# Improving Whole Person Care:
# What the Church and Health Care Ministry Can Do Together


***A Collaborative Initiative of the California Catholic Conference and the Alliance of Catholic Health Care***


## 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 the experience a terminal illness. A 2014 Institute of Medicine report 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 berefit and bewildered, unsure how to get through each day or how to plan for the future. Worse still was the realization later on 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.

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[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.

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 Church's Response**

The Bishops and Catholic health care leaders[2] 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 includes not only 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.[3]

## Whole Person Care Initiative
## Vision, Purpose, Timing and Definitions

The Whole Person Care Initiative is a collaborative project of the Bishops and Catholic health care leaders in California, which will be organized through their respective statewide offices: the California Catholic Conference (CCC) and the Alliance of Catholic Health Care.[4] The Iniatitive is guided by a Leadership Council comprising representatives from the two organizations, including Bishops, Catholic health care executives, and thought leaders. The Leadership Council met regularly during 2016 to design the Initiative. The Bishops and health care leaders affirmed the Council's work on October 19, 2016.

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

[3] 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.

[4] The California Catholic Conference is the public policy voice of the Roman Catholic bishops in California. The Alliance of Catholic Health Care represents California's Catholic health care systems and their 51 Catholic and Catholic-affiliated hospitals.

The Initiative's **Vision** is:

*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.*

The Intiative has a twofold **Purpose**:

- Strenghten 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.

**Palliative Care** emphasizes quality of life and comfort. A specially-trained interdisciplinary team supports patients and their families in identifying goals of care and works to prevent and relievce all forms of suffering. Although it is often the focus of end-of-life care, palliative care can be provided for people at any age and in any stage of disease. It can be provided along with curative and life-prolonging therapies, but focuses on helping people reach their best possible functioning (e.g., activities of daily living, self-care, etc.). It also helps with patient and family decision making to achieve medical and personal goals and provides spiritual care and emotional support to patients and their families.

**Hospice Care** is a speciality level of palliative care available to those whose illness is terminal and who are not expected to live beyond six months. Substantial research has shown that hospice and palliative care significantly improve quality of life, relieve the burdens of illness and caregiving, and reduce health care costs, and – for some patients – even extend survival.[5]

**Whole Person Care** is a further extension of the principal goals of palliative care into and through the entire culture of health care and parishes generally. As defined by this Initiative:

> *Whole Person Care attends to people in their basic human needs, strives to optimize health, alleviate suffering, bring comfort, prevent injury and illness, and foster physical, functional, emotional, social, interpersonal, and spiritual well-being.*
>
> *Whole Person Care is applicable throughout the course of life and is made available through the collaborative efforts of health care, social services, congregations, and communities in the context of an individual's family and home environment.*

## Whole Person Care Initiative
## In Pastoral and Clinical Settings

The Whole Person Care Initiative will leverage diocesan training systems to develop networks of volunteers in 1000+ parishes that will provide skilled and compassionate pastoral support to the dying. The health care systems will significantly improve palliative care services in their 51 Catholic and Catholic-affiliated hospitals. Together, these pastoral and clinical initiatives will provide a holistic system of care for the terminally ill and their families that will provide them with spiritual and emotional supports, help them make decisions to achieve their medical and personal goals, and alleviate their suffering.

[5] For a round-up of key articles on outcomes and benefits of palliative care, see https://www.capc.org/providers/palliative-care-resources/palliative-care-articles/

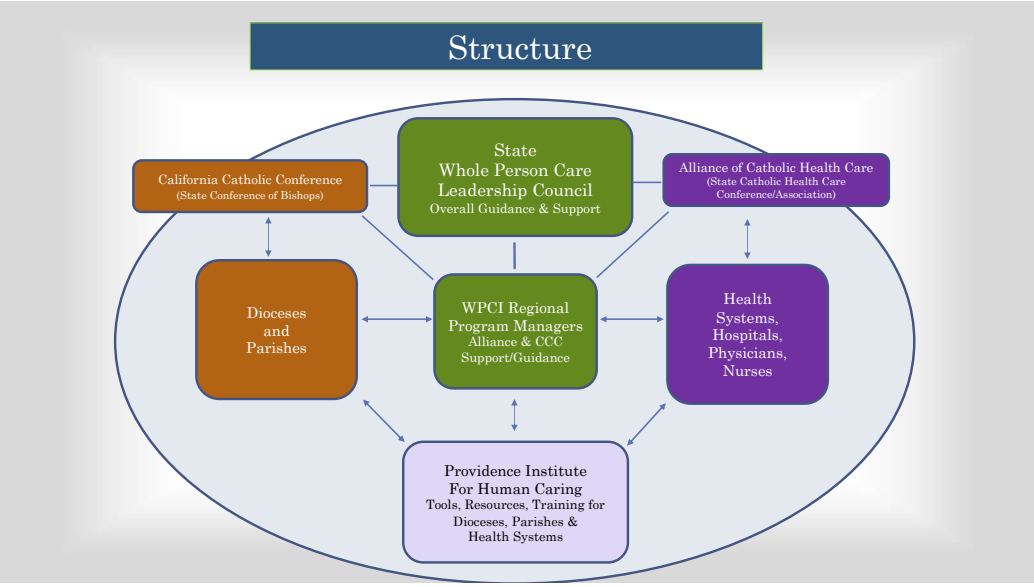
In the clinical settings, over the next five years, the Whole Person Care Initiative will meet standards comparable to the Joint Commission's Palliative Care Advanced Certification requirements – a standard few hospitals in the nation meet. These standards include the following attributes:

- A formal, organized palliative care program led by an interdisciplinary team whose members have advanced training in palliative care;
- Leadership endorsement and support of program goals to provide care, treatment and services;
- A special focus on patient and family engagement;
- Processes that support the coordination of care and communication among all providers in hospital settings;
- Use of evidence-based national guidelines or expert consensus to support patient care processes;
- A full-time service, where patients can access palliative care as needed, 24 hours per day; and
- The ability to provide palliative care to the entire inpatient population.

The WPCI will have a short- and long-term positive impact on the quality of palliative care programs within the 51 Catholic and Catholic-affiliated health care facilities. It will also result in an increased number of:

- Parish members utilizing advance care planning
- Parish members informed about options for palliative and hospice care
- Parish members informed about Catholic teaching re: the experience of illness, acceptance /refusal of treatment, and dying
- Parish programs to support members who are sick or in health crisis
- Patients whose pain and symptoms are controlled to desired degree
- Patients who are satisfied and comfortable due to humanized environments

## Whole Person Care Initiative Structure



# Health System and Diocesan Investments

The Catholic-affiliated health systems and their 51 California hospitals, the 12 dioceses and their 1,073 California parishes will establish and meet specific, annual metrics in order to achieve the Whole Person Care Initiatives' five-year goals and vision. This will require the health systems and dioceses to make important investments. Initially, these will be determined by the organizations' current status of programs and services, strategic priorities, and available resources.

**Health Systems' Investments**

In order to meet the palliative care needs of their growing and aging populations living with serious and complex chronic illnesses, Dignity Health and Providence St. Joseph Health (PSJH) are committed to making substantial investments during the next five years to improve the quality of the palliative care teams and programs in each of their 51 California hospitals. While all the hospitals report having palliative care programs, few of them meet national guidelines, such as the Joint Commission's standard of including a physician, an advanced practice or other registered nurse, a social worker, and a chaplain. Other professionals who should be included in palliative care teams are pharmacists, rehabilitation therapists, and other clinical and nonclinical specialists. Filling the gaps in their hospitals' palliative care programs will require personnel recruitment, mid-career education and attention to the risk of turnover among palliative care personnel related to the stress and emotional labor of the work – burnout rates as high as 62 percent have been reported.[6]

**Diocesan Investments**

Each of the 12 dioceses in California have committed to assigning key personnel to lead and develop the pastoral and parish component of the Whole Person Care Initiative in each of their parishes. The Bishops of California have repeatedly voiced the importance of this program and their understanding that significant resources at the diocesan and parish levels will have to be devoted to this goal.

While titles vary by diocese, personnel assigned will be senior leaders responsible for the primary pastoral, education, training, communication or evangelization programs within a diocese or directors of existing medical, end-of-life or health-related ministries. Their task is to integrate WPC goals, principles and resources into lay leadership training programs, deaconate formation classes, seminary curriculum and other key ministries such as Family Life and Respect Life. Reformulating these training and formation programs will require a considerable expenditure of staff time, facility use and other diocesan resources. As that process matures at the diocesan level, it will be repeated in parishes around California – again demanding a significant devotion of time, resources and facilities.

[6] *Few Hospital Palliative Care Programs Meet National Staffing Recommendations*, Health Affairs, September 2016.