April 1, 2013

The Honorable Earl Blumenauer
1111 Longworth House Office Building
United States House of Representatives
Washington, DC  20515

Dear Representative Blumenauer:

On behalf of the American Bar Association, with nearly 400,000 members, I want to convey our appreciation for your untiring efforts in advocating for meaningful access to patient-centered advance care planning. We commend you for your leadership in introducing H.R. 1173, the Personalize Your Care Act of 2013.

The ABA has for almost three decades strongly promoted the value of advance care planning and the use of advance health care directives by all adults. In our two most recent policies, we urge widespread support of protocols such as Physicians Orders for Life-Sustaining Treatment (POLST) and strengthening of the Patient Self Determination Act. A complete record of ABA policies on health decisions is attached.

In the last few years, an expanding body of medical literature has demonstrated the importance of recurring physician-patient-family communications as essential to making patients’ values and goals of care known and honored in the course of their health care. We also know that advance care planning is not a one-time event. Priorities and preferences evolve over time. Moreover, most older individuals respond positively when their health care provider initiates these conversations as a voluntary part of routine care.

The Personalize Your Care Act recognizes that these opportunities for consultation are an integral part of patient-centered quality care by providing coverage under Medicare and Medicaid for periodic voluntary consultations. Advance care planning is effective when it succeeds in identifying and respecting the individual’s treatment goals and personal values, particularly as individuals begin to confront serious, progressive, life-limiting conditions. The process ensures that patients’ values and goals drive their care, rather than the preferences of providers, insurers, government, or others.

The Personalize Your Care Act also recognizes that the quality of care for patients with advanced, progressive illness is greatly enhanced when a systemic process exists that converts the wishes of these patients into an effective set of medical orders. The clinical protocol, most commonly called Physicians Orders for Life-Sustaining Treatment, has
been shown effective in eliciting goals of care for patients and incorporating those goals into a plan of care reflected in actionable medical orders that address high probability medical contingencies, including hospitalization, cardiopulmonary resuscitation, and the use of artificial nutrition and hydration. About a third of states have adopted some version of POLST and a majority of the remaining states are considering it. The Personalize Your Care Act provides valuable support to the states to initiate and expand POLST programs.

Finally, the Personalize Your Care Act will ensure the portability of health care advance directives across the states and affirm the fundamental principle that, in the absence of an advance directive, the patient’s wishes should still be honored. This is important. While advance directive laws were enacted in every state to assist individuals in exercising their right to consent to or refuse any proposed medical treatment, they can become a barrier when interpreted to require strict compliance with detailed legal rules and procedures. It is important to understand advance care planning as fundamentally a communication task and not a legal ordeal.

We appreciate your leadership on patient-centered advance care planning and look forward to working with you on this important legislation.

Sincerely,

Thomas M. Susman
ABA HEALTH DECISIONS POLICIES

The ABA has addressed patient self determination in health care in nine policy enactments.

(1) In 1986, the ABA House of Delegates recognized the "Uniform Rights of the Terminally Ill Act" (URTIA) promulgated by the National Conference of Commissioners on Uniform State Laws and amended in 1989. The URTIA was intended to promote uniform legislation for authorizing and implementing so-called "Living Wills." Because the URTIA was soon deemed to be too narrowly focused, the Uniform Law Commissioners replaced the URTIA with an expansive advance directive/surrogate decision making model in 1993, entitled the Uniform Health Care Decisions Act (UHCDA). The ABA officially recognized the new UHCDA by resolution adopted by the House of Delegates in February 1994.

(2) In February, 1986, the ABA House adopted a recommendation supporting legislation to expand the availability of Medicare reimbursement for hospice care services with the following language:

BE IT RESOLVED, That the American Bar Association supports the enactment of legislation which extends and expands the availability of Medicare reimbursement for hospice care services.

(3) In 1989, the ABA adopted the following policy encouraging the use and recognition of health care powers of attorney:

BE IT RESOLVED that the American Bar Association encourages the use and recognition of durable powers of attorney for delegating health care decision-making authority in the event of decisional incapacity of the principal. Steps to encourage such use and recognition include:

1. Explicit authorization in state law for recognizing delegations of health care decision-making authority under durable power of attorney laws of the enacting state or that of another state.
2. Procedures to ensure ease of use by the public, with appropriate protections to ensure that delegations of authority are made voluntarily with full appreciation of the consequences.
3. Regulations mandating all health care providers and facilities to (a) have policies in place regarding health care powers of attorney and other advance directives, (b) determine whether or not patients have prepared any such directive, and (c) inform patients of their legal rights to control health care decisions, including the right to appoint an agent or surrogate through a durable power of attorney.
4. Immunity from liability for health care providers who, in good faith and consistent with reasonable medical standards, act in accordance with a health care power of attorney.
5. Educational efforts to ensure that all adults have knowledge of health care powers of attorney and other advance directives and easy access to the means for establishing such directives.

(4) In 1990, the ABA adopted a resolution supporting the principle that individuals have the right to consent to and to refuse suggested health care interventions. Specifically, the policy states:

BE IT RESOLVED, That the American Bar Association supports the principle that individuals who are capable of making health care decisions generally have the right to consent to and to refuse suggested health care interventions, even if the result would be to shorten life's span;

BE IT FURTHER RESOLVED, That the American Bar Association supports the principle that an appropriate surrogate may exercise this right on behalf of an individual who is incapable of making such decisions. This resolution does not commit the American Bar Association to any particular position as to who are "appropriate surrogates," how they chosen or what standards govern their actions.

(5) The ABA adopted a resolution addressing physician-assisted suicide (physician aid-in-dying) in August 1997, as follows:

RESOLVED, That any consideration of the matter of physician-assisted suicide which involves personal, religious, emotional, medical, legal and ethical considerations and considerations of appropriate care alternatives, supportive services, pain relief, potential for abuse, legal protection, competency and needed research in many fields, should be left to be resolved by state legislatures and their electorates after extensive and informed public discussion.

FURTHER RESOLVED, That in the event that any state or territory chooses to adopt legislation permitting physician-assisted suicide, it should ensure that information and reporting systems are established to achieve close monitoring of the impact of such practices, especially with respect to vulnerable populations who may be particularly at risk if such practices are authorized.

(6) In August 1994, the ABA adopted a resolution supporting preemption of state law by any advance medical directive prepared for members of the Armed Forces:

BE IT RESOLVED, That the American Bar Association supports the enactment of federal legislation to provide that advance medical directives prepared for members of the Armed Forces, their spouses, and other persons eligible for legal assistance be recognized as lawful and given full legal effect notwithstanding state and territorial law.
(7) In August, 1995, the ABA supported better planning opportunities, including the use of advance medical directives, for people with HIV, AIDS, or other serious eventually fatal illnesses:

   RESOLVED, That the American Bar Association supports action by federal, state, territorial and local governments to create legal mechanisms that allow people with HIV, AIDS or other debilitating, chronic, fatal illnesses to better plan for long-term care for themselves and their families, including standby guardianships, advance medical directives, and viatical settlements.

   FURTHER RESOLVED, That the American Bar Association supports educational activities and other efforts designed to encourage implementation of appropriate legislation on standby guardianships, advance medical directives, and viatical settlements.

   FURTHER RESOLVED, That where legislation is implemented concerning standby guardianships, advance medical directives, or viatical settlements, such legislation should contain appropriate consumer safeguards.

(8) At its 2000 annual meeting, the ABA adopted a policy supporting access to effective palliative care and review of controlled substances laws to ensure that they do not create unintended barriers to access to care:

   RESOLVED, that the American Bar Association urges federal, state, and territorial governments to construe, apply, and if necessary, amend laws regulating the health professions, controlled substances, insurance, and both public and private health benefit programs so that these laws do not impose barriers to quality pain and symptom management.

   FURTHER RESOLVED, that the American Bar Association urges federal, state, and territorial governments to support fully the right of individuals suffering from pain to be informed of, choose, and receive effective pain and symptom evaluation, management, and ongoing monitoring as part of basic medical care, even if such pain and symptom management may result in analgesic tolerance, physical dependence, or as an unintended consequence shorten the individual’s life.

(9) In 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:

   RESOLVED, That the American Bar Association urges federal, state, tribal, and territorial legislative bodies, governmental agencies, and health care providers to establish
and support decision-making protocols to ensure that the wishes, including those expressed in any prior advance directive, of those who have advanced chronic progressive illnesses are appropriately translated into visible and portable medical orders such as “Physicians Orders for Life-Sustaining Treatment” or “POLST,” that address higher probability medical contingencies, including hospitalization, cardiopulmonary resuscitation, artificial nutrition and hydration, antibiotics, and ventilation.

(10) In 2012, the ABA House urged strengthening of the Patient Self Determination Act as follows:

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.

Commission on Law and Aging
American Bar Association
Washington, D.C.