WHOLE PERSON CARE INITIATIVE A Collaborative Project of the California Bishops and Catholic Health Care Leaders

Introduction

When the California End-of-Life Options Act took effect on June 9, 2016, California joined Oregon, Washington and Vermont in legalizing physician-assisted suicide (PAS). In November 2016, Colorado voters overwhelmingly approved a ballot-initiated PAS statute, and Washington, D.C. recently enacted a similar measure. In the past two years, PAS legislation has been introduced in more than half the states, and public opinion polls reveal that upwards of 65% of U.S. voters now support legalizing it.

The Crisis in U.S. Health Care

Growing public support for PAS is, in large measure, indicative of a deep crisis in the U.S. health care system. For good reasons, many Americans do not trust that they and their loved ones will be appropriately and effectively cared for when they experience a terminal illness. A 2015 Institute of Medicine study revealed that the experience of dying in the United States is often characterized by fragmented care, inadequate treatment of distressing symptoms, frequent transitions among care settings, and enormous care responsibilities for families. According to this report, the current health care system of rendering more intensive services than are necessary and desired by patients, and the lack of coordination among programs increases risks to patients and creates avoidable burdens on them and their families. ¹

Nearly everyone knows or has heard of someone who has died badly while receiving sophisticated and expensive life-sustaining treatments in hospitals or nursing homes. Many of these people endured their final days in pain, feeling undignified and a burden to others. At the same time, their loved ones were feeling bereft and bewildered, unsure how to get through each day or how to plan for the future. Worse still was the realization later that much of this suffering was unnecessary. It is not surprising, then, that fearing the possibility of dying badly in a health care facility, the public increasingly believes terminally ill patients should have the legal option of ending their lives.

Impact on Families

Advances in treating disease have multiplied both the complexity and duration of family caregiving. Today, more than 60 million Americans are tending a frail elder, other adult or sick child at home. Even otherwise excellent medical treatments and hospital care may leave a family not knowing how to care well for an ill loved one. By the end of a long illness, family members are often physically and emotionally exhausted. Up to a third of close family members of patients treated in an ICU experience anxiety or depression consistent with post-traumatic stress disorder. Moreover, the collective impact of longer lives and periods of physical dependency affect the economic well-being of individuals and families. Families commonly miss the lost income that results from sickness and caregiving, absorb often large out-of-pocket expenses, and worry that costs might exceed the lifetime limits of their insurance coverage.

Clearly, a transformation is needed in the way society – not merely our health care system – cares for seriously ill people and supports family caregivers.

¹ Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life,
Committee on Approaching Death: Addressing Key End-of-Life Issues, Institute of Medicine of the National Academies, Washington, D.C., 2014.

Care Transformation vs. Assisted Suicide

Physician-assisted suicide is not the answer. It represents patient abandonment, rather than dignified, compassionate, loving care and accompaniment through the end of life. The people most likely to be abused by assisted suicide are the poor, poorly educated, dying and depressed patients who are perceived as – or encouraged to perceive themselves as – a burden to their families or society. As society becomes comfortable with this practice, and as the responsibility and financial cost of chronic illness continue to shift to patients and families, pressure will build to extend it to others who, in society's view, are suffering and leading so-called "purposeless lives." Finally, the growing acceptance of physician-assisted suicide will create powerful economic and political disincentives against making the public and private investments required to transform and improve the quality and availability of palliative care for the terminally ill and their loved ones.²

The Church's Response

The Bishops and Catholic health care leaders³ in California believe that the need to transform the way in which society cares for the chronically and terminally ill requires urgent and decisive action on the part of the Church. Accordingly, they recently resolved to focus their collective energies during the next five years on developing a robust **Whole Person Care Initiative** to ensure that their parishioners and patients are loved and supported, can openly talk with their spiritual leaders, clinicians, and family members about their wishes at the end of life, and have access to quality palliative care before they suffer needless medical procedures. On October 19, 2016, the Bishops and health care leaders adopted the following Aspirational Statement:

"As Church and Catholic health care leaders in California, we believe that physician-assisted suicide, while legal, is not yet an entrenched cultural or clinical reality. Recognizing this, we are committed to developing together, and in collaboration with other leaders in the palliative care field, a medical and pastoral approach to care through the end of life that provides a dignified, compassionate, and loving alternative to physician-assisted suicide for seriously ill people and their families. Our intent is to create a Church and Catholic health care collaborative model that serves our California parishioners and patients well, and that can be replicated by Church and Catholic health care leaders in other states."

The California Bishops and health care leaders believe that by caring well for the frailest and most vulnerable in their dioceses, parishes and health care facilities, they can improve care for many people now and in the years to come; they can make clear that the best care possible not only includes excellent disease treatments, but also concern for a person's physical comfort, and emotional and spiritual well-being; and they can raise broader cultural expectations about the kind of end of life care people need, deserve and should demand. In so doing, they believe we can protect the breadth of our human endowment in ways that will be felt long into the future. And that the healthiest response to death is to love, honor, and celebrate life.⁴

² For example, for budgetary reasons, California Governor Jerry Brown recently delayed implementation of SB 1004, which requires Medi-Cal to establish standards and provide technical assistance to Medi-Cal managed care plans and ensure the delivery of palliative care services to Medi-Cal beneficiaries. 10 million low income Californians are covered by Medi-Cal managed care plans. Meanwhile, Medi-Cal has budgeted \$2.5 million to cover lethal drugs in the first year of the End of Life Option Act. http://coalitionccc.org/2014/09/gov-brown-signs-sb-1004-medi-cal-to-cover-palliative-care-for-adults/

The Chief Executive Officers of Dignity Health and Providence St. Joseph Health, respectively Lloyd Dean and Rod Hochman, MD.

⁴ For an extended treatment of the issues addressed here, see: *The Best Care Possible: A Physician's Quest to Transform Care Through the End of Life*, Ira Byock, MD, Avery, New York, N.Y., 2013.