

---

July 2015

## Advance Directive Accessibility: Unlocking the Toolbox Containing Our End-of-Life Decisions

Vanessa Cavallaro

Follow this and additional works at: <https://digitalcommons.tourolaw.edu/lawreview>



Part of the [Estates and Trusts Commons](#), and the [Health Law and Policy Commons](#)

---

### Recommended Citation

Cavallaro, Vanessa (2015) "Advance Directive Accessibility: Unlocking the Toolbox Containing Our End-of-Life Decisions," *Touro Law Review*. Vol. 31: No. 3, Article 16.

Available at: <https://digitalcommons.tourolaw.edu/lawreview/vol31/iss3/16>

This Comment is brought to you for free and open access by Digital Commons @ Touro Law Center. It has been accepted for inclusion in Touro Law Review by an authorized editor of Digital Commons @ Touro Law Center. For more information, please contact [lross@tourolaw.edu](mailto:lross@tourolaw.edu).

## ADVANCE DIRECTIVE ACCESSIBILITY: UNLOCKING THE TOOLBOX CONTAINING OUR END-OF-LIFE DECISIONS

*Vanessa Cavallaro\**

### I. INTRODUCTION

Johnny Hypothetical did everything right; his attorney drafted and executed a Last Will and Testament, as well as a Living Will and Health Care Proxy, all reflecting his specific wishes should he not be able to make medical decisions for himself. Johnny slept peacefully at night knowing that his attorney had a copy of these documents and he had a copy in his home-office. Imagine Johnny is involved in a horrific car accident and transported to the hospital unconscious. In the emergency room, the medical personnel, who are legally required to provide life-sustaining medical treatment,<sup>1</sup> put Johnny on a breath-

---

\* J.D. Candidate 2016, Touro College Jacob D. Fuchsberg Law Center; B.A. in History, Stony Brook University. Special thanks to Professor Rena Sepowitz and Alyssa Wanser for their support and guidance for this Comment, and to the many professionals who offered opinions and insight.

<sup>1</sup> Under the Emergency Medical Treatment and Active Labor Act (42 U.S.C. § 1395dd(b)(1) (West 2011)), if an individual comes to a hospital and the hospital determines that the individual has an emergency medical condition, the hospital must provide further medical examination and such treatment as may be required to stabilize the medical condition. According to 42 U.S.C. § 1395dd(e)(1)(A), an “emergency medical condition” means:

[A] medical condition manifesting itself by acute symptoms of sufficient severity (including severe pain) such that the absence of immediate medical attention could reasonably be expected to result in--(i) placing the health of the individual . . . in serious jeopardy, (ii) serious impairment to bodily functions, or (iii) serious dysfunction of any bodily organ or part.

*Id.* According to 42 U.S.C. § 1395dd(e)(3)(A), “to stabilize” means:

[W]ith respect to an emergency medical condition described in paragraph (1)(A), to provide such medical treatment of the condition as may be necessary to assure, within reasonable medical probability, that no material deterioration of the condition is likely to result from or occur during the transfer of the individual from a facility . . . .

*Id.*

ing ventilator. Johnny later regains consciousness to learn that he was given medical treatment that he did not desire, as stated in his advance directives.<sup>2</sup> Johnny thought that his advance directives protected him from this sort of occurrence. Was that not the purpose of paying his lawyer to execute documents, which expressed his pre-made health care decisions?

Johnny now suffers from brain damage, a consequence of temporary lack of blood flow to the brain, which renders him incapable of everyday activities such as walking, speaking coherently, toileting himself, and eating without assistance. Johnny can no longer work and must rely on his family and in-home health aide to help him with simple tasks such as dressing, grooming himself, and taking his medications. Johnny's health insurance company will be compelled to pay for the unwanted treatment and the life-long care he now requires.

The National Cancer Institute, an agency of the federal Department of Health and Human Services (HHS), defines advance directives as legal documents, namely Living Wills, Medical Powers of Attorney, and Health Care Proxies, that "allow people to communicate their decisions about medical care to family, friends, and health care professionals in the event that they are unable to make those decisions themselves."<sup>3</sup> These documents are revocable and each state has specific laws regarding advance directives, including execution and recognition of out-of-state documents.<sup>4</sup>

According to the Centers for Disease Control and Prevention, most people prefer to die at home, but only one-third of adults have an executed advance directive stating their wishes for end-of-life treatment.<sup>5</sup> Among those sixty years and older, about half have an executed advance directive, but only 24-35% of physicians whose patients have an advance directive are aware of its existence.<sup>6</sup> Fewer than 50% of severely or terminally ill patients have advance direc-

---

<sup>2</sup> *Advance Directives*, NAT'L CANCER INST., <http://www.cancer.gov/cancertopics/managing-care/advance-directives> (last visited Apr. 13, 2015).

<sup>3</sup> *Id.*

<sup>4</sup> *Id.*

<sup>5</sup> Nancy Aldrich & William F. Benson, *Advance Care Planning: Ensuring Your Wishes Are Known and Honored If You Are Unable to Speak for Yourself*, CTRS. FOR DISEASE CONTROL & PREVENTION 1 (2012), <http://www.cdc.gov/aging/pdf/advanced-care-planning-critical-issue-brief.pdf> (last visited Apr. 13, 2015).

<sup>6</sup> *Id.*

tives in their medical records, compared to about 88% of patients in hospice care who have an advance directive on file with the hospice facility.<sup>7</sup>

Living Wills are a declaration that denote the type of medical care, specifically life-sustaining care, individuals do or do not want to receive if they are unable to make decisions for themselves.<sup>8</sup> A Living Will does not designate an agent to act on the individual's behalf, but rather accompanies the designation of an agent to make known the individual's wishes.<sup>9</sup> Life-sustaining treatment, such as dialysis, ventilation, artificial or withholding of hydration and nutrition, organ and tissue donation, "do not resuscitate" (DNR), and "do not intubate" (DNI) orders are typical types of care addressed in Living Wills.<sup>10</sup> Individuals may also indicate whether they want to spend their final days at home or in a hospital, and the degree of pain management they want to receive.<sup>11</sup> Living Wills are not currently enforceable as a matter of law in Massachusetts, Michigan, and New York, but can provide clear and convincing evidence of an individual's wishes should they be called into question.<sup>12</sup> Living Wills conform with deeply held religious and personal beliefs.

A Health Care Proxy<sup>13</sup> is a document which appoints a person to make medical decisions for an individual who is unable to make those decisions.<sup>14</sup> This document is only in effect when a physician declares that a patient is unable to make medical decisions, but is not limited to end-of-life decisions.<sup>15</sup> The person designated as the health care agent<sup>16</sup> is often a family member or trusted friend because this role of fiduciary carries the heavy burden of stepping into the pa-

<sup>7</sup> *Id.*

<sup>8</sup> *Advance Directives*, *supra* note 2.

<sup>9</sup> Aldrich, *supra* note 5, at 11.

<sup>10</sup> *Advance Directives*, *supra* note 2.

<sup>11</sup> Pam Belluck, *Coverage for End-Of-Life Talks Gaining Ground*, N.Y. TIMES (Aug. 30, 2014), [http://www.nytimes.com/2014/08/31/health/end-of-life-talks-may-finally-overcome-politics.html&assetType=nyt\\_now&\\_r=0](http://www.nytimes.com/2014/08/31/health/end-of-life-talks-may-finally-overcome-politics.html&assetType=nyt_now&_r=0).

<sup>12</sup> N.Y. ELDER LAW PRACTICE § 7:28 (McKinney 2014).

<sup>13</sup> Also known as Medical Power of Attorney, Appointment of Health Care Agent, or Durable Power of Attorney for Health Care. See *Advance Directives*, *supra* note 2.

<sup>14</sup> *Advance Directives*, *supra* note 2. A Health Care Proxy is "a document delegating the authority to make health care decisions." N.Y. PUB. HEALTH LAW § 2980(8) (McKinney 2010).

<sup>15</sup> *Advance Directives*, *supra* note 2.

<sup>16</sup> The designated person is also known as an attorney-in-fact or surrogate. See *Id.*

tient's shoes to make medical decisions on his or her behalf.<sup>17</sup> Health Care Proxies, as compared to Living Wills, take the pressure from the patient and assign the difficult decision-making process to the agent.

Advance directives give individuals the tools to make decisions regarding their health care treatment in advance to allow patients to remain in control of their medical treatment even when they are temporarily or permanently incapacitated.<sup>18</sup> Advance directives embody the theory that "no one knows me better than I do," and recognize the need to be yourself, even when incapacitated. The right to self-determination is firmly rooted in American values as "[e]very human being of adult years and sound mind has a right to determine what shall be done with his own body; and a surgeon who performs an operation without his patient's consent commits an assault, for which he is liable in damages."<sup>19</sup> The Supreme Court gives weight to authentic expressions of patient wishes because there is a constitutional basis in the Due Process Clause for the right to refuse life-sustaining treatment.<sup>20</sup> The self-autonomy promoted by advance directives is established in legislative policy such as the Patient Self-Determination Act, which encourages patients to draft advance directives while they are still competent.<sup>21</sup>

Choices about end-of-life care can be stressful for patients and family members, especially if there are conflicting desires.<sup>22</sup> To ensure that wishes are honored, patients should have discussions with their family, friends, and physicians about their intentions and execute advance directives, ideally, when healthy.<sup>23</sup> While thinking about death and having these conversations are difficult, it is important to make wishes known to avoid problems in the future.<sup>24</sup> Ear-

---

<sup>17</sup> *Id.*

<sup>18</sup> *Id.*

<sup>19</sup> *Schloendorff v. Soc'y of N.Y. Hosp.*, 105 N.E. 92, 93 (N.Y. 1914).

<sup>20</sup> *Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261, 281 (1990).

<sup>21</sup> Angela Fagerlin & Carl E. Schneider, *Enough: The Failure of the Living Will*, HASTINGS CTR. REPORT, Mar.–Apr. 2004, at 30, 31; 42 U.S.C. § 1395cc(f)(1) (providing that all health care facilities that receive Medicare or Medicaid funds must document whether a patient has an advance directive in his or her medical record, provide education to the staff and community about advance directives, maintain written policies and procedures to implement a patient's right to accept or refuse life-sustaining treatment and execute advance directives, and provide written information about such policies to patients).

<sup>22</sup> *Advance Directives*, *supra* note 2.

<sup>23</sup> *Id.*

<sup>24</sup> *Id.*

ly and frequent communication helps to ensure that patients can receive treatment in accordance with their personal beliefs, whether religious or otherwise.<sup>25</sup>

Obtaining and executing an advance directive may be done simply and free of charge. Advance directive forms are widely available on the Internet through state or private websites and do not require an attorney.<sup>26</sup> Some states require that some advance directives be witnessed, notarized, or both,<sup>27</sup> although New York requires only the signature of two witnesses on the Health Care Proxy form.<sup>28</sup> After executing the document, an individual should ask a health care professional or lawyer to review the document to confirm its proper execution.<sup>29</sup>

Once creation and execution are complete, storing advance directives can prove difficult. While we want our personal and sensitive documents to be free from prying eyes, these documents must be accessible to be useful. Without access to advance directives, they are mere useful tools in a locked toolbox. Copies should be made of each document and given to the health care agent, each doctor and hospital the patient frequents, important family members, and the individual's attorney.<sup>30</sup> A copy should be kept in a safe and easily accessible location, and a wallet-card should be carried at all times with a statement announcing the existence of an advance directive and its location.<sup>31</sup> There are private and also state registries, an optimal solution to the problem of accessibility, where advance directives can be electronically stored and accessed on the patient's behalf in a timely

---

<sup>25</sup> *Id.*

<sup>26</sup> The New York State Bar Association makes living will and health care proxy forms available to all New Yorkers free of charge. See *Living Wills and Health Care Proxy Forms*, N.Y. STATE BAR ASS'N, <http://www.nysba.org/CustomTemplates/SecondaryStandard.aspx?id=26501> (last visited Apr. 13, 2015).

<sup>27</sup> *E.g.*, N.C. GEN. STAT. ANN. § 32A-16(3) (West 2007) (requiring that an instrument appointing a health care power of attorney be notarized). However, health care power of attorney instruments executed in other jurisdictions will be valid in North Carolina if they were executed in accordance with that jurisdiction's requirements or North Carolina's requirements. *Id.* § 32A-27.

<sup>28</sup> *Health Care Proxy: Appointing Your Health Care Agent in New York State*, N.Y. STATE DEP'T OF HEALTH, <https://www.health.ny.gov/forms/doh-1430.pdf> (last visited Apr. 13, 2015).

<sup>29</sup> *Advance Directives*, *supra* note 2.

<sup>30</sup> *Id.*

<sup>31</sup> *Id.*; *Who Will Speak for You?*, N.Y. STATE DEP'T OF HEALTH, [http://www.health.ny.gov/professionals/patients/health\\_care\\_proxy/index.htm](http://www.health.ny.gov/professionals/patients/health_care_proxy/index.htm) (last visited Apr. 13, 2015).

fashion.<sup>32</sup>

This Comment will focus on advance directives as tools for advance health care planning and the locked toolbox that prevents these tools from maximizing their potential for usage and efficiency. Part II of this Comment will identify specific problems that arise in the current state of advance directives. Part III will explore the current systems of advance directives, with an emphasis on New York law and policy. Part IV will propose solutions, particularly federal reform and the establishment of advance directive registries, to the identified problems. Part V will pinpoint potential problems with the proposed solutions. With such a sensitive topic deeply rooted in human life and emotions, there is no ultimate solution, but the process of accessing advance directives can be improved. Small steps must be taken to alleviate some of the stress of end-of-life decision-making.

## II. A LOCKED TOOL BOX

Without advance directives, extreme personal and familial conflicts may arise, particularly in end-of-life situations when differences of opinion and wishes for a person's sick or injured loved one arise. The death of Terri Schiavo, the focal point of a decade-long litigation and national news stories, made the topic of end-of-life decisions and treatment very real to the American population.<sup>33</sup> After Schiavo collapsed in 1990 and fell into a "persistent vegetative state" due to loss of oxygen to the brain, Schiavo's husband, Michael, sought to detach the feeding tube providing nourishment as he believed Schiavo would not have wanted to be kept alive in that manner.<sup>34</sup> Robert and Mary Schindler, Schiavo's parents, fought Michael to keep the tube in place, as they were sure their daughter would have wanted such care.<sup>35</sup> Florida courts supported Michael, but the State Legislature became involved in 2003 by giving Governor Jeb Bush the authority to prevent removal of the feeding tube with the passing

---

<sup>32</sup> *Advance Directives*, *supra* note 2.

<sup>33</sup> Clyde Haberman, *From Private Ordeal to National Fight: The Case of Terri Schiavo*, N.Y. TIMES (Apr. 20, 2014), available at <http://www.nytimes.com/2014/04/21/us/from-private-ordeal-to-national-fight-the-case-of-terri-schiavo.html>.

<sup>34</sup> *Id.*

<sup>35</sup> *Id.*

of “Terri’s Law,”<sup>36</sup> which was later deemed unconstitutional by the Florida Supreme Court.<sup>37</sup> As if this attention was not enough for a torn family, President George W. Bush and Congress became involved in 2005 by enacting and signing legislation to transfer the case’s jurisdiction from the state to the federal court system. Ultimately, Florida’s court orders prevailed and Schiavo’s feeding tube was removed after fifteen years.<sup>38</sup> Had Schiavo expressed her wishes in written advance directives, perhaps her family could have been spared the unnecessary turmoil and litigation.

The Emergency Medical Treatment and Active Labor Act (“EMTALA”),<sup>39</sup> which requires a hospital to provide medical treatment to stabilize an emergency medical condition, authorizes health care providers to act even if the patient’s intent is not ascertainable.<sup>40</sup> The EMTALA incorporates the presumption that a patient would choose life over death and would thus favor procedures that sustain, prolong, and enhance life.<sup>41</sup> However, the decision to provide medical treatment for an incapacitated person is subject to a balancing of the State’s interest, as *parens patriae*,<sup>42</sup> in preserving the life of citizens, against the individual’s right of privacy in not being subjected to medical procedures without giving informed consent.<sup>43</sup> The EMTALA negates this need for informed consent in an emergency situation based on the understandably default presumption that most would choose life over death. However, if life-sustaining treatment is given during what began as a nonemergency situation when there was ample time for discussion regarding the potential for use of such treatment (for example, when a patient is admitted to a hospital for

---

<sup>36</sup> Act for the Relief of the Parents of Theresa Marie Schiavo (“Terri’s Law”), Pub. L. No. 109-3, 119 Stat. 15 (2005) (providing the United States District Court for the Middle District of Florida jurisdiction to review *de novo* whether “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” regardless of whether a State court previously made a determination); Haberman, *supra* note 33.

<sup>37</sup> Haberman, *supra* note 33.

<sup>38</sup> *Id.*

<sup>39</sup> *See supra* note 1 and accompanying text.

<sup>40</sup> *Id.*

<sup>41</sup> *See* 65A N.Y. JUR. 2D *Hospitals* § 45 (2015).

<sup>42</sup> “*Parens patriae*” is Latin for “parent of his or her country” and refers to “[t]he power of the state to act as guardian for those who are unable to care for themselves, such as children or disabled individuals.” *Parens Patriae*, LEGAL INFO. INST., [https://www.law.cornell.edu/wex/parens\\_patriae](https://www.law.cornell.edu/wex/parens_patriae) (last visited Apr. 13, 2015).

<sup>43</sup> *In re Beth Israel Med. Ctr.*, 510 N.Y.S.2d 511, 513 (Sup. Ct. 1987).



voluntary surgery), a patient could theoretically state a tort claim of prolongation of life,<sup>44</sup> civil battery,<sup>45</sup> or negligence against the treating physician and facility.<sup>46</sup>

Moreover, failure to follow expressed desire for treatment can end in severe consequences for health care providers. In 2014, New York Attorney General Eric T. Schneiderman announced that a registered and supervising nurse at a Kingston, New York nursing home was arrested following the death of a patient for failing to administer cardio-pulmonary resuscitation (“CPR”).<sup>47</sup> The patient and her family requested that life-saving measures be taken should the need arise.<sup>48</sup> It is unknown whether the patient had written advance directives or whether the nurse was unaware of oral communication, but this serves as a strong example of the importance of written documentation of medical wishes and the duty to abide by an individual’s wishes. If there was written documentation of the resident’s wishes, perhaps the nurse would have been aware of the desire for CPR, and at the very least, there would be concrete evidence on which the family could state a claim. Similarly, in St. Petersburg, Florida, Jarcaranda Manor nursing home was fined \$16,000 by the Florida Agency for Health Care Administration after workers gave CPR and used a defibrillator on a seventy-five year old man, despite the presence of a DNR in his file.<sup>49</sup> Each health care worker attending to a patient should be familiar with the patient’s medical file, especially the details of advance directives.

---

<sup>44</sup> The causation element of “wrongful living” is satisfied when “it is established that but for the conduct of the medical professional, death would have resulted . . . .” *Anderson v. St. Francis-St. George Hosp.*, 671 N.E.2d 225, 227 (Ohio 1996).

<sup>45</sup> A tortious battery is “[a] nonconsensual, intentional, and offensive touching of another without lawful justification, but not necessarily with the intent to do harm or offense as required in a criminal battery.” BLACK’S LAW DICTIONARY 16c (10th ed. 2014).

<sup>46</sup> *Anderson*, 671 N.E.2d at 227-29. “Either negligently or intentionally disregard[ing]” a patient’s express wishes gives rise to a wrongful living, but more specifically a prolongation of life cause of action. *Id.* at 227. Interference with an individual’s right to die breaches the duty to honor the patient’s wishes; however, there must be causation based on the *sine qua non* test of the medical professional’s conduct and the patient’s suffering. *Id.* Thus, only battery damages are recoverable. *Id.* at 229.

<sup>47</sup> *Kingston Nurse Charged with Failure to Give Life-Saving Care to Nursing Home Resident*, N.Y. STATE OFFICE OF THE ATT’Y GEN. (June 5, 2014), <http://www.ag.ny.gov/press-release/kingston-nurse-charged-failure-give-life-saving-care-nursing-home-resident>.

<sup>48</sup> *Id.*

<sup>49</sup> *State Fines St. Petersburg Nursing Home for Violating Resident’s Do-Not-Resuscitate Order*, TAMPA BAY TIMES (June 4, 2014, 4:25 PM), <http://www.tampabay.com/news/state-fines-st-petersburg-nursing-home-for-violating-residents/2182898>.

Advance directives may also outline desired medical treatment, or lack thereof, based on religious beliefs.<sup>50</sup> Imagine Johnny Hypothetical is a Jehovah's Witness and his advance directive explicitly identifies his religion, along with the direction that he refuses any blood transfusion, even if it would save his life. Legally required emergency medical treatment through the EMTALA could be violating religious beliefs of patients like Johnny whose advance directives reflect their deeply rooted religious beliefs.<sup>51</sup> The Free Exercise Clause in the First Amendment to the United States Constitution provides that "Congress shall make no law . . . prohibiting the free exercise" of religion.<sup>52</sup> While this freedom is only absolute for individual belief and not individual conduct,<sup>53</sup> the EMTALA may be interfering with the free exercise of religion by essentially forcing medical treatment on those who would have elected against it for religious reasons. The Court of Appeals of New York proclaimed that "self-determination, standing alone, may be restricted if it is outweighed in any degree by cognizable State interests," but when the State requires a patient to undergo treatment in violation of his or her religious beliefs, it interferes with the individual's constitutional rights.<sup>54</sup> In order to require a medical treatment, the State must demonstrate that it pursues an "unusually important or compelling goal and that permitting [the individual] to avoid the treatment will hinder the fulfillment

---

<sup>50</sup> For example, Jehovah's Witnesses do not accept blood transfusions under any circumstances. See *What Does the Bible Say About Blood Transfusions?*, JEHOVAH'S WITNESSES, <http://www.jw.org/en/bible-teachings/questions/bible-about-blood-transfusion/> (last visited Apr. 13, 2015); *Why Don't Jehovah's Witnesses Accept Blood Transfusions?*, JEHOVAH'S WITNESSES, <http://www.jw.org/en/jehovahs-witnesses/faq/jehovahs-witnesses-why-no-blood-transfusions/> (last visited Apr. 13, 2015).

<sup>51</sup> For example, Jehovah's Witnesses refuse blood transfusions. *Id.*

<sup>52</sup> U.S. CONST. amend. I.

<sup>53</sup> 16A AM. JUR. 2D *Constitutional Law* § 443 (2015).

<sup>54</sup> *Fosmire v. Nicoleau*, 551 N.E.2d 77, 86 (N.Y. 1990) (Simons, J., concurring) (holding that the lower court should not have authorized the administration of blood by a hospital to a Jehovah's Witness who submitted hospital admission forms stating she did not want blood, pooled plasma, or other derivatives administered). After the patient and her husband refused to consent to a blood transfusion following a substantial loss of blood from a hemorrhage post-birth, the hospital was granted court order for blood transfusions necessary to preserve her life. *Id.* at 79. However, a New Jersey court found that the trial court did not err in appointing a temporary guardian to authorize a blood transfusion for a Jehovah's Witness who had given written instructions prior to operation that she refused blood transfusion and released the hospital of any liability when there was a lack of clear and convincing evidence that the patient understood the gravity of that decision. See *In re Hughes*, 611 A.2d 1148, 1149-53 (N.J. Super. Ct. App. Div. 1992).

of that goal.”<sup>55</sup>

Now imagine that Johnny Hypothetical is on vacation visiting states other than the state in which he executed his advance directives. Upon admission to the emergency room, a nurse finds copies of Johnny Hypothetical’s advance directives in his pocket, seemingly negating the problem of accessibility already posed. However, imagine that Johnny is in a state that does not recognize out-of-state advance directives. Johnny’s planning is now moot and he will be subject to the physician’s decisions or statutory provisions if next of kin are not available. While New York will honor an advance directive executed in another state in accordance with that state’s laws,<sup>56</sup> some states will not recognize out-of-state documents or do not expressly address the issue.<sup>57</sup> This lack of absolute recognition across state lines presents a significant problem for travelers and an unnecessary interference with the goals of advance directives.

Physicians are ultimately the gatekeepers of whether advance directives are followed. They have an ethical obligation to follow DNRs<sup>58</sup> and not “permit their personal value judgments to obstruct implementation of the refusals.”<sup>59</sup> Holding advance directives in high esteem should be a staple in medical ethics, not only to avoid liability for battery and negligence, but because the underlying purposes of advance directives, choice and consent, are fundamental to human life, health, and the medical profession. However, with the

---

<sup>55</sup> *Fosmire*, 551 N.E.2d at 86.

<sup>56</sup> N.Y. PUB. HEALTH LAW § 2990 (McKinney 1990).

<sup>57</sup> See *What are Advance Directives?*, CARING CONNECTIONS, <http://www.caringinfo.org/i4a/pages/index.cfm?pageid=3285> (last visited Apr. 13, 2015).

<sup>58</sup> N.Y. PUB. HEALTH LAW § 2984(2) (McKinney 2010); N.Y. PUB. HEALTH LAW § 2994-ee (McKinney 2010), stating that “[e]mergency medical services personnel, home care services agency personnel, hospice personnel, or hospital emergency services personnel who are provided with a nonhospital order not to resuscitate” must honor the DNR unless:

(a) They believe in good faith that consent to the order has been revoked, or that the order has been cancelled; or

(b) Family members or others on the scene, excluding such personnel, object to the order and physical confrontation appears likely; and

2. Hospital emergency services physicians may direct that the order be disregarded if other significant and exceptional medical circumstances warrant disregarding the order.

*Id.*

<sup>59</sup> See *Opinion 2.22 - Do-Not-Resuscitate Orders*, AM. MED. ASS’N <http://www.ama-assn.org/ama/pub/physician-resources/medical-ethics/code-medical-ethics/opinion222.page?> (last visited Apr. 13, 2015).

default rule of medicine being to treat and ward off death, physicians are backed into an ethical dilemma of honoring their patients' wishes or following the basic premise of their training. Physicians may be reluctant to trust advance directives, especially if a significant amount of time has passed since their execution.<sup>60</sup> Physicians may not want to become embroiled in family feuding when a relative seeks to override the advance directives.<sup>61</sup> The American Medical Association (AMA) supports the provisions of the Patient Protection and Affordable Care Act,<sup>62</sup> which would pay physicians to discuss end-of-life issues with patients as "[t]he AMA is a business which profits from its monopoly over the billing codes that physicians use when they submit claims to Medicare. The more billing codes there are, the better it is for the AMA."<sup>63</sup> The new billing code created by the AMA, if adopted, would allow physicians to bill Medicare for advance care planning visits.<sup>64</sup> Currently, some physicians will participate in end-of-life planning conversations pro bono or include them in other patient visits, but physicians must regularly conduct these conversations in order to keep the documents relevant.<sup>65</sup>

---

<sup>60</sup> John R. Graham, *The Return of Death Panels? Government-Funded End-Of-Life Planning Is Morally Questionable*, FORBES, (Sept. 24, 2014, 4:07 PM), <http://www.forbes.com/sites/theapothecary/2014/09/24/the-return-of-death-panels-government-funded-end-of-life-planning-is-morally-questionable/>. In New York, a health care provider "shall comply with health care decisions made by an agent in good faith" as if the decision was made by the patient, subject to limitations contained in the Health Care Proxy. N.Y. PUB. HEALTH LAW § 2984(2) (McKinney 2010). Both the health care agent and the health care provider are immune from criminal and civil liability as long as he or she acts in good faith in acting upon the Health Care Proxy. N.Y. PUB. HEALTH LAW § 2986 (McKinney 2014).

<sup>61</sup> Graham, *supra* note 60.

<sup>62</sup> The "death panel" label coined by Sarah Palin originally killed advance care planning in the Patient Protection and Affordable Care Act. However, Medicare added the provision to a 2010 regulation that would allow the program to cover "voluntary advance care planning" during annual wellness visits. Unfortunately, the provision was scrapped due to the urging of the Obama administration in order to avoid more political unrest. Belluck, *supra* note 11.

<sup>63</sup> Graham, *supra* note 60.

<sup>64</sup> Belluck, *supra* note 11; Graham, *supra* note 60.

<sup>65</sup> See Belluck, *supra* note 11.

If Medicare covers end-of-life counseling, that could profoundly affect the American way of dying, experts said. But the impact would depend on how much doctors were paid, the allowed frequency of conversations, whether psychologists or other nonphysicians could conduct them, and whether the conversations must be in person or could include phone calls with long-distance family members. Paying for only one session and completion of advance directives would have limited value, experts said.

Advance directives allow us to have a say over our lives, even when we are not able to physically or mentally make those decisions. Despite the benefits of advance directives, some individuals still choose not to execute end-of-life instruments.<sup>66</sup> The conscious decision to not use advance directives may be due to the potential of costly attorney's fees, the confusion about the difference between palliative care<sup>67</sup> and prolongation of life treatment, or society's "denial of death" that keep individuals from planning their end-of-life care.<sup>68</sup> The perceived "omen" of planning for death is a denial that we will be unable to make our own decisions; however, death is an inevitable result of living so it is naïve to avoid consideration of how we want to spend the last days, weeks, or months of our lives. Patients should and can have a choice in their end-of-life experience; however, to do this, patients must have discussions with their physicians, family members, and lawyers to have their wishes honored. These conversations should be conducted periodically as wishes change over time. Aggressive end-of-life treatments may not extend patients' lives or help them feel better so it is necessary to know the desired type and level of care and to formalize those wishes in writing as memories fade and family members have conflicting desires for their loved ones.

The fear of death must be overcome in order to help our family members carry out our final wishes. Thus, the absence of advance directives is much worse than having the emotional conversation with loved ones. Patients rely on their doctors for information, but conversations about end-of-life decisions may be short, biased, or vague.<sup>69</sup> Doctors may be reluctant to spend significant time with pa-

---

*Id.*

<sup>66</sup> Aldrich, *supra* note 5, at 2-3.

<sup>67</sup> According to the Center to Advance Palliative Care, palliative care (also known as palliative medicine) provides "relief from the symptoms and stress of a serious illness" from healthcare workers "[s]pecially trained to deal with complex pain and symptoms." *About Palliative Care*, CTR. TO ADVANCE PALLIATIVE CARE, <https://www.capc.org/about/palliative-care/> (last visited Apr. 13, 2015). Palliative care addresses a wide range of issues including "pain, depression, anxiety, fatigue, shortness of breath, constipation, nausea, loss of appetite [and] difficulty sleeping." *Id.* This non-curative treatment focuses on pain management as well as emotional and spiritual support. *Comfort & Palliative Care*, THE WORLD FED'N OF RIGHT TO DIE SOC'YS, <http://www.worldrtd.net/comfort-palliative-care> (last visited Apr. 13, 2015).

<sup>68</sup> Aldrich, *supra* note 5, at 2-3.

<sup>69</sup> Fagerlin, *supra* note 21, at 33.

tients to inform them of possible scenarios they may confront if they are not being paid for these consultations through insurance or Medicare and Medicaid reimbursements, or simply do not have the time to spend with patients in advisory roles. While lawyers can explain to clients the uses and abuses of advance directives, as well as execute such documents, a lawyer likely does not have the medical knowledge or training to adequately describe medical procedures and their potential risks.

### III. CURRENT LAWS, PROCEDURES, AND REGISTRIES

All fifty states and the District of Columbia currently have statutory provisions recognizing advance directives in some manner,<sup>70</sup> be they Living Wills, Health Care Proxies, Physician Orders for Life Sustaining Treatment (“POLST”),<sup>71</sup> or other instruments. Studying the current laws, procedures, and registries already in existence can be beneficial in drafting and implementing advance directive reform. The positive aspects can be incorporated and expanded, and the pitfalls can be avoided.

#### A. New York

New York currently recognizes Health Care Proxies,<sup>72</sup> non-hospital orders to not resuscitate (DNR),<sup>73</sup> and orders to not intubate (DNI).<sup>74</sup> Living Wills are not currently governed by statute, but are used as “clear and convincing” evidence of a person’s wishes to supplement other advance directives, as directed by the Court of Appeals of New York.<sup>75</sup> The New York State Department of Health provides

---

<sup>70</sup> *Frequently Asked Questions (FAQ) About the U.S. Living Will Registry*, U.S. LIVING WILL REGISTRY, <http://www.uslivingwillregistry.com/faq.shtm> (last visited Apr. 13, 2015).

<sup>71</sup> *About the National POLST Paradigm*, POLST, <http://www.polst.org/about-the-national-polst-paradigm/> (last visited Apr. 13, 2015).

<sup>72</sup> N.Y. PUB. HEALTH LAW § 2981 (McKinney 2012).

<sup>73</sup> Defined as “an order that directs emergency medical services personnel, hospice personnel and hospital emergency services personnel not to attempt cardiopulmonary resuscitation in the event a patient suffers cardiac or respiratory arrest.” N.Y. PUB. HEALTH LAW § 2994-aa(13) (McKinney 2012).

<sup>74</sup> N.Y. PUB. HEALTH LAW § 2994-dd(6) (McKinney 2012). A DNI is an order that “no breathing tube will be placed in the throat in the event of breathing difficulty or respiratory arrest.” *What Does DNR/DNI Mean?*, <http://webspaces.webring.com/people/pm/mattcastens/nocode> (last visited Apr. 13, 2015).

<sup>75</sup> *In re Westchester Cnty. Med. Ctr.*, 531 N.E.2d 607, 613 (N.Y. 1988) (providing that

a Health Care Proxy form, but not a Living Will form, as this instrument is more complex and detailed than the appointment function of a Health Care Proxy.<sup>76</sup>

New York makes many efforts to provide advance care planning knowledge and resources to its citizens. The Office of the Attorney General of New York provides an online information guide regarding Health Care Proxies, Living Wills, DNRs, DNIs, hospice, pain management and organ donation.<sup>77</sup> New York's Health Care Proxy form, as provided by the New York State Department of Health, is a hybrid Health Care Proxy and organ or tissue donation form.<sup>78</sup> The optional section for anatomical gifts asks whether the signor would like to make a posthumous gift of "[a]ny needed organs and/or tissues" and provides space for particular organs to be listed as well as any desired limitations.<sup>79</sup> The New York State Department of Health endorses Medical Orders for Life-Sustaining Treatment ("MOLST")<sup>80</sup> for patients with serious health conditions who (1)

---

"clear and convincing" evidence was necessary to persuade a trier of fact that the patient had a firm and settled commitment to life support). The ideal clear and convincing evidence of a patient's wishes would be a writing, such as a living will. *Id.*

<sup>76</sup> However, the New York State Bar Association provides a form that could easily be misconstrued, especially by laypersons, as it may include unwanted provisions or exclude desired provisions. This document is better characterized as a sample rather than form. *See New York Living Will, Living Wills and Health Care Proxy Forms*, N.Y. STATE BAR ASS'N, <http://www.nysba.org/WorkArea/DownloadAsset.aspx?id=26506> (last visited Apr. 13, 2015).

<sup>77</sup> New York Attorney General Eric T. Schneiderman, *Planning Your Health Care in Advance: How to Make Your Wishes Known and Honored*, N.Y. OFFICE OF THE ATT'Y GEN., HEALTH CARE BUREAU, [http://www.ag.ny.gov/sites/default/files/pdfs/publications/Planning\\_Your\\_Health\\_Care\\_in\\_Advance.pdf](http://www.ag.ny.gov/sites/default/files/pdfs/publications/Planning_Your_Health_Care_in_Advance.pdf) (last visited Apr. 13, 2015).

<sup>78</sup> *Health Care Proxy*, *supra* note 28.

<sup>79</sup> *Id.*

<sup>80</sup> *Medical Orders for Life-Sustaining Treatment (MOLST)*, N.Y. STATE DEP'T OF HEALTH, [https://www.health.ny.gov/professionals/patients/patient\\_rights/molst/](https://www.health.ny.gov/professionals/patients/patient_rights/molst/) (last visited Apr. 13, 2015).

Completion of the MOLST begins with a conversation or a series of conversations between the patient, the patient's health care agent or surrogate, and a qualified, trained health care professional that defines the patient's goals for care, reviews possible treatment options on the entire MOLST form, and ensures shared, informed medical decision-making. Although the conversation(s) about goals and treatment options may be initiated by any qualified and trained health care professional, a licensed physician must always, at a minimum: (i) confer with the patient and/or the patient's health care agent or surrogate about the patient's diagnosis, prognosis, goals for care, treatment preferences, and consent by the appropriate decision-maker, and (ii) sign the orders derived from that dis-

“[w]ant to avoid or receive any or all life-sustaining treatment”; (2) live in a “long-term care facility or require long-term” treatment; and/or (3) may “die within the next year.”<sup>81</sup> Although similar to an advance directive, MOLST is a very specific list of physicians’ orders which include orders regarding antibiotics, intubation, hospitalization or transfers, artificial nutrition, and CPR.<sup>82</sup> MOLST promotes the ideology of informed consent<sup>83</sup> because it heavily fosters the “informed” element as physicians, and often other trained medical professionals, are crucial role-players in the conversation about treatment options<sup>84</sup> as they can provide the best explanations and advice possible.

In 2010, New York enacted the Family Health Care Decisions Act (“FHCDA”),<sup>85</sup> seventeen years after it was introduced,<sup>86</sup> which seemingly provides for a statutory hierarchy of health care agents. However, such legislation is not an adequate remedy for decision-making for incapacitated individuals who are without close family members with knowledge of their wishes or would not trust the default agents acting on their behalf to respect any known wishes. Ad-

---

cussion.

The MOLST form is one way of documenting a patient’s treatment preferences concerning life-sustaining treatment—providers may choose to use other forms. However, under State law, the MOLST form is the only authorized form in New York State for documenting both nonhospital DNR and DNI orders. In addition, the form is beneficial to patients and providers as it provides specific medical orders and is recognized and used in a variety of health care settings.

*Id.*

<sup>81</sup> *Id.*

<sup>82</sup> *Form: Medical Orders for Life-Sustaining Treatment*, N.Y. STATE DEP’T OF HEALTH, <http://www.health.ny.gov/forms/doh-5003.pdf> (last visited Apr. 13, 2015).

<sup>83</sup> Jon F. Merz, *On A Decision-Making Paradigm of Medical Informed Consent*, 14 J. LEGAL MED. 231, 232 (1993) (noting that a “legal obligation to make adequate disclosures of the medically recognized risks, benefits, and alternatives to any proposed diagnostic or therapeutic medical procedures to allow their patients to make informed decisions and to give an informed consent to those procedures”).

<sup>84</sup> *Medical Orders*, *supra* note 80.

<sup>85</sup> N.Y. PUB. HEALTH LAW § 2994-d (McKinney 2011) (providing a hierarchy of persons that would be appointed surrogate to make decisions for a patient once the patient was deemed incapacitated to do so by a physician).

<sup>86</sup> The FHCDA eliminated the uncertainty that families and care-givers faced before this bill was enacted when their loved one could not make decisions and empowered them to make decisions for the incapacitated individual. *See Senate Passes Family Health Care Decisions Act*, N.Y. STATE SENATE (Feb. 24, 2010), <http://www.nysenate.gov/press-release/senate-passes-family-health-care-decisions-act-0>.



vance directives are a better option because they keep the initial decision making power in the hands of the individual.

While New York has some of the tools necessary for individuals to plan for future health care, the tools are unavailable when needed unless individuals are proactive in making their existence known. A system of access to find these critical instruments would make New York's current recognition of advance directives significantly more effective. Providing a means for advance directives to fulfill their purpose should be a priority for legislators who want to improve the health care system.

### B. Current Systems of Registries

Accessibility to necessary information is not a novel issue. Systems of registry and information storage and compilation are created in order to make information available to those who need it. For example, potential home buyers can visit county offices to access information about real property within their territorial boundaries that might affect title. Similarly, organ donation registries exist so that hospitals are made aware of the identities of potential donors to effectuate matches with donees awaiting a transplant. These healthcare-type registries are strongly analogous to advance directive registries in that both contain information that is only relevant during limited periods of time, particularly near death. Several states already offer an advance directive registry<sup>87</sup> and several private registries exist for

---

<sup>87</sup> See, e.g., *Arizona Advance Directive Registry*, ARIZ. DEP'T OF STATE, OFFICE OF THE SEC'Y OF STATE, [http://www.azsos.gov/adv\\_dir/](http://www.azsos.gov/adv_dir/) (last visited Apr. 10, 2015); *Advance Health Care Directive Registry*, CAL. SEC'Y OF STATE ALEX PADILLA, <https://www.sos.ca.gov/ahcdr/> (last visited Apr. 10, 2015); *Health Care Directive Registry*, IDAHO SEC'Y OF STATE, <http://www.sos.idaho.gov/GENERAL/hcdr.html> (last visited Apr. 13, 2015); *End-of-Life Registry*, MONT. DEP'T OF JUSTICE, <https://dojmt.gov/consumer/end-of-life-registry/> (last visited Apr. 13, 2015); *Advance Health Care Directive Registry*, N.C. DEP'T OF THE SEC'Y OF STATE, <https://www.secretary.state.nc.us/ahcdr/> (last visited Apr. 10, 2015); *Advance Health Care Directive Registry*, OR. POLST REGISTRY, <http://www.orpolstregistry.org> (last visited Apr. 10, 2015); *Vermont Advance Directives Registry*, DEP'T OF HEALTH, AGENCY OF HUMAN SERVS., <http://healthvermont.gov/vadr/> (last visited Apr. 13, 2015); *Advance Health Care Directive Registry*, VA. DEP'T OF HEALTH, <https://www.virginiaregistry.org/?AspxAutoDetectCookieSupport=1> (last visited Apr. 13, 2015); *Living Will Registry*, WASH. STATE DEP'T OF HEALTH, <http://www.doh.wa.gov/AboutUs/ProgramsandServices/DiseaseControlandHealthStatistics/CenterforHealthStatistics/LivingWillRegistry> (last visited Apr. 13, 2015); *West Virginia E-Directive Registry*, W. VA. CTR. FOR END-OF-LIFE CARE, <http://www.wvendoflife.org/e-Directive-Registry> (last visited Apr. 13, 2015).

anyone's use.<sup>88</sup> Some states have taken a different approach by providing notice of an advance directive on drivers' licenses, similar to the organ donation symbols on drivers' licenses.<sup>89</sup>

### 1. *Organ Registries*

New York legislation established the "Donate Life Registry" in 2004 to permit the Department of Health to "establish an organ, eye, and tissue donor registry," which provides "a means to make and register" post-mortem anatomical gifts.<sup>90</sup> The registry is accessible at all times by the not-for-profit organization contracted to maintain it, the Department of Health, "federally designated organ procurement organizations, licensed eye and tissue banks," and other entities approved by the Department of Health for access.<sup>91</sup> The legislation takes security measures to protect identifiable data in the registry by allowing only those previously mentioned to have access to the database for purposes of determining donor status at or near the death of the individual and for purposes of quality assessment, improvement, and technical support. In addition, individual registrants may access the database to confirm the accuracy and validity of their registration, or to amend or revoke their registration.<sup>92</sup> There are four different ways to enroll in the New York Donate Life Registry: by registering online through the Department of Motor Vehicles and Department of Health website, mailing a form to the Department of Health, enrolling at the Department of Motor Vehicles when applying for or renewing a driver's license or non-driver identification card, or filling out a voter registration form by mail or in-person at the Board of Elections.<sup>93</sup> In addition, the New York Health Care Proxy form offers an optional section to pledge an anatomical gift and provides individuals

---

<sup>88</sup> See, e.g., *Our Mission*, U.S. LIVING WILL REGISTRY, <http://www.uslivingwillregistry.com/aboutus.shtm> (last visited Apr. 10, 2015); *Welcome to America Living Will Registry*, AM. LIVING WILL REGISTRY, <http://www.alwr.com> (last visited Apr. 13, 2015); *About DocuBank*, DOCUBANK, <https://www.docubank.com> (last visited Apr. 13, 2015).

<sup>89</sup> See, e.g., 625 ILL. COMP. STAT. ANN. 5/6-110(g) (West 2014); LA. REV. STAT. ANN. § 32:410(c)(1)(a) (2012); MINN. STAT. ANN. § 171.07(7)(a) (West 2014); MONT. CODE ANN. § 61-5-301(3) (West 2013); S.D. CODIFIED LAWS § 32-12-17.2 (2014).

<sup>90</sup> N.Y. PUB. HEALTH LAW § 4310(1) (McKinney 2014).

<sup>91</sup> *Id.* § 4310(7)(a).

<sup>92</sup> *Id.* § 4310(7)(b).

<sup>93</sup> See *Organ and Tissue Donations*, N.Y. STATE DEP'T OF HEALTH, <https://www.health.ny.gov/professionals/patients/donation/organ/> (last visited Apr. 10, 2015).

the opportunity to specify limitations on their anatomical gifts.<sup>94</sup> Registered organ donors may have a heart symbol on their driver's licenses that indicate their registration and intent to donate.<sup>95</sup>

New York's Donate Life Registry is a strong model for registries, which can connect essential information with those in need of that information. The Donate Life Registry is user-friendly by providing various ways to register, which encourages individuals to register for anatomical gifts. Security measures are taken in order to ensure privacy while still affording the immediate accessibility of relevant information to the proper authorities at all times.

## 2. *U.S. Living Will Registry and Other Private Registries*

The U.S. Living Will Registry (the "Registry") appears to be the most well known private advance directive registry. The organization, established in 1996 by Dr. Joseph Barmakian, electronically stores advance directives and other important personal documents and makes them available to health care providers at any given time.<sup>96</sup> The Registry, which currently has contracts with the states of Nevada<sup>97</sup> and Vermont<sup>98</sup> to maintain their state-sponsored advance directive registries, contains many beneficial features and serves as a model for what the government could create.

After completing the registration process and securing payment,<sup>99</sup> registrants can upload their documents into their accounts so that the Registry may scan the documents into read-only PDF files so information cannot be changed once in possession of Registry em-

<sup>94</sup> *Health Care Proxy*, *supra* note 28.

<sup>95</sup> See REV. UNIF. ANATOMICAL GIFT ACT § 5 (2006), available at [http://www.uniformlaws.org/shared/docs/anatomical\\_gift/uaga\\_final\\_aug09.pdf](http://www.uniformlaws.org/shared/docs/anatomical_gift/uaga_final_aug09.pdf). The Act has been adopted in 46 states plus the District of Columbia and U.S. Virgin Islands. See *Legislative Fact Sheet – Anatomical Gift Act* (2006), UNIF. LAW COMM'N, [http://www.uniformlaws.org/LegislativeFactSheet.aspx?title=Anatomical%20Gift%20Act%20\(2006\)](http://www.uniformlaws.org/LegislativeFactSheet.aspx?title=Anatomical%20Gift%20Act%20(2006)) (last visited Apr. 13, 2015).

<sup>96</sup> See *Our Mission*, *supra* note 88.

<sup>97</sup> *Nevada Selects U.S. Living Will Registry for Statewide Registry*, U.S. LIVING WILL REGISTRY, (Feb. 25, 2008), <http://www.uslivingwillregistry.com/nevadarelease.shtm>.

<sup>98</sup> *Id.*

<sup>99</sup> The price of registration is \$59.00 per registrant or two for \$99.00. See *Featured Products*, U.S. LIVING WILL REGISTRY, <http://www.uslivingwillregistry.com/store/pc/home.asp> (last visited Apr. 10, 2015).

ployees.<sup>100</sup> Documents are then virtually stored in a secured data center that maintains backups.<sup>101</sup> Registrants have the option to provide the address and exact physical location of original documents, as well as the names and telephone numbers of people who have a copy of the documents, in the Registry's "document locator" instead of, or in addition to, submitting their documents for scanning and virtual storing.<sup>102</sup> The Registry provides hyperlinks to each state's downloadable advance directive forms to encourage registrants to use the correct forms of the state in which they intend to use these instruments.<sup>103</sup> Registered health care providers can search the Registry database through the Internet by the patient's identifying information such as name, birth date, or registrant identification number listed on a wallet-size identification card.<sup>104</sup> Non-providers can still utilize the database, but must directly call the Registry.<sup>105</sup> The national attention of the Terri Schiavo case brought thoughts of advance directives to the forefront of many Americans' minds<sup>106</sup> and sparked an increase in individual registries of advance directives, but hospitals are still slow to become registered providers of the Registry due to finances and lack of approval from hospital ethics committees.<sup>107</sup>

The Registry voluntarily complies with the Health Insurance Portability and Accountability Act of 1996 ("HIPAA") by not selling or sharing registrant information with outside parties.<sup>108</sup> Information

---

<sup>100</sup> Interview with Dr. Joseph Barmakian, Founder, U.S. Living Will Registry (Oct. 29, 2014).

<sup>101</sup> *Id.*

<sup>102</sup> See *Frequently Asked Questions (FAQ) About the U.S. Living Will Registry*, U.S. LIVING WILL REGISTRY, <http://www.uslivingwillregistry.com/faq.shtm> (last visited Apr. 13, 2015).

<sup>103</sup> See *Advance Directive Forms*, U.S. LIVING WILL REGISTRY, <http://uslwr.com/formslist.shtm> (last visited Apr. 10, 2015).

<sup>104</sup> *FAQ About the U.S. Living Will Registry*, *supra* note 102.

<sup>105</sup> Interview with Dr. Joseph Barmakian, *supra* note 100.

<sup>106</sup> Aging with Dignity, an organization focusing on aging in America, received 6,000 requests per day for their *Five Wishes* pamphlet between March and June 2005, just after Terri Schiavo's death. "Over two million *Five Wishes* [were] distributed in 2005." See *Accomplishments (2005)*, AGING WITH DIGNITY, <https://www.agingwithdignity.org/accomplishments.php?yr=2005#2005> (last visited Apr. 13, 2015). The pamphlet is a legally binding document (depending on state law) that was written with the help of the American Bar Association's Commission on Law & Aging. See *Five Wishes FAQs*, AGING WITH DIGNITY, <https://www.agingwithdignity.org/faqs.php> (last visited Apr. 13, 2015).

<sup>107</sup> Interview with Dr. Joseph Barmakian, *supra* note 100.

<sup>108</sup> *FAQ by Hospitals and Health Care Providers*, U.S. LIVING WILL REGISTRY, <http://www.uslivingwillregistry.com/hospfaq.shtm> (last visited Apr. 13, 2015).

contained in the Registry is only provided to health care providers such as hospitals, nursing facilities, home health agencies, ambulatory surgery facilities, and hospices, should the need arise.<sup>109</sup> Exact copies of advance directives can be faxed or sent through a secure and encrypted Internet connection after the authentication of the requesting health care provider has been approved by the Registry.<sup>110</sup>

The Registry has features useful to creating and accessing advance directives which demonstrate the feasibility of such an institution. The Registry has built-in safety features and has addressed the transmission of information from registrants to the Registry and from the Registry to health care providers. Several states have endorsed the Registry's policies and performance by contracting with the Registry to run their state-sponsored registries.

#### IV. PROPOSED SOLUTIONS

Actions at both the state and federal level can be taken to increase the use and efficiency of advance directives. While federal law that mandates states to comply would be ideal, such provisions could be unrealistic because of Congressional delay. Until a legislative agreement can be reached, the states should develop reforms on their own.

##### A. Proposed New York Reform

While New York currently has advance care planning initiatives in place, such as statutory provisions for health care agents, these pieces do not necessarily work together or in a way that makes them most useful to patients and health care providers. New York should first evaluate the types of documents that are currently recognized by statute and then determine the best way to get these documents to the necessary parties. First, New York should consider recognizing Living Wills as legally enforceable documents to maintain consistency with the forty-seven other states, plus the District of Columbia, that already recognize Living Wills.<sup>111</sup> The legislature should consider whether a statute recognizing the “validity of living

---

<sup>109</sup> *FAQ About the U.S. Living Will Registry*, *supra* note 102.

<sup>110</sup> *FAQ by Hospitals*, *supra* note 108.

<sup>111</sup> N.Y. ELDER LAW § 7:28 (McKinney 2014).

wills, prescribing the means of execution of such documents, and the general guidelines that may be applicable to a broad range of situations” would honor the underlying purpose of advance directives.<sup>112</sup> However, opponents argue that Living Wills are too broad to encompass the specific circumstances in which an individual would choose to accept or forego life-sustaining treatment.<sup>113</sup>

New York has recently shown movement on the issue of advance directives reform. Legislative proposals include a requirement on driver’s license applications to indicate whether the driver has a Health Care Proxy or Living Will.<sup>114</sup> The proposed legislation providing for driver’s license identification of advance directives mirrors the organ donation symbol as it would give notice that an advance directive exists and effort should be made to locate such documents. If Johnny Hypothetical’s driver’s license featured a symbol that represented the presence of an advance directive, perhaps more effort would have been taken to search the hospital’s records or even contact private registries to locate such document. This measure would also make it possible to compile better data on the use of these advance directives than currently exists.

New York has already shown a willingness to create registries, which makes the proposed registry an obtainable goal. A proposed amendment to the Public Health Law would establish a Health Care Proxy registry through the New York State Department of Health, which would be accessible to physicians and health care providers.<sup>115</sup> A statewide registry modeled after various pieces of previously discussed registries (*e.g.*, security provisions, transmission procedures, and user access) is progressive in making advance directives visible and useable. A registry would encourage hospitals, physicians, and other healthcare providers to incorporate registry searches into their admission routines. Using an advance directives registry as a model, some New York legislators have proposed the creation of a registry for wills and codicils.<sup>116</sup> This could potentially streamline

---

<sup>112</sup> Saunders v. New York, 492 N.Y.S.2d 510, 516 (Sup. Ct. 1985).

<sup>113</sup> Christopher James Ryan, *Betting Your Life: An Argument Against Certain Advance Directives*, 22 J. MED. ETHICS 67, 98 (1996), available at <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1376921/pdf/jmedeth00301-0033.pdf>

<sup>114</sup> A.B. 7792, 2013 Leg., 236th Sess. (N.Y. 2013).

<sup>115</sup> A.B. 5484, 2013 Leg., 236th Sess. (N.Y. 2013).

<sup>116</sup> S.B. 1852, 2013 Leg., 236th Sess. (N.Y. 2013); A.B. 1454, 2013 Leg., 236th Sess. (N.Y. 2013). Each county is required to establish an electronic registry for wills and codicils

the process of will probate and contests in some cases if the Surrogate's Court could access the decedent's latest will on file with the wills and codicils registry. Even if the most recently executed will is not available through the registry, a past will could answer questions as to the testator's intent. However, the registry could make the process more complicated when the most recent will has not been filed and its whereabouts are unknown, thereby delaying the probate process.

New York needs advance care planning reform that will encourage citizens to execute advance directives and streamline the process of making these documents available to health care providers. While enforcing Living Wills or establishing a registry may not solve every problem, these reforms would represent a positive effort in improving the system.

### **B. Proposed Federal Reform of Uniformity and Registries**

In order to maximize the underlying purpose of advance directives, Congress should first pass legislation to create uniform advance directive forms and rules which would be legally enforceable in every state. A federal law making advance directives uniform throughout the country would facilitate their recognition and be particularly useful to travelers and snowbirds, those who vacation in or move to warm climates during cold weather.<sup>117</sup> The American Medical Association Code of Medical Ethics expresses the "need for better availability and tracking of advance directives, and more uniform adoption of form documents that can be honored in all states of the United States."<sup>118</sup> Travelers should feel secure in knowing that their

---

that would include the name of the testator, the date of execution, and the physical address of the location of the will or codicil. *Id.* "Public individuals" would have access to the database to search by name, date, or address. Filing would be optional and not affect validity of a will or codicil. The Bill was referred to the Judiciary Committee on Jan. 8, 2014 where it currently remains. *Id.* Some states already have such a registry. *See, e.g., End of Life Registry Programs*, LA. SEC'Y OF STATE, <http://www.sos.la.gov/OurOffice/EndOfLifeRegistries/Pages/default.aspx> (last visited Apr. 13, 2015); *Will Registry*, STATE OF N.J., DEP'T OF STATE, [http://www.nj.gov/state/dos\\_will\\_registry.html](http://www.nj.gov/state/dos_will_registry.html) (last visited Apr. 13, 2015).

<sup>117</sup> *Snowbird Definition*, DICTIONARY.COM, <http://dictionary.reference.com/browse/snowbird> (last visited Apr. 13, 2015).

<sup>118</sup> *Opinion 2.225 - Optimal Use of Orders-Not-to-Intervene and Advance Directives*, AM. MED. ASS'N, <http://www.ama-assn.org/ama/pub/physician-resources/medical-ethics/code-medical-ethics/opinion2225.page?> (last visited Apr. 13, 2015).

pre-made medical decisions will be honored, regardless of their location within the United States. After such legislation becomes law, the uniform advance directive forms should be made accessible online with clear instructions on execution and which may be filled out electronically through a series of questions and prompts.

While the government likely cannot force individuals to have advance directives,<sup>119</sup> Congress could enact legislation incentivizing the creation and execution of advance directives. Those receiving public benefits such as Medicare and Medicaid could be required to submit proof of an executed advance directive to continue receiving benefits. Additionally, more money could be used to fund physician meetings with patients regarding end-of-life care planning. In April 2014, Senator Thomas Coburn<sup>120</sup> introduced legislation in Congress that would establish a program to encourage the creation of advance directives and pay \$50-\$75 for each certified advance directive created and registered with the program, but the legislation has since stalled in committee.<sup>121</sup>

An advance directive registry, similar to the registries that are currently established and maintained by the government, would alleviate some of the problems arising from not honoring advance directives because their existence or whereabouts are unknown. An advance directive registry could advantage patients by giving them peace of mind that their wishes will be known to all health care institutions when they cannot make decisions and that their documents are safe from physical damage or simple misplacement. Physicians could also benefit by providing patient-centered care because they will have access to an exact copy of their patients' advance directives with just a few clicks on their computers. Families would avoid making difficult decisions for family members even if they do not possess physical copies or are unaware of their existence. Finally, health care providers would have a vehicle to verify whether an individual pur-

---

<sup>119</sup> This particular issue seems to be unclear and not litigated, but having advance directives is a voluntary decision rooted in personal autonomy. *See supra* note 28 and accompanying text; Bradley Geller, *Advance Directives: Planning for Medical Care in the Event of Loss of Decision-Making Ability*, MICH. LONG TERM CARE OMBUDSMAN PROGRAM 8 (2014), [https://www.michigan.gov/documents/miseniors/Advance\\_Directives\\_230752\\_7.pdf](https://www.michigan.gov/documents/miseniors/Advance_Directives_230752_7.pdf).

<sup>120</sup> *Sen. Thomas Coburn*, GOVTRACK.US, [https://www.govtrack.us/congress/members/thomas\\_coburn/400576](https://www.govtrack.us/congress/members/thomas_coburn/400576) (last visited Apr. 10, 2015).

<sup>121</sup> Belluck, *supra* note 11; Medicare Choices Empowerment and Protection Act, S. 2240, 113th Cong. (2014).



porting to be a patient's health care agent is in fact the designated health care agent.

Further, health insurance companies potentially will pay out less in end-of-life care costs if more patients are not receiving unwanted treatments as stated in their advance directives because a great deal of money is spent on end-of-life care.<sup>122</sup> In 2011, health care accounted for approximately 18% of the nation's monetary spending with Medicare spending nearly \$554 billion, which amounted to only 21% of the total amount spent on health care in the United States that year.<sup>123</sup> Of Medicare's \$554 billion spent, about \$170 billion, or 28%, was used for patients within the last six months of their lives.<sup>124</sup> While it is unknown whether advance care planning produces significant savings, some studies show that it reduces hospitalization.<sup>125</sup>

The creation of the proposed registry is a reasonable feat as much of the foundational work has already been done by the existing organ donation and advance directive registries; the proposed registry can model its provisions on the best and most functional features of each to create a registry that could satisfy most of the logistics and privacy concerns already identified and solved by the existing registries. The advance directive registry should include Living Wills, Health Care Proxies, DNRs, DNIs, funeral and burial designations, and other documents relaying end-of-life wishes. Downloadable forms, whether uniform throughout the states or not, should be provided online with easy to understand explanations of the meaning and legal implications of each document, suggestions for what information can be included, instructions for executing the documents properly, and information on revocation. However, registrants would still have the ability to scan and submit their current documents, if preferred. The registry should be available electronically for health care providers' ease of access, which would incentivize health care institutions to utilize the registry. Security of the registry should be ensured with backups and encryption to guard against human error,

---

<sup>122</sup> Susan Pasternak, *End-of-Life Care Constitutes Third Rail of U.S. Health Care Policy Debate*, MEDICARE NEWSGROUP (June 3, 2013), <http://www.medicarenewsgroup.com/context/understanding-medicare-blog/understanding-medicare-blog/2013/06/03/end-of-life-care-constitutes-third-rail-of-u.s.-health-care-policy-debate>.

<sup>123</sup> *Id.*

<sup>124</sup> *Id.*

<sup>125</sup> Belluck, *supra* note 11.

natural disasters, electrical outages, and hacking. Registry employees would be able to verify that advance directives were executed properly and, therefore, increase the usage of valid documents and decrease litigation over validity. Similar to the U.S. Living Will Registry, the registry system should contact registrants periodically to request that registrants review their advance directives and resubmit new forms if any information or preferences have changed since the last submission.

### C. Health Insurance Companies and Health Care Providers

A viable alternative to a government-sponsored advance directive registry would be for health insurance companies to develop and maintain registries for their members. The private insurance sector, a multi-billion dollar industry,<sup>126</sup> not only has an abundance of monetary resources but also has financial incentive for its members to consciously opt-out of costly end-of-life treatment.<sup>127</sup>

Hospitals and other healthcare institutions could be provided access to advance directives in insurance sponsored registries as easily as they could view a particular patient's coverage. If the federal or and state governments were to consider the establishment of a registry, insurance companies would probably lobby for such legislation. Even without their own registries, insurance companies could incentivize, but not require, the execution of advance directives because New York and other states prohibit such a requirement as a condition of providing insurance.<sup>128</sup> Health insurance companies could offer lower premiums to their members with proof of advance directive execution (and filing with an approved registry) because patients would have a "push" to consider their health care wishes, which may ultimately decrease end-of-life care payments by the insurance companies.

Since the advance care planning reimbursement provision of the Patient Protection and Affordable Care Act was eliminated, insur-

---

<sup>126</sup> Ethan Rome, *The Truth About Health Insurance Company Profits: They're Excessive*, HUFFINGTON POST (July 18, 2011, 5:12 AM), [http://www.huffingtonpost.com/ethan-rome/the-truth-about-health-in\\_b\\_863632.html](http://www.huffingtonpost.com/ethan-rome/the-truth-about-health-in_b_863632.html).

<sup>127</sup> *Id.*

<sup>128</sup> N.Y. PUB. HEALTH LAW § 2988 (McKinney 2015); FLA. STAT. ANN. § 765.108 (West 2014).

ance companies took action at the urging of physicians.<sup>129</sup> Insurance companies have created other ways to cover the conversations by creating their own billing codes.<sup>130</sup> Blue Cross Blue Shield of Michigan pays an average of \$35 per conversation to health care institutions, whether face-to-face or by telephone, conducted by doctors, nurses, social workers, or others.<sup>131</sup> Excellus Blue Cross Blue Shield of New York pays \$150 for an hour of conversation and completion of the form, and \$350 for two hours of conversation.<sup>132</sup> End-of-life planning conversations have proven beneficial as “[p]atients with cancer are more likely to receive [end-of-life] care that is consistent with their preferences when they have had the opportunity to discuss their wishes for [end-of-life] care with a physician.”<sup>133</sup>

Large health care institutions with an extensive network of affiliates would benefit from their own registries, but may be reluctant to institute their own private advance directive registries for fear of liability if employees fail to search the database for the existence of advance directives. However, like any other procedure that could result in liability, such as taking vital signs and correctly documenting notes in patient medical files, searching for advance directives should be routine and performed carefully in any healthcare facility.

#### D. Individual Reform

Public attitudes regarding death and other end-of-life topics are rather bleak, but this naivety only leads to more problems. The taboo surrounding death that prevents society from speaking of death freely hinders the ability to keep control over bodily decisions. Public awareness campaigns like “Breast Cancer Awareness Month” and “Worlds AIDS Day” are commemorative periods of time used to raise awareness of specific issues.<sup>134</sup> Essentially, these campaigns

---

<sup>129</sup> Belluck, *supra* note 11.

<sup>130</sup> *Id.*

<sup>131</sup> *Id.*

<sup>132</sup> *Id.*

<sup>133</sup> Jennifer W. Mack et al., *End-of-Life Discussions, Goal Attainment, and Distress at the End of Life: Predictors and Outcomes of Receipt of Care Consistent with Preferences*, 28 J. CLINICAL ONCOLOGY 1085, 1208 (2010).

<sup>134</sup> Celebrated in October, February, and December, respectively, to raise awareness about the history and issues. Office of Disease Prevention and Health Promotion through the U.S. Department of Health and Human Services provides a toolkit for individual consumers and event organizers with ideas to advertise statistics and services with sample Tweets and media

start dialogue and normalize subjects usually left outside the realm of acceptable thought and conversation. Social campaigns such as dedicatory time periods regarding advance care planning may provide the education necessary to understand illnesses and the potential risks and benefits of various treatments that assist a competent person to make decisions regarding treatment. Although “National Healthcare Decisions Day” takes place annually on April 16th to “inspire, educate, and empower the public and providers about the importance of advance care planning,”<sup>135</sup> it does not garner the attention that Breast Cancer Awareness Month and World AIDS Day do that make their fundraising and social awareness operations so successful. As Americans, we rally behind efforts to cure and prevent disease, but shy away from death and the time period leading up to it. Accepting the reality of death leads to an increase in conversations with family and perhaps the creation of advance directives that would protect individuals’ interests in the future.

## V. POTENTIAL ROADBLOCKS TO REFORM OF ACCESSIBILITY

Proposals for more uniformity in advance directive laws and the establishment of a registry are not without flaws. Issues of cost and registry security, along with individual fear of receiving sub-par treatment and the potential for fraud, are obstacles to the adoption of advance directive accessibility reform. However, with strategy, education, and the acceptance of risk, these barriers can be overcome.

### A. Financial Burden on Taxpayers

Establishing and maintaining an advance directive registry would add yet another item to the government’s budget that would ultimately become the taxpayers’ burden. A 2005 study on a statewide advance directive registry in Maryland concluded that it

---

announcements. See *October National Health Observances*, U.S. DEP’T OF HEALTH & HUMAN SERVS., OFFICE OF DISEASE PREVENTION & HEALTH PROMOTION, <http://healthfinder.gov/NHO/PDFs/OctoberNHOToolkit.pdf> (last visited Apr. 13, 2015); see also *December National Health Observances*, U.S. DEP’T OF HEALTH AND HUMAN SERVS., OFFICE OF DISEASE PREVENTION & HEALTH PROMOTION, <http://healthfinder.gov/NHO/PDFs/DecemberNHOToolkit.pdf> (last visited Apr. 13, 2015).

<sup>135</sup> *Plan Ahead for You and Your Family*, CTR. FOR DISEASE CONTROL & PREVENTION, <http://www.cdc.gov/features/AdvancedCarePlanning/index.html> (last visited Apr. 13, 2015).

would cost \$90,000 to create the registry and \$80,000 to maintain it each year.<sup>136</sup> In 2007, the state of Washington partnered with the U.S. Living Will Registry to bring its citizens a statewide advance directive registry,<sup>137</sup> but, unfortunately, the state ran out of money and ended the program, resulting in a savings of \$104,000 in the two-year budget.<sup>138</sup> Fortunately, the registrants who joined before the abolition of the program were offered continued registration for life, free of charge.<sup>139</sup> Despite the cost, establishing and maintaining a registry should be seen as an investment, as the money saved on end-of-life care could easily exceed the amount spent on extended and complex end-of-life care.

### B. Privacy and Potential for Hacking

Security and privacy issues may deter individuals from wanting their advance directives digitized as hackers can steal this information. Medical records on the black market sell for fifty times more than credit card information because medical records can be used to fraudulently bill Medicare or insurance.<sup>140</sup> Illegally acquired material includes identifying information such as names and birth dates, as well as policy numbers, billing information, and medical diagnosis codes.<sup>141</sup> Hackers, posing as patients, can use this information to obtain prescription drugs for later sale on the secondhand market.<sup>142</sup> Individuals who access protected health information without authorization in order to sell, transfer, or use it for personal or commercial advantage face a fine up to \$250,000, ten years imprisonment, or

---

<sup>136</sup> *Study On A Statewide Advance Directive Registry*, STATE ADVISORY COUNCIL ON QUALITY CARE AT THE END OF LIFE 1-2 (2005), <http://www.oag.state.md.us/healthpol/ADregistry.pdf>.

<sup>137</sup> *Washington State Selects U.S. Living Will Registry for New Advance Directive Registry*, U.S. LIVING WILL REGISTRY (Aug. 1, 2007), <http://www.uslivingwillregistry.com/Washingtonrelease.shtm>.

<sup>138</sup> *Washington State Ends Living Will Registry*, THE COLUMBIAN (July 1, 2011, 9:43 PM), <http://www.columbian.com/news/2011/jun/30/washington-state-ends-living-will-registry/>.

<sup>139</sup> *Id.*

<sup>140</sup> Jose Pagliery, *90% of Hospitals and Clinics Lose Their Patients' Data*, CNN MONEY (Aug. 20, 2014, 11:06 AM), <http://money.cnn.com/2014/08/20/technology/security/hospitals-data/>.

<sup>141</sup> Caroline Humer & Jim Finkle, *Your Medical Record Is Worth More To Hackers than Your Credit Card*, REUTERS (Sept. 24, 2014, 2:24 PM), <http://www.reuters.com/article/2014/09/24/us-cybersecurity-hospitals-idUSKCN0HJ21I20140924>.

<sup>142</sup> *Id.*

both.<sup>143</sup> However, the prospect of a large financial gain has outweighed the penal deterrence as large-scale cyber attacks on the healthcare industry continue.<sup>144</sup> In a society that relies on electronic data for most aspects of business and daily living, the threat of data breaches is constant and unwavering. However, if society is willing to take the chance of identity theft by banking online, certainly society will adapt to the risk of theft in the medical record realm. Furthermore, the proposed registry can mirror the organ donation registry policy which allows only certain individuals to have access to the database and only for purposes of searching and acquiring data, quality assessment, and technical support.<sup>145</sup>

While the desire to bar strangers from seeing our personal end-of-life decisions is understandable, advance directives are not meant to be for the creator's eyes only. Individuals must give up a degree of privacy in order for their advance directives to be useful. Just as credit companies, banks, and online retailers make efforts to protect their customers' information through encryption and firewalls,<sup>146</sup> the proposed registry will take similar protective measures. As HIPAA currently stands, a registry would not be a covered entity that would be required to protect privacy and security of health information. However, similar to the U.S. Living Will Registry, the proposed registry could voluntarily comply with HIPAA mandates<sup>147</sup> that "ensure the privacy of individually identifiable health information"<sup>148</sup> and the security of electronic protected health infor-

---

<sup>143</sup> 42 U.S.C. § 1320d-6(b)(3) (2010).

<sup>144</sup> See Jose Pagliery, *Hospital Network Hacked, 4.5 Million Records Stolen*, CNN MONEY (Aug. 18, 2014), <http://money.cnn.com/2014/08/18/technology/security/hospital-chs-hack/>; Gail Sullivan, *Chinese Hackers May Have Stolen Your Medical Records*, WASH. POST (Aug. 19, 2014), <http://www.washingtonpost.com/news/morning-mix/wp/2014/08/19/chinese-hackers-may-have-stolen-your-medical-records/>. Forty percent of healthcare organizations reported a criminal cyber attack in 2013, up from 20 percent in 2009. Humer & Finkle, *supra* note 141.

<sup>145</sup> N.Y. PUB. HEALTH LAW § 4310(7)(b) (McKinney 2014).

<sup>146</sup> *What Is a Firewall?*, Safety & Security Center, MICROSOFT, <http://www.microsoft.com/security/pc-security/firewalls-what-is.aspx> (last visited Apr. 10, 2015).

<sup>147</sup> *FAQ by Hospitals*, *supra* note 108.

<sup>148</sup> 42 U.S.C. § 1320d(6).

[A]ny information, including demographic information collected from an individual, that-- (A) is created or received by a health care provider, health plan, employer, or health care clearinghouse; and (B) relates to the past, present, or future physical or mental health or condition of an individual, the provision of health care to an individual, or the past, pre-

mation.”<sup>149</sup> Alternatively, the requirements under HIPAA could be changed to encompass the registry. Regardless, those who would access the registry, namely healthcare workers, are subject to HIPAA, as required by their job, so there is already a required layer of protection for registry access abuse.<sup>150</sup>

### C. Society’s Fear of Inferior Treatment

Myths and rumors often fueled by the media breed fear and misunderstanding. There is a long-standing myth that physicians and health care institutions will provide sub-par treatment if the patient has an advance directive that disfavors life-sustaining treatment,<sup>151</sup> similar to the myth that those registered to be organ donors will not receive adequate medical treatment.<sup>152</sup> Choosing to forego certain life-sustaining treatments does not indicate that doctors and families “push someone in the corner and . . . just watch and wait until they’re dead.”<sup>153</sup> Rather, wishes are honored and the interested parties “go through that [end-of-life] process,”<sup>154</sup> which might include comfort care and pain management. These myths, like the “death panel” con-

---

sent, or future payment for the provision of health care to an individual, and-- (i) identifies the individual; or (ii) with respect to which there is a reasonable basis to believe that the information can be used to identify the individual.

*Id.*

<sup>149</sup> *Study On a Statewide Advance Directive Registry*, *supra* note 135, at Appendix C-1.

<sup>150</sup> N.Y. PUB. HEALTH LAW § 4310(7)(b). In Vermont, persons who access the registry without authorization are “subject to review and disciplinary action by the appropriate licensing, accreditation, or approving entity.” *See* VT. STAT. ANN. tit. 18, § 9714(b) (West 2011).

<sup>151</sup> *See Myths and Facts About Health Care Advance Directives*, AM. BAR ASS’N COMM’N ON LAW & AGING, [http://www.americanbar.org/content/dam/aba/migrated/Commissions/myths\\_fact\\_hc\\_ad.authcheckdam.pdf](http://www.americanbar.org/content/dam/aba/migrated/Commissions/myths_fact_hc_ad.authcheckdam.pdf).

<sup>152</sup> *See Organ Donation: Don’t Let These Myths Confuse You*, MAYO CLINIC, <http://www.mayoclinic.org/healthy-living/consumer-health/in-depth/organ-donation/art-20047529> (last visited Apr. 10, 2015). A Donate Life America advocacy group conducted an online survey which found that 50% of the 5,100 participants were concerned that doctors would not try as hard to save them if they registered as organ donors. Tara Parker-Pope, *The Reluctant Organ Donor*, N.Y. TIMES (Apr. 16, 2009), <http://well.blogs.nytimes.com/2009/04/16/the-reluctant-organ-donor/>.

<sup>153</sup> Mark Rivera, *St. Pete Nursing Home Fined for Saving Man’s Life*, WTSP 10 NEWS (June 5, 2014), <http://www.wtsp.com/story/news/local/pinellascounty/2014/06/05/st-pete-nursing-home-fined/10003143/>.

<sup>154</sup> *Id.*

troversy<sup>155</sup> that many media outlets read into the Patient Protection and Affordable Care Act, cause unnecessary hysteria. The “death panel” controversy of 2009, fanned by media outlets, caused the Senate to discard a provision in the Patient Protection and Affordable Care Act<sup>156</sup> that would have permitted Medicare to pay doctors to discuss end-of-life treatment decisions with patients.<sup>157</sup> There is a common misunderstanding that if a Health Care Proxy is executed, the patient no longer has the right to make decisions, but this is untrue because a competent patient can override any decision made by the health care agent and even revoke the directive entirely.<sup>158</sup> An advance directive registry is vulnerable to political attacks and could receive death panel-like negative attention that would slaughter the bill before enactment. However, with proper education about the function of advance directives, these fears can be dispelled.

#### D. Change in Preferences and the Potential for Fraud

Living Wills promote “patients’ autonomy,”<sup>159</sup> but many criticize their ability to be an “effective instrument of social policy.”<sup>160</sup> Living Wills have the potential of providing specificity, but the average person and even the average lawyer do not know enough about

---

<sup>155</sup> See Ben Cosman, ‘Death Panels’ Will Be Sarah Palin’s Greatest Legacy, *THE WIRE* (May 30, 2014), <http://www.thewire.com/politics/2014/05/death-panels-will-be-sarah-palins-greatest-legacy/371888/>. In 2009, Sarah Palin took to Facebook to criticize the Patient Protection and Affordable Care Act:

The America I know and love is not one in which my parents or my baby with Down Syndrome will have to stand in front of Obama’s “death panel” so his bureaucrats can decide, based on a subjective judgment of their “level of productivity in society,” whether they are worthy of health care. Such a system is downright evil.

*Id.*

<sup>156</sup> Patient Protection and Affordable Care Act, Pub. Law No. 111-148, 124 Stat 119 (2010).

<sup>157</sup> During yearly wellness visits, patients could voluntarily obtain information about Living Wills, Health Care Proxies, specific types of medical treatment, and hospice care. See Robert Pear, *Obama Returns to End-Of-Life Plan That Caused Stir*, *N.Y. TIMES* (Dec. 25, 2010), <http://www.nytimes.com/2010/12/26/us/politics/26death.html?pagewanted=all>; Christi Parsons & Andrew Zajac, *Senate Committee Scraps Healthcare Provision that Gave Rise to “Death Panel” Claims*, *L.A. TIMES* (Aug. 9, 2009), <http://articles.latimes.com/2009/aug/14/nation/na-health-end-of-life14>.

<sup>158</sup> *Advance Directives*, *supra* note 2.

<sup>159</sup> Fagerlin, *supra* note 21, at 30.

<sup>160</sup> *Id.*



life-sustaining and other medical treatment to make informed decisions. Living Wills can become irrelevant when types of medical care change due to technological advances and other scientific discoveries. Deciding preferences for prospective situations is daunting when patients already have difficulty making contemporaneous decisions.<sup>161</sup> In an instant, preferences can change, and Living Wills cannot always be revoked at the last minute to account for individuals who decide that they want life-sustaining treatment after all,<sup>162</sup> especially when the situation imagined occurs differently. Living Wills should be utilized as supplements to broader instruments such as Health Care Proxies.

Health Care Proxies offer more flexibility than Living Wills by appointing a person to make decisions based on current circumstances as opposed to specific pre-made decisions. However, Health Care Proxies may not be used in the manner the patient desired. A problem arises when a designated health care agent has more than an emotional interest in the life and death of a person. Agents who are beneficiaries of life insurance policies may make decisions based on their pending financial gain as opposed to the patients' best interests and wishes. Employment pensions may be a reason to keep patients alive instead of honoring their wishes or acting in their best interests. Although legitimate concerns, these are risks that advance care planners must take. Situations like these can best be avoided by choosing a trustworthy health care proxy and periodically communicating end-of-life desires to them orally and in a writing such as a Living Will.

## VI. CONCLUSION

No amount of advance directive reform can solve the problems that surround human life, death, and emotion, but the current system of creating and accessing advance directives can be improved.

---

<sup>161</sup> *Id.* at 33.

<sup>162</sup> A study of eighteen women in a "natural childbirth" class found that preferences to avoid anesthesia and pain medication were relatively stable before childbirth, but at the beginning of labor, that preference shifted to the desire to avoid labor pains. During later stages of labor, that new preference was stable, but after childbirth, that preference shifted back toward avoiding anesthesia during the mother's next childbirth. These findings imply that patients may make less reliable decisions about distant situations that they have never experienced and the difference between current and long-term desires can create a problem. See J.J. Christensen-Szalanski, *Discount Functions and the Measurement of Patients' Values: Women's Decisions During Childbirth*, 4 MED. DECISION MAKING 3, 47 (1984).

With an increasingly mobile society, our pre-made medical decisions should follow us whether we are in our home state or elsewhere in the country, and those advance directives should be legally valid, recognized, and honored. The passage of federal law that would bring clarity and consistency to advance directives across the nation and a government created advance directive registry, either by the federal or state government, that would make these documents more readily available to health care providers would be significant changes. Such reform would allow health care providers the necessary tools to give patients the treatment they desire when they cannot speak for themselves. Until such reforms are adopted, individuals should be proactive in executing advance directives with specificity, which includes appointing a strong and trusted health care agent (and substitute), discussing their decisions with each doctor and family member, and ensuring that these instruments are a part of their medical files at each doctor's office, hospital, and nursing facility which treats them.<sup>163</sup> Although "[w]e will never have a perfect world, [it is] not romantic or naïve to work towards a better one."<sup>164</sup>

---

<sup>163</sup> Paula Span, *When Advance Directives Are Ignored*, N.Y. TIMES (June 24, 2014, 5:00 AM), <http://newoldage.blogs.nytimes.com/2014/06/24/when-advance-directives-are-ignored>.

<sup>164</sup> Seandor Szeles, *Steven Pinker's Two-Minute Case for Optimism*, PBS (July 14, 2014), <http://www.pbs.org/wgbh/nova/blogs/secretlife/blogposts/steven-pinkers-two-minute-case-for-optimism/>.