

Campaign to End Unwanted Medical Treatment

Federal Policy Agenda - 114th Congress February 2015

Three-Step Process to Honor Patients Wishes:

1. Ensure person expresses and records wishes and preferences consistent with his/her values.

All individuals must have access to the proper tools, decision-making aids, and a team of care professionals who can help discuss wishes and care options. 2. Ensure person revisits and revises preferences/wishes over time, if appropriate.

Wishes and preferences must be continuously renewed to ensure that records are up-to-date and reflects the person's most recent values, choices, preferences.

3. Care is delivered that is consistent with the person's preferences and wishes.

Quality of care for those with advanced illness and nearing the end of life is measured by how closely the care adheres to the stated preferences of the individual.

I. Goal and Objectives

Our goal is for people to receive the medical treatment that they want consistent with their goals and preferences – nothing less and nothing more. In order to accomplish our goal, we must overcome and remove barriers in current laws that prevent individuals from receiving treatment that is inconsistent with their wishes. This requires the above three-step process to ensure that care objectives are properly discussed, recorded, and honored.

II. Policy Principles to Achieve Preference-Driven Care and Avoid Unwanted Treatment

1. Preference-Driven Advanced Illness Care

The first step to honor patient choice and preference is to ensure that patients have access to the full range of care services, including hospice care, palliative care, and curative care. Furthermore, physicians and allied health professionals must be empowered to meaningfully engage individuals in conversations about their patients' values, beliefs, and ultimately their preferences. To support this, payment and delivery system mechanisms must be in place to ensure appropriate reimbursement that prioritizes individual needs and preferences.

2. Consumer and Family Support



Consumers and families must be empowered to make informed decisions about the care they wish to receive during advanced illness and through to the end-of-life. In addition, it is critical to provide a full range of supports for families and caregivers such as emotional and behavioral services to ensure truly person-centered care.

3. Provider Empowerment and Accountability

A collaborative, interdisciplinary care team must have access to appropriate training in order to successfully engage individuals, families, loved ones, and caregivers throughout the care process in order to ensure informed decision-making. Providers must inform patients of their right to decide how much and the kind of treatments they will receive – including the freedom to refuse unwanted, unnecessary, or excessive medical treatment. Providers should be held accountable if they do not inform patients properly and if they do not follow patients' wishes.

4. Outcomes-Based Quality Measurement and Improvement

Quality measurement is critical to assess whether individual goals, values, and preferences are properly followed and honored. Consensus-based measures should be further developed, tested, and implemented.

III. Policy Mechanisms to Achieve Objectives

Policy Objective	Mechanism
1. Preference-Driven Advanced Illness Care	 Require coverage of voluntary advance care planning under Medicare, Medicaid, and other federally funded programs. Expand the protection and validity of advance directives. Ensure portability and validity of advance directives across state lines and care settings. Develop and fund the operation of state advance directive registries. Support periodic reassessments of individual care goals and wishes every five years or any time patient health status changes. Instruct hospitals to develop "compassionate non-discharge policies" for instances when death is imminent but the physician and family wish to have the patient remain in the hospital. Promote flexible delivery models that allow for innovative approaches to end-of-life care delivery and pay for value-based rather than volume-based care. Advocate for a patient consultation bill, and other federal legislation that advances our preference-driven care objectives, that includes funding and accountability measures.
2. Consumer and Family Support	 Promote the development of employer incentives and government tax credits to provide caregiver respite care and support. Increase access to psychological, spiritual, and emotional supports for individuals in order to ensure fully person-centered care.



	 Create a national campaign to generate public awareness of advance directives. Develop an online advance care planning database of advance directive materials including a tool kit. Launch a website for providers under Medicare, Medicaid, CHIP and others to highlight resources on patient decision-making rights. Establish a 24-hour toll free telephone hotline to provide resources to consumers and providers on end-of-life decision-making. Requiring facilities to provide at admission and before any procedure/surgery an opportunity to fill out an advance care form and discuss advance care planning with an appropriately trained individual.
3. Provider Empowerment and Accountability	 Award federal grants and contracts to states for establishing palliative care and hospice education programming, including in graduate medical education. Provide mandatory Education in Palliative and End-of-Life Care (EPEC) training for physicians and End-of-Life Nursing Education Consortium (ELNEC) training for nurses and expand training initiatives for social workers, psychologists, and direct care workers. Establish medical school guidelines for a minimum amount of end-of-life training as a requirement for obtaining a degree in both allopathic and osteopathic medicine. Exempt palliative medicine fellowship training from Medicare graduate medical education caps. Direct the Health Resources and Services Administration to identify health professional shortage areas (HPSAs) within geriatric care. Reimburse health care professionals for their time consulting with patients about advanced illness planning and end-of-life decisions.
4. Outcomes-Based Quality Measurement and Improvement	 Standardize and implement quality metrics that assess patient and family satisfaction. Develop quality measures for each relevant provider setting and for care coordination. Develop protections against fraudulent providers. Develop specific quality measures pertaining to planning services such as linking patient goals to treatment received and outcomes. Create "look back" surveys on patients with advance directives and POLST forms to see if wishes were honored. Further development measurements including quality of patient-physician conversations, the level of shared informed decision-making, and the extent to which patient wishes, goals, and values were honored. Establish an entity to develop requirements, standards, and procedures for accreditation of hospital- based palliative care programs.