



March 9, 2017

Chairwoman Schmidt and members of the Senate Public Health Committee. I am Mitzi McFatrach, executive director of Kansas Advocates for Better Care (KABC). I appreciate the opportunity to come before the committee in support of HB 2031 to establish the advisory council on palliative care and quality of life and the palliative care education program.

It is estimated that 75% of people with dementia will spend time in a nursing home, most typically in the moderate and advanced states. The average time between diagnosis and death is 8 to 10 years, but some people live with dementia up to 20 years. As the number of older adults in Kansas grows and the number of persons with dementia also increases, it becomes critical that our adult care homes be positioned to provide the person-directed care that manages residents' symptoms. Bringing comfort to people with advanced dementia should be the highest priority of health care policy and among providers.

HB 2031 provides a cornerstone to reaching that goal. The advisory council established by HB 2031 would signal that palliative care is a priority by assuring that information is available to the public and education opportunities are available for professionals who care for persons with dementia.

When a person with advanced dementia experiences distress, his/her actions, rather than their words are most likely to be their attempt to communicate their distress. Professional caregivers and families often don't understand these behavioral expressions, such as moaning, calling out, striking out or grimacing. Palliation can prevent or relieve a person's distress by focusing on symptom management, helping to ease stress for the person and for the family. Palliative care takes active steps to discover what comforts and/or gives a person pleasure and prevents or avoids unnecessary distress or pain.

These behavioral expressions too often are managed through anti-psychotics, anti-anxiety and sedative medications which do not take away pain or distress that is not non-psychosis related, nor do they comfort someone who may be hungry, cold, too warm, tired, lonely or frightened by noises or activity in the environment.

An emphasis on palliative care could have a dramatic impact in improving the quality of care and life for Kansans diagnosed with dementia. It has proven to be an important tool for reducing our over-reliance on chemical restraints. Kansas currently ranks 50th worst in the U.S for inappropriate use of anti-psychotic drugs on older adults with dementia. Anti-psychotic drugs are being used to chemically restrain elders with dementia despite the black box warnings of the high danger they pose to older adults. They continue to be overused in Kansas adult care homes even though there is no approved anti-psychotic drug use for treatment of dementia.

Organizational systems must be aligned to support a palliative approach and to insure staff efforts are effective. A palliative care guidebook by the CaringKind, notes that “dementia-capable palliative care requires a commitment to education of staff at all levels. Sustainability of these improved practices is dependent on the degree to which organizational policies, procedures and protocols are in place to support them. HB 2031 sets up a process to maximize palliative care initiatives by ensuring comprehensive and accurate information and education is available to the public, health care providers, adult care homes and caregivers. Palliative care is also consistent with the requirements of person-centered care within the federal settings rule.

Thank you for the opportunity to stand with the American Cancer Society Action Center Network and other organizations which support the passage of HB 2031. On behalf of Kansas older adults and their families, we ask you to pass BH 2031.

Mitzi E. McFatrach, Executive Director - On behalf of Board of Directors and Members

KABC is a not-for-profit organization whose mission is to improve the quality of long-term care for elders in all settings – nursing and assisted facilities and in-home. KABC is not a provider of government funded services. For more than years KABC’s role has been as a resource and advocate for older adults and families and as a resource to policy makers on aging and quality care issues. KABC provides consumer education information and tracks and reports on quality care performance issues.