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# The Case for Advance Care Planning

## The problem

Too few Americans have planned the care that they wish to receive near the end of their lives, despite the many proven benefits that such planning provides for patients and their families. As a result, many people receive care that does not align with their preferences and values.

## The solution

Increase the use of advance care planning, which will give more patients the opportunity to understand their options, communicate their preferences, and ensure that their wishes are recorded and honored by health providers and family members.

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## What Is Advance Care Planning?

Advance care planning is the “discussion of end-of-life care, clarification of related values and goals, and embodiment of preferences through written documents and medical orders.”\* These discussions occur among patients, their doctors, and their families and are revisited as needed. Advance care planning conversations can help people understand their diagnoses, the health care choices they are likely to face, and the potential risks and benefits of different treatment options.

\* Institute of Medicine, *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*, (Washington, DC: National Academies Press, 2014), 3-4.

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## Why is advance care planning important?

Numerous studies demonstrate that even the sickest people rarely discuss their preferences for end-of-life care—the medical treatment received in the final months and weeks of life—with loved ones or their medical care teams. For example, a recent study of patients with advanced cancer found that only 27 percent had discussed end-of-life issues with their oncologists, and most had never discussed pain management with any doctor.<sup>1</sup> A 2012 survey by the California HealthCare Foundation found that more than three-quarters of respondents wanted to talk to their doctors about their end-of-life care wishes, yet 90 percent said a doctor had never asked them about those issues.<sup>2</sup>

Unfortunately, health care agents, or surrogates, often have to make decisions on behalf of seriously ill loved ones. When advance care planning conversations have not occurred, caregivers are forced to guess what patients would want.<sup>3</sup> Research has found that people often receive aggressive treatments in the intensive care unit and ultimately die in the hospital when they would have preferred to die in their homes. Furthermore, family members struggle to make decisions for dying patients and experience stress, guilt, and regret when they aren't confident that they know their loved one's wishes.<sup>4</sup>



It's always too early, until it's too late."

The Conversation Project, 2013

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## Benefits of advance care planning

Rigorous research has demonstrated that people who participate in advance care planning reap many benefits. They are more likely to have their end-of-life wishes known and respected.<sup>5</sup> Patients and their families are more satisfied with the care received after they have these conversations with doctors.<sup>6</sup> Furthermore, people are less likely to receive unwanted aggressive medical treatments in their last weeks of life;<sup>7</sup> less likely to die in the hospital or intensive care unit;<sup>8</sup> and more likely to enroll in hospice,<sup>9</sup> a comprehensive care program that supports patients and their families in the final phase of terminal illness with a focus on comfort and quality of life.

Some people worry that talking about death can cause patients and families to lose hope and even become sicker. However, research shows that advance care planning does not lead to depression, anxiety, or emotional suffering<sup>10</sup> and has no impact on patient survival.<sup>11</sup> Although these conversations can be very emotional, families and patients generally find them helpful and appreciate the opportunity to prepare for the future.

### How Advance Care Planning Helps Families

Family members of dying patients also benefit from advance care planning. Relatives of those who participate have a better understanding of the patient's wishes, and therefore greater confidence and less stress in making end-of-life treatment decisions for their loved one.\* Families that have frank conversations in preparation for death experience less burden as caregivers<sup>†</sup> and go through less post-traumatic stress, depression, anxiety, and emotional trauma after the patient's passing.<sup>‡</sup> A 2013 survey revealed that more than 9 in 10 Americans think it is important to talk about their wishes for end-of-life care, yet only 3 in 10 have held these discussions.<sup>§</sup>

\* David Wendler and Annette Rid, "Systematic Review: The Effect on Surrogates of Making Treatment Decisions for Others," *Annals of Internal Medicine* 154, no. 5 (2011): 344, doi: 10.7326/0003-4819-154-5-201103010-00008.

† Rhea A. Stein et al., "Randomized Controlled Trial of a Structured Intervention to Facilitate End-of-Life Decision Making in Patients With Advanced Cancer," *Journal of Clinical Oncology* 31, no. 27 (2013): 3406, doi: 10.1200/JCO.2011.40.8872

‡ Karen M. Detering et al., "The Impact of Advance Care Planning on End-of-Life Care in Elderly Patients: Randomized Controlled Trial," *The BMJ* 340 (2010): 4-5, doi: 10.1136/bmj.c1345.

§ The Conversation Project, "New Survey Reveals 'Conversation Disconnect': 90 Percent of Americans Know They Should Have a Conversation About What They Want at the End of Life, Yet Only 30 Percent Have Done So" (2013), [http://theconversationproject.org/wp-content/uploads/2013/09/TCP-Survey-Release\\_FINAL-9-18-13.pdf](http://theconversationproject.org/wp-content/uploads/2013/09/TCP-Survey-Release_FINAL-9-18-13.pdf).

## Increasing the use of advance care planning

Given the importance of advance care planning, we all must work together to eliminate barriers to its effective use. One historical barrier has been that providers have not been paid for these conversations with patients.<sup>11</sup> In July 2015, however, Medicare addressed this challenge by proposing to pay providers for time spent engaging with patients on advance care planning.

Other challenges remain, however. For example, it can be difficult to access advance care planning documents across different care settings. We also lack good ways to measure the quality of care received at the end of life, and whether that care was consistent with a patient's preferences. The Care Planning Act, sponsored by Senators Johnny Isakson (R-GA) and Mark Warner (D-VA), would address these and other issues. The passage of this and similar legislation can ensure that some of the most vulnerable patients are able to express their preferences and have their wishes honored at the end of their lives.

## Endnotes

- 1 Jennifer W. Mack et al., "End-of-Life Discussions Among Patients With Advanced Cancer: A Cohort Study," *Annals of Internal Medicine* 153, no. 3 (2012): 4–5, doi: 10.7326/0003-4819-156-3-201202070-00008.
- 2 California HealthCare Foundation, "Final Chapter: Californians' Attitudes and Experiences With Death and Dying" (2012), <http://www.chcf.org/publications/2012/02/final-chapter-death-dying>.
- 3 Maria J. Silveira, Scott Y. H. Kim, and Kenneth M. Langa, "Advance Directives and Outcomes of Surrogate Decision Making Before Death," *New England Journal of Medicine* 362, no. 13 (2010): 12141216, doi: 10.1056/NEJMsa0907901.
- 4 David Wendler and Annette Rid, "Systematic Review: The Effect on Surrogates of Making Treatment Decisions for Others," *Annals of Internal Medicine* 154, no. 5 (2011): 344, doi: 10.7326/0003-4819-154-5-201103010-00008.
- 5 Karen M. Detering et al., "The Impact of Advance Care Planning on End-of-Life Care in Elderly Patients: Randomized Controlled Trial," *The BMJ* 340 (2010): 4–5, doi: 10.1136/bmj.c1345.
- 6 Ibid.
- 7 Joan M. Teno et al., "Association Between Advance Directives and Quality of End-of-Life Care: A National Study," *Journal of the American Geriatrics Society* 55, no. 2 (2007): 192, doi: 10.1111/j.1532-5415.2007.01045.x.
- 8 Rhea A. Stein et al., "Randomized Controlled Trial of a Structured Intervention to Facilitate End-of-Life Decision Making in Patients With Advanced Cancer," *Journal of Clinical Oncology* 31, no. 27 (2013): 3406, doi: 10.1200/JCO.2011.40.8872; Detering et al., "The Impact of Advance Care Planning," 4–5.
- 9 Lauren H. Nicholas et al., "Regional Variation in the Association Between Advance Directives and End-of-Life Medicare Expenditures," *Journal of the American Medical Association* 306, no. 13 (2011): 1451, doi: 10.1001/jama.2011.1410.
- 10 Stein et al., "Randomized Controlled Trial of a Structured Intervention," 3406.
- 11 Detering et al., "The Impact of Advance Care Planning," 4–5.

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## For further information, please visit:

[pewtrusts.org/en/projects/improving-end-of-life-care](http://pewtrusts.org/en/projects/improving-end-of-life-care)

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