“THEY WANT ME DEAD”—ACTIVE KILLING—
AN OPTION IN MODERN HEALTH CARE
DECISION MAKING

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INTRODUCTION

“Thousands of medical ethicists and bioethicists, as they are called, professionally guide the unthinkable on its passage through the debatable on its way to becoming the justifiable until it is finally established as the unexceptional.”¹

According to the published statements of British medical practitioners in June of 2012, more than 100,000 patients each year are put on a “death pathway” protocol by their doctors, thereby hastening their deaths.² The death pathway is invoked for a variety of reasons, including the difficulty of the treatment involved, or to free up additional beds in overcrowded health care facilities. The protocol can include withdrawal of treatment—including water and nourishment—and usually results in death within thirty-three hours. Observers were not slow to equate the use of this protocol to euthanasia, which although legal in some jurisdictions,³ remains illegal in the United Kingdom.⁴

¹ J.D. Oakbrook College of Law and Government Policy, 2008; staff counsel for the Life Legal Defense Foundation, a non-profit, public interest law firm with the mission of giving innocent and helpless human beings of any age a trained and committed defense against the threat of death and to support their advocates in the nation’s courtrooms. Many thanks to Ave Maria School of Law student Joan Hetzler for her research assistance, and to my colleagues at Life Legal for their input, help, and encouragement.


³ Physician assisted suicide is legal by statute in the Netherlands, Luxembourg, Belgium, and Switzerland; in the United States, it is legal by statute in Oregon and Washington. MARLISA TIEDEMANN ET AL., EUTHANASIA AND ASSISTED SUICIDE: INTERNATIONAL EXPERIENCES, at i, 7, 10, 12 (2011)
Although the death pathway protocol occurs under a system of nationalized health care, this shocking revelation serves as a reminder of a deadly threat facing those who are most vulnerable—namely, the elderly, sick, and disabled. Cases in the United States demonstrate that similar practices that hasten death are widely accepted, albeit not as a result of an official government protocol, and affirmative legal steps may be necessary to protect a life threatened by such practices. This hastening of death, while distinguishable in social consciousness from actions generally considered to constitute homicide, will be referred to as “active killing.”

Modern healthcare has embraced practices leading to letting people die and even helping people die in certain circumstances. The medical, ethical, and legal issues involved with these life and death decisions should be re-examined. Such a re-examination must consider the legal landscape that enables these practices and the cultural forces that encourage them. Accordingly, Part I explores the underlying theories that propel these practices. Part II discusses the public policies that either protect or advance active killing in practice. Lastly, Part III lays out practical responses available when facing a threat of active killing. While all citizens have a direct interest in preserving life and promoting justice for those who cannot speak for themselves, this Article specifically focuses on the essential role of the attorney and the legal system in the defense of life.

I. THE THEORY

Undergirding Western law is a morality that holds killing the innocent to be unequivocally wrong. This is the principle that humans are equal in value by virtue of their very humanness. This has been called the “sanctity of life ethic,” and is akin to the “equality of human life” ethic. This affirmation of the value of the individual underlies much of American social policy, and the nation’s law traces this principle to its founding documents. The Declaration of Independence proclaimed the self-evident truth that “all men are created equal,” endowed with “life,” among other inalienable rights.

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4. See infra Part I.B. for further definition of “active killing.”
7. Id. at 67.
8. THE DECLARATION OF INDEPENDENCE para. 2 (U.S. 1776).
Principles of individual equality are further enshrined in the Constitution. 9 Extending its reach beyond the law, this principle has been called the “keystone of Western medicine,” 10 providing the moral impetus for physicians as healers and helpers of the human family.

It is at this intersection of morality and medicine that this traditional ethical principal is being eroded, leaving some observers to predict its eventual abandonment. 11 Acceptance of an alternative ethic in modern medical practice has led, by degrees, to a serious threat of unnaturally hastened death for the elderly, seriously ill, and disabled. Examples abound of these vulnerable individuals being dispatched into the next life without their consent, 12 and cases arise involving loved ones fighting to achieve continued treatment for disabled patients. 13 The erosion of the traditional ethic that recognizes the value of all human life has many causes, including perceived social burdens and needs, but one of the greatest is the belief that cognitive ability and quality of life—at least a sense of self-awareness—should be elevated above the right to live itself. 14

The loss of the sanctity of human life ethic has coincided with the acceptance of other ethical principles and the adoption of the “futile care theory.” Futile care, as defined by medical texts, is care that in medical judgment “will not have a reasonable chance of benefiting [the] patient.” 15 Thus, if a particular treatment will not, in best medical judgment, benefit the patient, the physician has no obligation to administer it. 16 However, as the sanctity of human life ethic erodes, a new, more dangerous, ethic arises that not only views some treatments as futile, but also views some patients as

10. A New Ethic for Medicine and Society, supra note 6, at 67; see also In re Quinlan, 355 A.2d 647, 667 (1976) (referencing the Judeo-Christian tradition of regard to human life, and moral matrix of medicine “to heal”).
11. A New Ethic for Medicine and Society, supra note 6, at 67–68 (“[H]ard choices will have to be made . . . that . . . will of necessity violate and ultimately destroy the traditional Western ethic with all that it portends. It will become necessary and acceptable to place relative rather than absolute values on such things as human lives . . . .”).
13. See infra Part II.
16. See id.
futile—as worthless and therefore unworthy—of further existence. If something more than merely being human is required for a human life to have value, such as possessing an undefined level of cognitive ability, sustaining the life of a cognitively damaged individual may be viewed as an act of futility. Thus a medically effective treatment would be considered futile when a patient’s life is viewed as futile. Such a result goes beyond patient choice or the rejection of unwanted medical treatment; it leads to the health care provider’s refusal to provide wanted care and life-sustaining treatment, such as foods and fluids, precisely because that treatment would be effective in prolonging life.

A. Societal Acceptance

Historically, state laws regarding the withdrawal of nutrition and hydration were grounded in the common law theory of battery and the concept of informed consent—the right to refuse medical treatment. Less than fifty years ago, providing food and fluids through a feeding tube was considered standard humane care. Through a gradual process of elimination, this type of care has been redefined to mean “medical treatment.” This is the result of a deliberate campaign that has followed an identifiable trajectory. It began with the rejection, at least in some academic circles, of the traditional ethic that all human life is of equal worth. A new field emerged, bioethics, in which philosophers—bioethicists—worried about the cost of caring for the dependent and elderly within an increasingly aging society. Many factors contributed to a widespread rejection of the traditional ethic, such as the cultural upheaval combined with technological advances of the past fifty years.

As the traditional ethic continued to erode, factors such as autonomy, quality of life, cost, and convenience tended to predominate decision-making. Finding a way to hasten death became a solution to these shortfalls. Values such as privacy and autonomy became driving forces in medical ethics. Arguments for, and suggestions regarding, hastening death were

20. See id.
21. FORCED EXIT, supra note 18, at 44.
originally made within a framework of supposedly strict medical
guidelines—which largely control medical treatment options.22
Following the promulgation of the academic theories, a campaign
commenced to test the theories in court and, if necessary, to stretch the
bounds of the law. Convincing the courts proved to be an achievable goal.
The courts accepted that the ethical issues had been carefully worked out,
and that the power to remove sustenance would be exercised within the
strictest guidelines.23 However, legally, there had already been a rejection of
the ethical principal of the equality of human life regarding certain members
of the human family through the legalization of abortion.24

Today, the impetus for limiting care has never been stronger. Spiraling
healthcare costs have led to measures aimed at curbing costs and providing
more people with insurance coverage, such as the Patient Protection and
Affordable Care Act (popularly dubbed “Obamacare”).25 As cost-saving
elements of this law are implemented, additional pressure may be brought to
bear in favor of terminating treatment for a broader range of individuals.26
Interestingly, the increasing acceptance of early termination of life-sustaining
treatment has not led to a corresponding decrease in nation-wide health care
costs.27 Studies indicate that the actual cost savings of replacing curative
treatment until death with a palliative model appear to be small when
compared to national health care expenditure.28 In a discussion of the
economics associated with care at the end of life, Michael Ash and Stephen
Arons estimated that a very small percentage of total national health care
expenditure might be saved by a less-aggressive treatment paradigm:

3.3% of total national health care expenditure might be saved by a
conversion away from aggressive curative treatment, [but] . . . the growth
rate of health care expenditure would be unaffected. Furthermore, end-of-
life care has not been a site of disproportionate growth of health care

22. Kathryn L. Tucker, When Dying Takes Too Long: Activism for Social Change to Protect and
Expand Choice at the End of Life, 33 WHITTIER L. REV. 109, 150 (2011) (arguing that physicians should
have greater latitude to aid patients in dying).
23. See FORCED EXIT, supra note 18, at 44–45.
24. See A New Ethic for Medicine and Society, supra note 6, at 68. A lengthy discussion of
abortion is beyond the scope of this Article.
26. See ROBERT POWELL CENT. FOR MED. ETHICS, LIFE AT RISK: HOW THE OBAMA HEALTH
CARE PLAN WILL RATION YOUR FAMILY’S MEDICAL TREATMENT—A FACTSHEET (2012),
27. See Michael Ash & Stephen Arons, Economic Parameters of End-of-Life Care: Some Policy
28. Id. at 317.
expenditure, so changes only to this component of health care cannot reduce
the rapid growth that has been the focus of cost-control efforts.29

Thus, the pressure to decrease national health care costs by forgoing care
appears to be ill-founded when considering the actual monetary benefits this
strategy has achieved, not to mention the danger it presents disabled
individuals. As the debate evolves from refusing to provide food and fluids,
to openly assisting suicide, to downright euthanasia, it becomes clearer that
the rejection of the human equality ethic has opened the door for increasingly
intrusive measures to end human life.30

B. Terminology

Throughout this Article, “active killing” refers to the situation where
caregivers, decision makers, or both, take affirmative steps to withdraw life-
sustaining medical care from a patient with the intent to shorten a patient’s
life or hasten her death. While this is often the result of some seemingly
altruistic motive, it too often occurs when it is unclear whether the patient
would have opted to refuse such treatment. There is a passiveness in “letting
the patient die” that belies the term “active killing.” Nonetheless, the term
“active” is appropriate since volitional deprivation of care is involved in
hastening death. The word “killing” is used deliberately, because although a
motive might be considered acceptable by society (e.g., to end suffering,
conserve scarce resources, etc.), the decision results in the patient’s death. In
addition, the terms “life-sustaining treatment” and “life-sustaining medical
care,” as used in this Article, include not only medical intervention, but also
the provision of the food and water necessary to sustain life—whether
administered by tube or by the usual oral means.31 Lastly, the term “health
care provider” is used broadly to refer to physicians, hospitals, and other
medical professionals in various other settings in which an incapacitated
patient might receive treatment and care.

29. Id. Ash and Arons further stated: “Although end-of-life care represents approximately a
quarter of Medicare spending and overall Medicare spending has grown sharply over time, the end-of-life
share of Medicare spending has been remarkably stable. New developments or applications of expensive
interventions have not been disproportionately focused on end-of-life care.” Id. at 318 (footnote omitted).
30. See generally CULTURE OF DEATH, supra note 19, at 11 (discussing Joseph Fletcher).
31. See FORCED EXIT, supra note 18, at 43–44 (discussing changes in the definition of
“medical treatment”).
C. Threats

Many may view the food and fluids cases as a primarily good trend in medicine—a necessary pushback against past practices in which some healthcare providers seemed to stray toward aggressive treatment whether a patient wanted it or not. Thoughtful observers, however, will realize that there is an essential distinction between allowing competent patients to refuse unwanted medical treatments and the denial of medical care to a patient because he is incapable of demanding it.32 Looking at a patient’s quality of life, rather than the fact that he or she is alive, as the basic litmus test for whether the patient ought to receive treatment opens a Pandora’s Box of evils, including: a decrease in patient control over medical choice; increased devaluing of the disabled; increased practice of assisted suicide and euthanasia; increased risk of neglect and abuse of the elderly; and increased pressure on religious families to abandon their deeply held beliefs.

As mentioned, one of the dangers posed by the acceptance of active killing is that patients will face the removal of wanted medical care. Even twenty years ago, researchers studied the actions of physicians practicing in the area of adult intensive care, and looked at the impact, if any, that a patient’s or surrogate’s decision making had on the withdrawal of life-sustaining treatment, particularly where treatment was deemed to be medically futile.33 Many physicians reported withholding life-sustaining treatment without the patient’s or the patient’s family’s consent.34 Some physicians reported doing so without a patient’s or family’s knowledge.35 Some even withheld life-sustaining treatment over the objection of the patient or a family member.36

Patient wishes appear to be respected even less so in jurisdictions that have embraced physician assisted suicide. In 1998 in Belgium it was estimated that while 1.3 percent of all deaths were from physician assisted suicide, 3.3 percent of all deaths were from the administration of lethal drugs.

32. See id.
34. Id. at 303 n.64 (citing Asch et al., supra note 33, at 291) (noting twenty-five percent reported doing so without patient or family consent).
35. Id. (noting fourteen percent reported withholding treatment without a patient’s or family’s knowledge).
36. Id. (noting three percent reported withholding treatment over objections).
without the patient’s explicit request. \(^{37}\) Another Belgian study found that “in 2001, 1.5 percent of all deaths involved ending life without the patient’s request.”\(^ {38}\)

Recent experience indicates that health care providers in the United States tend to be closer to, not further from, a willingness to remove care. For example, in 2011, an immigrant woman diagnosed as being in a persistent vegetative state had her health care decisions relegated to a court-appointed guardian when the hospital that she was being treated at decided to end her treatment. \(^{39}\) The guardian argued that the woman’s feeding tube should be removed, despite the objection of the patient’s family. \(^{40}\) In e-mail correspondence with a reporter inquiring about the case, the guardian explained her reasoning: “Generically speaking, what gives any one family or person the right to control so many scarce health care resources in a situation where the prognosis is poor, and to the detriment of others who may actually benefit from them?”\(^ {41}\)

The medical profession itself is threatened by a standard of care that seeks to eliminate “futile” patients, rather than futile treatments. Traditions dating back to Hippocrates put physicians in the place of healer as opposed to harmer. As the Supreme Court pointed out in *Washington v. Glucksberg*, states have a legitimate interest in “protecting the integrity and ethics of the medical profession.”\(^ {42}\) At the time of the *Glucksberg* decision, the American Medical Association had concluded that “[p]hysician-assisted suicide is fundamentally incompatible with the physician’s role as healer.”\(^ {43}\) But the acceptance of active killing logically leads to the incremental acceptance of physician assisted suicide (PAS). Although legal by statute in only two states,\(^ {44}\) there is an active lobby for legalizing PAS throughout the nation. Indeed, the practice receives active promotion in state legislatures nearly

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38. Id.
40. See Smith, supra note 39.
41. Id.
42. 521 U.S. 702, 731 (1997).
43. Id. (alteration in original) (quoting American Medical Association, Code of Ethics § 2.211 (1994)).
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every legislative session. Further, scholarly articles argue for the acceptance of assisted death, whether explicitly through legalization, through the refusal to prosecute a health care professional who assists a patient in dying, or through expanding practice guidelines to implicitly allow PAS.

There is a short step between PAS and active euthanasia—the killing of those unable or unwilling to make the decision for themselves. Some assert that there is little practical difference between the acceptance of PAS for terminally ill patients and the acceptance of euthanasia, since jurisdictions that embrace PAS seldom prosecute doctors for practicing involuntary assisted suicide, which could rightly be called euthanasia. Further, PAS can increase suicide among persons who are not terminally ill. For example, studies of the PAS law in Belgium reveal the very real fear that the law has opened the door for physically healthy persons to request their lives be ended because they are tired of life.

Once law and medical practice accept a procedure, such as PAS, the actions of practitioners tend to go further. For instance, Belgium enacted an assisted suicide law that included practice guidelines. In the very first case following this law (one week after its passage), a physician did not adhere to the guidelines. Thirty-nine year old Mario Verstraete, who suffered from multiple sclerosis, was dead within a week of the law’s passage, despite the requirement that at least one month must elapse between a written death request and the euthanasia. Moreover, Mr. Verstraete was not in the final stages of a terminal illness. In another case, an eighty-seven year old dementia patient was killed by her physician who gave her a drink containing barbiturates. Although this killing violated numerous aspects of the applicable law, including the requirement of informed consent, prosecutors decided not to prosecute the physician. Even the most innocent and helpless members of society, newborn infants, are directly impacted by the


46. See, e.g., Tucker, supra note 22, at 157–59.

47. See Cohen-Almagor, supra note 37, at 207–08.

48. See id.

49. Id. at 207.

50. Id. at 208.

51. Id.

52. Id.
acceptance of active killing. In Flanders, a 2005 study revealed that three out of four doctors were willing to shorten the life of critically ill babies through the withdrawal of treatment or—in some cases—the administration of drugs.\(^{53}\)

When death is considered a treatment option, its abuse is not limited to medical practitioners that believe they have altruistic motives such as relieving their patients of a painful life. It also becomes an option for those who seek to benefit from the patient’s death outside of the doctor-patient relationship. In other words, a greedy decision maker (who may be in line to inherit upon the patient’s death) can save thousands of dollars by shortening the patient’s life. Indeed, inexplicable changes of heart by decision makers in notable cases leave the bitter taste of greed. For example, in the aftermath of the infamous Terri Schiavo case, it was pointed out that Michael Schiavo stood to benefit financially from his wife’s death when he brought the petition for removal of her feeding tube.\(^{54}\)

A recent and particularly chilling trend in active killing cases affects those who are strong adherents to particular religious values, such as the belief that human life is a sacred gift from God. Bioethicists have suggested that “‘fundamentalist Christian’ parents” cause “unnecessary” suffering to their children when refusing to remove life support.\(^{55}\) Indeed, the argument was floated that strict adherence to life-affirming religious values should be grounds for disqualifying parents from choosing continued care for their minor children.\(^{56}\) Thus, the targeting of religious beliefs is yet another danger posed by the acceptance of active killing.

While a balanced view of patient care would reduce unwanted and intrusive treatment, the enormous shift in theory of the past four decades overreaches and effectively devalues individual patients, particularly when they have a diminished capacity to make their own decisions.

II. PUBLIC POLICY

The past forty years have seen much growth in policy and law regarding heath care decision-making, particularly in the area of making decisions on

\(^{53}\) Id. at 210.

\(^{54}\) Discussed infra Part II.A.3. See FORCED EXIT, supra note 18, at 71.


\(^{56}\) See id.
behalf of the incapacitated. The following sections focus on some of the groundbreaking cases in this area, as well as on the general statutory approach.

A. Case Law

To illustrate the evolution of the law in the area of life-sustaining treatment for incapacitated individuals, this section focuses on four significant and groundbreaking cases. The first three cases deserve attention for their high-profile nature and long-term impact as well as the policies underlying their rulings. The fourth will receive closer treatment so that the practical aspects of this type of case can be referenced and highlighted.57

1. In re Quinlan58

The parents of Karen Ann Quinlan, a young woman who had been unconscious for several years, sued her hospital to obtain the right to remove their daughter’s life support, including her respirator, without which she would die.59 The case eventually went to the New Jersey Supreme Court, which ruled that Karen’s father would be appointed her guardian, and would have the right to determine her care.60 This included the power to refuse treatment, even if it meant Karen would die, if there was consensus from the doctor and hospital ethics committee that there was no possibility of the patient ever recovering or regaining sentient function.61

This case is mostly famous for the proposition that since a patient can refuse unwanted medical treatment, it is logical for a decision maker, such as a parent or guardian, to exercise the ability to refuse such treatment on behalf of the incapacitated patient. However, this case took the proposition one step further by ruling that this refusal could be exercised even when the result would be, almost certainly, the death of the patient. Nevertheless, surprising everyone, Karen ended up living ten years after her respirator was removed (the removal of her nutrition and hydration was never a consideration).62

57. See infra Part II.A.4.
59. Id. at 655.
60. Id. at 671.
61. Id.
62. CULTURE OF DEATH, supra note 19, at 92.
Cruzan v. Director, Missouri Department of Health 63

In 1983, Nancy Cruzan was injured in a car accident that left her with profound cognitive dysfunction, although authorities dispute the actual level of her abilities. 64 She recovered to the extent that she was neither in critical care, nor on a ventilator, 65 although she did require nutrition and hydration to be administered through a feeding tube. 66 Her parents sought to have the feeding tube removed, but the hospital refused. 67 The parents sued, requesting a court order directing the withdrawal of Nancy’s nutrition and hydration equipment. Initially, the parents won. 68 The Missouri Supreme Court, however, reversed by holding, inter alia, that the court lacked authority to effectuate the request because of the lack of clear and convincing evidence that Nancy desired to have life-sustaining treatment withdrawn as required under Missouri’s Living Will statute. 69 Eventually, the case was appealed to the United States Supreme Court, which affirmed and held that the Due Process Clause 70 did not require the state to repose judgment on matters concerning the right to refuse treatment in anyone other than the patient herself. 71 The Court further held that a state could choose to defer only to the patient’s wishes rather than entrust the decision to close family members. 72 Finally, the state could require clear and convincing evidence of the patient’s desires and wishes. 73

On remand to the original Missouri trial court, new evidence was presented, including testimony by some of Nancy’s former co-workers regarding statements Nancy made in casual conversations. 74 The court ruled that based on this new—albeit slim—evidence, the Cruzans were indeed able to meet

64. FORCED EXIT, supra note 18, at 46–47 (stating that there was evidence she could see and hear; she smiled at amusing stories and sometimes cried when visitors left).
65. See id. at 47.
66. Cruzan, 497 U.S. at 266.
67. Id. at 267–68.
68. Id. at 268.
69. Id. at 268–69 (construing MO. REV. STAT. § 459.010 (1986)).
70. U.S. CONST. amend. XIV, § 1.
71. Cruzan, 497 U.S. at 286.
72. Id. at 286–87.
73. See id. at 284–85 ("In sum, we conclude that a State may apply a clear and convincing evidence standard in proceedings where a guardian seeks to discontinue nutrition and hydration of a person diagnosed to be in a persistent vegetative state.").
74. FORCED EXIT, supra note 18, at 48.
the clear and convincing evidence standard. upon removal of her food and fluids, nancy died of starvation and dehydration in december of 1990.

3. *in re schiavo*

because of the widespread familiarity with the schiavo case, this overview will seek only to highlight those aspects that are particularly relevant to this discussion. terri schiavo became severely cognitively disabled following an unexplained collapse in 1990. eventually, she was diagnosed as being in a persistent vegetative state (“pvs”), although this designation was controversial. eventually, terri improved to the point that the only treatment she required was a feeding tube. terri’s husband michael worked with her parents, the schindlers, for the first several years to provide for her care. when the three experienced a falling out, years of court battles ensued. in 1993, the schindlers sought guardianship of their daughter following michael’s refusal to have her treated for an infection. they clashed again in 1998 over michael’s attempt to remove terri’s feeding tube. up until terri’s death in march of 2005, they battled at all levels of the state and federal judiciaries, legislatures, and the court of public opinion. at each stage of the conflict, the courts unanimously upheld the pinellas county circuit court’s order to remove terri’s nutrition and hydration.

to this day, legal and cultural commentators continue to explain why terri’s death was such a profound injustice. for instance, they point out that the court accepted evidence of statements purportedly made by terri in

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75. *id.*
76. *id.*
77. *id.*
78. *id.*
79. *id.*
80. *id.*
81. *id.*
82. *id.*
83. *id.*
84. *id.*
85. *id.*
86. *id.*

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*see*, e.g., gibbs & demois, *supra* note 79. in addition, the schindler family has since set up a foundation in terri’s memory to assist families that find themselves in similar situations. *see* terri schiavo life and hope network, http://www.terrisfight.org/ (last visited sept. 9, 2012).
various casual conversations that asserted she would not want “tubes” to sustain her in such a situation. These were ruled sufficiently “clear and convincing” evidence of her desires despite contrary testimony that Terri had disapproved of the death of Karen Ann Quinlan.87

Further, commentators note that Michael Schiavo, Terri’s husband and guardian, had told different stories to different courts. In an earlier medical malpractice action brought on Terri’s behalf, Michael presented evidence that Terri would likely live a normal lifespan. In addition, he stated that he would become a nurse, dedicate his life to Terri’s care, and that monies awarded in the suit would be used for her care and rehabilitation.88 The verdict of $1.3 million left ample money for Terri’s care—money Michael would inherit if Terri died.89 But when he was subsequently in court seeking the removal of care, Michael claimed his wife never wanted to live with such a disability.

For this and other reasons, Michael had serious conflicts of interest as Terri’s guardian. Indeed, the financial conflict was coupled with the fact that he had fallen in love, moved in, and fathered children with another woman. These conflicts should have precluded him from acting as Terri’s guardian, as was pointed out by Terri’s initial guardian ad litem, Richard Pearse.90

Finally, in addition to the court’s tenuous evidentiary findings, and Michael’s inconsistent positions and conflicts of interest, commentators point out that many came forward disputing the diagnoses of PVS, Terri’s cognitive abilities, and her potential for recovery with proper therapy (of which she was entirely deprived).91 In the end, none of the arguments and efforts for Terri’s life prevailed. Deprived of all forms of nutrition and hydration, Terri died in March of 2005.92

4. Wendland v. Wendland93

As the result of a single-car automobile accident, Robert Wendland was left in a coma for approximately sixteen months.94 Contrary to his doctors’

87. See FORCED EXIT, supra note 18, at 68.
88. Id. at 69–70.
89. Id. at 70. See In re Schiavo, 780 So.2d. 176, 178 (Fla. 2d DCA) (noting that Michael stood to inherit under Florida’s intestacy laws).
90. FORCED EXIT, supra note 18, at 70–73 (citing Report of Guardian ad Litem, In re Schiavo, Case No. 90-2908BGD-003).
91. GIBBS & DEMOSS, supra note 79, at 63–66.
92. Id. at 170.
94. Id. at 154; Conservatorship of Wendland, 93 Cal. Rptr. 2d 550, 554 (Cal. Ct. App. 2000).
predictions, he awoke in January of 1995.\textsuperscript{95} He regained voluntary reactions and became able to respond to directives and operate both a manual and a motorized wheelchair.\textsuperscript{96} Additionally, he performed other neurologically complex tasks such as throwing and catching a ball, balancing in a standing frame, blinking his eyes in response to questions, turning pages, drawing circles, and writing the letter “R” with his left hand.\textsuperscript{97}

Robert’s wife, Rose, in consultation with Robert’s doctor, initially agreed that he should undergo an extensive program of speech and physical therapy.\textsuperscript{98} However, after Robert began the program, Rose determined that his feeding tube should not be replaced when it became dislodged—as it had on three prior occasions.\textsuperscript{99} This decision would constitute a death sentence since he received all of his nutrition and hydration through that feeding tube. Robert had no written directive for health care. Rose, along with Robert’s doctor, sought and obtained the endorsement of the hospital’s ethics committee to remove his feeding tube.\textsuperscript{100} Under their plan, Robert would be discharged and moved to a convalescent home where he would be starved and dehydrated to death.\textsuperscript{101}

Before the plan could be executed, an anonymous caller notified Robert’s sister, Rebekah Vinson, and his mother, Florence Wendland, about the plan to move Robert and discontinue his care.\textsuperscript{102} Attorneys for Rebekah and Florence persuaded the court to grant injunctive relief, prohibiting the cessation of Robert’s life-sustaining treatment and prohibiting his transfer from the hospital.\textsuperscript{103}

Rose petitioned the court to be appointed as Robert’s conservator, and was so appointed over the objections of Rebekah and Florence.\textsuperscript{104} Whether Rose had the authority to terminate Robert’s food and nutrition was litigated separately,\textsuperscript{105} and included the foundational question of whether nutrition and hydration could legally be removed from a conscious patient who was neither terminally ill nor in a persistent vegetative state—an issue of first impression.

\textsuperscript{95} Conservatorship of Wendland, 93 Cal. Rptr. 2d at 554.
\textsuperscript{96} Id. See also FORCED EXIT, supra note 18, at 61–62.
\textsuperscript{98} The Underlying Facts of Conservatorship of Wendland, supra note 97.
\textsuperscript{99} Id.
\textsuperscript{100} Conservatorship of Wendland, 28 P.3d at 155.
\textsuperscript{101} FORCED EXIT, supra note 18, at 63.
\textsuperscript{102} Id., Conservatorship of Wendland, 28 P.3d at 155.
\textsuperscript{103} Conservatorship of Wendland, 28 P.3d at 155.
\textsuperscript{104} Id.
\textsuperscript{105} Id.
in California. The court held that Rose would be allowed to withhold nutrition and hydration only if it would be in Robert’s best interest, taking into account any wishes he may have expressed before becoming incompetent. It also determined that Rose would have to prove the facts justifying her decision by clear and convincing evidence.

In the second phase of litigation, the court adjudicated whether these standards had been met. The trial court found the evidence insufficient to prove that Rose’s decision was in accordance with Robert’s wishes or best interest, based on a clear and convincing evidence standard. Essentially, the course of action Robert would have chosen if capable of making his own decision was in dispute. Rose argued that Robert had made pre-accident verbal statements of his intent. However, at least one of these statements was made in a heated discussion while Robert was suffering from a hangover and at a time when he was abusing alcohol and grieving the death of a close family member. Thus, the court determined the evidence insufficient to justify removal of Robert’s nutrition and hydration. Rose appealed this decision, and the California Court of Appeal reversed, holding that the court was required to defer to Rose’s good faith decision as to Robert’s best interest, and that there need not be proof of Robert’s expressed desire.

However, the California Supreme Court reversed the Court of Appeal, upholding the trial court’s ruling. It held that when applying the clear and convincing evidence standard, Rose was required to show either that Robert wished to refuse life-sustaining treatment under these circumstances, or that to withhold such treatment would have been in his best interest. Since such evidence was ultimately lacking, the request for permission to withdraw artificial hydration and nutrition was unsuccessful. Unfortunately, Robert died of pneumonia several weeks before this victory.

106. Id. at 156.
107. Id.
108. Id. at 157.
109. Id.
110. Id.
111. Id.
113. Conservatorship of Wendland, 28 P.3d at 174 (construing CAL. PROB. CODE § 2355 (West 2000)).
114. Id. at 175.
115. Id.
116. FORCED EXIT, supra note 18, at 65.
B. Legislation

Health care decision making, particularly when the patient is facing a terminal condition, is statutorily regulated in all states. Each state incorporates unique elements in its statutes, but there is generally some consensus on the basic approach. Consistent with the traditional ethic of the value of individual persons, these statutes usually focus on protecting the patient. Further, in accord with the desire to promote individual rights and personal autonomy, these statutes seek to protect and enforce the patient’s decisions.

As Professor Alan Meisel discusses, these statutes generally incorporate, in some form, the following principles:

1) competent individuals have a legal right to refuse treatment;\(^{117}\)
2) incompetent individuals have a right to have treatment refused for them;
3) end-of-life decisions should ordinarily be made in clinical settings and not courts;
4) close family members have the legal authority to act as surrogates and make medical decisions for patients who lack decisionmaking [sic] capacity;
5) in making end-of-life decisions, surrogates should apply the substituted judgment standard [meaning they should act as the patient would have under like circumstances];
6) surrogates may rely on advance directives to ascertain patients’ wishes; [and]
7) artificial nutrition and hydration are medical treatments . . . .\(^{118}\)

Meisel adds an eighth point: “actively hastening death is impermissible.” Here, he is speaking about euthanasia, or assisting the death of another without their consent.\(^{119}\) However, he does not recognize the fact that removal of nutrition and hydration may in and of itself actively hasten death. Further, in a notable exception to this eighth point, two states, Oregon and Washington, have enacted physician assisted suicide laws.\(^{120}\)

All states have adopted procedures whereby patients can designate an individual to make health care decisions on their behalf, should they become incapacitated. These give competent patients the ability to make numerous

\(^{117}\) Conversely, patients also have the right to receive treatment—a principle under attack—but nonetheless assumed in most statutory schemes. Further, federal law requires most hospitals to provide emergency treatment to patients. \textit{See, e.g.}, 42 U.S.C. § 1395dd(b) (2012).


\(^{119}\) \textit{Id}.

\(^{120}\) \textit{See Oregon’s Death with Dignity Act, OR. REV. STAT. §§ 127.800–897 (2012); Washington’s Death with Dignity Act, WASH. REV. CODE §§ 70.245.010–904 (2009).}
health care decisions prior to incapacity—for instance, through a living will—and to designate an individual to make those decisions through power of attorney for health care. Not all states use the “living will” or “power of attorney for health care” terminology, but all states recognize the underlying right of patients to make their own informed decisions, and have adopted procedures to protect that right.121

Studies indicate that although these procedures are universally available and relatively simple to execute, few people actually have living wills or powers of attorney for health care.122 A California study in February of 2012 indicated that although eighty percent of patients believe it is important to have their wishes in writing, seventy-six percent of them neglect such planning.123 When patients fail to designate a decision maker, most states have statutes controlling who may make decisions. The most common hierarchy follows this basic outline: if the patient does not have an agent or guardian, the spouse (unless legally separated) will control decision making; followed by an adult child; then a parent; adult sibling; adult grandchild; and finally, a niece, nephew, or some other close relative.124 Further, most states have safeguards in place to protect the patient. For example, in many states, any interested person who feels that the patient is not receiving care in accordance with his or her wishes or best interests may challenge the decisions of a health care decision maker in court.125

C. Reforms

The reality that relatively few persons execute living wills, combined with the high-profile nature of the court cases involving end-of-life care, has

121. See Appendix: Health Care Decisions Laws infra.


124. See, e.g., DEL. CODE ANN. tit. 16, § 2507(2) (2012). See Appendix infra for each state’s approach.

125. See, e.g., CAL. PROB. CODE § 4765 (West 2012) (stating that a challenge to a decision may be brought by a patient, spouse, relative, agent or surrogate, conservator, investigator, public guardian, health care provider, or “any other interested person or friend of patient”). In Indiana, a health care provider or any interested individual may petition the court to make a health care decision, order health care for an individual incapable of consenting, or appoint a representative to act for the individual. IND. CODE § 16-36-1-8 (2012). See Appendix infra.
prompted some to urge reforms—particularly to relieve caregivers of liability for exercising their own discretion in making decisions regarding the care of incapacitated persons. Suggestions for legislative reform in this area have included: (1) physician counseling of patients to participate in advance planning;126 (2) increasing direct-physician involvement with decision-making through forms such as Physician’s Orders for Life Sustaining Treatment (POLST) or Medical Orders for Life Sustaining Treatment (MOLST);127 and (3) changing the paradigm for settling disputes from the courtroom to alternative dispute resolution or mediation.128

Although there is disagreement over whether advance directives, including the newer POLST and MOLST forms, are good for patients, the reality is that there is an increasing risk that health care providers will simply ignore patient instructions with regard to life-sustaining treatment.

Most states allow health care providers to refuse to comply with a health care decision if it would either violate the ethical or moral policies of the provider, or if it would require medically futile treatment.129 The difficulty lies in the increasingly broad view of what constitutes medical futility. Providers are generally required to allow transfer of the patient to a different provider in a situation where they are no longer willing to provide requested care.130 The difficulty arises when the provider claims that further treatment is medically futile, and no other provider is willing to take the patient. When this happens, the question becomes: Does the original health care provider have the duty to continue to provide life-sustaining care?

The answer is “not necessarily” under most state statutes. Thus, an increasing number of controversies arise when family members attempt to get the care required for a loved one and the provider refuses to comply with their requests. Research available from the Robert Powell Center for Medical Ethics indicates that in all but eleven states, doctors and hospitals may disregard advance directives when they call for certain treatment.131 In Texas, for example, a hospital committee can decide to deny life support

126. O’Reilly, supra note 123.
127. See Bomba, supra note 123, at 483–87.
130. Id.
131. Id. at 10.
against the will of a patient or his family.\textsuperscript{132} After such a refusal, the family has ten days to try to find another hospital willing to give the patient life-sustaining treatment.\textsuperscript{133}

This is precisely the situation faced by the mother of a twelve-year old boy in Fort Worth, Texas.\textsuperscript{134} He underwent trauma from a bullet wound, causing an indeterminate amount of damage to the brain.\textsuperscript{135} Unbeknownst to his mother, the treating physician removed food and water, and inserted a do-not-resuscitate order into his medical chart.\textsuperscript{136} Although the child was improving to the point of breathing on his own, the doctor made it clear that the hospital would no longer treat him—and all they needed was the affirmation of the hospital’s ethics committee to achieve that very result.\textsuperscript{137}

If the hospital deemed his care “futile,” the mother would have ten days to transfer her son, or they would discontinue the requested care.\textsuperscript{138}

Indeed, over the last fifteen years, the trend has reversed from most cases involving patients seeking to end unwanted care, to patients or their decision-makers seeking continued or more aggressive treatment, with their health care providers refusing to honor their wishes.\textsuperscript{139} Reports indicate physicians are willing to withdraw or withhold treatment they consider futile without informing the patient or his or her family. In one study, more than eighty percent had withdrawn treatment over the family’s objections.\textsuperscript{140}

A legislative solution to the threat facing patients in refusal of care situations is available: the law could be modified to require life-sustaining

\begin{thebibliography}{10}
\bibitem{132} Id. at 9.
\bibitem{133} Id.
\bibitem{134} Martin Barillas, \textit{Mother Pledges to Doctor to Restore Son’s Food and Water}, SPERO NEWS (Aug. 20, 2012), \texttt{http://www.speroforum.com/a/RQGKOJONJQ15/73038-Mother-pleads-to-doctor-to-restore-sons-food-and-water}.
\bibitem{135} Id.
\bibitem{136} Id.
\bibitem{137} Id.
\bibitem{138} Id. In a happy epilogue to this story, a new hospital was found and the child, instead of being left to die, is now conscious, able to talk, and is receiving therapy. Rachel Bohannon, \textit{Boy Who Doctor Claimed Was in PVS State Makes Miraculous Recovery}, LIFE NEWS (Oct. 8, 2012), \texttt{http://www.lifenews.com/2012/10/08/boy-who-doctor-claimed-was-in-pvs-state-makes-miraculous-recovery/}.
\bibitem{139} ROBERT POWELL CTR. FOR MED. ETHICS, supra note 129, at 3 (citing Pam Belluck, \textit{Even as Doctors Say Enough, Families Fight to Prolong Life}, N.Y. TIMES (Mar. 27, 2005)).
\bibitem{140} Id. at 6 (citing Patricia O’Donnell, \textit{Ethical Issues in End-of-Life Care: Social Work Facilitation and Practice Intervention, in Living with Dying: A Handbook for End-of-Life Healthcare Practitioners} (Joan Berzoff & Phyllis Silverman eds., 2004)).
\end{thebibliography}
care to be provided until transfer can be completed. The Oklahoma rule provides a model:

[I]f the physician or other health care provider refuses to comply with a medical treatment decision made by or on behalf of the patient . . . and if the refusal would in reasonable medical judgment be likely to result in the death of the patient, then the physician or other health care provider must comply with the medical treatment decision pending the completion of the transfer of the patient to a physician or health care provider willing to comply with the decision.

If the legislative advances of the past forty years are to continue to be effective in achieving the patient’s wishes, it is necessary that health care providers continue to be required to honor those wishes—not circumvent them by advancing notions of futility.

III. DEFENDING AGAINST ACTIVE KILLING

The current cultural and legal landscapes create a serious need for patients who find themselves deprived of life-sustaining care. These patients need advocates to quickly and forcefully invoke their right to continued treatment. Persons entangled in a medical crisis are not in the best position to defend their own interests. Into this void have stepped a variety of public policy and advocacy organizations, as well as individuals who often provide support for families and contribute legal aid where needed. These organizations are often the voices for change in legislation and are the vanguard of those standing in opposition to continuing trends such as legalization of assisted suicide. Practical steps are available to protect against the involuntary removal of life-sustaining treatment, and attorneys play a paramount role in executing these steps.

A. Advance Planning

As has been hammered into the American consciousness over the last decade, pre-incapacity decision-making is an essential element of planning for the future, especially for the elderly. While the methods of advance planning vary from state to state and from individual to individual, an

141. See id. at 9–10.
142. OKLA. STAT. tit. 63, § 3101.9 (2012).
143. See supra Part II.C.
attorney plays the essential role in assisting the client in thinking through and properly executing advance directives and powers of attorney for health care. This is often a routine part of estate planning for clients, as it makes logical sense to incorporate all aspects of end-of-life planning.

The need for advance health care planning cannot be overemphasized in its importance in protecting the patient’s wishes and values. It is not, however, the end of the equation. Many living wills and other advance planning documents hailed from an era when the primary concern of a patient was the ability to refuse unwanted medical treatment. As discussed above, today the most important issue is just as likely, or more likely, to be the patient’s ability to obtain wanted medical treatment. Based on the recent trend in which hospitals sometimes ignore even clearly expressed wishes of patient surrogates, it is unrealistic to depend upon an advance directive alone for protection against active killing.144

Having a clearly designated agent for health care decisions is the best protection a patient has once they become incapacitated. Directives, such as the living will, provide general, static instructions for care; they often fail to offer the flexibility needed for specific situations. An agent, on the other hand, is a person who preferably knows the patient intimately. He or she can make decisions in gray areas not covered by a directive, and can ensure that the patient’s wishes are being honored. In California, as in most states, a patient may designate a surrogate to make health care decisions, 145 and may execute a power of attorney for health care by following the same procedures and observing the same formalities as are required for an advance directive.146 Encouraging patients to take the step of designating an agent for health care decisions is a large step toward protecting their interests should they become incapacitated.

B. Advocacy

When decision-making on behalf of a patient breaks down, such as when a family member or health care provider makes a treatment decision that does not appear to be in the best interests of the patient, the need to challenge the decision on behalf of the patient becomes apparent, and is usually urgent. Responding to a hospital’s refusal to continue treating a patient may involve seeking an order to restore food and fluids, or to remove a do not resuscitate

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144. See supra Part II.C.
145. CAL. PROB. CODE § 4711 (West 2012).
146. CAL. PROB. CODE § 4680 (West 2012).
order from a patient’s chart. The decision to end life-sustaining treatment in a hospital environment often goes through a recommendation process from the ethics committee. Since these committees are arms of the health care provider, the committee usually sanctions the removal of life-sustaining treatment when recommended by the treating physician. The findings made by the ethics committee, and facts upon which its decision is based, may be helpful (or harmful) to the patient. If possible, the interested person who disagrees with the decision to remove life-sustaining care should seek to participate in the ethics committee process. This may be accomplished by appearing at the meeting and expressing the patient’s desires, or by having an attorney present to represent the patient’s interests. When health care providers continue to refuse treatment, the remaining option is usually for the patient to be transferred to a different care provider.\footnote{147}

Termination of treatment controversies may involve relatives who dispute a decision to end life-sustaining treatment for the patient. Since each individual’s circumstances are unique, this may involve a variety of parties, potential claims, and problems.

As to the parties, in most states, almost anyone may challenge a decision made on behalf of an incapacitated patient. Some statutes provide for a direct challenge to the health care decision; others use the vehicle of a guardianship proceeding. For example, in California, a treatment decision may be challenged under California Probate Code § 4765:

[A] petition may be filed under this part by any of the following persons:
(a) The patient.
(b) The patient’s spouse, unless legally separated.
(c) A relative of the patient.
(d) The patient’s agent or surrogate.
(e) The conservator of the person of the patient.
(f) The court investigator, described in section 1454, of the county where the patient resides.
(g) The public guardian of the county where the patient resides.
(h) The supervising health care provider or health care institution involved with the patient’s care.
(i) Any other interested person or friend of the patient.\footnote{148}

Thus, anyone interested in the welfare of a patient is a potential party to an action on behalf of the patient in California.

\footnotesize
147. \textit{See, e.g., supra Part II.C.}
148. \textit{CAL. PROB. CODE § 4765 (West 2012) (emphasis added). See also Appendix infra.}
In cases involving the removal of life-sustaining treatment, the potential claims center on efforts to resume treatment. In California, if efforts to convince caregivers to continue treatment are ineffective, a petition for an order authorizing medical treatment may be filed in the Superior Court.\textsuperscript{149} It may be necessary to include a petition for an emergency \textit{ex parte} order requiring the requested health care of the patient in the short term, such as an injunction prohibiting removal of a feeding tube.

The unique problems raised in litigating this type of case deserve detailed attention. The following discussion seeks to highlight a few of the more unique issues raised in litigating these cases—particularly some of the unique evidentiary hurdles, the use of expert testimony, the use of evidence of the patient’s condition, and specific arguments that persuade and educate throughout the trial process.\textsuperscript{150}

1. \textit{Evidentiary Hurdles}

There may be unique evidentiary hurdles involved at a hearing on a petition for removal of life-sustaining treatment. For instance, in the \textit{Wendland} case, witnesses testified at pretrial hearings that the ethics committee sanctioned the requested removal of the feeding tube.\textsuperscript{151} Later, during depositions, when questions were asked about those same ethics committee proceedings, the witnesses who had previously testified about the ethics committee hearing objected to questions on the grounds of privilege.\textsuperscript{152} During trial, legal counsel for the hospital brought a motion to quash a subpoena requesting hospital documents from the ethics committee proceedings, also on the basis of privilege.\textsuperscript{153} Since the ethics committee recommendation would carry weight in the final analysis, it was important for the court to be fully aware of the issues the committee considered. Eventually, the court ruled that the ethics committee proceedings were privileged, but the privilege had been waived due to the witnesses’ testimony at the pretrial hearing.\textsuperscript{154} Thus, questions regarding the hospital committee’s decision process were appropriate and were within the scope of the previous

\textsuperscript{149} \textit{CAL. PROB. CODE} §§ 4765–4767 (West 2012).
\textsuperscript{150} These issues arose in \textit{Conservatorship of Wendland}, 28 P.3d 151 (Cal. 2001) (discussed \textit{supra} Part II.B.4).
\textsuperscript{151} \textit{LIFE LEGAL DEF. FOUND., ACTIVE KILLING: WHAT THE LAW ALLOWS} 12 (2012).
\textsuperscript{152} \textit{Id.} at 12–13.
\textsuperscript{153} \textit{Id.}
\textsuperscript{154} \textit{Id.}
testimony. Notably, this further underscores the importance of the surrogate’s participation in ethics committee proceedings.

2. Use of Experts

Expert testimony will be necessary to establish standard of care, appropriate medical guidelines, and the patient’s condition. In Wendland, Dr. Ronald Cranford, a neurologist, provided expert testimony as to recommended guidelines for termination of the treatment of the “minimally conscious.” Under the guidelines he described, the parameters used to gauge whether a “minimally conscious” person should be deprived of life-giving care consisted of the following factors: (1) patient well being; (2) patient autonomy; (3) integrity of the medical profession; and (4) social justice or a proper allocation of resources.

Some of the expert testimony presented appeared to be aimed at minimizing Robert Wendland’s status as a person. Experts opined that Robert’s inability to conceptualize the significance of particular tasks he performed (such as combing his hair) likened him to a “trained animal.” The late Dr. Ronald Cranford, criticized efforts to help Robert improve and sustain his current condition as prolonging an existence he dubbed a “living death.” He concluded “Robert should be allowed to die so the family can grieve.”

In rebuttal to this testimony, medical experts testified that the guidelines Dr. Cranford advocated are valid neurological assessments only insofar as they categorize patients for the purposes of treatment, such as hospital placement and treatment plans. Such categories are not, and should not be, guidelines for making life and death decisions for minimally conscious or incapacitated patients. This type of rebuttal testimony is obviously essential since many are unfamiliar with appropriate medical standards.

Medical testimony is also useful in describing the dying process. It is one thing to discuss removing medical treatment, it is quite another to

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155. The late Dr. Cranford testified at other cases of this nature. CULTURE OF DEATH, supra note 19, at 200.
156. LIFE LEGAL DEF. FOUND., supra note 151, at 10.
157. Id.
158. Id. See description of Robert Wendland’s condition supra Part II.B.4; see also The Underlying Facts of Conservatorship of Wendland, supra note 97.
159. LIFE LEGAL DEF. FOUND., supra note 151, at 10.
160. Id. See also The Underlying Facts of Conservatorship of Wendland, supra note 97.
161. LIFE LEGAL DEF. FOUND., supra note 151, at 10.
understand the result of removing such treatment. Indeed, the process is often far from peaceful and easy.162

Further, medical experts in treatment termination cases are often personally acquainted with one another, which may present difficulty in obtaining an unbiased opinion, or even any alternative opinion. The field of bioethics, including the label “bioethicist,” is relatively new and unregulated. There is no licensure and few credentials officially tied to the term, and the profession lacks an official regulatory agency to maintain quality control.163 This means that there are no governing rules of conduct for bioethicists and no remedy for improper conduct from the profession. Therefore, it is appropriate to use direct questions as to the number of cases in which the expert has testified and been consulted, the similarity of the facts of those cases, and the bases of the opinions advanced—including the expert’s professional memberships, organizations, and publications.

Proponents of terminating treatment can easily misrepresent the physical and mental condition of the patient, since it is rare for the incapacitated patient herself to be in court. For example, in Terri Schiavo’s case, there was dispute over the issue of whether Terri was in a persistent vegetative state (a condition that is misdiagnosed an estimated forty-three percent of the time).164 One of the difficulties in that case was the inability to overcome the initial diagnosis of PVS. The trial court continuously reverted to this diagnosis in ruling for removal of life-sustaining care, even though there were a number of experts who expressed the opinion (out of court) that Terri had been misdiagnosed.165

3. **Use of Technology**

Video recordings are a useful tool in overcoming mischaracterizations of a patient’s condition. Recordings not only show the court, but also the public (via the media), the humanity and capacity of the patient. In Robert Wendland’s case, it was only after a videotape was released to the press that anyone seriously questioned whether his life-sustaining treatment should be terminated.166 Most were under the impression he was comatose, when in

162. See *FORCED EXIT*, *supra* note 18, at 52 (describing the painful and horrific process of starvation).
163. *LIFE LEGAL DEF. FOUND.*, *supra* note 151, at 15–16.
164. See *GIBBS & DEMOSS*, *supra* note 79, at 26, 64.
165. *Id.* at 64–65.
166. *LIFE LEGAL DEF. FOUND.*, *supra* note 151, at 14.
fact he was conscious and able to interact with his environment. The video conveyed his humanity.  

4. *Educating the Court*

As difficult as treatment termination cases are from an emotional perspective, as a matter of litigation, they present a unique opportunity to educate on issues of utmost importance, including reaffirming the traditional equality-of-life ethic. From the initial petition, to motions, to opening statements, to closing statements—and everything in between—there are unique opportunities not only to persuade the court, but also to educate. Some of the arguments that are useful in making the case for life and educating on the issues are discussed below.

The law itself is premised on the notion that people have value, and therefore rights, as individual humans—this is the traditional Western ethic.  

Thus, historically and traditionally in the United States, public policy has protected the weakest and most vulnerable members of society. Legislation such as the Americans with Disabilities Act reaffirms that policy, prohibiting discrimination on the basis of disability. Society should value and protect those who are disabled, and not see their incapacity as a license to eliminate them. Although often asserted, there is no constitutional right to die. This has been confirmed by the United States Supreme Court, and remains the law of the land—statutory rights to PAS in two states notwithstanding. Traditionally and socially, physicians and others in the medical profession have the role of healers, not harmers.

A decision to end treatment may not be medically sound or in the patient’s best interest. Regardless of whether the patient is terminally ill, there are other treatment options available besides death through dehydration and starvation, including treatment for depression, pain, and other symptoms. Unanswered questions about the patient’s medical condition should lead decision makers to err on the side of preserving life. Any improvement in a patient’s condition can create hope for continued improvement. Improvement, or the promise thereof, should not, however, be the sole test by which the decision to end life should be made—the life itself still has

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167. *Id.*

168. *See supra* Part I.

169. *Id.*


inherent value. Although a patient can refuse continued treatment for herself through a written directive, determining the patient’s wishes absent a written statement is a serious undertaking when one considers the permanent nature of the consequences: death. If there is any doubt, the safest course is to preserve life. This option, at least, is not irrevocable.173

Cases often turn on evidence of the patient’s wishes. It is important to note the inherent unreliability in much of the testimony put forward as to what the patient’s wishes would be if they could be expressed. General statements should be viewed cautiously, especially if they are undocumented and uncorroborated. Most people have made general statements at one time or another such as, “I wouldn’t want to live like that.” It is one thing to make such a blanket statement in casual conversation, but quite another to realize the alternative: death by dehydration and starvation. Further, evidence of a patient’s wishes usually comes through family members or close friends of the patient. This raises questions as to the continued beneficence of these relatives. Care for an incapacitated patient can be burdensome. Family members who find the care of an incapacitated loved one tedious or unbearable may have underlying motives in wanting to terminate life-sustaining treatment. These may include inheritance, collection of life insurance proceeds, the need to move on with relationships, or simply the emotional difficulty inherent in such a painful situation.174

Each case will present its own unique set of facts and opportunities to educate on the issue of active killing. Some cases will never reach the litigation stage and may be resolved through some form of mediation between the parties. Whether through advocacy, litigation, mediation, or any other means, strong efforts should be made to affirm, argue, and reestablish the value of the individual—no matter the age or disability.

CONCLUSION

Law and medicine have inherited a sure foundation in the ethic that human life is worth protecting. Although the equality of human life ethic has generally been undermined, modern health care within the United States is still administered by talented and dedicated medical professionals, who, on the whole, deliver the highest standards of care. But what was once

173. An unwillingness to err on the side of life, even when there is reasonable doubt, has been acknowledged as one of the most puzzling features of some of these cases, as was present in the Schiavo case. See, e.g., Gibis & DeMoss supra note 79, at 106–08.

174. Most of these circumstances were present in the Terri Schiavo case, although none of them were satisfactorily addressed by the court. See FORCED EXIT, supra note 18, at 69–71.
unthinkable—depriving helpless individuals of nourishment to hasten their deaths—has indeed become the unexceptionable. The increasing pressure to engage in active killing of “futile” patients cannot be ignored.

All persons are equally entitled to the protection of the law and to the care of society. Those with intellectual or physical disabilities are not only included among those worthy of protection, they are especially worthy of protection. The time has come for members of the medical and legal professions, indeed all citizens, to stand up and defend this truth: all persons have inherent value, and therefore, all lives are worth protecting.

APPENDIX: HEALTH CARE DECISIONS LAWS

<table>
<thead>
<tr>
<th>State</th>
<th>Presumptive decision maker</th>
<th>Who may challenge treatment decision?</th>
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<tbody>
<tr>
<td>Arizona</td>
<td>Agent under power of attorney; guardian; surrogate as follows spouse, adult child, parent, domestic partner, sibling, close friend. ARIZ. REV. STAT. §§ 36-3223(A)–(B), -3231(A), 14-5303(A)–(B) (2013). A surrogate who is not the patient’s agent or guardian may not decide to withdraw food or fluid. §§ 36-3203, -3231.</td>
<td>Any interested person. ARIZ. REV. STAT. § 36-3206 (2012).</td>
</tr>
<tr>
<td>California</td>
<td>Agent under power of attorney for health care; Patient, spouse, relative, agent or</td>
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175. See Neuhaus, supra note 1.
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<tr>
<th>State</th>
<th>Presumptive decision maker</th>
<th>Who may challenge treatment decision?</th>
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<tbody>
<tr>
<td>Connecticut</td>
<td>Health care representative, under living will; physician to notify prior to termination of life-support: health care representative, next-of-kin (spouse, child, etc.), guardian, conservator. CONN. GEN. STAT. §§ 19a-575a, -580 (2012).</td>
<td>Person whose appointment as health care representative has been revoked. CONN. GEN. STAT. § 19a-580c (2012).</td>
</tr>
<tr>
<td>Delaware</td>
<td>Agent under health care directive/power of attorney for health care; if no agent or guardian: spouse, adult child, parent, sibling, grandchild, niece, or nephew. DEL. CODE ANN. tit. 16, §§ 2501, 2507(2) (2012).</td>
<td>Anyone with reason to believe withholding of health care is against wishes may petition the Court of Chancery for appointment of a guardian. DEL. CODE ANN. tit. 16, § 2511 (2012).</td>
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<tr>
<td>Florida</td>
<td>Surrogate, designated health care representative; proxy at request of care facility (guardian, spouse, child, parent, etc.). FLA. STAT. §§ 765.202, .304, .401 (2012).</td>
<td>Patient’s family, health care facility, attending physician, or any other interested person reasonably expected to be affected FLA. STAT. § 765.105 (2012).</td>
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<tr>
<td>Georgia</td>
<td>Health care agent; if no agent or guardian named: spouse, child, parent, sibling, grandparent, grandchild; relative in first degree; or an adult friend. GA. CODE ANN. §§ 31-9-2, -32-7 (2012).</td>
<td>Any interested person or the ward. GA. CODE ANN. § 29-4-20 (2012).</td>
</tr>
<tr>
<td>Hawaii</td>
<td>Designated surrogate; if no agent or guardian, surrogate appointed from interested persons: spouse, child, parent, sibling, grandchild, or adult who has exhibited special care and</td>
<td>Patient’s agent, guardian, or surrogate, or a health-care provider or institution involved with the patient’s care may petition for change in care. HAW. REV.</td>
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<td>Idaho</td>
<td>Guardian; agent under durable power of attorney; spouse, adult child, parent, relative, etc.</td>
<td>Ward or any person interested in his welfare may challenge guardianship.</td>
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<td>Indiana</td>
<td>Appointed health care representative; if none surrogate in following order: guardian, spouse, parent, child, sibling, or religious superior (if patient is member of religious order).</td>
<td>A health care provider or any interested individual. IND. CODE § 16-36-1-8 (2012),</td>
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<td>Iowa</td>
<td>When patient is in terminal condition, after consultation with physician, decisions to be made by: designated attorney in fact, guardian, spouse, child, parent, sibling (in that order).</td>
<td>The principal (§ 144B.6); any person may file for conservatorship. IOWA CODE § 633.566 (2012).</td>
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<td>Louisiana</td>
<td>If no designation by patient, judicially appointed tutor or curator, anyone previously designated by patient, souse, child, parents, sibling, etc. LA. REV. STAT. ANN. § 40:1299.58.5 (2012).</td>
<td>Any person may file for interdiction. LA. CIV. CODE ANN. art. 4541, 389, 391 (2012).</td>
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<td>Maine</td>
<td>Agent under power of attorney for health care, or surrogate in following order: spouse or adult in such relationship, adult child, parent, sibling, grandchild, niece or nephew, etc. ME. REV. STAT. tit. 18-A, §§ 5-801, -802, -5-</td>
<td>Patient, the patient’s agent, guardian or surrogate, a health-care or social services provider, adult protective services, or an adult relative or adult friend of the patient. ME. REV. STAT. tit. 18-A, § 5-</td>
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<td>Maryland</td>
<td>If no surrogate or agent available, guardian, spouse or domestic partner, adult child, parent, brother or sister, friend or relative. MD. CODE ANN., HEALTH-GEN. § 5-605 (2012).</td>
<td>Health care provider; spouse, domestic partner, parent, child, grandchild, sibling, friend or other relative who has qualified as a surrogate under MD. CODE ANN., HEALTH-GEN. §§ 5-605, 5-612 (2012).</td>
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<td>Massachusetts</td>
<td>Designated agent under health care proxy; if no designation physician may rely on consent of “responsible parties.” MASS. GEN. LAWS ANN. ch. 201D, §§ 1 – 4, 16 (West 2012).</td>
<td>Health care provider, conservator, guardian, members of the principal’s family, close friend, or commissioner of public health. MASS. GEN. LAWS ANN. ch. 201D, § 17 (West 2012).</td>
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<td>Minnesota</td>
<td>Agent under directive, or proxy, MINN. STAT. ANN. §§ 145B.03, 145C.07 (West 2012); guardian: order of priority of appointment includes agent, spouse, child, parent, etc. § 524.5-309.</td>
<td>In guardianship: incapacitated person, or person interested. MINN. STAT. ANN. § 524.5-302(h) (West 2012).</td>
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<td>Mississippi</td>
<td>Agent under power of attorney for health care; surrogate, spouse, adult child, parent, sibling, or adult who has shown concern and is familiar with patient’s values. MISS. CODE. ANN. §§ 41-41-209, -211 (2012).</td>
<td>Patient, the patient’s agent, guardian or surrogate, a health-care provider or institution involved with the patient’s care, or a surrogate. MISS. CODE. ANN. § 41-41-229 (2012).</td>
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<td>Nevada</td>
<td>Agent under declaration regarding life sustaining treatment, if no declaration, written consent may be by spouse, child, parents, sibling, nearest adult relative. NEV. REV. STAT. §§ 449.600, .626 (2012).</td>
<td>In guardianship: any interested person, NEV. REV. STAT. § 159.044 (2012).</td>
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<td>New Mexico</td>
<td>Agent under power of attorney for health care; guardian; spouse or one in similar relationship, child, parent, sibling, grandparent, person who has exhibited special care and concern. N.M. STAT. ANN. §§ 24-7A-1, -2, -5 (2012).</td>
<td>Patient, agent, guardian or surrogate, health-care provider or health-care institution. N.M. STAT. ANN. § 24-7A-14 (2012).</td>
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<td>New York</td>
<td>Agent under health care proxy; if no proxy surrogate: guardian, spouse, child, parent, sibling, close friend. N.Y. PUB. HEALTH §§ 2980, 2994-d (McKinney 2012).</td>
<td>Any person connected with the case and any member of the hospital ethics review committee. N.Y. PUB. HEALTH § 2994-r (McKinney 2012).</td>
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<td>Ohio</td>
<td>Attorney in fact; for withdrawal of life support (patient must be unconscious for twelve months): guardian, spouse, child, parent, sibling, nearest relation, and then after court order. OHIO REV. CODE ANN. §§ 1337.13, 2133.08 (LexisNexis 2012).</td>
<td>Individuals authorized to consent may object to decision within forty-eight hours. OHIO REV. CODE ANN. § 2133.08(E), .09 (LexisNexis 2012).</td>
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<td>Oregon</td>
<td>Attorney-in-fact for healthcare; guardian; for terminal condition where not designated, guardian, spouse, person designated by other decision-makers, children, parents, siblings, relative or friend, if none available, then physician. OR. REV. STAT. §§ 127.545, .635 (2012).</td>
<td>Health care representative, spouse, parents, sibling or child, relative or friend familiar with desires of principal, guardian, conservator, attending physician or health care provider. OR. REV. STAT. § 127.550(3) (2012).</td>
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<td>South Dakota</td>
<td>If no guardian or agent, spouse, child, parent, sibling, grandparent or grandchild, aunt, uncle, cousin, niece or nephew, or close friend. S.D. CODIFIED LAWS § 34-12C-3 (2012).</td>
<td>Incapacitated person, person authorized to make a health care decision, health care provider, or any other interested person. S.D. CODIFIED LAWS § 34-12C-5 (2012).</td>
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<td>Tennessee</td>
<td>If no guardian or agent, a surrogate may be designated by patient or appointed from the following: spouse, child, parent, sibling, other adult relative, person familiar with patient and his values. TENN. CODE ANN. § 68-11-1806 (2012).</td>
<td>Patient, patient’s agent, guardian, surrogate, health care provider, or individual described in TENN. CODE ANN. § 68-11-1806(c)(5) (2012).</td>
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<td>Texas</td>
<td>Medical power of attorney/agent; if no directive, surrogate: spouse, children, etc. TEX. HEALTH &amp; SAFETY CODE ANN. § 166.039 (West 2012).</td>
<td>Patient’s guardian, any person who is a relative or directly interested. TEX. HEALTH &amp; SAFETY CODE ANN. § 166.165 (West 2012).</td>
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**State** | **Presumptive decision maker** | **Who may challenge treatment decision?**
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Utah | Agent under directive, guardian; in absence of directive: spouse, parent, sibling, grandchild or grandparent; person who has exhibited special care. **Utah Code Ann. § 75-2a-108 (LexisNexis 2012).** | Health care provider, patient, agent, guardian, surrogate, health care provider or facility or default surrogate. **Utah Code Ann. §§ 75-2a-108(7), -120 (LexisNexis 2012).**
West Virginia | Medical power of attorney representative; if not designated, surrogate decision maker, chosen by the caregiver from roster of close family, friends, or any other person designated by the Department of Health and Human Resources. **W. Va. Code §§ 16-30-3, -4, -8-9 (2012).** | Other “potential” surrogate; challenger may seek injunctive relief or file a petition for review. **W. Va. Code § 16-30-8(c) (2012).**
Wisconsin | Agent under power of attorney for health care. **Wis. Stat. § 155.05 (2012).** For commitment to certain facilities: if no power of attorney for health care or guardian, spouse, child, parent, sibling, grandparent, grandchild, then close friend. **§ 50.06(3).** | Any interested party. **Wis. Stat. § 155.60(4)(a) (2012).**
Wyoming | Agent under power of attorney for health care; guardian or surrogate: spouse, child, parent, Patient, agent, guardian or surrogate, or health care provider. **Wyo. Stat. Ann. §** |
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