



## Policy Brief Compendium 2015



*Patients should receive the medical  
treatments they want.*

*Nothing less... Nothing more.*

# CAMPAIGN TO END UNWANTED MEDICAL TREATMENT GUIDING PRINCIPLES

Honoring the dignity, values, and healthcare choices of every person at each stage of his or her illness.

Ensuring that consumers are empowered and have access to the full range of well-coordinated medical care and treatment, including curative care, palliative care, and hospice care.

Educating the public, patients, families, caregivers and providers about the rights of patients to determine how much and the types of treatments they receive ranging from all treatment options available — to their right to refuse unwanted, unnecessary, costly, or life-prolonging treatment if they so choose.

Improving the quality of discussions between patients and healthcare professionals about advanced and terminal illness and end-of-life decisions.

Encouraging the use of and compliance with legal documents that articulate patients' care preferences, including advance directives.

Creating economic incentives and reimbursement policies for health care providers that reward those who follow patients' expressed wishes and penalize those that do not.

Creating a formal mechanism to record, report, and evaluate unwanted treatment.

Production of these briefs was supported by Compassion & Choices, the Elder Justice Coalition and the Consumer Coalition for Quality Health Care as supporters of the broad-based Campaign to End Unwanted Medical Treatment: A campaign dedicated to ensuring patients and consumers receive the medical care they want — nothing less and nothing more.

■

The views expressed in the policy briefs are those of the authors and do not necessarily reflect the organizations with which they are affiliated nor the board and staff of the National Academy of Social Insurance. In accordance with the procedures of the Academy, the briefs were reviewed by a committee of the Board for completeness, accuracy, clarity, and objectivity.

■

The National Academy of Social Insurance (NASI) is a nonprofit, nonpartisan organization made up of the nation's leading experts on social insurance. Its mission is to advance solutions to challenges facing the nation by increasing public understanding of how social insurance contributes to economic security. The National Academy of Social Insurance partnered with the Campaign to End Unwanted Medical Treatment to research and write the policy briefs that are published in this compendium.

# TABLE OF CONTENTS

## **Unwanted Medical Treatment at the End of Life**

By G. Lawrence Atkins .....1

## **Getting the Treatment You Want: Is Anyone Listening?**

By Anne H. Montgomery .....3

## **Respecting Choices: A Case Study for Incorporating Advance Care Planning into Person and Family Centered Health Care Delivery**

By Janet H. Forlini and Lee Goldberg.....9

## **Dignity Driven Decision Making: What Is It and Why Is It So Important?**

By Anne H. Montgomery ..... 13

## **Concurrent Palliative and Curative Services: The Next Step in Evolution of Medicare Hospice Care**

By Janet H. Forlini and Lee Goldberg..... 19

## **Empowering Consumer-Directed Advance Care Planning**

By Janet H. Forlini and Lee Goldberg..... 25



# Unwanted Medical Treatment at the End of Life

By G. Lawrence Atkins

Over the last two decades, person-centered health care, built around the informed preferences of individuals and their families, has become an important benchmark for what constitutes an effective and efficient care system. This model of care has influenced public programs and private payers, providing beneficiaries and enrollees with care in the least restrictive setting and with caregivers of their own choosing. Unfortunately, this model of care is often not followed when it comes to end-of-life care. Millions of Americans with advanced illness continue to suffer needlessly from undertreated pain and other agonizing symptoms, undergoing pointless and costly invasive tests and treatments, often in their last days and hours. Those at or near the end-of-life often have their treatment preferences or advance directives overridden by healthcare professionals and others.

This year, a diverse group of organizations representing both consumer advocates and thought leaders in health care came together to focus on policy measures needed to protect persons and their most sacred wishes regarding the care they receive. In launching the Campaign to End Unwanted Medical Treatment, the collaborating organizations sought to extend the model of person-centered care to patients with advanced illness and especially those at the end-of-life who want and need access to a full range of medical care and treatment options. Patients, families, and their advocates deserve to have their treatment preferences followed by health care professionals and institutions. This includes their legally protected choice to forego unwanted medical treatments. Unfortunately, the informed choices and treatment preferences, including those articulated in an advance directive, are all too often ignored or overridden, harming patients and compromising their dignity.

As part of its public outreach effort, the collaborating organizations commissioned a series of policy briefs written by experts at the National Academy of Social Insurance, primarily on topics discussed at a series of policy luncheons hosted by the Campaign. The briefs collected in this volume explore new ways of understanding advanced care planning and provide an overview of the regulatory and legislative developments around end-of-life treatment. The volume captures the work of a diverse group of thought leaders and policymakers and can be utilized by different audiences, ranging from government officials to consumers. The papers are authored by a trio of analysts who are working with the coalition: Lee Goldberg is Vice President for Health Policy and a member of the Academy; Anne H. Montgomery is a senior policy analyst at the Altarum Institute and a member of the Academy; and Janet H. Forlini is an independent health care consultant.

Our opening contribution, *Getting the Care You Want: Is Anyone Listening?* provides a useful overview of the federal statutory framework that includes a patient's right to accept or refuse treatment and execute an advance directive, as well as a provider's obligation to inform consumers and permit these decisions. The paper provides an up-to-date listing of policy proposals pending in the 114th Congress.

Our second paper, *Respecting Choices: A Case Study for Incorporating Advance Care Planning into Person and Family-Centered Health Care Delivery*, covers a presentation on the innovative model developed by Bernard "Bud" Hammes, Director of Medical Humanities at Gundersen Health System in LaCross, WI. The paper also discusses the different stages of advance care planning that are appropriate for people at different ages, depending on their health status.

The third paper, *Delivery Dignity-Driven Decision Making: What Is It and Why Is It So Important* explores a flexible model for individuals with advanced illness and their family caregivers to be in an ongoing and broad relationship with their care teams so that all aspects of treatment are addressed. Based on a presentation by Bruce C. Vladeck, the paper also examines domestic and international programs that incorporate elements of dignity-driven decision making, such as the Advanced Illness Management.

The fourth paper, *Concurrent Services: The Evolution of Medicare Hospice Care*, is based on a presentation by Chris Dawe, a former Special Assistant to the President for Health Policy during the Obama Administration. Dawe discussed the launch of a demonstration project, authorized under the Affordable Care Act, that opens up hospice care to Medicare beneficiaries seeking to continue curative care. The paper also explores the impact of hospice care on quality of care and costs, as well as reasons for underutilization, which the demonstration program hopes to change.

The fifth and last paper, *Empowering Consumer-Directed Advance Care Planning*, summarizes scholarly work by Charles Sabatino, Director of the American Bar Association's Commission of Law and Aging on the evolution of various legal tools at the state level that consumers can use for advanced care planning. The paper also discusses the shift in thinking about advanced care planning from a process that is focused on the legal formalities and procedural requirements to one that is focused more on a person-centered process of communication over time. The paper also provides some useful resources for consumers interested in decision-aids for advance care planning.

It is our hope that these papers, along with the work of the Campaign to End Unwanted Medical Treatment, will increase awareness of advocates' efforts to ensure consumer preferences are honored, especially during advanced illness and end-of-life treatment. We believe consumers should have access to a full range of well-coordinated medical care and treatment, including curative care, palliative care, and hospice care. It is essential that we improve the quality of discussions between patients and health care professionals about advanced and terminal illness and end-of-life decisions. This compendium will hopefully raise public awareness about those discussions and provide consumers with useful tools and resources to start the process.

G. Lawrence Atkins is a Board Member of the National Academy of Social Insurance.

# Getting the Treatment You Want: Is Anyone Listening?

By Anne H. Montgomery

Many of us – tens of millions, in fact – are on track to live into our 80s and beyond. Scientific breakthroughs accompanied by improved public health programs in many countries have led to rising longevity in industrialized countries and elsewhere. In the United States, however, there are also clear signs of chaos. Often patients do not have access to the full range of treatments they want, or their wishes are ignored and they receive unwanted medical treatment. Multiple hospitalizations during the last year of life are common<sup>1</sup> and many may be unnecessary<sup>2</sup> and/or unwanted. Invasive and costly treatments are a frequent result — though many older adults and those with advanced illness also suffer from undertreated pain.<sup>3</sup>

Major challenges remain in figuring out how to provide patient centered, high quality health care for those in advanced old age and those who are younger but very ill. The health care system is not well organized to provide consistent, reliable support to older adults who know and are able to express how they want to approach the end of their lives. Studies show that even when treatment preferences are recorded – in advance directives, living wills and other types of statements – they may be misinterpreted<sup>4</sup> or overridden.<sup>5</sup> And some argue that overtreatment can rise to the level of elder abuse when an older adult's expressed wishes at the end of life are ignored.<sup>6</sup>

Altering these dynamics will require a series of straightforward conversations about the cultural context in which patients live and the legal and ethical imperatives health care professionals face. Ideally, these conversations would be accompanied by a clear understanding of a patient's legal rights that assure autonomy and choice, and include an understanding of how individual choices can best be communicated in everyday life. They would focus on the need to document and carefully interpret patient and surrogate wishes across various medical settings, and lead to forward looking strategies that proactively incorporate patient treatment decisions into the operations of evolving systems of care.

More specifically, greater awareness is needed about:

- Principles of patient centered decision making based on informed consent as a key component of good end of life care;
- How some health care systems have altered their treatment protocols for individuals with advanced illness, and how this success can be recognized and measured;
- Steps that the federal government can take to promote public and provider education about unwanted medical treatment;
- How advance directives and other legal tools can best be used to protect patients' wishes and treatment preferences; and
- Additional legislative and administrative strategies to improve treatment at the end of life.

To be successful, conversations about these issues will require strong commitment, close cooperation and a desire to forge consensus across a variety of stakeholders – the physician and nursing

communities, religious leaders, family organizations, hospice and palliative care organizations, long-term care providers, those working to advance the interests of older adults, representatives of the legal and bioethics communities, advocates for the terminally ill and disease specific organizations, and the input of ordinary Americans, especially older adults. These conversations could result in careful and thoughtful shifts in medical practice, including the underlying vitalistic philosophy of medicine<sup>7</sup> that prevents many physicians from foregoing treatment they believe is in the patient's best interest.

## **Law and Policy**

Principles of bioethics, a series of court decisions and state and federal law all support patient autonomy and self-determination. The Patient Self Determination Act (PSDA), a federal statute enacted in 1990, requires that health care institutions participating in Medicare and Medicaid – including hospitals, nursing homes, managed care plans, hospices and home health agencies – must inform patients of their rights upon admission. Based on principles of informed consent, the law specifically requires institutions to inform patients in writing that they can: 1) accept or refuse treatment as permitted under state law; 2) execute an advance directive in accordance with relevant state law; and 3) receive information about an institution's policies on the withholding or withdrawing of life sustaining treatments. In addition, the PSDA requires institutions to educate their employees and the general public about patient rights, as well as opportunities for drafting and signing advance directives. Finally, the law also gives the Secretary of Health and Human Services the authority to withhold payment from institutions that do not follow these requirements.

While the PSDA's requirements appear to be straightforward, there have been numerous problems in implementation. First, health care providers often notify admitted patients of their rights in a perfunctory manner that falls short of an educational and informed shared decision-making process. Second, most Americans have not prepared an advance directive.<sup>8</sup> Third, studies show that individual doctors in private practice – who are not bound by the PSDA – have a difficult time fulfilling the law's intent. It is often difficult, for example, for physicians to translate the legal language used in advance directives into clear and actionable medical orders. Also, conflicts sometimes arise between what patients say they want (or do not want) in advance directives and what a surrogate decision maker requests. There may also be disagreement among surrogates.<sup>9</sup> Finally, a person with an advanced illness or nearing the end of life would likely be better served by considering their treatment options earlier, appointing a health care agent, and giving that agent (and the primary physician) as much guidance about his or her health care goals and preferences as possible.

## **Recent Developments**

Over time, additional policy has been developed, but not without difficulty. In 2009, the health care reform proposal introduced by Representative John Dingell (D-MI) and approved by the House of Representatives, included policy authorizing Medicare reimbursement for physician counseling on advance directives (once every five years). This policy was originally crafted by Representative Earl Blumenauer (D-OR), a steadfast champion and pioneer of policy on unwanted medical treatment. However, misplaced concerns that such counseling could lead to “death panels” that would deny wanted treatment ultimately lead to this provision being dropped in the final version of the Affordable Care Act. The Obama Administration did publish a final rule promulgating criteria for Medicare “wellness visits” that included coverage for “voluntary advance care planning,” but dropped the policy after nine days due to political opposition.



Finally, in December 2011, the administration was able to finalize regulatory changes based on an earlier April 2010 White House memorandum. The memo directed the Dept. of Health and Human Services (HHS) to issue guidance underscoring the need for “all hospitals participating in Medicare or Medicaid to ensure that patients’ advance directives, such as durable powers of attorney and health care proxies are respected, and that patients’ representatives otherwise have the right to make informed decisions regarding patients’ care.”<sup>10</sup> Although the President’s memorandum did not stipulate similar guidance on advance directives for nursing facilities, the Centers for Medicare & Medicaid Services in March 2013 revised the rules for state survey agencies that are charged with inspecting Medicare and Medicaid participating nursing homes.<sup>11</sup>

There are interesting differences between the hospital and nursing home documents. Whereas the hospital guidance does not mention advance care planning, the nursing home guidance states that “whether or not the resident chooses to execute an advance directive, discussion and documentation of the resident’s choices regarding future health care should take place during the development of the initial comprehensive assessment and care plan and then periodically thereafter. The process of having such discussions, regardless of when they occur, is sometimes referred to as ‘advance care planning.’” According to the nursing home guidance, the ability of a dying person to control decisions about medical care and daily routines is “one of the key elements of quality care at the end of life.” Whether or not a resident has executed an advance directive, the guidance states, an individual that declines treatment, “may not be treated against his/her wishes. If a resident is unable to make a health care decision, a decision by the resident’s legal representative to forego treatment may, subject to State requirements, be equally binding on the facility.”

The more minimalist guidance for hospitals requires them to establish policies and procedures that assure a patient’s right to request or refuse treatment and indicate such a request will be addressed. However, hospitals are not obligated to fulfill a patient’s request for a treatment or service that a responsible physician believes is either medically unnecessary or inappropriate. The document further states that the patient may “provide guidance as to his/her wishes concerning provision of care in certain situations” [emphasis added]. And it notes that while a “hospital’s advance directive policy” is required to be provided only when individuals are admitted as inpatients, institutions should “also provide the advance directive notice to outpatients (or their representatives) who are in the emergency department, who are in an observation status, or who are undergoing same day surgery.”

## **Care Planning Act of 2013 and Personalize Your Care Act**

It was against this policy backdrop, that Senators Mark Warner (D-VA) and Johnny Isakson (R-GA) recently introduced the Care Planning Act of 2013. The proposal takes a deliberately comprehensive approach to rationalizing services provided to individuals in advanced old age. Below are some of the major features of the bill, which amends the PSDA and would apply to both Medicare and Medicaid. The bill has been referred to the Senate Finance Committee, but no action has been scheduled. In the House, Representative Blumenauer introduced the Personalize Your Care Act – a similar though more narrowly focused bipartisan bill that amends Medicare and Medicaid to cover voluntary advance care planning; directs HHS to expand and enhance POLST programs (an approach to end of life planning that emphasizes patients’ wishes about the care they receive and documents them in the form of a medical order); requires that advance directives and POLST forms be part of electronic health record development; and that advance directives developed in one state be recognized by other states as “authentic expressions” of a patient’s wishes.

## Care Planning Act of 2013<sup>12</sup>

- Establishes Medicare and Medicaid reimbursement for health care professionals to engage in a voluntary and structured discussion about the goals and treatment options for individuals with serious illness, resulting in a documented care plan that reflects the informed choices made by patients in consultation with members of their health care team, faith leaders, family members and friends.
- Tests new models of intensive services for those with advanced illness, and provides funding to support the development of a public information campaign to encourage effective care planning. Provides grants to develop materials and maintain a web site with information about advanced care planning, portable treatment orders, palliative care, hospice, and planning services.
- Directs that providers identify evidence of patient preferences, such as directives from other states or past discussions about treatment goals, and requires documentation of plans made prior to discharge from health facilities to assure that care plans travel with patients after discharge.
- Directs HHS to develop quality metrics that will measure synchronicity among the individual's stated goals, values, and preferences with documented care plans, the treatment that is delivered, and the outcome of treatment.
- Creates a Senior Navigation Advisory Board, comprised of a diverse range of individuals including faith leaders, health care professionals and patient advocates to monitor and advise HHS.

## Concluding Observations

Honest conversations among patients, providers and family members are needed to understand what an individual may want during advanced illness and at the end of life. Equally honest conversations must be held between policymakers and stakeholders to ensure that individuals get the care they want, but not more. It is time to develop a multipronged strategy that focuses on the consistent promotion of a patient's right to informed consent and self-determination in all major services settings, while at the same time identifying and preventing unwanted medical treatment. The starting point for achieving these goals is to get a clear commitment to intensive provider education and engagement, along with broad dissemination of patient decision aids. The time may now be ripe for a consumer driven movement to shift physician behavior and health care system action.

## Endnotes

- 1 Riley, Gerald F., and James D. Lubitz. 2010. "LongTerm Trends in Medicare Payments in the Last Year of Life," Health Services Research, 45(2) 565576.
- 2 Gozalo, Pedro, Joan M. Teno, Susan L. Mitchell, Jon Skinner, Julie Bynum, Denise Tyler, and Vincent Mor. 2011. "End of Life Transitions among Nursing Home Residents with Cognitive Issues," *New England Journal of Medicine*, 365:12121221.
- 3 Sawyer P, Bodner EV, Ritchie CS, Allman RM. 2006. "Pain and pain medication use in community dwelling older adults," *American Journal of Geriatric Pharmacotherapy*, 4(4):316324.
- 4 Pope, Thaddeus M., 2013. "Clinicians May Not Administer Life Sustaining Treatment Without Consent: Civil, Criminal, and Disciplinary Solutions," *Journal of Health & Biomedical Law*, 9 J. Health & Biomed. L. 213.
- 5 Berman, Amy, "Can Someone Override Your Advance Directive," *Health AGenda John A. Hartford Foundation blog*, March 27, 2012, <http://www.jhartfound.org/blog/cansomeoneoverrideyouradvancedirective/>.
- 6 Carson, Ashley B., "Elder Abuse: A National Tragedy," *The Huffington Post Blog*, June 13, 2013, [http://www.huffingtonpost.com/ashleybcarson/worldelderabuseday\\_b\\_3436475.html](http://www.huffingtonpost.com/ashleybcarson/worldelderabuseday_b_3436475.html). Accessed October 21, 2013.
- 7 See supra, note 4.
- 8 U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation. 2008. *Advance Directives and Advance Care Planning: Report to Congress*. <http://aspe.hhs.gov/daltcp/reports/2008/adcongrpt.htm>. Accessed October 18, 2013.
- 9 See supra, note 4.
- 10 White House Memorandum, "Respecting the Rights of Hospital Patients to Receive Visitors and to Designate Surrogate Decision Makers for Medical Emergencies," April 15, 2010, <http://www.whitehouse.gov/thepressoffice/presidentialmemorandumhospitalvisitation>. Accessed October 18, 2013.
- 11 Centers for Medicare & Medicaid Services (CMS). 2013. *F tag 155 — Advance Directives — Revised Advance Copy*. [http://www.cms.gov/Medicare/ProviderEnrollmentandCertification/SurveyCertificationGenInfo/ Downloads/ SurveyandCertLetter1316.pdf](http://www.cms.gov/Medicare/ProviderEnrollmentandCertification/SurveyCertificationGenInfo/Downloads/SurveyandCertLetter1316.pdf). Accessed October 18, 2013.
- 12 News Release, Sen. Johnny Isakson, "Sens. Weren and Isakson Introduce Bipartisan Care Planning Act of 2013," Aug. 1, 2013, <http://www.isakson.senate.gov/public/index.cfm/newsreleases?ID=010950ec7cbd414f87e519c309524b4b>. Accessed October 18, 2013.



# **Respecting Choices: A Case Study for Incorporating Advance Care Planning into Person and Family Centered Health Care Delivery**

**By Janet H. Forlini and Lee Goldberg**

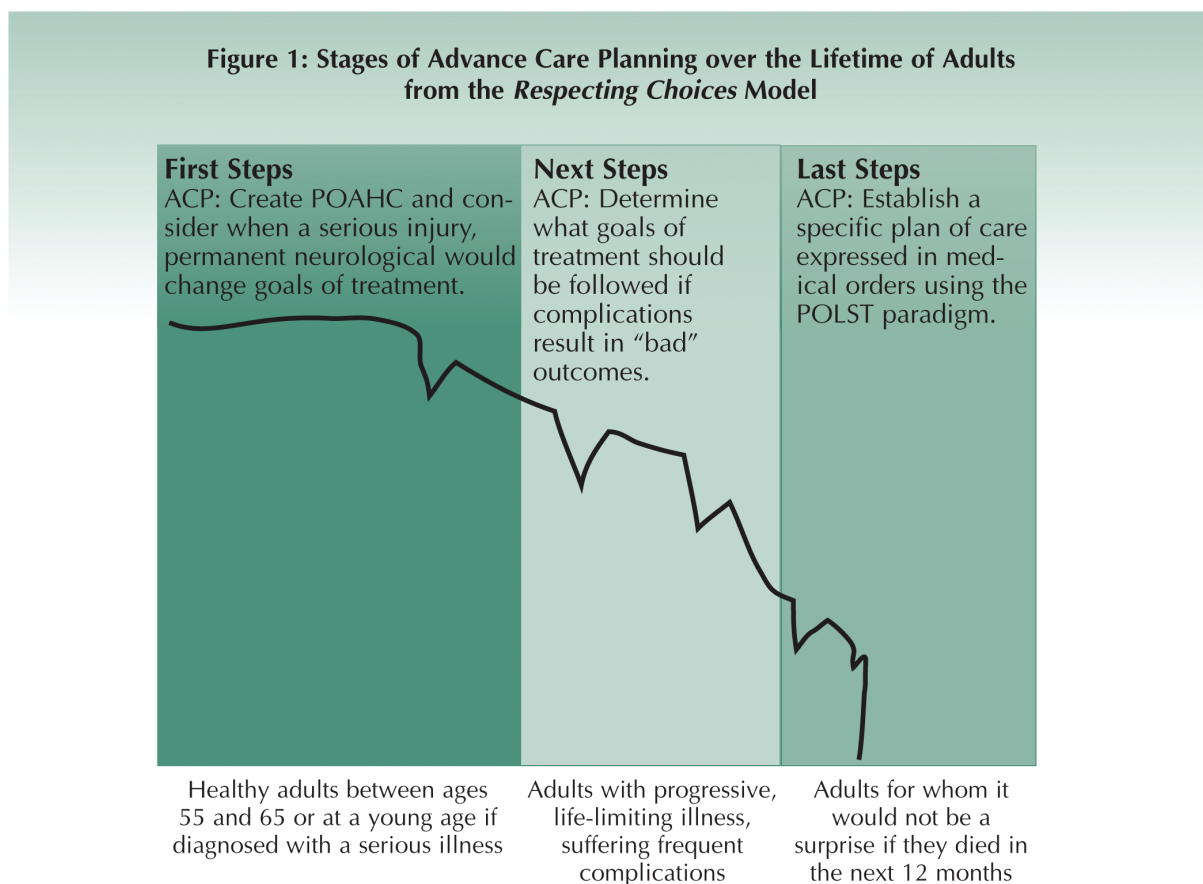
There has been a paradigm shift in the relationship between the health care system and consumers. The Institute of Medicine (IOM), in its 2001 report *Crossing the Quality Chasm*, highlighted the importance of patient centered care, defining it as “care that is respectful of and responsive to individual patient preferences, needs, and values” and care that ensures “that patient values guide all clinical decisions.” Similar to patient centered care is the concept of person centered care that focuses on accumulated knowledge of individuals’ health problems and needs over time; it is a viewpoint that can be traced back to the independent living movement in the early 1970s. Person and family centered care, which has also gained attention in recent years, is an orientation to the delivery of health care and supportive services that addresses an individual’s needs, goals, preferences, cultural traditions, family situation and values.

The person centered approach inherent in advance care planning reflects this evolution. Advance care planning is a process of planning for future medical decisions. But in order to be effective, it must meet a higher standard of involvement than the process of informed consent: individuals need to consider how their health may change; reflect on how treatment may impact their life goals, values and preferences; and over a period of time discuss their choices and plans with those who might be responsible for implementing them.<sup>6</sup> This policy brief, the second in a series that highlights issues raised by the Campaign to End Unwanted Medical Treatment, makes the case that advance care planning can play a crucial role in ensuring that people receive the care they want throughout various stages of their lives.

Implemented in 1991 by the Gundersen Lutheran Health System in LaCrosse, Wisconsin, Respecting Choices is a comprehensive program that aims to engage patients and families in informed conversations about end of life decision-making. The program provides standardized materials to patients across all health settings in the community; trains non physician facilitators to guide patients and families in advance care planning; and implements common policies and practices for collecting, maintaining, retrieving and utilizing advance care planning documents across settings. According to Bernard “Bud” Hammes, PhD, Director of Medical Humanities for Gundersen, one of the greatest misconceptions about advance care planning is that it is a static process — a one time event. Attempting to plan for all possibilities in a single document or at a single point in time is both impossible and unnecessary, according to Hammes. In the Respecting Choices model, advance care planning is an ongoing process of communication, integrated into the person centered care routine and appropriately staged to the individual’s state of health.

Respecting Choices is only one model that addresses advance care planning. From a public policy perspective, fairly extensive peer reviewed research of the model offers instructive lessons for improving outcomes not only for individuals but also for families. Having been successfully replicated in communities across the U.S. as well as internationally, the model appears to have also addressed the issue of scalability that has been a challenge for other programs aimed at meeting the needs of people with chronic care conditions. Most importantly, the Respecting Choices model allows for advance care planning over the course of a person’s life – not just when an individual is approaching the last phase of life – and adapts as individuals move through various stages of health.

This ongoing process allows for the possibility that individual preferences might change over time as health status worsens due to chronic illness or an acute episode (see Figure 1). Respecting Choices breaks the stages of planning into three possible categories that reflect a person's stage in life. The first category is for healthy adults between 55-65 or a young person diagnosed with a serious illness. These individuals would create a power of attorney for health care decisions and would begin to consider whether a significant change in health status might change their goals for treatment. The second category in the diagram captures adults with progressive, life limiting illnesses who are suffering frequent complications. These individuals may want to begin considering how treatment should be adjusted if complications result in undesired outcomes. The third and final category includes adults for whom it would not be surprising if they died within a year. These individuals should establish a plan of care expressed in medical orders.



Source: Hammes, Bernard. "How Can A 'Care Planning System' Improve Care?" Campaign to End Unwanted Medical Treatment Series presentation on December 3, 2013.

Acronyms:

ACP = Advance Care Planning

POAHC = Power of Attorney for Health Care

POLST = Physician orders for Life-Sustaining Treatment

Advance care planning is not part of the average person's current experience in the health care system in this country. Instead, much more common is a onetime utilization of statutory documents — generally living wills and durable powers of attorney for health care — that allow individuals to indicate preferences and name a proxy in the event they become unable to make decisions for themselves. Advance directives, however, can be provided orally or in writing. They can even be in the form of a patient's letter to a loved one. Many options exist.



Commonly used legal documents may address the disposition of property and the transfer of decision-making power, but research has shown that such documents may not serve the purpose of accurately identifying a patient's wishes and values. A preferable approach to advance care planning may be one that relies not on forms but on carefully structured conversations that explore patients' values. The process of advance care planning, with its inclusion of meaningful discussion and reflection, does not have the same risk.

Research also shows that the Respecting Choices model improves outcomes not only for the patients involved but also for the family members. A 2010 study<sup>8</sup> looked primarily at the proportion of patients whose end of life wishes were known and respected by the physician. The secondary measure assessed the impact of the patient's death on relatives. Results found that end of life wishes were known and respected for 86 percent of the patients in the intervention group who died compared to only 30 percent of those in the control group. Similarly, 76 percent of the deaths in the intervention group were associated with positive comments from family members compared to only 19 percent of the control group. The researchers concluded that advance care planning improves end of life care for the patient and reduces stress, anxiety and depression in surviving relatives.<sup>9</sup>

Gundersen is also part of an ongoing Medicare Health Care Quality Demonstration,<sup>10</sup> the goal of which is to examine health delivery factors that lead to improved quality of care. The demonstration project, which began in 2010 and is scheduled to end in 2014, will allow the Gundersen Lutheran staff to share strategies and potentially operationalize the program on a broader scale. While the demonstration project is still underway and results are not yet known, the hope is that Gundersen's approach may be able to improve quality of care for Medicare beneficiaries in a more sustainable way.

Under current law, institutions participating in Medicare and Medicaid must inform patients of their rights to accept or refuse treatment and to execute an advance directive. But neither Medicare nor Medicaid provides reimbursement to health care professionals engaging in voluntary advance care planning discussions with patients. Two legislative proposals—The Care Planning Act of 2013 (S. 1439) and the Personalize Your Care Act (H.R. 1173)—are efforts to change that.

In the meantime, the Respecting Choices model is being implemented by other health care systems in the U.S. and abroad. Honoring Choices Wisconsin is a statewide initiative to build system change, advocacy and education around advance care planning. As part of Honoring Choices Wisconsin, the state medical society serves as a convener, coordinator and catalyst to build clinical improvements combined with outreach in communities across the state. Participating health care organizations systems have agreed to embrace a common emphasis on improving the conversation across health systems; use patient tested forms and informational materials; share lessons learned formally and informally; and support community outreach.<sup>11</sup> Australia and Singapore have also successfully piloted efforts to incorporate advance care planning based on the Respecting Choices model.

Health reform has changed the way policymakers, providers and the public view health care delivery for individuals. Significant progress has been made with regard to an individual's right to make informed, person centered decisions about their health care options and to refuse unwanted medical treatments. Increased use of advance care planning is needed to ensure the evolution of our nation's health care system in a manner that promotes person centered choices in all stages of life.

## ENDNOTES

- 1 Institute of Medicine. *Crossing the Quality Chasm: A New Health System for the 21st Century*. Vol. 6. Washington, DC: National Academy Press; 2001.
- 2 Id.
- 3 “*Is Patient Centered Care the Same as Person Focused Care?*” Perm. J. 2011 Spring; 15(2) 6369.
- 4 Feinberg, Lynn. “*Moving Toward Person and Family Centered Care,*” AARP Public Policy Institute, March 2012.
- 5 Id.
- 6 Hammes, Bernard. “*How Can a ‘Care Planning System’ Improve Care?*” Campaign to End Unwanted Medical Treatment Series Presentation on December 3, 2013.
- 7 Id.
- 8 Detering, Karen M., Andrew D. Hancock, and William Silvester. “*The Impact of Advance Care Planning on End of Life Care in Elderly Patients: Randomised Controlled Trial,*” BMJ 2010; 340; c1345.
- 9 Id.
- 10 Section 1866C of the Social Security Act, as amended by Section 646 of the Medicare Prescription Drug, Improvement, and Modernization Act of 2003, P.L. 108173, Section 1866C(b).
- 11 Wisconsin Medical Society: <https://www.wisconsinmedicalsociety.org/professional/hcw/>. Accessed December 5, 2013.



# Dignity Driven Decision Making: What Is It and Why Is It So Important?

By Anne H. Montgomery

*This brief is based in part on a forum hosted by the Campaign to End Unwanted Medical Treatment on March 12, 2014, in Washington, D.C. The session featured remarks by Bruce Vladeck, senior adviser for Nexera, Inc., and head of the Health Care Financing Administration from 1993 to 1997. This paper is intended to provide a broad overview of the issue featuring a variety of sources and views.*

Dignity driven decision making (DDDM) is beginning to move into wider circulation in the U.S. health care system, driven by an accelerating push on two fronts: an imperative to substantially improve the quality of services for individuals with advanced illness by recognizing and incorporating their stated preferences into all aspects of care, and the goal of establishing a degree of consistency and control over costs late in life.<sup>1</sup> Achieving both will be difficult, Vladeck acknowledged at the forum, in part because in the policy and research arena, “we’ve locked ourselves into narrow boxes” with regard to building highly tailored models of care, with the result that “nobody knows what components are essential.”

To try to tackle these challenges together, DDDM is being formulated as a flexible model for deeply involving individuals with advanced illness, along with their family caregivers, in all aspects of treatment, in an ongoing relationship with care teams. In contrast with advance directives, Vladeck emphasized that “this is not a onetime decision...it is a continuing relationship over time...[with] sustained support.” The DDDM approach can be incorporated into various service delivery models, he noted, and is best practiced not only by physicians, but also social workers and nurses who are part of an interdisciplinary team.

The core formal mechanisms needed for making DDDM possible include 24/7 access to a patient’s medical record; formal care planning and structured care processes such as standardized protocols or checklists; case management; an emphasis on home and community based service (HCBS) delivery in the patient’s home outside of any medical setting; and close communication between HCBS providers and other community providers. In the current fractured U.S. delivery system, these elements are far from universal, and existing gaps are exacerbated by the lack of a strong information technology infrastructure in many care systems to connect providers working in different settings. But the biggest barrier right now, according to Vladeck, is that “most practitioners don’t know how to do this.”

## **What is DDDM and Where Does it Fit in Service Delivery and Financing Reforms?**

It starts simply, with a clinical team asking individuals with advanced illness and their family caregivers, “What do you need today? How do you feel?” Vladeck said. At its essence, the model requires that clinicians spend enough time with and understand their patients “well enough to help you where you are.” This means knowing a patient’s relationships, living situations, family caregiver(s), preferences for care, and personal goals. That information must then be made a central part of the medical record and the care plan, and revised and updated as circumstances change. DDDM also requires ongoing, sustained collaborative decision making among clinicians, patients and family caregivers. All of this suggests that organizations that undertake DDDM must be “really committed to doing this and to investing in their patients.”

Development of the DDDM model has taken off autonomously among several health care providers. One of the leaders to date in developing DDDM is Sutter Health, an integrated health system of 24 hospitals, physician groups and surgery centers based in California. The system was part of The SCAN Foundation funded “Learning Collaborative” that also includes several types of integrated health systems, including selected Programs of All-inclusive Care for the Elderly (PACE) and large multispecialty group practices. The SCAN Foundation has also supported financial sustainability analyses for several different kinds of DDDM based programs, and in 2012, the Center for Medicare and Medicaid Innovation (CMMI) awarded Sutter Health a three-year \$13 million grant to expand its Advanced Illness Management (AIM) program throughout northern California.<sup>2</sup> Preliminary data on costs as reported by Sutter show a 75 percent reduction in Intensive Care Unit (ICU) days within three months of enrollment, a 60 percent reduction in hospitalization, high patient and family satisfaction scores, and overall reduced costs of about \$5,000 per patient after three months, with the major cost savings going to Medicare and Medicaid.

According to Sharyl Kooyer, a Regional Administrator in Sacramento, Sutter Health has developed a fourday training program for nurses and social workers in the AIM model in which DDDM is embedded. The training consists of a half day training on advance care planning, including use of the Physician Orders for Life Sustaining Treatment (POLST) paradigm; a half day on techniques for having “deep conversations” with individuals who are declining; two days on the AIM model of care; and a day on pain and symptom management for those with advanced illness. Once trained, Kooyer said, nurses and social workers, working either independently or in teams, visit an individual’s home, often several times, to assess and develop a relationship that is based on the premise of “How can we help make your goals happen? How can we manage your symptoms so you can meet your goals?” Information gathered during the home visits is then coordinated with treating physicians. As the relationship develops, subsequent conversations are held by phone.

Within the last several years, the American Hospital Association (AHA) has also begun urging its members to pay close attention to implementing AIM models. AHA defines comprehensive AIM programs as having several distinct and also occasionally overlapping phases. The first encompasses individuals who can recover and have reversible illnesses, and frequently includes preparation of an advance directive. The second is for individuals with chronic illness who can be managed, and whose treatment may be supplemented with palliative care to improve quality of life. The third phase is usually characterized by a need for assistance with activities of daily living, and a period when advance care planning is recommended. The fourth phase is for individuals who are deemed to be hospice eligible. During this process, AHA notes, “the treatment plan will increasingly be driven by the personal goals and decisions of the patient and his or her family.”

Evidence for AIM is summarized in a 2012 report from the AHA’s Committee on Performance Improvement.<sup>3</sup> The Association’s report cites research and analytic findings, a few of which are highlighted below, to support hospital use of AIM. It asserts that:

- Evidence is accumulating that hospitals and integrated health systems using AIM may provide patients with improved quality of life, reduced major depression and increased length of survival:
- Median survival among early palliative care patients is longer (11.6 months versus 8.9 months).<sup>4</sup>

- Patients with cancer who died in an intensive care unit or hospital experienced more physical and emotional distress and worse quality of life at the end of life compared with patients who died at home with hospice.<sup>5</sup>
- Overall, patients enrolled in AIM experience a lower utilization of clinical treatments and hospital admissions at the end of life, due to improved coordination and honoring the patient and family's wishes:
- Medicare patients with AIM use 13.5 days of hospital care in the last 2 years of life compared to 23.5 as the national average.<sup>6</sup>
- Fewer ICU admissions<sup>7</sup> and as much as an 85 percent reduction in ICU days.<sup>8</sup>
- AIM programs lead to improved satisfaction scores reported by patients, family caregivers and multidisciplinary AIM trained staff for these indicators:
- Knowledge and respect of patient's preferences.<sup>9</sup>
- Increased time devoted to family meetings and counseling.<sup>10</sup>
- Reduced family and caregiver depression, distress, and documented anxiety.<sup>11</sup>
- Due to improved care coordination and associated prevention of crises, a secondary impact of AIM programs is a reduction in aggregate spending:
- On average, patients who received palliative care incurred \$6,900 less in hospital costs during a given admission than a matched group of patients who received usual care.

In a subsequent report focusing on AIM and the health care workforce's readiness to implement these programs, AHA concludes that "the success of AIM programs is contingent upon the education and training of health care providers as the demand grows for managing multiple chronic conditions, as well as for palliative and end of life care."<sup>13</sup> But it further notes that at present, "there are not enough health care professionals who are ready, willing and able to manage advanced illness with patients and their families, and there is a constant need to engage in conversations and provide guidance to more expert resources."

This point is in agreement with earlier points from a June 2012 Health Affairs article written by Vladeck with The SCAN Foundation's Erin Westphal, who argue that "for interdisciplinary teams to function effectively... appropriate training is required, and organizational practices must be in place to support necessary information sharing and decision making. Formal care planning is also a necessity, and in some organizations the care plan itself serves as the focus for interdisciplinary collaboration and information sharing." Vladeck and Westphal view development of replicable DDDM training programs for "dedicated clinicians and committed organizations...struggling to improve care for those with advanced illness" as a worthy goal. The Health Affairs article argues for the importance of patient and family satisfaction as a primary goal and performance measurement for DDDM based programs, stating: "This kind of care requires skills and experience that are teachable, but that are rarely part of physicians' and nurses' training and that require regular reinforcement and updating...informal, continuous monitoring of patient and family perceptions of the care delivery process is at the core of dignity driven decision making."<sup>16</sup> In addition, the article asserts that "robust measures of patient and family control of

decision making and satisfaction” are needed. Current quality measurement tools that try to assess patient satisfaction “do not even come close to capturing patients with advanced illness and their relationship with the care system,” according to Vladeck.

Having appropriately targeted populations for further development of DDDM is important. Patients with congestive heart failure and chronic obstructive pulmonary disease are among the most appropriate, according to Vladeck. The lack of explicit payment for the time intensive work required by DDDM may make it a difficult fit for the Medicare fee for service system, he noted, but suitable for capitation arrangements with adequate risk adjustment, and potentially a good fit for shared savings models such as Accountable Care Organizations (ACOs). At Sutter Health, DDDM in the context of the AIM program is being tested in both a home health based model and in the hospital environment. Kooyer also noted that work is ongoing to try to make the resulting longitudinal care plan an integral part of Sutter Health’s electronic health record system, with information gathered available across all settings of care.

## **International “Dignity in Care” Models**

Interest in developing “dignity in care” protocols is not confined only to the U.S. In the U.K., the Social Care Institute for Excellence (SCE) issued a document in June 2010 on “choice and control” that is designed to empower people to “make choices about the way they live and the care they receive.” SCE urges providers to take a range of specific actions to achieve dignity in care for their patients, including:

- Taking time to understand and know the person, their previous lives and past achievements, and support people to develop ‘life story books’;
- Empowering people by making sure they have access to jargon free information about services when they want or need it;
- Ensuring that people are fully involved in any decision that affects their care, including personal decisions (such as what to eat, what to wear and what time to go to bed), and wider decisions about the service or establishment (such as menu planning or recruiting new staff);
- Giving staff sufficient training to include people with cognitive or communication difficulties in decision-making;
- Working to develop local advocacy services and raise awareness of them; and
- Involving people who use services in staff training.”

The Institute warns that choice and control are “particularly at risk where a person needs support to meet their most basic and private needs... [and] is more easily lost where people have impairments that affect their ability to communicate, including dementia.” It also notes that older Europeans found dignity to be an essential manifestation of autonomy, suggesting that care providers must “understand the importance of a person’s identity by ensuring time is taken to understand and know the person, their previous lives and past achievements.” Empowering patients and focusing on ways to ensure that their dignity remains intact as they approach the end of life is also the aim of research conducted in Canada by Harvey Max Chochinov. A leader in palliative care, a psychiatrist and author of *Dignity Therapy: Final Words for Final Days*, Chochinov’s “dignity therapy” model engages individuals with advanced illness in structured interviews that produce a “generativity” legacy document – a record of key moments in an

individual's life that can then be given to heirs. Based on a framework of questions (a sample of which are below) that guide participants, dignity therapy allows individuals to “share their thoughts, reminiscences, advice, hopes and dreams with those they are about to leave behind.”

- Are there particular things that you feel need to be said to your loved ones, or things that you would want to take the time to say once again?
- What are your hopes and dreams for your loved ones?
- What have you learned about life that you would want to pass along to others? What advice or words of guidance would you wish to pass along to your [son, daughter, husband, wife, and parents, others (s)]?
- Are there important words or perhaps even instructions that you would like to offer your family?

In an August 2011 “Healthy Blog” written for the Altarum Institute’s Center for Elder Care and Advanced Illness, The SCAN Foundation President Bruce Chernof succinctly summarizes the challenge ahead: “The specific focus of [DDDM] is to transform health care decision making to explicitly include quality of life, dignity, and self determination as key outcomes for all and particularly for those with advanced illness. . . .Dignity driven decision making offers the opportunity to improve a person’s quality of life outcomes while reducing costly services that may be unnecessary or even harmful. Dignity driven decision making begins and ends with the seriously ill person’s quality of life as the basis for a better, more cost effective delivery system.”<sup>21</sup>

The challenge is how to push DDDM beyond the boundaries of initial development. After SCAN examines DDDM sustainability as part of its analysis in Sutter’s AIM program and various community based health and aging services in California, the Foundation plans to continue to invest in this work through building the business case for person centered care models that value dignity, choice, and independence. Some of this work could potentially be adopted for the next phase of development of ACOs and other types of shared savings models, which the Centers for Medicare and Medicaid Services has already signaled its intent to pursue. Meanwhile, Sutter Health is expanding its AIM program steadily across its health care system in California, with the goal of having the program active at all sites. With proper planning, the CMMI grant, which ends in June 2015, may further the goal of widespread sharing of DDDM techniques and the AIM program during the evaluation and dissemination phase.

## Endnotes

- 1 Advanced illness may be defined as “occurring when one or more conditions become serious enough that general health and functioning decline, and treatments begin to lose their impact. This is a process that continues to the end of life.” See Coalition to Transform Advanced Care. What is Advanced Illness. Retrieved from <http://advancedcarecoalition.org/whatisadvancedillness/>.
- 2 Advanced Illness Management encompasses four phases as a patient’s health declines, from basic good health and chronic care management through palliative care and hospice care.
- 3 Diegel, J. A., American Hospital Association, Committee on Performance Improvement, Advanced Illness Management Strategies: Engaging the Community and a Ready, Willing and Able Workforce. Chicago, December 2012.
- 4 Temel, J.S., Greer, J.A., Muzikansky, A., Gallagher, E.R., Admame, S., Jackson, V.A., Dahlin, C.M., Blinderman, C.D., Jacobsen, J., Pirl, W.F., Billings, J.A., Lynch, T.J. (2010). “Early palliative care for patients with metastatic nonsmallcell lung cancer”, *New England Journal of Medicine*, 363(8), 733742.
- 5 Wright, A.A, Keating, N.L., Balboni, T.A., Matulonis, U.A., Block, S.D., Prigerson, H.G. (2010). “Place of death: Correlations with quality of life of patients with cancer and predictors of bereaved caregivers’ mental health”, *Journal of Clinical Oncology*, 28(29), 44574464.
- 6 Gundersen Lutheran Health System presentation to AHA Committee on Performance Improvement. April 2, 2012.
- 7 Id.
- 8 Diegel, supra.
- 9 Gundersen, supra.
- 10 Id.
- 11 Id.
- 12 Morrison, R.S., Penrod, J.D., Cassel, J.B., Caust Ellenboegen, M., Litke, A., Spragens, L., Meier, D.E. (2008). “Cost savings associated with US hospital palliative care consultation programs”, *Archives of Internal Medicine*, 168(16), 17831790.
- 13 Diegel, supra.
- 14 Id.
- 15 Vladeck, B.C. and Westphal, E. (2012). “DignityDriven DecisionMaking: A Compelling Strategy for Improving care for People with Advanced Illness”, *Health Affairs*, 31(6), 12691276.
- 16 Id.
- 17 Social Care Institute for Excellence. (June 2010). Dignity in Care – The Dignity Factors: Choice and Control. Retrieved from [http:// www.scie.org.uk/publications/guides/guide15/factors/choice](http://www.scie.org.uk/publications/guides/guide15/factors/choice).
- 18 Id. 19 Chochinov, H. M. (2012). *Dignity Therapy: Final Words for Final Days*. New York, NY: Oxford University Press.
- 20 Id.
- 21 Chernof, B. (August 4, 2011). Dignity as the Cornerstone to Better Care. Altarum Institute. Received from <http://altarum.org/healthpolicyblog/dignityasthecornerstonetobettercare>.



# Concurrent Palliative and Curative Services: The Next Step in Evolution of Medicare Hospice Care

By Janet H. Forlini and Lee Goldberg

*The Campaign to End Unwanted Medical Treatment hosted a briefing on April 11, 2014 that featured Chris Dawe, former health policy advisor to the National Economic Council at the White House. Dawe discussed the recent announcement of the “Medicare Care Choices Model” that would expand the availability of hospice services. What follows is a brief based on the issues raised in that discussion.*

Although the Affordable Care Act (ACA) is best known for its provisions to expand coverage, it may be the many demonstration projects authorized by the legislation that have the most significant impact on the health care delivery system. One key provision in the ACA, at least from the perspective of personcentered care, is new authority to open up hospice care to Medicare beneficiaries who want to continue with curative care. The demonstration project, which targets Medicare beneficiaries with advanced cancers, chronic obstructive pulmonary disease, congestive heart failure and HIV/AIDS, is an effort to see whether expanded care options for seriously ill people will improve quality of life, increase patient and family satisfaction, and prove to be costeffective; it also seeks to increase utilization of hospice care.

The demonstration project has implications for individuals who are in the early stages of a serious illness and who may have no interest in traditional hospice care. Members of the Campaign to End Unwanted Medical Treatment see this demonstration is as an important development in ensuring that individuals are able to tailor care for chronic and serious illness to meet their individual preferences.

## Background

Hospice care was developed by physician Dame Cicely Saunders, who created the first modern hospice in London in 1967.<sup>1</sup> In the 1970s, the hospice movement spread to the United States and continues to gain support: the Medicare Hospice Benefit became available as a demonstration project in 1982<sup>2</sup> and was made a permanent part of the program by Congress in 1986.<sup>3</sup>

Medicare paid for approximately 84 percent of the hospice care received in the United States in 2012.<sup>4</sup> The benefit covers palliative and support services for terminally ill beneficiaries who have a life expectancy of six months or less if the illness follows its normal course.<sup>5</sup> All Medicare covered hospice services are available even if the beneficiary is in a Medicare Advantage Plan.<sup>6</sup> States can offer hospice as an optional benefit for Medicaid beneficiaries, and most private health insurance companies include hospice as a covered benefit.

A broad set of services is covered under the hospice benefit including nursing care; physician services; counseling and social work services; hospice aide and homemaker services; short-term inpatient care; drugs and biologicals for symptom control; home medical equipment; physical, occupational and speech therapy; bereavement services for the patient’s family; and other services for palliation of the terminal condition. However, by electing the Medicare hospice benefit, beneficiaries agree to forgo Medicare coverage for conventional treatment of the terminal illness.<sup>7</sup> Although Medicare will cover treatment for health problems unrelated to the beneficiary’s terminal condition, the decision to opt for hospice care is a difficult one for beneficiaries and their families. From a clinical point of view,

there is in most cases no need to choose between palliative care and life prolonging care. The three year demonstration is expected to launch in early 2015. The Centers for Medicare and Medicaid Services (CMS) will select a diverse group of 30 rural and urban certified hospice providers and, from within those, expects to enroll approximately 30,000 beneficiaries. CMS will pay a fee of \$400 per beneficiary per month to participating hospices; providers offering curative services will be able to continue to bill Medicare for the reasonable and necessary medical services.<sup>9</sup>

## **Impact of Hospice Care**

Traditional hospice care has the potential to improve the quality of care and lower costs. In a 2013 study using data from the Health and Retirement Study and individual Medicare claims, researchers found that hospice enrollment resulted in savings to the Medicare program across a number of different lengths of stay.<sup>10</sup> More specifically, findings showed that reductions in the use of hospital services, hospital days, hospital admissions, and hospital deaths rose as the period of hospice enrollment lengthened within the study period.<sup>11</sup> These researchers noted that such outcomes are not only less costly but also are associated with improved quality and increased accord with patients' preferences.<sup>12</sup>

This is not the first instance of providers offering concurrent care to hospice patients. Aetna's Compassionate Care Program allows a liberalized hospice benefit for some of its members, expanding the definition of eligibility to having a terminal illness with a life expectancy of twelve months rather than the usual six months and allowing members to access hospice benefits without being required to first discontinue curative therapy.<sup>13</sup> Cost analyses of the program showed a net decrease in medical costs of 22 percent.<sup>14</sup> Children also have increased access to concurrent care: the "Concurrent Care for Children" provision of the ACA applies to individuals under age 21 who are eligible for Medicaid or the Children's Health Insurance Program (CHIP) and requires all state Medicaid programs to pay for both curative and hospice services for this population.<sup>15</sup>

A randomized trial undertaken at the University of Michigan's Comprehensive Cancer Center revealed cost savings when concurrent care was provided. Results from this study found a 27 percent cost reduction when conventional oncology management was combined with hospice services.<sup>16</sup> However, while the study did find significant cost savings as well as improved quality of life for the patients, the study conclusions did not indicate any significant difference in survival rates. It should be noted that some research has actually shown a link between foregoing care and extending length of life: a 2010 study of patients with metastatic lung cancer who received less aggressive care at the end of life had longer survival rates.<sup>17</sup>

## **Increasing Utilization**

A critical part of the demonstration project is to measure its effects on utilization of the Medicare Hospice Benefit.<sup>18</sup> Use of hospice in the U.S. has been on the rise: the number of people using hospice increased from 870,000 patients in 2005 to 1.2 million in 2011.<sup>19</sup> Despite its growth, however, hospice remains significantly underutilized. According to the National Hospice and Palliative Care Organization (NHPCO),<sup>20</sup> the median length of service in 2011 was only 19 days, and the average length of service was 69 days that same year. This suggests that, while there were some very long hospice stays, there were a great many more short stays reflecting the underutilization of the benefit. One goal of the demonstration project is to address this underutilization.



Underutilization of hospice may be the result of hospice providers' own enrollment policies. A recent study found that a significant number of hospices have enrollment policies in place that restrict access for those patients with high cost needs.<sup>21</sup> Given that the Medicare per diem hospice reimbursement rate is not adjusted for cost or intensity of care, there is a financial disincentive to enroll patients who require chemotherapy or intravenous nutrition, for example. The study authors propose increasing the hospice per diem rate for patients requiring complex treatment, which thereby might encourage more hospices to expand their enrollment policies.

While research has explored the causes of hospice underutilization, there has, at the same time, been concern over utilization that is the result of misguided incentives and even fraud among hospice providers. MedPAC's Report to Congress in 2008 stated: "our current work suggests that the hospice payment system provides an incentive for hospices to seek patients likely to have long hospice episodes, which are more profitable than short episodes."<sup>23</sup> More recently, in 2013, the U.S. Department of Justice filed a lawsuit against the largest for-profit chain in the country, alleging false Medicare billings for hospice services.<sup>24</sup> While this demonstration is not intended to address issues of fraud in the program, it nevertheless remains a concern in any discussion that would expand eligibility or increase utilization.

The demonstration program has raised concerns as to whether the \$400 per beneficiary per month payment is adequate to cover patient costs given the complex needs of the hospice eligible population or whether payment levels will reinforce the incentives that dampen utilization. Limited funds may lead to creative solutions, such as hospice organizations partnering with community providers such as local aging or transportation services providers.

Offering concurrent curative and palliative care for Medicare beneficiaries may increase hospice utilization rates generally, particularly among certain ethnic and cultural groups that currently do not use the benefit much. In 2009, 41 percent of people who died in the United States used hospice services; cancer was the single most common diagnosis, comprising approximately 40 percent of this population. Although African Americans have a higher incidence rate of cancer, shorter survival time after diagnosis, and higher cancer death rates, African Americans comprised only 8.7 percent of the hospice population that year. They were also less likely to use hospice services than other racial groups.

There are different theories about the disparity in utilization. For some demographics, the notion of comfort care only may be incompatible with cultural norms; for some minority populations, the demand for aggressive treatment is tied to the perception that this was care that was for many years denied to their community.<sup>27</sup> Others posit that the lower utilization of hospice may be due to variation in referrals, geographic disparities in health care service provision or lack of awareness.<sup>28</sup> This is an issue that has consistently been raised as a challenge in expanding the provision of hospice and the demonstration project may provide some guidance as to how it can be addressed. The Campaign to End Unwanted Medical Treatment strongly supports efforts to ensure that everyone gets the care they want and this demonstration may help to ensure this. Articulation of a patient's needs is critical to ensuring that the care they receive reflects their wishes (for instance, quality of life may be a higher priority than extending length of life); this demonstration may allow individuals considering hospice care to make the same kinds of distinctions with respect to palliative and curative care.

## Conclusion

This demonstration is yet another example of an ongoing trend toward more person centered health care, as it looks at ways to improve quality of life while also ensuring the individual gets the type of care they want as opposed to measuring success in terms of how much care was provided. As Dawe suggested, the findings of the demonstration may also have broader implications for patients not yet ready for hospice – helping them address questions of how best to prepare for advanced illness. These issues will be more pressing as more and more Americans continue to live longer lives than previous generations.

Janet H. Forlini is an independent consultant focusing on aging, end of life, and longterm care public policy. Lee Goldberg is Vice President for Health Policy at the National Academy of Social Insurance.

© National Academy of Social Insurance, 2014.

## Endnotes

- 1 National Hospice and Palliative Care Organization: “History of Hospice Care.” Available at: <http://www.nhpco.org/historyhospicecare>.
- 2 Tax Equity and Fiscal Responsibility Act of 1982, P.L. 97248, 96 Stat. 324 (1982).
- 3 See NHPCO, supra note 1.
- 4 National Hospice and Palliative Care Organization: “NHPCO’s Facts and Figures Hospice Care in America (2013 Edition).” Available at: [http://www.nhpco.org/sites/default/files/public/Statistics\\_Research/2013\\_Facts\\_Figures.pdf](http://www.nhpco.org/sites/default/files/public/Statistics_Research/2013_Facts_Figures.pdf)
- 5 Certification of Terminal Illness, 42 C.F.R. Sec. 418.22 (2011).
- 6 Centers for Medicare and Medicaid Services (CMS). “Medicare Hospice Benefits.” Baltimore, MD. Revised August 2013. Available at: <http://www.medicare.gov/pubs/pdf/02154.pdf>.
- 7 Medicare Payment Advisory Commission’s March 2012 Report to Congress. Available at: [http://www.medpac.gov/documents/reports/chapter11hospiceservices\(march2012report\).pdf?sfvrsn=4](http://www.medpac.gov/documents/reports/chapter11hospiceservices(march2012report).pdf?sfvrsn=4)
- 8 Kaiser Health News. July 29, 2014. “Medicare Experiment Could Signal Sea Change for Hospice.” Available at: <http://www.kaiserhealthnews.org/Stories/2014/July/29/MedicareExperimentCouldSignalSeaChangeForHospice>
- 9 Centers for Medicare and Medicaid Services (CMS). “Fact Sheet: Medicare Care Choices Model.” Baltimore, MD. Released March 18, 2014. Available at: <http://www.cms.gov/Newsroom/MediaReleaseDatabase/Factsheets/2014Factsheetsitems/20140318.html>
- 10 Kelley, A.S. et al. 2013. “Hospice Enrollment Saves Money for Medicare and Improves Care Quality Across a Number of Different Lengths of Stay.” *Health Affairs* 3: 552561.
- 12 Id.

- 13 Krakauer, R., Spettell, C.M., Reisman, L. et al. 2009. "Opportunities to Improve the Quality of Care for Advanced Illness" *Health Affairs* 28: 135759.
- 14 Id.
- 15 Section 2302 of the "Patient Protection and Affordable Care Act of 2010."
- 16 Finn, J.W., Pienta, K.J., Parzuchowski, J. et al. 2002. "Palliative Care Project: Bridging Active Treatment and Hospice for Terminal Cancer Patients." *Proc Am Soc Clin Oncol*, 1452.
- 17 Temel, J.S. et al. 2010. "Early Palliative Care for Patients with Metastatic NonSmallCell Lung Cancer" *N. Engl. J. Med* 363: 733742.
- 18 Id.
- 19 "Medicare Revises Nursing Home Rating System" *New York Times*, October 6, 2014. Available at: [http://www.nytimes.com/2014/10/07/business/medicarealtersitsnursinghomeratingsystem.html?\\_r=0](http://www.nytimes.com/2014/10/07/business/medicarealtersitsnursinghomeratingsystem.html?_r=0). See also American Society of Clinical Oncology 2008 "The Debate in Hospice Care." *J. Oncol. Pract.* 4(3); 153157.
- 20 National Hospice and Palliative Care Organization: "NHPCO's Facts and Figures: Hospice Care in America (2012 Edition)." Available at: [http://www.nhpco.org/sites/default/files/public/Statistics\\_Research/2012\\_Facts\\_Figures.pdf](http://www.nhpco.org/sites/default/files/public/Statistics_Research/2012_Facts_Figures.pdf).
- 21 Aldridge Carlson, M.D. et al. 2012. "Hospices' Enrollment Policies May Contribute to Underuse of Hospice Care in the United States." *Health Affairs* 12: 26902698.
- 22 Id.
- 23 Medicare Payment Advisory Commission's June 2008 Report to Congress. Available at: [http://www.medpac.gov/documents/reports/Jun08\\_EntireReport.pdf?sfvrsn=0](http://www.medpac.gov/documents/reports/Jun08_EntireReport.pdf?sfvrsn=0)
- 24 U.S. Department of Justice Press Release dated May 2, 2013. Available at: <http://www.justice.gov/opa/pr/unitedstatesfilesfalseclaimsactlawsuitagainstlargestprofithospicechainunited>
- 25 Kaiser Health News, *supra*, note 8.
- 26 Spruill A.D., Mayer, D.K. and Hamilton, J.B. 2013 "Barriers in Hospice Use Among African Americans with Cancer" *Journal of Hospice and Palliative Nursing* 15(3): 136144.
- 27 Cerminara, K. "Health Care Reform at the End of Life: Giving With One Hand but Taking With the Other." *American Society of Law, Medicine and Ethics: Blogs and Forums* June 7, 2010. Available at: [http://www.aslme.org/print\\_article.php?aid=460404&bt=ss](http://www.aslme.org/print_article.php?aid=460404&bt=ss)
- 28 Connor S.R., Elwert F., Spence C., and Christakis, N.A. 2008 "Racial Disparity in Hospice Use in the United States in 2002." *Palliat Med.* 22; 205213.
- 29 Center for Medicare Advocacy, Inc. "Tinkering with Hospice: The Medicare Care Choices Model." Available at: <http://www.medicareadvocacy.org/medicarecarechoicesmodelisitbetterforhospice/>



# Empowering Consumer-Directed Advance Care Planning

By Janet H. Forlini and Lee Goldberg

*The Campaign to End Unwanted Medical Treatment hosted a briefing in the U.S. Capitol Building on June 19, 2015, featuring Charles Sabatino, Director of the American Bar Association Commission on Law and Aging. In the briefing, Sabatino provided background on the legal, policy and practical issues related to advance care planning. His presentation also included useful resources for promoting effective documentation and conversation relating to treatment preferences. This paper serves as an overview of that discussion.*

## The Early Model: A Legal Transactional Approach

The importance of capturing individual preferences related to end-of-life care has long been seen as invaluable, but the emphasis on how best to accomplish this goal has shifted over time. In the mid-1970s, states began to adopt legislation related to health care advance directives.<sup>1</sup> California was the first to adopt such a statute in 1976, creating its Directive to Physicians, better known as a “living will.” The statute provided not only a standardized tool for individuals to express their wishes about life-sustaining treatment, but also a way for health care practitioners to gain statutory immunity as long as they complied with patient wishes in good faith. By the mid-1980s, 41 states had adopted living will statutes.<sup>2</sup> Over time, states broadened the scope of such tools, enacting statutes authorizing the use of a durable power of attorney that allowed an agent to continue to be empowered even after the principle lost capacity. By 1997, every state had some form of a durable power of attorney.

Another wave of legislation began in the early 1990’s, triggered by concerns over unwanted resuscitations of terminally ill patients facing a foreseeable medical crisis. Advance directives were not adequate to prevent paramedics from seeking to revive patients whose heart or breathing stopped. By 1999, 42 states enacted legislation to allow seriously ill persons in the community to avoid these unwanted medical interventions through the use of out-of-hospital Do Not Resuscitate (DNR) orders.<sup>3</sup>

Though these tools were important, they did not address the situation where individuals lacked decisional capacity but had no appointed guardian. Family consent laws were developed in 44 states and the District of Columbia to address the question of who could make end of life decisions in such circumstances. But states differed significantly in specifying permissible surrogates and in the scope of authority granted.

The multiplicity of tools – living wills, proxies and surrogate decision-making in the absence of an advance directive – and their complexity may have contributed to their underuse. As a result, states sought to create a single advance directive for health care. New Jersey took the first step in this development and by 2009, 25 states had enacted comprehensive or combined statutes. The most sophisticated statutes authorized default surrogate decision makers in the absence of an advanced directive and provided organ donation as an additional option.<sup>4</sup>

## Shifting to a Communications Approach

For the last several decades, states created standardized legal forms with mandatory formalities and procedural requirements intended to protect individuals against abuse and error. This transactional approach has given way to a new approach, putting less emphasis on statutory language and legal documents and more weight on the significant role of a person-centered process of communications

over time. It is these broader conversations and ongoing processes around such decision-making that are best characterized today as “advance care planning”. Experts in the field have found consensus about the importance of advance care planning, and the role of documenting treatment goals and preferences. The Institute of Medicine (IOM) in its report “Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life” stated in its key findings:

Most people nearing the end of life are not physically, mentally, or cognitively able to make their own decisions about care. The majority of these patients will receive acute hospital care from physicians who do not know them. Therefore, advance care planning is essential to ensure that patients receive care reflecting their values, goals and preferences. Of people who indicate end-of-life care preferences, most choose care focused on alleviating pain and suffering. However, because the default mode of hospital treatment is acute care, advance planning and medical orders are needed to ensure that these preferences are honored.<sup>5</sup>

Studies testing the impact of advance directive documents have garnered mixed results. In one national study looking at the association between advance directives and quality end of life care, researchers concluded that utilization of advance directives was associated with greater use of hospice and fewer reported concerns for bereaved family members.<sup>6</sup> But another study found that preferences for treatment at the end of life had inconsistent trajectories, suggesting that preferences may be influenced by transient factors and do not always reflect stable core values.<sup>7</sup>

According to Sabatino, there is no one way to engage in advance care planning. The process needs to have a role for the advance directive, but it also needs to reflect that a person’s treatment preferences change over time.<sup>8</sup> Several easily accessible tools (see “Resources”) are now available to help people consider their health care goals and values, initiate conversations with loved ones, make plans, and communicate their wishes. Since everyone approaches (or avoids) the subject of death and dying differently, having a wide variety of tools is valuable. The tools do not necessarily result in a formal advance directive and one’s treatment goals and preferences need not be memorialized in a legal document to make a difference. But the one task that does require a formal legal document is the appointment of a health care agent or proxy.

As Sabatino noted in his presentation, advance directives have significant value – they can support advance care planning, empower a health care agent, clarify goals and priorities and avoid unwanted treatment-- but they have their inherent limitations as well. They are not a substitute for broader discussion; they cannot eliminate individual ambivalence and may not always dictate the ultimate care delivered, according to Sabatino. He also pointed out that for an individual who does have an advance directive there are certain events (he calls them the “Five D’s”) that present timely occasions for reviewing the document. These are: (1) reaching a new decade; (2) experiencing the death of a close family member or friend; (3) getting divorced; (4) receiving a new diagnosis; or (5) experiencing a decline in condition.

Multiple considerations should be taken into account before drafting an advance directive, according to Sabatino. For example, in selecting a health care proxy, the ideal person not only should be qualified under state law to serve as a surrogate, but should also be likely to live longer than the individual for whom he/she is serving as agent; moreover, the person selected should be able to understand and communicate the values, goals and treatment preferences of the individual being represented and be able to manage interpersonal conflict, should the need arise. A well-drafted advance directive should also be explicit about the agent’s scope of authority and discretion. It should take into account the respective state laws regarding an individual’s incapacity to make decisions that would trigger the



agent's authority. Individuals unsure about whether someone should be their health care proxy should either provide that person with training or find someone else to serve in the role. If no other option exists, then a person could spell out his or her wishes explicitly in a living will. These considerations are critical to avoid having to endure unwanted medical treatment.

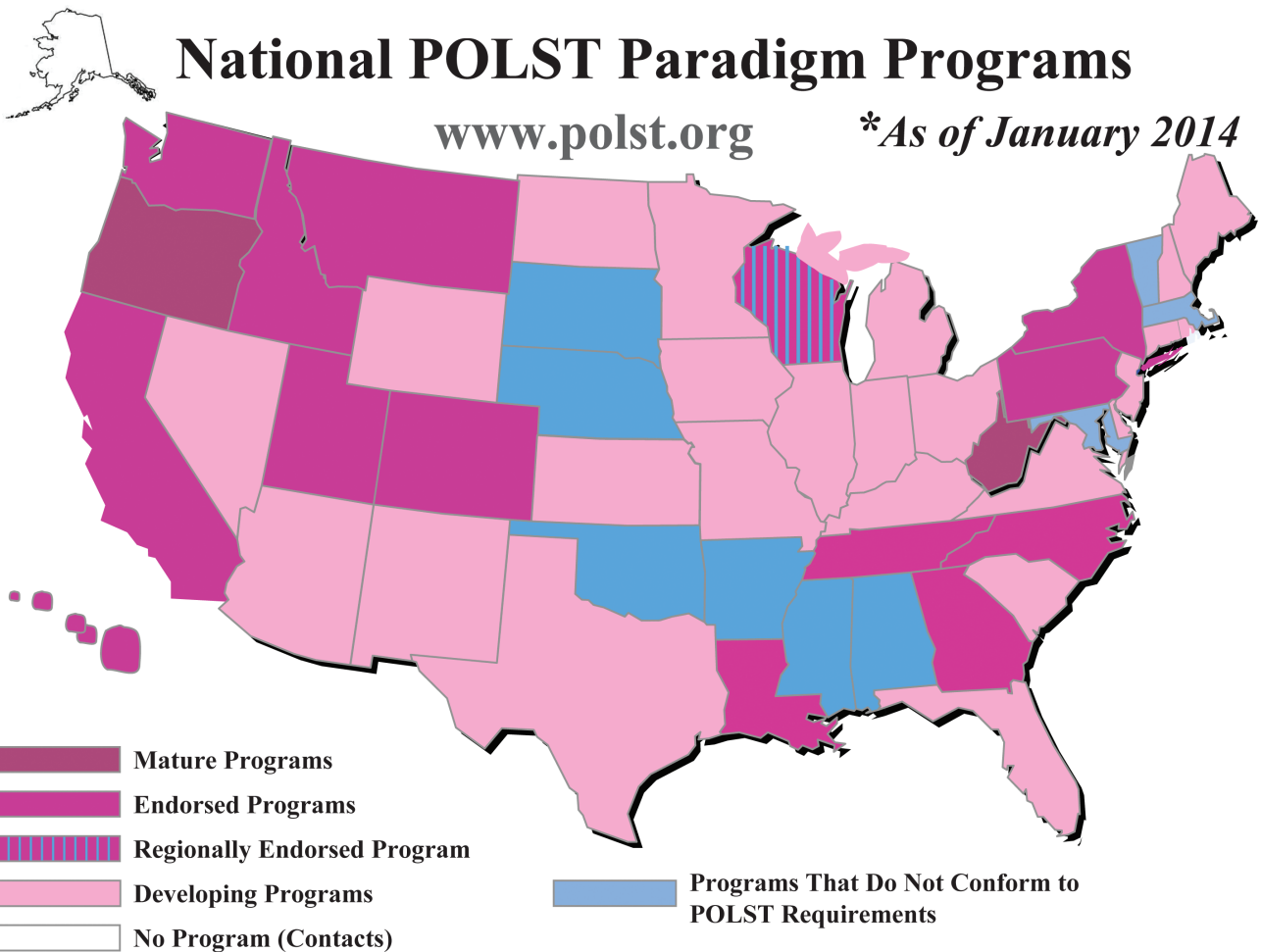
Consumers may find it easier to engage in advance care planning under a proposed federal regulation that would reimburse physicians for conversations with Medicare beneficiaries about advanced directives and similar standard forms. The proposed regulation would, if finalized, remove a significant disincentive for physicians to engage in these conversations.<sup>9</sup> The Centers for Medicare and Medicaid Services (CMS) must now consider public comment before issuing a final regulation.

## **POLST: Translating Preferences into a Plan of Care**

Given the trend toward a more flexible and less standardized approach to advance care planning and the need for modifying care preferences over time, questions arise about how best to translate an individual's preferences into a care plan. Even when an individual and family have had extensive discussions and documented the individual's goals and preferences, those goals and preferences often do not result in a clear care plan, especially near the end of life when individuals are more likely to be confronted with a number of complex and emergent critical care decisions. The result is that an individual's care goals may not play a part in treatment decisions; the individual may be subject either to unwanted medical treatment or treatment that is quite different than what was expected. A growing number of states have sought to address the gap between a patient's goals and his or her actual treatment by adopting what is commonly known as the POLST (Physician Orders for Life-Sustaining Treatment) protocol.<sup>10</sup>

Originating in Oregon, this protocol facilitates shared and informed decision-making between health care professionals and patients with advanced, progressive illness and/or frailty.<sup>11</sup> The program uses a unique, brightly-colored medical order form that is placed at the front of a patient's medical record or stays with the patient if he/she is homebound. The medical order form covers several key decisions common to seriously ill patients regarding cardiopulmonary resuscitation, nutrition and hydration, and hospitalization.<sup>12</sup> To improve continuity of care across care settings, providers should take steps to make sure that the POLST form travels with the patient.<sup>13</sup>

The National Quality Forum recommended nationwide adoption of the POLST paradigm in its 2006 consensus report on palliative and hospice care.<sup>14</sup> Prescriptive state requirements for out-of-hospital DNR orders may be incompatible with certain elements of the POLST form and may be a major barrier to nationwide adoption; another impediment includes state witnessing requirements that make utilization of a POLST form more complicated, although they may not preclude its use.<sup>15</sup> States interested in adopting the POLST form would need to review the compatibility of the protocol with existing laws and regulations.<sup>16</sup> Despite such laws, a majority of states have either adopted the POLST protocol or are in the process of doing so, as the map below indicates.



The POLST protocol is not intended to replace other forms of advance care planning. Prior advance care planning and the completion of an advance directive make the POLST protocol easier since the patient or patient's proxy already has had some experience in planning. POLST complements advance directives and has the advantage of being helpful for patients who have not yet done any advance care planning. It is important to note that there are some risks associated with the program's adoption. The protocol must be implemented with the concurrent engagement between the patients (or their surrogates) and the health care professionals treating them, or may not reflect the patient's wishes in a comprehensive way.<sup>17</sup>

## Resources

The following are tools and decision aids developed to facilitate advance care planning and documentation of treatment preferences. This list is not by any means exhaustive and should be supplemented by other sources.

### Conversation Aids:

- Consumer Toolkit for Health Care Advance Planning ([www.ambar.org/healthdecisions](http://www.ambar.org/healthdecisions))
- PREPARE Website ([www.prepareforyourcare.org](http://www.prepareforyourcare.org))
- The Conversation Starter Kit ([www.theconversationproject.org](http://www.theconversationproject.org))



## Documenting Goals, Values and Wishes:

- Caring Conversations ([www.practicalbioethics.org](http://www.practicalbioethics.org))
- Five Wishes ([www.agingwithdignity.org](http://www.agingwithdignity.org))
- Giving Someone a Power of Attorney for Your Health Care: a Guide with an Easy-to-Use Legal Form for All Adults ([www.ambar.org/healthdecisions](http://www.ambar.org/healthdecisions))
- MyDirectives ([www.MyDirectives.com](http://www.MyDirectives.com))

## Conclusion

It is clear from the academic literature as well as clinical experience that advance care planning and the documentation of treatment preferences can significantly increase the likelihood that treatment at the end of life will follow an individual's personal preferences. No one single path exists for ensuring that desired outcome. The legal tools and protocols discussed in this brief are intended to supplement — not replace — honest communication among individuals, their loved ones and health care professionals. As Sabatino noted in closing his presentation: “The beating heart, as well as the Achilles heel, of any advance care planning document is the quality of the conversation behind it.”

## Endnotes

- 1 Sabatino C. 2010. “*The Evolution of Health Care Advance Planning Law and Policy.*” *The Milbank Quarterly*, 88(2): 211-239.
- 2 *Id.* at 213.
- 3 *Id.* at 215.
- 4 *Id.* at 216.
- 5 Institute of Medicine of the National Academies. 2014. *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life — Key Findings and Recommendations.* p. 1.
- 6 Teno JM, Gruneir A, Schwartz Z, Nanda A, and Wetle T. 2007. “Association Between Advance Directives and Quality End-of-Life Care: A National Study.” *Journal of the American Geriatrics Society*, 55(2): 189-94.
- 7 Fried TR, O’Leary J, Van Ness P, and Fraenkel L. 2007. “Inconsistency Over Time in the Preferences of Older Persons with Advanced Illness for Life-Sustaining Treatment.” *Journal of the American Geriatrics Society*, 55 (7): 1007-14.
- 8 Sabatino, C. 2014. “Advance Care Planning Tools that Educate, Engage and Empower.” *The Gerontological Society of America Public Policy and Aging Report*, 24: 107-111.
- 9 42 CFR Parts 405, 410, 411, 414, 425, 495 [CMS-1631-P] RIN 0938-AS40 *Medicare Program; Revisions To Payment Policies Under The Physician Fee Schedule And Other Revisions To Part B For CY 2016.* Published by Department Of Health And Human Services, Centers For Medicare & Medicaid Services on July 15, 2015. Available online at <http://Federalregister.Gov/A/2015-16875>.
- 10 Sabatino, *supra* note 1, at 228.
- 11 Shared decision making (SDM) is a collaborative process that allows patients and their providers to make health care decisions together, taking into account the best scientific evidence available, as well

as the patient's values and preferences. SDM is particularly important when it comes to preference-sensitive care, where there is more than one clinically appropriate treatment option for the condition, each with benefits and drawbacks, and in which the patient's values and preferences should be critical in determining the chosen intervention. The Informed Medical Decisions Foundation, *What is Shared Decision-Making* (2015). Available online at <http://www.informedmedicaldecisions.org/what-is-shared-decision-making/>. SDM is quite different from just saying "yes" or "no" to the treatment the doctor offers; it means a patient must take in more information, ask more questions, share more about themselves and take more time to sort through your options together. The American Cancer Society, *How is Shared Decision-Making Different from Informed Consent* (2015) . Available online at <http://www.cancer.org/treatment/findingandpayingfortreatment/understandingfinancialandlegal-matters/informedconsent/informed-consent-shared-decision-making>.

12 Id. at 229.

13 Id.

14 National Quality Forum, 2006. *A National Framework and Preferred Practices for Palliative and Hospice Care Quality: a Consensus Report*. p. 43.

15 Hickman SE, Sabatino CP, Moss AH, and Nester JW. 2008. "The POLST (Physician Orders for Life-Sustaining Treatment) Paradigm to Improve End-of-Life Care: Potential State Legal Barriers to Implementation." *Journal of Law, Medicine and Ethics*, 36: 119-140.

16 Id.

17 Sabatino, *supra* note 1, at 230.

# **CAMPAIGN TO END UNWANTED MEDICAL TREATMENT COLLABORATORS**

ABA Commission on Law and Aging  
Altarum Institute's Center for Elder Care and Advanced Illness  
Catholics in Alliance for the Common Good  
Center for Medicare Advocacy  
Compassion & Choices  
Consumer Coalition for Quality Health Care  
Elder Justice Coalition  
Medicare Rights Center  
National Academy of Elder Law Attorneys  
National Alliance for Caregiving  
National Association of State Long-Term Care Ombudsman Programs  
National Caucus and Center on Black Aging  
National Committee to Preserve Social Security and Medicare  
National Council on Aging  
National Hispanic Council on Aging  
OWL – The Voice of Midlife and Older Women  
The Gerontological Society of America  
The National Consumer Voice for Quality Long-Term Care  
Women's Institute for a Secure Retirement (WISER)



Care and Choice at the End of Life

NATIONAL  

---

ACADEMY  

---

OF • SOCIAL  

---

INSURANCE

[www.endumt.org](http://www.endumt.org)