

BACKGROUND

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End-of-Life Care: Expanding Patient Choice of Ethical Options

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Abstract

End-of-life care affects all Americans. There is a large gap between what most Americans want and the circumstances that most Americans will face at the end of their lives. A key policy task is to help close that gap. Too often, partisans frame the national debate as if the only choice were between patients receiving drastic interventions or physician-assisted suicide. There is, however, a wide area between these two extreme options; policymakers should seek to support patients and families who want better options based on informed patient consent. Seriously ill patients, with assistance of their families, physicians and trusted advisors, should be the ones to decide when continued medical interventions are useful or futile, proportionate or disproportionate. The role of public officials is to ensure that patients, with their families, physicians and trusted advisors, are equipped to make difficult decisions well before they face a personal and family crisis.

End-of-life care issues are complex and difficult, and in the realm of public policy—where a zero-sum game over ethical alternatives is the norm—these issues can further divide an already polarized nation. Too often, partisans frame the national debate as if the only choice were between patients receiving drastic interventions (such as being hooked up to a machine that artificially extends life indefinitely) or allowing physicians to assist in the suicides of their patients. There is, however, a wide area between these two extreme options. Policymakers need to exercise prudence and pursue sound public policy to create the conditions that allow individuals and families to pursue rational alternatives.

KEY POINTS

- There is a large gap between what most Americans want and the circumstances that most Americans will face at the end of their lives. A key policy task is to help close that gap.
- Too often, partisans frame the national debate as if the only choice were between patients receiving drastic interventions or physician-assisted suicide.
- There is, however, a wide area between these two extreme options; policymakers should seek to support patients and families who want better options.
- The role of public officials is to ensure that patients, with their physicians, families, and trusted advisors, are equipped to make difficult decisions well before they face a personal and family crisis.

This paper, in its entirety, can be found at <http://report.heritage.org/bg3377>

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In the 21st century, death routinely follows advanced age and physical decline. The patterns of mortality have been changing; far more Americans are living longer and dying at the end of a relatively slow process of physical decline. Because the fastest-growing cohort of the American population is aged 85 and older, end-of-life issues are of increasing concern. By 2030, according to the U.S. Census Bureau, over 20 percent of Americans will be aged 65 and over, compared to just 13 percent in 2010 and only 9.8 percent in 1970.¹ In addition, for Americans who have reached age 65, life expectancy has been rising.²

There is a large gap between what most Americans want and the circumstances that most Americans will face at the end of their lives. A key policy task is to help close that gap. Most Americans want to die at home,³ surrounded by loved ones, but under current arrangements, these wishes often remain unfulfilled: Over one-third of all deaths take place in hospitals, including hospital intensive care units.⁴ Most older Americans who suffer from a debilitating illness surely want the best care that can be available to them. Most also want their care to be governed by strong ethical or moral standards.

According to a major report published by the Institute of Medicine, “A substantial body of evidence shows that improved care for people near the end of life is a goal within the nation’s reach. Improving the quality of care for people with advanced serious illness and focusing on their preferences may help stabilize both total health care and social costs over time.”⁵

Sound Policy. America’s public officials should ensure that end-of-life decisions are left to the informed judgment of patients, with the assistance of trusted members of their families, or persons specifically designated to act on their behalf, with the advice and coun-

sel of their physicians and, if they so desire, members of the clergy. Patients should be ultimately responsible for their decisions about when continued medical interventions would be useful or futile, proportionate or disproportionate, in view of their condition. Because end-of-life care issues necessarily involve deeply personal ethical, moral, and religious convictions, public officials must respect those convictions while affirming the inherent value and dignity of human life.

To facilitate this goal, policymakers should advance the following recommendations:

- **Educate the public on the advantages of advance planning for end-of-life care.** Policymakers have a role—albeit a limited one—in encouraging such conversations and the adoption and use of end-of-life care planning documents. While policymakers should not be permitted to specify the content of end-of-life care planning documents, they should nonetheless encourage patients to adopt them in accordance with their personal ethical, moral, and religious convictions. Policymakers should remove barriers to a broader public acceptance of such planning, particularly among Medicare beneficiaries. Greater patient engagement and public awareness of the advantages of such planning can help to reduce confusion and the often bitter and costly conflict over ethical alternatives that confronts patients and their families at the end of life.
- **Test new payment models for palliative care and hospice care in Medicare.** Policymakers should remove barriers to broader access to palliative and hospice care, both in traditional Medicare and in Medicare Advantage. The current fee-for-service Medicare payment system results

1. Sandra L. Colby and Jennifer M. Ortman, “The Baby Boom Cohort in the United States: 2012 to 2060,” U.S. Census Bureau, *Current Population Reports*, May 2014, p. 2, <https://www.census.gov/prod/2014pubs/p25-1141.pdf> (accessed December 13, 2018).

2. See Table 15, “Life Expectancy at Birth, at Age 65, and at Age 75, by Sex, Race, and Hispanic Origin: United States, Selected Years 1900–2014,” in U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, National Center for Health Statistics, *Health, United States, 2015: With Special Feature on Racial and Ethnic Disparities*, May 2016, pp. 95–96, https://www.ncbi.nlm.nih.gov/books/NBK367640/pdf/Bookshelf_NBK367640.pdf (accessed December 13, 2018).

3. Associated Press, “CDC Survey Finds Most Americans Prefer to Die at Home,” *Journal of Emergency Medical Services*, February 28, 2013, <http://www.jems.com/articles/2013/02/cdc-survey-finds-most-americans-prefer-d.html?c=1> (accessed December 13, 2018).

4. James Flory, Yinong Young-Xu, Ipek Gurol, Norman Levinsky, Arlene Ash, and Ezekiel Emanuel, “Place of Death: U.S. Trends since 1980,” *Health Affairs*, Vol. 23, No. 3 (May/June 2004), pp. 194–200, <https://www.healthaffairs.org/doi/abs/10.1377/hlthaff.23.3.194> (accessed December 13, 2018).

5. Institute of Medicine, *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life* (Washington: National Academies Press, 2015), p. 3, <https://www.nap.edu/catalog/18748/dying-in-america-improving-quality-and-honoring-individual-preferences-near> (accessed December 13, 2018).

in fragmented and disjointed palliative care for many of the most costly of the program's beneficiaries. Moreover, with the growing popularity of the more flexible Medicare Advantage plans, the Administration should pursue appropriate demonstrations to allow for integration of hospice care in the Medicare Advantage program.

- **Expand Americans' personal choice.** In both the public and private sectors, patients may discover that with respect to the most sensitive questions concerning end-of-life care, their insurance carriers or care providers may be indifferent or even hostile to their ethical, moral, or religious beliefs. The best way to resolve this serious problem would be to create a robust consumer choice system that enables individuals to choose the health plans, benefit packages, and medical treatments and procedures that work best for them. Individuals should be able to choose health plans that offer care delivery, especially at the end of life, that reflects their religious values and moral convictions. Such a change would allow individuals and families to channel their health care dollars to the plans, medical professionals, and medical institutions that respect or share their moral and religious values concerning care at the end of life.
- **Oppose physician-assisted suicide.** America's population is rapidly aging, and our citizens face the rising personal and public costs of caring for a fast-growing cohort of senior citizens. Meanwhile, the personal and family discussions of the appropriate medical procedures for loved ones at the end of life are taking place amid an intensifying pub-

lic debate over physician-assisted suicide. While federal law prohibits the use of federal funds for physician-assisted suicide, six states and the District of Columbia have legalized the practice, and other state legislatures are currently considering measures to legalize it. Such legislation not only repudiates traditional medical ethics and undermines the doctor-patient relationship, but also is likely to endanger the poor, the uneducated, the disabled, and the vulnerable.

Death and America's Demographic Evolution

Life expectancy has increased dramatically. In 1900, the average American life span was 47.3 years; in 2007, it reached 77.9 years;⁶ and by 2016, it had risen to 78.8 years.⁷ The pattern of death has also changed dramatically. The President's Council on Bioethics has neatly summarized the data: "In 1900, the usual place of death was at home; in 2000, it was the hospital. In 1900, most people died from accident or infections without suffering a long period of disability. In 2000, people suffered, on average, two years of severe disability on the way to death."⁸

Today, two factors shape American death and demographic trends. The first is that, overwhelmingly, the leading cause of death in persons over the age of 65 is chronic illness, most notably heart disease, cancer, and chronic respiratory disease.⁹ The second, as noted, is that persons over the age of 65 are also living longer. Between 1950 and 2016, mortality rates for persons between the ages of 65 and 74 declined by 56 percent.¹⁰ Medical advances, particularly advances in medical technology, have greatly contributed to this welcome expansion in longevity.¹¹ However, the

6. This is life span at birth. Elizabeth Arias, "United States Life Tables, 2007," U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, National Center for Health Statistics, National Vital Statistics System, *National Vital Statistics Reports*, Vol. 59, No. 9 (September 28, 2011), https://www.cdc.gov/nchs/data/nvsr/nvsr59/nvsr59_09.pdf (accessed December 13, 2018).

7. Irene Papanicolas, Liana R. Woskie, and Ashish K. Jha, "Health Care Spending in the United States and Other High-Income Countries," *Journal of the American Medical Association*, Vol. 319, No.10 (March 13, 2018), p. 1030.

8. President's Council on Bioethics, *Taking Care: Ethical Caregiving in Our Aging Society*, September 2005, p. 12, https://repository.library.georgetown.edu/bitstream/handle/10822/559378/taking_care.pdf?sequence=1&isAllowed=y (accessed December 13, 2018).

9. U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, National Center for Health Statistics, *Health, United States, 2016: With Chartbook on Long-Term Trends in Health*, May 2017, p. 4, https://www.ncbi.nlm.nih.gov/books/NBK453378/pdf/Bookshelf_NBK453378.pdf (accessed December 13, 2018).

10. Maryaline Catillon, David Cutler, and Thomas Getzen, "Two Hundred Years of Health and Medical Care; The Importance of Medical Care for Life Expectancy Gains," National Bureau of Economic Research *Working Paper* No. 25330, December 2018, p. 6, <https://www.nber.org/papers/w25330> (accessed January 7, 2019).

11. "Conditions such as cardiovascular disease and cancer were relatively untreatable prior to the mid-1950s. Subsequently, developing technologies allowed both conditions to be treated more effectively. One consequence was higher spending." *Ibid.*, p. 36.

rising costs, particularly Medicare entitlement costs, have been formidable. In 1953, for example, per capita medical spending on the elderly was 70 percent higher than spending on the nonelderly; by 1970, the fourth year of Medicare's implementation, it had jumped to 250 percent higher.¹² The data show that the onset of death is largely a prolonged process of physical decline among the elderly, that medical interventions have contributed significantly to increased longevity among persons over the age of 65, and that ever larger numbers of persons are living longer in retirement.

Along with many other industrial countries with aging populations, America is confronting the daunting challenge of Alzheimer's disease, a progressive, slow, costly, and fatal dementia for which there is no cure. According to the Partnership to Fight Chronic Disease, over the period 2017–2030, the “cumulative total cost” of Alzheimer's will be \$7.7 trillion, and among the payers, Medicare and Medicaid (the taxpayers) will absorb an estimated 70 percent of third-party payment costs.¹³

Medicare, which pays for seniors' and certain disabled citizens' care, is “the largest insurer of medical care provided at the end of life.”¹⁴ Approximately eight out of 10 American decedents are Medicare recipients. Not surprisingly, end-of-life care regularly consumes about one out of every four dollars in total Medicare spending.¹⁵ Inpatient hospital care and physician reimbursement accounts for the largest proportion of Medicare spending, but the program also finances hospice care, specialized care for the dying, and skilled nursing and home health care.¹⁶

The most expensive Medicare beneficiaries are the so-called dual-eligible, elderly patients covered by both Medicare and Medicaid.¹⁷ In 2014, for example, traditional Medicare's average per capita spending was \$33,676 for enrollees in the last year of life but \$36,037 for those who were dually eligible in Medicare and Medicaid.¹⁸

Three powerful, rising, and converging trends—a rapidly aging population, the emergence of unprecedented federal entitlement costs, and the deterioration of traditional medical ethics—are the ingredients of a polarizing political storm. As *New Atlantis* Editor Eric Cohen has warned, “In an aging society, in which the elderly come to seem and come to feel like a paralyzing burden, the seduction of euthanasia may be too strong to resist.”¹⁹

Of these three trends, the most dangerous for the elderly and disabled is the weakening of traditional medical ethics including a new openness to the medical killing of persons who suffer from disability or dementia. Consider the international experience. In Quebec, Canada, where euthanasia, often called “mercy killing,” is legal, a survey of caregivers found that 72 percent favored euthanizing Alzheimer's patients, even if those patients did not previously request or consent to it.²⁰ Such actions would directly repudiate the traditional medical ethics embodied in the Hippocratic Oath, the venerable standard of medical ethics that specifically forbids physicians from practicing euthanasia.

Patients and their families must be vigilant because the traditional Hippocratic Oath is often

12. Ibid.

13. This total cost includes an estimate of the cumulative health care costs of the disease as well as the projected cost of “unpaid” care. See Partnership to Fight Chronic Disease, “What Will Alzheimer's Disease Cost the United States? \$7.7 Trillion,” [https://www.fightchronicdisease.org/sites/default/files/PFCD_USA_Alzheimers_Factsheet_v13%20\(1\).pdf](https://www.fightchronicdisease.org/sites/default/files/PFCD_USA_Alzheimers_Factsheet_v13%20(1).pdf) (accessed December 13, 2018).

14. Juliette Cubanski, Tricia Neuman, Shannon Griffin, and Anthony Damico, “Medicare Spending at the End of Life: A Snapshot of Beneficiaries Who Died in 2014 and the Cost of Their Care,” Henry J. Kaiser Family Foundation, July 14, 2016, <https://www.kff.org/medicare/issue-brief/medicare-spending-at-the-end-of-life/> (accessed December 13, 2018).

15. Ibid.

16. U.S. Department of Health and Human Services, Centers for Medicare and Medicaid Services, “How Is Medicare Funded?” <https://www.medicare.gov/about-us/how-is-medicare-funded> (accessed December 14, 2018).

17. Korbin Liu, Joshua M. Wiener, and Marlene R. Niefeld, “End of Life Medicare and Medicaid Expenditures for Dually Eligible Beneficiaries,” *Health Care Financing Review*, Vol. 27, No. 4 (Summer 2006), pp. 95–110, <https://www.cms.gov/Research-Statistics-Data-and-Systems/Research/HealthCareFinancingReview/downloads/06Summerpg95.pdf> (accessed December 13, 2018).

18. Cubanski et al., “Medicare Spending at the End of Life.”

19. Eric Cohen, “In Whose Image Shall We Die?” *The New Atlantis*, No. 15 (Winter 2007), pp. 21–39, <https://www.thenewatlantis.com/publications/in-whose-image-shall-we-die> (accessed December 13, 2018).

20. Wesley J. Smith, “Euthanasia for Alzheimer's Patients?” *First Things*, September 29, 2017, <https://www.firstthings.com/web-exclusives/2017/09/euthanasia-for-alzheimers-patients> (accessed December 13, 2018).

ignored, watered down, or rejected.²¹ As Dr. Gene Dorio, a palliative care physician, reports, “As a physician who screened patients for hospice eligibility, I periodically saw doctors abandon the Hippocratic Oath and misrepresent medical information.”²² Some practitioners believe that this decline in traditional medical ethics reflects the modern structure and organization of medical care delivery. Writing in the *British Medical Journal*, surgeon Imre Loefer observes that:

The Hippocratic ethics take no account of the impact of modern medicine. This is why the Hippocratic oath, particularly in respect to its three most essential principles—the sanctity of life, the privacy of patients, and the “do no harm” command—is increasingly subverted, ignored, altered, reinterpreted. The Hippocratic ethics do not tally any more with the reality of modern society. Whether this is regrettable or not, doctors and society must get to grips with the ethical consequences of the medical revolution.²³

Of course, no human behavior is inevitable. Americans can recover the humane tradition of medical ethics, including the Hippocratic principle that the physician is the servant of the patient and, as a servant, obligated to safeguard the privacy of the patient and protect the patient from medical harm. Public education and robust debate can change public attitudes and reverse prevailing cultural and intellectual trends. Public policy can promote ethical alternative courses of action.

Appropriate Medical Treatment. Life-saving technologies have contributed to the steady increase in American life expectancy, but they also have complicated Americans’ discussions about their own care

at the end of life. As Dr. Jerry Menikoff, Director of the Office for Human Research Protections at the U.S. Department of Health and Human Services (HHS), has observed, “People often say that life used to be simpler. Whether or not that is the case, it certainly is true that death used to be simpler.”²⁴

Today, major advances in medical technology enable medical professionals to treat and recover seriously ill patients who once were given up as lost. Boston University School of Public Health Professor George Annas warns that the routine resort to technology is overwhelming both common sense and patients’ wishes: “Death is feared and even dreaded in our culture, and few Americans are able to die at home, at peace, with our loved ones in attendance, without seeking the ‘latest new treatment.’”²⁵

Advances in medical technology and pharmaceutical innovation have helped and will continue to help countless patients, but technological bias saturates our culture: Because we *can* do something, we too often assume we *should* do something. In fact, one may *not* necessarily choose to resort to advanced medical technology in certain cases. There is a broadly recognized distinction between the use of proportionate, *ordinary* medical interventions and disproportionate, *extraordinary* medical interventions. Failure to distinguish between the two at the right time entails huge costs, both human and financial. According to Dr. Jessica Zitter, a physician providing intensive care services:

As an ICU physician, I’ve used technologies like breathing machines and feeding tubes to save lives that would have been lost just a few decades earlier. But I’ve also seen the substantial costs, both human and financial, of some medical advances. Many patients die protracted deaths while being

21. For an excellent historical account of the philosophical assault on the Hippocratic Oath, see C. L. Gray, *The Battle for America’s Soul: Health Care, the Culture War, and the Future of Freedom* (Hickory, NC: Eventide Publishing, 2011), pp. 43–65; see also Wesley J. Smith, “Hippocratic Oath Adapts,” *First Things*, October 2, 2007, <https://www.firstthings.com/blogs/firstthoughts/2007/10/hippocratic-oath-adapts> (accessed January 7, 2019).
22. Gene Uzawa Dorio, “Doctor’s Diary November 20, 2018: Hospice Abuse,” *SCV Physician Report*, November 20, 2018, <http://scvphysicianreport.com/2018/11/20/doctors-diary-november-20-2018-hospice-abuse/> (accessed January 7, 2019).
23. Imre Loefer, “Why the Hippocratic Ideals Are Dead,” *British Medical Journal*, Vol. 324, Issue 7351 (June 15, 2002), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1123413/> (accessed December 13, 2018). For a sobering analysis of the ethical predicament of modern physicians subjected to clinical, scientific, and political cross-cutting pressures, see M. Gregg Bloche, M.D., *The Hippocratic Myth: Why Doctors Are Under Pressure to Ration Care, Practice Politics, and Compromise Their Promise to Heal* (New York: Palgrave Macmillan, 2011).
24. Jerry Menikoff, *Law and Bioethics: An Introduction* (Washington: Georgetown University Press, 2001), p. 443.
25. George J. Annas, “Cancer and the Constitution—Choice at Life’s End,” *The New England Journal of Medicine*, Vol. 357, No 4 (July 26, 2007), p. 413, <http://www.nejm.org/doi/full/10.1056/NEJMhle070625> (accessed December 14, 2018).

kept alive by machines—which, research shows, they would not have chosen had there been adequate communication about their options beforehand.²⁶

When a patient has entered the final phase of illness, there is often severe disagreement among family members, as there is in the general population,²⁷ about the right and proper course of action. Ideally, patients and families should have candid discussions well before action must be taken and should be equipped to distinguish between futile measures that prolong life artificially and rash actions that would result in a premature death.

While proportionate, ordinary medical care is proper, a resort to disproportionate, extraordinary medical care may not be. Likewise, terminally ill patients ought not to be pressured into being subject to “heroic” measures, especially if those measures incur severe discomfort; nor should doctors, lawyers, or government officials pressure patients into collaborating in their own suicides. Instead, to the extent possible, policymakers should facilitate a legal and regulatory environment that encourages these sensitive and informed conversations among patients and their families, their doctors, and—depending on the patient’s wishes—members of the clergy or other trusted persons.

Key Policies Relating to End-of-Life Care

“More than a quarter of all adults, including those aged 75 and older, have given little or no thought to their end-of-life wishes, and even fewer have captured these wishes in writing or through conversation,” according to the Institute of Medicine. “This is the case despite the results of recent polls showing that Americans worry about the potential of high costs of care near the end of life and desire not to be a burden—financial or otherwise—on family members.”²⁸

Advance Directives. Advance planning can take several forms. Before they become patients, persons can authorize a planning document, such as an advance directive, often in standardized legal forms that specify the person’s instructions concerning medical care. Advance directives enable persons to specify, for example, that they do not wish to be subject to “heroic” medical interventions (“extraordinary medical care”) that keep them alive artificially in the face of a terminal illness. They can authorize a medical “power of attorney” and instruct another person, usually a family member or friend, to act on their behalf to make medical treatment decisions or issue specific instructions that are compatible with their ethical, moral, and religious convictions. These instructions can cover a wide range of items such as the kinds of life-sustaining treatments that they wish to have administered in the event that they are unable to communicate their wishes—a common problem in the final stages of advanced illness.²⁹

The execution and transmission of these documents is also sensitive. When a patient is seriously ill and rushed to an intensive care unit within a hospital, medical professionals need to make correct and decisive decisions concerning the patient’s care, and these decisions often involve risks to the patient’s life and health. The patient and his or her family are often under great stress, breakdowns in communication can occur, and tensions often arise within the family and sometimes between the family and the medical professionals. These problems can continue or even worsen in the transfer of patients from hospitals to skilled nursing facilities and, in many cases, right back to the hospital.

In a paper-driven world, the patient’s advance directive—assuming the patient even has such a directive—may not be immediately available; it may be misplaced or in the possession of a family member who may be absent. Under pressure to take an extraordi-

26. Jessica Zitter, “Pricey Technology Is Keeping People Alive Who Don’t Want to Live,” *Wired*, April 10, 2017, <https://www.wired.com/2017/04/pricey-technology-keeping-people-alive-dont-want-live/> (accessed December 14, 2018).

27. On the resort to heroic or extraordinary medical interventions, such as the aggressive use of medical technologies to maintain life, researchers at the Pew Foundation also found sharp cultural and racial differences within the American population on end-of-life care issues. While 65 percent of Caucasians would want to die if they had an “incurable” disease and were suffering, only 26 percent would ask their doctors to do “everything possible.” In contrast, 61 percent of African Americans and 55 percent of Hispanics would ask their doctors to do everything if they had an incurable disease and a great amount of pain. Pew Research Center, “Views on End-of-Life Medical Treatments,” November 21, 2013, <http://www.pewforum.org/2013/11/21/views-on-end-of-life-medical-treatments/> (accessed December 14, 2018).

28. Institute of Medicine, *Dying in America*, p. 3.

29. For a more detailed discussion of these options, including their advantages and shortcomings, see President’s Council on Bioethics, *Taking Care*, pp. 53–93.

nary medical intervention, doctors and other medical professionals may have absolutely no idea what the patient has determined with regard to his own care—assuming the patient has made any such determination at all. In such a situation, Dr. Dorio warns, “[i]f there is no paperwork, hospitals get their legal teams to argue with your family over the direction of your medical care.”³⁰

Advance directives increasingly are included among patients’ confidential medical records and transmitted electronically. Today, given the growth of electronic health records and the rise of cybercrime, the security of these electronic communications and records is another concern. Between 2014 and 2017, more than 147 million medical records were breached nationwide.³¹ With advances in information technology, the safe and efficient transmission of patients’ directives, as well as appropriate access to these directives by medical professionals, skilled nursing facilities, and hospitals, is vitally important.

There is, of course, no perfect legal instrument. Patients can and do change their minds, particularly when they find themselves in a potentially terminal condition. Nonetheless, the President’s Council on Bioethics strongly emphasizes the broader advantages of such advance planning, particularly the fruitful conversations between patients and their families:

Such conversation[s] might focus not so much on specific medical treatments a patient would or would not want as on other aspects of aging and dying that might matter even more to the person:

for example, being steadily cared for during the long period of illness, having the company of one’s family and friends at the end, making peace with God, having a chance to say goodbye to a particular person, dying in a quiet and dignified setting, sparing one’s family additional anguish, and other considerations not strictly medical.³²

Laws governing legal arrangements conferring powers of attorney or advanced planning directives for patients facing terminal illness, as well as permission for physician-assisted suicide, largely fall under state jurisdiction. State legislators can take steps to help patients plan for care when they are suffering from a dangerous medical condition. Many state laws, for example, require that medical facilities that provide long-term or post-acute care for patients transferred to them must provide these patients with a standardized form—a “medical order for life-sustaining treatment”—that outlines the treatment options available to them.³³ Patients must, however, scrutinize these forms before signing them and make sure that they authorize only medical procedures that are in line with their own ethical, moral, or religious convictions when they are facing a potentially terminal condition.

Medicare also has a role in end-of-life discussions by covering the costs of such discussions with a physician.³⁴ By 2015, the Kaiser Health Tracking Poll found that nine out of 10 Americans support the availability of such end-of-life discussions covered by Medicare, although only 17 percent of respondents report having such a discussion.³⁵ By 2016, an

30. Gene Uzawa Dorio, “Doctor’s Diary June 10, 2018: Fear the ICU,” *SCV Physician Report*, June 10, 2018, <http://scvphysicianreport.com/2018/06/10/doctors-diary-june-10-2018-fear-the-icu/> (accessed December 14, 2018).

31. Maryland Health Care Commission, *Health Care Data Breaches: 2017 Findings*, September 2018, p. 6, http://mhcc.maryland.gov/mhcc/pages/hit/hit/documents/HIT_Breach_2017_findings_20180924.pdf (accessed December 14, 2018).

32. President’s Council on Bioethics, *Taking Care*, p. 90.

33. See, for example, Maryland Health Care Commission, *Strategy for Implementing Electronic Advance Directives & MOLST Forms*, revised June 2012, p. 3, http://mhcc.maryland.gov/mhcc/pages/hit/hit/documents/HIT_Strategy_Implement_Electronic_Adv_Directives_MOLST_Rpt_20120601.pdf (accessed December 14, 2018).

34. Pursuant to regulations under the Affordable Care Act (ACA) of 2010. This was a regulatory action. Pam Belluck, “Medicare Plans to Pay Doctors for Counseling on End of Life,” *The New York Times*, July 9, 2015, <http://www.nytimes.com/2015/07/09/health/medicare-proposes-paying-doctors-for-end-of-life-counseling.html> (accessed December 13, 2018). At the time, this was controversial. “There is clearly the potential for a conflict of interest if the federal government is paying medical professionals for end-of-life counseling and also paying for our end-of-life care.” Grace Marie Turner, James C. Capretta, Thomas P. Miller, and Robert E. Moffit, *Why Obamacare Is Wrong for America: How the New Health Care Law Drives Up Costs, Puts Government in Charge of Your Decisions, and Threatens Your Constitutional Rights* (New York: HarperCollins, 2011), p. 92.

35. Bianca DiJulio, Jamie Firth, and Mollyann Brodie, “Kaiser Health Tracking Poll: September 2015,” Henry J. Kaiser Family Foundation, September 30, 2015, <https://www.kff.org/health-costs/poll-finding/kaiser-health-tracking-poll-september-2015/> (accessed December 14, 2018).

estimated 575,000 Medicare beneficiaries reported participating in end-of-life discussions with their physicians, and “[n]early 23,000 providers submitted about \$93 million in charges, including more than \$43 million covered by the federal program for seniors and the disabled.”³⁶

Whatever mechanism a person employs, whether it is an advance directive or a power of attorney, policymakers should secure and protect the central “space” for the nongovernmental institutions of civil society—patients and their families, religious organizations, and other trusted social institutions—to play the primary advisory role in assisting persons as they make the key decisions about their care at the end of life. If government officials usurp the primary role of patients and their families in these sensitive decisions, then both can become the downstream victims of transient ideological fashions or the impersonal exercise of bureaucratic power.³⁷

Palliative and Hospice Care. According to the Institute of Medicine:

Expecting people to understand or have meaningful conversations about end-of-life care issues presumes a common vocabulary; however, surveys show people do not understand what palliative care is or what role it plays near the end of life, do not have a clear concept of “caregiver”, and may be confused by the various titles assigned by state laws to people who serve as health care agents (such as surrogate decision makers or proxies).³⁸

In light of these issues, physicians may feel reluctant to refer seriously ill patients out of fear of upsetting patients and their families—a problem that is aggravated by the common confusion of palliative care with hospice care.³⁹

Palliative care provides a wide range of medical and related services such as pain management, including the appropriate use of drugs, and emotional support, including the relief of psychological stress. Palliative care can be used appropriately for anyone with a serious illness, regardless of his or her prognosis. Such care can help such patients manage their pain and symptoms effectively and can be provided to patients who are not necessarily suffering from a terminal condition. If the prognosis for these patients becomes terminal, then they are candidates for hospice care. As Doctor Dorio warns, however, “[g]oing on hospice should be a decision made by the patients or their loved ones, and not coerced by doctors or hospitals who might have an economic self-interest.”⁴⁰

A review of various studies in the professional literature shows that the use of palliative care reduces patient pain and discomfort, increases patient and family satisfaction, reduces hospitalization, and reduces hospital readmissions in addition to achieving cost savings.⁴¹ A *New England Journal of Medicine* study compared outcomes of cancer patients enrolled in palliative care with outcomes of cancer patients enrolled in standard cancer treatment. Patients receiving palliative care had fewer instances of depression, lived

36. JoNel Aleccia, “End-of-life Advice: More than 500,000 Chat on Medicare’s Dime,” *USA Today*, August 14, 2017, <https://www.usatoday.com/story/news/health/2017/08/14/end-of-life-advice-more-than-500-000-chat-medicares-dime/550629001/> (accessed December 14, 2018).

37. In the recent case of Alfie Evans, a 23-month-old child with a degenerative neurological condition, British hospital officials determined, doubtless correctly, that the child’s prognosis was terminal. But they went further and then prevented the parents from seeking alternative medical treatments outside of the British National Health Service (NHS). For a summary of the case, see Robert Moffit, “In Government-Controlled Health Care, Bureaucrats’ Whims Trump Parents’ Rights,” *The Daily Signal*, May 4, 2018, <https://www.dailysignal.com/2018/05/04/in-government-controlled-health-care-bureaucrats-whims-trump-parents-rights/>. Likewise, as the late Peter Augustine Lawler, a prominent political scientist, warned, “Today, it’s clear everywhere that public bureaucracies are far more likely than private concerns to be infused with the self-indulgent, narcissistic cultural excesses of our intellectuals. Certainly, we wouldn’t want those bureaucracies deciding about rationing or compelling abortions or even making hard calls about the profoundly disabled or those near death. We wouldn’t want to turn health care decisions over to those most contemptuous of the moral choices of the least narcissistic Americans.” Peter Augustine Lawler, *Modern and American Dignity: Who We Are as Persons, and What That Means for Our Future* (Wilmington, DE: ISI Books, 2010), p. 202.

38. Institute of Medicine, *Dying in America*, p. 24.

39. Pippa Hawley, “Barriers to Access to Palliative Care,” *Palliative Care: Research and Treatment*, February 20, 2017, <https://journals.sagepub.com/doi/10.1177/1178224216688887> (accessed December 14, 2018).

40. Gene Uzawa Dorio, “Doctor’s Diary December 21, 2018: Who Should Be on Hospice?” *SCV Physician Report*, December 20, 2018, <http://scvphysicianreport.com/2018/12/20/doctors-diary-december-21-2018-who-should-be-on-hospice/> (accessed January 7, 2019).

41. Maryland Health Care Commission, *Maryland Hospital Palliative Care Programs: Analysis and Recommendations*, December 1, 2015, pp. 15–17, [http://dlslibrary.state.md.us/publications/Exec/DHMH/MHCC/HB581Ch379\(2\)2013.pdf](http://dlslibrary.state.md.us/publications/Exec/DHMH/MHCC/HB581Ch379(2)2013.pdf) (accessed December 14, 2018).

longer, and reported a higher quality of life than those who pursued more expensive and aggressive cancer treatment.⁴²

Palliative care also serves as the humane alternative for desperate patients who might otherwise consider opting for physician-assisted suicide.⁴³ It is especially relevant for patients in states that have legalized the practice. According to the World Health Alliance, palliative care “improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”⁴⁴

There are barriers to more widespread use of palliative care: a lack of public awareness that such a spectrum of specialized care even exists; an insufficient number of medical professionals trained to serve patients enrolled in palliative care programs;⁴⁵ and—importantly—a Medicare payment system that is incompatible with an effective system of integrated team-based care.

Hospice care is for terminally ill patients. Under the Medicare program, which delivers the largest share of such care, patients with a medical prognosis of six months or less to live are eligible.⁴⁶ Patients receive personalized care, counseling, and medications aimed at relieving pain and symptoms and providing comfort during the course of their terminal illness.⁴⁷ It is comprehensive and specialized care, providing services to control pain and distress, and it provides these patients with emotional as well as physical comfort in their last days.⁴⁸

Hospice care has grown rapidly in recent years. Researchers at the Kaiser Family Foundation reported that “[o]f all Medicare beneficiaries who died in 2014, 46 percent used hospice—a rate that has more than doubled since 2000 (21 percent).”⁴⁹ That year, Medicare hospice payments totaled \$15.1 billion, or an average of \$11,393 per beneficiary.⁵⁰

Under current law, however, hospice is available to Medicare patients only through traditional Medicare.⁵¹ Beneficiaries in Medicare Advantage plans may still receive Medicare hospice benefits under the

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42. Jennifer S. Temel, Joseph A. Greer, Alona Muzikansky, Emily R. Gallagher, Sonal Admane, Vicki A. Jackson, Constance M. Dahlin, Craig D. Blinderman, Juliet Jacobsen, William F. Pirl, J. Andrew Billings, and Thomas J. Lynch, “Early Palliative Care for Patients with Metastatic Non-Small-Cell Lung Cancer,” *The New England Journal of Medicine*, Vol. 363, No. 8 (August 19, 2010), pp. 733-742, <http://www.nejm.org/doi/full/10.1056/nejmoa1000678> (accessed December 14, 2018).
 43. “Some opinion polls show support for assisted suicide when it is presented as the only relief for a dying patient in unbearable pain. But when Americans are offered an alternative, they overwhelmingly say that society should concentrate on ensuring pain control and compassionate care for such patients—not on helping them take their lives. This preference is even stronger among dying patients themselves.” Richard M. Doerflinger and Carlos F. Gomez, “Killing the Pain Not the Patient: Palliative Care vs Assisted Suicide,” United States Conference of Catholic Bishops, 2018, <http://www.usccb.org/about/pro-life-activities/respect-life-program/killing-the-pain.cfm> (accessed December 14, 2018).
 44. World Health Alliance, “WHO Definition of Palliative Care,” 2018, <http://www.who.int/cancer/palliative/definition/en/> (accessed December 14, 2018).
 45. Debra Bradley Ruder, “From Specialty to Shortage,” *Harvard Magazine*, March–April 2015, <https://harvardmagazine.com/2015/03/from-specialty-to-shortage> (accessed December 14, 2018).
 46. U.S. Department of Health and Human Services, Centers for Medicare and Medicaid Services, “Medicare Hospice Benefits,” revised March 2018, pp. 4, 7, and 12, <https://www.medicare.gov/Pubs/pdf/02154-Medicare-Hospice-Benefits.PDF> (accessed December 14, 2018). If after six months the patient is still alive, Medicare regulations require the physician to certify for a second time that the patient has six months or less to live. In fact, only a very small percentage of Medicare patients exceed the six-month benefit period; the median time for patients receiving the Medicare hospice benefit is 17 days. Personal communication with Jason Bennett, Centers for Medicare and Medicaid Services, May 4, 2018.
 47. These teams include physicians, nurses, and pharmacists, among other professionals.
 48. As a practical matter, many of the professional services for these patients are the same for palliative care patients.
 49. Henry J. Kaiser Family Foundation, “10 FAQs: Medicare’s Role in End-of-Life Care,” September 26, 2016, <http://www.kff.org/medicare/fact-sheet/10-faqs-medicares-role-in-end-of-life-care/#footnote-153315-21> (accessed December 14, 2018).
 50. Table 1, “National Hospice Spending and Utilization, 2014,” in U.S. Department of Health and Human Services, Centers for Medicare and Medicaid Services, “Medicare Hospice Transparency Data (CY2014),” October 6, 2016, <https://www.cms.gov/newsroom/fact-sheets/medicare-hospice-transparency-data-cy2014> (accessed December 14, 2018).
 51. Medicaid also funds hospice care. In the case of Medicaid, however, the definition of terminal illness varies, and each individual state defines the condition. Some states opt for the federal standard of a six-month medical prognosis; others extend hospice care to cover persons with a 12-month prognosis. While state policies vary, the general practice is the same as Medicare: a physician recertification of hospice eligibility. Only a small percentage of patients, either under age 65 or legally ineligible for Medicare, are hospice beneficiaries.

terms and conditions of traditional Medicare while maintaining enrollment in Medicare Advantage.

Coverage Choices. Today, 48 percent of total spending on health care is direct government spending.⁵² Government also heavily regulates private health care spending. Thus, government officials influence, supervise, and control the current organization, financing, and delivery of American medical care. In the private sector, large and often notoriously noncompetitive third-party payment systems, not patients, make the key benefit, financing, and care delivery decisions.

In both the public and the private sectors, patients may discover that when it comes to questions concerning end-of-life care, their insurance carriers or care providers may be indifferent to their ethical, moral, or religious beliefs. The best way to resolve this serious problem would be to create a robust consumer choice system that enables individuals to choose the plans, benefit packages, and medical treatments and procedures that work best for them. Such a consumer-oriented shift would require substantial changes in federal policy with respect to medical payment and the financing of health insurance.

Sharing ministries—health arrangements based on voluntary cooperation among patients who pay into a common health fund for mutual care—are an alternative to conventional health insurance. The attractiveness of these programs, which are mostly Christian cooperatives, stems precisely from the fact that the doctors and medical professionals in such programs deliver medical services in accordance with the religious principles of the subscribers. Although sharing ministries are a valid option for many patients, Congress and the Administration should go further to ensure that Americans have a personal choice of health insurance plans that can

also provide care delivery in accordance with the ethical, moral, and religious convictions of their enrollees.⁵³

Physician-Assisted Suicide. Patients suffering from serious illness are not limited to the choice of unwanted life-prolonging care or assisted suicide to end their lives. This is a false dilemma. As noted previously, many alternatives are available to seriously ill patients, including the appropriate referral for palliative and hospice care.

The original Hippocratic Oath for physicians states: “I will keep [the sick] from harm and injustice. I will neither give a deadly drug to anybody who asked for it, nor will I make a suggestion to this effect.” Accordingly, doctors should provide ordinary medical care to alleviate pain and suffering, and thus enable patients to die a dignified natural death, but they should not kill patients or assist them in killing themselves. Medical killing is the ugly reality that such euphemisms as “death with dignity” and “aid in dying” seek to conceal.⁵⁴

Federal law prohibits federal funding for “any health care item or service furnished for the purpose of causing, or for the purpose of assisting in causing, the death of any individual such as by assisted suicide, euthanasia, or mercy killing.”⁵⁵ Six states (California, Colorado, Hawaii, Oregon, Vermont, and Washington) as well as the District of Columbia, however, have enacted laws legalizing physician-assisted suicide. State legislators who resort to the legalization of physician-assisted suicide, as explained in a Heritage Foundation analysis,⁵⁶ are enacting statutes that would endanger the weak and the vulnerable, corrupt the practice of medicine, undercut the traditional doctor–patient relationship, compromise family relationships, and betray the dignity and equality of human persons.

52. Jessica Banthin, Deputy Assistant Director, Congressional Budget Office, “Health Spending Today and in the Future: Impacts on Federal Deficits and Debt,” Presentation to a Conference Organized by the Center for Sustainable Health Spending, July 18, 2017, p. 10, <https://www.cbo.gov/system/files/115th-congress-2017-2018/presentation/52913-presentation.pdf> (accessed December 14, 2018).

53. For a more extensive discussion of this proposal, see Robert E. Moffit, Jennifer A. Marshall, and Grace V. Smith, “Patients’ Freedom of Conscience: The Case for Values-Driven Health Plans,” Heritage Foundation *Background* No. 1933, May 12, 2006, http://s3.amazonaws.com/thf_media/2006/pdf/bg1933.pdf.

54. For an excellent discussion of this pressing issue, see Ryan T. Anderson, “Always Care, Never Kill: How Physician-Assisted Suicide Endangers the Weak, Corrupts Medicine, Compromises the Family, and Violates Human Dignity and Equality,” Heritage Foundation *Background* No. 3004, March 24, 2015, http://thf_media.s3.amazonaws.com/2015/pdf/BG3004.pdf.

55. 42 U.S.C. § 14402. See the Assisted Suicide Funding Restriction Act, Public Law 105-12, 105th Cong., April 30, 1997, <https://www.congress.gov/105/plaws/publ12/PLAW-105publ12.pdf> (accessed December 17, 2018).

56. Anderson, “Always Care, Never Kill.”

Of particular concern is the fact that normalization of this practice endangers those who are poor, weak, or socially marginalized. As Marilyn Golden, a senior policy analyst with the Disability Rights Education and Defense Fund, warns:

The legalization of assisted suicide always appears acceptable when the focus is solely on an individual. But it is important to remember that doing so would have repercussions across all of society, and would put many people at risk of immense harm. After all, not every terminal prognosis is correct, and not everyone has a loving husband, family or support system.⁵⁷

Similarly, Dr. Ezekiel Emanuel, a professor of health policy at the University of Pennsylvania and adviser to former President Barack Obama, offers the poignant observation that in the final analysis, the legalization of physician-assisted suicide will have a disparate impact:

Whom does legalizing assisted suicide really benefit? Well-off, well-educated people, typically suffering from cancer, who are used to controlling everything in their lives—the top 0.2 percent. And who are the people most likely to be abused if assisted suicide is legalized? The poor, poorly educated, dying patients who pose a burden on their relatives.⁵⁸

The example of several European countries—the Netherlands, Belgium, Luxembourg—suggests that safeguards to ensure effective control have proved inadequate. In the Netherlands, “legal and medical guidelines” specify that patients can be euthanized based on a “free and explicit” request by the patient. In fact, an independent examination of the data shows that patients have been euthanized without such requests in thousands of cases, including cases

in which doctors “hastened” death by the inappropriate use of pain-killing drugs or medical care was withheld or withdrawn to “hasten” death.⁵⁹

The most common justifications for physician-assisted suicide are pain or the fear of pain and extended suffering, the prospect of being kept alive artificially by advanced medical technology, and the belief that the practice will guarantee a large number of patients a “good death.”⁶⁰ In fact, as Dr. Emanuel explains, these justifications are largely groundless:

Patients themselves say that the primary motive is not to escape physical pain but psychological distress; the main drivers are depression, hopelessness and fear of loss of autonomy and control.... Typically, our response to suicidal feelings associated with depression and hopelessness is not to give people the means to end their lives but to offer them counseling and caring.⁶¹

Victoria Reggie Kennedy, the wife of the late Senator Edward M. Kennedy of Massachusetts, perhaps said it best, writing in opposition to “a so-called ‘Death with Dignity’ initiative” that was on the ballot in Massachusetts in 2012:

My late husband Sen. Edward Kennedy called quality, affordable health care for all the cause of his life. Question 2 turns his vision of health care for all on its head by asking us to endorse patient suicide—not patient care—as our public policy for dealing with pain and the financial burdens of care at the end of life. We’re better than that. We should expand palliative care, pain management, nursing care and hospice, not trade the dignity and life of a human being for the bottom line.⁶²

57. Marilyn Golden, “The Danger of Assisted Suicide Laws,” CNN, updated October 14, 2014, https://awesomeenglish.weebly.com/uploads/1/3/5/5/13557234/the_danger_of_assisted_suicide_laws.pdf (accessed January 7, 2019).

58. Ezekiel J. Emanuel, “Four Myths About Doctor-Assisted Suicide,” *The New York Times*, October 27, 2012, <https://opinionator.blogs.nytimes.com/2012/10/27/four-myths-about-doctor-assisted-suicide/> (accessed December 14, 2018).

59. John Keown, “Euthanasia in the Netherlands: Sliding Down the Slippery Slope,” *Notre Dame Journal of Law, Ethics & Public Policy*, Vol.9, Issue 2 (1995), pp. 407–448, <https://scholarship.law.nd.edu/cgi/viewcontent.cgi?article=1427&context=ndjlepp> (accessed December 14, 2018).

60. Emanuel, “Four Myths About Physician-Assisted Suicide.”

61. *Ibid.*

62. Victoria Reggie Kennedy, “Question 2 Insults Kennedy’s Legacy,” *Cape Cod Times*, updated November 3, 2012, <http://www.capecodtimes.com/article/20121027/OPINION/210270347> (accessed December 14, 2018).

Strengthening End-of-Life Care

Much has been done and there is more that can be done to help fulfill patients' wishes at the end of life. Policymakers should develop policies that support the ability of patients and their families or designated representatives to make good decisions about end-of-life care in consultation with their doctors, other trusted advisers, and members of the clergy.⁶³ Specifically:

- **Educate the public and promote advance planning directives through the private sector, states, and Medicare.** First, private associations or religious institutions can undertake public awareness campaigns that highlight the potential benefits of advance planning for end-of-life care. Churches and religious organizations, in particular, can (and some do) provide the appropriate guidance for their congregants in such planning documents, clarifying the ethical and moral issues involved in the provision of end-of-life care. This planning can take the form of appointment of persons with power of attorney in health matters and specific medical instructions in instances of terminal illness, including advance directives. In all cases, whatever the legal instrument a person chooses, the law should guarantee that any such planning instruments are compatible with patients' ethical, moral, and religious values.

Second, states should make sure that the transmission of advance directives is effected in accordance with relevant privacy laws. States can promote the safe and efficient transmission of medical records, including patients' advance directives, as part of their responsibility to write laws and regulations. Maryland, for example, has established an "electronic advance directives" registry that allows 48 acute-care Maryland hospitals to receive and transmit patients' advance directives while protecting patient privacy.⁶⁴

At the federal level, Medicare should provide enrollees with unbiased information on advance planning in its annual *Medicare and You* handbook for beneficiaries. In addition, the Center for Medicare and Medicaid Innovation (CMMI) could test the effect of economic incentives, whether premium discounts or reduced cost sharing, for enrollees in traditional Medicare and Medicare Advantage who voluntarily choose to file personal advance directives that are compatible with their ethical, moral, and religious convictions.⁶⁵ Conceptually, the use of economic incentives for advance planning would be analogous to the practice of some private businesses and health insurers that provide their enrollees with premium discounts if they enroll in wellness programs or participate in prevention programs. Today, for example, 46 percent of large firms already lower premiums or cost sharing for employees who complete a health risk assessment.⁶⁶

- **Move forward with innovative payment models for palliative care in Medicare.** Traditional Medicare covers about two-thirds of all Medicare beneficiaries. Traditional Medicare currently finances palliative care services at standard government reimbursement rates under its existing fee-for-service system, but care for specific services, funded through Medicare Parts A or B, is unnecessarily fragmented and incompatible with the team approach that such care requires. Thus, palliative care is burdened by Medicare's rigid and inflexible bureaucratic payment system. To remedy this, HHS should continue to move forward with three promising changes to expand access to palliative care.

In Medicare Advantage, the Centers for Medicare and Medicaid Services (CMS) is proposing rule changes that would give Medicare Advantage plans greater flexibility in providing supplemental benefits. With regard to seriously ill patients, the proposal would allow these plans to offer "home-

63. "The final phase of life often has a spiritual and religious component, and recent research has shown that spiritual assistance is associated with quality of care." Institute of Medicine, *Dying in America*, p. 11.

64. See Maryland Health Care Commission, "Health Information Technology: Electronic Advance Directives," last updated July 27, 2018, http://mhcc.maryland.gov/mhcc/pages/hit/hit_advancedirectives/hit_advancedirectives.aspx (accessed December 14, 2018).

65. Under current law, Medicare Advantage plans may not offer premium discounts. Plans potentially could use cost-sharing incentives.

66. Figure 12.5, "Among Large Firms Offering an Incentive to Workers Who Complete a Health Risk Assessment, Percentage of Firms Using Different Types of Incentives, by Firm Size, 2018," in Henry J. Kaiser Family Foundation, *Employer Health Benefits: 2018 Annual Survey*, October 2018, p. 192, <http://files.kff.org/attachment/Report-Employer-Health-Benefits-Annual-Survey-2018> (accessed December 14, 2018).

based palliative care,” a benefit for persons with a life expectancy beyond six months: “This change will allow MA-contracted nurses and social workers—whose time is not directly billable under traditional Medicare Fee for Service—to go into the home to provide the high quality services that palliative care includes.”⁶⁷

HHS Secretary Alex Azar is also examining two new payment models that would aim to secure better value for palliative care dollars.⁶⁸ A proposal from the American Academy of Hospice and Palliative Care Medicine would test a Medicare payment arrangement for interdisciplinary palliative care teams that would consist of base payments adjusted for measures of performance. These Medicare palliative care teams, alternatively, could share bonuses and losses in meeting performance goals in taking on the total cost of care for enrolled patients.⁶⁹

The Coalition to Transform Advanced Care proposes the creation of an alternative payment arrangement for the care of patients in their final year of life. Its Advanced Care Model would replace traditional Medicare payment with a payment system that includes quality bonuses for performance by a multidisciplinary team of doctors, nurses, and social workers.⁷⁰

- **Test innovative proposals in Medicare Advantage to expand access to hospice care.** Traditional fee-for-service Medicare alone has the legal authority to provide hospice services. Yet Medicare Advantage, a system of competing private health plans, covers more than one-third of the Medicare population and is growing rapidly.

CMMI could test the provision of hospice care within the Medicare Advantage program through a demonstration to allow Medicare Advantage plans to offer hospice benefits with the broad flexibility to meet the holistic needs of dying patients. Such a demonstration would determine whether these private health plans could secure lower costs, better outcomes, and higher satisfaction among hospice-care patients and their families than is achieved through traditional Medicare.

- **Expand personal choice of health plans and providers.** In both the public and the private sectors, patients may discover that their insurance carriers or care providers are indifferent to their ethical, moral, or religious beliefs with respect to end-of-life care. Resolution of this serious problem could best be achieved through creation of a consumer choice system that enables individuals to choose the insurance coverage, benefit packages, and medical treatments and procedures that work best for them. Such a consumer-oriented shift would require substantial changes in federal policy on medical payment and the financing of health insurance.

Washington policymakers should start by inviting religious organizations to sponsor health plans within the two federally organized, consumer-driven health insurance programs, Medicare Advantage and the Federal Employees Health Benefits Program (FEHBP). Such plans would be able to offer services, including end-of-life care, that are consistent with the religious values of their subscribers or policyholders. Likewise, Congress and the Administration should eliminate any regulatory or statutory barriers, particularly the restrictive tax treatment of health insurance, that today

67. Stacie Sinclair, Allison Silvers, and Torrie Fields, “Change Is Coming to a Medicare Advantage Plan Near You,” Center to Advance Palliative Care, *The Palliative Pulse*, June 4, 2018, <https://palliativeinpractice.org/palliative-pulse/the-palliative-pulse-june-2018/change-is-coming-to-a-medicare-advantage-plan-near-you/> (accessed December 14, 2018). For a further discussion of this new rule, see Meridian Paulton and Robert E. Moffit, “Expanded Health Benefits for Seniors; The Trump Administration’s Changes to Medicare Advantage’s Supplemental Benefits,” *Heritage Foundation Issue Brief* No. 4900, October 1, 2018, https://www.heritage.org/sites/default/files/2018-10/IB4900_0.pdf.

68. “Under both models, doctors, nurses, and spiritual providers would work together under such incentivized payment arrangements as risk payments or care-management fees to develop and execute a coordinated care plan for seniors in advance stages of illness.” Virgil Dickson, “Federal Advisory Panel Urges Creation of Palliative-Care Model,” *Modern Healthcare*, March 26, 2018, <http://www.modernhealthcare.com/article/20180326/NEWS/180329932> (accessed December 14, 2018).

69. American Academy of Hospice and Palliative Medicine, *Payment Reforms to Improve Care for Patients with Serious Illness: Patient and Caregiver Support for Serious Illness*, August 2017, <https://aspe.hhs.gov/system/files/pdf/255906/ProposalAAHPM.pdf> (accessed December 14, 2018).

70. Coalition to Transform Advanced Care, *Advanced Care Model (ACM) Service Delivery and Advanced Alternative Payment Model*, October 4, 2017, <https://aspe.hhs.gov/system/files/pdf/253406/ACM.pdf> (accessed December 14, 2018).

frustrate or penalize individuals and families who may wish to purchase new and innovative health plans in the individual health insurance markets.⁷¹

- **Oppose physician-assisted suicide.** Thus far, six states (California, Colorado, Hawaii, Oregon, Vermont, and Washington) and the District of Columbia have enacted laws legalizing physician-assisted suicide. Notwithstanding favorable polling, there seems to be a residual moral uneasiness about these laws. The District of Columbia enacted its assisted suicide law in 2017, for example, but not one patient has invoked the law, and only two out of the District's 11,000 physicians have signed up to assist in suicide.⁷² Policymakers at the state and federal levels should oppose further efforts to legalize physician-assisted suicide, and state legislators should roll back existing laws that legitimize physician-suicide.

Conclusion

Given the combination of a rapidly aging population and the increasing budgetary pressures of federal health entitlements, end-of-life care issues require the attention of all Americans—patients and their families and friends as well as policymakers. As Eric Cohen has observed:

The real challenge upon which the future of American bioethics will turn is learning how to live and die without trampling on the principle of human equality in the name of medical research, and learning how to step aside for the next generation without treating the debilitated elderly with a fiscally responsible inhumanity.⁷³

The role of public policy in this area is limited. Policymakers should oppose physician-assisted suicide, an option that is incompatible with the inherent value of human life. They should encourage advance planning for end-of-life care and access to the benefits of palliative care by promoting public awareness and by improving

Medicare payment. At a time when there is deepening conflict over moral values in health care, policymakers should break down barriers that prevent Americans from exercising their personal choice from among different types of health plans and teams of medical professionals. Specifically, Americans should be able to choose the kinds of health plans they want, including those that respect their ethical values and religious convictions, as they make these sensitive end-of-life decisions.

Congress and the Administration need to improve the financing and delivery of care in Medicare with a goal of expanding greater patient choice and injecting, to the degree possible, market competition that will improve care delivery and secure better patient outcomes. The Trump Administration should follow through on other Medicare demonstrations that would lay the groundwork for major improvements in the care of the seriously or terminally ill. Most important, the Administration should test and report progress on alternative payment models for palliative care and hospice care in Medicare.

Public officials should recognize that their role is a supportive one. The key decision-makers in this area are individual persons, as patients, in consultation with their families or designated caregivers and with the advice, counsel, and assistance of trusted medical and religious authorities. Public officials' contribution is to ensure that patients and their families, with the assistance of their doctors and other trusted advisers, have the necessary space and resources to discuss and sort through difficult decisions well before they face a personal and family crisis.

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71. For a more detailed discussion of the impediments to personal health plan choice in the federal tax code, see Edmund F. Haislmaier, Robert E. Moffit, and Alyene Senger, "Fairness in the Federal Tax Treatment of Health Insurance: The Linchpin of Real Reform," Heritage Foundation Issue Brief No. 4659, February 24, 2017, https://www.heritage.org/sites/default/files/2017-02/IB4659_0.pdf.

72. Fenit Nirappil, "A Year after D.C. Passed Its Controversial Assisted Suicide Law, Not a Single Patient Has Used It," *The Washington Post*, April 10, 2018, https://www.washingtonpost.com/local/dc-politics/a-year-after-dc-passed-its-assisted-suicide-law-only-two-doctors-have-signed-up/2018/04/10/823cf7e2-39ca-11e8-9c0a-85d477d9a226_story.html?noredirect=on&utm_term=.7522e323f705 (accessed December 14, 2018).

73. Cohen, "In Whose Image Shall We Die?"