

THE CLINICAL REALITIES OF ADVANCE DIRECTIVES

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“The choice between life and death is a deeply personal decision of obvious and overwhelming finality.”¹

I. INTRODUCTION

Advances in modern medicine are capable of delaying the dying process for weeks, months, or years, and frequently involve diminished quality of life and significant pain and suffering.² Despite such advances, most individuals fear the dying process more than death itself and, as such, are reticent to discuss either.³ This fear includes dying in a hospital or nursing home with tubes, wires and drains, or suffering pain and humiliation.⁴ Some individuals, however, overcome this fear; they engage in conversations about death and the dying process.⁵ Some of these individuals even find hope in legal documentation, i.e. advance directives. While the concept of advance directives is noble in its efforts to prevent ‘bad deaths,’ the clinical reality of these documents falls far short of nirvana.⁶

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1. *Cruzan v. Mo. Dep’t of Health*, 497 U.S. 261, 281 (1990).

2. See Emily Clough, *A Critique of Advance Directives and Advance Directives Legislation*, 11 APPEAL REV. CURRENT L. & L. REFORM 16, 20-21 (2006); Joseph T. Monahan & Elizabeth A. Lawhorn, *Life-Sustaining Treatment and the Law: The Evolution of Informed Consent, Advance Directives and Surrogate Decision Making*, 19 ANNALS HEALTH L. 107, 107 (2009-2010); Ben Kusmin, Note, *Swing Low Sweet Chariot: Abandoning the Disinterested Witness Requirement for Advance Directives*, 32 AM. J.L. & MED. 93, 93 (2006).

3. See Ira R. Byock, *Foreword: The American Consciousness Regarding the End of Life* to Elisabeth Belmont et al., *A Guide to Legal Issues in Life-Limiting Conditions*, 38 J. HEALTH L. 145, 147 (2005); Karen Anne Meehan, *Advance Directives: The Clinical Nurse Specialist as a Change Agent*, 23 CLINICAL NURSE SPECIALIST 258, 259 (2009); Lauren Vogel, *Advance Directives: Obstacles in Preparing for the Worst*, 183 CAN. MED. ASS’N J. at E39, E40 (2011).

4. Clough, *supra* note 2, at 18. Furthermore, “[p]eople feared ‘the prospect of dying away from home in impersonal and unfamiliar surroundings and of having to endure prolonged and often needless suffering.’” *Id.* at 20-21 (quoting GERALD DWORKIN ET AL., EUTHANASIA AND PHYSICIAN-ASSISTED SUICIDE 84 (1998)). For a perspective on patients implementing advance directives out of fear that physicians will make treatment choices for them, see Theresa S. Drought et al., *Advance Directives: Changing Our Expectations*, 110 CHEST 589, 589 (1996), available at <http://chestjournal.chestpubs.org/content/110/3/589.full.pdf+html>.

5. For a discussion of the approximate number of individuals who implement advance directives, see Kusmin, *supra* note 2. See also Byock, *supra* note 3, at 147-151; Clough, *supra* note 2.

6. Susan Brink, *Living Wills Often Ignored*, MSNBC.COM (Feb. 26, 2010, 6:13 PM), available at http://www.msnbc.com/id/35610499/ns/health-health_care/.

This article offers the view that advanced directives are not as effective in a clinical setting as the individuals who wrote them may have hoped they would be. Part II provides a brief background of advance directives. The applicable advanced directive statutes for Delaware, as well as the overlay of federal law, are discussed in Part III. Part IV of this article offers case studies from one of the author's clinical experience. Finally, Part V provides recommendations for better implementation of advanced directives, which will, in turn, allow them more practical application in real-world clinical environments.

II. BACKGROUND OF ADVANCE DIRECTIVES

In general, advance directives are intended to provide an individual a means of expressing his or her wishes for medical treatment when he or she is no longer able to make those wishes known due to incapacity.⁷ Included within the document is the ability to express how little or how much of a medical intervention an individual desires under certain clinical circumstances.⁸

Although scholars often argue that advance directives are implemented in a variety of documents,⁹ this article takes the view that there are two primary types of documents that constitute advance directives: living wills and durable powers of attorney.¹⁰ Living wills, also known as treatment directives, are created by an individual in advance of incapacity and contain instructions for medical personnel regarding that individual's preferences for end-of-life

7. Alexis Gregorian, *Post-Mortem Pregnancy: A Proposed Methodology for the Resolution of Conflicts Over Whether a Brain Dead Pregnant Woman Should be Maintained on Life-Sustaining Treatment*, 19 ANNALS HEALTH L. 401, 412 (2010).

8. Meehan, *supra* note 3, at 259. See also Keith E. Sonderling, *POLST: A Cure for the Common Advance Directive—It's Just What the Doctor Ordered*, 33 NOVA L. REV. 451, 451-52 (2009) (describing advance directives as tools capable of specifying treatments a patient wishes to receive or refuse).

9. Meehan, *supra* note 3, at 259 (stating that "living wills, healthcare proxies, durable powers of attorney, and do-not-resuscitate orders are all tangible documents formulated from discussions of advance directives").

10. Kusmin, *supra* note 2, at 93. The article discusses advance directives in a two-fold manner: first, as a living will which allows for an individual to express his or her treatment decisions in advance of incapacity; and second, as a durable power of attorney for health care which permits an individual to designate someone he or she trusts to make decisions on his or her behalf if he or she becomes incapacitated. *Id.* See also Anita K. Gordon, *Advance Directives Revisited: A Proposal to Amend Advance Directive Laws*, 28 J. HEALTH & HOSP. L. 85, 85 (1995). The rationale for the viewpoint taken by the authors of this article is supported by Delaware law. Under Chapter 25 of Title 16 of the Delaware Code, an "Advance health-care directive" is defined as "an individual instruction or a power of attorney for health care, or both." DEL. CODE ANN. tit. 16, § 2501(a) (2006). An "individual instruction" is the functional equivalent of a living will in that it is defined as "an individual's direction concerning a health-care decision for the individual." *Id.* § 2501(k). Furthermore, the Delaware Code includes a durable power of attorney for health care by defining a "power of attorney for health care" as "the designation of an agent to make health-care decisions for the individual granting the power." *Id.* § 2501(p).

treatment.¹¹ Durable powers of attorney, in contrast, are known as proxy directives, and they allow for a named individual to make decisions on behalf of a patient once that patient becomes personally unable to make the decisions.¹²

Despite these available options, and despite attempts by doctors to increase patient use of advance directives, very few individuals have prepared an advance directive.¹³ Furthermore, even though they have been endorsed by Congress and promoted by public health agencies, a 2006 paper estimated that only thirty-six percent of Americans implemented a living will, despite the fact that seventy-four percent of people believe it is very important to have such a document.¹⁴ However, the exact number of individuals who have an advance directive is difficult to ascertain from year to year; for example one scholar relied on a 2005 study that showed only five to fifteen percent of individuals in the United States have implemented an advance directive.¹⁵ Regardless of the exact number of individuals who have executed either a living will or durable power of attorney as an advance directive, it is known that the number is relatively low and that most individuals have not discussed advance directives or end-of-life planning with their physicians or, more importantly, with their families.¹⁶

The final piece of information necessary to obtain a brief understanding of advanced directives, before the focus of this article shifts to the applicable law and clinical reality in Delaware, is a general understanding of the law of advance directives in other states. All states now have legislation regarding advance directives.¹⁷ In many states the distinction between living wills and durable powers of attorney has been lost through clumsy legislation, illustrated by the fact that some states have separate statutory provisions relating to these documents while other states include them in the same statutory provision.¹⁸ Furthermore, statutory provisions relating to advance directives can differ

11. Belmont, *supra* note 3, at 154. See also Ashley Bassel, Note, *Order at the End of Life: Establishing a Clear and Fair Mechanism for the Resolution of Futility Disputes*, 63 VAND. L. REV. 491, 500 (2010).

12. Bassel, *supra* note 11, at 500; Belmont, *supra* note 3, at 154-55.

13. Gregorian, *supra* note 7, at 421. See also Meehan, *supra* note 3, at 259, 263.

14. Kusmin, *supra* note 2, at 97.

15. Clough, *supra* note 2, at 27. This article also mentions federal legislation requiring health care organizations to inform patients of their rights under existing state laws concerning advance directives. *Id.* That topic will be discussed *infra* at notes 58-64 and accompanying text. The apparent discrepancy in the number of individuals that have an advance directive has existed for quite some time. As of January 1, 1992, experts estimated that “only between [four] and [twenty-four] percent of adults had executed advance directives.” Gordon, *supra* note 10, at 89.

16. Byock, *supra* note 3, at 148, 150.

17. Gregorian, *supra* note 7, at 412; Daniel P. Hickey, *The Disutility of Advance Directives: We Know the Problems, But Are There Solutions?*, 36 J. HEALTH L. 455, 455 (2003). See generally Bretton J. Horrtor, *A Survey of Living Will and Advanced Health Care Directives*, 74 N.D. L. REV. 233 (1998).

18. Kusmin, *supra* note 2, at 97.

substantially from state to state.¹⁹ Texas, for example, enacted a controversial advance directive statute that so highly values a patient's personal autonomy in making end-of-life decisions that any person who willfully interferes with this autonomy can be subject to criminal penalties or even lose his or her medical license.²⁰ The advance directive statutory provision in Florida, moreover, contains a framework for surrogate decision-making when a written directive does not exist that employs the evidentiary standard of clear and convincing evidence to determine the intentions of the patient.²¹ These statutory differences demonstrate the importance of educating patients and providers on the range of decision-making options and capability.

With this general understanding of what constitutes an advance directive, the knowledge of the low rate of utilization of advance directives within our population, and the differences that exist in the legislative landscape, this article now turns its focus to Delaware's statutory provisions.

III. ADVANCE DIRECTIVES IN DELAWARE

The law in Delaware relating to advance directives is the state's Health-Care Decisions Act, codified in chapter twenty-five of title sixteen of the Delaware code.²² While this legislation contains multiple provisions, only three sections are applicable to the scope of this article.²³ Those applicable provisions relate to a patient's right of self-determination,²⁴ advance healthcare directives,²⁵ and surrogate decision making.²⁶

The very first substantive section of Delaware's Health-Care Decisions Act, after the definitions section, sets out a basic principle underlying the entire act. Section 2502 states that "[a]n individual, legally adult, who is mentally competent, has the right to refuse medical or surgical treatment if such refusal is not contrary to existing public health laws."²⁷ This principle is consistent

19. These differences have led some scholars to recommend the adoption of a Uniform Health-Care Decisions Act. *See, e.g.,* Hickey, *supra* note 17, at 462.

20. Nora O'Callaghan, *Dying for Due Process: The Unconstitutional Medical Futility Provision of the Texas Advance Directives Act*, 60 BAYLOR L. REV. 527, 578 (2008).

21. Jay Wolfson, *Schiavo's Lessons For Health Attorneys When Good Law is All You Have: Reflections of the Special Guardian Ad Litem to Theresa Marie Schiavo*, 38 J. HEALTH L. 535, 545-56 (2005).

22. *See* DEL. CODE ANN. tit. 16, §§ 2501-2518 (2006).

23. The Health-Care Decisions Act contains provisions relating to revocation of advance directives, obligations of health-care providers, protection of confidential health-care information, immunities from suit for medical professionals if certain criteria are met, procedural safeguards for incompetent individuals and individuals with disabilities, civil and criminal penalties including fines and imprisonment for offenses to this chapter, recognition of advance directives from other states, and a sample optional advance directive form. *See id.*

24. *Id.* § 2502.

25. *Id.* § 2503.

26. *Id.* § 2507.

27. *Id.* § 2502.

with the theoretical underpinnings of advance directives in that it allows for individuals to choose the treatment they wish to accept or reject.²⁸

Section 2503 of the Health-Care Decisions Act gives a competent adult the ability to both give an individual instruction regarding treatment and to create a power of attorney for health care.²⁹ To implement a valid advance directive under this section it must be in writing, signed by the patient, dated, and witnessed by two disinterested persons.³⁰ Additionally, advance directives only become effective upon a determination that the patient presently lacks capacity.³¹ If, however, an “advance healthcare directive is to be applied to the providing, withholding or withdrawal of a life-sustaining procedure” then it only becomes effective upon a determination that the patient now lacks capacity and that the patient has a qualifying condition.³²

In order for a patient’s designated power of attorney for health care to make a “decision to treat, withdraw or withhold treatment on behalf of the patient” he or she must consult with a physician regarding the patient’s condition and capacity to make decisions, and must make decisions in accordance with the patient’s wishes as set out in an individual instruction, if any.³³ If the patient’s exact wishes are not known for a given scenario or are not clearly applicable, the designated power of attorney must make the treatment decision “conform as closely as possible to what the patient would have done or intended under the circumstances.”³⁴ Here, the statute specifically enumerates factors for the designated power of attorney to consider in making his or her decision.³⁵ Those factors include the patient’s personal values, likelihood of regaining capacity, likelihood of death, the burdens and benefits of treatment, and reliable statements the patient previously made regarding life-sustaining treatment.³⁶ If the designated power of attorney cannot determine what the patient would have intended, his or her decision then “shall be made in the best interest of the patient.”³⁷ This framework of decision-making, of moving from the contents of any written document to what the patient would have wanted, then finally to the patient’s best interest, is further expounded upon in the discussion below regarding section 2507.

28. See Gregorian, *supra* note 7, at 412.

29. DEL. CODE ANN. tit. 16, § 2503(a)(1)-(2) (2006).

30. *Id.* § 2503(b)(1)(a)-(d). Subsection (b)(1)(d) specifically enumerates the requirements of what constitutes a disinterested witness. One scholar believes that statutes requiring a disinterested witness for an advance directive signing, although written with the intent to protect patients, instead creates a barrier to the use of these documents. See Kusmin, *supra* note 2, at 115. It is argued that “[s]ince relatives and doctors already have a substantial role in guiding the care of a terminally ill patient, it is illogical to disqualify them as witnesses.” *Id.*

31. Tit. 16, § 2503(c) (2006).

32. *Id.* The term “qualifying condition” and its specific requirements are defined in *id.* § 2501(r).

33. *Id.* §§ 2503(a)(1), 2503(f).

34. *Id.* § 2503(f).

35. *Id.* § 2503(f)(1)-(5).

36. *Id.*

37. DEL. CODE ANN. tit. 16, § 2503(f) (2006).

Based on one of the author's clinical practice experience in Delaware, there are multiple difficulties with written advance directives under this statute. One of the most basic problems is the healthcare providers' ability to obtain a copy.³⁸ Most advance directives are completed with the assistance of lawyers or members of a patient's family years before they are actually needed.³⁹ When advance directives are not readily available, it becomes difficult for healthcare providers to honor the wishes of patients.⁴⁰ In order to provide better access to advance directives, it is recommended that copies be given to the patient's primary care physician, "specialist physicians, family members, hospital, nursing facility, hospice, friends, clergy, and home health agency."⁴¹ Furthermore, in emergency situations in which a determination as to the existence of an advance directive is impracticable, healthcare providers will engage in life-sustaining treatment that is potentially against the patient's wishes.⁴² Finally, patients and their family members may be too overwhelmed, nervous or stressed at the time of admission to a healthcare facility to mention the existence of an advance directive or to place a high priority on locating the document.⁴³

As a result of these realities in clinical practice, all-too-often medical providers are forced to look past section 2503 of the Health-Care Decisions Act and instead rely on section 2507 relating to surrogate decision-making.⁴⁴

Section 2507 of the Health-Care Decisions Act first sets out two possibilities: (1) it allows for mentally competent patients to designate any individual to act as his or her surrogate decision maker, and (2) it creates a hierarchy of family members to act as the patient's surrogate decision maker if the patient otherwise did not designate or is unable to designate.⁴⁵ Once the surrogate decision maker is identified, any decision they make to "treat, withdraw or withhold treatment" must meet specific requirements.⁴⁶ These requirements set out the aforementioned framework for decision making, very similar to the requirements of section 2503.

In making a treatment decision, a surrogate must first make the decisions that are in accordance with any known individual instructions given by the

38. See Byock, *supra* note 3, at 150 (stating that "even when advance directives have been completed, they often can't be found").

39. Sonderling, *supra* note 8, at 473.

40. Hickey, *supra* note 17, at 460.

41. *Id.* at 461.

42. DEL. CODE ANN. tit. 16, § 2510(a)(4) (2006). And in providing such care, the actions of health-care providers will receive immunity from civil or criminal liability for unprofessional conduct. *Id.*

43. See Sonderling, *supra* note 8, at 473.

44. Tit. 16, § 2507 (2006).

45. See *id.* § 2507(b)(1)-(2) (2006). This hierarchy consists of the spouse, an adult child, a parent, an adult sibling, an adult grandchild, or an adult niece or nephew. *Id.* § 2507(b)(2)(a)-(f).

46. *Id.* § 2507(b)(7).

patient.⁴⁷ Next, if the patient's exact treatment decisions are not known, the surrogate uses substituted judgment to make the decision.⁴⁸ Finally, if it is unknown what the patient would have done under the circumstances, the surrogate makes the treatment decision that he or she believes represents the best interest of the patient.⁴⁹ As a result of this legislative framework, there are two possible standards to employ when making treatment decisions: substituted judgment and best interest.

The substituted judgment standard is applicable when the surrogate relies on the patient's known preferences.⁵⁰ This standard is used under two scenarios: either (1) the patient has provided previous, and explicit, statements as to his or her treatment preferences, or (2) the surrogate can infer the treatment decision the patient would have made based on prior conversations, actions, statements, treatment decisions, etc.⁵¹ Simply put, substituted judgment allows the surrogate to determine what the patient him or herself would have chosen regarding treatment.⁵² Applying this standard, "the surrogate is not making medical decisions for the patient but merely is giving effect to decisions the patient made" for him or herself before becoming incapacitated.⁵³ Surrogates should use knowledge of the patient's values and beliefs to aid in the decision-making process.⁵⁴

47. *Id.* § 2507(b)(7)(b)(1).

48. *Id.* § 2507(b)(7)(b)(2).

49. *Id.* § 2507(b)(7)(b)(3).

50. ALBERT R. JONSEN ET AL., *CLINICAL ETHICS: A PRACTICAL APPROACH TO ETHICAL DECISIONS IN CLINICAL MEDICINE* 89 (6th ed. 2006). See Bassel, *supra* note 11, at 502.

51. JONSEN ET AL., *supra* note 50, at 90.

52. Gregorian, *supra* note 7, at 421. The substituted judgment "standard requires 'that the surrogate's decisions correspond to what the incompetent patient would have preferred in advance of losing decisionmaking capacity had he or she given thought to the matter.'" *Id.* (quoting Alan Meisel, *Suppose the Schindlers Had Won the Schiavo Case*, 61 U. MIAMI L. REV. 733, 744-45 (2007)).

53. JONSEN ET AL., *supra* note 50, at 90.

54. *Id.* It is important to note that "[s]urrogates must be careful to avoid the common ethical pitfall of injecting their own values and beliefs into the decision-making process, because only the patient's values and beliefs are relevant to the decision." *Id.* The Delaware Supreme Court followed this view in stating:

The purpose of the "substituted judgment" doctrine is to ensure that the surrogate decisionmaker effectuates the decision that the incompetent patient would have made if he or she were competent. "Under the substituted judgment doctrine, where an incompetent's wishes are not clearly expressed, a surrogate decisionmaker considers the patient's personal value system for guidance. The surrogate considers the patient's prior statements about and reactions to medical issues, and all the facets of the patient's personality that the surrogate is familiar with—with, of course, particular reference to his or her relevant philosophical, theological, and ethical values—in order to extrapolate what course of medical treatment the patient would choose."

In re Tavel, 661 A.2d 1061, 1068-69 (Del. 1995) (quoting *In re Jobes*, 529 A.2d 434, 444 (N.J. 1987)).

When the patient's preferences are unknown, the best interest standard is applicable.⁵⁵ This standard mandates that the surrogate's treatment decision promote the patient's welfare.⁵⁶ Making a decision based on what the surrogate believes represents the best interest of the patient requires an understanding and acceptance of a quality of life presumption that all individuals "have an interest in being alive, being capable of understanding and communicating their thoughts and feelings, and being able to control and direct their lives and to attain desired satisfactions."⁵⁷ Beyond state law, any discussion of the law of advance directives in Delaware, or any state for that matter, is incomplete without mention of the overlapping federal law.

Congress enacted the Patient Self-Determination Act of 1990 (PSDA) as part of the Omnibus Budget Reconciliation Act of 1990.⁵⁸ The PSDA creates no new rights for patients; rather, its purpose is to afford patients an opportunity to express their wishes for end-of-life treatment as well as to generally educate the public about advance directives.⁵⁹ All healthcare institutions that receive funds from Medicare or Medicaid fall under the scope of the PSDA.⁶⁰ All healthcare institutions⁶¹ under the scope of the PSDA must meet the following requirements:

1. Provide written information to each adult patient on admission (in-patient facilities), enrollment (HMOs), and at first receipt of care (hospices and home health or personal care agencies). The information provided must describe the individual's legal rights under state law to accept or refuse medical care and to write advance directives for incorporation into his/her medical record;
2. Maintain written policies and procedures regarding advance directives and to provide written information to the patients about those policies;

55. JONSEN ET AL., *supra* note 50, at 91.

56. *Id.* A patient's welfare is defined as "making those choices about relief of suffering, preservation or restoration of function, and the extent and sustained quality of life that reasonable persons in similar circumstances would be likely to choose." *Id.* See also Bassel, *supra* note 11, at 502.

57. JONSEN ET AL., *supra* note 50, at 114.

58. Gordon, *supra* note 10, at 88. It is interesting to note that the PSDA was the first piece of legislation to "focus on advance directives and an adult's rights to refuse life-sustaining treatment." *Id.* Debate remains as to whether Congress enacted the PSDA in response to the Supreme Court's decision in *Cruzan* or as an effort to reduce health-care costs associated with the extension of life. *Id.*

59. OFFICE OF INSPECTOR GEN., DEP'T HEALTH AND HUMAN SERVS., PATIENT ADVANCE DIRECTIVES: EARLY IMPLEMENTATION EXPERIENCE 1 (1993), available at <http://oig.hhs.gov/oci/reports/oci-06-91-01130.pdf>.

60. Gordon, *supra* note 10, at 88.

61. Health care institutions "include, but are not limited to, hospitals, rehabilitation clinics, skilled-nursing facilities, hospices, home health and personal care agencies, and Health Maintenance Organizations (HMOs)." *Id.*

3. Document in the patient's medical record whether the individual has executed an advance directive;
4. Ensure compliance with state law requirements regarding advance directives; and
5. Provide, either independently or with other like institutions, for education for the staff and community on issues concerning advance directives.⁶²

The future of federal legislation and regulation in the area of advance directives, however, remains quite uncertain. On April 15, 2010, President Obama issued a memorandum to the Secretary of Health and Human Services requesting that the Secretary take steps to ensure that all hospitals receiving federal funding under Medicare or Medicaid are in compliance with the requirements enumerated above.⁶³ Furthermore, President Obama requested that the Secretary issue new guidelines on how healthcare institutions can better comply with these requirements and on how the Department of Health and Human Services can better enforce them.⁶⁴

With this understanding of the law of advance directives in Delaware, as well as an understanding of the federal laws and regulations that influence its direction, this article now turns its focus to the application of these principles.

IV. CLINICAL EXAMPLES AND APPLICATION

Through one of the author's own clinical experience, the following case studies are offered as examples of how the applicable laws of Delaware function in a real-life clinical environment. To protect the confidentiality of the patients discussed, no real names or other means of identification are used.

A. Case Study I: The Story of "AH"

The story of AH exemplifies some of the challenges of surrogate decision-making. AH was ninety-six years old when she was admitted to the hospital from her nursing home. AH had an advance directive stating that she wished to receive all available care to preserve her life.⁶⁵ She named her niece, MP, as her durable power of attorney for health care.⁶⁶ AH was diagnosed with breast

62. *Id.* For the regulatory codification of the exact requirements on health care institutions, see 42 C.F.R. § 489.102 (2010).

63. Proclamation No. 9211, 75 Fed. Reg. 20511, 20512 (Apr. 15, 2010).

64. *Id.*

65. Based on the Delaware statutes discussed above, since AH actually has a written advance directive (i.e., an individual instruction), it appears that § 2503 applies to this situation. *See* DEL. CODE ANN. tit. 16, § 2503(a)(1) (2006).

66. The structure of the Health-Care Decisions Act allows for both an individual instruction and a power of attorney for health care. *Id.* § 2503(a)(1)-(2). Here, AH exercised both her options under the statute by enacting a written directive and naming her niece as her power of attorney for health care.

cancer twenty years prior to her admission but chose not to have it treated. She also suffered from a decubitus ulcer on her sacrum. The initial reason for AH's admission to the hospital was shortness of breath, which prevented her from getting out of bed and was making her very weak. AH was found to have fluid in her lungs as well as renal failure. It was suspected that the cancer had metastasized to her lungs. MP, however, would not authorize a biopsy, believing that AH's prior refusal to treat her breast cancer meant she would not want to know of or treat metastasis.⁶⁷ AH stopped eating, a feeding tube was placed to improve her nutrition, and she was becoming less alert.

Six weeks after admission, AH's other family members, i.e. MP's sisters, began to express dismay; they did not believe that AH intended aggressive care such as a feeding tube when there was no hope of recovery. Nor did they believe that AH's intent, as expressed in her advance directive, was the basis on which MP made her decisions.⁶⁸ Rather, they believed she was suffering. MP became very angry with her sisters for interfering, and was verbally abusive to the nurse manager. MP demanded that no medical information be given to her sisters.

AH decompensated further and required intubation and mechanical ventilation. She was sedated and treated for pain. AH's blood pressure, other vital signs, and organ function also deteriorated to the point that she required life support within eight weeks of admission.

Nine weeks after admission, the treating team requested a family meeting. During this meeting, the treatment team told MP that AH had no chance of surviving from this illness. The team further suggested that resuscitation attempts would not be appropriate when AH dies. MP fired those physicians and threatened litigation if any medical treatment were withheld from AH.⁶⁹

Ethics consultations occurred six months after AH's admission. This consultation resulted in a suggestion that it was ethical to write a 'do not resuscitate' order over MP's objections. Fearing litigation, however, the

67. This raises an interesting problem with the application of advance directives. AH's written individual instruction stated that she wanted all available care to preserve her life. Surely it can be argued that this biopsy could lead to additional care in the effort to preserve her life. MP, however, based her decision not to allow the biopsy on the fact that AH previously refused such a procedure. Did MP act contrary the law by effectively using a substituted judgment standard when she first should have followed the individual instruction? *See id.* § 2503(f).

68. This fact raises an interesting point regarding the thoroughness necessary to complete an advance directive. For recommendations and further discussion in this area see *infra* Part V.

69. Under § 2503(f), MP was required to consult with physicians prior to making the treatment decision. *See* DEL. CODE ANN. tit. 16, §2503(f) (2006). The question arises, however, as to how much deference and consideration a decision maker is required to give to such consultations. Too much deference would result in undermining the autonomous purpose of advance directives. Little or no consideration of the physician's opinion makes the consultation nearly worthless.

attending physician never wrote that order.⁷⁰ AH survived on life support for nine months before she died.

At the time of her death, AH received an attempt at resuscitation resulting in obvious fracture of all her ribs with the first compression. MP was present when AH arrested but did not stay until the resuscitation effort ended. The nurses and physicians who participated in caring for AH have experienced differing levels of moral distress, believing they contributed to torturing her but were powerless to stop it.

It is difficult to know, as a healthcare provider, if MP was truly using substituted judgment in making decisions for her aunt. From the healthcare team's perspective, she was not using the best interest standard. Continued aggressive treatment at nine weeks after admission was deemed ineffective by the treatment team at restoring AH to health. Continued aggressive treatment in situations deemed futile contributes to moral distress and burnout in healthcare providers.⁷¹

B. Case Study II: Mrs. K's Dilemma

Problems still occur even when copies of advance directives are readily available and decision makers wish to comply with their loved one's instructions. One challenge adding to this dilemma is that medicine is not an exact science; it is as much an art as a science. Not all human bodies respond the same way to medicines, infections, or diseases. People are unique in their disease processes, thus it is difficult to predict who will recover from an illness or injury and who will not. Families, therefore, are given what seems like conflicting information from different specialists, making it very difficult to know when to stop aggressive treatment. Clinicians rarely use the term "life support" to describe treatments; rather, they use medical terminology of equipment and procedures, such as ventilator, dialysis, and "pressors" that are actually supporting the vital organs of the lungs, kidneys, and heart, respectively. The dilemma that arises, then, is that decision makers are unsure if terminology in the advance directive, such as "life support" or "heroic measures" has been "triggered."⁷²

The case of Mrs. K provides an example of this type of dilemma. Mrs. K was in the intensive care unit and her chart contained an advance directive.

70. While not discussed above, the fact that this happens in clinical settings raises serious concerns as to the strength of the safe harbor/immunity provisions of the statute. *See id.* § 2510. For a discussion of one scholar's belief as to the appropriate way to structure a safe harbor statute, see Thaddeus Mason Pope, *Medical Futility Statutes: No Safe Harbor to Unilaterally Refuse Life-Sustaining Treatment*, 75 TENN. L. REV. 1 (2007).

71. Moral distress is defined as knowing in one's own heart the right action to take but either being constrained by forces outside of one's control or being forced to act against the right action, contributing to harm. *See* ANDREW JAMETON, *NURSING PRACTICE: THE ETHICAL ISSUES* 6 (1984).

72. Linda Emanuel & Ezekiel Emanuel, *The Medical Directive: A New Comprehensive Advance Care Document*, 10 EST. & TR. J. 134, 136 (1991).

She had named her son and her friend as decision makers.⁷³ Both of these individuals strongly desired to follow Mrs. K's request not to be kept alive on life support if not expected to recover. Mrs. K was on her second admission to critical care suffering from an overwhelming blood infection that spread from her colon. After her colon ruptured and she had emergency surgery, Mrs. K recovered to a certain extent and was getting stronger when she suffered a cardiac arrest.

At the time of her ethics consultation, Mrs. K was on a ventilator, on pressors, and was unconscious with no hope of recovery or regaining consciousness. She had been in this condition for two weeks, and the intensive care team asked the family if Mrs. K would want a permanent airway (tracheostomy) and a feeding tube. Her son believed she would not want the feeding tube, but he was not sure about the tracheostomy.⁷⁴ He thought that his mom might be dying, but he also believed the doctors must think she would recover if they were recommending these procedures. In reality, there are often questions regarding the tracheostomy because the ventilator requires access to the lungs via the trachea. An emergently placed tube cannot remain for an extended period of time due to the damage it causes to the mouth and trachea. Critical care doctors would rather have a permanent airway to prevent damage to the trachea. Mrs. K's decision makers are not sure if they should permit the tracheostomy or not.

C. Case Study III: Mr. H's Family in Crisis

Yet another challenge for advance directives is the family in crisis. Mr. H's story exemplifies this situation. Mr. H was a sixty-nine-year-old gentleman with a history of kidney disease, multiple strokes that left him unstable on his feet, and was blind. Over the course of a few weeks he suffered several falls at home, resulting in multiple rib fractures and the inability to get out of bed. Mr. H had an advance directive requesting no "heroic measures" should he become terminally ill.⁷⁵ In the past, Mr. H has refused dialysis, telling his

73. Here, assuming Mrs. K was competent when she made this decision, under tit. 16, § 2507(b)(1), she had the authority to name any individual(s) as her surrogate decision maker(s).

74. Under the decision making framework set out by the Health-Care Decisions Act, as discussed in *supra* Part II, Mrs. K's son would first have to use the substituted judgment standard and then use the best interest standard. *See* DEL. CODE ANN. tit. 16, § 2503(f) (2006); Gregorian, *supra* note 7, at 421. Here, it appears that the son did use a substituted judgment standard regarding the feeding tube (because he thought his mother would not want such care). The tracheostomy is a different matter, however, as it appears the son misunderstood the doctor's request to mean that the doctors believed that the tracheostomy was in the best interest of Mrs. K. See the recommendations for a suggested solution to this dilemma *infra* Part V.

75. Under the Health-Care Decisions Act, the fact that Mr. H has a written advance directive suggests that section 2503 is the applicable section. *See* DEL. CODE ANN. tit. 16, § 2503(a)(1) (2006). There is an issue here because the use of the term 'heroic measures' does not allow a decision maker to know exactly what Mr. H wishes, and that term can never be "clearly applicable" to any given situation. *Id.* § 2503(f). As such, the decision maker will have no

doctor that he never wants that treatment. He was admitted to the hospital with swelling and pain from his most recent fall. Once admitted, Mr. H's blood pressure dropped and it was determined that he had developed an overwhelming blood infection and kidney failure. He had two daughters and one son. The son recognized that his father may be at the end of his life, but Mr. H's daughters demanded provision of all aggressive care. Mr. H's son informed the treating team of his father's past refusals of dialysis. Mr. H's daughters disagreed with this position, and the son stopped coming to the hospital.

The treating team believed that continued aggressive treatment would not restore Mr. H to his previous health, and that at best he would require nursing home placement because of his need for continued mechanical ventilation. His daughters continued to demand dialysis, invasive catheters, and treatments and resuscitation should he arrest. The unfortunate result of this type of conflict is that healthcare professionals give more authority for decision making to families than to advance directives, mostly out of a fear of potential litigation from surviving family members.⁷⁶

V. RECOMMENDATIONS

There are countless issues and complexities surrounding the use of advance directives. Due to the highly individualized nature of medical care, as well as the deep personal issues that advance directives address, it is extremely unlikely that a one-size-fits-all solution will ever emerge. Despite that, however, the clinical experiences illustrated in the article have demonstrated that the following recommendations are the most important tenets to good decision making.

First of all, family members and healthcare providers alike should encourage patients to name surrogates who they know will follow their instructions. As part of this discussion, an attempt should be made to make clear to the patient the amount of power that a surrogate may have in the decision making process as well as the difficulties the surrogate may face from his or her own emotions and from the divergent points of view of family members.

Second, creating an advance directive should involve discussions of beliefs and values.⁷⁷ Instead of providing narrow boundaries, an advance directive should be used "as an instigator of conversation and thought."⁷⁸ Only through use of the patient's values, preferences, and beliefs can the best

choice but to move forward with substituted judgment. For a further discussion of the use of terms such as 'heroic measures,' see *infra* Part V.

76. See tit. 16, § 2510.

77. "Advance directives should be seen as tools that facilitate making difficult decisions in uncertain times, not as static, dogmatically binding documents." Kristi L. Kirschner, *When Written Advance Directives Are Not Enough*, 21 *CLINICS GERIATRIC MED.* 193, 203-04 (2005).

78. Clough, *supra* note 2, at 19.

possible treatment result come to fruition.⁷⁹ One scholar stated this view eloquently when he said:

It's not sufficient for an individual's advance directive to merely comply with prevailing statutes; to be most useful, it must be crafted in a manner that is meaningful in contemporary clinical settings and situations. Advance directives are most useful when the choices encompassed are based on conversations within families.⁸⁰

Only when individuals engage in such value-based discussions with their family, friends, clergy, attorney, and healthcare providers, and then document such discussions and values, can advance directives become more effective in a clinical setting.

As a final recommendation, families should push for involvement in care teams based on patient and family centered care. At the core of patient and family centered care is the philosophy that patients as well as families should contribute to medical decision making.⁸¹ The use of such a model in making difficult end-of-life decisions would help to eliminate, or at least reduce clinical "pitfalls" in the current legislative framework.

VI. CONCLUSION

As advances in medical technology continue to grow, and as state legislatures continue to create and modify legislation, it seems inevitable that the impact of advance directives on clinical settings will continue to change. The fact will remain, however, that despite our fear of death and the dying process, open communication about our beliefs and values with our loved ones and the professionals to whom we entrust our care is essential to ensure appropriate and desirable end-of-life treatment.

79. Hickey, *supra* note 17, at 464-65. It has also been suggested that physicians, as part of their duty of care, should be required to become aware of a patient's values and preferences regarding end of life treatment and should document these in the patient's chart. *Id.* at 465.

80. Byock, *supra* note 3, at 150-51. The Delaware Court of Chancery appears to agree with this view. See *In re L.M.R.*, No.4392-S-MG, 2008 Del.Ch. LEXIS 255, at *10-11 (Jan. 24, 2008) (stating that in determining the decision that a ward would have made, evidence should include facts relevant to the ward's personal values, philosophy, theology and ethics).

81. See generally *Frequently Asked Questions*, INST. FOR PATIENT AND FAMILY CENTERED CARE (Dec. 10, 2010), <http://www.ipfcc.org/faq.html>. "Patient-and family-centered care is an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families." *Id.*