

July 2015 (Update) | Fact Sheet

## 10 FAQs: Medicare’s Role in End-of-Life Care

About three-quarters of the 2.5 million people who die during the year in the US are ages 65 and older, making Medicare the largest insurer of health care provided during the last year of life.<sup>1</sup> In fact, roughly one-quarter of traditional Medicare spending for health care is for services provided to Medicare beneficiaries in their last year of life—a proportion that has remained steady for decades.<sup>2</sup> The high overall cost for health care received in the last year of life is not surprising given that many who die have multiple serious and complex conditions.

Aside from cost, several other factors contribute to difficult clinical and policy discussions about whether patients are getting the care they want or need as they approach the end of their lives. Research has found, for example, that most adults (90 percent) say they would prefer to receive end-of-life care in their home if they were terminally ill, yet data show that only about one-third of Medicare beneficiaries (age 65 and older) died at home.<sup>3</sup>

In recent years, Medicare’s role with respect to end-of-life care has come to the forefront as policymakers and the Administration grapple with whether or not physicians and other health professionals should be reimbursed for talking to patients about their options. Policy discussions on this topic are not easy, and perhaps even more challenging following the highly politicized allegations of “death panels” that followed the enactment of the ACA.<sup>4</sup>

The following 10 FAQs provide information on Medicare’s current role in end-of-life care and advance care planning. In addition to defining relevant terms, and explaining Medicare coverage for end-of-life care, these FAQs also describe policy proposals being considered by the Administration and Congress regarding advance care planning and care for people with serious and terminal illness.

### **Q1: WHAT IS “END-OF-LIFE CARE” AND DOES MEDICARE COVER IT?**

**A:** End-of-life care encompasses all health care provided to someone in the days or years before death, whether the cause of death is sudden or a result of a terminal illness that runs a much longer course. For people ages 65 and over, the most common causes of death include cancer, cardiovascular disease, and chronic respiratory diseases.<sup>5</sup> Medicare covers a comprehensive set of health care services that beneficiaries are eligible to receive up until their death. These services include care in hospitals and several other settings, home health care, physician services, diagnostic tests, and prescription drug coverage through a separate Medicare benefit. Many of these Medicare-covered services may be used for either curative or palliative (symptom relief) purposes, or both. Medicare beneficiaries with a terminal illness are eligible for the Medicare hospice benefit that includes additional services—not otherwise covered under traditional Medicare—such as bereavement services. The Medicare hospice benefit is discussed in more detail in Question 5.

## Q2: WHAT IS “ADVANCE CARE PLANNING” AND DOES MEDICARE COVER IT?

A: Advance care planning involves multiple steps designed to help individuals a) learn about the health care options that are available for end-of-life care; b) determine which types of care best fit their personal wishes; and c) share their wishes with family, friends, and their physicians. In some cases, patients who have already considered their options may need only one advance care planning conversation with their physician. However, experts state that frequently, beneficiaries may require a series of conversations with their physician or other health professionals to clearly understand and define their end-of-life wishes.<sup>6</sup>

Under current law and regulation, Medicare only covers advance care planning under limited circumstances. Neither physicians nor beneficiaries may seek reimbursement from Medicare for advance care planning if those discussions are the sole purpose of the visit.<sup>7</sup> Instead, to be covered under Medicare, these discussions must occur either when they are part of appointments made for other reasons (such as illness or injury) or during the one-time “Welcome to Medicare” visit that may occur within a beneficiary’s first 12 months of Medicare enrollment.<sup>8</sup> Previously, the agency that runs Medicare—the Centers for Medicare and Medicaid Services (CMS)—included advance care planning as a voluntary part of the ACA-established *annual* wellness visit in Medicare, but retracted this provision before it could take effect in January of 2011. CMS explained that it retracted this provision because the agency did not have ample “opportunity to consider prior to the issuance of the final rule the wide range of views on this subject held by a broad range of stakeholders.”<sup>9</sup>

## Q3: ARE POLICYMAKERS, SUCH AS CMS OR CONGRESS, CONSIDERING CHANGES IN MEDICARE’S COVERAGE OF ADVANCE CARE PLANNING?

A: Yes. CMS is proposing that Medicare begin paying physicians and other qualified health care professionals for advance care planning as a separate service.<sup>10</sup> Specifically, in a proposed regulation released July 8, 2015, CMS introduced two new billing codes—previously recommended by the American Medical Association—for advance care planning provided to Medicare beneficiaries. These new billing codes would be available to physicians and other qualified health professionals starting January 1, 2016. CMS is seeking public comment on these proposed regulations through September 8, 2015. A final determination is expected in the Fall of 2015, with CMS’s release of the final rule for the 2016 Medicare physician fee schedule.

In Congress, two bipartisan bills pertaining to advance directives and end-of-life care have been recently introduced—one in the Senate and one in the House. In the Senate, Sen. Mark Warner and Sen. Johnny Isakson introduced the Care Planning Act of 2015 (S.1549), with other cosponsors.<sup>11</sup> This legislation would provide coverage under Medicare for advanced illness planning and care coordination services, including structured discussions about treatment options and patient preferences, to Medicare beneficiaries who have a serious progressive or life-threatening illness. In the House, Rep. Earl Blumenauer and 59 cosponsors introduced the Personalize Your Care Act of 2013 (H.R.1173).<sup>12</sup> This legislation would establish Medicare and Medicaid coverage for advance care planning consultations between patients and doctors or other health care professionals.

## **Q4: WHAT ARE “ADVANCE DIRECTIVES”? ARE HEALTH CARE FACILITIES, SUCH AS HOSPITALS OR SKILLED NURSING FACILITIES, REQUIRED TO KEEP RECORDS OF MEDICARE PATIENTS’ ADVANCE DIRECTIVES?**

A: Advance directives are written instructions that are intended to reflect a patient’s wishes for health care to guide medical decision-making in the event that a patient is unable to speak for her/himself. Advance directives typically result from advance care planning and often take the form of a living will, which defines the medical treatment that patients prefer if they are incapacitated, or designation of a certain person as a medical power of attorney.<sup>13</sup> Advance directives fall under state regulation, and the required forms for formal advance directives vary from state to state.<sup>14</sup>

Studies have found that about 4 in 10 Americans ages 65 and older do not have advanced directives or have not written down their own wishes for end-of-life medical treatment.<sup>15</sup> Additionally, demographic differences appear to play a role in the likelihood of having advanced directives.<sup>16</sup> Specifically, African Americans and Hispanics have advance directives at lower rates compared to whites, as do people with lower incomes and lower levels of completed education.<sup>17</sup> Researchers have identified several factors that contribute to these differences, including cultural and religious differences, communication challenges between patients and medical staff, distrust of medical care systems, and awareness of advance directive options.<sup>18</sup>

The Patient Self-Determination Act, which took effect in 1991, included a list of Medicare requirements for health care facilities regarding advance directives. Under this law, facilities such as hospitals and skilled nursing facilities must ask each patient upon admission if he or she has an advance directive and record its existence in the patient’s file.<sup>19</sup> Facilities cannot require any patient to create an advance directive before providing treatment or care, and likewise, Medicare patients are not required to have an advance directive before they receive care.<sup>20</sup> Recent surveys show that among long-term care patients, those receiving care in a facility (such as a nursing home or hospice facility) are more likely to have advance directives in place.<sup>21</sup>

## **Q5: DOES MEDICARE COVER HOSPICE CARE? HOW MANY MEDICARE BENEFICIARIES USE HOSPICE?**

A: Yes. For terminally ill Medicare beneficiaries who do not want to pursue curative treatment, Medicare offers a comprehensive hospice benefit covering an array of services, including nursing care, counseling, palliative medications, and up to five days of respite care to assist family caregivers. Hospice care is most often provided in patients’ homes.<sup>22</sup> Medicare patients who elect the hospice benefit have little to no cost-sharing liabilities for most hospice services.<sup>23</sup> In order to qualify for hospice coverage under Medicare, a physician must confirm that the patient is expected to die within six months if the illness runs a normal course. If the Medicare patient lives longer than six months, hospice coverage may continue if the physician and the hospice team re-certify the eligibility criteria.

Of all Medicare beneficiaries who died in 2013, 47 percent used hospice—a rate that has more than doubled since 2000 (23 percent).<sup>24</sup> The rate of hospice use increases with age, with the highest rate existing among decedents ages 85 and over. Hospice use is also higher among women than men and among white beneficiaries than beneficiaries of other races/ethnicities. Hospice care accounts for about 10 percent of traditional Medicare spending in beneficiaries’ last year of life.<sup>25</sup> Medicare Advantage plans do not cover hospice care; therefore,

when a Medicare Advantage enrollee receives hospice care, his or her hospice coverage falls under traditional Medicare (Parts A and B).<sup>26</sup>

While many researchers, policymakers, and patient advocates cite the numerous benefits of hospice care in providing appropriate end-of-life care to Medicare patients, questions have been raised about the growth in for-profit hospice agencies, citing differences in the average care needs of the patients they serve compared with those served by non-profit agencies.<sup>27</sup>

## Q6: WHAT IS “PALLIATIVE CARE” AND DOES MEDICARE COVER IT?

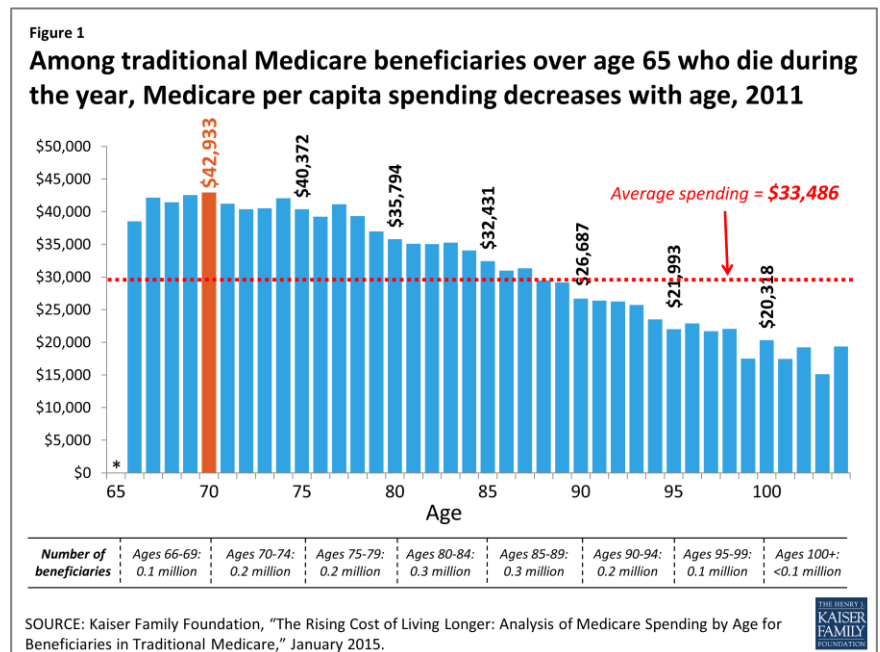
A: Palliative care can be integral to end-of-life care in that it generally focuses on managing symptoms and providing comfort to patients and their families. While palliative care is common among people receiving end-of-life care, it is not necessarily restricted to people with terminal illnesses. The Center to Advance Palliative Care emphasizes that palliative care is commonly used among people living with serious, complex, and chronic illnesses, including cancer, heart disease, general pain, or depression.<sup>28</sup> Close to half (45 percent) of all Medicare beneficiaries have four or more chronic conditions for which palliative care services may be clinically indicated to alleviate symptoms—either in combination with or instead of curative treatment.<sup>29</sup> The Medicare hospice benefit (described in Question 7) also covers palliative care for beneficiaries with terminal illness.

## Q7: HOW MUCH DOES MEDICARE SPEND ON END-OF-LIFE CARE, AND FOR WHICH SERVICES?

A: Among seniors in traditional Medicare who died in 2011, Medicare spending averaged \$33,500 per beneficiary (Figure 1) – about four times higher than the average cost per capita for seniors who did not die during the year. Other research shows over the past several decades, roughly one-quarter of traditional Medicare spending for health care is for services provided to beneficiaries ages 65 and older in their last year of life.<sup>30</sup>

Medicare spending during the year of death decreases with age after age 70, suggesting that patients, families, and providers may be opting for less intensive

and less costly end-of-life interventions for beneficiaries as they grow older. Specifically, per capita Medicare spending among decedents in 2011 peaked at age 70 (\$42,933) and decreased by about half (\$21,993) by age 95.<sup>31</sup> Approximately half of total Medicare spending for people who died in a given year goes toward hospital inpatient expenses, while hospice and skilled nursing services each accounted for about 10 percent of Medicare spending.<sup>32</sup>



## Q8: DID THE AFFORDABLE CARE ACT (ACA) AFFECT MEDICARE COVERAGE FOR END-OF-LIFE CARE OR ADVANCE CARE PLANNING?

A: No. The final ACA legislation did not include provisions that would allow physicians or other health professionals to seek separate Medicare payment for consultations on advance care planning. A House-passed predecessor bill (H.R.3200) included provisions that would have established Medicare reimbursement for advance care planning, as well as programs to increase public awareness of advance care planning, but these provisions were dropped from the final ACA legislation.<sup>33</sup>

Prior to the passage of the ACA, incorrect claims surfaced during the 2008 election that the inclusion of advance care planning provisions for Medicare beneficiaries would result in government “death panels.”<sup>34</sup> Confusion among people persisted even after the ACA passed, as seen in a Kaiser Family Foundation survey which found that in 2013, more than one-third (35 percent) of people ages 65 and over incorrectly believed that a death panel was created by the ACA in order to make end-of-life decisions for Medicare beneficiaries.<sup>35</sup>

## Q9: HAS THE INSTITUTE OF MEDICINE (IOM) MADE ANY RECOMMENDATIONS REGARDING ADVANCE CARE PLANNING AND END-OF-LIFE CARE?

A: The IOM recently released a comprehensive report, *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*, which included five recommendations aimed to increase the quality of end-of-life care and improve the ability for patients to choose their own treatment plan.<sup>36</sup> In brief, the IOM recommendations call for:

- Coverage of comprehensive care for patients with advanced serious illnesses who are nearing the end of life by both government and private health insurers;
- The development of quality metrics and standards for clinician-patient communication and advanced care planning, with insurance reimbursement tied to performance on these standards;
- Strengthening clinical training and licensing/credentialing requirements in palliative care;
- Federal and regulatory action to establish financial incentives for integrating medical and social services for people nearing the end of life, including electronic health records that incorporate advanced care planning;
- Widespread efforts to provide information to the public on the benefits of advance care planning and the ability for individuals to choose their own course of treatment.

## Q10: HOW DOES THE PUBLIC FEEL ABOUT ADVANCE CARE PLANNING AND MEDICARE’S ROLE IN END-OF-LIFE PREFERENCES?

A: Public opinion generally supports the concept that patients should be aware of end-of-life options, with one recent survey finding that the vast majority of adults (97 percent) agreed with the following statement: “It is important that patients and their families be educated about palliative care and end-of-life care options available to them along with curative treatment.” This poll also found that 81 percent of adults ages 18 and over reported that they agreed with the statement that “discussions about palliative care and end-of-life care treatment options should be fully covered by Medicare.”<sup>37</sup> Another survey among Californians found that the same percentage of adults (81 percent) said it was a “good idea” for insurance plans to cover a doctor’s time to talk with patients about treatment options towards the end of life.<sup>38</sup> Despite this finding, most adults have not completed an advance directive. However, the rate among the Medicare-eligible or near-Medicare-eligible population is higher: about half of adults ages 60 and over have created an advance directive.<sup>39</sup>

# Endnotes

- <sup>1</sup> Centers for Disease Control and Prevention, “Deaths: Final Data for 2010,” National Vital Statistics Report 2013;61(4), Table 3, [http://www.cdc.gov/nchs/data/nvsr/nvsr61/nvsr61\\_04.pdf](http://www.cdc.gov/nchs/data/nvsr/nvsr61/nvsr61_04.pdf).
- <sup>2</sup> Gerald F. Riley and James D. Lubitz, “Long-Term Trends in Medicare Payments in the Last Year of Life,” *Health Serv Res* 2010;45 (2): 565-76; Christopher Hogan et al., “Medicare Beneficiaries’ Costs of Care In The Last Year of Life,” *Health Aff (Millwood)* 2001;20(4):188-95.
- <sup>3</sup> Approaching Death: Improving Care at the End of Life, Institute of Medicine, 1997; Joan M. Teno et al., “Change in End-of-Life Care for Medicare Beneficiaries,” *JAMA* 2013;309(5):470-77.
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- <sup>5</sup> “Deaths: Final Data for 2010” 2013, Table 10.
- <sup>6</sup> Pam Belluck, “Coverage for End-of-Life Talks Gaining Ground,” *NY Times*, August 30, 2014, <http://www.nytimes.com/2014/08/31/health/end-of-life-talks-may-finally-overcome-politics.html>.
- <sup>7</sup> Michael Ollove, “Feds to Consider Paying for End-of-Life Planning,” The Pew Charitable Trusts: Stateline, May 30, 2014, <http://www.pewtrusts.org/en/research-and-analysis/blogs/stateline/2014/05/feds-to-consider-paying-for-end-of-life-planning>.
- <sup>8</sup> Centers for Medicare and Medicaid Services, “Your Medicare Coverage: Preventive visit & yearly wellness exams,” Medicare.gov, accessed May 29, 2015, <http://www.medicare.gov/coverage/preventive-visit-and-yearly-wellness-exams.html>.
- <sup>9</sup> 76 Fed. Reg. 1366 (January 10, 2011), available at <http://www.gpo.gov/fdsys/pkg/FR-2011-01-10/pdf/2011-164.pdf>.
- <sup>10</sup> Centers for Medicare and Medicaid Services, 42 CFR Parts 405, 410, 411, 414, 425, 495, July 8, 2015, <https://s3.amazonaws.com/public-inspection.federalregister.gov/2015-16875.pdf>.
- <sup>11</sup> Care Planning Act of 2015, S.1549, 114<sup>th</sup> Cong., available at <https://www.congress.gov/114/bills/s1549/BILLS-114s1549is.pdf>.
- <sup>12</sup> Personalize Your Care Act of 2013, H.R.1173, 113<sup>th</sup> Cong., available at <https://www.congress.gov/113/bills/hr1173/BILLS-113hr1173ih.pdf>.
- <sup>13</sup> U.S. House, *Omnibus Budget Reconciliation Act of 1990*, Conference Report (to Accompany H.R. 5835), 101 H. Rpt. 101-964, printed Oct. 27, 1990, Sec. 4206; Adrienne L. Jones, Abigail J. Moss, and Lauren D. Harris-Kojetin, “Use of Advance Directives in Long-term Care Populations,” Centers for Disease Control and Prevention: Division of Health Care Statistics, January 2011, <http://www.cdc.gov/nchs/data/databriefs/db54.pdf>.
- <sup>14</sup> National Institute on Aging, “Advance Care Planning: Tips from the National Institute on Aging,” reprinted March 2014, [http://www.nia.nih.gov/sites/default/files/advance\\_care\\_planning\\_tipsheet\\_o.pdf](http://www.nia.nih.gov/sites/default/files/advance_care_planning_tipsheet_o.pdf).
- <sup>15</sup> Pew Research Center, “Views on End-of-Life Medical Treatments,” November 2013, <http://www.pewforum.org/2013/11/21/views-on-end-of-life-medical-treatments/>.
- <sup>16</sup> Anne Wilkinson, Neil Wenger, and Lisa R. Shugarman, “Literature Review on Advance Directives” HHS Office of the Assistant Secretary for Planning and Evaluation, June 2007, available at <http://aspe.hhs.gov/daltcp/reports/2007/advdirlr.pdf>; Deborah Carr, “Racial Differences in End-of-Life Planning: Why Don’t Blacks and Latinos Prepare for the Inevitable?” *OMEGA* 2011;63(1):1-20; GB Zaide et al., “Ethnicity, race, and advance directives in an inpatient palliative care consultation service,” *Palliat Support Care* 2013;11(1):5-11; Lauren H. Nicholas et al., “Regional Variation in the Association Between Advance Directives and End-of-Life Medicare Expenditures,” *JAMA* 2011;306(13):1447-53; Kimberly S. Johnson, Maragatha Kuchibhatla, and James A. Tulsky, “What explains racial differences in the use of advance directives and attitudes toward hospice care?” *J Am Geriatr Soc* 2008;56(10):1953-58.
- <sup>17</sup> Nicholas et al. 2011.
- <sup>18</sup> Johnson, Kuchibhatla, and Tulsky 2008; Wilkinson, Wenger, and Shugarman 2007.
- <sup>19</sup> American Bar Association: Division for Public Education, “Law for Older Americans,” accessed May 29, 2015, [http://www.americanbar.org/groups/public\\_education/resources/law\\_issues\\_for\\_consumers/patient\\_self\\_determination\\_act.html](http://www.americanbar.org/groups/public_education/resources/law_issues_for_consumers/patient_self_determination_act.html).
- <sup>20</sup> Health care providers can, however, refuse a treatment, but must notify the patient and/or their agent upon admission of any objections to the advance directive. For more information, see GAO report “Patient Self-Determination Act: Providers Offer Information on Advance Directive but Effectiveness Uncertain,” p. 45, August 1995, available at <http://www.gpo.gov/fdsys/pkg/GAOREPORTS-HEHS-95-135/pdf/GAOREPORTS-HEHS-95-135.pdf>.
- <sup>21</sup> Jones, Moss, and Harris-Kojetin 2011.
- <sup>22</sup> Medicare Payment Advisory Commission, *Report to the Congress: Medicare Payment Policy*, Chapter 12: “Hospice Services,” March 2015.

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- <sup>23</sup> There is no deductible for hospice care in traditional Medicare. In general, cost-sharing is limited to copayments of up to \$5 per prescription for outpatient prescription drugs (typically for pain and symptom management) and 5 percent coinsurance for inpatient respite care, if used.
- <sup>24</sup> MedPAC 2015.
- <sup>25</sup> Riley and Lubitz 2010.
- <sup>26</sup> MedPAC 2015.
- <sup>27</sup> Melissa W. Wachterman, Edward R. Marcantonio, Roger B. Davis, and Ellen P. McCarthy, “Association of hospice agency profit status with patient diagnosis, location of care, and length of stay.” *JAMA* 2011;305(5):472-9; R. C. Lindrooth and B. A. Weisbrod, “Do religious nonprofit and for-profit organizations respond differently to financial incentives? The hospice industry.” *J Health Econ* 2007;26(2):342-57.
- <sup>28</sup> Center to Advance Palliative Care, “About Palliative Care,” accessed May 29, 2015, <https://www.capc.org/about/palliative-care/>.
- <sup>29</sup> Kaiser Family Foundation, *A Primer on Medicare: Key Facts About the Medicare Program and the People it Covers*, March 2015, <http://kff.org/medicare/report/a-primer-on-medicare-key-facts-about-the-medicare-program-and-the-people-it-covers/>.
- <sup>30</sup> Riley and Lubitz 2010; Hogan et al. 2001.
- <sup>31</sup> Tricia Neuman, Juliette Cubanski, Jennifer Huang, and Anthony Damico, “The Rising Cost of Living Longer: Analysis of Medicare Spending by Age for Beneficiaries in Traditional Medicare,” Kaiser Family Foundation, January 14, 2015, <http://kff.org/medicare/report/the-rising-cost-of-living-longer-analysis-of-medicare-spending-by-age-for-beneficiaries-in-traditional-medicare/>.
- <sup>32</sup> Riley and Lubitz 2010.
- <sup>33</sup> H.R. 3200, “America’s Affordable Health Choices Act of 2009,” 111th Cong. (2009), available at <https://www.congress.gov/bill/111th-congress/house-bill/3200/text#toc-H896364C11C714348B7CF0E5B4357ADD0>.
- <sup>34</sup> Robert Pear, “U.S. Alters Rule on Paying for End-of-Life Planning,” *NY Times*, January 4, 2011, <http://www.nytimes.com/2011/01/05/health/policy/05health.html>.
- <sup>35</sup> Kaiser Family Foundation, “Kaiser Health Tracking Poll: March 2013,” March 2013, <http://kff.org/health-reform/poll-finding/march-2013-tracking-poll/>.
- <sup>36</sup> Institute of Medicine, *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*, September 17, 2014, pp. S-8 – S-16; For more information, see David G. Stevenson, Presentation at National Action Conference, March 20, 2015, Washington, D.C., available at <http://www.iom.edu/Activities/Aging/TransformingEndOfLife/2015-MAR-20/Videos/Panel%20on%20Financing%20for%20Health%20and%20Social%20Services/21-Stevenson-Video.aspx>.
- <sup>37</sup> “Living Well at the End of Life: A National Conversation,” National Journal and The Regence Foundation, February 16-17 & 19, 2011, available at <http://syndication.nationaljournal.com/communications/NationalJournalRegenceToplines.pdf>.
- <sup>38</sup> “Final Chapter: Californians’ Attitudes and Experiences with Death and Dying,” California HealthCare Foundation, February 2012, available at <http://www.chcf.org/publications/2012/02/final-chapter-death-dying>.
- <sup>39</sup> Nancy Aldrich, “Advance Care Planning: Ensuring Your Wishes Are Known and Honored If You Are Unable to Speak for Yourself,” Centers for Disease Control and Prevention, 2012, <http://www.cdc.gov/aging/pdf/advanced-care-planning-critical-issue-brief.pdf>.