

SESSION OF 2018

SUPPLEMENTAL NOTE ON HOUSE BILL NO. 2031

As Amended by Senate Committee on Public
Health and Welfare

Brief*

HB 2031, as amended, would create the Palliative Care and Quality of Life Interdisciplinary Advisory Council (Council) and the State Palliative Care Consumer and Professional Information and Education Program (Program) within the Kansas Department of Health and Environment (KDHE). The Council would be responsible for developing recommendations and advising KDHE on matters related to the establishment, maintenance, operation, outcomes evaluation of palliative care initiatives in the state, and effectiveness of the Program. The Program's purpose would be to maximize the effectiveness of palliative care initiatives in the state by ensuring comprehensive and accurate information and education about palliative care is available to the public, health care providers, and health care facilities. The bill would also define "palliative care." Additional bill details follow.

Council

Council Composition, Appointment, Terms, and Compensation

The Council would consist of 13 members appointed on or before October 1, 2018, with appointments as follows:

- Two members by the Governor;

*Supplemental notes are prepared by the Legislative Research Department and do not express legislative intent. The supplemental note and fiscal note for this bill may be accessed on the Internet at <http://www.kslegislature.org>

- Two members by the Speaker of the House of Representatives;
- One member by the Majority Leader of the House of Representatives;
- One member by the Minority Leader of the House of Representatives;
- Two members by the President of the Senate;
- One member by the Minority Leader of the Senate;
- One member of the House Committee on Health and Human Services by the Chair of the House Committee;
- One member of the Senate Committee on Public Health and Welfare by the Chair of the Senate Committee;
- One member by the Secretary of Health and Environment to represent KDHE; and
- One member by the Secretary for Aging and Disability Services to represent the Kansas Department for Aging and Disability Services (KDADS).

Council members would serve for three years and at the pleasure of their respective appointing authorities. The Council members would appoint the Chairperson and Vice-chairperson, whose duties would be established by the Council. KDHE would be required to fix the time and place for regular Council meetings, with at least two meetings required annually.

Council members would serve without compensation but would be reimbursed for actual and necessary expenses incurred in the performance of their duties.

Council Member Qualifications

The bill would require Council members to be individuals with experience and expertise in interdisciplinary palliative care medical, nursing, social work, pharmacy, and spiritual guidance. Health care professionals with palliative care work experience or expertise in palliative care delivery models in a variety of settings and with a variety of populations would be specifically required to be included in Council membership. The Council would be required to have a minimum of two members who are board-certified hospice and palliative medicine physicians or nurses and at least one member who is a patient or caregiver.

Definition of Palliative Care

Palliative care would mean an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual. Palliative care would:

- Provide relief from pain and other distressing symptoms;
- Affirm life and regard dying as a normal process;
- Intend neither to hasten or postpone death;
- Integrate psychological and spiritual aspects of patient care;
- Offer a support system to help patients live as actively as possible until death;

- Offer a support system to help the family cope during the patient's illness and their own bereavement;
- Use a team approach to address the needs of patients and their families, including bereavement counseling, if indicated;
- Enhance the quality of life, and may also positively influence the course of illness; and
- Apply early in the course of illness, in conjunction with other therapies intended to prolong life, such as chemotherapy or radiation, and include investigations needed to better understand and manage distressing clinical complications.

KDHE's Program Responsibilities

With regard to the Program, KDHE would be required to publish information and resources on its website, including links to external resources about palliative care for the public, health care providers, and health care facilities; develop and implement any other initiatives regarding palliative care services and education KDHE determines would further the Program's purposes; and consult with the Council. The information to be published on the KDHE website would include, but not be limited to, health care provider continuing education opportunities, information about palliative care delivery in home and other environments, and consumer educational materials and referral information for palliative care, including hospice. Palliative care would have the meaning as described in the section regarding the Council.

Background

The bill was introduced by the House Committee on Health and Human Services at the request of the American Cancer Society Cancer Action Network (ACS CAN). In the

House Committee hearing, a cancer survivor, a cancer patient advocate, and representatives of the Center for Practical Bioethics, the Family Policy Alliance of Kansas, the National Multiple Sclerosis Society, the University of Kansas Health System, Via Christi Health, and Wesley Healthcare testified in support of the bill. The proponents generally stated palliative care improves the quality of life for patients and families facing serious or advanced chronic illness and noted the growing need for such care. The proponents stated the team approach in palliative care is valuable to address distressing physical symptoms, emotional and spiritual needs, and assistance in navigating an often complex health care system. Written-only proponent testimony was provided by representatives of AARP Kansas, ACS CAN, the Alzheimer's Association in Kansas, the American Heart Association, the Kansas Academy of Family Physicians, the Kansas Association of Area Agencies on Aging and Disabilities, the Kansas Chapter of the National Association of Social Workers, the Kansas Hospice and Palliative Care Association, the Kansas Hospital Association, Midland Care Connection, and the National Alliance on Mental Illness.

No neutral or opponent testimony was provided.

The House Committee amended the bill to increase the Council membership by one member appointed by the Majority Leader of the House of Representatives, require at least one Council member be a patient or caregiver, prohibit Council members from studying physician-assisted suicide, and define palliative care.

The House Committee reconsidered its previous action on the bill and amended the bill to remove the language regarding the Council member prohibition on studying physician-assisted suicide.

The House Committee of the Whole amended the bill to require KDHE to implement the provisions of the bill within the limitations of existing moneys and resources already allocated to the agency.

On March 9, 2017, in the Senate Committee on Public Health and Welfare hearing, two cancer survivors, a mother of a cancer survivor, a palliative care chaplain, and representatives of the Family Policy Alliance of Kansas, Lawrence Memorial Hospital, and the University of Kansas Medical Center testified in favor of the bill.

Written-only proponent testimony was provided by representatives of the AARP Kansas, ACS CAN, Alzheimer's Association in Kansas, American Heart Association, Center for Practical Bioethics, Kansas Association of Area Agencies on Aging and Disabilities, Kansas Academy of Family Physicians, Kansas Advocates for Better Care, Kansas Chapter of the National Association of Social Workers, Kansas Hospital Association, Kansas LIFE Foundation, Midland Care, National Alliance on Mental Illness Kansas, National Multiple Sclerosis Society, Via Christi Health, and Wesley Healthcare. No other testimony was provided.

On January 31, 2018, the Senate Committee held an informational hearing on palliative care. A palliative care patient and representatives from the Kansas Clinical Improvement Collaborative and ACS CAN provided information to the Senate Committee. Written-only information was provided by a cancer patient and representatives from Saint Luke's Health System, Stormont Vail Health, and the University of Kansas Health System.

On February 7, 2018, the Senate Committee amended the bill by changing the date for Council members to be appointed from October 1, 2017, to October 1, 2018, and by deleting the requirement for KDHE to implement the provisions of the bill within the limitations of existing moneys and resources already allocated to the agency

According to the fiscal note prepared by the Division of the Budget on the bill, as introduced during the 2017 Session, enactment of the bill would have no fiscal effect on KDADS. The fiscal note states the costs for actual expenses of the Council members and KDHE staff would increase

expenditures for KDHE for FY 2018 by \$113,000, including \$83,000 from the State General Fund (SGF), and by \$115,000 for FY 2019, including \$85,000 from the SGF. The expenditures for FY 2018 would include those for one FTE Program Director; a one-time computer cost; printing costs; telephone, travel, and office supplies; Council expenses calculated at \$1,000 each for 12 members; and data collection and evaluation costs. For FY 2019, KDHE estimates a 2.0 percent increase in expenditures. Any fiscal effect associated with enactment of the bill was not reflected in *The FY 2018 Governor's Budget Report*.