



Kentucky Palliative Care  
Interdisciplinary Advisory Council

# 2021 Annual Report

# Contents

- 3** Executive Summary
- 4** Key Takeaways
- 5** Background to the Kentucky Palliative Care Interdisciplinary Advisory Council
- 6** Palliative Care: Improving Care for the Seriously Ill
- 7** Understanding the Need For and Impact of Palliative Care
- 9** 2021 Priorities
- 12** 2021 Recommendation
- 14** Case Studies on the Value of Palliative Care
- 18** References
- 20** Kentucky Palliative Care Interdisciplinary Advisory Members

# 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, increases in health care utilization aligned with a person's goals, preferences, and values, and decreases in non-beneficial use of health care services. 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.

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. The inaugural 2020 annual report led to improvements in the visibility of palliative care in the state, the dissemination of reputable content on palliative care for health care professionals and consumers, and the development of a state-wide registry for organizations to self-report providing access to palliative care services. The 2021 report includes a description of palliative care, an overview of the 2021 priorities identified by the council, a description of the value of palliative care for patients, families and the health care system, and a key recommendation for the state.

# Key Takeaways

- There is inadequate access to palliative care in Kentucky. While palliative care programs are increasing in the state, access is improving too slowly to adequately support the growing number of seriously ill Kentuckians. According to national registry data:
  - Kentucky receives the letter grade "C" from the Center to Advance Palliative Care and ranks 40th in the United States for access to hospital-based palliative care.
  - Of the 130 hospitals in Kentucky, fewer than 15 report providing access to palliative care.
  - Only 20 health care organizations in Kentucky report providing palliative care.
  - Palliative care in nursing homes is only available in seven counties in the state.
  - Clinic-based palliative care services are only available in four counties.
  - While home-based palliative care is available in 71 counties, this service is often limited to individuals in certain health plans.
- Over the past year, the recommendations and work of the council has led to increased visibility of palliative care. The Cabinet for Health and Family Services created a webpage with reputable content for health care professionals and consumers on palliative care. Moreover, the Cabinet created a statewide registry for organizations to self-report providing access to palliative care.
- Palliative care interventions have been shown to improve clinical outcomes, enhance satisfaction with health care, and reduce unwanted and non-beneficial utilization of health care services. Additionally, the COVID-19 public health emergency highlighted the need for more community-based health care and more access to health care professionals with expertise in pain and symptom management and effective communication skills for those living with serious illness.
- Scaling access to palliative care, particularly in the community settings is significantly limited by the lack of sustainable payment options. Consequently, the Kentucky Palliative Care Interdisciplinary Advisory Council unanimously recommends that Kentucky establish a palliative care benefit for seriously ill Kentuckians.

# 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.

## 2020 ACCOMPLISHMENTS

The council produced an annual report that described palliative care and included recommendations to the General Assembly and Department for Medicaid Services.

Since the annual report, the Cabinet for Health and Family Services has:

- Created a webpage that provides reputable content for consumers and professionals on palliative care.
- Developed a registry for organizations providing palliative care.

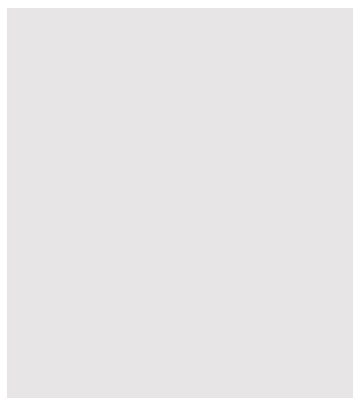


# Palliative Care: Improving Care for the Seriously Ill

**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.”

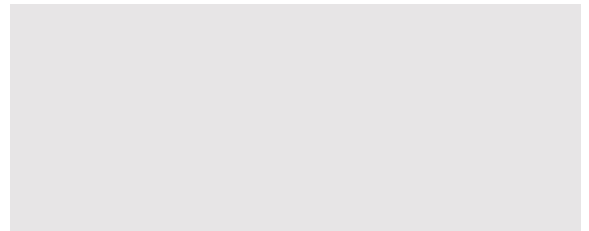
Palliative care is often conflated with or used synonymously with hospice care. Unlike palliative care, hospice care is a prescribed benefit in the Medicare and Medicaid programs and is limited to individuals living with a terminal illness who forgo curative treatment for support from a specialized palliative care team. In short, hospice care is a type of palliative care for individuals living with a terminal illness.



# Understanding the Need For and Impact of Palliative Care

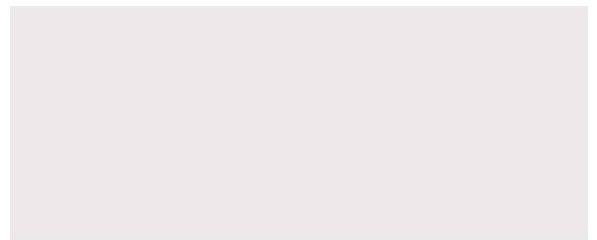
The health care system often fails the seriously ill. Seriously ill individuals report experiencing:

- Poor communication from health care providers in the form of conflicting recommendations and duplicative tests and procedures.
- High burden of pain and bothersome symptoms.
- Lower satisfaction with health care services.
- Treatment discordant with stated preferences.
- Inattention to emotion and spiritual suffering.
- Feelings of anxiousness, helplessness and confusion.
- Loneliness and isolation.
- Inadequate education about disease progression, care and self-management.
- Inattention to the needs of caregivers.



**The health care priorities reported by seriously ill individuals include:**

- Maintaining independence for as long as possible.
- Care in a community setting; patients rarely wish to receive care in high acuity settings like hospitals and nursing care facilities.
- Expert management of pain and symptoms.
- Attention to emotional and existential needs that can exacerbate physical health symptoms.
- Time with their health care professionals.
- Recurring conversations about disease progression.
- Highly coordinated care.



**Value of palliative care for patients and families, payers of health care, hospitals and health system, and providers:**

Patients and Families	Payers	Hospitals and Health Systems	Providers
<ul style="list-style-type: none"> <li>• Improved quality of life.</li> <li>• Improved satisfaction.</li> <li>• Fewer symptom crises.</li> <li>• Less caregiver stress and exhaustion.</li> <li>• Reduction in non-beneficial utilization: fewer 911 calls, ED visits, hospitalizations.</li> <li>• Improved advance care planning.</li> <li>• Improved care coordination.</li> <li>• Proactive attention to social factors that exacerbate poor health outcomes.</li> <li>• Timely access to hospice care.</li> </ul>	<ul style="list-style-type: none"> <li>• Improved clinical outcomes.</li> <li>• Reduction of non-beneficial utilization of health care.</li> <li>• Care in lower cost settings.</li> <li>• Greater member satisfaction.</li> <li>• Critical to population health strategies.</li> </ul>	<ul style="list-style-type: none"> <li>• Improved clinical outcomes.</li> <li>• Fortifies health system loyalty.</li> <li>• Assists with designations: Joint Commission, National Cancer Institute.</li> </ul>	<ul style="list-style-type: none"> <li>• Improved clinical outcomes.</li> <li>• Added layer of support for sickest patients.</li> <li>• Support with difficult conversations around prognosis and goals of care.</li> </ul>



# 2021 Priorities

The council identified two priorities for 2021 to highlight the most important starting points for improving serious illness care in Kentucky.

## 1. POLICY AND PAYMENT ISSUES AFFECTING ACCESS TO PALLIATIVE CARE

While palliative care interventions have been shown to improve clinical outcomes, increase satisfaction with health care, and reduce unwanted and non-beneficial utilization of health care services, scaling access to palliative care in Kentucky has been limited due to inadequate payment options for services. Financing for palliative care



services is contingent primarily on fee-for-service billing as there is no palliative care benefit in Kentucky's Medicare program. Revenue from fee-for-service billing is insufficient to cover the cost of providing interdisciplinary care in a community setting to complex patient populations. Consequently, palliative care programs almost always operate at a financial loss which threatens accessibility to palliative care services in the future. Moreover, 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. Because of the clinical and financial misalignment between the interdisciplinary approach of palliative care teams and a fee-for-service payment structure, some states have established a palliative care benefit in their Medicaid programs to ensure the viability and sustainability of palliative care programs. A palliative care benefit not only ensures a path to financial sustainability for palliative care programs, but it reduces the variation in palliative care services to ensure all seriously ill patients receive high quality care.

## 2. HOSPITAL-BASED PALLIATIVE CARE

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. Specifically, of the 130 hospitals in Kentucky, fewer than 15 report providing access to palliative care.

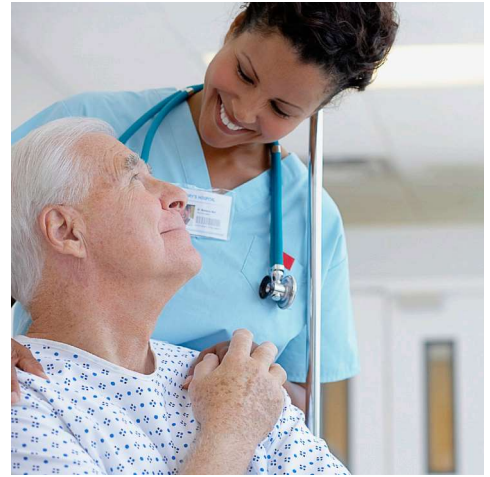


The research literature on hospital-based palliative care is compelling. **Hospital-based palliative care programs have been shown to:**

- Improve experience of care and lower costs of hospital care.
- Ensure expert pain and symptom management by palliative care teams when other providers might shy away from providing pain relief in the midst of the opioid crisis.
- Enhance quality of life for seriously ill patients and their families.
- Improve care coordination for patients and families dealing with multiple doctors across potentially multiple health care systems.
- Support patients and families faced with complex decision making.
- Provide superior goals of care conversations (patient wishes and expectations for care across settings, advanced care planning, etc.).



- Increase the likelihood of patients transferred from the intensive care unit to lower intensity beds.
- Improve discharge planning by supporting the attending physician and discharge planning staff to efficiently transition patients to settings that meet patient needs and personal goals for quality of life (such as home or other non-acute care settings).



Because of the impacts of hospital-based palliative care programs, the Center to Advance Palliative Care and American Hospital Association announced a strategic initiative to support hospitals and health systems in improving serious illness care. **Similar strategic initiatives at the state level could improve care for hospitalized Kentuckians living with a serious illness.**





## 2021 Recommendation

**RECOMMENDATION:** Kentucky should establish a palliative care benefit in its Medicaid program.

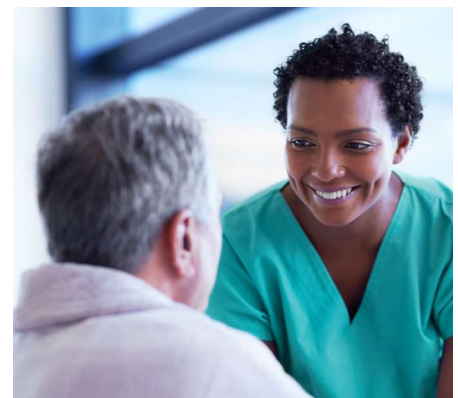
**RATIONALE:** While access to palliative care in Kentucky is increasing, it is still inadequate in meeting the needs of the growing number of Kentuckians living with serious illness. Moreover, as this report details, the clinical and financial misalignment between interdisciplinary palliative care teams supporting seriously ill individuals in a community setting and a fee-for-service payment system that pays only certain providers on volume threatens the sustainability and scalability of palliative care programs. A palliative care benefit would both ensure the financial viability of palliative care programs and reduce variation in palliative care services to ensure that all seriously ill Kentuckians receive access to high quality health care.

## 2021 Recommendation (cont.)

Considerations for creating a benefit that meaningfully improves the lives of the seriously ill include, but are not limited to:

- **Eligibility:** how should seriously ill be defined?
- **Required services and provider types:** what are the types of organizations with the expertise in their workforce to skillfully and expertly support the seriously ill?
- **Payment for services:** what payment options best support seriously ill patients by creating a path to financial sustainability for palliative care programs that provide programs the flexibilities required to tailor services to best support the unique individualized needs of the seriously ill person. Examples include a per-member per-month payment for supportive palliative care services and enhanced fee-for-service payments.
- **Quality and monitoring:** What quality measures and outcome measures should be established to assess the impact of the benefit on patients and the Medicaid program?

**INITIAL STEPS:** There are two advisable first steps. First, the Cabinet for Health and Family Services should work with the Kentucky Palliative Care Interdisciplinary Advisory Council on the considerations for a palliative care benefit. Second, a significant barrier to electing hospice care (hospice care is palliative care for individuals with a terminal diagnosis) is that individuals must choose between electing hospice care and continuing curative treatment. Kentucky can remove this barrier to allow concurrent hospice care and curative care for all terminally ill individuals, not just pediatric patients.



# Case Studies Highlighting Impact of Palliative Care

## PATIENT:

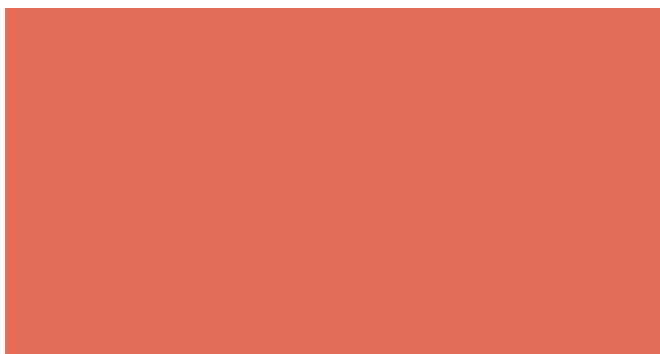
**Mrs. M is a 79-year-old female with a primary palliative diagnosis of heart failure with comorbid COPD.** She wears 1.5-2L/min nasal cannula support at night and lives alone with family in the area. She has chronic back pain from numerous surgeries, a frequent cough, congestion, and shortness of breath. Mrs. M uses a walker for ambulation and has increasing falls and is now requiring some help with activities of daily living.

## PRIORITIES

Mrs. M's main priority is to remain independent, perform her own activities of daily life, and remain in an environment with social support. Her preference is to avoid any additional hospitalizations if necessary. Moreover, she wants her pain and symptoms managed effectively while limiting the role of opiate medications.

## PALLIATIVE CARE INTERVENTION

Mrs. M was referred to a community-based palliative care program to effectively manage her pain and symptoms, reduce the likelihood she would be reliant on the hospital to manage her medical conditions, and foster her goals to live independently in the community for as long as possible. The community-based palliative care team is interdisciplinary and composed of a specially trained nurse, physician, social worker, and nursing assistant. The interdisciplinary team brings expertise in pain and symptom management and communication skills with seriously ill patients and families.



# Case Studies Highlighting Impact of Palliative Care

## IMPACT

The standard way health care is delivered did not work for Mrs. M and, consequently, she was at the mercy of the emergency department and hospital for support for her medical conditions. The palliative care team discussed Mrs. M's understanding of her diagnoses and goals for health care with her. Based on her goals, a plan of care was developed that focused on maintaining independence, managing pain and anxiety, and avoiding further non-beneficial hospitalizations. The physician with expertise in effective pain and symptom management brought her pain to an acceptable level while limiting the use of opiate medication. Mrs. M completed a Medical Orders for Scope of Treatment document which brought peace of mind to Mrs. M and elevated her sense of autonomy and independence. The nurse and social worker provided Mrs. M and her family with education on disease progression and caregiver support, and developed a plan to increase safety in the home which included reducing falls risk and installing grab rails in the bathroom. As a result of the palliative care intervention, Mrs. M's quality of life has increased, she has thrived in the community setting and is no longer dependent on the hospital for emergent health care needs.



# Case Studies Highlighting Impact of Palliative Care

## PATIENT:

**Will is a 16-year-old male with a primary diagnosis of Cystic Fibrosis.**

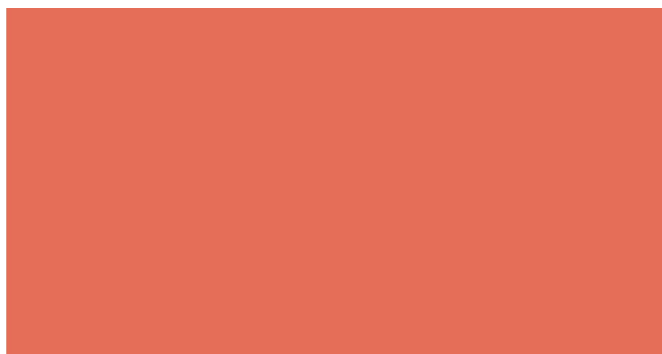
Moreover, he has Type 2 diabetes mellitus and chronic weight loss. Will is on 20 different prescription medications to manage his conditions in addition to daily nebulizer treatments and vest therapies. He frequently contracts drug resistant infections, which is complicated by the number of medications he must take. Will lives with his mother and three siblings.

## PRIORITIES

Will's main priority is to remain independent, enjoy being a "kid" as much as possible, and not allow his illness to limit what he is able to do. Hospitalizations are draining and scary to Will, and he hopes to avoid subsequent stays in the hospital. Additionally, Will finds the number of medications to take daily overwhelming and difficult to keep track of.

## PALLIATIVE CARE INTERVENTION

Because of Will's desire for an enhanced quality of life and to stay out of the hospital, he was referred to a pediatric palliative care program. The pediatric palliative care program provides care patient's homes and is composed of a specially trained team that includes a clinical social worker, nurse, nurse practitioner, chaplain and psychologist. The interdisciplinary team brings expertise in pain and symptom management and communication skills with seriously ill patients and families. Additionally, the team has specialization in caring for seriously ill children in community settings.





# Case Studies Highlighting Impact of Palliative Care

## IMPACT

The standard way health care is delivered did not work for Will given his health conditions and priorities. The palliative care supported Will in a way that improved his quality of life and enabled him to enjoy being a kid. The nurse provided ongoing education about disease progression to ease concerns for Will and his family. Additionally, the nurse skillfully discussed the benefits and burdens of the medications Will was taking. The social worker facilitated a family meeting among the palliative care team, Will's family and Will's pulmonology and endocrine teams improving coordination among providers and adding clarity to the family. The palliative care physician was able to expertly manage protracted bothersome symptoms for Will. Will's health conditions have stressed his family's financial resources. The palliative social worker assisted the family in applying for Social Security income which resulted in increased monthly income alleviating some financial stress for the family. Additionally, the social worker arranged for other community resources to support Will including SNAP EBT cards, pandemic EBT cards, identified donations of a stove and clothing, and found resources to keep the electricity on. Will's case demonstrates how community-based palliative care teams can make a meaningful difference in the lives of seriously ill children and their families.



## References

- Bakitas, M. A., T. D. Tosteson, Z. Li, K. D. Lyons, J. G. Hull, Z. Li, J. N. Dionne-Odom, J. Frost, K. H. Dragnev, M. T. Hegel, A. Azuero, and T. A. Ahles. 2015. Early versus delayed initiation of concurrent palliative oncology care: Patient outcomes in the ENABLE III randomized controlled trial. *Journal of Clinical Oncology* 33(13):1438-1445. <https://doi.org/10.1200/JCO.2014.58.6362>
- Beales, J. L., and T. Edes. 2009. Veteran's Affairs Home-Based Primary Care. *Clinics in Geriatric Medicine* 25(1):149-154. <https://doi.org/10.1016/j.cger.2008.11.002>
- Bruera. 2015. Integration of oncology and palliative care: A systematic review. *Oncologist* 20:77-83. <https://doi.org/10.1634/theoncologist.2014-0312>
- CAPC. The Case for Hospital Palliative Care. <https://www.aha.org/system/files/media/file/2019/07/the-case-for-hospital-palliative-care.pdf>
- Cassarett D et al. *J Am Geriatr Soc*, 2008. Do Palliative Consultations Improve Patient Outcomes? <https://pubmed.ncbi.nlm.nih.gov/18205757/>
- Cassel, B. J., K. M. Kerr, D. K. McClish, N. Skoro, S. Johnson, C. Wanke, and D. Hoefler. 2016. Effect of a home-based palliative care program on healthcare use and costs. *Journal of the American Geriatrics Society* 64(11):2228-2295. <https://doi.org/10.1111/jgs.14354>
- Driessen, J. and West, T., "Variation in End-of-Life Care Is An Open Invitation For Accountable Care Organization Innovation," *Health Affairs Blog*, August 25, 2017. <https://www.healthaffairs.org/doi/10.1377/hblog20170825.061646/full/>
- Dumanovsky T, Augustin R, Rogers M, Lettang K, Meier DE, Morrison RS. The growth of palliative care in the US hospitals: a status report. *Journal of Palliative Medicine* 2016. <http://www.ncbi.nlm.nih.gov/pubmed/26417923>
- Enguidanos S, Vesper E, Lorenz K. 30-day readmissions among seriously ill older adults. *Journal of Palliative Medicine* 2012. <http://www.ncbi.nlm.nih.gov/pubmed/23045990>

## References (cont.)

- Kamal, A. H., D. C. Currow, C. S. Ritchie, J. Bull, and A. P. Abernethy. 2013. Community-based palliative care: The natural evolution for palliative care delivery in the U.S. *Journal of Pain and Symptom Management* 46(2):254-264. <https://doi.org/10.1016/j.jpainsymman.2012.07.018>
- Kelley, A. S., K. Covinsky, R. J. Gorges, K. McKendrick, E. Bollens-Lund, R. S. Morrison, and C. S. Ritchie. 2017. Identifying older adults with serious illness: A critical step toward improving value of health care. *Health Services Research* 52(1):113-131. <https://doi.org/10.1111/1475-6773.12479>
- Morrison RS et al. Cost Savings Associated With US Hospital Palliative Care Consultation Programs. *Arch Intern Med*, 2008. <https://pubmed.ncbi.nlm.nih.gov/18779466/>
- Morrison, R. S. 2013 Models of palliative care delivery in the United States. *Current Opinion in Supportive and Palliative Care* 7(2):201-206. <https://doi.org/10.1097/SPC.0b013e32836103e5>
- National Consensus Project for Quality Palliative Care. 2013. Clinical practice guidelines for quality palliative care. Fourth edition. Pittsburgh, PA: National Consensus Project for Palliative Care. National PACE Association. Facts and trends. Available at: <https://www.nationalcoalitionhpc.org/ncp/>
- O'Quinn LP, Giambra BK. Evidence of improved quality of life with pediatric palliative care. *Pediatric Nursing* 2014. <http://www.ncbi.nlm.nih.gov/pubmed/25929123>
- Temel JS et al. Early Palliative Care for Patients with Metastatic Non-Small-Cell Lung Cancer. *NEJM*, 2010. <https://www.nejm.org/doi/pdf/10.1056/NEJMoa1000678Temel%20JS%20et%20al>.
- Twaddle, M. L., and E. McCormick. 2016. Palliative care delivery in the home. (Accessed December 1, 2016). Available at: <http://www.uptodate.com/contents/palliative-care-delivery-in-the-home>
- Yoong J. Early Palliative Care in Advanced Lung Cancer: A Qualitative Study. *JAMA Intern Med*, 2013. <https://pubmed.ncbi.nlm.nih.gov/23358690/>

# Kentucky Palliative Care Interdisciplinary Advisory Members

- Dr. DeLana 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
- Dr. Jessica Beal Korhonen, Psy.D.
- James William Patton, JD
- Dr. Lindsay Ragsdale, MD, FAAP, FAAHPM
- Dr. Bethany Cox Snider, MD HMDC FAAHPM
- R. Turner West II, MPH, MTS
- Addia Kathryn Wuchner, RN, LDh
- Kristy Young

For more information,  
please contact:  
Turner West, Chair  
Kentucky Palliative Care  
Interdisciplinary Advisory Council  
twest@bgcarenav.org  
859.296.6850