Testimony in Support of SB 2226

Residential End-of-Life Facilities
House Human Services Committee
March 9, 2021 • 2:45 p.m. • Pioneer Room
Dr. Laura Archuleta

Introduction

Chairman Weisz and members of the House Human Services Committee. My name is Dr. Laura Archuleta, and I am here to ask you to support SB 2226, which will enable North Dakota to have residential end-of-life facilities. As a medical director for a hospice program, I work with individuals who have a terminal illness by educating them on palliative medicine and the beauty of hospice care. Because of my unique background serving North Dakota's terminally ill individuals in communities located in and around Bismarck, Dickinson, Williston, and Valley City, I appreciate the opportunity to testify on behalf of this bill, as by doing so I am advocating for North Dakota's aging population.

Giving North Dakotans the option of a residential end-of-life facility could greatly impact patients' quality of life and provide them with the dignity they deserve during end-of-life care. Today I will illustrate just how important residential end-of-life facilities are to the continuum of care for North Dakotans by sharing three patient stories – stories that have kept me awake at night knowing how different their end-of-life experience could have been.

Real People a Residential End-of-Life Facility Could Have Helped

First, I will introduce you to Elizabeth. She was a 52-year-old female with stage IV lung cancer which spread to her brain. After discussion with her doctors, she decided the side effects of treatment were worse than the underlying disease itself. As a single woman, she wanted to stop treatment and enjoy the time she had left with her three children, all of whom work full-time to support their own families, and her four grandchildren. Elizabeth was physically strong enough to take care of herself, go out on day trips, and live a relatively full life. However, because of her brain metastases she did need 24-hour care. At age 52, she was young and active enough that she hated the idea of being "trapped" in a nursing home. She

moved in with her son and other family pieced together caregiving, but it created significant emotional and financial burdens on them. Elizabeth was adamant that she **DID NOT** want to die in her son's home because she did not want her grandchildren to face those memories every time they went into her room. At the end of life, when her family was no longer able to care for her, she was admitted to the hospital and died there. If we had a residential end-of-life facility, Elizabeth would have had the help she needed, but would have been able to come and go with family and friends while she was still well enough to do so. She would have had expert care 24 hours a day, trained to meet her needs near end-of-life. Her family could have focused on building memories with her instead of experiencing the stress and anxiety they had from being her caregivers.

Next, I want to introduce you to David, who was a 68-year-old gentleman with stage IV colon cancer. He was in and out of the hospital several times for abdominal obstruction due to his tumor. But, since he was not a good candidate for surgery, and unable to complete additional cancer-directed therapies, he chose comfort care. His wife had early dementia and could not handle his complex caregiving needs at home, and his children were unable to provide in-home caregiving as well. His only option was a nursing home. He was very angry at the idea of going to a nursing home and made his family promise they would not, "Put him in a home." At the same time, nursing homes were hesitant to accept him because of the level of care he needed, even with the hospice program's assistance. Unfortunately, we were unable to find placement for David, and he passed away in the hospital. I'll never forget his last wish. He wanted to sit on his back deck with a cup of coffee and enjoy the flowers and birds in his backyard. He never had the opportunity to do that. Now, granted, a residential end-of-life facility would not have been the same; but it would have given him a private, home environment where he could have spent his final days receiving the care he needed. He would have had a chance to have that cup of coffee and enjoy the flowers and birds in his new backyard.

Conclusion

For the past 11 years, I have specialized in helping aging and terminally ill North Dakotans. This calling has been with me since I was a little girl because of my grandparents, and the vastly different end-of-life experiences they each had, which is my third story. My grandfather spent his last weeks hospitalized, surrounded by medical equipment in an institutional room. When I look at pictures of his final day, I see his dull and lifeless eyes, and a spirit that left prior to his passing. On the flip side, my grandmother had the opportunity to receive hospice in her home, in which she was surrounded by her children and grandchildren. Pictures of her last days show her eyes bright, and she has a sense of peace that was present up until she took her last breath. I want my future patients who are unable to receive hospice in their home to have a choice of living in a residential end-of-life facility, where they can have a true home experience. That's the next best alternative to being at home, in my humble and professional opinion.

Thank you, Chairman Weisz, and the members of the House Human Services Committee, for your time and for hearing my testimony today.