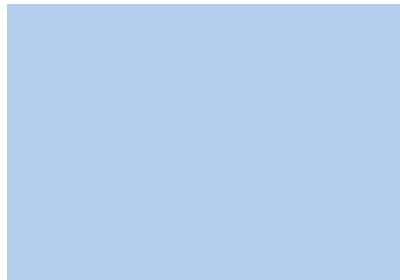


Kentucky Palliative Care  
Interdisciplinary Advisory Council

# 2020 Annual Report



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# Executive Summary

**Palliative care** is specialized medical care for individuals living with a serious illness. Numerous studies have shown that palliative care interventions lead to reductions in intractable pain, resolutions in complex symptom burden, improved emotional and spiritual well-being and increased alignment of health care utilization with a person’s goals, preferences and values. Given the appreciable increase in the number of individuals living with serious illness, the need to ensure access to palliative care services, improve clinical education on caring for the seriously ill and raise awareness of palliative care is exigent. Consequently, in 2019, the Kentucky General Assembly passed legislation creating the Kentucky Palliative Care Interdisciplinary Advisory Council to determine opportunities to advance access to palliative care in Kentucky. This inaugural annual report describes palliative care, addresses the current difficulties in determining access to palliative care in Kentucky, contextualizes barriers to scaling access to palliative care and provides actionable recommendations for the state of Kentucky to advance the work of improving serious illness care in the state.

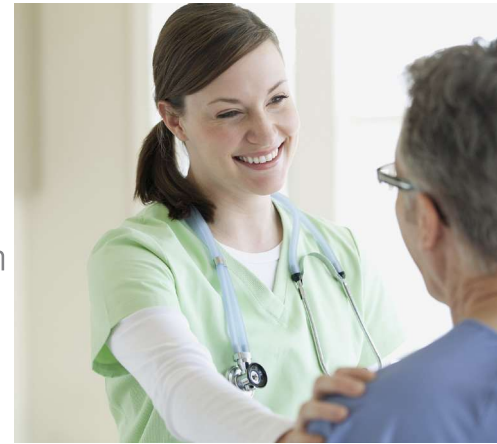


## Key Takeaways

- **Palliative care and hospice care** are not synonymous; hospice care is a specific form of palliative care. Palliative care is specialized health care for people living with a serious illness. This type of care focuses on providing relief from the symptoms and stress of a serious illness, can be provided alongside curative treatments and can be provided at any stage of serious illness. Hospice care is a prescribed benefit in the Medicare and Medicaid programs for individuals typically in the last six months of life, who choose to forgo curative treatments and elect support from an interdisciplinary team with expertise in palliation.
- **There is medical research and academic literature** demonstrating that specialist level palliative care improves quality of life, reduces pain and symptom burden and improves the value of health care expenditures by mitigating the likelihood a seriously ill person utilizes the hospital or emergency department to manage their medical conditions.



- **Kentucky lacks a comprehensive database of palliative care programs** in the state. The best assessment of access to specialist-level palliative care in Kentucky comes from the Center to Advance Palliative Care’s state report card. Kentucky ranks 40th in the United States and receives the letter grade “C”.
- **A primary barrier to scaling access to palliative care is financing.** Palliative care teams are interdisciplinary in their composition. Currently, the primary, often exclusive source of revenue for palliative care teams is fee-for-service billing for physician and nurse practitioner services, and consequently palliative care programs operate at a financial loss.
- **There is no palliative care benefit** in the Medicare program or in the Kentucky Medicaid program. Because of the lack of a prescribed benefit, there is wide variation in the composition, setting and availability of palliative care programs. Due to the variation in access to palliative care programs and models of palliative care programs, health care experts developed the National Consensus Project (NCP Guidelines) for Quality Palliative Care to distinguish best practices in the delivery of palliative care.



# Background to the Kentucky Palliative Care Interdisciplinary Advisory Council

On March 25, 2019, the Kentucky Governor signed Senate Bill 65 establishing the Palliative Care Interdisciplinary Advisory Council to improve the quality and delivery of patient and family-centered care throughout the Commonwealth and to advise the Cabinet for Health and Family Services on matters related to the establishment, maintenance, operation and evaluation of palliative care initiatives. This thirteen-member council provides an annual report with recommendations on advancing palliative care in Kentucky. Additionally, the Council encourages the dissemination of consumer education that increases awareness of palliative care and professional education that supports the development of skills and competencies associated with improvements in care for the seriously ill.

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## Definition of Palliative Care



The Center to Advance Palliative Care defines palliative care as “specialized medical care for people living with a serious illness. This type of care is focused on providing relief from the symptoms and stress of a serious illness. The goal is to improve quality of life for both the patient and the family. Palliative care is provided by a specially trained team of palliative care physicians, nurses and other specialists who work together with a patient’s other doctors to provide an extra layer of support. It is appropriate at any age and at any stage in a serious illness, and it can be provided along with curative treatment.” Palliative care is often conflated with or used synonymously with hospice



care. Unlike palliative care, hospice care is a prescribed benefit in the Medicare and Medicaid program and is limited to individuals living with a terminal illness who forgo curative treatment for support from a specialized palliative care team.

In addition to defining palliative care vis-à-vis hospice care, it is also helpful to make the distinction between primary palliative care and secondary or specialist-level palliative care. Primary palliative care refers to the basic skills and competencies, such as pain and symptom management and skilled

communication skills focusing on prognosis and goals of care, that are relevant to any health care provider caring for the seriously ill. Secondary palliative care, also known as specialist palliative care, refers to the specialist clinicians and organizations that provide expert consultation and/or co-management for the seriously ill person.

Financing for palliative care services is contingent primarily on fee-for-service billing, as there is no palliative care benefit in the Medicare program and most states lack a palliative care benefit in their Medicaid programs. A consequence of the absence of a clearly defined palliative care benefit is that palliative care interventions take a variety of forms, varying in clinical models, target populations, and settings of care. Examples of palliative care interventions include consultations with palliative care specialists in the hospital and community settings, telephonic care management support and full interdisciplinary services tailored to the need and setting of the seriously ill person. The variation in palliative care interventions led to the development of a national consensus project that provides guidelines on best practices in the delivery of specialist palliative care.



Specialist level palliative care, as described and prescribed by national consensus project guidelines, has shown to be effective at improving quality of life, reducing pain and symptom burden, enhancing emotional and spiritual well-being, and mitigating the likelihood a person receives health care that is not aligned with their goals of care. In short, palliative care interventions have proven successful in improving outcomes and diminishing non-beneficial utilization of health care services in some instances. Conversations on improving serious illness care in Kentucky must keep in mind the NCP Guidelines for high-quality palliative care and note the distinction between primary and specialist-level palliative care.

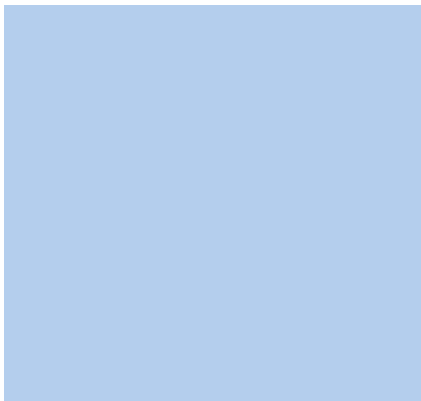
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## **Assessing Access to Palliative Care in Kentucky**

To distill the wide variation in design of palliative care programs into organizing principles, the NCP Guidelines emerged charged with defining the elements of specialist-level palliative care programs. Because of the wide variation in palliative care programs, identifying the adequacy of access to specialist level palliative care programs has proved to be a challenge. The best assessment of the adequacy of access to palliative care comes from the Center to Advance Palliative Care (CAPC). Using hospital registry data, CAPC has assessed access to hospital-based palliative care programs and provided a grade to states based on the proportion of hospitals with more than 50 beds that report having a palliative care team at the hospital. Kentucky ranked 40th in the United States and received the letter grade “C,” suggesting much more work can be done to advance access to palliative care in the Commonwealth.



# A Barrier to Scaling Access to Palliative Care



Providing specialist-level palliative care requires an interdisciplinary approach to address the complex medical, psychological, emotional, social and spiritual needs of the seriously ill. Typically, palliative care teams include, at a minimum, a physician, nurse practitioner, nurse, social worker and chaplain, all with specialization in caring for the seriously ill person. Currently, the primary reimbursement mechanism for palliative care is fee-for-service billing, which only covers the efforts of the physicians and nurse practitioners. Put directly, palliative care programs, given their interdisciplinary approach and complex patient population, are financially unsustainable in a fee-for-service payment environment. Because palliative care has been shown to improve health care outcomes while reducing non-beneficial utilization of health care services, some states have developed a palliative care benefit in their Medicaid programs to provide a better path to financial sustainability. While Kentucky does not currently have a palliative care benefit in the Medicaid program or require a palliative care benefit be provided by Medicaid Managed Care organizations (MCOs), Kentucky does require MCOs provide concurrent curative and hospice care for pediatric patients.

# Case Study on the Value of Palliative Care

Mr. B is an 88-year-old man with dementia admitted to the emergency department for management of back pain due to prostate cancer, spinal stenosis and arthritis. His pain is an eight out of ten on admission for which he is taking 5 gm of acetaminophen daily. Mr. B had been admitted three times in two months for pain, falls and altered mental status due to constipation. His only family is his 83-year-old wife who is overwhelmed providing care. Mr. B has repeatedly expressed his desire to stay home. Mrs. B must depend on the emergency department and hospital to support his medical care. “He hates being in the hospital, but what could I do? The pain was terrible, and I couldn’t reach the doctor. I couldn’t even move him myself, so I called the ambulance. It was the only thing I could do.” Mr. B was referred to a home-based palliative care program for pain and symptom management. This program provides house calls, 24/7 telephonic support, support for caregivers, Meals on Wheels services and a friendly visitor program to combat social isolation. Prior to referral to the palliative care program Mr. B had four calls to 911 in a three-month period, leading to four emergency department visits, three hospitalizations, hospital acquired infection, functional decline and family distress. Because the palliative care team was able to expertly manage Mr. B’s pain and symptoms, support Mrs. B., conduct skilled conversations on what mattered to Mr. and Mrs. B and provide around-the-clock telephonic support, Mr. B had no 911 calls, no emergency department visits and no hospitalizations in the last 18 months of life (adapted from Diane Meier, Director-Center to Advance Palliative Care).



## Recommendations

Given the challenges in gauging patient access to palliative care, as well as the long-standing financial barriers to broader provision in the fee-for-service environment, the Kentucky Palliative Care Interdisciplinary Advisory Council recommends the following steps to assess the existing palliative care infrastructure in the Commonwealth and identify unmet needs and challenges in the current health care delivery landscape for the seriously ill.

### Department for Medicaid Services:

1. Request Kentucky Medicaid health plans submit an assessment of current internal and external strategies to support seriously ill members by December 30, 2021. This report may include how seriously ill populations are defined, specific interventions for these populations, data infrastructure for monitoring effectiveness of any interventions, identification of quality measures relevant to these populations, a review of pediatric concurrent care utilization and areas for improving care for these populations.
2. Explore and review palliative care benefits in Medicaid managed care programs in other states. This review can include an assessment on the feasibility, costs and benefits associated with creating a similar benefit embedded in Kentucky Medicaid health plans by December 30, 2021.
3. Consider opportunities to include serious illness strategies and access to palliative care services for inclusion in any 2023 or subsequent year performance improvement requirements for Kentucky Medicaid health plans.
4. Evaluate the benefits and implications of revising state licensure requirements for hospitals and nursing facilities with 50 or more beds to provide access to specialist-level palliative care or mandate education for all clinicians on pain and symptom management, and communication skills for the seriously ill person.
5. Evaluate the benefits and implications of revising state health professional licensure and continuing education requirements, specifically in the areas of medicine, nursing, psychology, social work and behavioral health, to include a minimum number of hours of instruction on palliative care.
6. Create an online portal on the CHFS website for health care organizations in Kentucky to self-identify as offering palliative care services to inform the



creation of a geomap that will highlight access points to palliative care within the state.

7. Convene the Kentucky Palliative Care Interdisciplinary Advisory Council, interested individuals from the Cabinet for Health and Family Services, the Department for Medicaid Services, Department of Insurance, Kentucky Medicaid health plans and provider associations for education on opportunities to improve access to palliative care in Kentucky.

### **Kentucky General Assembly:**

1. Request that the Interim Joint Committee on Health, Welfare, and Family Services conduct bi-annual hearings on the state of serious illness care in Kentucky. These hearings can include a review of the annual report produced by the Kentucky Palliative Care Interdisciplinary Advisory Council, an overview of palliative care and its benefits, workforce development for supporting serious illness and payment policy for expanding access to palliative care services.

## **Kentucky Palliative Care Interdisciplinary Advisory Members**

- Jessica K. Beal, Psy.D.
- Dr. DeLanna Clark, APRN
- Dr. Todd Robert Cote, MD, HMDC, FAAFP, FAAHPM
- Delores Arlene Gibson
- Gretchen Horton, MSW, CSW
- Dr. Marlene Huff, LCSW, PhD
- Michelle Jarboe, RN
- James William Patton, JD
- Dr. Lindsay Ragsdale, MD, FAAP, FAAHPM
- Dr. Bethany Cox Snider, MD HMDC FAAHPM
- Turner West, MPH, MTS
- Addia Kathryn Wuchner, RN, LDh
- Kristy Young, MS, CHES



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