

Advance Care Planning: A Patient's Choice

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“Let our advance worrying become advance thinking and planning” – Winston Churchill

INTRODUCTION

The topic of advance care planning too often arises after the opportunity to express choices and preferences has passed. It is, at times, the elephant in the room that remains ignored because it seems too depressing or too early to think or talk about it. Some people are unfamiliar with advance care planning beyond the ill-conceived notion that it is for those about to die. Both patient and doctor alike have a duty to understand and appreciate the importance of this tool that can help lessen or avoid family conflict and unwanted medical treatment.

HISTORY OF ADVANCE CARE PLANNING

Advance care planning and its associated laws and legal documents did not appear until the second half of the 20th century. The concept was most formally introduced in 1967 by the Euthanasia Society, an international group focused on fighting for the right to die for those facing a terminal illness.¹ A prominent human rights attorney, Luis Kutner, proposed the concept of the Living Will in a law journal article published in 1969 titled *“Due Process of Euthanasia: The Living Will, a Proposal.”*² Although much of Kutner’s article focused on the right-to-die, and criminal cases arising out of assisted suicide, he also discussed a patient’s right to decline medical treatment at the end of life, and the inability of the incapacitated patient to express these wishes.

In that era physicians were expected to take every measure possible to extend the patient’s life if the patient was incompetent or incapacitated and unable to request otherwise.³ But as medical technology advanced, and medical providers were increasingly able to extend patients’ lives, the need to document choices legally became apparent.⁴ Over time, the advance care planning movement developed momentum and gained supporters.

RIGHT TO DIE

The advance care planning movement also received publicity due to infamous “right-to-die” issues that drew an onslaught of public attention and opinion. Several right-to-die cases were so notorious that simply mentioning them still stirs up emotional debate and disagreement. These include the cases of Karen Quinlan,⁵ Terry Schiavo,⁶ and Nancy Cruzan.⁷

In January 1983, Nancy Cruzan sustained severe brain injuries as the result of a car accident that left her in a persistent vegetative state. She had no advance care planning documents. When it became clear that Nancy would never awaken from her unconscious state, her parents requested that the medical team remove her nutrition and hydration. The hospital refused to comply with their request without a court order. The trial court ordered the hospital to comply with the Cruzans’ wishes, noting that the Missouri statute, by prohibiting the withholding or withdrawal of such life sustaining measures, violated Nancy’s right to liberty, due process, and equal protection under the law.⁸ Unfortunately, the patient had no advanced care planning documents and the only evidence her parents could provide of Nancy’s was testimony from a few witnesses that the patient had stated at one time or another that she “never would want to live as a vegetable” or “would not want life support if she was permanently unconscious.”

Multiple appeals ensued until the case reached the United States Supreme Court, which held that in the absence of advance care planning documents the State of Missouri was permitted to require clear and convincing evidence of the patient’s wishes. While a competent individual possesses the right to refuse such treatment, a surrogate decision maker must meet this burden of proof.

The case made its way back to state court where a judge ultimately ordered removal of the feeding tube. While the Supreme Court’s decision in and

of itself was not a landmark decision, the mere fact that the case reached the High Court demonstrates the highly contested nature of this issue, which could have been avoided altogether with the right planning tools.

THE PATIENT SELF-DETERMINATION ACT

In 1991, and, not coincidentally, towards the end of the Cruzan legal battles,⁹ the federal government enacted The Patient Self-Determination Act, which requires health care providers to (1) inform patients of their rights to make decisions concerning their medical care under state law; (2) document in the patient's chart whether or not the patient has executed an advance directive; (3) not discriminate against patients who have executed an advance directive; (4) ensure that advance directives and documented medical care wishes are respected and implemented to the extent permitted by law; and (5) provide education for staff, patients, and the community on ethical issues concerning medical choices and advance directives.¹⁰ The Act recognizes a patient's right to refuse medical treatment, including life-sustaining interventions, and the importance of advance care planning to help avoid the situations involved in cases such as *Cruzan and Quinlan*.¹¹

The Patient Self-Determination Act was not the only legislative development resulting from these controversial cases. Many states responded by passing legislation – or amending existing legislation – that governed living wills and powers of attorney to help avoid legal uncertainty and confusion.¹² States continue to update their advance care planning laws, and some have passed “death with dignity” laws¹³ that grant a terminally ill patient the right to choose when and how he or she dies. The advance care planning movement sparked in the late 1960s continues with new developments on both federal and state levels.

PENNSYLVANIA

The Commonwealth of Pennsylvania updated its advance care planning laws in 2006 when Governor Ed Rendell signed Act 169 into law.¹⁴ The Act, which was arguably long overdue, modified and restructured the statute governing advance care planning. Among other changes and additions, it defines “competent” and “permanently unconscious” and redefines “incompetent.” It also provides

a framework for designated individuals to act on the patient's behalf. Individuals named in an existing power of attorney are termed “health care agents.” When no power of attorney exists, they are designated by statute as “health care representatives” who may make decisions for the patient.¹⁵ Importantly, it also provides liability protection for a physician who follows the instructions in a patient's living will or the order of a health care agent.¹⁶ While the Act did provide much needed clarification and guidance, gaps remain and some questions cannot be answered by looking to the law.¹⁷

THE DOCUMENTS

“Advance care planning” is a general term to describe conversations about goals and values related to future health care decisions, and the recording of those decisions in a legal document to be referenced if an individual becomes medically incompetent. The advance care plan is memorialized in a *living will*, a *Physician Order for Life-Sustaining Treatment* (“POLST”),¹⁸ or a *health care power of attorney*. While every person does not necessarily need one of each document on file at all times, the documents all comprise the plan that should guide the medical professionals and surrogate decision-maker in the event the person is deemed medically incompetent.

A *health care power of attorney* designates an individual or individuals who may make health care-related decisions on behalf of the patient. Under Pennsylvania law, it becomes active when the document is provided to the attending physician and the physician finds the patient to be incompetent, unless the power of attorney states otherwise.¹⁹ Unlike a living will or a POLST, which are more commonly used by terminally ill or elderly individuals, a health care power of attorney can be drafted broadly to grant complete decision-making authority outside of situations involving the end of life. The agent's authority can include granting access to the patient's medical records and signing informed consent forms on behalf of the patient for procedures.²⁰ The power of attorney may outline the patient's specific detailed requests for end-of-life care, or simply name a health care agent. Most powers of attorney do provide guidance in addition to naming successor agents in the event the first-named individual is unable or unwilling to perform the duties. If a patient has two powers of attorney, the medical provider will look to the most recently executed document.

In the absence of any legal documents, the Pennsylvania statute provides a list of individuals to whom the medical team can turn for decisions.²¹ Depending on whether the first person on the list is willing and able to stand in as the health care representative, the team must go down the statutory list until they can find a willing and able person. Though a representative selected in this fashion is usually able to act in the patient's best interests, they may not be familiar with the patient's wishes or comfortable acting upon them, if they are known. Furthermore, without absolute certainty as to the nature of the patient's true wishes, other family members may disagree with the representative, and the decision may result in emotional distress and family disagreement. Devising a plan and having the necessary conversations with family members early on avoids this unwanted scenario.

MORAL AND ETHICAL CONSIDERATIONS

The advance care planning process is not particularly complicated when viewed in a technical, objective light. What many people fail to consider in the planning process is the family-discussion that should accompany completion of the documents. Ideally, the named health care agent is someone who will speak on the patient's behalf, is willing and able to act on the patient's wishes, understands the patient's spiritual and moral values, and can help to manage family conflict.²² Creating a plan is more than checking boxes or naming an agent, it is having meaningful conversations with loved ones so they will understand the choices. The avoidance of this awkward, difficult topic often results in delay that can permanently defer discussion and execution of the documents. Medical providers who raise the topic must consider the patient's condition and how the topic may be perceived: is discussing advance care planning with an oncology patient attending his second follow-up visit sending the wrong message? If the patient initially reacts negatively, when is it appropriate to raise the topic again, if ever? Medical providers have a duty to dispel myths surrounding advance care planning as well. For example: some

people may believe that by encouraging a patient to have a POLST or living will in place, the hospital is trying to limit its responsibility to keep a patient alive for fiscal reasons, or that the patient will be left to suffer without any type of palliative measures in place. Knowledge and understanding can help patients and their families overcome such fears or mistaken beliefs.

Depending on the patient's condition and life expectancy, the discussion can include an introduction to palliative care. In the past, physicians treating patients facing end-stage, terminal illnesses would often raise the option of hospice care as opposed to pursuing additional attempts at curative or life-lengthening treatment. Patients with serious illnesses that were not yet end-stage did not have the benefit of palliative care that now helps with more than just pain management. Today, palliative care is not limited to patients with very short life expectancies, but seeks to improve overall quality of life by treating the symptoms and stress of a serious illness through medical, spiritual, emotional, and therapeutic care. Palliative care is not hospice care, though a palliative care provider will often treat a patient receiving concomitant hospice care. Regardless of the context, palliative care has facilitated communication between provider and patient about advance care planning.

CONCLUSION

Planning for the future is a common theme in life. While still young, most people learn about the importance of saving money for a "rainy day" or why we all need health or car insurance. Advance care planning is no different. On its most basic level, it is simply planning ahead for the unknown. However, in today's society, conflicting views and beliefs as well as discomfort about end-of-life discussions often prevent the necessary planning and thus create larger problems later. Medical providers should encourage their patients to contemplate these decisions, and family members should encourage their loved ones to create a plan together.

REFERENCES

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2. 44 Ind. L. J. 539 (1969).
3. *Id.* at 550.
4. Sabatino at 211-12.
5. *In re Quinlan*, 70 N.J. 10 (1976).
6. Macina, RP. Advance Directives; Since Schiavo, more important than ever. *J Lanc Gen Hosp.* 2006; 1: 15-17.
7. *Cruzan by Cruzan v. Director, Missouri Department of Health*, 497 U.S. 261 (1990).
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9. Lewin, T. (1990) Nancy Cruzan Dies, Outlived by a Debate Over the Right to Die, *The New York Times* retrieved from <http://www.nytimes.com/1990/12/27/us/nancy-cruzan-dies-outlived-by-a-debate-over-the-right-to-die.html>
10. 42 U.S.C. § 1395cc(f).
11. Despite this beneficial legislative action, right-to-die cases have not disappeared. The Terri Schiavo matter, which surfaced shortly after the federal law's enactment, spanned over a decade until Ms. Schiavo died in March 2005 after the United States Supreme Court rejected the petition to appeal the Eleventh Circuit Court's ruling to remove nutrition and hydration.
12. Advance Directives and Advance Care Planning: Report to Congress, August 2008, retrieved from <https://aspe.hhs.gov/basic-report/advance-directives-and-advance-care-planning-report-congress#history>.
13. At the time this article was published, five states had "Death with Dignity" or "Aid in Dying" laws enacted: Oregon, California, Washington, Montana and Vermont.
14. See 20 Pa. C.S. §§ 5421 et seq.
15. *Id.* §§ 5456, 5461.
16. *Id.* § 5431(a).
17. Pennsylvania legislators are currently drafting legislation that will govern Physician Orders for Life Sustaining Treatment ("POLST"). At the time of publication, no such statute existed.
18. Costella, MF. Pennsylvania Orders for Life Sustaining Treatment (POLST): Taking Patient Autonomy to the Next Level. *J Lanc Gen Hosp.* 2011;6 (4): 127-128.
19. 20 Pa. C.S. § 5454(a). "Incompetent" is defined as being a "condition in which an individual, despite being provided appropriate medical information, communication supports and technical assistance, is documented by a health care provider to be (1) unable to understand the potential material benefits, risks and alternatives involved in a specific proposed health care decision; (2) unable to make that health care decision on his own behalf; or (3) unable to communicate that health care decision to any other person." *Id.* § 5422. "The term is intended to permit individuals to be found incompetent to make some health care decisions, but competent to make others." *Id.*
20. 20 Pa. C.S. § 5456.
21. *Id.* § 5461(d)(1). The statutory list is as follows: "(i) The spouse, unless an action for divorce is pending, and the adult children of the principal who are not the children of the spouse. (ii) An adult child. (iii) A parent. (iv) An adult brother or sister. (v) An adult grandchild. (vi) an adult who has knowledge of the principal's preferences and values, including, but not limited to, religious and moral beliefs, to assess how the principal would make health care decisions." *Id.*
22. Sabatino, C. (2010) Five Myths of Advance Care Planning [PowerPoint slides] retrieved from http://www.americanbar.org/content/dam/aba/migrated/health/documents/ABA_Advance_Care_2010.auth-checkdam.pdf.

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