

ADVANCE HEALTH CARE DIRECTIVES: PROBLEMS AND SOLUTIONS FOR THE ELDER LAW AND ESTATE PLANNING PRACTITIONER

BROOKE M. BENZIO, J.D.*

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I. INTRODUCTION

“Remember that what you possess in the world will be found at the day of your death to belong to some one else; but what you are, will be yours forever.”¹ -Henry Van Dyke.

* Ms. Benzio is a 2005 graduate of the Florida State University. She received her J.D. from Loyola University Chicago School of Law in 2008, where she received a certification from Loyola’s nationally-ranked Beazley Institute of Health Law and Policy. She is accredited by the Department of Veterans Affairs (“VA”), and she is presently a member of THE ESTATE, TRUST & ELDER LAW FIRM, P.L., in Port Saint Lucie, Florida, where she specializes in Estate and Long-Term Care Planning.

1. HENRY VAN DYKE, THE STORY OF THE PSALMS 22 (7th ed. 1913).

Since the modern movement for patient autonomy began gathering steam in the 1900s, individual concerns about the purpose, nature, and quality of medical care have become a larger component of the practice of medicine.² However, state and federal law has been relatively slow to respond, and establishment of the relevant legal framework is relatively recent. New Jersey courts led the charge with their decision in *In re Quinlan*,³ regarding the right of an individual to decline medical treatment based on the constitutional right to privacy.⁴ Fourteen years later, the United States Supreme Court showed support for the *Quinlan* ruling by holding that an individual's constitutionally established right to refuse medical treatment may be broader than the rights granted by state statutes.⁵ However, in the same decision, the Court also held that states have the right to require that evidence of an incompetent person's wishes as to the withdrawal of life-sustaining treatment be proved by clear and convincing evidence and that the states have a legitimate interest in the preservation and protection of human lives within their borders.⁶

In an effort to protect patient autonomy, many states began authorizing advance health care directives as a method of providing evidence for unforeseen future health needs.⁷ In 1990, the Patient Self Determination Act⁸ (hereinafter "PSDA") passed, requiring Medicare-participating health care facilities to: inquire whether patients have advance health care directives; document this information in the patient's chart; and provide information to all patients about their rights with regard to medical treatment decision making.⁹ Additionally, under the PSDA, Medicare and

2. E.g., Jonathan F. Will, *A Brief Historical and Theoretical Perspective on Patient Autonomy and Medical Decision Making: Part II: The Autonomy Model*, 139 *CHEST* 1491, 1491–97 (2011), available at [http://journal.publications.chestnet.org/article.aspx?volume=139&issueno=6&page=1491&etoc#Part2—PatientKnowsBest\(theAutonomyModel\)](http://journal.publications.chestnet.org/article.aspx?volume=139&issueno=6&page=1491&etoc#Part2—PatientKnowsBest(theAutonomyModel)).

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

4. *Id.* at 663.

5. *Cruzan v. Dir., Mo. Dep't. of Health*, 497 U.S. 261, 277–81 (1990); see also *Washington v. Glucksberg*, 521 U.S. 702, 720 (1997) ("We have also assumed, and strongly suggested, that the Due Process Clause protects the traditional right to refuse unwanted lifesaving medical treatment.").

6. *Cruzan*, 497 U.S. at 281–84.

7. See, e.g., David Y. Nakashima, *Your Body, Your Choice: How Mandatory Advance Health-Care Directives Are Necessary to Protect Your Fundamental Right to Accept or Refuse Medical Treatment*, 27 *U. HAW. L. REV.* 201, 206–08 (2004).

8. Omnibus Budget Reconciliation Act of 1990, Pub. L. No. 101–508, 104 Stat. 1388 (codified as amended at 42 U.S.C. §§ 1395cc, 1396a (1994)).

9. Diana Anderson, *Review of Advance Health Care Directive Laws in the United States, the Portability of Documents, and the Surrogate Decision Maker When No Document is Executed*, 8 *NAELA J.* 183, 184 (2012); see also Omnibus Budget Reconciliation Act sec. 1866(f) (requiring health care institutions to provide patients with information on health care advance

Medicaid participating facilities may not condition the provision of care, or otherwise discriminate against an individual, based on whether or not a patient has executed an advance directive, and participating facilities must provide their staff and the community with regular education and training on issues related to advance directives.¹⁰

Generally, advance health care directives are legal documents by which competent adults give instructions regarding their medical care in the event that they lose the ability to make their own health care decisions in the future. These documents serve two distinct purposes: (1) designating an individual to make health care decisions on behalf of the designator; and (2) providing guidance about the type and amount of medical care the individual desires.¹¹ Loss of the ability to make medical decisions may be due to a variety of circumstances, including: mental infirmity, unconsciousness (including temporary unconsciousness), or the inability to communicate verbally or otherwise.

Legal practitioners in the fields of Estate Planning and Elder Law have found that planning for end-of-life treatment, decision-making, and health care surrogacy has become an area of much concern for their clients, especially with the prevalence of highly-publicized cases like the case of Terri Schiavo.¹² This article will concentrate primarily on critiques of advance directives and practical issues relevant to the Florida practitioner,¹³ and will provide some possible solutions.¹⁴ However, a number of the problems addressed in this article are similar to those faced by out-of-state peers.

II. PRACTICAL PROBLEM #1: INTERPRETING PRECISE MEDICAL (AND LEGAL) TERMINOLOGY

Many practitioners in this area of the law are aware of a consensus among their clients that the language utilized in Estate Planning documents, for example, is “legalese”; therefore, clients rely on the attorney for interpretation of the text. Although the terms are, for the most part, “plain

directives).

10. KRISTEN J. COLELLO ET AL., CONG. RESEARCH SERV., R40235, END-OF-LIFE CARE: SERVICES, COSTS, ETHICS, AND QUALITY OF CARE 15 (2009), http://assets.opencrs.com/rpts/R40235_20090223.pdf.

11. Susan P. Shapiro, *Advance Directives: The Elusive Goal of Having the Last Word*, 8 NAELA J. 205, 205 n. 1 (2012).

12. See *Schindler v. Schiavo* 780 So. 2d 176 (Fla. Dist. Ct. App. 2001); *Schindler v. Schiavo*, 800 So. 2d 640 (Fla. Dist. Ct. App. 2001).

13. See discussion *infra* Parts II.C, III, IV.A–B, V.

14. See discussion *infra* Parts II.D–F, IV.C, V.A.

English,” the document is written from the perspective of a legal practitioner. One of the major critiques of standard advance directive forms is that they are not readily understood by the average person and they cannot, therefore, ensure informed decision-making. There may be some merit to this critique: the mean reading level of U.S. adults is an eighth-grade level, but for U.S. adults over the age of sixty-five, the mean reading level drops to fifth grade.¹⁵ Most advance directives, even those not drafted by attorneys, are written at a twelfth-grade level.¹⁶ Similarly, much of the operative language in advance health care directives is comprised of medical terminology that has a precise definition that the individual creating the advance directive may not actually understand. This disconnect can lead to some tense and heart-wrenching scenarios for surrogate decision makers.

Some examples of particularly troublesome medical terms are: “terminal condition,” “permanently unconscious,” “persistent vegetative state,” and “irreversible coma.”¹⁷ Many times, this terminology is utilized to indicate that the advance directive will only become operative upon the happening of a specific condition. Individuals who are not health care professionals generally have a sense of what they think many of these words mean, however, sometimes they rely on their internal definitions to their detriment. Take for example the following, regarding the definition of an “irreversible coma”:

Attending Physician: I see that you brought in the power-of-attorney document. It was from 2001.

Patient’s Son: She was at [a different hospital] at the time. I believe that a chaplain brought the form in. He read it to us. She could barely understand it.

Attending Physician: I’ve looked over the form. You see here, your mother checked this box that says that she wants to have aggressive care unless she is in an irreversible coma.

Patient’s Son: Yes. I never really read the form. That’s what she is now.

Attending Physician: Unfortunately, a coma is a medical term with a very precise meaning. Your mother is not in a coma. She may experience some cognitive limitations—severe cognitive limitations—but they are not a coma, and not an irreversible coma. This hospital

15. Richard Scott, *5 Problems with Advance Directives*, DORLAND HEALTH (Feb. 3, 2011), http://www.dorlandhealth.com/social_work/trends/5-Problems-with-Advance-Directives_1663.html.

16. *Id.*

17. See Anderson, *supra* note 9, at 186–87.

has a strict policy that if this box is checked, we have to provide aggressive care, even if that's not what the patient would have wanted or even told their family¹⁸

In the example above, the problem appears to be twofold: (1) the advance directive document was limited to a very particular medical condition that may never be applicable to the patient (though there may be a number of other applicable conditions not addressed by the form that become relevant), and (2) the patient (and her son) did not understand the specific limitations of the document the patient signed. Frequently, patients and their families are under the impression that there is a “generally applicable” advance directive that can cover the entire spectrum of possible scenarios. Some critics contend that advance directives fail to effectuate a patient’s true choices because people cannot foresee (and therefore cannot truly contemplate) their future medical needs well enough to have the proper context.¹⁹ In fact, one study asserts that sixty-four percent of “dying patients’ living wills do not actually cover the clinical realities they face.”²⁰ The difficult truth is that medical care, especially that which is received at the end of a person’s life, is highly individualized and advance directives must be carefully utilized in consideration of this fact.

A. WHEN IS AN ADVANCE DIRECTIVE EFFECTIVE?

As you will recall from the example in the prior section, sometimes problems are created when the advance directive document has a particular operational condition that has not been met. For example, a living will might contain the following language: “I direct that life-prolonging procedures be withheld or withdrawn when the application of such procedures would serve only to prolong artificially the process of dying.” A patient or surrogate relying on a document with the aforementioned language would need information from the physician regarding the prognosis of the illness in order to know if the living will had become operative. Unfortunately, it can be difficult for physicians to conclusively determine a particular prognosis in certain instances, which can have a chilling effect on utilization of the advance directive.²¹

18. Shapiro, *supra* note 11, at 212.

19. John K. Davis, *Precedent Autonomy, Advance Directives, and End-of-Life Care*, in THE OXFORD HANDBOOK OF BIOETHICS 349, 350 (Bonnie Steinbock ed., 2007).

20. Kevin B. O’Reilly, *Defective directives? Struggling with end-of-life care*, AM. MED. NEWS (Jan. 5, 2009), <http://www.amednews.com/article/20090105/profession/301059970/4/>.

21. See Angela Fagerlin & Carl E. Schneider, *Enough: the Failure of the Living Will*, 34 HASTINGS CTR. REPT., Mar–Apr. 2004, at 30, 36.

Determination of operative conditions can be especially problematic when dealing with illnesses that involve a slow decline, such as Alzheimer's Disease, because it can be nearly impossible for medical personnel to conclusively establish that a particular operative condition has been met, or to give a prognosis, when there is technically no probability of recovery.

The competency of patients with impaired capacity may fluctuate. Therefore, in an effort to protect the patient's right to self-determination for as long as possible, medical practitioners may be reluctant to certify that operative conditions for surrogacy have been met. Additionally, when the patient's capacity fluctuates, medical personnel may be hesitant to take any particular affirmative action, especially where the effects cannot be "undone," for fear of legal action.

In the absence of an advance directive or in the absence of language describing the "triggering" condition(s) upon which the advance directive will become effective, state law will control. Nearly half of the states have codified some form of "triggering" condition.²² Florida Statutes section 765.305 contains the following regarding procedure in the absence of a living will:

Before exercising the incompetent patient's right to forgo treatment, the surrogate must be satisfied that: (a) [t]he patient does not have a reasonable medical probability of recovering capacity so that the right could be exercised by the patient [and] (b) [t]he patient has an end-stage condition, the patient is in a persistent vegetative state, or the patient's physical condition is terminal.²³

Such language applies in a situation where there is no living will, but where the patient has a surrogate health care decision maker. What if the patient did not designate a surrogate prior to their incapacity?

B. QUALIFICATION OF SURROGATES

Generally, the order of surrogacy expressed in a written advance directive will control. However, Florida Statutes section 765.401 establishes an order of priority for naming surrogates when there is no written document establishing a medical surrogate:

(a) The judicially appointed guardian . . . ; (b) [t]he patient's spouse; (c) [a]n adult child of the patient, or if the patient has more than one adult child, a majority of the adult children who are reasonably available for consultation; (d) [a] parent of the patient; (e) [t]he adult

22. See Anderson, *supra* note 9, at app. B, 202-03 (summarizing the number of states with default provisions).

23. FLA. STAT. § 765.305(2)(a)-(b) (2013).

sibling of the patient, or, if the patient has more than one sibling, a majority of the adult siblings who are reasonably available for consultation; (f) [a]n adult relative of the patient who has exhibited special care and concern for the patient and who has maintained regular contact with the patient and who is familiar with the patient's activities, health, and religious or moral beliefs; or (g) [a] close friend of the patient.²⁴

The significance of the codified order of priority is twofold: (1) individuals who wish to avoid involving certain family members need to be aware of the default provisions and should be cautioned to execute advance directives to ensure their preferred surrogate(s); and (2) individuals who assume their significant other or spouse will automatically be first in priority need to be aware of some special concerns.

One special concern regards designation of the spouse as surrogate: what happens if, after execution of the advance directives, an individual subsequently divorces or separates from the spouse whom they have named as their surrogate? Florida law allows the individual executing the advance directive to make provisions (in the advance directive itself, or in the order for dissolution or annulment) to allow a former or estranged spouse to continue to serve, but absent such language, dissolution or annulment will revoke the designation to the former spouse.²⁵

Another important note for practitioners concerns clients who have same-sex domestic partners or spouses. Under present law, Florida's constitution contains no provision for the recognition of same-sex marriages. Thus, it is important for such individuals living in (or frequently visiting) Florida to ensure that they have executed advance directives (specifically documents appointing a health care surrogate or proxy decision maker) that comply with Florida law, to provide their spouse or partner the necessary authority to act on their behalf, especially in situations where there are tense family dynamics. Even with the recent developments in the U.S. Supreme Court regarding the Defense of Marriage Act,²⁶ the best protection for the recognition of same-sex partners can be achieved easily by maintaining valid advance directives in every state in which each partner regularly lives or visits.²⁷ Irrespective of

24. FLA. STAT. § 765.401(1)(a)–(g) (2013); *see also* § 765.401(1)(h) (providing for the appointment of a clinical social worker if (a) through (g) fail).

25. FLA. STAT. § 765.104(2) (2013).

26. *See* *United States v. Windsor*, 133 S. Ct. 2675, 2696 (2013) (finding the Defense of Marriage Act unconstitutional).

27. *See generally* Lesley S. Castillo et. al., *Lost in Translation: The Unintended Consequences of Advance Directive Law on Clinical Care*, 154 ANNALS OF INTERNAL MED. 121, 123 (2011) (discussing why advance directives are especially beneficial for same-sex partners).

marital status, it is also advisable for all clients to name additional “successor” surrogates who can act in the event that the primary designation fails to ensure that priority decisions made by the patient will not be undermined by a failure to protect against this contingency.

C. SPECIAL PROBLEM AREA: DO NOT RESUSCITATE ORDERS

One of the most pronounced areas of public misinterpretation is related to the Do Not Resuscitate Order (“DNRO”). The DNRO is a medical order issued by a physician that directs clinicians not to provide cardiopulmonary resuscitation (“CPR”) in the event of cardiac or respiratory arrest.²⁸ Some physicians may be reluctant to sign this order unless a patient is terminally ill or otherwise not expected to recover from cardiac arrest due to the finality of withholding such life-saving intervention. However, the DNRO can be an integral part of end-of-life planning for certain individuals.

Despite the narrow applicability of the DNRO, individuals frequently misconstrue it as either a substitute for advance directives regarding end-of-life treatment (e.g., a living will), and/or interpret the DNRO to mean “do not treat.”²⁹ However, a DNRO is specifically limited to resuscitative efforts following cardiac or respiratory arrest and does not preclude otherwise appropriate treatments (e.g., for pain or symptom management), or other life-sustaining interventions that might be applicable under the circumstances. A DNRO is not permission to terminate a patient’s life, and it is not a substitute for a living will or other documents memorializing a patient’s choices regarding designation of a medical surrogate or their end-of-life treatment desires.

Critics have suggested changing the name of the DNRO to “AND,” which stands for “Allow Natural Death,” to relay a more accurate picture of the purpose of the order.³⁰ When contemplating whether a DNRO should be part of a patient’s end-of-life care plan, conversations with physicians should contain the following elements: (1) the patient’s treatment goals

who live in states that do not recognize same-sex unions).

28. FLA. STAT. § 401.45(3) (2013).

29. See EMS ADVISORY COUNCIL AD HOC COMM FOR END-OF-LIFE CARE, FLORIDA END-OF-LIFE-CARE FOR THE EMERGENCY MED. SERV. PROVIDER, INSTRUCTORS GUIDE 20 (2002), <http://www.doh.state.fl.us/demo/trauma/DNRO/EOLCInstctrManual503.pdf>.

30. See, e.g., Reverend Chuck Meyer, *New Designation for Allowing a Natural Death (“A.N.D.”) would Eliminate Confusion and Suffering When Patients are Resuscitated Against their Wishes*, HOSPICE PATIENTS ALLIANCE, <http://www.hospicepatients.org/and.html> (last visited Sept. 23, 2013) (stating that the time has come to change the name from DNR to “AND” to avoid confusing patients and their families).

(e.g., restoration and/or maintenance of specific mental or physical functionality, rehabilitation, or curative measures); (2) specific medical procedures declined by patient because of pain, difficulty, or impediment of function (e.g., feeding tubes); (3) physician discretion with regard to ability for a particular treatment to meet the patient's specific goals; (4) the congruence of the patient's goals with the availability of appropriate medical interventions; and (5) creation of a care plan that can be easily discerned by any physician first responder in an emergent situation.³¹

D. PRACTICE SOLUTION #1: COOPERATIVE PLANNING WITH HEALTH CARE PROFESSIONALS

One of the best ways the patient can ensure that their medical treatment decisions will be honored, is by open and continuous communication with their physicians and other health care providers. Such discussions should not be limited merely to the abstract or vague, and should include: (1) the benefits and burdens of contemplated treatments; (2) comfort and symptom management/palliative care;³² and (3) aggressive attempts to restore function or life as opposed to withdrawal of treatment if the patient's goals cannot be met. Legal practitioners can facilitate these important discussions by establishing relationships with the medical professionals involved with the patient-client, and by participating in cooperative planning with these individuals. Frequently, we rely on the client and/or their family members to provide important and sensitive health information about the client for the purposes of legal planning. However, much like the disconnect between the legal and medical terminology used in advance directives and the interpretation of same by individuals outside the medical and legal fields, such reliance can be to the client's detriment. Signed releases allowing the provision of sensitive

31. Vicki Lachman, *Do-Not-Resuscitate Orders: Nurse's Role Requires Moral Courage*, 19 *MEDSURG Nursing* 249, 250 (2010); see also AM. NURSES ASS'N, POSITION STATEMENT ON NURSING CARE AND DO-NOT-RESUSCITATE (DNR) DECISIONS (2003), <http://ana.nursingworld.org/MainMenuCategories/EthicsStandards/Ethics-Position-Statements/Copy%20of%20dnr0414405.aspx>. The American Nurses Association (ANA) *Position Statement on Nursing Care and Do-Not-Resuscitate (DNRO) Decisions* addresses the duty nurses have in educating patients and families on the realities of CPR and DNRO, as well as helping them gain access to explicit discussions of DNRO with physicians. AM. NURSES ASS'N, *supra*.

32. *WHO Definition of Palliative Care*, WORLD HEALTH ORG., <http://www.who.int/cancer/palliative/definition/en/> (last visited Sept. 23, 2013). The World Health Organization (WHO) defines palliative care as: "an approach that improves the quality of life of patients and their families facing the problem[s] associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual." *Id.*

health information to a client's attorney for the purposes of assisting with the overall Estate and/or Long-Term Care Plan, including decisions regarding patient self-determination, will ensure more accurate understanding of the client's health status and treatment options. Legal practitioners armed with a more specific understanding will be better equipped to explain the client's rights with regard to self-determination within the context of their actual prognosis.

Even those individuals whose Elder Law practice is limited to assistance with public benefits (such as Medicaid, VA compensation, and pension claims) will find that they are frequently asked or expected to perform additional services and provide counsel with regard to ancillary issues such as: decisions about maintaining Medicare advantage plans and supplemental health care policies; advice regarding the purchase of long-term care insurance products; assistance in locating a facility placement or home-health company; questions about the Baker Act³³ process; and assistance in dealing with uncooperative elders and/or difficult family dynamics.

Recent changes in the law, regarding how health and social services are delivered by state and federal programs,³⁴ have emphasized the notion that the modern Elder Law practitioner must have a greater exposure to health and social service delivery system mechanisms than ever before. As each new piece of legislation expands or restricts the services and benefits available to clients, legal practitioners must continue to evolve and adjust their practices to ensure that clients are appropriately informed and advised. One way to provide the ancillary services and information required by clients, without causing a substantial burden on the legal practitioner who does not have a health care background, is through the development of relationships with professionals in health service delivery fields. The unfortunate reality is that clients are frequently uninformed about available resources and are in crisis by the time they have sought the assistance of an attorney. However, the multi-disciplinary nature of this area of the law provides great opportunities to ensure the best results for clients by collaborating with other professionals, including attorneys who practice in related areas, such as: medical malpractice, personal injury, Social Security disability, and bankruptcy, to name a few.

33. Florida Mental Health Act, FLA. STAT. §§ 394.451–394.47891 (2013).

34. *See generally, e.g.*, Patient Protection and Affordable Care Act, Pub. L. No. 111–148, 124 Stat. 119 (2010) (reforming the structure and execution of the national health care system in the United States of America); Medicaid Managed Care, FLA. STAT. §§ 409.961–409.985 (2013) (outlining how health care facilities should deliver services to Medicaid recipients).

Developing relationships with physicians can also be a useful way to assist clients in achieving eligibility for public benefits. Generally speaking, the eligibility requirements for means-based, long-term care benefits specify that the applicant must need a certain level of care, based on their ability or inability to perform various “activities of daily living.”³⁵ Many legal practitioners are currently seeing clients who are over eighty-five years of age, and although relatively healthy (i.e., frail, but managing any chronic conditions and not presently suffering from a particular diagnosis that would warrant immediate acute care) these clients frequently outlive their retirement savings, either in their homes or in an assisted-living facility. Physicians, who have a long-term relationship with the client and a good working relationship with their legal advocate, can assist in providing accurate, detailed, and updated diagnoses that can assist the client in achieving eligibility. Frequently, patients misrepresent or under represent their needs, often due to the desire to appear independent (either out of pride or fear of being institutionalized against their will) without understanding the scope of their care needs and the benefits available to them. Additionally, physicians can be reluctant to take action that will cause a hardship for their patient. For example, consider the physician who believes that the patient is reaching a stage where they should stop driving, but who knows the patient and his wife will be stranded in their home if the husband can no longer drive because they have no family nearby and have been unwilling to consider facility placement. If the physician was able to coordinate with the patient’s attorney to ensure that transportation services would be provided and/or to provide a united front in discussing transition to an assisted-living facility, the patient may be more willing to comply, and certainly a safer and more beneficial result could be achieved. Many elderly clients place a significant level of trust in their attorney and physician because of the assistance provided by both with regard to sensitive personal matters. If the patient-client is able to have two of his most trusted advisors working together for his benefit, greater service can be provided overall.

Discussion of the new Medicaid Reform initiatives³⁶ being phased in this year is somewhat outside the scope of this article. However, it bears

35. See JOSHUA M. WIENER, RAYMOND J. HANLEY, THE BROOKINGS INST., ROBERT CLARK & JOAN F. VAN NOSTRAND, U.S. DEP’T OF HEALTH AND HUMAN SERVICES, MEASURING THE ACTIVITIES OF DAILY LIVING: COMPARISONS ACROSS NATIONAL SURVEYS 1, 1 (1990), <http://aspe.hhs.gov/daltcp/reports/meacmpes.pdf> (defining “activities of daily living” as “the basic tasks of everyday life, such as eating, bathing, dressing, toileting, and transferring”).

36. See generally Medicaid Managed Care §§ 409.961–409.985 (providing Florida-specific guidelines for compliance with federal Medicaid requirements).

mentioning that the implementation of these programs will undoubtedly affect service delivery and the benefits available to the clients of the Florida Elder Law practitioner. Thus, it would be wise for any such practitioner to maintain contacts with the Department of Children and Families, Area Agencies on Aging, and regional service providers to ensure that their clients are abreast of changes. Ideally, implementation of the Medicaid Reform initiatives will expand home and community-based services, allowing clients to stay in their homes and remain independent for as long as possible.

E. PRACTICE SOLUTION #2: HEALTH CARE PROFESSIONALS ON STAFF

A number of trailblazers in the field of Elder Law have recently discussed the future of the practice in light of significant changes in health care legislation and shifts in the demographics of our country. One of the common themes of these predictions for the future of the practice is the movement away from the concept that Elder Law is simply “Medicaid planning.” On the contrary, the practice of Elder Law is constantly changing to fit the needs of the clientele, and includes a number of related services, including, but not limited to: medical care management; advocacy for health care services; assistance with securing housing and obtaining public benefits in addition to Elder Law’s “big two” (Institutional Care Program Medicaid and VA Aid & Attendance); assisting with issues of domestic violence, financial fraud, abuse and neglect; advocacy with regard to matters of patient autonomy; and medical malpractice, both in and outside of the institutional setting.

A major factor contributing to this dynamic shift is the disproportionate growth of the “aged” population compared to the amount of individuals in the workforce. By 2050, the “dependency ratio”—the number of persons of working age per “dependent” person (children under the age of eighteen and adults over the age of sixty-five)—will have decreased from two-and-a-half to one, to one to one.³⁷ At the beginning of the twentieth century, women and men had a combined average life expectancy of approximately 49.2 years.³⁸ The majority of people died before reaching the age of sixty-five, which we now consider to be a milestone for retirement from the workforce.

37. Thomas Caffrey & Mary WanderPolo, *A Brave New World Awaits: The Elder and Special Needs Law Practice of the Future*, 9 NAELA J. 115, 118 (2013).

38. COLELLO, *supra* note 10, at 1.

Currently, the life expectancy of the average woman in the United States is eighty-one years and the life expectancy of the average American man is seventy-six years.³⁹

During the early twentieth century, the majority of deaths took place in the home.⁴⁰ Over the last century, that trend has changed drastically, and now deaths primarily occur in an acute-care setting even when the cause of death is non-emergent.⁴¹ Many people have become fearful that the combination of advanced age and the increase in modern medical technologies will result in a dying process that is more drawn out and difficult than necessary. Conversely, a number of people fear the exact opposite: that their advanced age and illness (often when combined with economic factors affecting access to health care) will result in a lack of needed treatment or medical intervention. “Health care is already a [relatively] scarce resource . . . in the United States, [and as this demographic shift continues,] . . . [u]ltimately, overt rationing of health care [services] will . . . be necessary, as there will not be enough resources to provide . . .” what many Americans have come to expect and could once afford.⁴²

Another challenge for the legal practitioner is dealing with the varied personalities of his or her clients. The typical client for an Elder Law attorney will be between sixty-five and ninety-five years old, which encompasses individuals in the generations commonly referred to as “World War II” (those born before 1946) and “Baby Boomers” (those born between 1946–1965). Those from the World War II generation are frequently described as understanding and hardworking, respectful of authority, rational, and emotionally resilient. “Baby Boomers” present a different viewpoint.⁴³ Many in this generation grew up expecting to receive Medicare and Social Security benefits, have a higher incidence of college education than their “World War II” counterparts, live in single households, are childless, and have worked outside the home.⁴⁴

Additionally, it is frequently the children of the elder who first

39. *World Fact Book*, Central Intelligence Agency, <https://www.cia.gov/library/publications/the-world-factbook/geos/us.html> (last updated Oct. 25, 2013).

40. COLELLO, *supra* note 10, at 3.

41. See Bradford H. Gray, *England's Approach to Improving End-of-Life Care: A Strategy for Honoring Patients' Choices*, THE COMMON WEALTH FUND, July 2011, at 1, 2, http://www.commonwealthfund.org/~MEDIA/Files/Publications/Issue%20Brief/2011/Jul/1527_Gray_Englands_approach_endoflife_care_intl_brief_v2.pdf.

42. Caffrey & WanderPolo, *supra* note 37, at 118.

43. *Id.* at 117.

44. *Id.*

approach the attorney regarding the needs of their parent. These children typically fall into the younger end of the “Baby Boomer” generation. Moreover, they can also be categorized as members of a “sandwich” generation because, in many cases, they have both grandchildren and aging parents to take care of simultaneously. This can be an extremely difficult family dynamic to navigate, and an Elder Law practice would benefit greatly from the presence of a social worker, counselor, or geriatric nurse practitioner to assist with the delicate family dynamics that frequently pose a threat to the elder’s overall legal plan.

Utilization of a health care professional on staff may also provide some answers to the scarcity problem by allowing clients to work with an individual who is “plugged in” to the health care service delivery model. Additionally, this can help coordinate medical services, facility placement, and remedies for inadequate care and resulting damages. As practitioners have discovered under the current circumstances, referring a client to outside assistance for coordination of service delivery can sometimes have negative unintended consequences. For example, clients do not follow up or accurately report the outcome of contact with service providers; they fail to understand the mechanisms of service delivery and inadvertently refuse appropriate services; or they fail to understand continuing maintenance of benefits programs and do not report changes in circumstances to their attorneys for assistance. Yet, frequently when benefits are discontinued, denied, or fail to meet expectations, clients often feel as though the legal practitioner has failed to be their advocate. Thus, the Elder Law practitioner cannot prosper long in a world in which they limit the services they offer to their clients. We must recognize that this is a multi-faceted area in which the solution to our clients’ problems must consider a variety of factors and dynamics. Furthermore, we must enlist help from professionals in related disciplines.

Many practitioners are able to provide these services by forming relationships with other professionals within the senior care services network. However, Elder Law attorneys have decided to provide such services “in-house” by hiring a geriatric nurse practitioner or care manager to assist with the provision of services that are inexplicably linked to the legal services provided. Frequently, clients requiring the services of an Elder Law attorney are in the midst of (or have recently experienced) a major health crisis. Without specialization in Health Law or prior experience in health or social services, many attorneys find themselves ill-equipped to provide the kind of guidance their clients want, need, and deserve.

F. MACRO SOLUTION #1: EDUCATION AND TRAINING FOR HEALTH CARE PROFESSIONALS AND THE PUBLIC

Generally, health care professionals have continuing educational requirements to keep them abreast of changes in law and policy within their field. However, policymakers concerned with patient autonomy and the quality of medical care have suggested greater emphasis on training of health professionals (including physicians, nurses, social workers, and aides) regarding end-of-life decision-making and supportive services, including palliative care.⁴⁵ A suggested focus for such training has been the communication skills necessary to address the sensitive issues surrounding end-of-life treatment and decision making with patients and their families. Such policymakers theorize that increased training and education will lead to more comfortable and frequent discussions, less confusion, and greater patient and family satisfaction with the perceived quality of care.⁴⁶

A component of exemplary Elder Law practice must be continuing education not only for the practitioner and his or her staff, but also for existing clients and the public at-large. Many attorneys provide informational seminars as a way to generate business, but such seminars offer an ancillary service by prompting individuals in the community to discuss issues they may not previously have considered or been concerned about. Additionally, whenever legal professionals and health care professionals can provide opportunities for “cross training” in the areas of health care service delivery, utilization and application of advance directives, and management of care for patients in the institutional setting, each professional group (and the public they serve) will benefit greatly.

III. PRACTICAL PROBLEM #2: PORTABILITY ISSUES

“Advance health care directives are [presently] recognized [in some format,] in all 50 states and the District of Columbia . . .”⁴⁷ However, there is a great deal of variation among the different states with regard to both the laws regulating such advance directives, the terminology used, the scope of decision-making addressed in the directive, restrictions on who may serve as a proxy or surrogate in the absence of an advance directive, and how and when such documents become effective.⁴⁸

45. See Gray, *supra* note 41, at 11.

46. See *id.*

47. Anderson, *supra* note 9, at 183.

48. See *id.* at 185.

The Uniform Health-Care Decisions Act of 1993⁴⁹ (“UHCD”) aimed to create greater uniformity among advance health care directives between the states due to the recognition that directives given in one state are frequently required to be interpreted in another.⁵⁰ As of the date of this article, the UHCD has only been adopted by six states,⁵¹ and there is still a large amount of variation between the states with regard to advance health care directive laws.

There is a pilot program currently underway in South Florida and a handful of other states regarding the use of a document called “Physician Orders for Life-Sustaining Treatment” (“POLST”), which is a single document intended to encompass both the end-of-life treatment decision-making in a traditional living will and a DNRO.⁵² Proponents of this program contend that promulgation of a generally accepted and applicable advance directive that contains detailed information and is easily understood by the public will improve access and portability.⁵³

A. INSTITUTION AND/OR TREATMENT-SPECIFIC DOCUMENTS

The example from Part II concerning the interpretation of an “irreversible coma” is also illustrative of another common problem in this area—that of forms from other institutions being relied on as blanket advance directive forms. Frequently, individual health care institutions have their own internal forms that are intended to be specific to a particular stay or medical procedure. For example, an individual receiving emergency surgery may sign an advance directive indicating that they do not wish for aggressive measures to be taken due to the nature of the emergency and probability of recovery. However, if the surgery is successful and they recover, would they continue to make the same election with regard to future treatment? If not, it is important that the patient take

49. UNIFORM HEALTH-CARE DECISIONS ACT (1994), http://www.uniformlaws.org/shared/docs/health%20care%20decisions/uhcda_final_93.pdf. The Uniform Health-Care Decisions Act was drafted, approved, and recommended by the National Conference of Commissioners on Uniform State Laws at an annual conference meeting in Charleston, S.C. held July 30–August 6, 1993. *Id.*

50. UNIFORM HEALTH-CARE DECISIONS ACT (1994), Prefatory Note (1994).

51. See National Conference of Commissioners on Uniform State Laws, *Legislative Fact Sheet - Health-Care Decisions Act*, UNIFORM LAW COMM’N (2013), <http://www.uniformlaws.org/LegislativeFactSheet.aspx?title=Health-Care%20Decisions%20Act> (stating that only Alaska, Hawaii, Maine, Mississippi, New Mexico, and Wyoming have adopted the UHCD).

52. See Marshall B. Kapp, *Beyond Medical Advance Directives: Implementing the POLST (Physician Orders for Life-Sustaining Treatment) Paradigm in Florida*, 17 FLA. B. HEALTH L. NEWSL. 10 (2011).

53. See *id.* at 1.

measures to ensure that their care plan will be appropriately updated to avoid misinterpretation. However, without guidance from attorneys and/or health care providers, patients frequently forget to revisit this issue, especially after the instant medical crisis has been averted. “Form” documents have also been criticized for being geared toward “Western” values without consideration for important individual preferences, such as religious and cultural considerations.⁵⁴ However, this issue can be easily overcome by detailed discussions with the patient-client and their family members, and conscious drafting choices.

B. OUT-OF-STATE DOCUMENTS

(i) An Advance Directive by Another Name

One of the most obvious areas of confusion for individuals dealing with out-of-state documents is related to the different naming conventions for documents that purport to serve essentially the same function. The documents utilized in the fifty states and the District of Columbia generally fall into one of three categories: “(1) living wills or advance health care directives; (2) durable powers of attorney for health care; and (3) a single document that encompasses both [(1) and (2)].”⁵⁵ Although these naming conventions fall into some generally applicable categories, they are not necessarily consistent, even within a particular geographical region. For example, Florida technically refers to all of the documents in this area broadly as “advance directives,” as does Georgia.⁵⁶ However, Alabama utilizes the terms “living will” and “health care power of attorney.”⁵⁷

In addition to the fact that there is frequently something lost in translation when it comes to medical terminology as interpreted by health care professionals and patients/family members, each state defines certain medical terminology differently for the purposes of their statutes regarding advance directives. Further, each state has defined the condition that triggers the effectiveness of an advance health care directive according to independent terms. As a result, reliance upon an out-of-state advance directive may result in confusion and extreme distress. Consider the following case from Illinois:

54. See Anderson, *supra* note 9, at 184.

55. *Id.* at 185.

56. See FLA. STAT. § 765.101 (2013) (defining “advance directive”); GA. CODE ANN. § 31-32-2 (2013) (defining “advance directive”).

57. See Anderson, *supra* note 9, at 199.

One patient in the study had been in the [Intensive Care Unit] for two weeks. After days of wrenching conversations, the family decided to remove her life support. At the insistence of a physician, the patient's daughter brought in a copy of the power-of-attorney form; however, the document only addressed the handling of financial matters. Under Illinois law, only a designated power of attorney for health care is permitted to remove life support from a patient who does not have a qualifying medical condition, which this patient did not have. The family was stunned and infuriated that the life support had to continue.⁵⁸

This issue is exceptionally relevant to practitioners in Florida (and other states with a large population of retirees and individuals who are residents of one particular state, but are only physically located in that state for part of the year). Generally, conventional wisdom among Estate Planning practitioners is that one should have one's Estate Planning documents (specifically those dealing with the administration of your property and person during life and incapacity) drafted in the state in which one resides. However, part-time residents pose a special challenge in this regard.

(ii) Reciprocity and Execution Formalities

There is no reason why individuals who travel to the same states frequently or who spend part of the year residing in another state cannot execute documents in each state in which they frequently spend time to ensure maximum protection of their autonomy—especially in situations where the laws of the states in question substantially differ. Although a number of states have adopted some form of “reciprocity provision,” not every state has done so. Furthermore, the reciprocity can be limited or conditional in those that have adopted a reciprocity provision, Full Faith and Credit Clause notwithstanding.⁵⁹

Florida's reciprocity provision is relatively expansive and reads as follows: “An advance directive executed in another state in compliance with the law of that state or of this state is validly executed for the purposes of this chapter.”⁶⁰ However, consider the familiar situation where a “snowbird” client is a part-time resident of Florida and a part-time resident

58. Shapiro, *supra* note 11, at 212 n.27.

59. See U.S. CONST. art. IV, § 1; see also Anderson, *supra* note 9, at 192 (summarizing the Full Faith and Credit provision in the United States Constitution). “Full faith and credit shall be given in each state to the public Acts, Records, and judicial Proceedings of every other State. And the Congress may by general Laws prescribe the Manner in which such Acts, Records, and Proceedings shall be proved, and the Effect thereof.” U.S. CONST. art. IV, § 1.

60. FLA. STAT. § 765.112 (2013).

of Michigan, where there is no reciprocity provision.⁶¹ If the client has Florida documents only, they are only half protected. In fact, if they were only going to have one set of documents, validly executed documents from Michigan would offer better overall coverage. However, best practice might suggest that they have both Michigan and Florida documents to protect against unforeseen changes in Florida's laws regarding the recognition of documents from other states.

Execution requirements can also pose a special challenge to reciprocity. Some state reciprocity provisions are drafted so that the out-of-state advance directive will only be accepted if validly executed according to the laws of the interpreting state. This kind of "limited" reciprocity provision can create barriers to the mobility of advance directives in some strange and often unforeseen ways. For example, most states require an individual to be eighteen years old in order to execute an advance directive, but there are two states that require the principal to be nineteen.⁶² Because eighteen is frequently considered the "age of legal majority" for a number of other purposes, it is easy to see how provisions like these can lead to confusion and frustration. Additionally, states have different requirements with regard to witness and notary provisions, and failure to meet the execution requirements of the state in which you attempt to utilize the advance directives could have disastrous consequences.⁶³

IV. PRACTICAL PROBLEM #3: CHANGING YOUR MIND

The decision about whether to execute advance directive documents is sometimes predicated upon some faulty premises on the part of the client. For instance, the client may be under the mistaken impression that if they execute a living will now, but later decide they want life-prolonging measures to continue as long as possible, they will be bound by the directive they previously executed. Practitioners know that this is not the case, and that as long as the individual has the requisite mental capacity, they can change their mind with regards to all facets of their Estate Planning, including decisions regarding medical treatment.

Furthermore, there is evidence to suggest a relatively widespread failure among families to proactively discuss wishes about medical treatment. Recall the heart-wrenching case of Terri Schiavo, where one of

61. See Anderson, *supra* note 9, at 202-03 (listing the seven states that presently have no reciprocity provisions: Kentucky, Michigan, Missouri, New Mexico, South Dakota, Utah, and Wyoming).

62. *Id.* at 199-201.

63. See *id.* at 198.

the main issues of contention was whether Terri's husband or parents had a more accurate understanding of Terri's desires, specifically regarding the continuance of life-support if she was in a "persistent vegetative state."⁶⁴ Unfortunately, because Terri did not have any sort of advance directive, there was no way to know whether her wishes were ultimately honored by the actions of her surrogate, (former) husband, Michael Schiavo, on March 18, 2005.⁶⁵

Even in less contentious situations, family members designated as surrogates can feel as though they have been saddled with an enormous responsibility, and they may feel ill-equipped to make the decisions they are called to make because they have never explicitly discussed these issues with the individual for whom they are serving as a surrogate. Further, when conversations about medical treatment and end-of-life care⁶⁶ are not revisited throughout the patient's lifetime and continuum of care, antiquated ideals of the patient's values can lead to decisions that are contrary to the patient's actual wishes at the time the decision is required.

Similarly, subjective terms can cause added stress for surrogates, especially when the patient's wishes are contingent upon a particular prognosis. For example, patients who would choose aggressive curative treatment as long as they could "return to a meaningful existence" need to ensure that their surrogates know what they consider a "meaningful existence." Would a patient who loves to paint choose to return to an existence in which he or she could no longer see or utilize his or her upper extremities? When surrogates are called to make such subjective judgments on behalf of the patient, it can be extremely difficult to avoid imparting their own feelings, and surrogates, especially significant others and close family members, can be paralyzed by indecision.

Additionally, accurate or definitive prognostic information may be difficult to elicit from health care professionals, especially in the early stages of an illness or injury, for a variety of reasons including the fact that

64. See generally Timothy E. Quill, *Terri Schiavo—A Tragedy Compounded*, 352 NEW ENG. J. MED. 1630 (2005) (summarizing the Terri Schiavo case).

65. *Id.* at 1633 (indicating that the feeding tube was removed on March 18, 2005, and Terri died on March 31, 2005).

66. See COLELLO, *supra* note 10, at summary.

End-of-life care can be broadly defined as health care provided to persons who are very ill, have a prognosis that is likely to worsen, and most likely will die in the near term from their illness. End-of-life care may be in the form of acute care provided in the days or months prior to death or palliative care, which focuses on relieving the patient's suffering and reducing the severity of disease symptoms as well as improving quality of life.

Id.

physicians and other health care personnel may feel the weight of their involvement in the decisions surrounding the death of a patient. It is also important to understand that there can be some difference in opinion about prognosis among health care professionals. In the *Schiavo* case, there was discord between the medical professionals hired by Michael Schiavo, who asserted that Terri was in a “persistent vegetative state,” and those hired by Terri’s parents, who asserted that Terri’s condition could possibly improve via the utilization of as-yet unproven therapies.⁶⁷

Research has also shown that even among patients who generally want all attempts to be made to restore their health and functioning, this desire is not absolute. As their prognosis changes over the course of their injury, illness, or treatment, so does their desire to continue with medical intervention, especially when such intervention is futile, harmful, or likely to cause additional and unnecessary suffering without having any positive effect.⁶⁸ Substantial research has also indicated that patient preferences are relatively unstable and often inconsistent, even over the course of one isolated health event.⁶⁹

A. RELUCTANT AND OVERZEALOUS SURROGATES

With so many possible contingencies in medical treatment scenarios, there is no way to account for all possibilities, which can place undue pressure on surrogate decision-makers. Some surrogates will rise to the occasion certain that they know what their loved one would have wanted, and others will be paralyzed by guilt or fear of failing to honor their loved one’s wishes. Sometimes surrogates discount changes in a patient’s wishes regarding treatment because they feel the changes are “colored by depression, confusion, dementia, fear, [or] loneliness.”⁷⁰ However, especially in circumstances in which the condition coloring the patient’s wishes is likely to continue, is it not a relevant part of the equation?

Sometimes family members and surrogates create problems by substituting their own judgment for that of the patient. Consider the following:

Critical Care Fellow: So, last night he developed what he had before, called septic shock. The infections are over-taking [Patient’s] body

67. See Quill, *supra* note 64, at 1631.

68. See generally Kristi L. Kirschner, *When Written Advance Directives Are Not Enough*, 21 CLINICS IN GERIATRIC MED. 193 (2005) (summarizing the existing research on advance directives).

69. See *id.*

70. See Shapiro, *supra* note 11, at 223.

despite the optimal antibiotic treatments that we're giving him. Because of the tumor, the infections went into his blood stream. His blood pressures [sic] dropped to a point that is not consistent with life. We have him on three medications to keep his blood pressures [sic] up, and even still his blood pressure is pretty low We're doing everything we can, but his body is not able to fight off all these infections. I know that you love him so much. I can see how much you love him. The main reason I wanted to talk to you is because his blood pressures [sic] are dropping, and so we're concerned that his heart may stop. If he were to have a cardiac arrest, we would try to resuscitate him by doing chest compressions. This is an absurdly painful process. In situations where we think that someone could recover, we often do cardiac resuscitation. But in [Patient's] case, because so many of his organ systems are down—his blood pressure, the cancer overtaking his body, his immune system, the infections—the chances of being able to bring him back are pretty much as close as they get to the smallest chance. I would not want to put [Patient] through that pain, since I don't believe it would allow him to come back.

Mother: I don't have a choice. This is what [Patient] wanted. [Patient] told his doctor, [Oncologist]. He said, "Mama, I do not want DNR."

Critical Care Fellow: I do not want to what?

Mother: Do Not Resuscitate, or whatever. Do not Do Not Resuscitate. Well he didn't say it that way, but he said he wanted to be resuscitated. I wish that I could do it differently, but that's what [Patient] wanted.

Father: I know you probably think we don't care about him.

Critical Care Fellow: No, I absolutely think you do.

Father: I've heard the comment, "How could you?" And that hurts so much. This is what [Patient] wanted. He was insistent. He said it in front of [Oncologist] and his mother. [Patient] is very strong willed He decided exactly what he wanted, where he wanted his funeral and everything. We have to do everything we can to honor his wishes, as hard as that may be. So the question is not, "How could we?" The question is, "How could we not?" I can't be in the room; I have to walk out every time I hear the machine beeping when his blood pressure drops. I can't watch it happen. It's so hard. When I see him—
[FATHER GETS CHOKED UP AND BEGINS SOBBING.]

Mother: We were talking to [Oncologist], and he was telling [Patient] that it's so painful to go through, and that he should just be DNR. [Patient] said, "Mama, we talked about this. I want everything done." I wish that at this point we could just take him off the machines. But I would feel guilty for the rest of my life if I didn't carry out his wishes. I don't have a choice. I need to follow his wishes to let him keep his dignity. We understand; we really do. We know what's happening. And you know that. But this is what he wanted, and so I will fight

tooth and nail to do everything I can for him, because that is what he wanted. I don't want to talk about any of this again. I just want to go back and be with [Patient]. Your mother would do the same thing for you. She'd fight for you.⁷¹

Later, some information surfaced in the patient's medical chart that indicated that "Patient" had actually changed his mind over the course of the disease process, as his cancer prognosis got worse.⁷² There was additional evidence that suggested that "Patient" might have been influenced or pressured by his parents' wishes in this regard.⁷³ In certain instances, especially when a patient has particularly domineering family members, the patient might express one set of wishes when alone with medical staff, and either express something different in the presence of family members, or passively assent to the treatment they have previously refused or otherwise would have refused.⁷⁴ In situations where an individual has cause for concern that certain family members might not accurately honor their wishes, the legal practitioner is in a unique position to ensure that the individual chooses the correct surrogate and not simply the person they assume would be best in terms of proximity or birth order, for example. Studies of Intensive Care Units, where patients are generally in poorer health, have found that of all decisions regarding withholding or withdrawal of life support, only three- to four-percent of the patients were capable of making the decision themselves.⁷⁵ All other patients lacked decisional capacity at the relevant time.⁷⁶ Thus, perhaps, the best measure a patient can take to protect their autonomy is to choose the correct surrogate decision-maker.

B. FAILURE TO FOLLOW THE ADVANCE DIRECTIVE

One study has suggested that twenty-five percent of patients receive care that is inconsistent with their living will or other advance directive.⁷⁷ There are two possible explanations: (1) the document was unavailable to the treating physician, and therefore, could not be utilized; and (2) physicians sometimes act according to their own preferences with regard to

71. *Id.* at 222–23.

72. *See id.* at 223.

73. *See id.*

74. *See id.* at 225.

75. *See* John M. Luce & Thomas J. Prendergast, *The Changing Nature of Death in the ICU*, in *MANAGING DEATH IN THE INTENSIVE CARE UNIT: THE TRANSITION FROM CURE TO COMFORT* 19, 21–22 (J. Randall Curtis & Gordon D. Rubenfield eds., 2001).

76. *Id.*

77. *See* Fagerlin & Schneider, *supra* note 21 at 36.

the treatment they provide to patients.⁷⁸ Some of the factors physicians consider include: probable treatment outcomes, the patient's projected quality of life, and family input and preferences.⁷⁹ As to the first explanation, it has been estimated that three out of five patients with living wills do not give them to their physicians, and families are often equally unaware of their location.⁸⁰ This problem is especially noteworthy in Florida, where many clients are not native to the area, and their family members are not local.

Other reasons that advance directives are ignored include: interpretation problems, difficulty establishing prognosis or that an operative condition has been met, objections from physicians based on reasons of conscience, and issues related to emergency medical service personnel protocols.⁸¹ Emergency providers are not always aware that an individual has an advance directive or DNRO, especially when the individual has an emergent health event in an unfamiliar area (for example, while on vacation). Legal practitioners frequently advise their clients to give copies of their advance directives to their physicians and other family members, but legal practitioners should also advise their clients to take copies of these documents with them when they travel even if they are not going far. Additionally, a service like the U.S. Living Will Registry can be used by both individuals and health care providers.⁸² This third-party service will electronically store advance directives and information regarding organ and tissue donation, and provide the individual with a wallet card that has information about accessing the documents in the registry.⁸³ Individuals who do not feel comfortable with electronic storage of such sensitive documentation can opt to simply register information about where their documentation is located so that health care professionals can contact the necessary individual(s) acting as custodian of the documents and gain access to the advance directives as necessary.⁸⁴

Legal practitioners may want to look closely at the Living Will Registry model with regard to ensuring safeguards for clients in their own

78. *See id.* at 35–36; *see also* Luce & Prendergast, *supra* note 75, at 21 (showing that physicians usually recommend treatment according to the circumstances of the patient and manage death in the Intensive Care Unit as they would manage other patient conditions).

79. *See* Fagerlin & Schneider, *supra* note 21, at 36.

80. *See id.* at 35.

81. *See id.* at 36.

82. *See* U.S. LIVING WILL REGISTRY, <http://www.uslivingwillregistry.com> (last visited Sept. 24, 2013).

83. *How it Works*, U.S. LIVING WILL REGISTRY, <http://www.uslivingwillregistry.com/howitworksind.shtm> (last visited Sept. 24, 2013).

84. *id.*

practice. It is an unfortunate reality that the patient-client frequently will misremember, misunderstand, or simply agree with medical personnel when questioned about their advance directive status, especially in situations where the patient-client is experiencing diminished mental capacity.⁸⁵ Even more unfortunate is the fact that family members, who may be called upon to make treatment decisions as the patient's surrogate, are even less likely to have correct and updated information in this regard.⁸⁶ The legal practitioner could, for example, provide their client with a wallet card indicating that a copy of the most recent advance directives known to the attorney are housed electronically by the firm, thereby creating an opportunity to avoid undue confusion and stress by providing a connection between the health care provider and the attorney to ensure informed advocacy for the patient-client.

C. PRACTICE SOLUTION #3: LAWYER AS ADVOCATE AND MEDIATOR

Sometimes, the culprit of influence on the patient can be a misguided application of the physician's zeal in fulfilling their oath. The American health care system, in general, is geared toward doing everything possible to "fight," "cheat," or simply postpone death. Sometimes, this objective dominates the care plan, and patients undergo therapies that do not actually advance their personal goals under the circumstances or align with their individual values.⁸⁷ This is one area in which dialogue between the attorney, as advocate, and the physician, as care provider, can greatly enhance the patient experience by helping to guide the physician away from their role as champion in the patient's fight against death toward a role where the physician comforts and guides the patient (and their family) through the process of dying. It can be incredibly confusing for families to navigate the care continuum from acute services to custodial and skilled care onto hospice⁸⁸ and end-of-life treatment.

85. See Terri R. Fried, et al., *Agreement Between Older Persons and Their Surrogate Decision-Makers Regarding Participation in Advance Care Planning*, 59 J. AM. GERIATRICS SOC'Y 1105, 1105-08 (2011).

86. See *id.* at 1105.

87. PRESIDENT'S COMMISSION FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE AND BIOMEDICAL AND BEHAVIORAL RESEARCH, *DECIDING TO FOREGO LIFE-SUSTAINING TREATMENT* 15 (1983), http://bioethics.georgetown.edu/pcbe/reports/past_commissions/deciding_to_forego_tx.pdf.

88. See *id.* at 111-12; see also Colello, *supra* note 10, at 6. Hospice care is a type of palliative care that provides comfort to patients who have a life expectancy of months (under a variety of circumstances and for various reasons). Colello, *Supra*.

Connecting the patient and family members with services, such as hospice, respite care for familial caregivers, and counseling and bereavement services should be an integral element of the care and advocacy provided by doctors and attorneys.

V. PRACTICAL PROBLEM #4: ACCESS

Despite *Schiavo* and other high-profile cases involving end-of-life medical treatment increasing public awareness of issues related to patient self-determination, the likelihood that an individual has actually completed an advance directive is not as high as you might estimate. A 2008 survey by the American Association of Retired Persons (“AARP”) found that although ninety-percent of respondents aged thirty-five and older reported that they had heard of advance directives, only thirty-seven percent reported establishing some kind of health care surrogacy document, and only thirty-six percent reported having a living will.⁸⁹ The study found that individuals over age sixty were more likely than younger adults to have advance directives.⁹⁰

A. MACRO SOLUTION #2: UTILIZING TECHNOLOGY TO INCREASE ACCESS FOR TRADITIONALLY UNDERSERVED POPULATIONS

One explanation for this may be that there are institutional and psychological barriers that result in a failure of many individuals to execute such documents for themselves. One culprit may be access. Although preparation of such documents by an attorney is generally the preferable scenario because the individual will have access to advice and counsel, there are a number of states that allow advance directives to be prepared by other means. There are online resources that provide advance directive forms tailored to each state,⁹¹ and non-profit organizations, such as Aging With Dignity,⁹² which created the “Five Wishes” document aimed at improving patient autonomy through detailed discussion of the intricacies of end-of-life care in a form that can be easily understood by individuals without medical or legal training.⁹³ This document can serve a valuable

89. See DAWN V. NELSON, AARP, “GETTING READY TO GO” EXECUTIVE SUMMARY 1–3 (Kathi Brown, ed., 2008), http://assets.aarp.org/rgcenter/il/getting_ready.pdf.

90. *Id.* at 1.

91. See CARING CONNECTIONS, <http://www.caringinfo.org/i4a/pages/index.cfm?pageid=3289> (last visited Sept. 24, 2013).

92. See AGING WITH DIGNITY, <http://www.agingwithdignity.org/five-wishes.php> (last visited Sept. 24, 2013).

93. See *id.* Presently there are only eight states in the U.S. that do not recognize the “Five Wishes” document as legally effective: Alabama, Indiana, Kansas, New Hampshire, Ohio,

purpose by fostering discussion among the patient and family members regarding the patient's specific wishes, even in states that do not recognize the "Five Wishes" document as legally effective, or in states that recognize the document, but for practical reasons, the patient would prefer to have an advance directive prepared by an attorney.

Although there are some obvious problems with widespread utilization of such forms, most notably ensuring that such documents are accurate reflections of current state law, these resources are vital to ensure the protection of self-determination for individuals who either cannot or will not access formal legal services for one reason or another. One reason for the lack of widespread utilization of advance directives is lack of access to education and/or resources. At least one study has suggested that the prevalence of such "pre-planning" is highest among Caucasians from wealthier residential neighborhoods who have Medicare and/or private health insurance coverage.⁹⁴ Prevalence was lowest among individuals of color, those from the poorest residential neighborhoods, and individuals receiving public assistance or who had no health insurance at all.⁹⁵ Such traditionally underserved populations might be better off with an internet form which includes medical surrogate designations than none at all. However, without adequate counsel, is the patient's designation truly an informed one?

VI. CONCLUSION

Despite criticism of advance directives and the practical and functional issues faced in utilizing them, they are still ultimately a useful component of the patient's self-determination arsenal. Even if patients simply use advance directive documents as a tool to foster discussion of end-of-life treatment with family and possible surrogates, the patient will have ensured greater protection for their autonomy by putting their surrogate in a better position to act on their behalf, regardless of the medical circumstances in which the patients may find themselves in the future. Moreover, there are a number of actions attorneys, individuals, and health care providers can take to ensure greater transparency and more effective communication, and ultimately, a better quality of care for the patient-client.

Oregon, Texas and Utah. *Id.*

94. *See* Shapiro, *supra* note 11, at 213-14.

95. *Id.* at 214.