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**Public Health Committee  
March 15, 2013  
American Cancer Society Cancer Action Network Testimony**

**SB 991 (RAISED) - AN ACT CONCERNING AN ADVISORY COUNCIL ON PALLIATIVE CARE.**

**Achieving Patient Centered & Family Focused Care in Connecticut**

It goes without question that our nation has made significant progress in the treatment of cancer. Today, we are saving 350 more lives per day than we were in 1990. However, as doctors focus on the treatment of a patient's cancer, the patients' comfort and concerns are frequently overlooked. People with cancer often suffer not only from the disease, but also from pain, nausea, shortness of breath, anxiety and other symptoms in their struggle to get well.

The American Cancer Society Cancer Action Network (ACSCAN) is pleased to support SB 991 (Raised) An Act Concerning an Advisory Council on Palliative Care and the importance of providing concurrent palliative care to promote quality of life and prevent suffering for every patient, in every care setting, and for every type of serious illness experienced by patients and their families in Connecticut.

This bill would establish an interdisciplinary council of experts to look at where we are and what needs to be done to get us to where we need to be. The council will analyze existing policies and practices and work with the Department of Health on palliative care issues moving forward. It provides an opportunity for the best minds in the state to get together and dedicate time and energy to concentrate on the big picture, to formulate a common agenda, and develop better communication and coordination on palliative care and quality of life issues.

What is palliative care? It's a growing field of specialized medical care that improves the quality of life of patients and their families by focusing on symptoms of treatment for a serious disease such as cancer or other chronic illness. Palliative care *is appropriate at any age and any stage of a serious or chronic illness* and can be provided with curative treatment. Palliative care is delivered by trained specialists who work together with doctors and nurses in a team-based approach that focuses on the patients' needs, explains treatment options and gives patients and their families a voice in determining their treatment and care.

Treating the whole patient—not only the disease but also the physical and psychological consequences of treatment—is the key to both extending life and enhancing the quality of the time gained. Evidence building over the past decade has consistently demonstrated the benefits of palliative care in improving quality of life and addressing the harmful effects of pain, symptoms and emotional distress as well as family caregiver burden, making a clear case for the importance and value of providing palliative care at

the same time patients are provided disease-directed treatments. More recent evidence also shows that palliative care may enhance survival and reduce costs driven by unnecessary use of hospitals, diagnostic and treatment interventions, and non-beneficial intensive care.

Palliative care is a big change in health care delivery, and it works in favor of the patient. But despite the benefits, thousands of patients who are suffering from the side effects of treatment for chronic disease have no idea that palliative care is available to them and can help relieve their symptoms and help them focus on getting well. Recent public opinion research shows that a majority (70%) of Americans are “not at all knowledgeable” about palliative care.<sup>1</sup> Yet the survey also revealed that once consumers understand palliative care as an increased emphasis on relief of symptoms, pain, and stress that is appropriate at any stage of serious illness, a large majority (92%) would be likely to consider it for themselves or their families and think it should be available in hospitals nationwide. The overwhelming majority (95%) of these consumers also agreed on the need for patients and families to be educated about palliative care, consistent with subsequent poll findings among physicians, of whom 96% confirmed the importance of educating consumers.<sup>2</sup>

The American Cancer Society and ACS CAN, together with national partners like the Center to Advance Palliative Care (CAPC) and National Palliative Care Research Center (NPCRC), are taking action to integrate palliative care earlier in the course of illness as an essential element of providing quality patient-centered and family-focused care. Connecticut ranks average nationally, achieving an “B” grade on access to hospital-based palliative care teams in the most recent evaluation from CAPC and NPCRC, with 100% of its larger hospitals (300+ beds) reporting a palliative care team and 72% of its more smaller hospitals (50< beds).<sup>3</sup> Despite this growth, significant disparities continue to exist in access to and delivery of concurrent palliative care. Moreover, the remarkable increase in the number of palliative care teams in recent years has not been matched by growth in the number of trained clinicians to lead and staff these programs.

Patients and families facing serious illness need to be educated about palliative care so they can find their way to the best choices that minimize symptoms and suffering while fighting disease. Pain, worry and other symptoms and side effects of cancer and its treatment, for example, are not an inevitable consequence of cancer. They typically can be controlled. While enhancing palliative care information and awareness, we must also enact policies to cultivate and support development of more health care professionals who are trained to provide this multidisciplinary care to meet the growing community need.

ACS CAN is encouraged that the Public Health committee has made palliative care a focus for quality care delivery now and in the longer term. With greater access to palliative care, cancer patients will suffer less and be able to focus more on getting well.

SB 991 comes at a time when federal policy is both promising and yet still somewhat uncertain, and when state policy makers remain very active on issues affecting end-of-life care, establishing a

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<sup>1</sup> Center to Advance Palliative Care: 2011 Public Opinion Research on Palliative Care: A Report Based on Research by Public Opinion Strategies. <http://www.capc.org/tools-forpalliative-care-programs/marketing/public-opinion-research/2011-public-opinionresearch-on-palliative-care.pdf>

<sup>2</sup> National Journal and The Regence Foundation: Living Well at the End of Life Poll—Topline Results. [http://syndication.nationaljournal.com/communications/National\\_JournalRegenceDoctorsToplines.pdf](http://syndication.nationaljournal.com/communications/National_JournalRegenceDoctorsToplines.pdf)

<sup>3</sup> Meier DE, Morrison RS, America’s Care of Serious Illness: A State-by-State Report Card on Access to Palliative Care in Our Nation’s Hospitals (2011). <http://www.capc.org/reportcard/>

framework for collaboration and consensus-building at the state level is all the more important. This is particularly important for the growing population of older adults living with chronic, serious illnesses such as cancer, heart disease, lung disease, and dementia. SB 991, will ultimately lead to patients and families having more control and choice about treatment options and will encourage more informed and shared decision making.

*We would respectfully request that the bill be amended to better reflect the intent that palliative care is appropriate for any stage of a serious or chronic illness, not just end of life. To that end, we request that the phrase "terminal illness" be replaced with "serious or chronic illness" throughout the bill, including the position qualifications.*

ACS CAN stands ready to support passage of this and future proposals to ensure that patients and families are made aware of these available services and that health professionals are equipped and able to address patients' quality of life concerns so that all Connecticut residents facing serious illness like cancer will have meaningful access to this more comprehensive model of patient centered and family focused concurrent care.

Thank you.

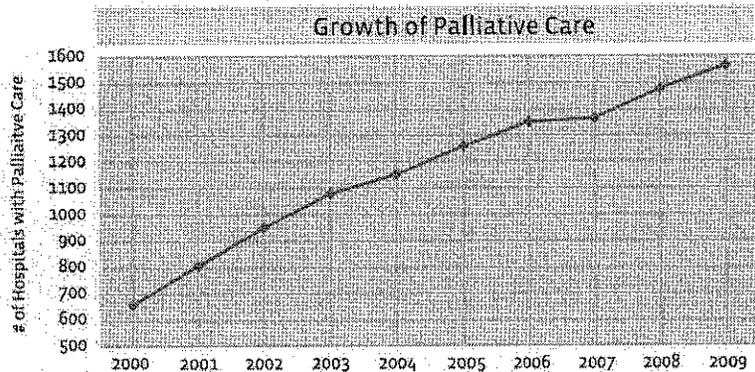
# Palliative Care at a Glance

## What is Palliative Care?

Palliative care, or palliative medicine, is specialized medical care for people facing serious and chronic illness. It focuses on relief from symptoms, pain, and stress—whatever the diagnosis. The goal is to improve quality of life for both patient and family. Palliative care is provided by a team that includes physicians, nurses, and other specialists who work together with a patient's own doctor to provide an extra layer of support. It is appropriate at any age and any stage in a serious illness and can be provided along with curative treatment.

## Growing Trend in Health Care

Over the last ten years palliative care has been one of the fastest growing trends in health care. In fact, the number of palliative care programs within hospital settings has increased approximately 138%, from more than 600 in 2000 to more than 1500 today.



Source: Center to Advance Palliative Care, March 2011

This growth has occurred primarily in response to the increasing number of Americans living with serious and chronic illnesses and to the caregiving realities faced by their families. But palliative care has also been embraced for the simple reason it gives patients and families control and choice over their own care. The strong partnership of patient, family and the palliative care team assures that treatment goals are established and coordinated and full communication is maintained in what is often a long, complex course of serious illness.

## People Want Palliative Care

Palliative care is expected to increase as the public becomes more aware of its benefits. Recent public opinion research by the national polling firm Public Opinion Strategies reveals that even for those patients who are uninformed about palliative care, once they understand what it is, **92% report they would be highly likely to consider palliative care** for themselves or their families if they had a serious illness. **92% also said they believe patients should have access** to this type of care at hospitals nationwide.

## Quality Care Leads to Cost Reduction

Today, approximately 90 million Americans are living with serious illness, and this number is expected to more than double over the next 25 years. About 20% of all Medicare beneficiaries have 5 or more chronic conditions, and two-thirds of Medicare spending goes to cover their care. This patient population is also the most likely to benefit from palliative care. Recent studies indicate that by closely matching treatments with a patient's goals, and improving their quality of life, palliative care can provide substantial cost reduction.

## Policy Changes Would Help

Policy initiatives that address workforce needs, research and patient access could rapidly bring palliative care to scale in the United States. The implementation of such policies would help meet the needs of our sickest children and a growing population of older Americans with long-term chronic conditions.

