RESOLVED, That the American Bar Association urges Congress to amend the Patient-Self Determination Act (PSDA) provisions of the Medicare and Medicaid law to require that:

1. Every patient or patient’s authorized representative be given an opportunity to discuss issues relating to advance care planning with an appropriately trained representative of the provider organization within a reasonable time after the patient’s admission;

2. Health insurance exchanges developed pursuant to the Patient Protection and Affordable Care Act of 2010 be required under the PSDA to provide advance care planning information and resource options for follow-up assistance; and

3. In the absence of a validly executed advance directive, any clear, undisputed expression of a person’s health care wishes should be honored, as long as consistent with applicable law.

FURTHER RESOLVED, That the American Bar Association urges Congress and the United States Department of Health and Human Services to require the annual Medicare wellness examination, or other periodic doctor-patient interactions, to include both an opportunity to engage in and have resource options available relating to advance care planning for health decisions.
REPORT

This resolution addresses a serious need for stronger mechanisms and protocols to ensure that patients and their families, especially those who rely on Medicare and Medicaid, receive the counseling and assistance they need to plan adequately for medical decisions that face them imminently or in the future. It further seeks to ensure that their goals and wishes are known to and appropriately honored by their health care providers. Both Congress and the Department of Health and Humans Services are urged to act to accomplish this policy.

I. Background

Since the mid-1970s, health care advance directives have been promoted as the primary legal tool to communicate one’s health care wishes regarding end-of-life care in a formal way and, presumably, enhance the likelihood that one’s wishes are followed by health care professionals. These are documents that spell out one’s health care goals and instructions and appoint an agent or proxy decision-maker in the event of incapacity.

The primary model for a flexible combined advance directive and default surrogate law has been the Uniform Health-Care Decisions Act. The Uniform Act was promulgated as a national model by the National Conference of Commissioners on Uniform State Laws in 1993. The Act establishes very simple rules for recognizing advance directives. Even witnessing is optional under the Uniform Act. However, states that have adopted the Uniform Act have almost always added more to the Act’s baseline requirements. Indeed, all states adopting it have mandated a witnessing requirement. The Uniform Act provides an optional sample form with provisions to appoint a health care agent, provide alternative instruction about one’s care, make an organ or tissue donation, and name a primary physician. The Act also recognizes default surrogates in the absence of an advance directive.

The federal legislative role in advance care planning has been minimal. The primary congressional foray into the subject is the Patient Self-Determination Act, enacted as part of the Omnibus Budget Reconciliation Act of 1990, Pub. L. No. 101-508. The Act was a fairly modest amendment to federal Medicare and Medicaid law, intended to encourage adults to think about and plan for health care decisions. 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 concerning their right under state law to make decisions about their medical care and the right to formulate advance directives;
2. maintain written policies and procedures regarding advance directives and make them available to patients upon request;
3. document whether or not the patient has executed an advance directive;
4. comply with the requirements of state law respecting advance directives;

1 Uniform Law Commission, Uniform Health-Care Decisions Act (1993)
2 Codified at 42 U.S.C. Sections 1395cc(a)(1)(Q), 1395mm(c)(8), 1395cc(f), 1396a(a)(57),(58), and 1396a(w)
(5) provide staff and community education on advance directives; and
(6) not condition the provision of care or otherwise discriminate against an individual based on whether or not the individual has executed an advance directive.

In 2008, Congress added “end-of-life planning” to the one-time only, initial preventive physical examination (sometimes called the “welcome to Medicare exam”) available to newly enrolled Medicare beneficiaries.\(^3\) In 2009, Congress fiercely debated major health reform proposals, one of which would provide Medicare coverage of voluntary advance care planning consultations, but such a provision was dropped from the final version of health reform.

As to the substantive elements of health-care decision making, federal law has generally deferred to state substantive law, including the selection and authority of appointed agents and default surrogates.

II. The Paradigm Shift in State Law

For most of the history described above, advance directive laws predominantly emphasized standardized legal forms characterized by mandatory formalities, restrictions, and procedural requirements intended to serve as protections against abuse and error. The approach has been characterized as a “legal transactional approach.”\(^4\)

*Legal Transactional Approach*

A *legal transactional* framework is much like that of a conventional conveyance of interest in property or a contract that establishes 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. And 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 by the user, as well as to ensure the recognition of and compliance by health care providers.

States have required several kinds of legal formalities for execution of advance directives. The following examples represent the state of the law in 2007:\(^5\)

(1) Standardized statutory forms.
(2) Required disclosures or warnings.
(3) Prescribed phrases for authorizing certain wishes.
(4) Witnessing requirements and restrictions.
(5) Limitations on who may serve as agent or proxy.

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\(^3\) See 42 U.S. Code §1395(x)vv(3).
\(^5\) Id., at 219-221.
The use of statutory forms creates potential barriers to the individual expression of one’s wishes, especially in states where the law provides that the advance directive must be “substantially in the following form” set forth in the statute. About a dozen states have this or similar language in their advance directive law or laws. The legal concept of “substantial compliance” arises frequently in many areas of law, but it lacks any authoritative construction with respect to advance directives. The uncertainty sometimes leads health care providers to adopt a restrictive view that substantial compliance requires verbatim use of statutory form language. Legal advisors often reinforce this view by advising providers or the general public that using the statutory advance directive form is the only safe thing to do.

Critique of the Legal Transactional Approach

The transactional approach to advance directives began with the goal of empowering patients to control medical decisions in advance through a document setting forth their directions. Unfortunately, this approach may have served to impede rather than promote effective health care planning for the end-of-life. 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:

1. Too few people make use of the legal tools.
2. When people use these legal tools, they do not understand the forms they complete nor the future decisions that might have to be made.
3. The forms themselves don’t provide much guidance.
4. Patients’ goals and preferences for care may change.
5. When individuals name an agent or proxy, the agent seldom understands the principal’s wishes.

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6 See Sabatino, supra n. 4, at 219, n. 3.
Even if individuals have completed a directive, health care providers usually don’t know about the directive.\(^{13}\)

Even if providers know an advance directive exists, it does not affect patient care.\(^{14}\)

**A Communications Approach**

In response to the shortcomings of the transactional approach, an alternative paradigm has emerged that may be called a “communications approach.”  This paradigm derives from the concept of *advance care planning* articulated by the Institute of Medicine:

> [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.\(^{15}\)

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 may participate in the health-care decision making process in the future.\(^{16}\)

Apart from this legislative evolution, counseling tools for advance planning are also changing. Initially, self-help materials available to the public consisted primarily of statutory forms, instructions, and related fact sheets. Beginning in the late 1990s, self-help tools began to focus on the process of 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 guides or workbooks for advance care planning. A written directive remains an outcome, but greater emphasis is placed on the process, not the form.\(^{17}\)


\(^{15}\) Institute of Medicine, Committee on Care at the End of Life, *Approaching Death: Improving Care at the End of Life* (M.J. Field & C.K. Cassel, eds) (1997).


Another key aspect of the communications approach is a systemic strategy to ensure multiple opportunities for advance care planning conversations to take place. More intensive and community-wide interventions that involve collaborative advance care planning mechanisms have demonstrated positive results. For example, Hammes and Rooney\textsuperscript{18} conducted a retrospective study of all adult decedents residing in a defined geographic area who died while under the care of health care organizations participating in a comprehensive, systematic community-wide advance directive education program (\textit{Respecting Your Choices}). They found that the prevalence of advance directives increased from 15\% to 85\% during the intervention and that the median time between advance directive documentation and death was 1.2 years. Most advance directives requested that treatment be forgone as death neared, and treatment followed these instructions in nearly all cases.

A modified version of this model was pilot tested on a small sample of chronically ill adults (congestive heart failure, end-stage renal disease, and preoperative open-heart surgery patients) and their caregivers using quality improvement techniques. The intervention significantly increased congruence in decision making between patients and caregivers for future medical treatment.\textsuperscript{19} In addition, the intervention group demonstrated greater satisfaction with the decision making process and less conflict about decisions.

The lessons of this evolution in advance care planning are that guided discussion regarding one’s treatment goals and wishes is the heart that makes advance directives come alive, and the more we can systemically ensure or at least encourage those discussions to take place and be documented, the more likely it is that the individual’s wishes and goals of care will be known and honored.

### III. What this Resolution Does

The resolution does four things – three of which address federal legislative change, calling on Congress to amend the provisions of the Patient Self-Determination Act of 1990 to require:

- One, that every patient or patient’s authorized representative be given an opportunity to discuss issues relating to advance care planning with an appropriately trained professional. The literature supportive of a stronger communications approach to advance care planning show that when these discussions take place between patients and providers, the likelihood of treatment congruent with the patient’s values and goals of care increases. Thus, the system needs to build in these opportunities into the normal care processes.

- Two, that Health Insurance Exchanges developed pursuant to the Patient Protection and Affordable Care Act of 2010 be required to provide advance care planning information


and resource options for follow-up assistance. Since a significant portion of the adult population will obtain health coverage through these exchanges, it provides another institutional opportunity to inform and remind adults of the importance of advance care planning and where to get help. This recommendation does not require the exchanges to provide opportunities to discuss advance care planning like the first recommendation does. The exchange is more suitably positioned to provide information and referral to resources, so that when the individual obtains coverage and seeks out a health care provider, he or she will be better prepared to engage in advance care planning discussions with health care providers.

- Three, that in the absence of a validly executed state advance directive, any clear and undisputed expression of a person’s wishes with respect to health care should be honored by health care providers. Some 70 percent of the adult population do not have a formal advance directive, but many of those adults have expressed their wishes in a variety of other ways, both orally and in writing. A communications approach to advance care planning invites all avenues of communication and accommodates broad cultural, social, and educational variation. In addition, both common law and constitutional principles strongly support the tenet that where a patient’s health care wishes are known, they should be respected as long as they are not contrary to generally accepted health-care standards applicable to the health-care provider or institution. The part of the resolution requires that the patient’s wishes be clear and undisputed, so that health care providers are not put in a position of having to judge authenticity of a patient’s wishes when there is a conflict between differing reasonable views.

The fourth part addresses both Congress and the U.S. Department of Health and Human Services, through its Centers for Medicare and Medicaid Services (CMS), calling on them to:

- Require that annual Medicare wellness examination, or other periodic doctor-patient interactions, to include an opportunity and assistance to engage in advance care planning for health decisions. Either CMS or Congress can accomplish this end. The Medicare Modernization Act of 2003 already included a beginning point for this process by establishing the initial preventive physical exam (“welcome to Medicare” exam), which includes as a component “end-of-life planning,” i.e., information regarding preparing an advance directive and services covered by Medicare.

The new annual wellness visit, added by Section 4103 of the Affordable Care Act (P.L. 111-148), built on the foundation to provide coverage for a recurring, annual wellness and prevention exam. The Secretary was given authority to define the required components of that exam, and her final rule, announced November 29, 2010, actually included “voluntary advance care planning” as an essential part of the exam. Within days of the rule becoming effective, the Secretary announced withdrawal of that part of the rule providing for voluntary advance care planning. It was speculated that the

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20 Harris Interactive Inc., survey for the American Bar Association, showing 30% of 2,092 respondents age 18 and over had signed an advance directive appointing a health care proxy (April 9-11, 2008).
Administration wished to avoid reigniting controversies over “death panel” fears that arose during the debate over the Affordable Care Act.\textsuperscript{21}

IV. Need for ABA Action

The ABA’s patient-focused advocacy on behalf of an individual’s right to control decisions about health care has played a role in the development of federal policy in this area since prior to the passage of the Patient Self-Determination Act in 1990. During pendency of that Act, the ABA testified in support of that Act, and again in 1994 when amendments were being considered to strengthen the Act. Amendments to strengthen supports for patient decision-making have been proposed in every Congress since 1990, but none have prevailed. The current Congress has one bill that would require voluntary advance care planning counseling.\textsuperscript{22} However, the goal can also be attained without Congressional action if the Department of Health and Human Services, through CMS, would exercise its authority to include such voluntary counseling as part of the annual Medicare wellness exam.

Today, a great deal of attention is being given both to addressing the quality of end-of-life care of Americans and its prohibitive costs.\textsuperscript{23} The fear-based furor over death panels has also subsided as these issues become examined apart from the controversies over the Affordable Care Act. This is an appropriate and opportune time for the ABA to reassert its long-standing advocacy for patients’ rights to be informed of and to exercise their health-care decision-making rights.

V. Related ABA Policy

The ABA has been active in the promotion of health care decision-making policies that promote the individual’s decision-making autonomy and quality end-of-life care since the 1980s. Key policies include the following:

- 1989. The House of Delegates adopted policies to encourage the use and recognition of durable powers of attorney for health care.
- 1990. The House adopted a policy to support the right of competent individuals to consent to or refuse suggested medical interventions and to recognize that an appropriate surrogate may exercise this right on behalf of an incompetent individual.
- 1990. The ABA also actively supported passage of the Patient Self-Determination Act in 1990, the federal law that promotes information and education on advance directives.


\textsuperscript{22}See the “Personalize Your Care Act of 2011” (HR 1589), introduced by Rep. Earl Blumenauer, April 15, 2011.

The ABA recognized a new Uniform Health-Care Decision-Making Act, promulgated by the National Conference of Commissioners on Uniform State Laws. 

The ABA also adopted a resolution supporting preemption of state law by any advance medical directive prepared for members of the Armed Forces. Such a law was passed by Congress in 1996. 

The ABA adopted policy supporting better planning opportunities, including the use of advance medical directives, for people with HIV, AIDS, or other serious eventually fatal illnesses:

The ABA adopted a resolution urging state, federal, and territorial governments to remove legal impediments to quality pain and symptom management, and to support a right to effective pain and symptom evaluation, management, and ongoing monitoring as part of basic medical care. In furtherance of this policy, the ABA petitioned the Health Care Financing Administration (now CMA) in 2001 to make clear that the Patient Self-Determination Act should be interpreted to require disclosure of a patient’s right to effective pain and symptom management.

The ABA House urged widespread support of protocols such as Physicians Orders for Life-Sustaining Treatment that help ensure that patients’ end-of-life care preferences are translated into visible and portable medical orders.

The policy proposed herein is entirely consistent with the above line of ABA policy and furthers the well-established goals of patient autonomy through enhanced supports determining one’s wishes and goals of care and in the strengthening of compliance incentives.

VI. Conclusion

This succession of ABA policy demonstrates consistent and long-standing support by the ABA of the rights of patients to have their treatment wishes known and honored by health care providers. The current policy resolution is both consistent with and a logical progression of existing ABA policy. Accordingly, the Commission on Law and Aging requests the House of Delegates to adopt the resolution herein.

Jeffrey J. Snell, Chair
ABA Commission on Law and Aging
August 2012
1. **Summary of Resolution(s).**
   The resolution has four elements. The first three points address Congress, urging it to amend the provisions of the Patient Self-Determination Act of 1990 to require:
   
   (a) That every patient or patient’s authorized representative be given an opportunity to discuss issues relating to advance care planning with an appropriately trained professional.
   
   (b) That Health Insurance Exchanges developed pursuant to the Patient Protection and Affordable Care Act of 2010 be required to provide advance care planning information and resource options for follow-up assistance.
   
   (c) That in the absence of a validly executed state advance directive, any clear and undisputed expression of a person’s wishes with respect to health care should be honored by health care providers. Some 70 percent of the adult population does not have a formal advance directive, but many of those adults have expressed their wishes in a variety of other ways, both orally and in writing.
   
   The fourth part addresses both Congress and the U.S. Department of Health and Human Services, through its Centers for Medicare and Medicaid Services (CMS), calling on them:
   
   (d) To require that the annual Medicare wellness examination, or other periodic doctor-patient interactions, include an opportunity and assistance to engage in advance care planning for health decisions.

2. **Approval by Submitting Entity.**
   Approved by the Commission on Law and Aging at its spring meeting, April 20, 2012.
   The following entities have informed us that they have approved or have agreed to co-sponsor the proposed policy:

   - Section of Family Law
   - Senior Lawyers Division

3. **Has this or a similar resolution been submitted to the House or Board previously?**
   No

4. **What existing Association policies are relevant to this Resolution and how would they be affected by its adoption?**
   The resolution is consistent with the principles postulated by all previous ABA policies on the subject of health-decisions and advance care planning and furthers the goals of patient autonomy through enhanced supports determining one’s wishes and goals of care and in the strengthening of compliance incentives.
   The past policies include:
• 1989. The House of Delegates adopted policies to encourage the use and recognition of durable powers of attorney for health care.

• 1990. The House adopted a policy to support the right of competent individuals to consent to or refuse suggested medical interventions and to recognize that an appropriate surrogate may exercise this right on behalf of an incompetent individual.

• 1990. The ABA also actively supported passage of the Patient Self-Determination Act in 1990, the federal law that promotes information and education on advance directives.

• 1994. The ABA recognized a new Uniform Health-Care Decision-Making Act, promulgated by the National Conference of Commissioners on Uniform State Laws.

• 1994. The ABA also adopted a resolution supporting preemption of state law by any advance medical directive prepared for members of the Armed Forces. Such a law was passed by Congress in 1996.

• 1995. The ABA adopted policy supporting better planning opportunities, including the use of advance medical directives, for people with HIV, AIDS, or other serious eventually fatal illnesses:

• 2000. The ABA adopted a resolution urging state, federal, and territorial governments to remove legal impediments to quality pain and symptom management, and to support a right to effective pain and symptom evaluation, management, and ongoing monitoring as part of basic medical care. In furtherance of this policy, the ABA petitioned the Health Care Financing Administration (now CMA) in 2001 to make clear that the Patient Self-Determination Act should be interpreted to require disclosure of a patient’s right to effective pain and symptom management.

• 2008. The ABA House urged widespread support of protocols such as Physicians Orders for Life-Sustaining Treatment that help ensure that patients’ end-of-life care preferences are translated into visible and portable medical orders.

5. **What urgency exists which requires action at this meeting of the House?**
   Action will enable the ABA to support proposed legislation consistent with the resolution in the current Congress and also being planned for the next Congress.

6. **Status of Legislation.** (If applicable)
   One bill is pending in current Congress, the ‘‘Personalize Your Care Act of 2011’’ (HR 1589), introduced by Rep. Earl Blumenauer (D-OR), April 15, 2011. Among other things, it proposes to strengthen provisions of the Patient Self-Determination Act. A bill with similar provisions is in the drafting stage by Sen. Mark Warner (D-VA).

7. **Brief explanation regarding plans for implementation of the policy, if adopted by the House of Delegates.**
   Advocacy and support of current and future proposed legislation in Congress consistent with the policy, and advocacy targeting the Department of Health and Human Services to cover advance care planning in the Medicare annual wellness examination.

8. **Cost to the Association.** (Both direct and indirect costs)
   None
9. **Disclosure of Interest.** (If applicable)
   None

10. **Referrals.**
    Standing Committee on Client Protection
    Standing Committee on the Delivery of Legal Services
    Standing Committee on Ethics and Professional Responsibility
    Standing Committee on Government Affairs
    Standing Committee on Lawyers’ Professional Liability
    Standing Committee on Legal aid and Indigent Defendants
    Standing Committee on Medical Professional Liability
    Special Committee on Bioethics and the Law
    Commission on Domestic and Sexual Violence
    Commission on Homelessness and Poverty
    Commission on Disability Rights
    Center for Human Rights
    Government and Public Sector Lawyers Division
    Section of Administrative Law and Regulatory Practice
    Section of Dispute Resolution
    Section of Family Law
    Section of General Practice, Solo and Small Firm
    Government and Public Sector Lawyers Division
    Section of Health Law
    Section of Individual Rights and Responsibilities
    Section of Litigation
    Section of Real Property, Probate, and Trust Law
    Section of Science and Technology Law
    Senior Lawyers Division
    Section of State and Local Government Law
    Section of Tort, Trial and Insurance Practice
    Young Lawyers Division
    National Association of Bar Executives
    National Legal Aid & Defender Association
    National Conference of Bar Presidents

11. **Contact Name and Address Information.** (Prior to the meeting. Please include name, address, telephone number and e-mail address)
    Charles Sabatino, Director, Commission on Law and Aging
    740 15th Street NW, Washington DC, 20005
    E-mail: charles.sabatino@americanbar.org
12. **Contact Name and Address Information.** (Who will present the report to the House? Please include name, address, telephone number, cell phone number and e-mail address.)
   Jeffrey J. Snell, Chair
   253 W Aurora Rd
   Sagamore Hills, OH 44067-2121
   330-467-9600 or
   216-288-5690 (cell)
   Email: jeff@attorneysnell.com
EXECUTIVE SUMMARY

1. Summary of the Resolution
The resolution has four elements. The first three points address Congress, urging it to amend the provisions of the Patient Self-Determination Act of 1990 to require:
(a) That every patient or patient’s authorized representative be given an opportunity to discuss issues relating to advance care planning with an appropriately trained professional.
(b) That Health Insurance Exchanges developed pursuant to the Patient Protection and Affordable Care Act of 2010 be required to provide advance care planning information and resource options for follow-up assistance.
(c) That in the absence of a validly executed state advance directive, any clear and undisputed expression of a person’s wishes with respect to health care should be honored by health care providers. Some 70 percent of the adult population do not have a formal advance directive, but many of those adults have expressed their wishes in a variety of other ways, both orally and in writing.
The fourth part addresses both Congress and the U.S. Department of Health and Human Services, through its Centers for Medicare and Medicaid Services (CMS), calling on them:
(d) To require that the annual Medicare wellness examination, or other periodic doctor-patient interactions, include an opportunity and assistance to engage in advance care planning for health decisions.

2. Summary of the Issue that the Resolution Addresses
This resolution addresses a serious need for stronger mechanisms and protocols to ensure that patients’ their families, especially those who rely on Medicare and Medicaid, receive the counseling and assistance they need to plan adequately for medical decisions that will inevitably face them. Some 70 percent of the adult population do not have a formal advance directive, and federal lack lacks sufficient systemic prompts and supports to make advance care planning a normal and expected part of health care for persons on Medicare and Medicaid.

3. Please Explain How the Proposed Policy Position will address the issue
The resolution addresses the problem by calling on Congress to strengthen the only federal law that seeks to encourage the use and recognition of advance directives, the Patient Self-Determination Act of 1990, which the ABA strongly supported at the time of its enactment. The resolution also calls on the Department of Health and Human Services to exercise its own authority to require voluntary advance care planning to be included in the annual Medicare wellness exam. While amendments to strengthen the Act have been introduced in every Congress since 1990, none have been enacted. The ABA’s disinterested, patient’s rights perspective on these issues can carry considerable influence in securing patient-centered changes in the law.

4. Summary of Minority Views
Currently none.