

# The University of Kansas Medical Center

February 7, 2017

To: Chairman Hawkins and Members of the House Committee on Health and Human Services

Re: Testimony in Support of House Bill 2031: Establishing the Advisory Council on Palliative Care and Quality of Life and palliative care education program.

As the Medical Director for Palliative Care Services at the University of Kansas Health System, and as a practicing physician with specialty certification in Hospice and Palliative Medicine for the past 14 years, I am pleased to speak today in support of House Bill 2031.

## **What is Palliative Care?**

Palliative Medicine as a specialty of practice grew out of the Hospice Movement in the 1990s, as patients, health care providers and systems recognized that patients and family members could benefit from Palliative Care much earlier in the process of their illness.

Palliative Care seeks to address needs for expert symptom management, skilled communication with regard to illness trajectory, prognosis, and determination of patient centered goals of care. These efforts partner with Palliative Care inter-professional expertise to address the emotional and spiritual needs of those dealing with serious illness, and to navigate complex health care systems in a way that honors each patient's individual goals and priorities for treatment over time.

Palliative Medicine was recognized as a specialty by the American Board of Medical Specialties in 2006, and specialty fellowship training programs in Palliative Medicine have been accredited by the ACGME since 2007. There are currently 6,052 Board certified Hospice and Palliative Medicine physicians in the United States.

## **Evidence of Benefits**

Excellent Palliative Care is best delivered as an integrated element of standard, high quality care. Research on the impact of Palliative Care among stage IV non-small cell lung cancer patients has shown that those who received Palliative Care services along with their traditional Oncology care had improved quality of life as well as a nearly 2-month survival advantage compared to those who received standard Oncology care alone (Temel, J. New England Journal of Medicine 2010).

As an operational example of early integration, at KU Cancer Center in Kansas City, Palliative Care is now a standardized element of care for all patients undergoing high risk allogeneic bone marrow transplant. We begin seeing the patients at the time of transplant and follow through that process as needed for symptom management. As they recover and symptom distress lessens, we play a "safety net" role, increasing support again if the patient develops debilitating effects of graft vs. host disease, if their cancer recurs and they

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face salvage treatments, or if they eventually face recalcitrant disease and end of life. The 5 year survival rate in relapsed AML undergoing allogeneic transplant is roughly 15% (Damiani, Ann Hematol 2012). I am most happy to care for the 15% long term survivors while also riding the wave with the other 85%, supporting them to live as well as they can through illness progression.

Many times when I first meet a patient and family, they are scared; they may think Palliative Care represents that death is near or that Palliative Care and Hospice are the same thing. I describe Palliative Medicine to my patients as a continuum: *I join my patients early and help them fight their disease, help them live as well as they can with it using all of the tools available to fight it, as a partner to their other providers.* I tell them that I will stay with them no matter what- if they have progression of disease down the line, I will stay with them and when the time comes I will be their hospice physician if they desire, working with their hospice team at home to make sure they stay comfortable. So many times once the patient and family understand what we really do, they light up and say something like, “Oh my God, this is what we have been needing. Thank you.”

### **What is the future for Palliative Care delivery?**

We are fortunate to have a large inter-professional Palliative Care team at KU. We will see more than 1,500 new inpatient consults and more than 1,200 outpatient clinical encounters this fiscal year. Even with those resources though, our system currently addresses less than half of the core Palliative Care needs of the seriously ill patients hospitalized at KU (Szekendi, J Pall Med 2016). We are one of the fortunate/large hospitals to have these resources-- in the most recent CAPC state report card on access to Palliative Care, Kansas received a grade of C, indicating that only 41-60% of hospitals with more than 50 beds report offering of any kind of Palliative Care Service. For hospitals less than 50 beds the percentage is even lower.

Everyone dealing with serious illness deserves to have Palliative Care needs recognized and addressed. That means provider *access to Palliative Medicine training* in core curricula of Medical and Nursing Schools, residency training, and ongoing professional education in the core concepts of Palliative Medicine for ALL health care professionals. That means strategies to leverage innovation in technology and strategies in payer-provider partnerships to improve patient access, especially in the frontier regions of our state. There will never be enough specialty level providers to meet the astounding volume of needs, especially as the population ages and lives with ever more complex co-morbidity. Strategies to improve care for our seriously ill population must hence be focused both on building specialty level capacity as well as Palliative Care skill sets for the primary providers. Many basic Palliative Care needs can and should be met by primary providers. Specialists can then focus their efforts on the needs of the most complex populations, on teaching the next generations of providers, and on improving our systems of education and care delivery.

### **Need for Education and Collaboration.**

Strategies to increase public and professional awareness and education in symptom management, communication about serious illness care planning, and understanding the value of Palliative Care integration into system workflows are important and needed. HB2031, in establishing a state advisory board, provides a foundation to improve access to such education, and a forum for policy development to improve access to Palliative Care services across the state. I am excited to see this legislation become a reality and am motivated to be a part of the workforce to make it happen.

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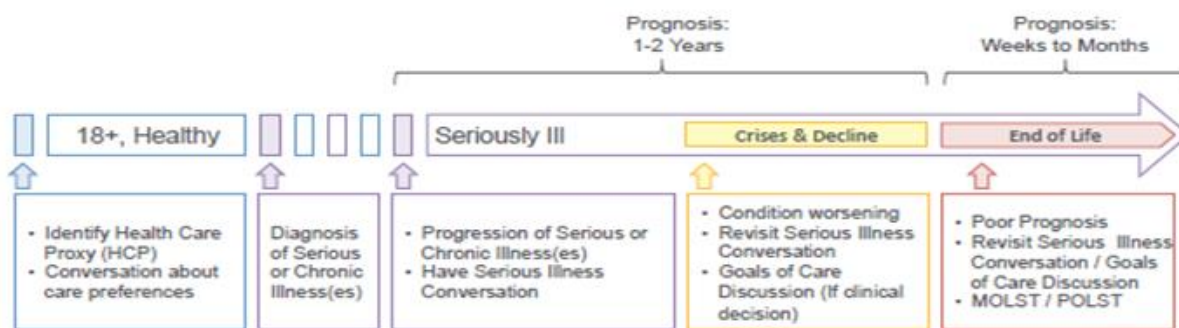
Thank you for your consideration of this bill.

Sincerely,

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Figure 1. Evolution of Advanced Care Planning and Serious Illness Care Planning terminology

Rachelle Bernacki, MD, MS, Associate Director, and Susan Block, MD Director, Serious Illness Care Program, Ariadne Labs



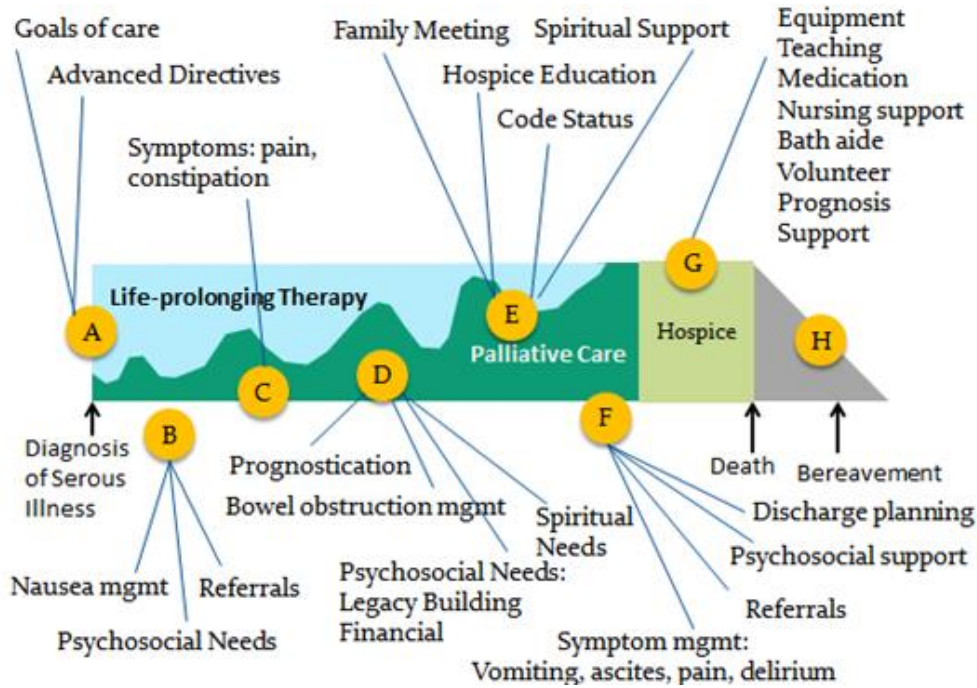
**Advance Care Planning** = Planning in Advance of Serious Illness

**Serious Illness Care Conversation** = Planning in the context of progression of serious illness

**Goals of Care Discussion** = Decision making in context of clinical progression / crisis / poor prognosis



Figure 2. Clinical example of early, integrated Palliative Care



Hennessy JE, Lown BA, Landzaat L, Porter-Williamson K. "Practical issues in palliative and quality-of-life care" J Oncol Pract. 2013 Mar;9(2):78-

Figure 3. Differences between Palliative Care and Hospice Care

	<b>Palliative Care</b>	<b>Hospice</b>
When	Anywhere in illness trajectory	Prognosis < 6 MONTHS
Where	Usually in hospital, some outpatient programs	Goes to patient (Hospice is not a place)
Goals of Care	Variable	Comfort Directed Usually avoiding hospitalization
Availability	Depends on individual program	Planned visits 24/7 on-call
Team Members*	Depends on individual program	Nurses, physicians, volunteers, chaplains, social workers, bereavement coordinators
Levels of Care	Primary Secondary Tertiary <small>(VonGunten)</small>	Routine Continuous Care General Inpatient Respite

Von Gunten, C. "Secondary and Tertiary Palliative Care in US Hospitals". JAMA Feb 20, 2002. vol 287, No 7. 875-881

## **Palliative Care**

Palliative care, also known as palliative medicine, is specialized medical care focused on relief of the symptoms and stress of serious illness. The goal is to improve quality of life for both patient and family. It is appropriate at any age and any stage in a serious illness and can be provided along with curative treatment.

Provided by a team that includes palliative care physicians, nurses, social workers and other specialists, palliative care specialists work with a patient's own doctor to provide an extra layer of support.

## **A Rapidly Growing Trend in Health Care**

Over the last decade palliative care has been one of the fastest growing trends in health care. In fact, the number of palliative care teams within U.S. hospitals with 50 or more beds has increased 164%, from 658 in the year 2000 to more than 1,700 today.<sup>1</sup>

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 that it gives patients and families control and choice over their own care. The strong partnership of patient, family and the palliative care team ensures that treatment goals are established and coordinated and full communication is maintained in what is often a long, complex course of serious illness. Learn more by reading the latest [State-by-State Report Card](#).

## **Research Shows 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 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.<sup>2</sup>

## **Improved Quality 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 patients' goals, and improving their quality of life, palliative care can provide substantial cost reduction.<sup>3</sup>

# Growing Demand, Limited Supply

A major barrier facing the expansion of palliative care services is the lack of palliative medicine physicians. Where there is approximately one cardiologist for every 71 persons experiencing a heart attack and one oncologist for every 141 newly diagnosed cancer patients, there is only one palliative medicine physician for every 1,200 persons living with a serious or life-threatening illness.

## Policy and Palliative Care

Despite the considerable growth in the number of palliative care programs across the United States, barriers in three key areas—[workforce](#), [research](#) and [access](#)—currently prevent full availability of palliative care for all patients and families facing serious or life-threatening illness. Specifically, three key palliative care policy initiatives are needed:

- Investment in a trained workforce to ensure sufficient numbers of specialists both to teach all clinicians the fundamentals and to directly provide high-quality palliative care for the highest-risk and most complex patients;
- Investment in the research necessary to establish a strong science base for palliative care and to expand palliative care's ability to improve both quality and length of life;
- Investment in health care system capacity by requiring delivery of high-quality palliative care in hospitals, nursing homes and community settings through changes in measurement, payment and accreditation standards.

**To learn more about specific recommendations for action to improve access to palliative care, please visit:**

<https://reportcard.capc.org/recommendations/>

**To learn more about palliative care in general, please see the following palliative care resources:**

<https://getpalliativecare.org>

<https://getpalliativecare.org/blog/>

## References

1. Center to Advance Palliative Care. [National Palliative Care Registry Annual Survey Summary](#). July 2014. Accessed Oct. 16, 2014.
2. Center to Advance Palliative Care. [2011 Public Opinion Research on Palliative Care](#). Accessed Oct. 16, 2014.
3. Morrison SR, Dietrich J, Ladwig S, et al. Palliative care consultation teams cut hospital costs for Medicaid beneficiaries. *Health Aff.* 2011;30:454-463.