

January 31, 2018

Testimony in support of HB 2031

Senate Public Health & Welfare Committee

Chairwoman Schmidt and members of the committee,

Thank you for allowing me to speak in support of House Bill 2031 and the importance of palliative care in my life. The palliative care that I have received at KU Medical Center has been so important in guiding me to be able to be a *person who lives with cancer, rather than a victim of cancer*. I would like to help others across the state learn about and benefit from this type of care.

I'm a retired high school counselor and was enjoying spending time with my family and involved many activities including my work as a Master Gardener when I was diagnosed with Multiple Myeloma (a treatable not curable cancer of plasma cells) in July of 2015. I received a stem cell transplant in December 2015 and continue to receive chemotherapy every two weeks. My pre and post-transplant symptoms have been both physical and mental.

To help address these symptoms, I was encouraged by a friend and fellow cancer patient Jen Olson (who spoke to you last spring) to seek palliative care. First, I had to Google "palliative care" to find what was involved, because I had no idea. **After my initial visit with the palliative care team, I felt understood and together we developed a plan for me to live better.**

It struck me that this was the first time anybody "got it" and really seemed to understand what my family and I were going through. My palliative care plan included ways to manage my physical symptoms as well as the emotional and spiritual challenges for me and my family. I worked with my palliative care team to determine my end of life wishes. This was a huge relief for me because it took those stressful decisions away from my husband and sons.

Beyond big issues like understanding and identifying my goals and wishes, the palliative care team also helped me with practical and day-to-day challenges. For the first year and a half after my treatment began, I hadn't been able to drive a car – this made me anxious and helpless because I felt that I had no independence. My palliative care physician referred me to have leg weakness assessed by physical therapy and interventional radiology for back pain treatment. Within two months, I was able to start driving again.

Since then, palliative care has helped me with symptoms of cancer and the transplant. They are my care coordinators. They help me find symptom relief, including pain, bowel problems, mental distress, low energy, and general lifestyle. **They are responsible for me taking the least amount of the most effective meds so I can live the best life possible.** They understand my cancer as if they too had lived the same past 28 months as I have. They are the lagniappe, the something more, in my cancer care.

I'm a palliative care success story, but that's only because my friend told me to seek this type of supportive care. And now, the palliative care nurses at KU tease me than I'm their biggest referrer! Getting the word out about palliative care is obviously important, as several times when I have mentioned palliative care, people have expressed sympathy assuming it is hospice care. The education components of HB 2031 will help address this lack of awareness and confusion about palliative care.

Before I got my symptoms under control with palliative care, I was using a walker to get around and had been hospitalized after my chemo treatments for vomiting. Now, I get lower doses of chemo more often to reduce nausea and vomiting. Now, **I get to spend more of my time doing what I love** – taking painting classes, being involved with Master Gardeners of Greater Kansas City and serving on the board of Gardeners Connect. I am enjoying time with my husband and friends, and I'm well enough to go visit my grandchildren in Chicago.

Just as important as the support for me and my physical symptoms, **palliative care has helped my family**. I often feel like my cancer is harder on my husband and kids than it is on me. My first husband was a healthy, fifty-one year old marathon runner when he was diagnosed with a rare form of lymphoma. In retrospect, I can see how palliative care could have helped him as well as my college-aged sons, myself, and other caregivers during his rapid decline. He was dead just eight weeks after diagnosis. It was not until a year after his death I found out how deadly a disease we faced. I feel I have an insurance policy with palliative care as they told me if and when I need hospice care, they will facilitate that transition.

Now palliative care helps us all manage the stress and worries that come with my cancer treatment and prognosis. Now, we're able to live a great life. **Please help other families benefit as mine has and support HB 2031.**

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