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### Reimbursing Clinicians for Advance-Care-Planning Consultations: The Saga of a Healthcare Reform Provision

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# THE HEALTH LAWYER

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## REIMBURSING CLINICIANS FOR ADVANCE-CARE-PLANNING CONSULTATIONS: THE SAGA OF A HEALTHCARE REFORM PROVISION

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### Introduction

Advance care planning is part of good healthcare. Thus, paying clinicians to talk with patients about advance care planning makes sense: it enhances advance care planning and thereby serves to effect good healthcare. “If end-of-life discussions were an experimental drug,” writes Atul Gawande in his recent book, *Being Mortal*, “the FDA would approve it.”<sup>1</sup>

Yet efforts to provide for reimbursement to clinicians for time and attention given to advance-care-planning conversations with Medicare patients have been stymied since 2009 (at least until quite recently) by the politics of healthcare reform. It seems now that Medicare will move forward by relying on regulatory processes to offer reimbursement for this care. This will be an important development toward better healthcare for Medicare patients and could provide a model on

which other healthcare insurers, not already offering a similar reimbursement opportunity, might rely in creating comparable coverage plans.

An early House bill<sup>2</sup> in the process that led to the Patient Protection and Affordable Care Act (“PPACA”)<sup>3</sup> provided for Medicare’s paying for advance-care-planning consultations.<sup>4</sup> However, the implications of the provision were reshaped as part of the national debate about healthcare reform – itself part of a larger national debate about a slew of matters implicating personhood, family, and reproduction, as well as dying and death.<sup>5</sup> As a result, the provision was omitted from PPACA.

This article briefly describes state-law provisions for advance care planning. It then reviews the message put forth by a set of conservative voices in 2009, aimed at undermining the provision to pay clinicians for advance-care-planning consultations with Medicare patients. The article contextualizes that response within the ideological debate about “Obamacare” that shook the nation during the summer of 2009. It then examines efforts to revivify the deleted provision that had proposed reimbursing clinicians for

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advance-care-planning consultations with Medicare patients. It concludes by examining renewed efforts on the part of The Centers for Medicare & Medicaid Services (“CMS”) in 2014 and 2015 to reimburse clinicians for advance-care-planning consultations beginning in 2016.

## The Evolution of Advance Care Planning

States constructed a statutory framework for advance care planning in the last years of the twentieth century in response to a set of court cases that brought public attention to the need for such laws.<sup>6</sup> Judicial disputes about end-of-life care were occasioned by significant changes in life-sustaining treatment that became available after World War II. In particular, new methods for providing respiratory support developed in the 1960s<sup>7</sup> and percutaneous gastrostomy (“PEG”) tubes for feeding patients not able to swallow on their own, developed in 1979,<sup>8</sup> dramatically reshaped options for the care of dying and very ill patients as well as for those with disorders of consciousness (such as patients diagnosed as being in a persistent vegetative state).

In 1976 the New Jersey Supreme Court was the first highest state court to find a federal constitutional right for a patient (whether acting on his or her own or through a surrogate decision maker) to forego life-sustaining care.<sup>9</sup> And in 1990, in *Cruzan v. Director, Missouri Dep’t of Health*, a case involving a request by the parents of a young woman rendered persistently vegetative as the result of an automobile accident, the United States Supreme Court “assumed” that a competent adult had the right to refuse life-sustaining care.<sup>10</sup> Although *Cruzan* made little new law, and its “assumption” about the right of competent adults to refuse care was offered

by way of dicta, every state in the nation soon thereafter provided for competent adults to name a surrogate decision maker and to offer guidance to that surrogate should the patient be in need of medical decision making but incapable of making his or her own decisions.<sup>11</sup> In 1990, Congress passed the Patient Self-Determination Act, which requires hospitals that receive federal funds (including, by definition, all hospitals accepting Medicare patients) to honor advance directives and inform patients about the opportunity to complete them.<sup>12</sup>

The frame within which advance-care-planning laws were designed stemmed from the respect for autonomous individuality at the center of the informed consent doctrine.<sup>13</sup> For patients capable of making their own decisions, consent to or refusal of recommended care does not depend on mediators. In theory, competent patients are able to and do speak directly with clinicians about their medical situation and about possible medical responses to it and then to reach a decision about medical care in light of that information and any other relevant information. For patients without capacity, the law has presumed that surrogate decision makers, selected by the patient when capable or by the law,<sup>14</sup> stand in for the patient and provide for the respect owed patient autonomy.

This approach to advance care planning has worked less successfully than might have been hoped. Most adults do not complete advance directives, do not discuss their preferences with loved ones, and do not engage in open conversations with their clinicians about preferences should they face the need for medical decisions and lack the capacity to make medical choices.<sup>15</sup> As important, the existing legal frame that provides for advance care planning has not always eased the emotional burden on

patients’ family members and surrogates<sup>16</sup> or precluded disputes among them. In part this is the case because preferences for care delineated on advance-directive documents may not address the particular issues at stake for the patient when medical decisions are actually needed; they may provide for medical decisions that do not seem to family members to reflect the once-capable patient’s preferences; or they may not speak at all to the medical situation that has, in fact, developed and to the medical choices to which that situation gives rise.<sup>17</sup>

The problems so often created by prepared instructions, often too specific – or too broad – to be useful in responding to concrete situations, are significantly limited in cases in which the patient, while capable of making medical decisions, entered into honest, open communication with family members and clinicians about his or her preferences for medical care. Such conversations, although still unusual as a general matter, have become familiar in a few communities.

## Case Study: LaCrosse, Wisconsin

LaCrosse, Wisconsin provides a model for conversations between family members or surrogates and clinicians about one’s medical preferences should one lose capacity and be in need of medical care. The program in LaCrosse – “Respecting Choices” – grew out of the realization of a medical ethicist at the Gundersen Lutheran Health System in LaCrosse that advance care planning is part of patient care.<sup>18</sup> Before Respecting Choices, family members asked to make choices for relatives in a “health crisis” resembled people in most of the country; they had virtually no idea what their loved one would want.<sup>19</sup>

As a result of a community-wide effort to help people in LaCrosse

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consider their own choices and to discuss those choices with family members and clinicians, intensive care units (“ICUs”) in LaCrosse are now different from those almost everywhere else.<sup>20</sup> Patients in the ICU at Gundersen Lutheran are terribly ill, as are patients in virtually all ICUs. However, far fewer of them than is usually the case have been diagnosed with terminal conditions.<sup>21</sup> The patients are very sick, but if they survive the immediate threat to health, they are likely to recover. They will not be faced with the continuation of end-stage cancer, “untreatable heart failure or dementia.”<sup>22</sup> Generally, in LaCrosse, patients with those conditions do not choose to be treated in ICUs. This has followed the serious and widespread consideration given to advance care planning in LaCrosse. By the mid-1990s, the vast majority of people who died in LaCrosse had prepared advance directives. Most had asked not to receive life-sustaining care were they to become terminally ill and be without the capacity to make their own medical decisions. Interestingly, one consequence (though not the motivation) for Respecting Choices has been a significant reduction in the cost of end-of-life care in LaCrosse compared to other places in the nation.<sup>23</sup>

However, the conversations themselves are not inexpensive. They require considerable clinician time. The medical ethicist in LaCrosse who initiated the creation of Respecting Choices acknowledges that end-of-life conversations with patients are themselves costly.<sup>24</sup> However, the benefits exceed the costs. Some of those benefits may ultimately be financial.<sup>25</sup> Many others are not. Yet, they are of enormous value. When patients consider care preferences before they face a health crisis, their decisions are likely to be more carefully reasoned. The burden on family members is eased enormously by the knowledge that they

are making decisions in tune with what a loved one wanted. And clinicians are not pushed into aggressive care, which is generally the default position when a patient’s own preferences were never articulated.<sup>26</sup>

Some patients who transition earlier than others into hospice care can expect actually to live longer than those who do not choose hospice or who choose hospice only very shortly before death. In particular, research has shown that patients with lung cancer, congestive heart failure, and pancreatic cancer tend to live longer in hospice care than those who do not choose hospice.<sup>27</sup>

Gundersen Lutheran covers the costs of advance care planning conversations for its patients, but most health systems cannot or simply do not cover those costs. Thus, for the successes gained in LaCrosse to be generalized across the nation, insurers must cover the time that clinicians devote to conversations with patients about advance care planning.

## Pre-PPACA Responses to Legislative Provisions Proposing Payments for Advance-Care-Planning Consultations

An early House bill in the series of bills that culminated in PPACA provided for payments to clinicians for “consultations regarding orders for life sustaining treatment.”<sup>28</sup> Importantly in light of what followed, that bill was introduced in April 2009 by a bipartisan group of House representatives (three Democrats and three Republicans).<sup>29</sup> In July, 2009 much of the bill was included in a new bill, H.R. 3200.<sup>30</sup> The new bill included the provision (Section 1233) that provided for payments to practitioners (defined to include physicians, nurse practitioners or physician assistants)<sup>31</sup> for

consultations about advance care planning with Medicare recipients. It was transparent in the language of Section 1233 that its passage would not have resulted in rationing care to Medicare patients.<sup>32</sup> The Section described the substance of the consultations to include discussion of the advance care planning process, advance directives, healthcare proxies, end-of-life services (including palliative and hospice care), and life-sustaining orders.<sup>33</sup> Further, it provided for directing patients to national and state resources that would assist people in implementing advance care plans.<sup>34</sup> Clinicians could receive payment for such consultations with a patient no more than once every five years<sup>35</sup> unless the patient’s health condition changed significantly within the five-year period.<sup>36</sup>

Serious misinterpretation of the Section’s language and intentions rendered it a tool of healthcare reform opponents during the summer of 2009. Opponents claimed that the provision aimed to ration healthcare and even that it would result in the construction of death panels. In the same month (July 2009) that House leaders introduced House bill 3200,<sup>37</sup> Elizabeth McCaughey, a former New York State lieutenant governor and a commentator who opposed the health reform proposals of both the Clinton and the Obama administrations, declared during an interview on former Senator Fred Thompson’s radio show that the provision would “make it mandatory – absolutely require” that Medicare recipients receive advance care counselling.<sup>38</sup> That claim misrepresented the provision which would have enabled practitioners to be paid for such consultations no more often than once every five years. McCaughey continued, arguing:

[The] required counseling session that will tell them how to end their life sooner, how to decline

nutrition, how to decline being hydrated, how to go in to hospice care. And by the way, the bill expressly says that if you get sick somewhere in that five-year period—if you get a cancer diagnosis, for example—you have to go through that session again. All to do what’s in society’s best interest or your family’s best interest and cut your life short. These are such sacred issues of life and death. Government should have nothing to do with this.<sup>39</sup>

A month later, in August 2009, the 2008 Republican vice-presidential candidate Sarah Palin suggested in a Facebook posting that the provision would ration care for elderly, vulnerable people and would enable the creation of government-run “death panels.” Palin wrote:

The Democrats promise that a government health care system will reduce the cost of health care, but as the economist Thomas Sowell has pointed out, government health care will not reduce the cost; it will simply refuse to pay the cost. And who will suffer the most when they ration care? The sick, the elderly, and the disabled, of course. The America I know and love is not one in which my parents or my baby with Down Syndrome will have to stand in front of Obama’s “death panel” so his bureaucrats can decide, based on a subjective judgment of their “level of productivity in society,” whether they are worthy of health care. Such a system is downright evil.<sup>40</sup>

Palin soon elaborated on the post: Yesterday President Obama responded to my statement that Democratic health care proposals would lead to rationed care; that the sick, the elderly, and the disabled would suffer the most under such rationing; and that under such a system these “unproductive” members of society could face the

prospect of government bureaucrats determining whether they deserve health care.

The President made light of these concerns.<sup>41</sup>

A PolitiFact 2009 poll chose Palin’s death panel claim as the “lie of the year.”<sup>42</sup> Yet, voiced through social media, the claim had enormous ideological consequences for public attitudes toward healthcare reform. It appeared in news reports thousands of times (6,000 by one count)<sup>43</sup> during the summer of 2009. McCaughey’s and Palin’s claims were particularly ironic in that coverage for advance-care-planning consultations had bipartisan support in the spring of 2009 when the notion was first introduced in House Bill 1898.<sup>44</sup> Yet, by late 2009 when the Senate passed House Hill 3590 (PPACA), the coverage provision was not included.<sup>45</sup> And even in 2013, several years after promulgation of PPACA, 40 percent of the public and 35 percent of seniors believed that the law created government panels that would make end-of-life decisions for Medicare recipients.<sup>46</sup>

In 2010,<sup>47</sup> again in 2011<sup>48</sup> and again in 2013, Rep. Blumenauer (D-Ore.), who introduced House Bill 1898 in April 2009, introduced (and then re-introduced) a bill to the House that provided for payment to clinicians consulting with Medicare and Medicaid recipients about “voluntary advance care planning.”<sup>49</sup> The bill failed to pass in 2010, and as re-introduced in 2011 and in 2013.<sup>50</sup> These bills noted the following findings:

(5) Advance directives (such as living wills and durable powers of attorney for health care) must be prepared while individuals have the capacity to complete them and only apply to future medical circumstances when decision-making capacity is lost. An individual can change or revoke an advance directive at any time.

(7) Advance care planning should be routinely conducted in community and clinical practices. Care plans should be periodically revisited to reflect a person’s changes in values and perceptions at different stages and circumstances of life. This shared decisionmaking and collaborative planning between the patient (or proxy or surrogate) and the clinician of their choice will lead to more person-centered, culturally appropriate care.

(8) Effective, respectful, and culturally competent advance care planning requires recognition that both overtreatment and undertreatment may be concerns of individuals contemplating future care.

(10) Studies funded by the Agency for Healthcare Research and Quality have shown that individuals who talked with their families or physicians about their preferences for care had less fear and anxiety, felt they had more ability to influence and direct their medical care, believed that their physicians had a better understanding of their wishes, and indicated a greater understanding and comfort level than they had before the discussion. Patients who had advance planning discussions with their physicians continued to discuss and talk about these concerns with their families. Such discussions enabled patients and families to reconcile any differences about care and could help the family and physician come to agreement if they should need to make decisions for the patient.<sup>51</sup>

In late 2014, Senator Blumenthal (D-Conn.) introduced a similar bill in the Senate, Senate bill 3009 (“Advance Planning and Compassionate Care Act of 2014”). The bill proposed paying clinicians for advance-care-planning consultation. It was referred to the Senate Finance Committee, but no vote was taken.<sup>52</sup>

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In sum, PPACA was promulgated without providing for advance-care-planning coverage for the clinicians of Medicare recipients. Further, Congress has not passed post-PPACA bills aimed at reviving the provision.

## Private Payors

However, in the period since PPACA's promulgation, some private insurers (including Excellus Blue Cross Blue Shield of New York), not beholden to political processes as directly as Medicare is, began to offer such coverage.<sup>53</sup> Generally the insurance industry's billing codes reflect Medicare's codes. However, in the event that insurance companies begin to cover services not covered by Medicare, the industry may develop its own codes. That has happened with regard to advance care planning.<sup>54</sup> And in at least two states (Oregon and Colorado), Medicaid now covers consultations about advance care planning.<sup>55</sup>

## Relying on the Regulatory Process

Further, during the years since passage of PPACA, two attempts (one in 2014 and another in 2015) have been made to rely on the regulatory process to provide for coverage through CMS for advance-care-planning consultations. In 2014, as noted below, CMS decided not to finalize implementation of the codes. The 2015 proposal is now under consideration.

More specifically, in 2014, almost five years after the promulgation of PPACA, the American Medical Association ("AMA") proposed that CMS implement a reimbursement provision through the regulatory process that would have reimbursed physicians for consulting with Medicare patients about advance care planning.<sup>56</sup> The suggestion was not

unusual; CMS routinely relies on the AMA recommendations in deciding about physician reimbursement codes for the next year.<sup>57</sup> Apparently, the immediate stimulus for the recommendation of the AMA regarding advance care planning came from the Illinois State Medical Society, which asked the AMA to create medical codes specific to advance-care-planning consultations.<sup>58</sup> The AMA created two billing codes. One of the codes (99497) was designed to reimburse practitioners for 30 minutes of consultation with patients, surrogate decision makers or family members about advance care planning, including consideration of "standard" advance directive forms.<sup>59</sup> The proposal requires face-to-face interaction but need not include the patient.<sup>60</sup> The second code (99498) pays for an additional 30 minutes of consultation when needed.<sup>61</sup> CMS did not agree to reimburse practitioners for either billing code<sup>62</sup> proposed for implementation in 2015. It explained that it wanted to offer the public a longer period within which to respond to the proposed codes.<sup>63</sup>

A year later, in May 2015, CMS again proposed paying for such consultations. This followed submission of a letter, signed by over 60 organizations, including the AMA, The American Association of Retired Persons, and the American Nurses Association, sent to Secretary of Health and Human Services Sylvia Mathews Burwell.<sup>64</sup> The letter urged reimbursement by Medicare through use of the two billing codes created by the AMA to allow compensation for advance-care-planning consultations (to begin in 2016). The signatories explained to the Secretary:

Complex ACP [advance care planning] involves one or more meeting(s), lasting 30 minutes or more, during which the patient's values and preferences are

discussed and documented, and used to guide decisions regarding future care for serious illnesses. These consultations are voluntary on the part of the patient and the patient's preferences are paramount. The patient may choose to include his/her family, caregiver (if applicable) in the decision making process.

Published, peer-reviewed research shows that ACP leads to better care, higher patient and family satisfaction, fewer unwanted hospitalizations, and lower rates of caregiver distress, depression and lost productivity. ACP is particularly important for Medicare beneficiaries because many have multiple chronic illnesses, receive care at home from family and other caregivers, and their children and other family members are often involved in making medical decisions.<sup>65</sup>

In July 2015, CMS accepted the recommendation and opened the proposal to a two-month comment period in its proposed physician payment schedule for 2016:<sup>66</sup>

Consistent with recommendations from the American Medical Association (AMA) and a wide array of stakeholders, CMS proposes to establish separate payment and a payment rate for two advance care planning services provided to Medicare beneficiaries by physicians and other practitioners. ... Establishing separate payment for advance care planning codes provides beneficiaries and practitioners [sic] greater opportunity and flexibility to utilize these planning sessions at the most appropriate time for patients and their families.

The AMA Current Procedural Terminology (CPT) Editorial Panel and the AMA Relative Value Update Committee (RUC) recommended new CPT codes

and associated payment amounts for calendar year 2015. CMS did not make the new codes payable for 2015 in order to allow the public full opportunity to comment on whether Medicare should pay separately for these services and, if so, how much beginning January 1, 2016.<sup>67</sup>

If the proposed rule is accepted by CMS, payments for advance-care-planning consultations are slated to begin in early January 2016.<sup>68</sup>

## Implications and Conclusion

Reimbursing practitioners (including physicians, nurse practitioners, and physician assistants) for these consultations will further goals delineated by the Institute of Medicine in its 2014 report on “Dying in America.”<sup>69</sup> It will increase the likelihood that healthcare and related social services will harmonize “with a person’s values, goals, informed preferences, condition, circumstances, and needs.”<sup>70</sup> However, the codes, as currently constructed, are limited. They do not, for instance, reimburse practitioners for advance-care-planning consultations sought “at the beneficiary’s discretion” or during the “annual wellness visit.”<sup>71</sup>

It seems likely that reimbursement for advance-care-planning consultation will be available to practitioners in 2016. Should the use of these codes prove beneficial to patients, family members, surrogate decision makers and clinicians, the gaps that remain (e.g., the availability of consultation reimbursement for conversations initiated by patients at their discretion) may be filled over time. In the meantime, the narrative that links section 1233 of House Bill 3200 with the newest Medicare reimbursement proposal reveals much about the flexibility of the law in responding to controversial public policy issues. Initially, inclusion of reimbursement for end-of-life conversations seemed a valuable component in legislation aimed at

reforming the nation’s healthcare system. Fierce public opposition to the reimbursement provision (largely grounded on a serious misunderstanding of its implications) resulted in the provision’s being deleted from subsequent bills and from PPACA. Later, clarification of the issues encouraged a variety of groups, especially professional organizations such as the AMA, to seek alternative means for effecting the reimbursement opportunity. It seems likely that this will soon have been accomplished through reliance on CMS’s authority to define reimbursement for clinicians treating Medicare recipients. The process as a whole illustrates the legal evolution of an idea and its implementation.



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## Endnotes

- 1 Atul Gawande, *Being Mortal* 178 (2015). Atul Gawande is a surgeon in Boston and a staff writer for the *New Yorker*. He has authored several popular books about the delivery and scope of healthcare in the United States.
- 2 See *infra* note 45 (noting complicated legislative process that preceded passage of the Patient Protection and Affordable Care Act).

- 3 Patient Protection and Affordable Care Act, Pub. L. 111-148, 124 Stat. (2010).
- 4 America’s Affordable Health Choices Act of 2009, H.R. 3200, Sec. 1233, 111th Cong. (2009).
- 5 See, e.g., Stephen L. Carter, *God’s Name in Vain: The Wrongs and Rights of Religion in Politics* 205 n.13 (2000) (citing James Davison Hunter, *Culture Wars: The Struggle to Define America* 34 (1991)). Carter opines that whether there has been a “culture war” or not, many Americans “with traditional views on matters of sex and family life, as well as the very nature of authority” have felt marginal to “the mosaic of contemporary America.” *Id.* at 44.
- 6 See, e.g., *Cruzan v. Director, Missouri Dep’t of Health*, 497 U.S. 261 (1990); *In re Conroy*, 98 N.J. 321, 359, 362; 486 A.2d 1209, 1228-29, 1230 (1985); *In re O’Connor*, 72 N.Y. 2d 517, 531 N.E.2d 607 (1988); *In the Matter of Quinlan*, 70 N.J. 10, 355 A.2d 647, *cert. denied*, 429 U.S. 922 (SCNJ 1976).
- 7 John J. Marini, *Mechanical Ventilation: Past Lessons and the Near Future*, 17 *Critical Care S1* (Suppl.) (2013), available at [www.ccforum.com/content/17/S1/S1](http://www.ccforum.com/content/17/S1/S1).
- 8 Sylvia Kuo et al., *Natural History of Feeding Tube Use in Nursing Home Residents with Advanced Dementia*, 10 *J. Am. Med. Dir. Assoc.* 264, available at [www.ncbi.nlm.nih.gov/pmc/articles/PMC2733212/](http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2733212/) (last visited June 16, 2015).
- 9 *Quinlan*, 70 N.J. 10, 40, 355 A.2d 647, 663.
- 10 *Cruzan*, 497 U.S. at 242 (“assum[ing] that the United States Constitution would grant a competent person a constitutionally protected right to refuse lifesaving hydration and nutrition”). In *Cruzan* the Court upheld Missouri’s “clear and convincing” evidence standard that required a surrogate decision maker to prove by clear and convincing evidence that the patient would have wished to have care withdrawn before being permitted to authorize the withdrawal of care from an incompetent patient.
- 11 See Barbara Noah, *In Denial: The Role of Law in Preparing for Death*, 21 *Elder L.J.* 1, 8 n.21 (2013); Norman Cantor, *Twenty-five Years After Quinlan: A Review of the Jurisprudence of Death and Dying*, 29 *J.L. Med. & Ethics* 182, 189 (2001).
- 12 Patient Self-Determination Act of 1990 (Omnibus Budget Reconciliation Act, 1990), Pub. L. No. 101-508 Sec. 4206, 104 Stat. 1388 (codified as amended in scattered sections of 42 U.S.C.). The Act became effective in 1991.
- 13 See, e.g., *Canterbury v. Spence*, 464 F.2d 772 (D.C. Cir. 1972) (grounding informed consent doctrine on respect for patient autonomy).
- 14 See, e.g., Uniform Health-Care Decisions Act (Uniform Law Commission 1993), available at [www.uniformlaws.org/Act.aspx?title=Health-Care%20Decisions%20Act](http://www.uniformlaws.org/Act.aspx?title=Health-Care%20Decisions%20Act) (last visited July 27, 2015). The Uniform Health-Care Decisions Act delineates surrogate decision makers, in order of priority, for patients without capacity who are in need of medical decisions and who did not identify a surrogate decision maker while still capable.
- 15 Institute of Medicine, *Committee on Approaching Death, Dying in America: Improving Quality and Honoring Individual*

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# Reimbursing Clinicians for Advance-Care-Planning Consultations

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- Preferences Near the End of Life p. 3-7 & 3-8 (2014) (reporting that “most people” in the U.S. have “no documentation” regarding their preferences for end-of-life care) (hereinafter “Dying in America”). There are many organizations that have been developed or are being developed that aim to educate people about advance care planning and to encourage people to consider completing advance directives. See, e.g., National Healthcare Decisions Day, available at [www.nhdd.org/#welcome](http://www.nhdd.org/#welcome) (last visited Aug. 26, 2015). See also Nathan Kottkamp, *The Importance of Advance Health Planning for Your Clients and Yourself*, 9(7) *ABA Health eSource* (Mar. 2013), available at [www.americanbar.org/content/newsletter/publications/aba\\_health\\_esource\\_home/aba\\_health\\_law\\_esource\\_1303\\_kottkamp.html](http://www.americanbar.org/content/newsletter/publications/aba_health_esource_home/aba_health_law_esource_1303_kottkamp.html).
- 16 The term “family members,” as used here, should be understood to include loved ones and good friends of a patient who may not all be legally defined as “family.”
- 17 Noah, *supra* note 11, at 7.
- 18 Joseph Shapiro, *Why This Wisconsin City Is the Best Place to Die*, NPR, Nov. 16, 2009, available at [www.npr.org/templates/story/story.php?storyId=120346411](http://www.npr.org/templates/story/story.php?storyId=120346411).
- 19 Shapiro, *supra*, note 18.
- 20 Gawande, *supra* note 1, at 178-79.
- 21 Gawande, *supra* note 1, at 179.
- 22 Gawande, *supra* note 1, at 179.
- 23 Gawande, *supra* note 1, at 179-180.
- 24 Shapiro, *supra* note 18. The cost, noted the medical ethicist, is built into the hospital’s overhead. But not all hospitals can do that. This would seem to reflect the commitment in LaCrosse and by its hospital system to advance care planning.
- 25 The cost of care for patients at Gundersen Lutheran in LaCrosse in the last two years of life is significantly less than the nation’s average cost (\$18,000 versus \$26,000 in one year, as documented by the Dartmouth Atlas of Health Care). Shapiro, *supra* note 18. This likely follows from the tendency in the United States to understand aggressive treatment for terminal patients as the default response. It seems as if the difference in the cost of care in LaCrosse and elsewhere can be attributed to the far more extensive preparation for end-of-life care in LaCrosse than elsewhere (where the default response that involves aggressive care until death happens more often).
- 26 Dean Reynolds, *Being Prepared for the Final Days*, CBS News, April 25, 2014, [www.cbsnews.com/news/being-prepared-for-the-final-days/](http://www.cbsnews.com/news/being-prepared-for-the-final-days/); Shapiro, *supra* note 18.
- 27 Gawande, *supra* note 1 at 178. Gawande notes that for patients with “breast cancer, prostate cancer, or colon cancer survival times seemed not to vary for those in hospice care and those not in hospice.” *Id.*
- Interestingly, CMS has announced a limited program that will allow terminally ill patients to receive hospice care and curative treatment at the same time. The program is slated to start in 2016 with 140 hospice providers. The program will operate within the Medicare Care Choices Model. CMS describes the Medicare Care Choices Model as offering “a new option for Medicare beneficiaries to receive palliative care services from certain hospice providers while concurrently receiving services provided by their curative care providers.” Centers for Medicare & Medicaid Services, Medicare Care Choices Model, available at [www.innovation.cms.gov/initiatives/Medicare-Care-Choices/](http://www.innovation.cms.gov/initiatives/Medicare-Care-Choices/) (last visited Aug. 27, 2015). The program will be assessed on the basis of patient satisfaction, level of care, and costs. Also, the number of patients who go into hospice care if curative treatments are also available will be assessed against numbers choosing hospice care more generally. Melanie Evans, CMS to Test Concurrent Coverage of Hospice And Curative Care, *Modern Healthcare*, July 20, 2015, available at [www.modernhealthcare.com/article/20150720/NEWS/150729994?utm\\_source=modernhealthcare&utm\\_medium=email&utm\\_content=externalURL&utm\\_campaign=am](http://www.modernhealthcare.com/article/20150720/NEWS/150729994?utm_source=modernhealthcare&utm_medium=email&utm_content=externalURL&utm_campaign=am) (last visited Aug. 5, 2015).
- 28 H.R. 3200, Sec. 1233, 111th Cong. (2009).
- 29 H.R. 1898, 111th Cong. (2009). The bill was introduced by Earl Blumenauer (D-Ore.), for himself and Charles Boustany (R-La.), Geoff Davis (R-Ky.), Ron Kind (D-Wis.), Patrick Tiberi (R-Oh.) and John Yarmouth (D-Ky.). The text of the bill is available at <https://congress.gov/bill/111th-congress/house-bill/1898/text>.
- 30 H.R. 3200, Sec. 1233, 111th Cong. (2009).
- 31 House bill 3200, Sec. 1233(a)(2)(A)-(B), 111th Cong. (2009).
- 32 America’s Affordable Health Choices Act of 2009, H.R. 3200, Sec. 1233, 111th Cong. (2009), available at [www.compassionandsupport.org/pdfs/about/HR\\_3200\\_pages\\_424\\_434.pdf](http://www.compassionandsupport.org/pdfs/about/HR_3200_pages_424_434.pdf). Section 1233 described an advance-care-planning consultation to include:
- “(A) An explanation by the practitioner of advance care planning, including key questions and considerations, important steps, and suggested people to talk to. (B) An explanation by the practitioner of advance directives, including living wills and durable powers of attorney, and their uses. (C) An explanation by the practitioner of the role and responsibilities of a health care proxy. (D) The provision by the practitioner of a list of national and State-specific resources to assist consumers and their families with advance care planning, including the national toll-free hotline, the advance care planning clearinghouses, and State legal service organizations (including those funded through the Older Americans Act of 1965). (E) An explanation by the practitioner of the continuum of end-of-life services and supports available, including palliative care and hospice, and benefits for such services and supports that are available under this title. ...” *Id.*
- 33 The Section defined an “order regarding life sustaining treatment” to mean:
- “an actionable medical order relating to the treatment of [an] individual that –
- is signed and dated by a physician ... or another health care professional ... and is in a form that permits it to stay with the individual and be followed by health care professionals and providers across the continuum of care;
  - effectively communicates the individual’s preferences regarding life sustaining treatment, including an indication of the treatment and care desired by the individual;
  - is uniquely identifiable and standardized within a given locality, region, or State ...; and
  - may incorporate any advance directive ... if executed by the individual.”
- House bill 3200, Sec. 1233(a)(2)(5)(A)(i)-(iv), 111th Cong. (2009).
- 34 House bill 3200, Sec. 1233(a)(A)-(F), 111th Cong. (2009).
- 35 *Id.* at Sec. 1233 (a)(1)(hhh)(1).
- 36 The provision defined a “significant change in the health condition of the individual” to include “diagnosis of a chronic, progressive, life-limiting disease, a life-threatening or terminal diagnosis or life-threatening injury, or upon admission to a skilled nursing facility, a long-term care facility (as defined by the Secretary), or a hospice program.” *Id.* at Sec. 1233 (a)(3)(B).
- 37 John Cannan, *A Legislative History of the Affordable Care Act: How Legislative Procedure Shapes Legislative History*, 105 *L. Libr. J.* 131, 137-38 (2013).
- 38 Fred Thompson, Betsy McCaughey Interview, July 16, 2009 (uploaded to YouTube Jul. 27, 2009), <https://youtube.com/watch?v=89hpyOljiGk>. Angie Drobnic Holan, *PolitiFact’s Lie of the Year: ‘Death Panels’*, Tampa Bay Times, *PolitiFact.com*, Dec. 18, 2009, [www.politifact.com/truth-o-meter/article/2009/dec/18/politifact-lie-year-death-panels/](http://www.politifact.com/truth-o-meter/article/2009/dec/18/politifact-lie-year-death-panels/). See also Brendan Nyhan, *Why the ‘Death Panel’ Myth Wouldn’t Die: Misinformation in the Health Care Reform Debate*, 8 *The Forum* (2010), at p. 10, [www.bepress.com/forum/vol8/iss1/art5](http://www.bepress.com/forum/vol8/iss1/art5) (citing Elizabeth McCaughey, *The Kudlow Report*, CNBC, June 15, 2009).
- 39 Fred Thompson, Betsy McCaughey Interview, July 16, 2009 (uploaded to YouTube Jul. 27, 2009), <https://youtube.com/watch?v=89hpyOljiGk>. Holan, *supra* note 38.
- 2009, [www.politifact.com/truth-o-meter/article/2009/dec/18/politifact-lie-year-death-panels/](http://www.politifact.com/truth-o-meter/article/2009/dec/18/politifact-lie-year-death-panels/). Nyhan, *supra* note 38, at p. 10.
- 40 Sarah Palin, *Statement on the Current Health Care Debate* (Aug. 7, 2009), <https://facebook.com/notes/sarah-palin/statement-on-the-current-health-care-debate/113851103434> (last visited June 5, 2015).
- 41 Sarah Palin, *Concerning the “Death Panels,”* (Aug. 12, 2009), [https://facebook.com/note.php?note\\_id=116471698434](https://facebook.com/note.php?note_id=116471698434) (last visited June 5, 2015).
- 42 Holan, *supra* note 38. *PolitiFact* reports on the assessment of putative facts for the St.

*Petersburg Times*. *Id.* PolitiFact polled about 5,000 readers, more than 60% of whom chose the Palin “death panel” claim as the “lie” of 2009.

- 43 Holan, *supra* note 38.
- 44 H.R. 1898, 111th Cong. (2009). This bill was co-sponsored by three Republicans and three Democrats. Joshua E. Perry, A Missed Opportunity: Health Care Reform, Rhetoric, Ethics and Economics at the End of Life, 29 *Miss. C.L. Rev.* 409, 413 (2010).
- 45 House bill 3590 (PPACA) was passed by the Senate on Dec. 24, 2009. House bill 4872 (Health Care and Education Affordability Reconciliation Act of 2010), was passed soon thereafter. The latter bill was separate from House bill 3590 and was passed through the reconciliation process which precluded the need for 60 votes in the Senate. H.R. 4872, 111th Cong. (2010) (became Pub. L. No. 111-152, 124 Stat. 1029). The bills omitted any reference to Medicare’s covering advance-care-planning consultations.
- The legal history of the multiple healthcare reform bills that preceded passage of PPACA is extraordinarily complicated. In his excellent review of this legislative history, John Cannan reports that Senator Majority Leader Harry Reid (D-Nev.) referred House bill 3590 (the “Service Members Home Ownership Tax Act of 2009”) to the Senate because it was “obsolete” by that time, its provisions having already been incorporated into another law. This, in Reid’s view, allowed it to be treated as a “non-controversial” choice for amendment between the houses. Its text was “struck and replaced with the Reid health-care proposal, Sen. Amendment 2786.” Cannan, *supra* note 37, at 152-53.
- 46 Kaiser Family Foundation, Kaiser Health Tracking Poll: March 2013 (Mar. 20, 2013), available at <http://kff.org/health-reform/poll-finding/march-2013-trackingpoll/> (of the group remaining, over one-fifth reported not being sure whether the law created “death panels”).
- 47 “Personalize Your Care Act of 2010, H.R. 5795, 111th Cong. (2010), available at <https://govtrack.us/congress/bills/111/hr5795>.
- 48 “Personalize Your Care Act of 2011,” H.R. 1589, 112th Cong. (2011), available at <https://govtrack.us/congress/bills/112/hr1589/text>.
- 49 “Personalize Your Care Act of 2013,” H.R. 1173, 113th Cong. (2013), available at <https://govtrack.us/congress/bills/113/hr1173>. The full title of the bill was: “To amend the Social Security Act to provide for coverage of voluntary advance care planning consultation under Medicare and Medicaid, and for other purposes.” *Id.*
- 50 The 2013 bill, H.R. 1173, had 51 Democratic sponsors and eight Republican sponsors. H.R. 1173, 113 Cong. (2013). The 2010 bill was sponsored only by Democrats, <https://govtrack.us/congress/bills/111/hr5795>, and the 2011 bill was sponsored by 10 Democrats and one Republican, <https://govtrack.us/congress/bills/112/hr1589>.
- 51 H.R. 1173, 113th Cong. (2013), available at <https://govtrack.us/congress/bills/113/hr1173>
- text. The Agency for Healthcare Research and Quality (“AHRQ”), part of the U.S. Department of Health and Human Services, aims to “produce evidence to make health care safer, higher quality, more accessible, equitable, and affordable, and to work within the U.S. Department of Health and Human Services and with other partners to make sure that the evidence is understood and used.” AHRQ, Mission and Budget, available at [www.ahrq.gov/cpi/about/mission/index.html](http://www.ahrq.gov/cpi/about/mission/index.html) (last visited August 26, 2015).
- 52 S. 3009, Subtitle B, Pt I, Sec. 211, 113th Cong. (2014), available at <https://govtrack.us/congress/bills/113/s3009/text>. S. 3009 (“Advance Planning and Compassionate Care Act of 2014”) was introduced by Senator Blumenthal for himself and for Senator Rockefeller (D-W.Va.). See also <https://govtrack.us/congress/bills/113/s3009> and [https://govtrack.us/congress/bills/browse#congress=113&text=Advance+Planning+and+Compassionate+Care&current\\_status\[\]=2&bill\\_type\[\]=2](https://govtrack.us/congress/bills/browse#congress=113&text=Advance+Planning+and+Compassionate+Care&current_status[]=2&bill_type[]=2) (noting the bill’s having been referred to Senate Finance Committee).
- 53 Life Matters Media, Advance Care Planning: Medicare Declines to Reimburse Physicians for End of Life Discussions in 2015, Dec. 9, 2014, available at [www.lifemattersmedia.org/2014/12/medicare-declines-reimburse-physicians-end-life-discussions-2015/](http://www.lifemattersmedia.org/2014/12/medicare-declines-reimburse-physicians-end-life-discussions-2015/); Michael Ollove, Doctors May Get Paid for End-of-Life Planning, *U.S.A. Today*, June 4, 2014, available at [www.usatoday.com/story/news/nation/2014/06/02/stateline-end-of-life/9867615](http://www.usatoday.com/story/news/nation/2014/06/02/stateline-end-of-life/9867615).
- 54 Pam Belluck, Coverage for End-of-Life Talks Gaining Ground, *N.Y. Times*, Aug. 30, 2014, available [www.nytimes.com/2014/08/31/health/end-of-life-talks-may-finally-overcome-politics.html?\\_r=0](http://www.nytimes.com/2014/08/31/health/end-of-life-talks-may-finally-overcome-politics.html?_r=0). Blue Cross Blue Shield of Michigan is reported to have been paying \$35 per conversation (for phone or in-person advance-care-planning consultations). *Id.* In 2014, Excellus Blue Cross Blue Shield of New York was reported to pay \$150 for a consultation that lasts an hour. *Id.*
- 55 Pam Belluck, *supra* note 54. In May 2015, several Democrats in the New Jersey Assembly sponsored legislation (A-4233) to provide coverage for advance care planning consultations for Medicaid recipients in the state. Targeted News Service, Jasey, McKeon, Vainieri, Huttle & Mukerji, Bill to Provide Medicaid Coverage for Advance Care Planning Clears Panel, Targeted News Service, May 8, 2015, available in Lexis, News, [www.lexis.com](http://www.lexis.com).
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- 57 Ollove, *supra* note 53. The AMA’s Current Procedural Terminology Editorial Board proposes “medical nomenclature used to report medical procedures and services under public and private health insurance programs. AMA, About CPT, available at [www.ama-assn.org/ama/pub/physician-resources/solutions-managing-your-practice/coding-billing-insurance/cpt/about-cpt.page](http://www.ama-assn.org/ama/pub/physician-resources/solutions-managing-your-practice/coding-billing-insurance/cpt/about-cpt.page) (last visited Aug. 10, 2015).
- 58 Ollove, *supra* note 57.
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- 61 *Id.*
- 62 Thomas Harter, What Kind of Advance Care Planning Should CMS Pay For?, Health Affairs Blog, Mar. 19, 2015, available at <http://healthaffairs.org/blog/2015/03/19/what-kind-of-advance-care-planning-should-cms-pay-for/>.
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- 65 Letter to Burwell, May 12, 2015, *supra* note 64.
- 66 The comment period closed on Sept. 8, 2015. CMS.gov, Centers for Medicare & Medicaid Services, Proposed Policy, Payment, and Quality Provisions Changes to the Medicare Physician Fee Schedule for Calendar Year 2016 (July 8, 2015), <https://cms.gov/Newsroom/MediaReleaseDatabase/Fact-sheets/2015-Fact-sheets-items/2015-07-08.html> (last visited Aug. 4, 2015).
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- 69 Dying in America, *supra* note 15.
- 70 Dying in America, *supra* note 15, at p. 5-52.
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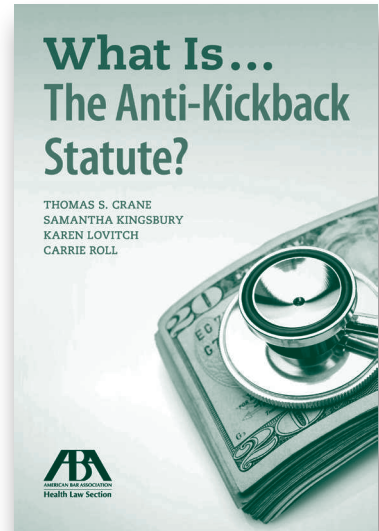
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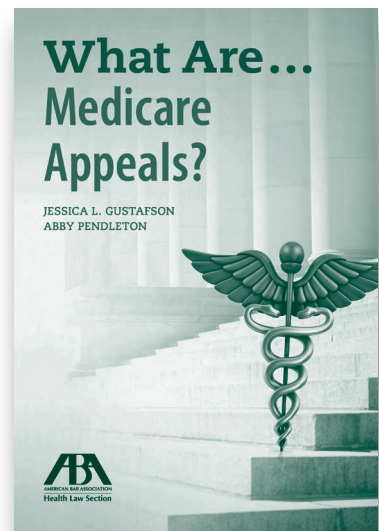
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