contemporary values and beliefs of

503. *See id.* at 374, 387 (Breyer, J., Sotomayor, J., and Kagan, J., dissenting).

504. *Id.* at 231 (majority opinion) (quoting Washington v. Glucksberg, 521 U.S. 702, 721 (1997)).

505. *Id.*

506. *See Glucksberg*, 521 U.S. at 735–36.

507. *See Dobbs*, 597 U.S. *passim*. Justice Alito's opinion spans more than sixty pages including two appendices. Substantial portions criticize at length the *Roe* and *Casey* precedents, respond to the arguments of *amici* in support of abortion rights and to the positions taken by the dissent and Justice Roberts' concurrence. *Id.*

508. *Id.* at 249.

509. *Id.*

510. *Id.* at 250.

511. *See id.* at 359–60 (Breyer, J., Sotomayor, J., and Kagan, J., dissenting).

512. *Id.* at 269 (majority opinion). For analysis and critique of the democracy rationale and its implications, see Melissa Murray & Katherine Shaw, *Dobbs and Democracy*, 137 HARV. L. REV. 728, 729–30 (2024).

today should control, but not those developed and established nationally over the fifty years prior.

The dissenters call *ipse dixit*.[513] Writing for the dissent, Justice Breyer contends that the majority has cherry-picked both its facts and the law. The dissent lays out the liberal view that substantive due process analysis and proper constitutional interpretation requires consideration of "fundamental constitutional principles, the whole course of the Nation's history and traditions, and the step-by-step evolution of the Court's precedents[,]" in a "disciplined but not static" fashion that "relies on accumulated judgments" from the past to the present day.[514] Standards may evolve while still remaining grounded in principle, history and precedent.[515] This approach has established a long line of precedents over more than fifty years that "are all part of the same constitutional fabric, protecting autonomous decisionmaking over the most personal of life decisions."[516] The guarantee of liberty protects "conduct today that was not protected at the time of the Fourteenth Amendment."[517] This constitutional regime also represents the need for balance between the interests and sovereignty of the individual and the interests of government.[518] In the view of the dissent, the majority abandons this balancing principle to achieve its desired result of sending the issue of abortion back to the states.[519]

513. The literal translation of the Latin term *ipse dixit* is "he himself said it." *Ipse dixit*, BLACK'S LAW DICTIONARY (12th ed. 2024). It means to make a dogmatic and unproven statement, based on the authority of the speaker. *See id.* The term has been used to criticize the authority of expert witnesses. *See* Gen. Elec. Co. v. Joiner, 522 U.S. 136, 146 (1997) ("[N]othing in either *Daubert* or the Federal Rules of Evidence requires a district court to admit opinion evidence that is connected to existing data only by the *ipse dixit* of the expert.").

514. *See Dobbs*, 597 U.S. at 387 (Breyer, J., Sotomayor, J., and Kagan, J., dissenting).

515. *Id.* at 376.

516. *Id.* at 362–63.

517. *Id.* at 367 (citing Planned Parenthood v. Casey, 505 U.S. 833, 848 (1992)).

518. *See id.* at 362–64 (discussing the balance between a woman's interests in autonomy and the government's interests and stating that "*Casey* is a precedent about precedent").

519. *Id.* at 364 ("The Court reverses course today for one reason and one reason only: because the composition of this Court has changed."). *See* David H. Gans, *This Court Has Revealed Conservative Originalism to Be a Hollow Shell*, ATLANTIC (July 20, 2022), https://www.theatlantic.com/ideas/archive/2022/07/roe-overturned-alito-dobbs-originalism/670561/ [https://perma.cc/VL85-GTML] ("This is a court that insists that it is following history and tradition where they lead, while cherry-picking the history it cares about to reach conservative results."); Linda Greenhouse, *Religious Doctrine, Not the Constitution, Drove the Dobbs Decision*, N.Y. TIMES (July 22, 2022), https://www.nytimes.com/2022/07/22/opinion/abortion-religion-supreme-court.html [https://perma.cc/XP34-E68M] (arguing that the Court abandoned sound reasoning to impose its own religious views in opposition to abortion). As these and other writers

On the liberal view, the Court must also be mindful of the consequences of its decisions, especially where, as here, overturning *Roe* and *Casey* would significantly disrupt settled rights embedded in culture and society. The dissent devotes significant space to identifying some of the dire consequences of taking away protections for a woman's right to choose—among them severe state restrictions on women's rights and coerced pregnancies, even at risk of death.[520] Sadly, more have happened since *Dobbs* was handed down.[521]

At the heart of the dissent is profound disagreement with the majority's core legal principle that "the sentiments of [the past]" should control our 21st-century present;[522] that the Fourteenth Amendment should be read and understood as those who ratified it did at the time.[523] Not only does the Constitution not freeze our rights for all time,[524] but the Founders themselves believed it was simply unreasonable to expect them to have the foresight to anticipate every conceivable right deserving of constitutional protection.[525] The world changes, and so should the meaning of the Constitution.[526] The majority has declared by judicial fiat that its narrow conservative approach to substantive due process rules is not because it is the better approach, but because, now that the Court has a conservative (super) majority, it can.[527]

Cruzan is not mentioned in the majority opinion. It is cited in passing in Justice Kavanaugh's concurrence,[528] and is discussed only briefly in

observe, just as the Constitution does not contain the word privacy, it also does not contain the word abortion, fetus or unborn.

520. *Dobbs*, 597 U.S. at 359–62 (Breyer, J., Sotomayor, J., and Kagan, J., dissenting).

521. At this writing more than twenty states have laws that prohibit or severely restrict abortion. All were enacted or took effect after *Dobbs* was handed down. Farzana Kapadia, Laura Ferguson & Wendy E. Parmet, *Understanding the Post-Dobbs Landscape for Abortion Care in the United States*, 114 AM. J. PUB. HEALTH 994, 994 (2024) ("Since the *Dobbs* decision, 24 states have banned or significantly restricted access to abortion care, whereas 21 states have enacted further protections for abortion access."); Allison McCann & Amy Schoenfeld Walker, *Tracking Abortion Laws Across the Country*, N.Y. TIMES (May 15, 2026, at 12:02 ET), https://www.nytimes.com/interactive/2024/us/abortion-laws-roe-v-wade.html [https://perma.cc/BRN5-QQ5V].

522. *Dobbs*, 597 U.S. at 381 (Breyer, J., Sotomayor, J., and Kagan, J., dissenting).

523. *Id.* at 372.

524. *Id.* at 374.

525. *Id.* at 364.*Id.* at 364.

526. *Id.* at 372–73.

527. *Id.* at 390 ("The majority has overruled *Roe* and *Casey* for one and only one reason: because it has always despised them, and now it has the votes to discard them."). The dissent is also highly critical of the majority's abandonment of *stare decisis*, a point that is made repeatedly. *Id.* at 390–-91. Legal experts have severely criticized *Dobbs* for its disregard of precedent. *See* Murray & Shaw, *supra* note 512, at 749–60.

528. *Dobbs*, 597 U.S. at 340 (Kavanaugh, J., concurring).

the dissent.[529] The concern for the end-of-life consensus is that since *Cruzan* relied on the liberty interest, like other substantive due process rights, it could be vulnerable to attack.[530] Should the *Cruzan* precedent be challenged and come squarely before the Court, we might expect a similarly divided court to *Dobbs* (assuming the same nine members), with each side applying a different standard of review and each telling a different story about the history of patients' rights and treatment refusal.[531]

A brief sketch of potential arguments shows striking parallels to *Dobbs*. Conservatives seeking to deny that this right is deeply rooted in our history and traditions—and is unencumbered by precedent—might point to the long history of physician paternalism and a commitment to an ethic of preserving life that existed before *Quinlan*. They might also argue that the modern array of high-tech interventions did not begin to emerge until the 1960s.[532] Liberals may counter that the common law has long recognized a right to bodily integrity that includes the right to refuse unwanted intrusions upon the body. Unwanted touching (let alone an unconsented medical procedure) was considered a battery at common law even before the founding of the nation.[533] And they can point to the Court's precedents protecting rights of autonomy and bodily integrity, as did the *Dobbs* dissent.[534] Most importantly, to argue that the right to refuse life-sustaining treatment is in fact a right deeply embedded in contemporary society and that its removal would have disastrous consequences, we need only look to the well-settled end-of-life consensus. This is ordered liberty.

This is not the place to further develop the arguments on either side, nor debate the finer points of substantive due process analysis, and of course, the posture of the case presented matters a great deal. The larger point is that even if the right to refuse treatment were suddenly no longer protected under the federal constitution, it would, in our estimation, make little practical difference. As a legal matter, end-of-life law does not

529. *Id.* at 379 (Breyer, J., Sotomayor, J., and Kagan, J., dissenting).

530. Cruzan v. Missouri Dep't of Health, 497 U.S. 261, 278 (1990).

531. As in *Dobbs*, we might expect the conservatives to subject whatever state action has brought the case before the Court only to the less demanding rational basis test, and not to the heightened scrutiny properly applied to restrictions on fundamental rights. *Dobbs*, 597 U.S. at 300–01.

532. *See* Sabatino, *Evolution*, *supra* note 288, at 213. In *Cruzan*, Justice Scalia in dissent incorrectly equated refusal of treatment with suicide. 497 U.S. at 293. Presumably today's court would not make this same mistake.

533. Johnson v. United States, 559 U.S. 133, 139 (2010) (citing 3 W. BLACKSTONE, COMMENTARIES ON THE LAWS OF ENGLAND 120 (1768)) (describing "force" as an element of common law battery "to be satisfied by even the slightest offensive touching").

534. Dobbs v. Jackson Women's Health Org., 597 U.S. 215, 239 (2022).

rely on substantive due process or the federal constitution. The logical outcome of overturning *Cruzan* is to return the matter to the states. But states—and the nation—have already spoken. The rights of patients and families to consent to and refuse treatment, including life-sustaining treatment, and our right to choose to die with dignity on our own terms, is deeply embedded in the fabric of law, medicine and society—no matter how one defines "tradition". It is difficult to imagine states suddenly reversing course and taking away their citizens' well-established and cherished rights.

B. Politicization: Lessons from Schiavo

Opponents of patients' rights may see an opportunity to push their agenda, as occurred in the 1990 case of Terri Schiavo, when the relevant law was clear and settled. Decisions of the Supreme Court have a way of doing that.

Terri Schiavo suffered a cardiac arrest at the age of twenty-six, apparently due to a potassium imbalance from an eating disorder.[535] She would be diagnosed with PVS as a result of oxygen deprivation to her brain, a diagnosis confirmed by multiple physicians.[536] Her husband, Michael, maintained close and caring involvement in her care for the next eight years, but with no signs of improvement after this long time, he filed a petition for authority as guardian to direct the withdrawal of Terri's feeding tube and allow her to die.[537] The petition was opposed by Terri's parents and siblings.[538] After an extensive review of the evidence that included testimony from eighteen witnesses and documentation of the patient's medical condition, Judge Greer, sitting in Pinellas County Circuit Court, applied the substituted judgment standard and found there to be clear and convincing evidence of Terri's wishes not to be sustained in this condition.[539] Her husband's request to follow her wishes was granted.[540]

On the law, this was a straightforward case. Relying on two precedent decisions of the Florida Supreme Court, *Browning*[541] and

535. C. Christopher Hook & Paul S. Mueller, *The Terri Schiavo Saga: The Making of a Tragedy and Lessons Learned*, 80 MAYO CLIN. PROC. 1449, 1450 (2005).

536. *Id.* at 1452.

537. *Id.* at 1450–52.

538. *Id.* at 1451.

539. *Id.*

540. *In re* Guardianship of Schiavo, No. 90-2908GD-003, slip op. at 7 (Fla. Cir. Ct. Feb. 11, 2000).

541. *See generally In re* Guardianship of Browning, 568 So. 2d 4 (Fla. 1990) (holding that a guardian for an incompetent patient who suffered from an incurable life-threatening

Bludworth,[542] the court held that both competent and incompetent patients have a constitutionally protected right to refuse life-sustaining treatment and that a surrogate may exercise this right on the patient's behalf based on substituted judgment.[543] Further, this right applies to all medical interventions, including artificial nutrition and hydration.[544] The ruling was upheld on appeal.[545]

This is a familiar story in the annals of end-of-life litigation. What distinguishes *Schiavo* from *Quinlan*, *Jobes*, *Cruzan*, and others is the intractable family disagreement.[546] Sadly, Judge Greer's ruling did not put the dispute to rest.[547] This would become a significant factor in the ongoing saga, as the Schindlers continued to challenge the ruling and Michael's authority to decide for his wife, engaging in a persistent pattern of litigation that spanned seven years, almost twenty judges, and countless hearings and proceedings.[548] Terri died on March 31, 2005, in a long-term care facility after surviving fifteen years in PVS connected to a feeding tube and other support against her wishes.[549]

condition that was neither PVS nor terminal could refuse the feeding tube on her behalf in the exercise of the patient's right of self-determination).

542. *See generally* John F. Kennedy Mem'l Hosp., Inc. v. Bludworth, 452 So. 2d 921 (Fla. 1984) (holding that life-sustaining treatment could be withdrawn from an imminently dying patient based on his living will without need for court approval).

543. Hook & Mueller, *supra* note 535, at 1454.

544. *See Schiavo*, slip op. at 7–9.

545. *In re* Guardianship of Schiavo, 780 So. 2d 176, 180 (Fla. Dist. Ct. App. 2001), *rehearing denied* (Feb. 22, 2001), *rev. denied* 789 So. 2d 348 (Fla. 2001).

546. *See generally* Hook & Mueller, *supra* note 535, at 1449, 51–54 (comparing the Schiavo family dispute over withdrawal of life support to Cruzan, where the patient's family and the State of Missouri disputed removal of the feeding tube).

547. *See id.* at 1451.

548. *See* Associated Press, *Key Dates in Schiavo Right-to-Die Case*, N.Y. TIMES (Apr. 1, 2005), https://archive.nytimes.com/www.nytimes.com/imagepages/2005/04/01/national/20050401schiavo_graphic.html [https://perma.cc/7KV4-A4PX] (last visited June 27, 2026) (timeline of key events in the *Schiavo* case).

549. *See* Lois Shepherd, *Terri Schiavo: Unsettling the Settled*, 37 LOY. U. CHI. L.J. 297, 311–12 (2006). The Schiavos' attorney published an insider's account of Terri's long saga where he discussed the growing acrimony within the family, including over funds from the malpractice settlement. *See* JON B. EISENBERG, USING TERRI: THE RELIGIOUS RIGHT'S CONSPIRACY TO TAKE AWAY OUR RIGHTS 14–15 (2005). Michael sued the physicians who had cared for Terri prior to her cardiac arrest for malpractice, and recovered a substantial settlement that would support the cost of her care. *See id.* at 14. Reportedly, the Schindlers were upset that none of the settlement was shared with them and stopped speaking with their son-in-law. *See id.* at 14–15. This may have been the beginning of the friction within the family. It would soon become apparent as well that the Schindlers never accepted the diagnosis of PVS—her mother reportedly found Terri to be interactive at the bedside—and held out hope for her recovery. *See* Charles Weijer, *A Death in The Family: Reflections on the Terri Schiavo Case*, 172 CAN. MED. ASS'N J. 1197 (2005). They were devoted to preserving their daughter's life at all costs regardless of its quality. *See id.* The Schindlers

The Schindlers' tenacity in the court was aided and supported by right-wing religious organizations and ideologues.[550] There were pickets and protests that included threats not only against Michael Schiavo, but also against Judge Greer, who required extra security.[551] In an unprecedented intrusion into the authority of the courts, after the feeding tube had been removed pursuant to yet another court order, the Florida legislature passed, and Governor Jeb Bush signed, a new law (dubbed "Terri's Law") giving the governor the power to, in effect, give a bedside order to reinsert the feeding tube, which was subsequently carried out for Terri.[552] Not long after, the law was unanimously held unconstitutional.[553]

The U.S. Congress also became involved, passing an "emergency measure" signed by President George Bush, which sought to force federal court review of the case, but these efforts proved unsuccessful.[554] In the theatre of the absurd, a number of congressional republicans who were physicians by training purported to diagnose Terri's condition without actually examining the patient, including one senator who did so through video footage.[555] Congressional Republicans announced hearings and drafted a subpoena for Terri Schiavo to testify.[556] Throughout, the case received outsized media attention, both national and international.[557] The assaults on Terri's rights made her a public spectacle and the symbol

were also strongly influenced by right-wing forces who made Terri's case a battleground for their cause. *See* EISENBERG, *supra* note 549, at 97–108, 207.

550. *See* Annas, *The Case of Terri Schiavo*, *supra* note 490, at 1712.

551. *Id.*

552. *See id.*; LegalClarity Team, *Bush v. Schiavo and the Separation of Powers*, LEGALCLARITY (July 26, 2025), https://legalclarity.org/bush-v-schiavo-and-the-separation-of-powers/ [https://perma.cc/AF8F-C9NU].

553. Bush v. Schiavo, 885 So. 2d 321, 328, 337 (Fla. 2004).

554. *See* Annas, *The Case of Terri Schiavo*, *supra* note 490, at 1713–14.

555. *See id.* at 1713; Sheryl Gay Stolberg, *Legislators with Medical Degrees Offer Opinions on Schiavo Case*, N.Y. TIMES (Mar. 23, 2005), https://www.nytimes.com/2005/03/23/politics/legislators-with-medical-degrees-offer-opinions-on-schiavo-case.html [https://perma.cc/TRU3-YWH3].

556. *See* Adam Liptak, *With Schiavo Subpoenas, Lawmakers Leap into Contested Territory*, N.Y. TIMES (Mar. 19, 2005), https://www.nytimes.com/2005/03/19/politics/with-schiavo-subpoenas-lawmakers-leap-into-contested-territory.html [https://perma.cc/9FKD-5XX5].

557. *See, e.g.*, *id.*

of a cause, often proclaiming her *right to life*.[558] No federal legislation resulted.[559]

Contrary to some media accounts, *Schiavo* did not change or make new law.[560] The case itself falls within the settled consensus.[561] It did, however, raise public awareness about the end of life and engendered strong reaction against the role of politicians in decisions best made privately by patients and families.[562] According to a TIME poll taken around the time of her death, "70% of respondents said they disapproved of the president's role in the issue and 54% said they would be more likely to vote against their representative in Congress if he or she sided with the president."[563] None can say with certainty what would have happened had the saga of Terri Schiavo played out differently. Law professor Alan Meisel speculates that had the Schindlers' cause succeeded, especially before Congress, this could well have jeopardized core tenets of the consensus.[564]

For the present purposes, of the many lessons we can take from this tragic saga, what stands out is the aggressive role of conservative, organized religious groups and the misguided, officious intermeddling of state and federal lawmakers. Looking back, the prolonged and bitter controversy can be seen as a battleground in a larger culture war over personal and family rights and freedoms at both the beginning and end

558. *See* EISENBERG, *supra* note 549, at 107–08. Eisenberg identifies the many *foot soldiers*—lawyers and religious organizations—that lined up against Terri's right to refuse treatment. *See id.* at 97–109. He also cautions that leaders of the religious right intended to use Terri's case to attack the end-of-life consensus. *Id.* at 207–18. Eisenberg's book includes the congressional subpoena that was issued for Terri. *Id.* at 239.

559. *See* Shepherd, *supra* note 549, at 297–99 (offering a medical-ethical perspective on the case); *see also* Timothy E. Quill, *Terri Schiavo – A Tragedy Compounded*, 352 NEJM 1630, 1630–33 (2005) (discussing her medical condition, family dynamics and lamenting the role of the law).

560. *See* Shepherd, *supra* note 549, at 298.

561. *See id.* at 298–99.

562. *See* Arthur Caplan & Dominic Sisti, *Terri Schiavo's Legacy*, HASTINGS CTR. FOR BIOETHICS (Mar. 13, 2025), https://www.thehastingscenter.org/terri-schiavos-legacy/ [https://perma.cc/82RC-VADW].

563. Josh Sanburn, *How Terri Schiavo Shaped the Right-to-Die Movement*, TIME (Mar. 31, 2015), https://time.com/3763521/terri-schiavo-right-to-die-brittany-maynard/ [https://perma.cc/YS8U-BUCT] ("Most polls today show that about seven in 10 Americans support the idea that state and federal governments should allow people to make end-of-life choices for themselves . . . .").

564. *See* Meisel, *supra* note 213, at 741, 760 (suggesting that had the Schindlers prevailed "a number of the consensus' essential features would have been overturned in Florida and seriously threatened elsewhere," and the legal consensus "would have suffered serious setbacks, if it had not been sent into total disarray").

of life.[565] The case of Terri Schiavo offers a poignant illustration of how end-of-life issues can be politicized even after law, ethics, and societal norms are well established, and with profound disregard for the heart-wrenching struggles of patients and families. Return of a settled question to the domain of politics and policy is, of course, the story of women's rights after *Dobbs*.

C. Treatment Refusal During Pregnancy

Though rare, there have been some instances of terminally ill, pregnant women and the agonizing decisions they face. Perhaps best known is the case of *In re A.C.*, where a young woman was imminently dying from cancer and was approximately twenty-six weeks pregnant.[566] On petition from the hospital, the trial court ordered that a caesarean section could be performed given that the procedure would not significantly affect the patient's condition because she "had, at best, two days left of sedated life" and the child "had a chance of surviving delivery."[567] The birth occurred at about twenty-eight weeks gestation.[568] Both patient and child died shortly thereafter. [569]

Several years later the court reviewed its decision for the purpose of establishing guidance for future cases.[570] After reciting the competing principles at stake, Judge John Terry, writing for the D.C. Court of Appeals, stated emphatically that the right to decide belongs to "the patient—the pregnant woman—on behalf of herself and the fetus."[571] For incompetent patients the decision should be made by substituted judgment.[572] The state's interest in protecting potential life must yield to the pregnant patient's personal rights.[573]

565. *See, e.g.*, Caplan & Sisti, *supra* note 562 ("The Schiavo affair quickly became a battlefront in the larger culture war raging over personal choices at both the beginning of life and at the end of life.").

566. *In re* A.C., 533 A.2d 611, 612 (D.C. 1987).

567. *Id.* at 617.

568. *See id.* at 613.

569. *Id.* at 612.

570. *In re* A.C., 573 A.2d 1235, 1237 (D.C. 1990). The prior controversy that first brought the case to court was now moot. This appeal was brought by the hospital. The court found that because this type of case "was capable of repetition, yet evading review" hospitals deserved to have clear guidance going forward. *Id.* at 1242 (quoting S. Pac. Terminal Co. v. ICC, 219 U.S. 498, 515 (1911)). The court had previously opined that these decisions would be better guided by legislation informed by medical and bioethics expertise. *In re* A.C., 533 A.2d 611, 612 (D.C. 1987).

571. *In re* A.C., 573 A.2d 1235, 1237 (D.C. 1990).

572. *Id.*

573. *See id.* The D.C. court's opinion appears to be the seminal ruling on this sort of controversy: "We have found no reported opinion applying the substituted judgment

This is a clear and correct statement of the principles involved and how they should be balanced, one that fits squarely within the end-of-life consensus. Yet it is unclear what A.C.'s actual wishes were, and thus whether a decision could have been based on her preferences.[574] Among the facts, physicians caring for her reported that at different times she stated that she would refuse the C-section, but at another time, said she would want the procedure.[575] Reportedly, after being informed of the trial judge's decision ordering the C-section, she agreed, but a short time later changed her mind.[576] The trial court states that she consented to the procedure "during a period of lucidity," but A.C.'s questionable capacity stands out in the analysis of this case.[577] The appeals court found that it could not be determined whether and when A.C. was competent, nor whether she would have consented to the c-section.[578]

Treatment has also been continued for the benefit of the fetus *after* the patient's death. Just recently, a thirty-year-old Georgia woman was declared brain dead at about nine weeks pregnant.[579] Relying on Georgia's six-week abortion ban, her organs and bodily functions were sustained for the purpose of bringing about a live birth.[580] There were no prior statements indicating what the patient would want for herself and the family was not asked for consent.[581] The baby was delivered prematurely by C-section, weighing less than two pounds.[582]

procedure to the case of an incompetent pregnant patient whose own life may be shortened by a caesarean section, and whose unborn child's chances of survival may hang on the court's decision." *Id.* at 1249.

574. *Id.* at 1247.

575. *Id.* at 1239.

576. *See id.* at 1240–41.

577. *In re* A.C., 533 A.2d 611, 613 (D.C. 1987).

578. *In re* A.C., 573 A.2d 1235, 1239, 1243 (D.C. 1990).

579. Mary Kekatos, *A Pregnant Brain-Dead Woman in Georgia Was Kept on Life Support. Experts Say It Raises Ethical, Legal Questions*, ABCNEWS (June 19, 2025, at 16:04 ET), https://abcnews.go.com/Health/pregnant-brain-dead-woman-georgia-life-support-experts/story?id=122963319 [https://perma.cc/8ZYP-26MT].

580. *See* Sam Gringlas, *A Brain-Dead Woman's Pregnancy Raises Questions About Georgia's Abortion Law*, NPR (May 21, 2025, at 08:55 ET), https://www.npr.org/2025/05/21/nx-s1-5405542/a-brain-dead-womans-pregnancy-raises-questions-about-georgias-abortion-law [https://perma.cc/S8ZF-HFHM].

581. The case of Adriana Smith is discussed in Katie Watson, *Brain Death in Pregnancy – Abortion, Advance-Directive, or End-of-Life Law?*, 393 NEJM 313 (2025). A very similar case that occurred in 2014 is discussed in Bertha A. Manninen, *Sustaining a Pregnant Cadaver for the Purpose of Gestating a Fetus: A Limited Defense*, 26 KENNEDY INST. ETHICS J. 399 (2016).

582. *See* Ross Williams, *Baby of Georgia Woman on Life Support Has Been Delivered Through Cesarean Section, Family Says*, GA. RECORDER (June 17, 2025, at 18:14 ET), https://georgiarecorder.com/briefs/baby-of-georgia-woman-on-life-support-has-been-delivered-through-cesarean-section-family-says/ [https://perma.cc/VUV8-SHY7].

There are important differences between the care of an incompetent, living terminally ill patient and the proper stewardship of the dead body. Legal approaches to advance directives and substituted judgment differ from those applicable to individuals who have died. As a general matter, there is no duty to treat a dead body, and ventilatory support for a brain-dead patient should be withdrawn in a timely manner after confirmation of neurological death. Families should be informed, but their consent to withdraw a ventilator is not required.[583]

While there are professional obligations to treat the newly deceased respectfully and to honor any applicable post-mortem wishes—for example, to donate organs—physicians have in the past understandably found fetal interests much stronger by comparison, and have favored continued interventions supportive of organ and bodily functions with the goal of progressing to a live birth.[584] The patient's interests are weightier when she has expressed her preference for or against interventions for the benefit of the fetus in the unlikely event she should suffer brain death, but this is rarely so.[585] It is a different matter altogether when the law compels sustaining a deceased woman as a fetal container.[586]

Well before *Dobbs*, states took positions on whether a terminally ill, now incompetent woman's refusal of treatment during pregnancy in an

583. *See* Ariane Lewis et al., *Determination of Death by Neurologic Criteria in the United States: The Case for Revising the Uniform Determination of Death Act*, 47 J.L. MED. & ETHICS 9, 15 (2019).

584. A systematic literature review published a year before *Dobbs* found thirty-five reported cases of brain death in pregnancy where somatic support was provided with the goal of a live birth—the mean gestational age at time of brain death determination was twenty weeks. Maria Gaia Dodaro et al., *Brain Death in Pregnancy: A Systematic Review Focusing on Perinatal Outcomes*, 224 AM. J. OBSTET. & GYNECOL. 445 (2021).

585. *See* Daniel Sperling, *Should a Patient Who Is Pregnant and Brain Dead Receive Life Support, Despite Objection from Her Appointed Surrogate?*, 22 AMA J. ETHICS 1004, 1005 (2020). How we are treated upon death is part of what it means to die with dignity. We have other important interests that survive death, including burial, cremation and other death rituals.

586. Manninen, *supra* note 581, offers a philosophical discussion of balancing these competing interests and discusses cases (pre-*Dobbs*) involving babies born to dead mothers. In one Texas case, she discusses (*Munoz*) the hospital applied that state's invalidation of treatment refusals in advance directives to continue treatment of a brain-dead pregnant patient. *Id.* at 399–400; *see also* Wade Goodwyn, *The Strange Case of Marlise Munoz and John Peter Smith Hospital*, NPR (Jan. 28, 2014, at 17:44 ET), http://www.npr.org/blogs/health/2014/01/28/267759687/the-strange-case-of-marlise-munoz-and-john-peter-smith-hospital [https://perma.cc/K435-GPUY] (discussing the Munoz case and noting the ruling in a suit brought by the husband that the Texas advance directive law did not apply to deceased patients, therefore treatment should be discontinued as had been requested by the patient's husband based on her previously expressed wishes).

advance directive or through a surrogate should be honored.[587] Many prioritize the state interest in preserving fetal life over the pregnant patient's wishes.[588] DeMartino and colleagues found that thirty-nine states had addressed pregnancy in their statutes, taking a range of approaches.[589] More than half of the states restrict decisions to withhold or withdraw life support during pregnancy, effectively rendering a woman's directive or that of her surrogate invalid.[590] Some achieve this result by prohibiting health care providers from forgoing treatment for a pregnant patient.[591] A number of states with restrictions, however, condition the decision on the physician's judgment as to whether continued treatment would result in a live birth.[592] Others require continued support for an incapacitated pregnant woman until delivery, seemingly without regard to the patient's wishes or interests, while some that require treatment make an exception if continued interventions would cause the patient pain and suffering.[593] Some states impose restrictions based on the stage of pregnancy and the likelihood that the fetus will survive with continued treatment for the woman;[594] some of these laws track the tripartite framework of *Roe*.[595] Still, other states' laws are simply silent on this question.[596]

Only a handful of state forms and materials prompt women to consider what they would choose in these circumstances and to give pregnancy-specific instructions.[597] This is problematic. When a directive is silent, family and healthcare providers may struggle mightily trying to balance the competing interests. Without this specific guidance, the patient's prior refusal of treatment and desire for a more comfortable, dignified dying process is less likely to be honored when balanced against fetal life, especially if there is reasonable likelihood that continued

587. *See* Erin S. DeMartino et al., *U.S. State Regulation of Decisions for Pregnant Women Without Decisional Capacity*, 321 JAMA 1629 (2019).
588. *See id.* at 1631.
589. *Id.* at 1630.
590. *See id.*
591. *See id.*
592. *See id.*
593. *See id.*
594. *See id.* at 1629.
595. *See* Katherine Speller, *These States Will Ignore Your Final Wishes Just Because You're Pregnant*, HUFFPOST (June 18, 2025), https://www.huffpost.com/entry/pregnancy-advance-directives-state-laws_l_68385919e4b06202aa9136d4 [https://perma.cc/658X-X7SB].
596. *See* DeMartino et al., *supra* note 587; Joan H. Krause, *Beyond Roe: Implications for End-of-Life Decision Making During Pregnancy*, 51 J.L. MED. & ETHICS 538, 540 (2023) [hereinafter Krause, *Beyond Roe*] (describing the legal landscape in very similar terms while offering a more detailed breakdown of statutory language).
597. *See* Krause, *Beyond Roe*, *supra* note 596, at 539–40.

treatment could result in a successful delivery.[598] Standard forms should be amended to follow Maryland's lead and ask women to provide explicit guidance for this very difficult circumstance.[599]

Law professor Joan Krause concludes that "*Dobbs* likely will have [a] significant impact on the pregnancy restriction debate."[600] Many states have already banned abortion or imposed serious restrictions, including criminalizing professional behavior to deter abortion services, and sometimes even requiring prenatal care.[601] These laws can be interpreted to require continued life support for however long until live birth, to permit overriding the patient's treatment refusal, and to do so notwithstanding her pain and suffering, even if they do not explicitly address this issue.[602] It is widely reported that in many places, fear of legal liability compels—coerces—healthcare providers to refuse to provide abortion services, and even needed medical care during pregnancy.[603] Some states have enacted "fetal personhood" laws that purport to give the fetus at least a coequal, if not greater, moral and legal status than that of a pregnant woman.[604]

On the other hand, states strongly supportive of abortion rights may find reason to strengthen these protections. We may see more states enshrine abortion rights in their constitutions through ballot initiatives, as a number of states have already done.[605] Or, with *Roe* and *Casey* overruled, some states supportive of abortion rights that have applied the *Roe* framework to protect a woman's right to choose up until fetal viability may find cause to reconsider the balance between a woman's right to bodily autonomy and the interests of the unborn fetus, and to

598. *Id.* at 540–41. Conversely, an advance directive with pregnancy-specific instructions asserts the patient's autonomy and is more likely to be honored when balanced against competing interests of the unborn fetus. *Id.* Krause seems to agree with this point and favors wider use of pregnancy-specific provisions in advance directives. *Id.*

599. Brian E. Frosh, *A Guide to Maryland Law on Health Care Decisions (Forms Included)*, MD. OFF. OF THE ATT'Y GEN. (July 2022), https://www.marylandattorneygeneral.gov/health%20policy%20documents/adirective.pdf [https://perma.cc/6KHQ-WXD3].

600. Krause, *Beyond Roe*, *supra* note 596, at 539. *Accord* Watson, *supra* note 581, at 313 (predicting that in the aftermath of *Dobbs*, states that ban pre-viability abortion will likely see more pregnant women with severe brain injury or brain death and no right to choose).

601. *See* Watson, *supra* note 581, at 313.

602. *See* Joan H. Krause, *Pregnancy Advance Directives*, 44 CARDOZO L. REV. 805, 813–14 (2023).

603. *See* BRITTNI FREDERIKSEN ET AL., A NATIONAL SURVEY OF OBGYNS' EXPERIENCES AFTER DOBBS 3–4 (2023), https://files.kff.org/attachment/Report-A-National-Survey-of-OBGYNs-Experiences-After-Dobbs.pdf [https://perma.cc/B4LA-HPW5].

604. *See* ALA. CONST. art. I, § 36.06; MO. REV. STAT. § 1.205 (2025).

605. *See* Mabel Felix, Laurie Sobel & Alina Salganicoff, *What's Next for State Abortion Ballot Initiatives?*, KFF (Dec. 18, 2024), https://www.kff.org/womens-health-policy/whats-next-for-state-abortion-ballot-initiatives/ [https://perma.cc/YXR2-D5N8].

restrict treatment refusal in a pre-viability stage.[606] Perhaps we will find that a husband's—or another surrogate's—request to continue support for the benefit of the fetus, contrary to the patient's prior treatment refusal, is more readily accepted. All are possibilities; some have already happened.

Restrictions on a woman's right to refuse treatment during pregnancy are not new. For so many, for law and practice to subordinate both the right to choose and the right to refuse treatment to the interests of the unborn fetus is to deny sacred personal rights; in both respects, it deprives women of the right to be the author of life's end. Post-*Dobbs*, with the protections of *Roe* and *Casey* gone, the ensuing and developing legal landscape makes navigating the conflict between a woman's right to bodily autonomy near the end of life *and* with respect to her own pregnancy, and fetal interests in potential life even more fraught. We would expect such tragic cases to continue to be rare, even as the law tilts more in the direction of fetal life. When they do arise, the decisions made should keep the pregnant woman's voice and interests front and center, respectful of patient and family, even when she cannot speak for herself, and her preferences can only be known through substituted judgment.

CONCLUSION

The clarion call of the end-of-life consensus is to put patients and families first. The judiciary did much of the work in first establishing the right to refuse treatment.[607] Cases at the heart of the judicial consensus bear the names of Karen Ann, Nancy Ellen, Nancy Beth, and others, and attest to the courage, conviction, and love of their families. Parallel to the elegant accretion of judicial rulings, state legislatures took up the mantle of patients' rights and resoundingly affirmed and established the patient's right of self-determination.[608] Advance directive laws give us a clear path to taking charge of the dying process in pursuit of death with dignity.[609] Chief Justice Hughes' bold pronouncements that the interests of patients and families must predominate, and that law, medicine, and society must be responsive to our shared moral values, are the foundation and north star of the end-of-life consensus.[610]

606. *See* Krause, *Beyond Roe*, *supra* note 596, at 541–42 (discussing some of these actual and possible responses to *Dobbs*).

607. *See supra* Sections I.B–C, II.A–B.

608. *See supra* Section III.

609. *Id.*

610. *See supra* Section I.

Looking ahead to the next fifty years, efforts to promote advance care planning—to document patient wishes and ensure that the patient's voice controls—will and must continue to expand and improve. More states should consider expanding patient rights by removing medical treatment limitations and adopting a broader understanding of the dying process that includes progressive and irreversible, but not yet terminal conditions. Law reform should forthrightly recognize the right of incompetent patients to refuse oral feeding. States should also consider amending their constitutions to include specific privacy protections where such protections do not already exist. And lawmakers should reject ideological efforts to revive long-settled debates about feeding tubes, institutional conscience, or other matters in ways that would limit, rather than protect, patient and family rights.