



# Advance Care Planning Leads to Wished-For Care

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In the 1950s, dying often occurred at home, with family present. Today, death often occurs in health care institutions, with strangers as witnesses. “In many ways, dying has become a lot harder,” writes Ira Byock, MD, chief medical officer of the Institute for Human Caring of Providence St. Joseph Health in Torrance, California.<sup>1</sup>

Most people are not familiar with death’s 21st-century guise. It is hard to imagine, because it often takes place hidden behind the walls of hospitals and skilled nursing facilities. Most people are blissfully unaware that the blitz of medical interventions that accompany modern death in no way resembles what they see in movies and on television. That is, of course, until it happens to them or their loved ones.

Our death “illiteracy” is further exacerbated by our collective denial about death and dying — an aversion to talking openly about the limits of medicine that is shared by both patients and clinicians. Although denial can be a protective defense in the face of adversity for the short term, it does have a dark side, and it can stand in the way of progress and moving forward.

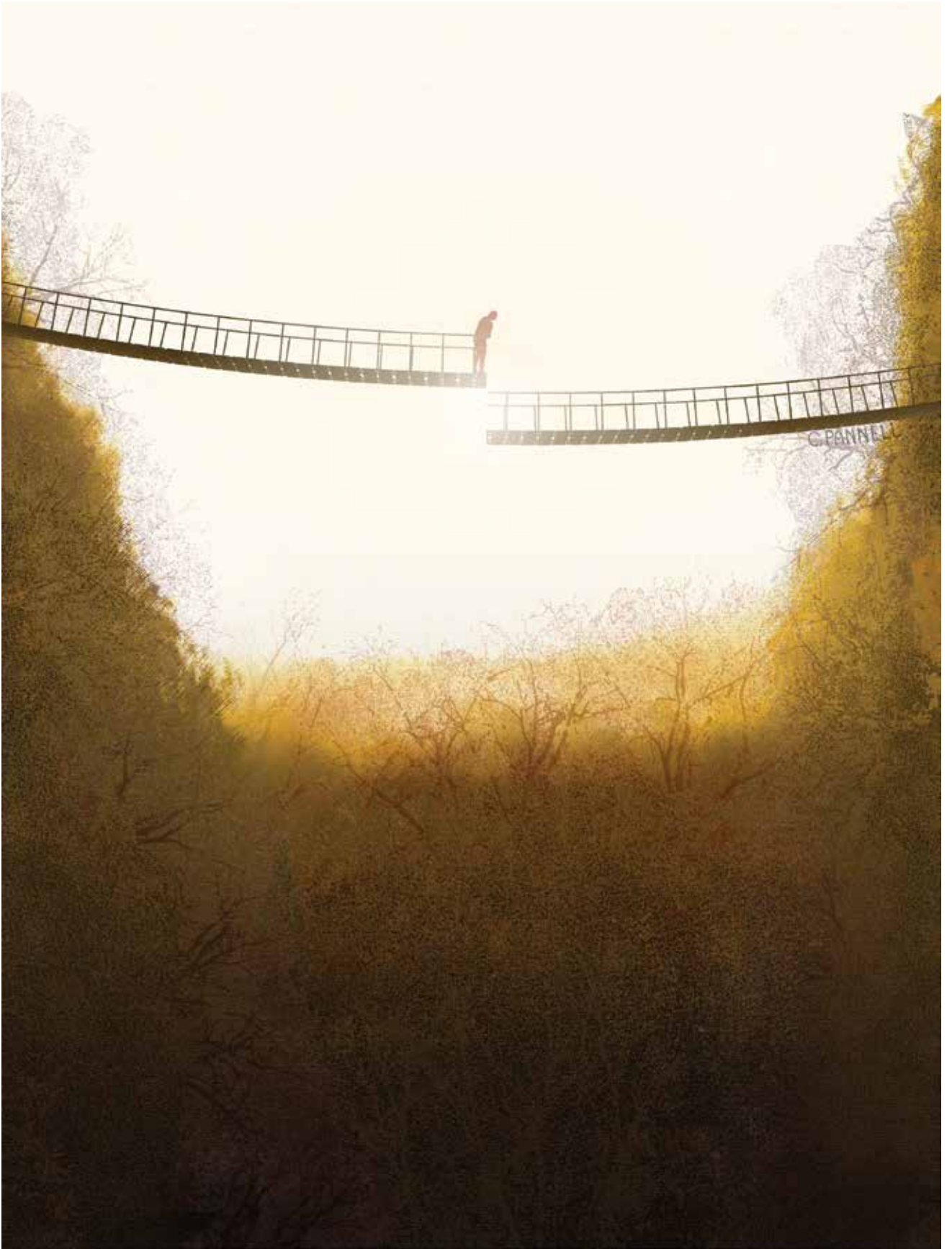
Notwithstanding our societal hang-ups, time has brought powerful demographic shifts. In the 1950s, nearly 10 percent of the population was older than 65.<sup>2</sup> Currently it is approximately 15 percent, and within the next few decades, 20 percent of the population is projected to be over age 65.<sup>3</sup> We are able to stave off death because of scientific breakthroughs and medical technology, but we do so at the cost of “prolonged serious illness, physical dependence, senescence, and senil-

ity” in our later years. Longevity is extended, but quality often is compromised.

As our increasingly diverse country ages, and chronic illness grows more prevalent, we need to reach back for the oldest tool in medicine: communication, namely, conversations about people’s values, goals and medical preferences. Such a discussion often is referred to as advance care planning or “the conversation.”

Advance care planning is a critically important, person-centered and family-oriented process to help people receive high-quality health care that is aligned with their values and goals. For example, such planning can prevent unwanted medical interventions or clearly state the patient’s treatment wishes if he or she should become unable to communicate.

When done well, advance care planning leads to an increase in the quality of communications, decreased conflict over decisions and less likelihood of dying in the hospital if the patient wishes to die at home.<sup>4</sup> It also can lead to the creation of a flexible and personalized care plan that: 1) recognizes the inherent uncertainty of predicting the future; and 2) appreciates that values and preferences often change over time as an individual’s medical condition changes.



## WHAT PEOPLE WANT VS. WHAT THEY GET

Although studies have shown that approximately 80 percent of Americans would prefer to die at home,<sup>5</sup> a little less than a quarter of Americans older than 65 are able to do so. People often want (and expect) to be in control of decisions about their health care. But the reality is often very different, as many people with advanced serious illness are not mentally or physically capable of making their own care decisions as they near the end of their life. Many unfortunately receive care that is not concordant with their values, goals and informed preferences.

When people with serious illness end up getting aggressive medical interventions that they would prefer not to receive in the advanced stages of a disease, it is a critical problem. Though it may cause additional pain and suffering, aggressive medical intervention clearly has saved millions of lives when performed in patients who have a treatable illness and a reasonable prognosis. But the risk-benefit calculus for burdensome treatment is far more difficult and uncertain for patients with a terminal illness. For them, the burdens may be great and the benefits minimal. Such aggressive — and frequently costly — medical interventions that often are ineffective in terminal illness should be called what they are: medical errors.

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Granted, medical errors usually are described as human errors in which doctors choose an inappropriate intervention or method of care, such as performing surgery on the wrong leg, or administering medication to the wrong patient. But even though they can be lifesaving, medical interventions like CPR, breathing machines and feeding tubes must be considered medical errors if they are performed only because the default in health care is to do more unless a patient says to stop. Exploring peoples' preferences and goals of care through advance care planning is paramount.

## WITHIN THE LARGER CULTURE

Once mischaracterized as “death panels,” advance care planning gained attention and support from the National Academy of Medicine, (formerly known as the Institute of Medicine) in a September 2014 consensus report that examined the need to improve the nation's end-of-life care system.<sup>6</sup> It also identified opportunities for improvement in advance care planning and shared decision-making. A succession of critically acclaimed and widely read books, including *Being Mortal: Medicine and What Matters in the End*, by Atul Gawande, MD; *When Breath Becomes Air*, by Paul Kalanithi, MD; and *Extreme Measures: Finding a Better Path to the End of Life*, by Jessica Nuttik Zitter, MD, have helped raise the national consciousness regarding modern death and the importance of advance care planning.

In January 2016, the Centers for Medicare and Medicaid Services finalized new Medicare billing codes and rates for reimbursing clinicians for time spent talking with patients and their loved ones about advance care planning. According to federal data, use of advanced care planning services in 2016 was nearly two times greater than some industry projections.<sup>7</sup> Clinicians billed for advance care planning conversations for more than half a million Medicare beneficiaries and received \$43 million in Medicare reimbursements and \$50 million in patient deductibles and coinsurance.<sup>8</sup> Now that advance care planning has hit the national stage, we need to step back and consider how to make it better.

## CHANGES IN APPROACH

Although clinicians have engaged in advance care planning with patients and their families for many years, the conceptual landscape has evolved from a legal transactional approach to a communications approach. Early on, the focus was on the completion of legal documents like advance directives that would describe an individual's health care goals and appoint an agent or proxy health care decision-maker in the event one is needed. Not surprisingly, the process was treated much like a contract in which there was a transfer of a property interest from one person to another, with accompanying rights and responsibilities.



Unfortunately (but not surprisingly), advance directives “have had relatively little impact on end-of-life decision making” and have been disappointingly ineffective. This is because of barriers that are conceptual (general reluctance to explore death and dying), structural (inadequate clinician training, etc.) and procedural (restrictions on who can serve as a health care agent or proxy), notwithstanding the passage of the Patient Self-Determination Act of 1990 and multiple initiatives to promote their use.<sup>10</sup>

To date, only about a third of Americans with advanced illness have completed advance directives.<sup>11</sup> Nearly 1 in 4 skilled nursing facility residents with dementia do not have an advance directive.<sup>12</sup> Furthermore, even when those documents are completed, they may not be readily available or followed, thereby having little effect on the care that patients receive at the end of life.<sup>13</sup> It is time to move beyond relying solely on advance directives.

#### SHIFT TO COMMUNICATION

Over the past 25 years, the legal transactional approach slowly has been replaced by one that is more comprehensive, an ongoing and flexible process of communication. This approach emphasizes continuing conversations between patients, their loved ones and their health care team. The goal is twofold: 1) to reach a shared understanding of the patient’s diagnosis, prognosis and medical options, as well as his or her values, beliefs and goals; and 2) to involve the patient’s loved ones (especially designated surrogates) as engaged, prepared and empowered participants in these careful discussions, so that they would be able to make decisions guided by the patient’s values and goals.

The conversations not only help lead to a care plan that matches patients’ values, goals, and preferences, they also illuminate possible medical complications, information patients and/or surrogates need to understand and discuss as they make choices. The focus is on shared decision-making in which the clinician and patient engage in a comprehensive give-and-take — not the completion of a standardized document nor satisfying the letter of the law/meeting institutional quality performance measures in a perfunctory or ritualistic way.

Among the important stakeholders in advance care planning initiatives are: 1) patients and their

loved ones; 2) clinicians; 3) health care systems; and 4) communities that are increasingly culturally, ethnically and spiritually diverse. To be effective, the initiatives must recognize — and navigate around — barriers in health care delivery. For example, people with low to moderate health

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literacy need specific tools that help educate and inform them of their medical options. Such tools once amounted to written pamphlets and documents, but newer, innovative media such as videos have shown great promise in helping patients during advance care planning.

For health care systems undertaking an advance care planning initiative, videos are cost effective and help scale the efforts faster. In terms of community engagement, advance care planning undertakings not only must be inclusive of our country’s changing demographics, they must focus on bringing information outside the health care system to engage people in houses of worship and in the public square.

#### CONCLUSION

Advance care planning is emerging as an important priority for patients, our society and our health care systems. The “silver tsunami” of older people facing chronic serious illness likely will leave a large imprint on the practice of medicine — as will heightened public consciousness of death and dying initiatives.

Conducting effective advance care planning conversations is a skill. Clinician training will need to begin in graduate school and continue during residency and post-graduate training. For more senior clinicians, instruction in advance care planning can be provided through recertification or continuing medical education.

Implementing advance care planning should focus on comprehensive patient, community and health care system innovations. Large-scale efforts to spread advance care planning within various health care systems are attempting to ensure patients’ values are respected and hon-

ored, but there is unlikely to be a quick or simple fix. Systems will need to learn how to use data analytics to identify patients who would most benefit from advance care planning and develop electronic health record standardized order sets that detail plans for end-of-life care.

Ultimately, advance care planning strives to rectify an intractable problem: the misalignment between the care patients desire and the care they are delivered. Anything less than a complex solution for such a complex problem is unlikely to be successful, but anything less than a full, concerted effort to honor patients' wishes is unacceptable.

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#### NOTES

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