



PALLIATIVE CARE:

IMPROVING THE QUALITY OF LIFE OF KANSANS WITH SERIOUS ILLNESS

February 26, 2024 Kansas Health Institute

Hello!

Kari Bruffett

President and CEO, Kansas Health Institute





Who We Are



- Nonprofit, nonpartisan educational organization based in Topeka.
- Established in 1995 with a multi-year grant by the Kansas Health Foundation.
- Committed to convening meaningful conversations around tough topics related to health.

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Hello!

Linda Sheppard, J.D.

Senior Analyst and Strategy Team Leader, Kansas Health Institute







In memory of Audrey, 15

My daughter, Audrey, remains an inspiration. She was brilliant, funny, creative and such a productive girl.

DONNA YADRICH

Let her story guide our work to reduce suffering and improve health outcomes.











History of Palliative Care Legislation in Kansas

- On July 1, 2018, Kansas Governor Colyer signed House Bill 2031 to create the Palliative Care and Quality of Life Interdisciplinary Advisory Council.
- Passage of HB2031 also created the State Palliative Care Consumer and Professional Information and Education Program.
- The palliative care statutes include KSA 65-1260 and KSA 65-1261.







Council Responsibilities

- Make recommendations to and advise Kansas
 Department of Health and Environment (KDHE) on the
 establishment, maintenance, operation, and outcomes
 evaluation of palliative care initiatives in the state
- Maximize effectiveness of the State Palliative Care Consumer and Professional Information and Education Program
 - The program serves to ensure availability of comprehensive and accurate information and education about palliative care for all Kansans.



KANSAS STATUTES

65-1,261. State palliative care consumer and professional information and education program; creation; duties of department of health and environment.

History: L. 2018, ch. 66, § 4; July 1.

65-1,260. Palliative care and quality of life interdisciplinary advisory council; creation; membership; duties.

History: L. 2018, ch. 66, § 3; July 1.





Council Representation

- 13 Legislatively Appointed Members
- Palliative Care Experience and Expertise in
 - interdisciplinary palliative care medical, nursing, social work, pharmacy and spiritual guidance
 - delivery models in a variety of inpatient, outpatient and community settings and with a variety of populations including pediatric, youth and adults
- At least two members shall be board-certified hospice and palliative medicine physicians or nurses
- At least one member shall be a patient or a caregiver



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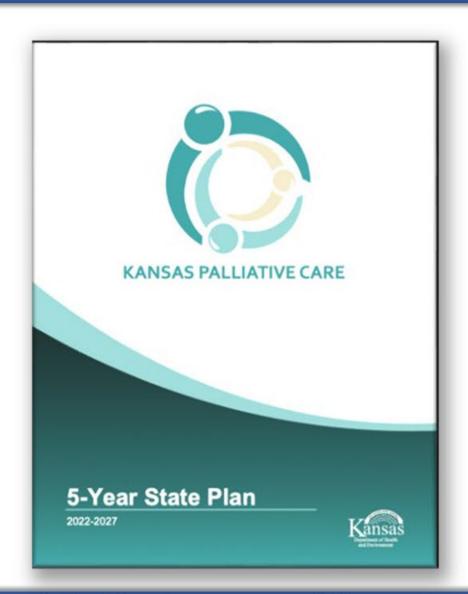
History: L. 2018, ch. 66, § 3; July 1.





Full Council Approval

January 25, 2023







Definition of Palliative Care

- Palliative care is comprehensive, interdisciplinary care for patients living with serious, potentially life-threatening or life-limiting conditions, with the goal of improving quality of life for both the patient and family.
- This approach to care prevents and relieves suffering through the early identification, assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual.
- Palliative care is delivered based on needs, not prognosis.
- It is appropriate at any age or any stage of an illness and can be delivered along with curative treatment.





Serious Illness Defined for a Population Health Approach

"Any condition that carries a high risk of mortality and either negatively impacts a person's daily function or quality of life, or excessively strains their caregivers." (Kelley, 2018)

Kelley AS, Bollens-Lund E. Identifying the Population with Serious Illness: The "Denominator" Challenge. J Palliat Med. 2018;21(S2): S7-S16. doi:10.1089/jpm.2017.0548





Patient Vignette

Council's
Founding
Patient
Representative

My name is Theresa Meyer and I have been living with breast cancer since 1998. After a period of remission, my breast cancer returned in 2013. I was diagnosed with terminal State IV Breast Cancer. I initially established my oncologic care in the Kansas City area, 180 miles from my home. Eventually I was able to obtain care closer to home in Manhattan, Kansas.

After years of maintenance therapy, my quality of life began to decline. I suffered from depression, poor appetite, low energy levels, severe weight loss, and pain. My husband became my caregiver, performing all the household duties.

Though my volunteer work with the American Cancer Society Cancer Action Network, I had the opportunity to work alongside a palliative care nurse practitioner who encouraged me to talk with my doctor about receiving palliative care. Unfortunately, in the community of Manhattan, I did not have access to specialty palliative care services. It was suggested by my oncologist to stop my treatment and enroll in hospice, but I knew as a former hospice volunteer that I was not ready for hospice care, let alone quality for this type of care.

Eventually I was able to connect with a palliative care team in Lawrence Kansas

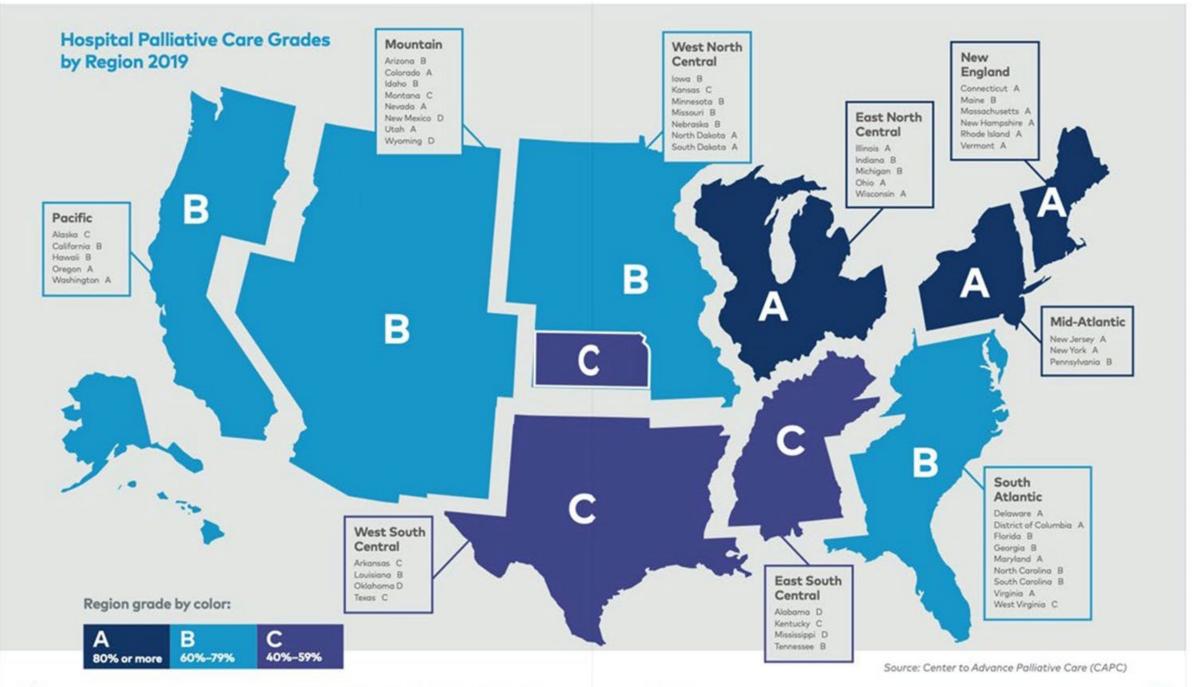
Within a year of establishing care with a palliative care specialist, my quality of life was back! I wanted to live again. All the things that had disappeared from our lives were back again! I now drive 4 hours round trip to attain this type of care. It is my hope that palliative care will be easily accessible for all Kansans someday soon!





Kansas Palliative Care Access

- According to the Center to Advance Palliative Care (CAPC) and the National Palliative Care Research Center (NPCRC), Kansas' access to palliative care currently ranks last in our region and 42 of 51 states and the District of Columbia.
- In 2021, only 3.6% Kansans had received palliative care.
- Adults surveyed for the Kansas Behavioral Risk Factor Surveillance System

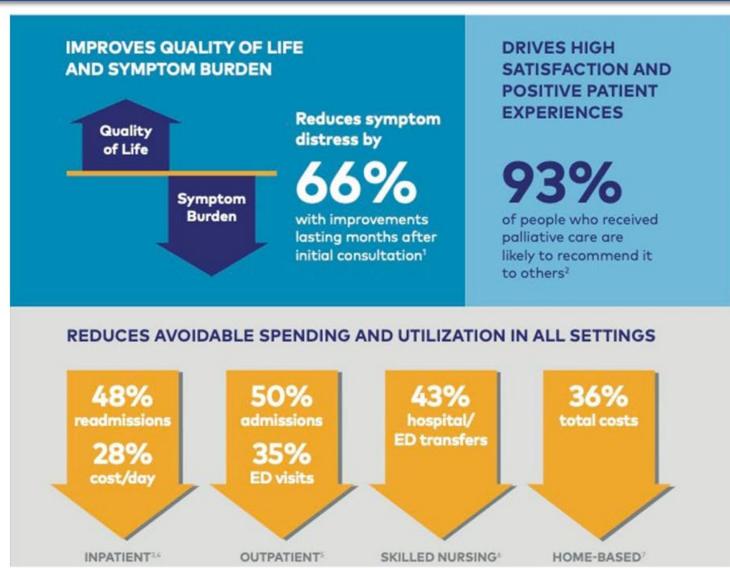






Palliative Care Ensures Value

- A strong evidence base exists
 proving its impact on quality,
 satisfaction, consumer demand,
 and cost. Because it focuses on
 the highest need and highest cost
 patient segment, palliative care is
 essentially a strategy for population
 health.
- Palliative care focuses on relieving the symptoms and stress of any serious illness, ideally alongside curative treatment.







The Council Identified Four Priority Areas of Focus

- 1. Access
- Education and Health Care Workforce Training
- 3. Public and Community Awareness
- 4. Emergency Preparedness and Disaster Planning





Priority #1: Access

 Expansion of broadband access and preservation of policy changes for delivery of telehealth services are essential in order to achieve access to timely palliative care for all Kansans, including those in rural and frontier communities.







Access Recommendations:

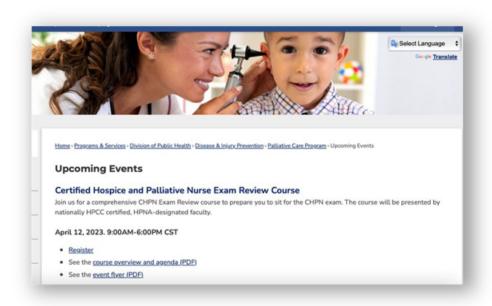
- Make permanent changes to broaden access to telehealth services.
- 2. Increase number of certified palliative care clinicians.
- 3. Enhance reimbursement of the full interdisciplinary palliative care team.
- Develop task force to determine feasibility of statewide assessment to understand the magnitude of seriously ill populations for appropriate resource allocation.





Priority #2: Education and Health Care Workforce Training

 Incentive programs to recruit, train and retain highly skilled palliative care clinicians, education on primary palliative care for all disciplines, and enhanced support for unpaid caregivers are crucial in order to address our State's palliative care workforce shortage.







Education and Health Care Workforce Training Recommendations:

- Increase primary palliative care education in the current workforce caring for those with serious illness.
- Increase palliative care in the future workforce caring for those with serious illness.
- Increase community and home-based support to reduce caregiver burden and enhance their knowledge and skillset in caring for someone with serious illness.
- Improve access to community and home-based services to individuals with serious/chronic illness.





Priority #3: Public and Community Awareness

 Efforts to engage and inform Kansans about palliative care are necessary in order to improve the general public's understanding and acceptance of palliative care, especially its differentiation from hospice.







Public and Community Awareness Recommendations:

- Engage and inform Kansans about palliative care with an emphasis on how it is differentiated from hospice and the positive impacts of palliative care at any stage of illness.
- Ensure that key palliative care knowledge is integrated into all communities, including the medically underserved, using culturally and linguistically inclusive and appropriate communication principles.





Priority #4: Emergency Preparedness and Disaster Planning

 Efforts to bring advance care planning and serious illness care planning to scale across care settings are necessary, so that Kansans are well informed and can express their wishes, values and treatment preferences.



Priority #4 Crosscuts Priorities 1-3

- 1. Access
- 2. Education and Health Care Workforce Training
- 3. Public and Community Awareness





Emergency Preparedness and Disaster Planning Recommendations:

- Engage and inform Kansans about palliative care with an emphasis on how it is differentiated from hospice and the positive impacts of palliative care at any stage of illness.
- 2. Enhance advance directive completion across the state of Kansas.





State Plan Accomplishment Moving Knowledge, Not Patients



Case-based learning using Project ECHO (Extension for Community Health Care Outcomes) delivered two continuing medical education series:

- "Palliative Care ECHO 2022: Establishing a Kansas Community of Practice to Improve Lives of People Experiencing Serious Illness"
 - 200+ participants across Kansas attended the 4 courses in June 2022.
- "Palliative Care ECHO 2022: Pain Management for People Living With Serious Illness"
 - 138 participants across Kansas attended the 5 courses in October 2022.





Council Guidance Needed

- How the council can be most efficient and effective in moving this forward?
- Where are potential synergies with efforts presently underway?
- What strategies for communication and advocacy are the most meaningful?



bit.ly/KS5YRPCQOLPlan





Thank You/Questions

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Panelists

Palliative Care



Greg Nelson, M.D.

Palliative care Physician and Internist



Julie Pinkerton, BS, RN, CHPN

Executive Director of Hospice of the Prairie and Prairie Home Health



Kate Shoemaker, LMSW, AHPSW-C

Advanced Hospice and Palliative Care Social Worker



Donna Yadrich, M.P.A.

Vice-chair, Palliative Care and Quality of Life Interdisciplinary Advisory Council



THANK YOU!

Any Questions?



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