

APPENDIX C.

ADVANCE DIRECTIVES AND ADVANCE CARE PLANNING: LEGAL AND POLICY ISSUES

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U.S. Department of Health and Human Services
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Office of Disability, Aging and Long-Term Care Policy



ADVANCE DIRECTIVES AND ADVANCE CARE PLANNING:

LEGAL AND POLICY ISSUES

October 2007

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ADVANCE DIRECTIVES AND ADVANCE CARE PLANNING: Legal and Policy Issues

Charles P. Sabatino, J.D.

American Bar Association
Commission on Law and Aging

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Office of Disability, Aging and Long-Term Care Policy
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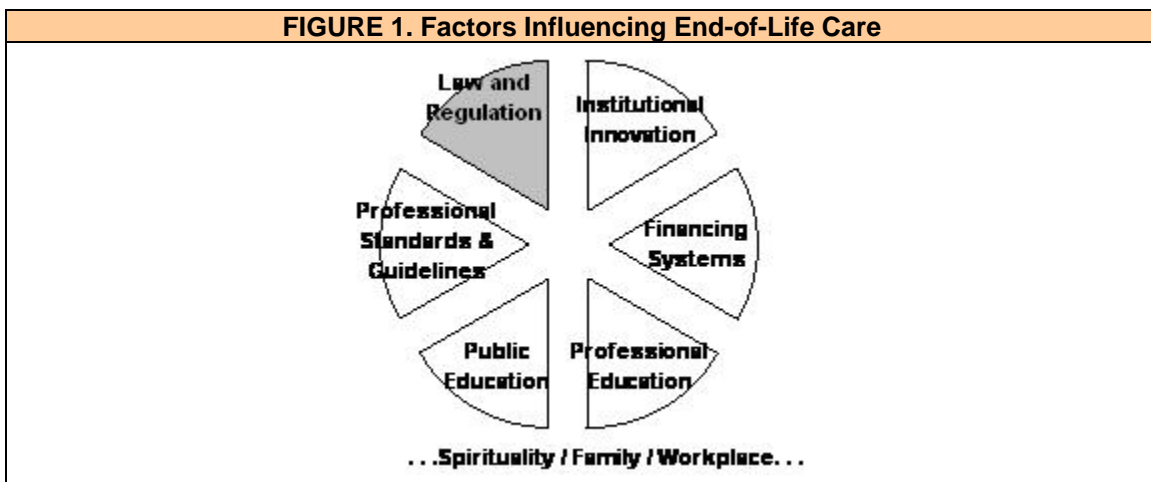
TABLE OF CONTENTS

I.	INTRODUCTION.....	C-5
II.	COMMON LAW AND CONSTITUTIONAL UNDERPINNINGS.....	C-8
III.	THE STATUTORY EVOLUTION OF ADVANCE DIRECTIVES	C-11
IV.	THE PARADIGM SHIFT IN STATE LAW.....	C-19
	The Legal Transactional Approach	C-19
	The Communications Approach.....	C-24
V.	A POSSIBLE NEXT STEP -- THE POLST PARADIGM.....	C-30
VI.	DEFAULT SURROGATES: THE PREVAILING REALITY	C-32
VII.	THE FEDERAL ROLE	C-37

I. INTRODUCTION

Since the mid-1970s, health care advance directives have become the central legal tool to make sure one's health care wishes are known in a formal way and, it is hoped, followed. However, whether advance directives laws can achieve that goal is still very much an open question. This paper provides an overview of the evolving legal landscape of end-of-life decision making generally, and advance directives specifically, and identifies current challenges and opportunities for promoting the goals of advance care planning.

A good starting point in understanding this landscape is a realization that law and regulation are but one slice of the universe of variables that profoundly affect the experience of dying in America. As illustrated in the pie chart below, other key variables include institutional innovation, the role of financing systems, professional and public education, and professional standards and guidelines. All these operate in a larger framework that is defined by family, workplace, community life and spirituality. Thus, the isolation of law and regulation as a strategy for behavior change requires a sense of humility in establishing expectations, lest we overstate the influence of law in the human experience of dying. At the same time, although it is but one piece, it is perceived as a very powerful variable in the big picture.



State **statutory law** stands out as the predominant feature of the legal landscape addressing the use and recognition of advance directives and surrogate decision making in general. Though predominant, these laws neither create substantive rights nor constitute the exclusive legal authority defining our decision making rights and responsibilities. The common law, as well as state and federal constitutional law, professional standards, and even custom and practice provide the underpinnings of the statutory law and provide the foundation for advance directive policy. Sometimes, statutory advance directive laws are perceived as the exclusive legal pathway for ensuring one's wishes are known and respected. The perception may arise partly because of the visibility and perceived authority that official legal forms carry, but also

because of the tendency of legal advisers to counsel conservatively (i.e., the only “safe” approach to use is the statutory form). The reality is that most end-of-life decisions take place through doctor-patient-family interactions without the involvement of these legal advance care planning tools, and most state advance directive laws assert explicitly that they do not pre-empt or change any existing rights regarding health care decision making authority or responsibility. Specifically, 33 states with living will, durable power of attorney for health care, or combined statutes expressly include non-pre-emption language, similar to the following examples from Florida and Illinois:¹

The provisions of this chapter are cumulative to the existing law regarding an individual's right to consent, or refuse to consent, to medical treatment and do not impair any existing rights or responsibilities which a health care provider, a patient, including a minor, competent or incompetent person, or a patient's family may have under the common law, federal Constitution, state constitution, or statutes of this state.²

Nothing in this Act shall impair or supersede any legal right or legal responsibility which any person may have to effect the withholding or withdrawal of death delaying procedures in any lawful manner. In such respect the provisions of this Act are cumulative.³

Several additional states that lack language similar to the above are modeled upon the Uniform Health Care Decisions Act,⁴ which provides such broad flexibility in the recognition of any form of advance directive -- written and oral -- that non-pre-emption

¹ Ala. Code 1975 §26-1-2(g)(9) (2007) [Durable Power of Attorney for Health Care, hereinafter “DPA”] and §22-8A-9(d) [Living Will, hereinafter “LW”]; Ark. Code. Ann. §20-17-210 (West 2007) [LW]; Colo. Rev. Stat §15-14-506(4)(a) (West 2007) [DPA]; DC. Code [HCDA]; Fla. Stat. Ann. §765.106 [combined act]; Ga. Code Ann. §31-32-14 (West 2007) [combined Act]; Iowa Code Ann. 144B.12 (West 2007) [DPA] and 144A.11 [LW]; Idaho Code §39-4508 (West 2007) [combined act]; 755 Ill. Comp. Stat. §35/9(d) (West 2006) [LW] and §45/4-3 [DPA]; Ind. Code §16-36-4-17(e) (West 2007) [LW]; Kan. Stat. Ann. §65-28,108(d) (2006) [LW]; Ky. Rev. Stat. §311.637(5) (West 2007) [combined act]; La. Rev. Stat. Ann §1299.58.10(C) (West 2007) [LW]; Md. Health-Gen. Code §5-616(a) (West 2007) [combined act]; Minn. Stat. Ann. §145C.10(e) (West 2007) [DPA] and Minn. Stat. Ann. §145B.17 [LW]; Mich. Comp. Laws Ann. §333.5660 and §333.5652 (West 2007); Mo. Ann. Stat. §459.055 (West 2007) [LW]; Mont. Code Ann. §50-9-205 (2007) [combined act]; Neb. Rev. Stat. §30-3401 (2006) [DPA] and §§20-402 & 20-412 [LW]; Nev. Rev. Stat. Ann. §449.680 (West 2007) [LW]; N.H. Rev. Stat. Ann. §137-J:10 (2007) [combined act]; N.C. Gen. Stat. Ann. §32A-15(b) (West 2007) [DPA] and §90-320(b) [LW]; N.D. Cent. Code §23-06.5-13(7) (2007) [combined act]; OK ST T.63 §3101.12(E) [combined act]; Or. Rev. Stat. Ann. §127.560(1) (West 2007)[combined act]; 20 Pa. Cons. Stat. Ann. §5421 & 5423 (West 2007) [combined act]; R.I. Gen. Laws §23-4.11-10(e) (2007) [LW] and §23-4.10-9(e) [DPA]; S.D. Codified Laws §34-12D-18 (2007) [LW]; Tex. [Health & Safety] Code Ann. §166.051 (Vernon 2007) [combined act]; Utah Code Ann. §75-2-1117(4) (West 2007) [combined act]; Va. Code Ann. §54.1-2992 (West 2007) [combined act]; Wis. Stat. Ann. §154.11(4) (West 2007) [LW]; W.Va. Code Ann. §§16-30-16(a) (West 2007) [combined act].

² Fla. Stat. Ann. §765.106.

³ 755 Ill. Comp. Stat. §35/9(d) (West 2006).

⁴ National Conference of Commissioners on Uniform State Laws (NCCUSL), The Uniform Health Care Decisions Act (1993), http://www.nccusl.org/Update/uniformact_factsheets/uniformacts-fs-uhcda.asp (accessed November 13, 2007).

language is unnecessary.⁵ The recognition that advance directive laws create no new substantive rights and, instead, provide only elective pathways for implementing existing rights is an important threshold principle with which to begin a review of the legal landscape, for it sets these laws in their proper legal context. The North Carolina statute states this perspective most succinctly in its statement of purpose of its advance directive law:

- a) The General Assembly recognizes as a matter of public policy the fundamental right of an individual to control the decisions relating to his or her medical care, and that this right may be exercised on behalf of the individual by an agent chosen by the individual.
- b) The purpose of this Article is to establish an additional, non-exclusive method for an individual to exercise his or her right to give, withhold, or withdraw consent to medical treatment, including mental health treatment, when the individual lacks sufficient understanding or capacity to make or communicate health care decisions.⁶

This review starts with a brief synopsis of the common law and constitutional underpinnings of advance directive policy in Section II. Section III examines the incremental evolution of the relevant statutory law, followed by an analysis of a fundamental paradigm shift in public policy in Section IV. Then, Section V turns to a description of a possible next step in evolution, represented by the Physician Orders for Life Sustaining Treatment (POLST) paradigm. Because only a minority of the adult population has historically used advance directives, Section VI fills in the rest of the surrogate landscape by addressing health care decision making authority where there is no advance directive in place. Finally, the federal role in health care advance care planning policy is examined in Section VII.

⁵ According to NCCUSL, nine states have substantially adopted the Uniform Health Care Decisions Act: Ala. Code 1975, §§22-8A-1 to 22-8A-13 (2007); Alaska Stat. §§13.52.010 to 13.52.395 (West 2007); Cal. Prob. Code §§4670 to 4743 (West 2007); 16 Del. Code §§2501 to 2517 (West 2007); Haw. Rev. Stat. §§327E-1 to 327E-16 (2007); 18-A Me. Rev. Stat. Ann. §§5-801 to 5-818 (West 2007); Miss. Code 1972, §§41-41-201 to 41-41-229 (West 2007); N.M. Stat. Ann. 1978 §§24-7A-1 to 24-7A-18; Wyo. Stat. Ann. §§35-22-401 to 35-22-416 (2007).

⁶ N.C. Gen. Stat. Ann. §32A-15 (West 2007) [DPA]. Also see §90-320 [LW].

II. COMMON LAW AND CONSTITUTIONAL UNDERPINNINGS

The common law right to refuse or discontinue medical treatment has been established and recognized for decades. Several grounds are asserted for this right. Virtually every judicial writing that has addressed the issue starts with the well-known tenet expounded by Justice Benjamin Cardozo in the 1914 case of *Schloendorff v. N.Y. Hospital*:

Every human being of adult years and sound mind has a right to determine what shall be done with his own body; and a surgeon who performs an operation without his patient's consent commits an assault.⁷

In the context of personal injury law, this right of self-determination was recognized first as the common law offense of battery which made any offensive, unconsented touching an actionable wrong. From these common law roots came two logical extensions -- the doctrine of "informed consent" and a corollary right to refuse treatment.

The "informed" component of consent was not directly acknowledged until the California cases of *Salgo v. Leland Stanford Jr. University Bd. of Trustees* in 1957 (a battery case),⁸ and *Natanson v. Kline* in 1960 (a malpractice case).⁹ Through the 1960s and beyond, informed consent criteria became the subject of a great deal of state legislation and litigation.¹⁰ Today, the failure to obtain informed consent is typically an issue of negligence in medical malpractice claims, rather than of battery.

In general terms, informed consent may be described as the physician's "legal obligation to make adequate disclosures of the medically recognized risks, benefits, and alternatives to any proposed diagnostic or therapeutic medical procedures to allow their patients to make informed decisions and to give an informed consent to those procedures."¹¹ Another way to describe informed consent -- as well as informed refusals of consent -- is through its three requisite elements: informed, voluntary, and competent.¹² Courts and legislators have taken differing tacks in defining the nature and depth of information required to be disclosed to patients, while the voluntary and

⁷ *Schloendorff v. Society of N.Y. Hospital*, 105 N.E. 92, 93 (N.Y. 1914).

⁸ 154 Cal.App.2d 560, 317 P.2d 170 (Cal.App. 1957).

⁹ 187 Kan. 186, 354 P.2d 670 (Kan. 1960).

¹⁰ See Paul Appelbaum, Charles Lidz, & Alan Meisel, *Informed Consent: Legal Theory And Clinical Practice* (Oxford U. Press 1987); Ruth R. Faden, Tom L. Beauchamp & Nancy M. P. King, *A History and Theory of Informed Consent* (Oxford U. Press 1986).

¹¹ See Jon F. Merz, *On A Decision-Making Paradigm of Medical Informed Consent*, 14 J. Legal Med. 231, *232 (1993).

¹² See Marshall B. Kapp, *Geriatrics and the Law: Understanding Patient Rights and Professional Responsibilities* 22-32 (3rd ed., Springer Pub. 1999).

competent components have remained more consistent in concept, but only in concept. In practice, the nuances, variability, and continuum of voluntariness and decisional capacity pose everyday challenges to health care providers.¹³

Constitutional bases of the right to refuse medical treatment have included:

- First Amendment religious grounds. Examples have typically involved Jehovah's Witnesses blood transfusion cases.¹⁴
- A right of privacy based primarily on the Due Process Clauses of the Fourteenth Amendment and on state constitutions. Several U.S. Supreme Court cases identify a constitutional right of privacy,¹⁵ although none, not even the decision in Supreme Court's Cruzan decision, discussed below, has extended the right of privacy to include refusals of life-sustaining treatment. But several state appellate level decisions, including the first well-known "right to die" case of Karen Ann Quinlan in 1976, have upheld decisions to refuse medical treatment on privacy grounds, relying on either or both state and federal constitutions.¹⁶
- A liberty interest, based on the Fourteenth Amendment. *Cruzan v. Director, Missouri Department of Health* -- based its analysis, though provisional, on a constitutional "liberty" interest.¹⁷

In *Cruzan*, the Court concluded that "[t]he principle that a competent person has a constitutionally protected liberty interest in refusing unwanted medical treatment may be inferred from our prior decisions."¹⁸ The Court declined the opportunity to base its analysis on a constitutional privacy right, instead explaining that: "[w]e believe this issue is more properly analyzed in terms of a Fourteenth Amendment liberty interest."¹⁹

The Court also rejected any legal distinction between artificially supplied nutrition and hydration and other forms of medical treatment: "[f]or purposes of this case, we assume that the U.S. Constitution would grant a competent person a constitutionally

¹³ *Id.*

¹⁴ See Alan Meisel & Katy L. Cerminara, *The Right to Die: The Law of End-of-Life Decisionmaking* §206 [C] (3rd ed., Aspen Pub. 2007).

¹⁵ See e.g., *Olmstead v. United States*, 277 U.S. 438, (1928) (Brandeis J., dissenting), overruled, *Katz v. United States*, 389 U.S. 347 (1967); *Griswold v. Connecticut*, 381 U.S. 479 (1965); *Roe v. Wade*, 410 U.S. 113 (1973); cf. *Webster v. Reproductive Health Services, et al.*, 492 U.S. 490, 109 S.Ct. 3040 (1989).

¹⁶ *Matter of Quinlan*. 70 N.J. 10, 355 A.2d 647, 663 (N.J. 1976) (based on federal and state constitutional right of privacy); see also, e.g., *In re Guardianship of Browning*, 568 So.2d 4 (Fla. 1990); *Rasmussen v. Fleming*, 741 P.2d 674, 681-82 (Ariz. 1987); *Bartling v. Superior Court*, 209 Cal. Rptr. 220, 225 (Ct. App. 1984); *In re Spring*, 405 N.E.2d 115, 119 (Mass. 1980).

¹⁷ *Cruzan v. Director, Missouri Department of Health*, 497 U.S. 261, 110 S.Ct. 2841 (1990), *aff'g* *Cruzan v. Harmon*, 760 S.W.2d 408 (Mo. 1988).

¹⁸ 497 U.S. at 278.

¹⁹ *Id.* at 278, n. 7.

protected right to refuse lifesaving hydration and nutrition."²⁰ This stance affirmed the view of the majority of state courts that had considered the question.

Finally, the Court held that the U.S. Constitution allows states considerable leeway in establishing, as Missouri did, a "procedural safeguard" for incompetent persons who cannot exercise the right to refuse treatment on their own.²¹ Specifically, it held Missouri's *clear and convincing* evidence standard to be a constitutionally permissible procedural safeguard, although not required. Only a few states have been nearly as restrictive as Missouri in imposing and defining such a standard.²²

The overwhelming impact of the *Cruzan* decision has been to solidify the constitutional basis to the right to refuse life-sustaining treatment. The acceptance of such a constitutional right reinforces the validity and weight of all authentic expressions of patient wishes. The more challenging constitutional issue for policy purposes continues to be to what extent states can dictate "procedural safeguards" in the advance care planning process, both in the way individuals articulate their wishes and in the empowerment of surrogate decision makers. While the latter option was not at issue in *Cruzan*, it was especially noteworthy that the concurring opinion of Justice O'Connor suggested that states may be constitutionally required to give effect to decisions made by a surrogate appointed by the patient.²³

An even more controversial issue related to end-of-life decision making confronted the U.S. Supreme Court just a few years after *Cruzan* -- whether there was a constitutional right to physician aid-in-dying for terminally ill patients who requested a prescription for lethal drugs. In a pair of decisions in 1997, the Court held that neither the Due Process clause nor the Equal Protection clause of the 14th Amendment created a constitutional right to assisted suicide.²⁴ At the same time, the decision did not preclude states from creating by statute, as Oregon has done, a process for aid-in-dying.²⁵

²⁰ *Id.* at 279.

²¹ *Id.* at 280.

²² See, e.g. *Westchester County Med. Ctr.* (O'Connor), 531 N.E.2d 607 (NY 1988); *Elbaum v. Grace Plaza of Great Neck, Inc.*, 544 N.Y.S.2d 840 (App.Div. 1989); *In re Martin*, 450 Mich. 204, 538 N.W.2d 399 (1995); *In re Tavel*, 661 A.2d 1061 (Del. 1995).

²³ 497 U.S. at 289-292.

²⁴ *Washington v. Glucksberg*, 117 S.Ct. 2258, 138 L.Ed.2d 772 (U.S. 1997); *Vacco v. Quill*, 521 U.S. 793, 117 S.Ct. 2293, 138 L.Ed.2d 834 (1997).

²⁵ See Or. Rev. Stat. Ann. §§127.800 to 127.897 (West 2007).

III. THE STATUTORY EVOLUTION OF ADVANCE DIRECTIVES

The common law concept of informed consent, buttressed by constitutional principles of privacy and liberty have formed the primary platform from which advance medical directives spring. But, unlike the process of obtaining informed consent for a present treatment, advance directives are usually made well before the time a patient can be fully informed of the risks, benefits, and alternatives to any proposed diagnostic or therapeutic medical procedures.

The first advance directive -- called a *living will* -- was proposed by the Euthanasia Society of America in 1967,²⁶ and Luis Kutner, a human-rights lawyer from Chicago who represented the Society, proposed it as a model in an oft-quoted 1969 Indiana Law Journal article. Kutner began with the common law and constitutional law premise that, "The law provides that a patient may not be subjected to treatment without his consent" and that the individual has "the right to refuse to permit a doctor to treat him, even if such treatment would prolong his life (sic)."²⁷ He continues:

The patient may not have had, however, the opportunity to give his consent at any point before treatment. He may have become the victim of a sudden accident or a stroke or coronary. Therefore, the suggested solution is that the individual, while fully in control of his faculties and his ability to express himself, indicate to what extent he would consent to treatment. The document indicating such consent may be referred to as "a living will," "a declaration determining the termination of life," "testament permitting death," "declaration for bodily autonomy," "declaration for ending treatment," "body trust," or other similar reference.²⁸

Interestingly, Kutner also analogized the living will to "a revocable or conditional trust with the patient's body as the *res*, the patient as the beneficiary and grantor, and the doctor and hospital as the trustees."²⁹ As with any trust instrument, the document sets forth the terms for managing the *res*, which in the context of medical care, means the extent to which the health care providers should undertake treatment. Both informed consent and trust paradigms are characteristic of a legal transactional approach that became the paradigm for state advance directive legislation.

The legislative landscape of health care advance directives evolved relatively quickly but incrementally, starting with California's adoption of the first living will statute

²⁶ Henry R. Glick, *The Right-to-Die: State Policymaking and the Elderly*, 5 *Journal of Aging Studies* 2830307, 285 (1991).

²⁷ Luis Kutner, *Due Process of Euthanasia: The Living Will, A Proposal*, 44 *Indiana Law Journal* 539, 550 (1969).

²⁸ *Id.* at 551.

²⁹ *Id.*

in 1976 (although it used the term “Directive to Physicians” rather than the popular “living will”). The paradigm offered individuals a standardized tool to express their wishes about life-sustaining treatment -- usually to withhold or withdraw it -- in the event of a terminal condition or permanent unconsciousness, and to physicians it offered statutory immunity if they complied with the patient’s wishes in good faith.

One might ask today, more than 30 years later, why physicians would want or need immunity to do what the underlying law already seemed to require (i.e., respecting patients’ wishes). The technological developments in medicine during the 1960s and 1970s thrust medicine into a new world where, for the first time, it often became difficult to distinguish saving life from prolonging suffering and death.³⁰ A *Time Magazine* review of the then pending Karen Ann Quinlan trial in New Jersey in 1975, captured the tenor of the time:

[A]lmost all doctors are decidedly uneasy about terminating treatment once it has been started, especially if doing so will mean the certain death of a patient. Many doctors, after all, are taught to regard death as an enemy and to do all they can to defeat it -- or at least to keep it at bay for a while. Many regard "pulling the plug" as an act akin to euthanasia, which is forbidden by both law and the medical code.³¹

The *Time* article ended with broader policy concerns that still resonate in today’s debates about termination of treatment:

For although the Quinlan case concerns mainly the maintenance of life by artificial means, it could, if carried to its logical conclusion, be applied in state hospitals, institutions for the mentally retarded and for the elderly. Such places currently house thousands of people who have neither hope nor prospects of a life that even approaches normality. A decision to remove Karen's life-support system could prompt new suits by parents seeking to end the agony of incurably afflicted children, or by children seeking to shorten the suffering of aged and terminally ill parents.

It was concerns such as these that resulted in a legal model of advance care planning that focused on conventional legal formalities or procedural protections intended to protect vulnerable populations from harm, specifically the premature termination of life due to lack of understanding, or diminished capacity of, or undue influence upon, the signor of the living will.

³⁰ Bill Colby provides an enlightening overview of the key medical developments leading up to major right to die cases from Karen Ann Quinlan to Terri Schiavo. See William H. Colby, *Unplugged: Reclaiming Our Right to Die in America* (AMACOM 2006).

³¹ Time Magazine, *A Life in the Balance*, Monday, November 3, 1975, <http://www.time.com/time/magazine/article/0,9171,913631,00.html> (accessed November 13, 2007).

The number of living will laws snowballed during the next ten years, so that by the end of 1986, 41 states had adopted living will laws.³² But it was not long before the shortcomings of living wills became apparent to policy makers, especially with respect to the narrow range of decisions it applied to. Policy makers turned to validating and reshaping the use of durable powers of attorney to apply to health care.³³

Powers of attorney existed in the common law as a tool by which a principal empowers an agent to act on the principal's behalf. It was originally used to delegate authority over property matters. However, in common law, a power of attorney was revoked by the incompetency or incapacity of the principal. Thus, the common law power had no utility as a planning tool for incapacity. In 1954, Virginia enacted the first "durable" power of attorney statute that allowed an agent to continue to act as empowered by a power of attorney even after the principal became disabled, incompetent, or incapacitated.³⁴ Other states followed suit, and the tipping point came in 1969 when the National Conference of Commissioners on Uniform State Laws promulgated a new Uniform Probate Code (UPC) that recognized durability if expressly provided for in the document. Thereafter, states adopted durable power of attorney laws at a rapid pace.³⁵

The conventional view of powers of attorney is that they can be used for any purpose not contrary to law or public policy of a given state.³⁶ Their use as a health care decision making tool has obvious advantages over the living will. The President's Commission favored their use for health care decision making in their 1983 report, but the Commission also voiced a common concern for the potential of abuse inherent in these statutes:

These statutes do not have rigorous procedures because they were enacted primarily to avoid the expense of full guardianship or conservatorship proceedings when dealing with small property interests. Adapting them to the context of health care may require that greater procedural safeguards be provided: precisely which safeguards are needed might best be determined after more experience has been acquired.³⁷

³² Henry R. Glick, *supra* note 26, at 289. By the early 1990s all states except Massachusetts, Michigan, and New York have living will statutes. These three states chose to adopt only health care power of attorney legislation, but their laws also permit the maker to include any wishes, guidance, or other directions.

³³ See Charles P. Sabatino, *Death in the Legislature: Inventing Legal Tools for Autonomy*, 19 N.Y. Rev. of Law & Social Change, 309-339 (1991-92).

³⁴ Va. Code Ann. §11-9.1 (West 2007).

³⁵ See Carolyn L. Dessin, *Acting As Agent Under A Financial Durable Power Of Attorney: An Unscripted Role*, 75 Neb. L. Rev. 574-620, at 576-580 (1996).

³⁶ Francis J. Collin, Jr., John J. Lombard, Jr., Alvert L. Moses, & Harley J. Spittler, *Durable Powers of Attorney and Health Care Directives* §3.01 (3rd ed., West Group 1997).

³⁷ President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, *Deciding to Forego Life-Sustaining Treatment* 147 (U.S. Government Printing Office March 1983).

To address these concerns while encouraging their use, states began crafting special durable power of attorney for health care statutes or, alternatively, adding proxy provisions to their living will statute. This wave of legislation took place roughly from the mid-1980s to the mid-1990s, with California again leading the pack with its 1983 law.³⁸ By the end of 1988, only 12 states had such statutes, but by mid-1993, the District of Columbia and every state, except Alabama, had enacted some version of a statutory health care power of care statute.³⁹ Alabama followed course in 1997.⁴⁰

A third wave of legislation began in the early 1990s, triggered by a growing awareness of unwanted resuscitations of terminally ill patients living at home or in hospice, occurring when the expected medical crisis arises and someone on the scene calls 911. Absent an out-of-hospital do-not-resuscitate (DNR) protocol, emergency medical services personnel are obligated to do everything possible to resuscitate a patient whose heart or breathing has stopped unless the patient himself or herself refuses help. An advance directive does not normally trump that obligation.⁴¹ To address these unwanted medical encounters, states began enacting legislation or regulations in the early 1990s to permit seriously ill persons in the community to avoid unwanted resuscitation through the use of out-of-hospital DNR orders (sometimes called do-not-attempt-resuscitation orders, comfort care orders, cardiopulmonary resuscitation (CPR) directives, or other name). These protocols most often required the signing of a DNR order by both physician and patient (with many states permitting a surrogate to sign) and the use of a specially designed identifier to be kept on or near the patient. The protocols, in effect, created a kind of hybrid special advance directive and portable doctor's order. By the end of 1999, 42 states had statewide protocols in place, most frequently created by legislation

A fourth wave of legislation was not so much a wave as a slowly rising tide, going as far back as the 1960's and continuing to the present. Unlike the advance directive waves, this trend addresses the other side of the coin -- how decisions are to be made *in the absence of an advance directive*. An awareness that the great majority of Americans were not utilizing advance directives fueled interest in this subject.⁴² As is still the case today, most decisions relating to end-of-life care for persons lacking decisional capacity were made without the guidance or authority of a health care

³⁸ 1983 Cal. Stat. ch. 1204, §10, at 4615-22 (enacting Cal. Civ. Code §§2430-2443).

³⁹ American Bar Association (ABA) Commission on Law and Aging, *Surrogate Decision-Making in Health Care: Legislative Overview* (June 1993) (unpublished legislative tracking report).

⁴⁰ Ala. Code 1975 §22-8A-1 to -14 (2007).

⁴¹ See K.V. Iserson, *Foregoing Prehospital Care: Should Ambulance Staff Always Resuscitate?* 17 *Journal of Medical Ethics* 3-4 (1991); K.L. Koenig *et al.*, *Do-Not-Resuscitate Orders. Where Are They In The Prehospital Setting?* 8(1) *Prehospital Disaster Medicine* 51-54 (1993); R.A. Partridge *et al.*, *Field Experience with Prehospital Advance Directives*, 32 *Annals of Emergency Medicine* 589-93 (1998) (survey of local EMS providers in Massachusetts and New Hampshire prior to creation of statewide protocols).

⁴² See Steven H. Miles *et al.*, *Advance End-of-life Treatment Planning. A Research Review*, 156 *Arch Intern Med* 1062 (May 27, 1996); U.S. General Accounting Office, *Patient Self-Determination Act: Providers Offer Information on Advance Directives but Effectiveness Uncertain*, HEHS-95-135 (1995); Dallas M. High, *Advance Directives and the Elderly: A Study of Intervention Strategies to Increase Use*, 33 *Gerontologist* 342 (1993).

advance directive. State law frequently failed to identify who, in the absence of an appointed agent or guardian, was authorized to make decisions in these instances.

Default surrogate consent or family consent laws provide an answer to that question. These exist in some 40 states and the District of Columbia, although they vary significantly in breadth and depth.⁴³ All create a list of permissible surrogates, usually starting with spouse and a next-of-kin priority list. Some limit surrogates to fairly close relatives. Iowa, for example, authorizes one's spouse, followed by an adult child, a parent, and adult sibling.⁴⁴ Others extend to any adult relative with no limitation of degree.⁴⁵

Seventeen states include "close friend" or its equivalent in the list of permissible surrogates, usually at or near the end of the order of priority.⁴⁶ Arizona additionally includes "patient's domestic partner," as an authorized surrogate for some health decisions, although the definition of close friend may be broad enough to encompass domestic partner in other states.⁴⁷

These laws differ, in part, according to the kind of statutory context in which they emerged.

- Some were included in *informed consent* statutes enacted in the 1960s and 1970s.⁴⁸ These laws provided for family consent to treatment primarily as a way to ensure access to care. They were not enacted with refusals of treatment especially in mind, nevertheless, are applicable given the conceptual unity of consent and refusal.
- Some *living will* statutes include family consent authority, but since these statutes are typically limited to patients in *terminal conditions* or in permanent unconsciousness and to decisions about life-sustaining treatment, their application to the full range of health care decisions may be in question.⁴⁹

⁴³ A summary chart of these laws, updated annually by the ABA Commission on Law and Aging, is available on the Internet at <http://www.abanet.org/aging/legislativeupdates/home.shtml> (last updated July 2006).

⁴⁴ Iowa Code Ann. §144A.7 (West 2007).

⁴⁵ See e.g., Ala. Code 1975 §22-8A-11 and -6 (2007); Ky. Rev. Stat. §311.631 (West 2007); La. Rev. Stat. Ann. §40:1299.58.5 (West 2007); Mont. Code Ann. §50-9-106 (2007); Nev. Rev. Stat. Ann. §449.626 (West 2007); Ohio Rev. Code Ann. §2133.08 (West 2007); Okla. Stat. Ann. tit. 63, §3102A (West 2007); Tenn. Code Ann. §68-11-1806 (West 2007); Tex. [Health & Safety] Code Ann. §166.039 (Vernon 2007); Va. Code Ann. §54.1-2986 (West 2007).

⁴⁶ *Id.*

⁴⁷ For example, Florida law defines "Close personal friend" as "any person 18 years of age or older who has exhibited special care and concern for the patient, and who presents an affidavit to the health care facility or to the attending or treating physician stating that he or she is a friend of the patient; is willing and able to become involved in the patient's health care; and has maintained such regular contact with the patient so as to be familiar with the patient's activities, health, and religious or moral beliefs." Fla. Stat. Ann. §765.101(c) (West 2001).

⁴⁸ See e.g., Ga. Code Ann., §31-9-2 (West 2007).

⁴⁹ See e.g., Ark. Code Ann. §20-17-214 (West 2007).

- Some are *decision-specific* laws, such as New York's narrow family consent provision that deals *only* with DNR orders.⁵⁰ A few other states have enacted family consent provisions specific to medical research consent.⁵¹
- Several states have included family/surrogate consent within *comprehensive* state health decisions statutes, as explained below.

These laws vary significantly in their scope of authority and other limitations, which will be discussed in Section VI below.

A fifth and most important wave of legislation began as a merging of the separate health care decisions acts states had already enacted. This was driven, in part, by the public's lack of understanding these legal tools and their lack of use. Most estimates of completion rates in the early 1990's hovered around 20 percent or less.⁵² A substantial lack of awareness and misunderstanding of advance directives persisted.⁵³

New Jersey enacted the first combined statute in 1991, merging the living will (called an "instruction directive") and the durable power of attorney for health care (called "a proxy directive") into a single "advance directive for health care."⁵⁴ By the beginning of 2000, some 16 states had comprehensive or combined advance directive statutes, which at a minimum, combined living wills and proxies in the same law.⁵⁵ By 2002, 20 states had combined statutes.⁵⁶ By early 2007, the number had inched up to 25. The more comprehensive of these statutes also recognize the authority of default surrogate decision makers in the absence of an advance directive and encourage, or at least provide the option, of combining organ donation instructions in one's directive.⁵⁷

⁵⁰ N.Y. Pub. Health Law §2965 (McKinney 2007).

⁵¹ See e.g., Okla. Stat. Ann tit. 63, §3102A (West 2007).

⁵² Edward J. Larson & Thomas A. Eaton, *The Limits of Advance Directives: A History and Assessment of the Patient Self-Determination Act*, 32 Wake Forest Law Review 249-293, at 276-278 (Summer 1997).

⁵³ *Id.* at 270-276.

⁵⁴ N.J. Stat. Ann. §26:2H-53 to -81 (West 2007).

⁵⁵ ABA Commission on Law and Aging, *End-of-Life Care Legal Trends 2000* (2000) (unpublished legislative tracking report, citing Alabama, Arizona, Connecticut, Delaware, Florida, Hawaii, Kentucky, Maine, Maryland, Minnesota, Mississippi, New Jersey, New Mexico, Oklahoma, Oregon, and Virginia).

⁵⁶ ABA Commission on Law and Aging, *Health Decisions Legislative Update, 2002* (unpublished legislative tracking report); also cited in Means to a Better End: A Report on Dying in America Today 70 (November 2002) <http://www.rwjf.org/files/publications/other/meansbetterend.pdf> (accessed November 13, 2007).

⁵⁷ During the 1990s, interest also grew in establishing special advance directives for mental health decisions, but because these focus on a distinctive set of issues not directly related to end-of-life decision making, they are not covered in this review. In their most comprehensive form, mental health advance directives allow individuals to bind themselves to psychiatric treatment in advance of needing it for the purpose of overcoming illness-induced refusals of treatment (sometimes called "Ulysses clauses"). Between 1991 and 2006, 27 states enacted statutes authorizing psychiatric advance directives in some form. Breanne M. Sheetz, *The Choice to Limit Choice: Using Psychiatric Advance Directives to Manage the Effects of Mental Illness and Support Self-Responsibility*, 40 U. Mich. J.L. Reform 401-433, at 408 (Winter 2007).

The primary model for a flexible combined advance directive and default surrogate law has been the *Uniform Health-Care Decisions Act*.⁵⁸ The *Uniform Act* was promulgated as a national model by the National Conference of Commissioners on Uniform State Laws in 1993, and recognized by the ABA in 1994. The Act establishes very simple rules for recognizing almost any kind of written or oral statement as an advance directive. Even unwitnessed documents are valid under the Uniform Act. However, states that have adopted the *Uniform Act* have almost always added more to the Act's baseline requirements.⁵⁹ Indeed, all states that have adopted it have added at least a witnessing requirement. The Act provides a comprehensive, sample form with options for instructions, appointment of an agent, organ donation, an option to name a primary physician, and it recognizes default surrogates in the absence of an advance directive.

The federal legislative role in the above evolution of advance directives has been minimal. The primary congressional foray into this subject is the Patient Self-Determination Act, enacted as part of the Omnibus Budget Reconciliation Act (OBRA) of 1990.⁶⁰ The Act was a fairly modest amendment to federal Medicare and Medicaid law, but it was hoped that it would have an effect on the way most adults make and plan for health care decisions. It also legislatively affirmed the use of the term "advance directive". At its heart, it is an information and education mandate. It does not create or change any substantive right to health care decision making. Rather, it requires all Medicare and Medicaid provider organizations (specifically, hospitals, skilled nursing facilities, home health agencies, hospices, and prepaid health care organizations) to do five things:

1. "provide written information" to patients at the time of admission concerning "an individual's right under state law (whether statutory or as recognized by the courts of the state) to make decisions concerning such medical care, including the right to accept or refuse medical or surgical treatment and the right to formulate advance directives;"
2. "maintain written policies and procedures" with respect to advance directives (e.g., living wills and health care powers of attorney) and to "provide written information" to patients about such policies;
3. "document in the individual's medical record whether or not the individual has executed an advance directive;"

⁵⁸ Uniform Health-Care Decisions Act available at <http://www.law.upenn.edu/bll/ulc/fnact99/1990s/uhcda93.htm> (accessed November 13, 2007). For a descriptive review of the Uniform Act, see Charles P. Sabatino, *The New Uniform Health-Care Decisions Act: Paving a Health Care Decisions Superhighway?* 53 Maryland Law Review 101 (1994).

⁵⁹ According to the NCCUSL, the Uniform Act has been adopted in whole or in part in Alabama, Alaska, Delaware, Hawaii, Maine, Mississippi, New Mexico, and Wyoming. http://www.nccusl.org/Update/uniformact_factsheets/uniformacts-fs-uhcda.asp (accessed November 13, 2007).

⁶⁰ The Patient Self-Determination Act was enacted as part of the OBRA of 1990, signed by the President on November 5, 1990. OBRA of 1990, Pub. L. No. 101-508, §§4206 and 4751 (Medicare and Medicaid, respectively), codified in part at 42 U.S.C. §§1395cc(a)(1)(Q), 1395cc(f), 1395mm(c)(8), 1396a(a)(57), 1396a(a)58, 1396a(w).

4. "ensure compliance with the requirements of state law (whether statutory or as recognized by the courts of the state) respecting advance directives at facilities of the provider or organization;" and
5. "provide (individually or with others) for education for staff and the community on issues concerning advance directives."⁶¹

Moreover, the Act specifically prohibits providers from any form of discrimination based on advance directives. Facilities cannot "condition the provision of care or otherwise discriminate against an individual based on whether or not the individual has executed an advance directive."⁶²

To promote the dissemination of more accurate and consistent information, the Act mandated states to develop written descriptions of relevant state law:

[T]he state, acting through a state agency, association, or other private non-profit entity, [shall] develop a written description of the law of the state (whether statutory or as recognized by the courts of the state) concerning advance directives that would be distributed by providers or organizations under the requirements of [the Act].⁶³

Finally, the Act required the U.S. Department of Health and Human Services (HHS) to undertake a public education campaign. This apparently includes developing or approving national educational materials, assisting states in developing state-specific documents, and mailing information to Social Security recipients. However, other than preparing a public information document (reprinted at 57 F.R. 8194, 8199, March 6, 1992), HHS has done relatively little.

⁶¹ 42 U.S.C.A. §1395cc(f); 42 U.S.C.A. §1396a(w). *See also* PSDA regulations at 42 CFR Parts 417, 430, 431, 434, 483, 484, and 489.

⁶² 42 U.S.C.A. §1395cc(f); 42 U.S.C.A. §1396a(w).

⁶³ 42 U.S.C.A. §1396a(a)(A)(58).

IV. THE PARADIGM SHIFT IN STATE LAW

One way to understand the evolution of health decisions legislation is to examine what is emphasized and regulated in the legislation. The result, as elaborated below, is a landscape that has predominantly emphasized standardized legal formalities and restrictions, with procedural requirements or limitations intended to serve as protections against abuse or error. For shorthand, we will refer to this as a “legal transactional approach.” However, these laws have been in a gradual but constant state of flux and moving incrementally toward an approach that more strongly acknowledges an ongoing and flexible process of communication (i.e., a “communications approach”).

The Legal Transactional Approach

A *legal transactional framework* focuses on the formal steps of creating and implementing the legal tools to direct or delegate health care decisions in advance of decisional incapacity. In this light, the creation of advance directives are treated much like conventional conveyances of interests in property or contracts that establish important rights and obligations. The validity of the transaction focuses on required legal formalities and standardization of the process.

Legal formalities are intended to impress upon the parties the seriousness of a transaction and the potential consequences of the transaction. Because this is a legal tool that will often be signed and used without the advice of legal counsel, detailed standardized formalities are relied upon to ensure the voluntary, knowing, and competent execution of the transaction -- the same elements central to informed consent. However, the task cannot be equated with giving informed consent to a particular treatment, because making a judgment about how one wants to be treated in a future hypothetical situation is by necessity far more value driven and far less fact driven than making a contemporaneous choice about a health care treatment for a condition about which the person has been fully informed.⁶⁴ Therefore the focus of the voluntary, knowing, and competent act is on the transaction that creates the advance directive.⁶⁵ Finally, another goal of standardization of forms is the enhancement of their recognition and compliance by health care providers.

⁶⁴ See Nancy K. Rhoden, *The Limits of Legal Objectivity*, 68 N.C. L. Rev. 845 (1990); Allen E. Buchanan & Dan W. Brock, *Deciding for Others: The Ethics of Surrogate Decision Making* 110 (Cambridge U. Press 1990); Rebecca S. Dresser, *Advance Directives, Self-Determination, and Personal Identity*, in *Advance Directives in Medicine* 155, 156 (Chris Hackler, Ray Moseley & Dorothy E. Vawter eds., Praeger Publishers 1989).

⁶⁵ One might also make a case that informed consent must be conceptualized differently in the context of advance care planning in that it is not necessarily transaction specific, although it may be (if for example, the individual has a definite view about a particular treatment). Instead, it is primarily “health state” specific, meaning that it requires a voluntary, knowing, and competent decision that certain future adverse health states are ones in which the individual chooses to continue or not continue living.

States have required several kinds of legal formalities for execution of advance directives:

1. *Standardized statutory forms.* In most states, these are provided as optional models, but they may sometimes be seen as the only safe option to use. Often they are perceived as mandatory if the law requires that the advance directive be “substantially” in the form contained in the statute. Six states require *any* advance directive to be “substantially” in the form contained in the statute;⁶⁶ four more apply the requirement only to health care powers of attorney;⁶⁷ and three more only to living wills.⁶⁸
2. *Required disclosures or warnings.* Eight states require specific disclosures or notice to persons executing health care powers of attorney.⁶⁹ In six of these states the requirement is part of the mandatory forms noted above, but two -- Ohio and Wisconsin -- apply the requirement to any preprinted form distributed in the state.
3. *Prescribed phrases for authorizing certain wishes.* A number of states require that the directive expressly address certain matters, such as nutrition and hydration, with specificity if it is the individual’s intent to authorize their withdrawal. The specificity required in four states rises to the level of mandatory “magic words.”⁷⁰ For example, Ohio requires that:

[T]he declarant’s declaration shall use either or both of the terms “terminal condition” and “permanently unconscious state” and shall define or otherwise explain those terms in a manner that is substantially consistent with the provisions of [code section].

Moreover, the declarant’s wishes must be communicated by:

Including a statement in capital letters or other conspicuous type, including, but not limited to, a different font, bigger type, or boldface type, that the declarant’s attending physician may withhold or

⁶⁶ Ala. Stat. §22-8A-4(h) (2007); Kan. Stat. Ann. §58-632 (2006); Ky. Rev. Stat. §311.625(1) (West 2007); Or. Rev. Stat. Ann. §127.531 (West 2007); S.C. Code Ann. §62-5-504(C)(1)(a) & (D) (2006); Utah Code Ann. §75-2-1104(4) (West 2007).

⁶⁷ Nev. Rev. Stat. Ann. §449.830 (West 2007); N.H. Rev. Stat. Ann. §137-J:3 (2007); Ohio Rev. Code §1337.17 (West 2007); Tex. [Health and Safety] Code Ann. §166.163 (Vernon 2007).

⁶⁸ D.C. Code §7-622(c) (2007); Ind. Code §16-36-4-9 (West 2007); Minn. Stat. Ann. §145B.04 (West 2007).

⁶⁹ Nev. Rev. Stat. Ann. §449.830 (West 2007); N.H. Rev. Stat. Ann. §137-J:3 (2007); Ohio Rev. Code §1337.17 (West 2007); Or. Rev. Stat. Ann. §127.531 (West 2007); S.C. Code Ann. §62-5-504(D) (2006); Tex. [Health and Safety] Code Ann. §166.163 (Vernon 2007); Vt. Stat. Ann. tit. 18, §5276 (West 2007); Wis. Stat. Ann. §155.30(1) (West 2007).

⁷⁰ Ind. Code §30-5-5-17 and §16-36-1-14 (West 2007); Mich. Comp. Laws Ann. §700.5507(4) (West 2007); N.C. Gen. Stat. Ann. §90-321 (West 2007); Ohio Rev. Code §2133.02(A)(2) & (3) and §1337.13(E) (West 2007).

withdraw nutrition and hydration [under conditions specified in the act].⁷¹

4. *Required witnessing and restrictions on who may be a witness.* In most states, two adult witnesses are sufficient for execution of a directive, although witness qualifications -- or rather disqualifications -- can be many. Most commonly disqualified as witnesses are the named agent, the treating health care provider and facility staff.⁷² Three states require the directive to be both witnessed and notarized.⁷³ Six states impose special witnessing requirements on directives executed in an institutional setting.⁷⁴ South Carolina provides an example of extensive witness disqualifications. Each witness must state in an affidavit that:

the witness is not related to the principal by blood, marriage, or adoption, either as a spouse, lineal ancestor, descendant of the parents of the principal, or spouse of any of them; not directly financially responsible for the principal's medical care; not entitled to any portion of the principal's estate upon his decease under a will of the principal then existing or as an heir by intestate succession; not a beneficiary of a life insurance policy of the principal; and not appointed as health care agent or successor health care agent in the health care power of attorney; and that no more than one witness is an employee of a health facility in which the principal is a patient, no witness is the attending physician or an employee of the attending physician, or no witness has a claim against the principal's estate upon his decease.⁷⁵

5. *Limitations on who may serve as agent or proxy.* Most states restrict who may serve as agent or proxy, most typically the treating health care provider or employees of the treating facility, although exceptions for relatives are common. In three states, the agent must accept their appointment in writing.⁷⁶

The legal transactional approach also utilizes an array of mandatory procedures or other limitations. A recent review of these limitations on surrogate decision making

⁷¹ Ohio Rev. Code §2133.02(A)(2) & (3) (for living wills) and §1337.13(E) (West 2007) (for health care powers of attorney).

⁷² ABA, *Health Care Power of Attorney and Combined Advance Directive Legislation* (Chart), September 1, 2004, available at <http://www.abanet.org/aging/legislativeupdates/home.shtml> (accessed November 13, 2007).

⁷³ Mo. Ann. Stat. §404.705(3) and §404.810 (West 2007); N.C. Gen. Stat. Ann. §32A-16(3) (West 2007); W.Va. Code Ann. §16-30-4(a) (West 2007).

⁷⁴ Cal. Prob. Code §4675(a) (West 2007); Conn. Gen. Stat. §19a-576(b) & (c) (West 2007); 16 Del. Code §2511(b) (West 2007); N.Y. Pub. Health Law §2981(2)(b) & (c) (McKinney 2007); N.D. Cent. Code §23-06.4-03, §23.06.5-10(2) & (3) (2007); Vt. Stat. Ann. tit. 18, §5271(b) & (c) (West 2007).

⁷⁵ S.C. Code Ann. §62-5-504(C)(1)(c) (2006).

⁷⁶ Mich. Comp. Laws Ann. §700.5507 (West 2007); N.D. Cent. Code §23-06.5-06 (2007); Or. Rev. Stat. Ann. §127.525 (West 2007).

conducted by the ABA Commission on Law and Aging identified the following limitations occurring in varying frequency:⁷⁷

- All living will statutes by definition impose medical diagnosis prerequisites before taking action (usually a diagnosis of terminal condition or permanent unconsciousness), but a dozen states also require a diagnostic precondition before an agent may forgo life-sustaining procedures. The complexity of the process of diagnosis and documentation also varies.
- A majority of states impose limitations on implementing advance directives if the patient is pregnant.
- Twelve states include limitations that prohibit a surrogate from consenting to medical interventions that are especially consequential or controversial, such as sterilization or abortion or psycho-surgery.
- Thirty-three states have special limitations on consent by agents, default surrogates, or guardians to forgo artificial nutrition or hydration. These range from an absolute bar on default surrogates to required diagnostic preconditions.⁷⁸

The legal approach to advance care planning may have served to impede rather than promote effective advance care planning. An ample body of research, summarized by Fagerlin and Schneider and others, reveals that conventional advance directives have had relatively little impact on end-of-life decision making. Tersely summarized, some of the significant reasons for the lack of impact include the following:

- too few people make use of the legal tools;
- when they do, they do not understand the forms they complete nor the future decisions that might have to be made;
- the forms themselves do not provide much guidance;
- patients' goals and preferences for care may change;
- when principals name an agent or proxy, the agent seldom understands the principals' wishes;

⁷⁷ Abigail Petersen, *Survey of State's Health Care Decision-Making Standards*, 28 BIFOCAL 59 (April 2007), <http://www.abanet.org/aging/docs/Apr07BIFOCAL.pdf> (accessed November 13, 2007).

⁷⁸ *Id.*

- even if they have done all the above, health care providers usually do not know about the directive; and
- even if providers know one exists, it does not affect patient care.⁷⁹

The Institute of Medicine in its seminal 1997 report on improving care at the end-of-life likewise questioned the value of conventional advance directives:

The committee, while recognizing the value of advance directives, questions the urgency of intensive efforts to universalize their use. In this area of decision making at the end-of-life, the law's favorite product -- the legally binding document -- may sometimes stand in the way of, rather than ease, the process, especially if these documents are naively viewed as ultimate solutions to the difficulties of decision making. Rather, the documents known as advance directives should be seen as a set of tools useful in the ongoing process of advance care planning.⁸⁰

Finally, the transactional approach leads to unnecessary concerns about the portability of advance directives across state lines. Most state advance directive statutes explicitly recognize the validity of advance directives executed in other states,⁸¹ although the recognition means only that the directive will be considered validly executed. It does not mean that the out-of-state directive will be interpreted according to the law of the state where it was executed. For both legal and practical reasons, it will likely be interpreted according to the law of the state where it is implemented. With the variability of limitations on authority, presumptions, and definitions of terms, the original wishes of the individual could be thwarted. If state law has no express recognition of out-of-state directives, the doctrine of comity supports such recognition. But, the lack of specific authority itself may engender greater doubt and confusion among medical providers, advisors, and the public.

There is virtually no empirical evidence to suggest portability is a large problem. However, anecdotally, this author has found it to be a common question among older

⁷⁹ See, e.g., Angela Fagerlin & Carl E. Schneider, *Enough: The Failure of the Living Will*, 34 *The Hastings Center Report* 30-42 (March-April 2004); Peter H. Ditto, et. al, *Advance Directives as Acts of Communication*, 161 *Arch. Intern. Med.* 421-430 (2001); E.J. Larson & T.A. Eaton, *The Limits of Advance Directives: A History and Assessment of the Patient Self-Determination Act*, 32 *Wake Forest L. Rev.* at 278 (1997); J. Teno et al, *Advance Directives for Seriously Ill Hospitalized Patients: Effectiveness with the Patient Self-Determination Act and the SUPPORT Intervention*, 45 *J. of the American Geriatrics Society* 500-507 (1997); David Orentlicher, *The Illusion of Patient Choice in End-of-Life Decisions*, 267 *JAMA* 2101-2104 (1992); Diane E. Hoffmann, Sheryl I. Zimmerman & Catherine J. Tompkins, *The Dangers of Directives or the False Security of Forms*, 24 *J. of Law, Medicine & Ethics* 5 (1996); Rebecca Dresser, *Confronting the 'Near Irrelevance' of Advance Directives*, 5 *J. Clin. Ethics* 55-56 (Spring 1994).

⁸⁰ Institute of Medicine, Committee on Care at the End of Life, *Approaching Death: Improving Care at the End of Life* (Marilyn J. Field & Christine K. Cassel, eds., Natl. Acad. Press 1997).

⁸¹ As of 2007, 42 states expressly recognize the validity of out-of-state directives, according to the legislative summary of the ABA Commission on Law and Aging, at <http://www.abanet.org/aging/legislativeupdates/home.shtml> (accessed November 13, 2007).

persons who attend programs on health care advance care planning. In such a highly mobile society, the concern may affect many people.

The Communications Approach

In response to the experienced shortcomings of the transactional approach, an alternative paradigm has emerged -- a communications approach. This paradigm derives from the concept of *advance care planning*:

[A]dvance care planning is a broader, less legally focused concept than that of advance directives. It encompasses not only preparation of legal documents but also discussions with family members and physicians about what the future may hold for people with serious illnesses, how patients and families want their beliefs and preferences to guide decisions..., and what steps could alleviate concerns related to finances, family matters, spiritual questions, and other issues that trouble seriously ill or dying patients and their families.⁸²

Advance care planning involves an iterative process over time to discern the individual's priorities, values, and goals of care and to engage a proxy and others who will participate in the health care decision making process at any time in the future when the individual is no longer able.⁸³ The call for an expanded approach to advance care planning is by no means new,⁸⁴ but only fairly recently have its implications for public policy, as reflected in advance directive laws, been directly addressed. The well-known tract by Fagerlin and Schneider has called for the elimination of living wills and greater emphasis on use of durable powers of attorney for health care.⁸⁵ Lo and Steinbrook have called for radical simplification of these statutes:

⁸² Institute of Medicine, *supra* n. 80, at 198-199.

⁸³ See also, Lauren G. Collins, Susan M. Parks, & Laraine Winter, *The State of Advance Care Planning: One Decade after SUPPORT*, 23 Am. J. Palliat. Care 378-384, at 380 (2006); The President's Council on Bioethics, *Taking Care: Ethical Caregiving in Our Aging Society* at 214-216 (September 2005) at http://www.bioethics.gov/reports/taking_care/index.html (accessed November 13, 2007); James A. Tulsky, *Beyond Advance Directives: Importance of Communication Skills at the End of Life*, 294 JAMA 359-365 (July 20, 2005); Bernard Lo & Robert Steinbrook, *Resuscitating Advance Directives*, 164 Arch. Intern. Med. 1501-06 (July 26, 2004); Joan M. Teno, Marguerite Stevens, Stephanie Spernak & Joanne Lynn, *Role of Written Advance Directives in Decision Making: Insights from Qualitative and Quantitative Data*, 13(7) J. Gen. Intern. Med. 439-447 (1998); Bernard J. Hammes & Brenda L. Rooney, *Death and End-of-Life Planning in One Midwestern Community*, 158 Arch Intern. Med. 383-390, at 390 (February 23, 1998).

⁸⁴ In 1995, Muriel Gillick argued: "Advance planning for future illness should be broadened from medical care in the event of incompetence to all medical care for the elderly. To plan effectively, patients need an assessment of their overall medical condition: whether they are robust, frail, demented, or dying. They need to understand the kinds of complications often engendered by aggressive treatment, given their underlying status. Given information about their circumstances and their capacity to withstand medical interventions, patients, together with their physicians, need to formulate broad goals for medical care." Muriel R. Gillick, *A Broader Role for Advance Medical Planning*, 123 Ann. Int. Med. 621-624 (October 15, 1995); see also Joan M. Teno & Joanne Lynn, *Putting Advance-Care Planning Into Action*, 7 J. Clin. Ethics 205-213 (Fall 1996).

⁸⁵ Angela Fagerlin & Carl E. Schneider, *supra* note 79, at 39.

Legal requirements that were intended to protect patients may be counterproductive. Requirements that written advance directives be witnessed or notarized place burdens on patients who complete them...Advance directives would be more useful if they emphasized advance care planning, particularly discussions of end-of-life care with physicians, rather than completing a legal document...

We suggest that such discussions between physicians and patients are at the core of informed advance planning. Documentation of discussions is important, but should not be so complicated as to discourage the discussions themselves...Patients should be able to designate health care proxies through oral statements to physicians.⁸⁶

While state advance directive law is far from the model advocated by Lo and Steinbrook, the growing prominence of a communications approach is reflected in incremental but real steps toward simplification of state law, especially with respect to mandatory forms or language. As noted earlier, the model for simplification has been the 1993 Uniform Health-Care Decisions Act, which has prompted a number of states to combine disparate pieces of health care decisions provisions into comprehensive acts. Another possible measure of simplification is to ask whether state law has become uncomplicated enough to enable a single advance directive form to meet the statutory requirements of all 50 states and the District of Columbia. The *Five Wishes* advance directive provides one such measure.

In the last ten years, the *Five Wishes* advance directive, created by the organization Aging with Dignity, Inc., has been the only form affirmatively marketed nationally.⁸⁷ As a consultant to Aging with Dignity, this author compared *Five Wishes* to the statutory requirements in all 50 states and the District of Columbia at the time it was released for national distribution in 1978 and periodically since then to determine its statutory compliance.⁸⁸ In the drafting of *Five Wishes*, Aging with Dignity sought to create a personal, easy-to-use, and non-legalistic instrument.⁸⁹ The most prominent barriers to the statutory compliance of *Five Wishes* in all jurisdictions have been the statutory provisions for substantial compliance with a statutory form (i.e., mandatory

⁸⁶ Bernard Lo & Robert Steinbrook, *supra* note 83, at 1502, 1504; *see also*, Charles P. Sabatino, *De-Balkanizing State Advance Directive Law*, 13(1) Public Policy & Aging Report 1 (National Academy on an Aging Society, Winter 2003); Charles P. Sabatino, *Will My Wishes Be Known and Honored? Policy and Practice Perspectives*, in *Improving End-of-Life Care: The Role of Attorneys General* 35-46 (National Association of Attorneys General 2003); David Orentlicher, *The Limitations Of Legislation*, 53 Md. L. Rev. 1255 (1994).

⁸⁷ Aging With Dignity, Inc., is a non-profit group that assists families with end-of-life issues. For more information, *see* <http://www.agingwithdignity.org> (accessed on November 13, 2007).

⁸⁸ Charles P. Sabatino, *National Advance Directives: One Attempt to Scale the Barriers*, 1 NAELA Journal 131-164 (Spring 2005).

⁸⁹ In theory, one could incorporate every differing state requirement into one form with directions explaining which options users should use. However, that approach would make such a document impossibly unwieldy and complicated. A goal of *Five Wishes* has been simplicity and understandability.

forms) along with prescribed phraseology and requirements for including a prescribed notice or warning.⁹⁰

In 1978 when *Five Wishes* was released for national distribution, it ostensibly met the statutory requirements in 33 states and the District of Columbia.⁹¹ By 2007, the number of state laws friendly to *Five Wishes* had grown to 40.⁹² The increase was made possible by the trend toward simplification of state law.

Another instructive measure of simplification is a trend toward the statutory recognition of oral advance directives documented in the patient's record. Prior to the 1993 Uniform Health-Care Decisions Act, no state recognized oral advance directives. Currently, 14 states recognize some form of oral directive.⁹³ Most of these states follow the approach of the Uniform Health-Care Decisions Act which recognizes an oral "instruction" documented in the record as valid and the appointment of a an orally designated "surrogate" where the appointment is personally communicated to the supervising health care provider.⁹⁴

A few of these 14 states recognize only oral instructional directives but not orally designated surrogates.⁹⁵ A couple states require witnesses as a prerequisite to validity.⁹⁶ Permitting oral directives affirms the form of communication most likely to occur between physician and patient and provides a marker of state flexibility.

Apart from legislative changes, one aspect of advance directive practice deserves notice. The tools available to the general public under the legal transactional paradigm have primarily been statutory forms and the instructions for completing them and related fact sheets. Indeed, these are still widely available from health care providers, medical and bar associations, Offices on Aging, and on the Internet from groups such as the National Hospice and Palliative Care Organization.⁹⁷ Beginning in the late 1990s, self-help tools began to appear intended to help the user to understand the process of

⁹⁰ Charles P. Sabatino, *supra*, note 88, at 150.

⁹¹ Aging with Dignity press release, *Revolutionary National Living Will Unveiled: Document is Legally Valid in 33 States* (October 22, 1998) (on file with author).

⁹² See Aging with Dignity announcement of new 2007 edition at <http://www.agingwithdignity.org/fw2007.html> (accessed November 13, 2007).

⁹³ Alaska Sta. §13.52.010(a) and 13.52.030(c) (West 2007); Cal. Prob. Code §§4623 and 4711 (West 2007); Conn. Gen. Stat §19a-578 (West 2007); 16 Del. Code §2507(b) (West 2007); Fla. Stat. Ann. §§765.101(1) and 765.101(11)(a) (West 2007); Haw. Rev. Stat. §327E-3 and §327E-5 (2007); La. Rev. Stat. Ann. 40:1299.58.3(3) (West 2007); 18-A Me. Rev. Stat. Ann. §5-802(a) (West 2007); Md. Health-Gen. Code Ann. §5-602(d)(1) (West 2007); Miss. Code Ann. §§41-41-205(1) and 41-41-211 (West 2007); N.M. Stat. Ann. §§24-7A-2(A) and 24-7A-5 (West 2007); Tenn. Code Ann. §68-11-1803 and -1806 (West 2007); Va. Code Ann. §54.1-2982 and 54.1-2983 (West 2007); Wyo. Stat. Ann. §35-22-403(a) (2007).

⁹⁴ Uniform Health-Care Decisions Act §5. See, e.g., N.M. Stat. Ann. §§24-7A-2(A) and 24-7A-5 (West 2007).

⁹⁵ See e.g., Conn. Gen. Stat §19a-578 (West 2007); Fla. Stat. Ann. §§765.101(1) and 765.101(11)(a) (West 2007); La. Rev. Stat. Ann. 40:1299.58.3(3) (West 2007); 18-A Me. Rev. Stat. Ann. §5-802(a) (West 2007).

⁹⁶ See e.g., Md. Health-Gen. Code Ann. §5-602(d)(1) (West 2007); Va. Code Ann. §54.1-2982 and 54.1-2983 (West 2007).

⁹⁷ See <http://www.caringinfo.org/stateaddownload> (accessed November 13, 2007).

planning, the values and goals to be considered, and how to discuss these matters with family, friends, proxy, and health care providers. These are essentially workbooks for advance care planning. The written directive is still an intended outcome, but greater emphasis is placed on the process, not the form.

Robert Pearlman and others at the Veterans Administration Medical Center in Seattle produced one of the first of these in 1998, entitled *Your Life Your Choices -- Planning for Future Medical Decisions: How to Prepare a Personalized Living Will*.⁹⁸ A small sampling of others that have appeared include:

- *Caring Conversations Workbook*, published by the Center for Practical Bioethics (1999).⁹⁹
- *Finding Your Way: A Guide for End-of-Life Medical Decisions*, by Sacramento Healthcare Decisions (1998).¹⁰⁰
- *The Critical Conditions Planning Guide*, by Georgia Health Decisions (1998).¹⁰¹
- *The Lawyer's Tool Kit for Health Care Advance Planning*, and *The Consumer's Tool Kit for Health Care Advance Planning* by the ABA Commission on Law and Aging (2000).¹⁰²

The *Lawyer's Toolkit* is especially significant in its targeting of the legal profession which assists a large proportion of individuals to complete advance directives.¹⁰³ The *Toolkit* does not provide guidance on drafting, but instead gives lawyers tools they can provide to clients to help them understand the planning process, self-reflect, and discuss the subject with family, physician, and others. Use of resources such as these by no means marks the end of the transactional legal model, but it does suggest a growing awareness of the central role of communication at the center of the process.

Two other approaches suggestive of a communications approach but without much evidence of effectiveness in the literature include the use of notice of an advance directive on driver's licenses and advance directive registries. Currently, at least six

⁹⁸ Robert Pearlman, Helene Starks, K. Cain, W. Cole, D. Rosengren & D. Patrick, *Your Life Your Choices -- Planning for Future Medical Decisions: How to Prepare a Personalized Living Will* (Department of Veterans Affairs 1998), product code PB98159437, available for order from the National Technical Information Service <http://www.ntis.gov> (accessed November 13, 2007).

⁹⁹ See <http://www.practicalbioethics.org> (accessed November 13, 2007).

¹⁰⁰ See <http://www.sachealthdecisions.org/publications.html> (accessed November 13, 2007).

¹⁰¹ See <http://www.critical-conditions.org>, (accessed November 13, 2007).

¹⁰² See <http://www.abanet.org/aging>, (accessed November 13, 2007).

¹⁰³ See e.g., Dorcas Mansell, Lewis Kazis, Leonard Glanz & Timothy Heeren, *Roles of Physicians, Attorneys, and Illness Experience in Advance Directives*, 92(2) Southern Med. J. 197-203 (February 1999); John M. Roe et al., *Durable Power of Attorney for Health Care: A Survey of Senior Center Participants*, *Archives of Internal Medicine* 152 (1992): 292-96.

states provide for driver's license notice of advance directives.¹⁰⁴ The purpose of these are to institutionalize the dissemination of information about advance directives at the time of driver's license application or renewal and to enable drivers to include a notice of having a directive on their licenses in much the same way that drivers may indicate their intent to be an organ donor on their license. No evaluative literature on how these notices function could be found.

A driver's license notice fits conceptually well with an advance directive registry, so that if an advance directive is indicated on a driver's license, there would be a single source to check for more information or a copy of the directive. At least eight private entities store advance directives, either as a stand-alone service or within a range of other services and products:

- America Living Will Registry (<http://www.alwr.com>);
- Choices Bank, established for the Missoula, Montana area but replicable elsewhere (http://www.lifes-end.org/products/choices_bank.php);
- DocuBank (<http://www.docubank.com/>);
- MyHealthDirective.com -- A Nationwide Registry of Advance Healthcare Directives (<http://myhealthdirective.com>);
- U.S. Living Will Registry (<http://www.uslwr.com>).
- Full Circle Registry (<http://www.fullcirculeregistry.com>)
- GIFTS Advance Directive Registry of Gateway files Systems, Inc. (http://www.giftsdirectives.com/Articles_pps/Giftsbooklet.pdf); and
- MedicAlert Foundation (<http://www.medicalert.com/Main/AdvanceDirectives.aspx>).

Nine states have created their own advance directive registries, starting with Louisiana in 1991 and California in 1999, followed by North Carolina (2002), Arizona (2004), Montana and Vermont (2005) and Maryland, Idaho and Washington (2006).¹⁰⁵ In addition, the Nevada legislature passed an advance directive registry bill in its 2007 legislative session.¹⁰⁶ All are delegated to state agencies and all are or will be accessible online.¹⁰⁷

¹⁰⁴ 625 Ill. Comp. Stat. §5/6-110 (West 2007); La. Rev. Stat. Ann. §32:410 (West 2007); Minn. Stat. Ann. §171.07 (West 2007); Mont. Code Ann. §61-5-301 (2007); S.D. Codified Laws §32-12-17.2 (2007); Vt. Stat. Ann. tit. 18, §9719 (West 2007).

¹⁰⁵ Ariz. Rev. Stat. Ann. §§36-3291 to -3297 (West 2007); Cal. Prob. Code Ann. §§4800-4802 (West 2007); Idaho Code §39-4515 (West 2007); Md. Code Ann. [Health-Gen] §§5-619 to -626 (West 2007); Mont. Code Ann. §§50-9-501 to -505 (2007); N.C. Gen. Stat. Ann. §§130A-465 to -471 (West 2007); Vt. Stat. Ann. tit. 18, §§9701, 9704, 9709, 9712, 9714, 9719 (West 2007); Wash. Rev. Code Ann. §70.122.130 (West 2007).

¹⁰⁶ Nevada Laws Ch. 473 (A.B. 158).

¹⁰⁷ California <http://www.ss.ca.gov/ahcdr/>; Arizona http://www.azsos.gov/adv_dir/; Idaho <http://www.sos.idaho.gov/general/hcdr.htm>; Maryland Md. Code Ann. [Health-Gen.] §5-619 to -626 (2007); Montana <http://www.montana.edu/wwwpb/pubs/mt200602.html>; North Carolina <http://www.secretary.state.nc.us/ahcdr/>; Vermont <http://healthvermont.gov/vadr/register.aspx>.

While both the driver's license and registry strategies seek in concept to enhance notice of, and access to, advance directives, there is little empirical evidence available with which to assess their effectiveness in reaching these goals. It is difficult to predict whether the strategies will actually increase awareness and usage, or whether the impact may be to reinforce the document approach further rather than the communication approach, or whether the public will ignore both.

Private national efforts have been tried for a number of years, but none have achieved the critical mass to be truly national. With proxy directives, it may be that most individuals will prefer to rely on their appointed proxy to step in when needed rather than rely on a registry. And with the expansion of electronic medical records, the need for a separate electronic registry may diminish. With respect to the latter issue, a 2005 legislative study on the need for a state registry by the State Advisory Council on Quality Care at the End of Life concluded:

Before deciding whether it is worthwhile to create an advance directive registry, especially given the substantial start-up and ongoing costs, the Maryland General Assembly should consider the likelihood that there will be national or statewide use of electronic medical records in the near future. If there is a good chance that electronic medical records will increasingly become part of routine practice, we are skeptical that the creation of a separate advance directive registry is worthwhile.¹⁰⁸

¹⁰⁸ Maryland State Advisory Council on Quality Care at the End of Life, *Study on a Statewide Advance Directive Registry* (December 2005), available at <http://oag.state.md.us/Healthpol/ADregistry.pdf>.

V. A POSSIBLE NEXT STEP --THE POLST PARADIGM

As law and practice move toward a less standardized, more flexible, communications approach, questions remains as to whether more flexibility in communication will have any greater impact on actual treatment decisions than do standardized advance directive forms. An emerging strategy that began in Oregon has had a positive impact in bridging this gap between patient goals and preferences -- expressed directly, through an advance directive, or by a proxy -- and the actual plan of care as reflected by physician orders.

The driver of medical interventions in hospitals and other health care settings remains physician orders along with standard clinical procedures. A small but growing number of states have recognized that patient wishes, no matter how communicated, must be methodically factored into or translated into the medical decision making engine. In the early 1990s, Oregon experimented with a protocol for seriously chronically ill patients, called *Physicians Orders for Life-Sustaining Treatment*, or POLST.¹⁰⁹ There are several ways to describe the POLST process, but relevant to this review are three key tasks it aims to accomplish.

One, the use of POLST prompts a discussion between the health care provider and patient or surrogate about key end-of-life care treatment options. The objective is to discern the wishes of the patient in light of his or her current condition and the available care options as explained by the treating health care provider.

Two, the patient's wishes are incorporated into doctor's orders that are recorded on a unique, visible (bright pink in Oregon) POLST form that serves as a cover sheet to the medical record and is reviewed periodically and as needed. The form covers several key decisions that are common for seriously chronically ill patients. The Oregon form addresses: CPR; the level of medical intervention desired in the event of emergency (comfort only/do not hospitalize; limited; or full treatment); use of antibiotics; and the use of artificial nutrition and hydration.

Three, providers must ensure that the POLST form travels with the patient whenever transfers from one setting to another are made, thus, promoting continuity of care decision making.¹¹⁰

POLST is not an advance directive in the conventional sense but it is an advance care planning tool that reflects the patient's here-and-now goals for medical decisions that could confront the patient in the immediate future.¹¹¹ It builds upon one's advance

¹⁰⁹ Susan W. Tolle *et al.*, *A Prospective Study of the Efficacy of the Physician Order Form for Life-Sustaining Treatment*, 46 *Journal of the American Geriatrics Society* 1 (1998).

¹¹⁰ Charles P. Sabatino, *supra* note 88, at 153.

¹¹¹ The core requirements for a POLST protocol, as stated by the national POLST Paradigm Initiative can be found at <http://www.ohsu.edu/polst/corereqs.shtml> (accessed November 14, 2007).

directive but can also function in the absence of an advance directive if the patient has decisional capacity. Research on the Oregon experience with POLST has shown positive outcomes.¹¹²

Another way to understand the POLST paradigm is to compare it to out-of-hospital DNR orders. POLST is a very similar process, except that it is not limited to the single decision of resuscitation, and it does not presumptively call for withholding medical interventions. It permits a full range of plans from comfort care only to full treatment.

Since Oregon's development of the POLST form, Washington State and West Virginia and parts of several other states have implemented similar protocols,¹¹³ and other states are considering following suit. In many ways, the POLST form represents a sea change in advance care planning policy by making key provider communications reflecting the plan of care highly visible and clinically routine and coupling elicitation of treatment preferences with orders for care, rather than focusing solely on standardizing patient communications.

The POLST paradigm has the additional advantage of being fairly adaptable in the face of variable state law. For example, it has been implemented both with legislation (as in West Virginia¹¹⁴) and without legislation through provider collaboration (as in Oregon¹¹⁵). To the extent that surrogates are authorized to make health decisions under state law, surrogates may complete POLST forms. POLST paradigms can be implemented statewide and/or locally depending upon legal and clinical receptivity. While POLST is a paper driven protocol, it is adaptable to electronic medical record environments. Its primary limitation with respect to advance care planning is that, by necessity, it focuses on immediate potential decisions and not on distant goal-based planning.

¹¹² Susan E. Hickman, Susan W. Tolle, Kenneth Brummel-Smith & Margaret M. Carley, *Use of the POLST (Physician Orders for Life-Sustaining Treatment) Program in Oregon Nursing Facilities: Beyond Resuscitation Status* 52 J. Amer. Geriatrics Soc. 1424-1429 (2004); Terri A. Schmidt, Susan E. Hickman, Susan W. Tolle & H. S. Brooks, *The Physician Orders for Life-Sustaining Treatment (POLST) Program: Oregon Emergency Medical Technicians' Practical Experiences and Attitudes*, 52 J. Amer. Geriatrics Soc. 1430-1434 (2004). Additional literature is summarized at <http://www.polst.org> (accessed November 14, 2007).

¹¹³ For more about the West Virginia form, *see* http://www.hsc.wvu.edu/chel/ad_forms/WVHA_POST_form_disc.htm (accessed November 14, 2007); *see also*, http://www.hsc.wvu.edu/chel/wvi/faq_post.htm (accessed November 14, 2007). The National POLST Paradigm Initiative reports POLST programs in parts of Georgia, Kansas, Missouri, New Mexico, Utah, Washington, West Virginia, Wisconsin, New York, and Pennsylvania. Information on POLST developments in all the states is available at <http://www.polst.org>.

¹¹⁴ W.Va. Code Ann. §16-30-1 to -25 (West 2007).

¹¹⁵ *See* Susan E. Hickman, *supra* n. 112.

VI. DEFAULT SURROGATES: THE PREVAILING REALITY

The fourth wave or tide of legislation described earlier addresses a far more common scenario in health care decision making: how are end-of-life decisions to be made in the *absence* of any advance directive, or in the absence of an authorized surrogate at all. Guardianship has not been seen as an effective solution for these situations in general unless there is a dispute or special concern that merits such review. The judiciary has had neither the resources nor the expertise for taking on responsibility in all such cases.¹¹⁶ Default surrogate laws have attempted to provide baseline principles and processes for default surrogate decision making. But several difficult issues have arisen in the structure and implementation of these laws.

The Order of Priority of Surrogates. The majority of existing family consent laws provide a fixed hierarchy under which family members are authorized to act -- usually starting with one's spouse and then next-of-kin, proceeding through some degree of kinship. Seventeen states and the District of Columbia authorize a close friend as surrogate but usually at or near the end of the priority list.¹¹⁷ Thus, most of these laws provide a poor framework for domestic partners or non-traditional families. Only two -- Colorado and Hawaii -- avoid imposing any priority. These two states contain a list of "interested persons" (made up of close family and friends) and require those available among this group to decide who among them will serve as the surrogate.¹¹⁸ The trade-off for this greater accommodation to non-traditional families is the reality that everyone will have to be in agreement among the group, or else the process will not work. On the other hand, even in states with a prescriptive order of authority, any interested person so inclined can use the judicial system to challenge the process. At best, default surrogacy rules can only reflect what most but not all people may prefer.

Limited Scope of Authority. Only eight states follow the Uniform Health-Care Decisions Act model that places no limitations on default surrogates.¹¹⁹ Eighteen states place limitations on the authority of a surrogate to consent to the forgoing of a

¹¹⁶ See generally Alan Meisel & Katy L. Cerminare, *supra* n. 14, at §§3.18 -3.24.

¹¹⁷ Alaska Stat. §13.52.030 (West 2007); Ariz. Rev. Stat. Ann. §36-3231 (West 2007); Colo. Rev. Stat. Ann. §15-18.5-103 (West 2007); 16 Del. Code §2507 (West 2007); D.C. Code §21-2210 (2007); Fla. Stat Ann. §765.401 (West 2007); Haw. Rev. Stat. §§327E-2 & E-5 (2007); 755 Ill Comp. Stat. §40/25 (West 2007); 18-A Me. Rev. Stat. Ann. §5-805(West 2007); Md. Health-Gen. Code Ann., §5-605 (West 2007); Miss. Code Ann. §§41-41-211; N.M. Stat. Ann. 1978 §24-7A-5 (West 2007); N.Y. Pub. Health Law §2965 (McKinney 2007) [Limited to DNR orders]; N.D. Cent. Code §23-12-13 (2007); Tenn. Code Ann §68-11-1806 (West 2007); W.Va. Code Ann. §16-30-8 (West 2007); Wis. Stat. Ann. §50.06 (West 2007) [Limited to certain facility admissions]; Wyo. Stat. Ann. §35-22-406 (2007).

¹¹⁸ Colo. Rev. Stat. Ann. §15-18.5-101 to -1033 (West 2007); Haw. Rev. Stat. §§327E-2 & E-5 (2007).

¹¹⁹ Ga. Code Ann. §31-9-2 (West 2007); Idaho Code §39-4503 (West 2007); Ind. Code §16-36-1-1 to -14 (West 2007); S.C. Code Ann. §44-66-10 to -80 (2006); S.D. Codified Laws §34-12C-1 to -8 (2007); Wash. Rev. Code Ann. §7.70.065 (West 2007); W.Va. Code Ann. §16-30-8 (West 2007); Wyo. Stat. Ann. §35-22-406 (2007).

life-sustaining treatment (or alternatively, nutrition and hydration).¹²⁰ Of these, Arizona and Ohio entirely bar surrogates from authorizing the withholding or withdrawal of nutrition and hydration, absent a court order. Most of the others place medical preconditions on such decisions, usually certification of a terminal condition or permanent unconsciousness.

Other restrictions prevent consent to certain mental health treatments,¹²¹ or to exceptional/controversial procedures (such as sterilization or abortion),¹²² or to decisions to limit any treatment when the patient is pregnant.¹²³ A few states limit their surrogate consent law to a single type of decision. For example, New York's default surrogate law addresses only DNR decisions,¹²⁴ while the Kansas and Oklahoma laws address only consent to medical research,¹²⁵ and Wisconsin's law addresses only admission to nursing homes and certain community-based residential facilities.¹²⁶

Certain ambiguities about the scope of authority of the surrogate also arise in some of these laws by virtue of their legislative context. For example, the surrogacy provision is contained in the state's living will statute in seven states. Because these statutes only focus on decisions made after a diagnosis of terminal condition or permanent unconsciousness,¹²⁷ it is not clear that the authority of surrogates extends to the full range of other, more routine medical decisions that need to be made for patients lacking decisional capacity. In three states, the surrogate provisions are contained in general informed consent statutes that predate legislative attention to end-of-life

¹²⁰ Alaska Stat. §13.52.030 (West 2007); Ariz. Rev. Stat. Ann. §36-3231 (West 2007); Ark. Code Ann. §20-17-214 (West 2007); Colo. Rev. Stat. Ann. §15-18.5-101 to -1033 (West 2007); Conn. Gen. Stat. Ann. §19a-571 (West 2007); 16 Del. Code §2507 (West 2007); Haw. Rev. Stat. §§327E-2 & E-5 (2007); 755 Ill. Comp. Stat. §§40/1 to 40/25 (West 2007); Iowa Code Ann. §144A.7 (West 2007); Ky. Rev. Stat. §311.631 (West 2007); La. Rev. Stat. Ann. §40:1299.58.5 (West 2007); 18-A Me. Rev. Stat. Ann. §5-805 (West 2007); Mont. Code Ann. §50-9-106 (2007); Nev. Rev. Stat. Ann. §449.626 (West 2007); N.C. Gen. Stat. Ann. §90-322 (West 2007); Ohio Rev. Code Ann. §2133.08 (West 2007); Or. Rev. Stat. Ann. §§127.505(12), 127.535(4), 127.635 (West 2007); Tenn. Code Ann. §68-11-1806 (West 2007).

¹²¹ Alaska Stat. §13.52.030 (West 2007); Ariz. Rev. Stat. Ann. §36-3231 (West 2007); Cal. Prob. Code §4711 to 4716 (West 2007); D.C. Code §21-2210 (2007); Fla. Stat Ann. §765.401 (West 2007); 755 Ill. Comp. Stat. §40/25 (West 2007); 18-A Me. Rev. Stat. Ann. §5-805 (West 2007); Md. Health-Gen. Code Ann. §5-605 (West 2007); Miss. Code Ann. §§41-41-211 & 227(5); N.M. Stat. Ann. 1978 §24-7A-5 (West 2007); N.D. Cent. Code §23-12-13 (2007); Tenn. Code Ann. §68-11-1806 (West 2007); Va. Code Ann. §54.1-2986 (West 2007).

¹²² D.C. Code §21-2210 (2007); Fla. Stat Ann. §765.401 (West 2007); 755 Ill. Comp. Stat. §40/25 (West 2007); N.D. Cent. Code §23-12-13 (2007); Va. Code Ann. §54.1-2986 (West 2007).

¹²³ Ark. Code Ann. §20-17-214 (West 2007); Conn. Gen. Stat. Ann. §19a-571 (West 2007); 16 Del. Code §2507 (West 2007); Fla. Stat Ann. §765.401 (West 2007); Iowa Code Ann. §144A.7 (West 2007); Mont. Code Ann. §50-9-106 (2007); Nev. Rev. Stat. Ann. §449.626 (West 2007); Ohio Rev. Code Ann. §2133.08 (West 2007); 20 Pa. Cons. Stat. Ann. §5461 (West 2007); Tex. [Health & Safety] Code Ann. §166.039 (Vernon 2007); Utah Code Ann. §75-2-1105, -1105.5 & -1107 (West 2007).

¹²⁴ N.Y. Pub. Health Law §2965 (McKinney 2007).

¹²⁵ Kan. Stat. Ann. §65-4974 (2006); Okla. Stat. Ann. tit. 63, §3102A (West 2007).

¹²⁶ Wis. Stat. Ann. §50.06 (West 2007).

¹²⁷ Ark. Code Ann. §20-17-214 (West 2007); Iowa Code Ann. §144A.7 (West 2007); La. Rev. Stat. Ann. §40:1299.58.5 (West 2007); Mont. Code Ann. §50-9-106 (2007); Nev. Rev. Stat. Ann. §449.626 (West 2007); N.C. Gen. Stat. Ann. §90-322 (West 2007); Ohio Rev. Code Ann. §2133.08 (West 2007).

decision making.¹²⁸ These laws refer only to who may consent to needed treatment and do not address refusals of consent. A narrow reading of these statutes could unduly restrict the authority of a surrogate; however, since the authority to consent is illusory without the ability to say no, these laws should be sufficient to authorize surrogates to withhold treatments, too.

Handling of Disagreements. Where there are multiple surrogates, such as in the case where there are multiple adult children authorized as decision makers, the issue of how to resolve disputes among the surrogates may arise. The most common approach is to permit the majority position to prevail, at least among adult children, if there is a majority.¹²⁹ However, a practical question that does not appear to have been the subject of research is whether providers will actually accept a majority decision in the face of a vocal or angry opposition by others. Defensive medicine instincts suggest not. Four states require the unanimous consent of all members in the same priority level.¹³⁰

Delaware and Maryland provide for referral to an institutional ethics or advisory committee as an option in the face of dispute;¹³¹ and Maine provides that the health care provider “may refer the members of the class or classes to a neutral third party for assistance in resolving the dispute.”¹³² Many simply do not specify what is to happen.¹³³ Thus, where disputes among authorized surrogates cannot be mediated, recourse to the courts may be the only option.

Lack of Available Surrogate (the “unbefriended patient”). Patients without a natural surrogate have been labeled “unbefriended” by some researchers.¹³⁴ These are patients who frequently have been socially isolated much of their lives, or they have simply outlived their family and social support network. The majority of these patients are encountered in hospitals or nursing homes, and frequently have multiple chronic

¹²⁸ Ga. Code Ann. §31-9-2 (West 2007); N.D. Cent. Code §23-12-13 (2007); Wash. Rev. Code Ann. §7.70.065 (West 2007).

¹²⁹ Alaska Stat. §13.52.030 (West 2007); Ariz. Rev. Stat. Ann. §36-3231 (West 2007); Ark. Code Ann. §20-17-214 (West 2007); Fla. Stat. Ann. §765.401 (West 2007); 755 Ill. Comp. Stat. §40/1 to 40/25 (West 2007); Iowa Code Ann. §144A.7 (West 2007); Ky. Rev. Stat. §311.631 (West 2007); 18-A Me. Rev. Stat. Ann. §5-805 (West 2007); Miss. Code Ann. §§41-41-203(s), -211, & -215(9); Mont. Code Ann. §50-9-106 (2007); Nev. Rev. Stat. Ann. §449.626 (West 2007); N.M. Stat. Ann. 1978 §24-7A-5 (West 2007); N.C. Gen. Stat. Ann. §90-322 (West 2007); Ohio Rev. Code Ann. §2133.08 (West 2007); Or. Rev. Stat. Ann. §§127.505(12), 127.535(4) & 127.635 (West 2007); 20 Pa. Cons. Stat. Ann. §5461 (West 2007); Utah Code Ann. §75-2-1105, -1105.5 & -1107 (West 2007); Va. Code Ann. §54.1-2986 (West 2007); Wyo. Stat. Ann. §35-22-406 (2007).

¹³⁰ La. Rev. Stat. Ann. §40:1299.58.5 (West 2007); S.C. Code Ann. §44-66-10 to -80 (2006); S.D. Codified Laws §34-12C-1 to -8 (2007); Wash. Rev. Code Ann. §7.70.065 (West 2007).

¹³¹ 16 Del. Code §2507(b)(8) (West 2007); Md. Health-Gen. Code Ann., §5-605(b)(1) (West 2007).

¹³² 18-A Me. Rev. Stat. Ann. §5-805(e) (West 2007).

¹³³ Ala. Code 1; 75 §22-8A-11 & -6 (2007); Conn. Gen. Stat. Ann. §1, a-571 (West 2007); D.C. Code §21-2210 (2007); Ga. Code Ann. §31-9-2 (West 2007); Idaho Code §39-4503 (West 2007); Ind. Code §16-36-1-1 to -14 (West 2007); Mich. Comp. Laws Ann. §§333.5653(g) & .5655(b) (West 2007); N.D. Cent. Code §23-12-13 (2007); Tex. [Health & Safety] Code Ann. §166.03 (Vernon 2007).

¹³⁴ Murial R. Gillick, *Medical Decision-making for the Unbefriended Nursing Home Resident*, 1(2) J. Ethics, L & Aging 87 (1995); Marshall B. Kapp, *Surrogate Decision-Making for the Unbefriended: Social and Ethical Problem, Legal Solution?* 1 J. Ethics, L. & Aging 83 (1995).

conditions that may require difficult decisions regarding major medical or life-sustaining treatments. It is difficult to estimate accurately how many individuals fall into this status, but a 2003 report by the ABA estimated that about 3-4 percent of nursing home residents are unbefriended.¹³⁵

Only eight states address non-judicial avenues of decision making for unbefriended patients, and one of these (Mississippi) explicitly authorizes only consent and expressly proscribes withholding.¹³⁶ North Carolina and Oregon defer to the attending physician as decision maker.¹³⁷ Alabama likewise defers to the attending physician but requires concurrence of an institutional ethics committee.¹³⁸ Tennessee and Texas do likewise but, alternatively, permit concurrence from a second disinterested physician if an ethics committee is not available.¹³⁹

Florida permits the provider's ethics committee to select a licensed clinical social worker who is a graduate of a court-approved guardianship program to serve as default decision maker.¹⁴⁰ Finally, West Virginia authorizes a state agency to serve as default decision maker:

Any other person or entity, including, but not limited to, public agencies, public guardians, public officials, public and private corporations and other persons or entities which the department of health and human resources may from time to time designate in rules promulgated pursuant to chapter 29.a of this code.¹⁴¹

Investigating non-judicial mechanisms for health care decision making on behalf of unbefriended patients, the authors of the ABA report confirmed that very few state laws address the needs of unbefriended elderly patients. Of those that do, the laws generally fall into four categories: (1) health care consent statutes specifying who can consent to treatment, often authorizing attending physicians (as described above); (2) creation of volunteer committees to make decisions, usually for mentally retarded or mentally ill individuals; (3) court processes authorizing limited consent to treatment; and (4) public guardianship.¹⁴² The last option was noted as significantly insufficient because public guardianship programs are costly and too often overburdened and under-funded. The report acknowledges that all of these mechanisms have drawbacks but move in the right direction. In addition, the report notes that some hospitals and nursing homes are beginning to develop innovative and patient-centered systems to address the needs of

¹³⁵ See, Naomi Karp & Erica Wood, *Incapacitated and Alone: Health Care Decision-Making for the Unbefriended Elderly* (ABA July 2003).

¹³⁶ Miss. Code Ann. §§41-41-215(9) (West 2007).

¹³⁷ N.C. Gen. Stat. Ann. §90-322(b) (West 2007); Or. Rev. Stat. Ann. §127.635(3) (West 2007).

¹³⁸ Ala. Code 1975 §22-8A-11(d)(7) (2007).

¹³⁹ Tenn. Code Ann §68-11-1806(c)(5) (West 2007); Tex. [Health & Safety] Code Ann. §166.039(e) (Vernon 2007).

¹⁴⁰ Fla. Stat Ann. §765.401(1)(h) (West 2007).

¹⁴¹ W.Va. Code Ann. §16-30-8(a)(7) (West 2007).

¹⁴² Naomi Karp & Erica Wood, *supra* n. 135, at 19.

unbefriended patients. Often, however, when state laws fail to authorize clear and ethical mechanisms to deliver or discontinue care for unbefriended patients, practitioners and institutions have to “fly below the radar screen” in making decisions.¹⁴³

The report includes consensus recommendations from an expert symposium addressing the following areas:

- using preventive and “pre-crisis” approaches such as educating at-risk individuals about advance directives and developing de facto surrogacy relationships through “buddy systems;”
- designing thoughtful mechanisms for decision making that may be internal to a facility (e.g., interdisciplinary ethics committees) or external surrogate decision making committees;
- incorporating key patient-centered characteristics into a well-designed system; and
- utilizing judicial remedies as a last resort.¹⁴⁴

¹⁴³ *Id.* at 32-33.

¹⁴⁴ *Id.* at 42-44.

VII. THE FEDERAL ROLE

Health care decision making has traditionally been considered a province of state law, not federal. Federal law generally defers to state substantive law in this area, including the selection and authority of chosen and default surrogates. For example, federal nursing home regulations provide:

In the case of a resident adjudged incompetent under the laws of a state by a court of competent jurisdiction, the rights of the resident are exercised by the person appointed under state law to act on the resident's behalf.

In the case of a resident who has not been adjudged incompetent by the state court, any legal surrogate designated in accordance with state law may exercise the resident's rights to the extent provided by state law.¹⁴⁵

In addition, the privacy rule under the Health Insurance Portability and Accountability Act (HIPAA) of 1996¹⁴⁶ likewise provides that those authorized under state law to make health care decisions for another must be treated as their legal representatives for the purpose of information access and disclosure.¹⁴⁷

However, Congress has taken action to mandate the availability of certain information and education under the 1990 *Patient Self-Determination Act*, described above; and to regulate access to health care information by others under HIPAA, as noted.

In addition to the above, Congress made a brief foray into an individual state court dispute involving the controversial case of Terri Schiavo when it enacted a bill (S.653 -- *Bill for the Relief of the Parents of Terri Schiavo*) on March 21, 2005, to authorize federal review of her case. However, the criticism and controversy that Congress generated by its action quickly caused it and the Administration to cool their activism after Terri Schiavo's death ten days later.

Finally and most directly related to advance directives, Congress in 1996 did enact a federal advance directive, applicable specifically to military personnel:

¹⁴⁵ 42 C.F.R. §483.10(a)(3) & (4).

¹⁴⁶ Public Law 104-191 (1996). The privacy rule can be found at 45 CFR Parts 160 and 164, and extensive explanatory information about the rule is available at <http://www.hhs.gov/ocr/hipaa>.

¹⁴⁷ 42 CFR Section 164.502(g)(2).

10 U.S.C.A. §1044c. **Advance medical directives of members and dependents: requirement for recognition by states**

- (a) Instruments to be given legal effect without regard to state law. --
An advance medical directive executed by a person eligible for legal assistance --
 - (1) is exempt from any requirement of form, substance, formality, or recording that is provided for advance medical directives under the laws of a state; and
 - (2) shall be given the same legal effect as an advance medical directive prepared and executed in accordance with the laws of the state concerned.
- (b) Advance medical directives. -- For purposes of this section, an advance medical directive is any written declaration that --
 - (1) sets forth directions regarding the provision, withdrawal, or withholding of life-prolonging procedures, including hydration and sustenance, for the declarant whenever the declarant has a terminal physical condition or is in a persistent vegetative state; or
 - (2) authorizes another person to make health care decisions for the declarant, under circumstances stated in the declaration, whenever the declarant is incapable of making informed health care decisions.

In light of the present nationwide challenges to improving advance care planning policy and practice, it is timely to re-examine the appropriate role of the Federal Government with respect to improving the tools and processes of advance care planning and surrogate decision making. Recommendations for possible avenues of federal action are included in a separate document.

Any federal strategy for action should take into account the central trend in state policy described in this overview -- the movement of the states away from a legal transactional mode of advance planning toward a communications model. While, much of the evaluative scholarly literature is supportive of that trend, many barriers persist. In some respects, the goal of this movement has been essentially to get the law out of the way of good planning (i.e., making it simpler, less legalistic in requirements, and more adaptable to the mode of communicating and decision making natural to the individual). At the same time, concerns about potential abuse cannot be blithely discarded. While no significant patterns of abuse have been identified in the research literature, the fact that these decisions do indeed involve life and death consequences, the protection of vulnerable persons will remain a challenge.

ADVANCE DIRECTIVES AND ADVANCE CARE PLANNING: REPORT TO CONGRESS

Files Available for This Report

Main Report

HTML: <http://aspe.hhs.gov/daltcp/reports/2008/ADCongRpt.htm>

PDF: <http://aspe.hhs.gov/daltcp/reports/2008/ADCongRpt.pdf>

APPENDIX A. Methods

HTML: <http://aspe.hhs.gov/daltcp/reports/2008/ADCongRpt.htm#appendA>

PDF: <http://aspe.hhs.gov/daltcp/reports/2008/ADCongRpt-A.pdf>

APPENDIX B. Literature Review on Advance Directives

HTML: <http://aspe.hhs.gov/daltcp/reports/2007/advdirlr.htm>

PDF: <http://aspe.hhs.gov/daltcp/reports/2008/ADCongRpt-B.pdf>

APPENDIX C. Advance Directives and Advance Care Planning: Legal and Policy Issues

HTML: <http://aspe.hhs.gov/daltcp/reports/2007/adacplpi.htm>

PDF: <http://aspe.hhs.gov/daltcp/reports/2008/ADCongRpt-C.pdf>

APPENDIX D. Advance Directives and Advance Care Planning for People with Intellectual and Physical Disabilities

HTML: <http://aspe.hhs.gov/daltcp/reports/2007/adacp.htm>

PDF: <http://aspe.hhs.gov/daltcp/reports/2008/ADCongRpt-D.pdf>

APPENDIX E. Commissioned Report: Advance Care Planning and Public Engagement

HTML: <http://aspe.hhs.gov/daltcp/reports/2007/acppe.htm>

PDF: <http://aspe.hhs.gov/daltcp/reports/2008/ADCongRpt-E.pdf>

APPENDIX F. Roundtable Materials

HTML: <http://aspe.hhs.gov/daltcp/reports/2008/ADCongRpt.htm#appendF>

PDF: <http://aspe.hhs.gov/daltcp/reports/2008/ADCongRpt-F.pdf>

APPENDIX G. Adrienne Asch's Comments at the October 2007 ASPE Roundtable

HTML: <http://aspe.hhs.gov/daltcp/reports/2008/ADCongRpt.htm#appendG>

PDF: <http://aspe.hhs.gov/daltcp/reports/2008/ADCongRpt-G.pdf>

APPENDIX H. Summary of the Roundtable Discussions on Advance Directives and Advance Care Planning

HTML: <http://aspe.hhs.gov/daltcp/reports/2008/ADCongRpt.htm#appendH>

PDF: <http://aspe.hhs.gov/daltcp/reports/2008/ADCongRpt-H.pdf>