

The Need

There is a health care crisis in America. Its impacts are felt in every aspect of the health care system, and none more significantly than in the availability of high quality palliative care for the terminally ill and their families. 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.

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.

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.

The Reponse

The Bishops and Catholic health care leaders 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 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 high quality, lower cost 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.”

By caring well for the frailest and most vulnerable in our dioceses, parishes and health care facilities, we can improve care for many people now and in the years to come; we 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 we can raise broader cultural expectations about the kind of end of life care people need, deserve and should demand. In so doing, we 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.

Whole Person Care Initiative | California

The Whole Person Care Initiative will create a Church and Catholic health care collaborative model that serves vulnerable parishioners/patients and others well and less expensively, can be replicated by Church and Catholic health care leaders in other states, made available on an ecumenical and interfaith basis to other faith traditions, as well as to other interested parties.

Vision. *Persons in our congregations, communities, and hospitals are loved, wanted and worthy, and will be prepared and supported in health and serious illness through the end of life.*

Purpose. Strengthen and improve the availability of Whole Person Care and palliative care services in Catholic health care systems and their hospitals, and Develop and implement Whole Person Care and palliative care programs in dioceses and parishes.

The Whole Person Care Initiative is governed by a Leadership Council comprised of health care and Church leaders and principals from the Alliance of Catholic Health Care, the California Catholic Conference, the Institute for Human Caring, and representatives from other medical centers. Catholic health care systems operate 50 hospitals in California. There are 2 archdioceses, 10 dioceses and more than 1,000 parishes in California. There are 10 million Catholics in California, constituting 28 percent of the state's population.

The Whole Person Care Initiative is being enthusiastically received in dioceses, parishes and clinical settings. It has also cemented an essential bond between Church and Catholic health care leaders.

Goals and Outcomes. The Whole Person Care Initiative (WPCI) will leverage diocesan training systems to develop networks of volunteers in 1000+ parishes that will provide skilled and compassionate pastoral support to the dying.

When fully implemented in mid-2022, WPCI will have dramatically improved the quality and availability of palliative care services in California's 50 Catholic hospitals; measurably improved the patient and family experience of serious illness and end of life care; reduced the cost of end-of-life care; equipped more than 1,000 parish communities to effectively support and care for their chronically and terminally ill members; and empowered persons to exercise value-based choice over medical decisions and treatment trajectories.

Specific pastoral results will include an increase in the number of:

- parish members utilizing advance care planning, and discussing with families
- parish members informed about options for palliative and hospice care
- parish members informed about Catholic teaching regarding the experience of illness, acceptance /refusal of treatment, and care at the end of life
- parish programs to support members who are seriously ill or in health crisis
- collaborative programs with Catholic health ministries
- availability of caregiver support resources

Within the health care setting, specific results will include an increase in the number of:

- patients being informed about and utilizing advance care planning, especially identifying health care agents, and discussing with family members
- patients receiving palliative care consults and services in hospital settings
- patient and community resources for medical decision making and end-of-life care
- patients whose pain and symptoms are controlled to desired degree
- patients satisfied with care and comfort due to humanized environments and relationship with health care providers
- patients' families/caregivers receiving additional support services to decrease stress of caregiving

In effect, the California Whole Person Care Initiative is a “proof of concept” or “demonstration project” that is creating tested and proven clinical and pastoral programs, services, materials and experiences that will become immediately available for adaptation and implementation in other states and regions.