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ELDER LAW—MY LIFE, MY CHOICE

Hyman G. Darling, Esq. & Andrew Adams†*

As the most recent past president of the National Academy of Elder Law Attorneys (NAELA) I have been involved in elder law for over thirty years, even before there was a sub-practice of estate planning called elder law. In fact, for estate planning, I recall when the primary document a client needed was a will. The required document has expanded and now includes a will, health proxy, power of attorney, a POLST form (Physician's Order for Life Sustaining Treatment), sometimes a living will, and other various documents a client may desire, such as a cremation order, a pre-arranged burial, and the like.

Many years ago, it was also the norm that many wished to be kept alive by machines, or did not take a stand as to their preference, with many families refusing to talk about it. It was also the norm that most people were buried and not cremated. Times have changed, and the pendulum has swung the other way in many cases. I remember how my mother was ill for many years, and it was determined that all measures would be taken to keep her alive, even at the end of her life when there was absolutely no chance of recovery.

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FOREWORD

BY HYMAN G. DARLING, ESQ.

The issue of end of life decisions was brought to the forefront when I attended a Dana Farber Society dinner in Boston, Massachusetts during which there was an awareness brought up by the keynote speaker Dr. Atul Gawande. One needs only to read any of Dr. Gawande's publications or enter his name in a Google search to allow him to educate people and focus on the issues relative to end-of-life decisions. In addition, at the 2018 annual meeting of the NAELA, one of my esteemed colleagues, Peter Strauss—one of the founders of elder law and an advocate for allowing end-of-life decisions to be made—suggested that elder law attorneys should advocate to discuss these issues more in-depth when meeting with their clients. After hearing both Dr. Gawande and Attorney Strauss, I began to think more about these issues when advising clients. However, it was not until recently that this matter personally hit home, causing me to reflect on the issue again and become more focused on writing an article on the topic. I probably spend more time than other attorneys discussing end-of-life situations with clients, especially those who are competent and not in a period of distress, allowing the discussion to be held more easily, as opposed to when a client is toward the end of his or her life and may not be as receptive to discussing the issue.

The story began in 1991 when I was appointed as conservator of Alan, who was then in his late twenties and a relatively healthy, though disabled, American Veteran. I was appointed because Alan was basically a spendthrift and unable to handle his finances, although he was mentally competent to make his own decisions. As with many Veterans of that era, he was a heavy smoker, and was not a very healthy eater as he lived alone for many years. Alan was always competent to make his decisions relative to day-to-day living, but it was my responsibility to make all of his payments, attend to his rent and taxes, and provide him an allowance based on the funds he received from the government.

Alan lived independently for many years until he moved into an apartment-like setting in a dormitory where his meals were covered, activities were provided to him on a daily basis, and he was with other Veterans who were similarly situated to Alan. I provided him with a bus pass so that he could get around wherever he wanted. He had sufficient spending money to attend to all of his needs, and if he wanted something additional, I usually provided it for him, as his needs were relatively minimal. Alan was a likeable guy who knew what he wanted, but he probably spoke with my legal assistant more than anyone else in his life

(sometimes three to five times a day) and he also spoke to me when it was needed. Most of our exchanges were conversational and merely to let me know what his plans were for the days or weeks ahead.

It was at the 2018 NAELA conference when I received a phone call and learned that Alan had fallen ill and was in the hospital. I was told that it was not life threatening and that Alan was competent and was allowed to make most of his medical decisions. I had intended to spend an extra day in New Orleans after the conference, but I decided to switch my schedule and return a day early. Upon returning, I received a voicemail that Alan was still in the hospital and was not doing too well. Over the previous few days I had been speaking with him, his physician, and his nurse, and it was determined that his breathing problems had exacerbated—probably as a result of years of smoking. He usually took a nebulizer and was afforded oxygen through a nasal tube, but since his oxygen levels had reduced, he was given oxygen directly through a mask. He was now confined to bed. All of this happened fairly quickly in a matter of a few days. Alan had attempted to quit smoking many times but could not kick the habit. I even attempted to reward him by offering him additional spending money if he quit, but this was beyond his ability.

Upon returning to my home, I received another voicemail from the doctor that Alan's condition was worsening. A decision had to be made as to whether he would have a tracheotomy. Otherwise, he would be on direct oxygen for some time. However, this would only be temporary until his lungs continued to weaken, causing respiratory failure.

It was a Sunday morning when I drove to the hospital to meet with Alan, his physician, and his nurse in the intensive care unit. Alan was able to communicate with me coherently, although he had to lift up the oxygen mask so that I could hear him. There was no question that he was mentally capable of making his own decisions, and he was somewhat unhappy that he could not eat since he was laying down and on oxygen. In order to get nutrition, Alan needed a tube inserted directly into his stomach as he could not tolerate a nasogastric tube because he still required an oxygen mask.

I had a long and hard discussion with the physician and nurse about Alan's options, the consequences of each option, time frames for living and mortality, and quality-of-life issues. The doctor suggested I discuss these options with Alan, and I insisted that the doctor be present during the discussion to be sure that I was communicating all options correctly. With tears in my eyes, I had to inform Alan, who had been my responsibility for over twenty-seven years, of the unfortunate prognosis.

Alan was given the opportunity to make these decisions himself. One being that he would need the tracheotomy and may be confined to an

institution for some time with no guarantees as to his future living arrangements since his lungs had already been compromised and probably would not repair, requiring him to have artificial respiration forever. The other option presented to him was that he could be taken off oxygen, at which time he would probably succumb to death within hours.

After presenting these options to Alan, I think that the nurse and doctor had to comfort me more than Alan. He took the news so well and it was amazing to hear him state unequivocally that he wished to die a painless death. He would not be required to be connected to any medical apparatus nor to be maintained through artificial means—even if the decision he made was to hasten the moment of his death. We discussed the options fully and clearly, and Alan was asked what his wishes were. He asked for a tuna fish sandwich and vanilla ice cream. Within minutes, they were delivered to him, and he was transferred from the bed to the chair, and his oxygen was removed. His oxygen levels went down approximately twenty percent almost immediately and continued to drop. After he ate his last meal, he asked to be put in bed, as he was having a bit of discomfort and difficulty breathing. He was given morphine for comfort, and we discussed lots of issues over the next several minutes before he drifted into a deep sleep. He told me he was done living, he had lived a good life with no regrets, and he was confident in his decision—basically without any emotion. Alan passed away within two hours while I sat there. His death was painless, peaceful, and non-invasive.

Without the education I had received in the months prior to this event, from my colleagues and Dr. Atul Gawande, I probably would not have been able to work with the medical personnel in allowing Alan to die the way he wished. Fortunately, I had been educated sufficiently to know that he could make his own decisions without the need for any court intervention or ethics committees. It was Alan's decision. It was based on the clear and concise advice provided by the physician, the nurse, and myself. This death should not be considered unfortunate or sad. It was the end of Alan's time, and he made the educated and informed decision to allow his death to occur without a long and arduous institutionalization where he probably would not have had the same quality of life. He knew he could not eat, smoke, take trips, or in any other way continue his lifestyle the way he had. With Alan's consent, and without any force or coercion, he vehemently refused aggressive treatment, and he made his decision, accepted it, and allowed his death to occur relatively swiftly, within only a few hours of his making the decision.

As a postscript to this story, Alan's funeral was held at the local Department of Veterans Affairs cemetery with the full honor guard, and it

was attended by several of his friends, personnel from the facility where he lived for many years, and my staff. Reflecting back, this was clearly a case where the patient made his own decision without the interference of others and, as a result, was allowed to die peacefully. I was inspired to put together an article relative to dying with dignity so that others may be in a position to guide their clients in making the most appropriate decisions for themselves.

Thank you, Dr. Gawande, Attorney Strauss, and most of all, Alan.

INTRODUCTION

First and foremost, this Article is focused on an individual's right to die, not an argument in support of medical aid in dying. While this Article does not proffer an opinion upon the merits of the latter, it is necessary to understand the differences between the two in order to fully appreciate the concepts that this Article will discuss hereinafter. The right to die refers to the right of an individual to protect their bodily privacy interest through either the refusal or removal of extraordinary life prolonging measures.¹ Medical aid in dying is a process through which terminally ill adults request a prescription for medication that they may self-administer to bring about a peaceful death.² In order to appreciate the argument for the right to die, it is essential to understand death as part of the natural process of life and, also, understand the choices that individuals face with end-of-life decisions.

I. THE RIGHT TO DIE, LIVING WILLS, AND THE MASSACHUSETTS RESPONSE

As recently as 1945, most deaths occurred in the home. By the 1980s, just 17 percent [of deaths were at-home deaths]. Lacking a coherent view of how people might live successfully all the way to the very end, we have allowed our fates to be controlled by medicine, technology, and strangers.³

1. *See Right to Die*, CAMBRIDGE DICTIONARY, <https://dictionary.cambridge.org/us/dictionary/english/right-to-die> [<https://perma.cc/CPF8-A49A>] (“[T]he belief that a person should be allowed to die naturally rather than being kept alive by medical methods when they are suffering and unlikely to get well.”).

2. *See* Caroline Simon, *With D.C. and California Laws in Jeopardy, a Fresh Debate Over Medical Aid in Dying*, USA TODAY, <https://www.usatoday.com/story/news/2018/06/25/washington-dc-california-medical-aid-dying-physician-assisted-suicide/713546002/> [<https://perma.cc/H6VN-YRZD>] (last updated June 27, 2018, 5:25 PM).

3. Atul Gawande, *No Risky Chances*, in *THE BEST AMERICAN SCIENCE AND NATURE WRITING* 65, 66 (Rebecca Skloot & Tim Folger eds., 2015).

To do otherwise requires “the courage to confront the reality of our mortality” and “the courage to act on the truth that we find.”⁴

Advances in medicine and technology have created a unique challenge for the courts as the paradigm of care has shifted to one in which prolonging life through any means has become the norm. Using life prolonging technology, such as artificial respiration and feeding tubes, has often become obligatory. For those who do not wish to use such devices, the path to prevent their use has become an arduous one.

Over the last forty years, case law has developed, beginning with *In re Quinlan*,⁵ that allows individuals to plan for the removal of these life prolonging measures. *In re Quinlan* was the seminal case in determining that an incapacitated individual’s right of privacy may be asserted on their behalf by a guardian.⁶ However, this decision did not come without its challenges and was only rendered after years of litigation, great financial expense, nationwide publicity, and an immeasurable emotional toll on the parents of Karen Ann Quinlan. Another major development that arose from *In re Quinlan* was the general acceptance by the courts of hospital ethics committees and their role in aiding families and courts in making end of life decisions.⁷ However, this was not always the case. With the advances in technology came challenges in the courts.

The movement continued toward a more formalized system of written documents that “allow an individual to express his or her personal intention . . . [regarding] whether to allow the extraordinary measure of life support to be discontinued . . . whe[n] a determination has been made about [the individual] being in a persistent vegetative state.”⁸ These documents are called living wills but are occasionally referred to by terms

4. *Id.*

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

6. *Id.* at 662–64.

7. Mark P. Aulisio, *Why Did Hospital Ethics Committees Emerge in the US?*, 18 *AMA J. ETHICS* 546, 547–48 (2016), <https://journalofethics.ama-assn.org/sites/journalofethics.ama-assn.org/files/2018-05/mhst1-1605.pdf>.

[T]he Quinlan case had very broad resonance, as nearly anyone could easily imagine him- or herself in the same position as Joseph, Julia, or Karen Quinlan. The New Jersey Supreme Court, apparently motivated in part by the fear of a torrent of cases that would grind the judicial system to a halt, suggested that “ethics committees” (meaning, albeit, mostly physician-dominated prognosis committees) might play an advisory role in such cases as an alternative to the courts.

Id. at 548.

8. Scott E. Squillace, *Incapacity Documents*, in *DRAFTING WILLS AND TRUSTS IN MASS.* § 50.4 (Mass. Continuing Legal Educ., 4th ed. 2017).

such as advanced health-care directives, health care proxy, POLST, or MOLST forms.⁹

Typically, a living will is a document that expresses an individual's desire to refuse extraordinary medical treatment by artificial or mechanical means that will probably not effect a cure but will result merely in the painful or insensate prolongation of life, or serve only to prolong the process of dying.¹⁰

However well intended, the living will is not specifically authorized by statute in Massachusetts, and for a period of time it appeared the State was not going to act upon this issue.¹¹ On this specific issue, Massachusetts has lagged behind other states, only passing legislation as recently as 1990 specifically authorizing the use of advanced health care directives or living wills.¹² Politicians in the Massachusetts legislature have on several occasions introduced bills that would codify the authority of living wills.¹³ However, these proposed bills almost always end up dead in committee. One theory regarding the failure of these bills is the lack of involvement from the affected population (i.e., the elderly) and the strong involvement of political opponents.¹⁴ In Massachusetts, it has been theorized that "the dominance of the Catholic Church has shaped the political conflict and overshadowed the power of all other groups" in their

9. *Id.* Although the cited source discusses the Massachusetts version of the form, the document is generally referred to as a POLST form (Physician Orders for Life Sustaining Treatment). *About, NAT'L POLST PARADIGM*, <https://polst.org/about> [<https://perma.cc/8U8M-38P5>].

10. Vicki L. Ehrlichman, *The 1990 Health Care Proxy Law: Beyond the Best Interests of the State*, 76 MASS. L. REV. 145, 145 (1991).

11. *See* *Cohen v. Bolduc*, 760 N.E.2d 714, 718 n.12 (Mass. 2002) ("Unlike some States, the Massachusetts statute does not provide for instructional, as opposed to agent-delegated, advance directives, and has no 'living will' provision."). Massachusetts law did, however, authorize the appointment of a health care proxy beginning in 1991. An Act Providing for the Execution of Health Care Proxies by Individuals, 1990 Mass. Acts 332 (codified as MASS. GEN. LAWS ch. 201D (1992)).

12. Ehrlichman, *supra* note 10, at 145 ("Although Massachusetts lagged years behind most states in enacting living will legislation, its legislative product offsets the years of living with a legal vacuum in this important area."). It should be noted that the Massachusetts General Laws still do not specifically authorize living wills but has authorized the use of a similar form called the Massachusetts Medical Orders for Life-Sustaining Treatment (MOLST), implementing a pilot program beginning in 2010. *See* 2008 Mass. Acts 305. The MOLST form will be discussed further herein.

13. *See* H.R. 1548, 188th Gen. Court, Reg. Sess. (Mass. 2013); H.R. 1354, 187th Gen. Court, Reg. Sess. (Mass. 2011); H.R. 3207, 177th Gen. Court, Reg. Sess. (Mass. 1992); H.R. 2129, 177th Gen. Court, Reg. Sess. (Mass. 1991).

14. *See* Henry R. Glick, *The Right-To-Die: State Policymaking and the Elderly*, 5 J. AGING STUD. 283, 300-01 (1991).

advocacy and lobbying efforts against the codification of living wills and similar statutes.¹⁵

As early as 1976, states passed legislation that codified the use of “specified directive” forms, which could identify an individual’s intent with regard to “withholding [or withdrawal] of life[-]sustaining procedures.”¹⁶ Prior to 1991, California law had recognized the use of specified directives, but put a five year limitation on the validity of the document from the date of its execution.¹⁷ In 2008, Massachusetts authorized the use of a Physician’s Order for Life-Sustaining Treatment (POLST) form that would come to be known as the Massachusetts Medical Orders for Life-Sustaining Treatment (MOLST) form.¹⁸ “[T]he MOLST [form] is a document signed by the patient and physician regarding a present treatment plan for a terminal illness, as opposed to the contemplation of a future condition and a direction to act if the patient is incapacitated.”¹⁹ While the introduction of the MOLST form was a major step forward in end-of-life decision-making, it can only be utilized by those with a current advanced illness,²⁰ and thus does not go far enough to protect the rights of citizens of the Commonwealth. In many cases, the selection by the patient when healthy may differ significantly from choices made when terminally ill.

15. *Id.* at 299.

16. Natural Death Act, 1976 Cal. Stat. ch. 1439, § 1 (codified as CAL. HEALTH & SAFETY CODE § 7185 (West)), *repealed by* Stats. 1991, ch. 895 (S.B. 980) (creating a form for a directive concerning life-sustaining procedures).

17. 1991 Cal. Legis. Serv. ch. 895 (S.B. 980) (“Existing law provides that the directive is effective for 5 years from the date of execution, as specified.”). The law was amended in 1991 to remove restrictions such as the five-year limitation on the validity of the form. *See id.* (“This bill would authorize the declarant to revoke the declaration at any time, as specified, but would not otherwise limit the length of time the declaration would be effective.”); Natural Death Act, 1991 Cal. Stat. ch. 895, § 1, *repealed by* Stats. 1999, c. 658 (2000).

18. An Act to Promote Cost Containment, Transparency and Efficiency in the Delivery of Quality Health Care, 2008 Mass. Acts ch. 305, §§ 41–43; *see Massachusetts Medical Orders for Life-Sustaining Treatment*, MASS. MED. ORDERS FOR LIFE-SUSTAINING TREATMENT, <https://www.molst-ma.org> [<https://perma.cc/VW7E-F4D6>] (providing further information regarding the MOLST form).

19. Squillace, *supra* note 8.

20. *The Massachusetts Health Care Proxy Form*, MASS. MED. ORDERS FOR LIFE-SUSTAINING TREATMENT, <https://www.molst-ma.org/forms/the-massachusetts-health-care-proxy-form> [<https://perma.cc/JNA6-98ZU>].

II. SCULPTING THE LANDSCAPE

A. *Karen Ann Quinlan*

The first landmark decision was *In re Quinlan*. Karen Ann Quinlan, a twenty-one-year-old woman residing in New Jersey, was admitted to the Newton Hospital via ambulance after two fifteen-minute bouts of unconsciousness during which she suffered from a complete cessation of respiration.²¹ She was subsequently examined and found to be in a “state of coma, with evidence of [decorticate posturing] indicating altered level of consciousness.”²² Karen was placed on a respirator due to her “chronic [and] ‘persistent vegetative’ state.”²³ While in this vegetative state, Karen lost forty pounds, became locked into a fetal-like position due to the extreme “rigidity of [her] arms, legs and related muscles and her joints [became] severely rigid and deformed.”²⁴ The *Quinlan* court approached the matter by utilizing a three-part discussion, but rested its decision primarily upon the fundamental right of privacy,²⁵ explaining that “the State’s interest . . . weakens and the individual’s right to privacy grows as the degree of bodily invasion increases and the prognosis dims.”²⁶ The court concluded that if the “hospital ‘Ethics Committee’ or like body of the institution” agreed that “there [wa]s no reasonable possibility of Karen’s ever emerging from her present comatose condition to a cognitive, sapient state, the present life-support system may be withdrawn.”²⁷ Karen was subsequently removed from her respirator and to the surprise of all, continued to breathe on her own. She went on to live another nine years before she died on June 11, 1985.²⁸

21. *In re Quinlan*, 348 A.2d 801, 806–07 (N.J. Super. Ct. Ch. Div. 1975), *modified and remanded*, 355 A.2d 647 (N.J. 1976); see 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>. The actual cause of Karen’s condition remained in controversy during the trial, as the barbiturates, Librium and Valium, found in her blood tests were considered to be within the therapeutic range. *In re Quinlan*, 348 A.2d at 806.

22. *In re Quinlan*, 348 A.2d at 807.

23. *In re Quinlan*, 355 A.2d 647, 655 (N.J. 1976).

24. *Id.*

25. The other focal points in their deliberation were the free exercise of religion and the right to be free from cruel and unusual punishment. *Id.* at 661–64.

26. *Id.* at 664.

27. *Id.* at 671–72.

28. Ravi Nessman, *Karen Ann Quinlan’s Parents Reflect on Painful Decision 20 Years Later*, L.A. TIMES (Apr. 7, 1996), http://articles.latimes.com/1996-04-07/news/mn-55744_1_karen-ann-quinlan [<https://perma.cc/G7VQ-3QSA>]. It should be noted that Karen’s parents

B. *Nancy Beth Cruzan*

The next time the courts were faced with such a challenge that attained national attention was in *Cruzan*. The *Cruzan* Court found that the Constitution did not prevent a state from requiring clear and convincing evidence of an incompetent person's wishes regarding the withdrawal of life-sustaining treatment.²⁹ This time the final decision came from the Supreme Court of the United States.

Nancy Beth Cruzan was rendered incompetent as a result of severe injuries sustained during an automobile accident.³⁰ Cruzan was determined to have been without oxygen for twelve to fourteen minutes. She was in a coma for three weeks, then progressed to an unconscious phase, commonly known as a persistent vegetative state.³¹ Cruzan's parents were informed that she "had virtually no chance of regaining her mental faculties."³² Upon learning such, they requested the hospital "terminate the artificial nutrition and hydration procedures," with the knowledge that doing so would effectively cause her death.³³ "The employees of the hospital refused to honor this request without court approval."³⁴ The Supreme Court of Missouri "recognized a right to refuse treatment embodied in the common-law doctrine of informed consent" but expressed doubt as to whether a fundamental right of privacy to refuse medical treatment in every circumstance exists under the United States Constitution.³⁵

The Supreme Court of the United States held that "requiring clear and convincing evidence of an incompetent patient's wishes . . . to withdraw[] or withhold[] . . . treatment does not violate that person's federal constitutional rights."³⁶ Additionally, the Court upheld the Supreme Court

"never sought to have her feeding tube removed during the nine years she lived after she was taken off the respirator." *Id.*

29. See *Cruzan ex rel. Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261, 286-87 (1990).

30. *Id.* at 265.

31. *Id.* at 266.

32. *Id.* at 267.

33. *Id.*

34. *Id.* at 268.

35. *Id.*; *Cruzan ex rel. Cruzan v. Harmon*, 760 S.W.2d 408, 427 (Mo. 1988).

We find no principled legal basis which permits the coguardians in this case to choose the death of their ward. In the absence of such a legal basis for that decision and in the face of this State's strongly stated policy in favor of life, we choose to err on the side of life, respecting the rights of incompetent persons who may wish to live despite a severely diminished quality of life.

Id.

36. 63 AM. JUR. TRIALS 1, *Decisionmaking at the End of Life* § 12 (1997).

of Missouri's rulings, including the idea that even though trial testimony was given regarding Nancy's own words in protest of ever facing life as a "vegetable" (and not wanting to live like that), she did not specifically "deal in terms with withdrawal of medical treatment or of hydration and nutrition."³⁷ The Court did not, however, hold that the clear and convincing standard of proof be required in all states. It left the setting of this threshold to the individual states and upheld the ruling that Missouri could defer to a standard of clear and convincing evidence of a patient's wishes "rather than confide the decision [to] close family members."³⁸

C. *Theresa Marie Schiavo*

Theresa Schiavo suffered cardiac arrest in the early morning hours of February 15, 1990, due to a potassium imbalance.³⁹ Within one year of this sudden cardiac event, Theresa was diagnosed as being in a permanent or persistent vegetative state.⁴⁰ For the next eight years, Theresa's husband, Michael, acted as guardian for his wife. He was repeatedly noted by her attending physicians and others responsible for her care as having been "very motivated in pursuing the best medical care for his wife, even taking her to California for a month or so for experimental treatment."⁴¹ After eight years of medical care and experimental treatments that failed to improve Theresa's medical state, Michael filed a petition on May 11, 1998, for an Order for the Authorization to Discontinue Artificial Life Support,⁴² which, after roughly a two-year legal battle, was finally granted.⁴³

This order marked the beginning of an exhausting and entrenched legal battle over the decision to remove Theresa's feeding tube. The battle lasted the better half of a decade, involved over fourteen separate appeals, the passing of new state legislation,⁴⁴ a witness intervention from

37. *Cruzan*, 497 U.S. at 285.

38. *Id.* at 286–87.

39. *In re Guardianship of Schiavo*, 780 So. 2d 176, 177 (Fla. Dist. Ct. App. 2001).

40. The Court explained that "a persistent vegetative state is not simply a coma. She is not asleep. She has cycles of apparent wakefulness and apparent sleep without any cognition or awareness. As she breathes, she often makes moaning sounds. Theresa has severe contractures of her hands, elbows, knees, and feet." *Id.*

41. *In re Guardianship of Schiavo*, No. 90-2908GD-003, 2000 WL 34546715, at *2 (Fla. Cir. Ct. Feb. 11, 2000), *aff'd*, 780 So. 2d 176 (Fla. Dist. Ct. App. 2001).

42. *Id.* at *6–7.

43. *Id.* at *7.

44. *See* An Act Relating to the Authority for the Governor to Issue a One-Time Stay, 2003 Fla. Laws ch. 418. Following years of litigation, "Terri Schiavo's feeding tube was removed, only to be reinserted six days later after the Florida Legislature, in emergency session, passed a

Congress and the President of the United States,⁴⁵ and culminated with a final denial of a petition for a writ of certiorari in 2005.⁴⁶ The Florida District Court of Appeals, in its final ruling upholding the lower court's Order for the Authorization to Discontinue Artificial Life Support, stated in its reasoning that "the Supreme Court of Florida had already determined that the express right of privacy in article I, section 23, of the Florida Constitution gave both competent and incompetent persons the right to forego life-prolonging procedures."⁴⁷

Further, the court relied on its own precedent in finding that this protection extended not only to those individuals with "the foresight and resources to prepare a living will, but also to those whose wishes have not been reduced to writing."⁴⁸ While ultimately supporting the contention of the husband-guardian—that Theresa's wishes were to forego life-sustaining treatment—the court found that court intervention would be reasonable in a future case such as this where "family members cannot agree or when a guardian believes that it would be more appropriate for a neutral judge to make the decision."⁴⁹ Again, the court refrained from shifting the onus of end-of-life decision-making from their hands to that of the individual citizen.

law that gave Gov. Jeb Bush the power to intervene in the case. The governor ordered the feeding tube reinserted." Rich Phillips, *Florida Court Strikes Down 'Terri's Law'*, CNN.COM: LAW CENTER (Sept. 23, 2004, 8:47 PM) <http://www.cnn.com/2004/LAW/09/23/schiavo/index.html> [<https://perma.cc/KU3S-ATKV>]; *see also* Bush v. Schiavo, 885 So. 2d 321, 324 n.1 (Fla. 2004) (holding "Terri's Law" to be unconstitutional as the precise wording of the law constituted a violation of the constitutional tenant of separation of powers).

45. *See* An Act for the Relief of the Parents of Theresa Marie Schiavo, Pub. L. No. 109-3, 119 Stat. 15 (2005).

The United States District Court for the Middle District of Florida shall have jurisdiction to hear, determine, and render judgment on a suit or claim by or on behalf of Theresa Marie Schiavo for the alleged violation of any right of Theresa Marie Schiavo under the Constitution or laws of the United States relating to the withholding or withdrawal of food, fluids, or medical treatment necessary to sustain her life.

Id. The Senate and House of Representatives met in emergency sessions on Sunday, March 20, 2005 in order to vote on the Act, later known as the "Palm Sunday Compromise," which was passed shortly after midnight and signed into law on March 21, 2005 at 1:11 a.m. by President George W. Bush, who had "cut short a visit to his ranch in Crawford, Texas . . . [in order to] return[] to the White House . . . to sign the measure." *Bush Signs Schiavo Bill*, FOX NEWS (Mar. 21, 2005), <http://www.foxnews.com/story/2005/03/21/bush-signs-schiavo-bill.html> [<https://perma.cc/RPY2-EDDT>].

46. Petition for Writ of Certiorari, Bush v. Schiavo, No. 04-757, 2004 WL 2790640 (U.S. Dec. 1, 2004).

47. *In re* Guardianship of Schiavo, 916 So. 2d 814, 815–16 (Fla. Dist. Ct. App. 2005).

48. *Id.* at 816 (citing Corbett v. D'Alessandro, 487 So. 2d 368 (Fla. Dist. Ct. App. 1986)).

49. *Id.*

D. *Earle N. Spring*

The Massachusetts courts faced a similar situation in 1980 in *Spring*.⁵⁰ Earle N. Spring was a Massachusetts resident who was found incompetent and “was receiving life-prolonging hemodialysis treatment.”⁵¹ Earle’s wife and son petitioned the Probate Court,⁵² which subsequently found that Earle “would, if competent, choose not to receive the life prolonging treatment.”⁵³ The court ordered an entry of judgment that Earle’s wife and son along with the attending physician were “to make the decision with reference to the continuance or termination of the dialysis treatment.”⁵⁴ This judgment was affirmed by the appeals court and appealed by the guardian ad litem for further appellate review.⁵⁵ In reviewing the facts of the case, the Supreme Judicial Court of Massachusetts found that

without the dialysis treatment the ward would die; with it he might survive for months. Survival for five years would be not probable, but conceivable. The treatment did not cause a remission of the disease or restore him even temporarily to a normal, cognitive, integrated, functioning existence, but simply kept him alive.⁵⁶

The *Spring* court discussed the balance of the state’s interests in the preservation of life against the individual’s constitutional privacy rights and freedom from “unwanted infringements of bodily integrity.”⁵⁷ The court further discussed the balance of timeliness and the desirability of expediting similar cases; that they did not wish to impose a duty upon future guardians ad litem to take appeals which they do not believe to be meritorious; and that court orders may be “useful [for the] purpose of resolving a doubtful or disputed question of law or fact, but . . . [would] not eliminate all risk of liability.”⁵⁸

50. See generally *In re Spring*, 405 N.E.2d 115 (Mass. 1980) (discussing the balancing of the State’s interest in the preservation of life and the right of incompetent persons to be free from invasions of bodily integrity).

51. *Id.* at 117.

52. *Id.* Earle’s son had been appointed his temporary guardian. *Id.*

53. *Id.* at 117, 122.

54. *Id.* at 117.

55. *Id.*

56. *Id.* at 118.

57. See *id.* at 119.

58. *Id.* at 122.

III. PRIVATE INTERESTS SHOULD BE PARAMOUNT

Spring is an excellent illustration of the ultimate issue in many of the previously noted cases. It directly outlines the central issue of the balance between the state's interest in the preservation of life and an individual's constitutional right to be free from unwanted infringements of bodily integrity.⁵⁹ What this Article seeks to highlight is that the individual rights of the citizenry should be paramount in this discussion, and that the interest of the state should be secondary to the individual's legal decisionmaker regarding personal medical decisions.

A. *No Place for the Court*

The courts should not be the primary decisionmaker when it comes to making end-of-life decisions. Courts and those appointed as guardian ad litem are not always properly designated to be the arbiters of family decisions. The choices that guardians make for their family members about withholding life-sustaining treatment are not ones that they make hastily or without contemplation. They are decisions made based upon years of conversations, family experiences, learned and inherited values, and the full understanding of the essence of a person in a way that can only be achieved by those with a deep intimate knowledge of the person. These are not decisions that should be made by a detached and uninvolved judge in the sterile environs of the courtroom. This idea has been encapsulated best by medical ethicist Nancy Dublar:

[T]he courts are not, by and large, the place for medical-care dilemmas to be settled. They are impersonal and far removed from patients' and families' private values. With so many eyes watching they may respond to personal and political interests other than the patients'. They are not geared to deal with the issues of medical care, procedure, and prognosis, the subtleties of how life actually works in a hospital. For all these reasons, courts are not places to entrust your most important health-care decisions if you can possibly avoid it.⁶⁰

There are currently approximately 480 lawyers in Massachusetts that belong to the Massachusetts Chapter of the National Academy of Elder Law Attorneys.⁶¹ These lawyers have special training and work with elderly clients, many of which prefer to sign a Health Care Proxy or Living

59. *See id.* at 119.

60. I. Glenn Cohen, *Negotiating Death: ADR and End of Life Decision-Making*, 9 HARV. NEGOT. L. REV. 253, 283 (2004) (quoting NANCY DUBLAR & DAVID NIMMONS, ETHICS ON CALL 151–53 (1992)).

61. Email from Peter G. Wacht, Executive Director, National Academy of Elder Law Attorneys, to Hyman G. Darling, Author (Mar. 11, 2019, 8:53 AM) (on file with law review).

Will that indicates their wish not to be kept alive unless there is a reasonable likelihood of recovery without a diminished quality of life. The author has asked hundreds of clients over many years their preferences, and both himself and the four other attorneys who practice in the elder law area in his firm have noticed that their clients do not wish to be kept alive by heroic means. We can probably count on one hand the number of clients who have indicated they wish to have some sort of life support, but usually only for some limited time.

Further supporting this point, the National Institute of Nursing Research has found “widespread dissatisfaction with end-of-life care.”⁶² This study found that “most individuals with serious, advanced illnesses preferred to die at home and receive a more conservative pattern of end-of-life care.”⁶³ However, a majority of individuals “died in hospitals and received more aggressive care than was desired.”⁶⁴ The study also showed that advanced planning and Physician Orders for Life-Sustaining Treatments (POLST) forms, similar to the MOLST forms, have reduced the receipt of “unwanted life sustaining treatments when compared to patients with traditional Do-Not-Resuscitate orders,” but did not entirely eliminate such.⁶⁵

The important take away from the National Institute of Nursing Research study is that most individuals would choose a less invasive process when it comes to end-of-life care and decisions regarding life-sustaining treatments.⁶⁶ The question therein is: why is life-sustaining treatment and the state’s interest superseding the personal interests and constitutional rights of individuals?

62. NAT’L INSTS. OF HEALTH, U.S. DEP’T OF HEALTH & HUMAN SERVS., FACT SHEET: END-OF-LIFE 1 (Oct. 2010), [https://report.nih.gov/NIHfactsheets/Pdfs/EndOfLife\(NINR\).pdf](https://report.nih.gov/NIHfactsheets/Pdfs/EndOfLife(NINR).pdf) [<https://perma.cc/FJX9-YPHP>].

63. *Id.*

64. *Id.*

65. *Id.* at 2.

66. *Id.* at 1.

In 1997, a report from the Institute of Medicine found widespread dissatisfaction with end-of-life care. While most individuals with serious, advanced illnesses preferred to die at home and receive a more conservative pattern of end-of-life care; the majority died in hospitals and received more aggressive care than was desired.

Id.; see COMM. ON CARE AT THE END OF LIFE, APPROACHING DEATH: IMPROVING CARE AT THE END OF LIFE (Marilyn J. Field & Christine K. Cassel eds., 1997), <https://www.nap.edu/read/5801/chapter/1> [<https://perma.cc/7GXX-UYLR>].

B. *Better Understanding Priorities and Better Serving the People*

While Massachusetts has made great strides introducing the MOLST form, it has not yet fully understood its citizens' desires and needs. The National Institutes of Health pointed out that most of those interviewed would prefer to die in the comfort of their own homes and avoid unnecessary and invasive life-prolonging treatment.⁶⁷ Why, then, does the accepted standard of care require the involuntary use of life-sustaining treatment in situations when it is clear that there will be no improvement in the individual's quality of life?

This Article proposes a new standard of care for patients with a terminal prognosis and those who suffer traumatic illnesses or injuries rendering them incompetent, who would normally be involuntarily subjected to invasive life-sustaining treatment. Given that the majority of individuals would not wish to be subjected to invasive treatments when their quality of life has no chance of improving, the standard of care should be to forego life-sustaining treatment and to put the constitutional privacy rights of individuals first.

As Massachusetts already has the MOLST form, a specifically authorized document that dictates end-of-life decision-making, it follows that such a form could shift its function. With appropriate legislation, the default standard of care could be changed to require removing involuntary life-sustaining treatment, in reference to specifically tailored criteria, and the MOLST form could be redrafted and become the required form for those who *wish* to receive life-sustaining treatment. This would better encapsulate the wishes of the majority of citizens and shift the burden of electing for life-sustaining treatment, or notifying healthcare providers of their intent to be placed on such treatment, to the minority of individuals who wish to receive these treatment measures. This Article does not suggest that these measures be ceased instantly and require the cessation of life-sustaining treatment in all situations, but it does propose that the impetus for challenging the removal of such should be placed upon the state. Further, such challenges should be the exception and should only be used in those extraordinary circumstances where clear and convincing evidence indicates what the intentions of the incapacitated person were as opposed to the health care proxy's actions.

C. *Other Options Still Do Not Go Far Enough*

Bioethicist John D. Arras, presented another option: "Instead of imposing a strict presumption of treatment requiring families to prove that

67. NAT'L INSTS. OF HEALTH, *supra* note 62, at 1.

they have a uniquely correct answer to the problem, we should rather presume that families and friends know best and that others should be required to prove them wrong.”⁶⁸ As noted in Cohen’s article, however, this approach is still an “adjudicatory model” that places the decision back into the arena of judicial control.⁶⁹ Shifting this presumption creates a more ideal scenario for families who are in touch with the wishes of the individual and protects the individual from the personal views of an appointed guardian ad litem, which may conflict with the intentions of the petitioner. However, the Arras model still does not go far enough in protecting the privacy interests of incompetent individuals.

A document should be afforded the integrity it deserves to make an individual’s medical decisions and either opt for or opt out of medical treatment at the time of an end-of-life decision. When a person is incapacitated to the extent that they cannot make decisions for themselves, and that person has not expressed a preference about end-of-life treatment, problems arise. Usually the ethics committee reviews the status of the patient. It is important to recognize that the four cases noted in this Article are the primary cases that have achieved national attention, with one gaining attention in the Commonwealth of Massachusetts. However, on a daily basis, decisions are made in hospitals, nursing homes, and hospice situations at home, about whether people are permitted to carry out their wishes and not adhere to the requirement of being kept alive by artificial nutrition, heroics, machines, or other extraordinary means.

D. *The Dangers of Parens Patriae*

States continue to grapple with the concepts of best interest and privacy rights and their balance in the equation of what is considered protecting health and welfare. Prior to 1999, existing New York case law and statutory law provided that “the state’s interest, as *parens patriae*, in protecting health and welfare” required a holding that a “guardian could not seek to discontinue treatment on behalf of a ward who was never competent.”⁷⁰

In 1999, Sheila Pouliot, “a severely mentally retarded woman,” became terminally ill “and suffered greatly, and needlessly, because the

68. Cohen, *supra* note 60, at 268 (quoting John D. Arras & James Rachels, *Beyond Cruzan: Individual Rights, Family Autonomy and the Persistent Vegetative State*, in CONTEMPORARY ISSUES IN BIOETHICS 404, 408 (Tom L. Beauchamp & LeRoy Walters eds., 1994)).

69. *Id.*

70. *In re Guardianship of Chantel Nicole R.*, 34 A.D.3d 99, 103 (N.Y. App. Div. 2006) (emphasis added).

[state's interest as *parens patriae*] required that she receive care, even though doctors concluded that it was futile."⁷¹ Sheila "lived on for several weeks, allegedly in pain" the entire time⁷² "over the [protests] of her sister and the ethics board of the treating hospital."⁷³ Sheila's case was widely publicized, and shortly thereafter New York passed the Health Care Decisions Act for Persons with Mental Retardation⁷⁴ to afford guardians some "latitude in determining whether medical care should be administered to a ward who was never competent to make decisions regarding medical treatment."⁷⁵

However, New York law still prohibited close family members, even spouses, from making health care decisions on behalf of incapacitated persons unless that person had prepared clear and convincing instructions outlining their wishes. Individuals without the foresight or knowledge of the need to have an advanced directive in place continued to be kept alive through the use of medical apparatuses such as life support—extraordinary means that states justified under the concept of *parens patriae*. It was not until some ten years later that the New York legislature passed the Family Health Care Decisions Act,⁷⁶ which provided that health care decisions for adult patients could be made by surrogates in the absence of a health care proxy or advanced directive.⁷⁷ While substantive changes in the law have afforded families, friends, and health care providers more guidance when it comes to end-of-life decision-making, cases such as that of Sheila Pouliot stand as an excellent reminder of the negative consequences of the *parens patriae* approach to end-of-life decision-making.

71. *Id.* at 104.

72. *Id.* Dr. Kathy Faber-Langendoen, Director of the Center for Bioethics and Humanities at SUNY Upstate Medical University, testified in Albany that "[Shelia] died a very painful, gruesome death. It was inhumane. She suffered greatly because of the law." *End-of-Life Decisions: New Law Will Make It Easier for Families and Doctors*, SYRACUSE.COM (Mar. 9, 2010, 5:02 AM), http://blog.syracuse.com/opinion/2010/03/end-of-life_decisions_new_law.html [<https://perma.cc/6762-L3JG>] (discussing Sheila Pouliot's death).

73. *In re Guardianship of Chantel*, 34 A.D.3d at 104.

74. Health Care Decisions Act for Persons with Mental Retardation, 2002 N.Y. Sess. Laws ch. 500 (McKinney) (codified as amended at N.Y. SURR. CT. PROC. ACT LAW §§ 1750 to 1750-b (McKinney 2019)).

75. *In re Guardianship of Chantel*, 34 A.D.3d at 104.

76. *See generally* N.Y. PUB. HEALTH LAW §§ 2994-a to 2994-u (McKinney 2018) (enacted on June 1, 2010).

77. *Id.*

CONCLUSION

Justice Cardozo stated that “[e]very human being of adult years and sound mind has a right to determine what shall be done with his own body.”⁷⁸ This language would precipitate the shaping of what would come to be a protected liberty interest in bodily integrity. The culmination of this was further evidenced by the Supreme Court through its statement that “[i]t is settled now . . . that the Constitution places limits on a State’s right to interfere with a person’s most basic decisions about . . . bodily integrity.”⁷⁹

The Supreme Court has determined that a “Constitutional recognition of the right to bodily integrity underlies the assumed right, good against the state, to require physicians to terminate artificial life support.”⁸⁰ But if this is so, why do states still require protracted legal battles when dealing with end-of-life decision-making and the termination of life-sustaining measures? Citizens possess an inherent legal “right to refuse lifesaving hydration and nutrition”⁸¹ and this inherent right should continue to be preserved beyond the incompetency of an individual. This is exactly the type of situation that could benefit from a modernized and re-purposed MOLST form, which would be used when an individual wishes to elect life-sustaining treatment, as opposed to the alternative preferred by a majority of individuals.

The time has come for a change to the existing law and procedure relative to the presumption of wanting to be kept alive by extraordinary means. Those who have a desire to maintain their lives by any means possible should have to exhibit a preference by signing a form so stating their preference, and all others will be presumed to not wish extraordinary means be utilized to preserve life. Until that time, every person should have a validated health care proxy, power of attorney, and properly drafted will outlining their wishes.

78. *Schloendorff v. Soc’y of N.Y. Hosp.*, 105 N.E. 92, 93 (N.Y. 1914) (discussing patients’ rights to direct their medical care).

79. *Washington v. Glucksberg*, 521 U.S. 702, 777 (1997) (alteration and omissions in original) (quoting *Planned Parenthood of Se. Penn. v. Casey*, 505 U.S. 833, 849 (1992)).

80. *Id.* at 778.

81. *Id.* at 703 (citing *Cruzan ex rel. Cruzan v. Mo. Dep’t of Health*, 497 U.S. 261, 279 (1990)).