

March 9, 2017
Testimony in Support of HB 2031
Senate Public Health & Welfare Committee

Chairman Schmidt and members of the Senate Public Health and Welfare Committee:

My name is Jennifer Olson. A former high school teacher, I now am so grateful to spend all of my time caring for my husband of 23 years and three terrific children and managing my chronic illness. Since April of 2015, I have been living with Stage IV metastatic lung cancer. Statistically, my prognosis is poor. But I have responded well to first line chemotherapy treatments and the cancer in my lungs, adrenal gland, and liver is stable.

I receive my care at the University of Kansas Cancer Center, and I feel truly blessed to live 10 minutes away from this premier institution. **I do not wish to imagine how different my story would be if I had not been diagnosed there, where by sheer luck I was at the location of one of the most highly developed Palliative Care departments in the State of Kansas and even the country.**

I have two stories about how the Palliative Care Department at KU Med profoundly impacted my life.

First, as my father's health rapidly deteriorated from bladder cancer, diabetes, COPD, blindness, heart disease, and more in 2014, my sister--a nurse in the KU Emergency Department-- asked his internist if she could resource Palliative Care to help us navigate the many decisions around his care, and in particular to have them oversee medications prescribed by so many different specialists, and provide pain and symptom management and emotional support. Thanks to persistent work by the Palliative Care team's interdisciplinary approach, Dad received excellent Palliative Care for several months. And when the time was appropriate, they helped him transition to a rehab center and then eventually to his home under the care of Catholic Community Hospice, allowing him to die in his armchair, surrounded by his loved ones.

Second, as a lung cancer patient, Palliative Care services have enabled me to resume the most important activities of my life. Before diagnosis, I was an active substitute teacher and volunteer at my children's school and our Church, a coach for my daughter's sports year-round, an active and healthy person who loved playing volleyball, lifting weights, practicing yoga, and running. Many of these activities are again part of my life, with modifications, now 2 years after diagnosis, and I owe much of my wonderful quality of life to Palliative Care services provided since immediately after my diagnosis.

A few weeks after my dad died, I was still feeling so exhausted, short of breath, and worthless at my weekly volleyball match. I assumed I had an upper respiratory infection or an extra-difficult flare up of my allergies, but five days after antibiotics, my primary care physician ordered a chest x-ray since I was not improving. Hospitalized, I was diagnosed two days later with Stage IV lung cancer. With my sister Gretchen by my side

to help me process it, we asked for a consult with Palliative Care specialist, Dr. Christy Bartlett. **Were it not for an informed nurse, my sister, who knew the tremendous difference between Palliative Care and Hospice Care, I would have likely continued in the system without the many advantages offered to me by our Palliative Care department.**

Having had a first lesson during my Dad's illness about Palliative Care and how it differs from Hospice care, no one needed to convince me to accept help from the Palliative care team. The first step in accepting Palliative Care is to acknowledge that you have a chronic disease that is impacting your ability to live fully. It does NOT mean you are "dying." An ideal patient of Palliative Care is not necessarily "dying" any more than any other one of us who is only guaranteed this moment now without guarantees for tomorrow. *I do have a terminal disease, but Palliative Care provides tools for me to live.*

With the help of Palliative Care, I am NOT dying - *I am living as fully as possible within the limitations of lung cancer.* Eventually, I may need Palliative Care professionals to also provide comfort and support for end of life care or a hospice program. But not yet! So, it is important to me that I will have these amazing Palliative Care professionals to know me now, help me make decisions that are right for me, and walk with me during the more difficult days that will be mine in the future.

Some examples of the care I have received through these services include the following:

- identifying and managing my allergic reactions to morphine and Dilaudid
- listening to my complaint, and trouble-shooting the terrible soreness of the inside of my nose as I wore an oxygen cannula around the clock
- prescribing a specific anti-anxiety medication to help with the panicky feeling of "I can't breathe", and teaching me to sit in front of a fan or wave a piece of paper in my face to help me feel like I have more air
- visiting me daily or more frequently during my second hospitalization when the drain for my lung became infected, managing the very long list of medications and symptoms while pulmonologists focused on my survival
- arranging an appointment for me with a social worker who helped me and my husband Andy discuss and develop my advanced directive
- scheduling a consult with my amazing therapist who specializes in psycho-oncology
- sending a dietician to see me after I rapidly lost 30 pounds
- helping me understand that my manic behavior and sleeplessness during chemo recovery is likely a side-effect of the steroid medication I require
- supporting my desire to decrease my dependence on pain medications while simultaneously arranging for a nerve block and balancing my desire with honest reality checks
- brainstorming and trying new approaches based on my feedback of how my lifestyle is impacted by meds and chemo side effects. They help me make decisions so that I can be at my very best at 3:30pm and through the evening and weekends when my focus is my family.

- caring for my emotional health as well as my physical health, acknowledging my fear of dying but balancing that with the facts of how extremely well I am doing right now.
- encouraging me to explore other care that interests me such as classes at a local cancer support center, meditation, and yoga for the variety of physical and emotional benefits.
- recommending books and articles to meet me where I am, and suggesting a Mindfulness Workshop offered through the Psychology Department at KU Cancer Center.

For months, my appointments with a Palliative Care doctor or nurse, psychologist, or dietician were always scheduled during my chemotherapy treatment: they rightly assumed that adding another appointment to my schedule would be exhausting, burdensome, and would detract from time I could spend living my life with my family and friends. Although I am under the care of oncology, pulmonology, psychology, spine/pain center, radiation oncology, and neurology, I rarely call those offices with questions; my two Palliative Care nurses are my very first go-to.

Because I speak so highly of how dramatically it has improved my life with cancer, I have brought several friends to ask their doctors about Palliative Care as a resource. Some require some convincing and nudging to ask their doctors about it. Some have found it to transform their experiences; others have found their hospital doesn't provide enough (or any) Palliative Care services. One friend spent four years miserably battling colon cancer, only to finally resource Palliative Care services in her last few months and missing out on a quality of life that could have been improved sooner. The lack of patient understanding and the broad spectrum of availability and quality of Palliative Care services result in too many Kansans living a much lower quality of life with chronic disease than they should. **How lucky I am that I had a knowledgeable nurse in my family; how lucky I am that my cancer center has a highly developed Palliative Care department. And how unlucky for so many others who do not.**

It is out of the gratitude that I speak to you today, to ask that you remember my face when you consider House Bill 2031 that will help others gain access to Palliative Care. My smiling face shows what excellent Palliative Care can help accomplish. These services can benefit so many people like me--actively pursuing a terrific life now while simultaneously living with chronic, incurable disease. Please support this bill so that good luck is not a primary determinant in how a patient like me lives with disease.

Thank you.
Jennifer Olson
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