

March 9, 2017

Senate Public Health and Welfare Committee

Testimony in Support of HB 2031

Chairwoman Schmidt and members of the committee,

My name is Michele Longabaugh, seven years ago today, at the age of 47, I was dismissed from a Wichita hospital with the diagnosis of stage 4 anal cancer and a poor prognosis. I was given three years expected survival with treatment. Being a devoted wife, mother, nurse and involved in my community I decided to fight the cancer with everything I had.

After multiple rounds of aggressive treatment, including chemo, radiation, and surgery both in Wichita and at MD Anderson, including one recurrence, I have been disease-free since 2014...but not problem free. My body was left weakened and I struggled to regain strength so I could re-enter the work force and resume a good quality of life once more. This has been a real struggle for me.

I now live with the fallout of not having organized palliative care integrated early in my treatment and throughout my miraculous recovery. At one point during my recovery I was being treated by ten different specialists. My quality of life was lost in the shuffle and my need for palliative care was minimized by my poor prognosis. I wish that I had been treated like I was going to survive! I was left with the responsibility for navigating my own recovery. I felt lost and without a voice. I didn't know what questions to ask or even who to ask. As a result, my recovery was impacted. **A palliative care program would have changed that for me. I know that my physical and emotional recovery would have been accelerated, the burden on my family lessened and some of the long term side effects minimized.**

I am not alone. Thousands of people in Kansas and their families are impacted by serious illnesses every year. If I as a health care worker struggled to orchestrate my own recovery, what happens to others not familiar with medical infrastructure at all?

There is a misperception in society that palliative care means hospice care. That's not true. Palliative care can apply to any one at any stage of their illness. By treating the pain, distress and all side effects that come with cancer, we can help families facing serious illnesses live better during and after treatment.

Palliative care, or I what I like to call comfort care, should be given throughout treatment and survivorship. Today I live with chronic pain and fatigue, digestive and nutritional challenges, marked lower body weakness and a chronic lung condition. I live with the

anxiety that comes from wondering if any new pain or symptom is my cancer returning. **I am committed to improving quality of life for others facing cancer. Palliative care can offer the necessary support to make a distinct difference to all diagnosed and impacted by any serious illness whether they are expected to survive three months, three years or three decades.**

Leadership and education about palliative care is vital. I am asking you to support the formation of the Palliative Care and Quality of Life Interdisciplinary Advisory Council to ensure no future patient feels they are worse off after surviving cancer because they did not know about or have access to palliative care.

Thank you for considering this important issue.

Michele Longabaugh, RN

Wichita, Kansas