

Testimony of Katherine Swenson  
In support of Raised Bill No. 179  
An Act Concerning The Alzheimer's Disease and Dementia Task Force's Recommendations on  
Training  
Aging Committee  
February 25, 2014

I would like to share my story in support of training, education, and respite for caregivers of individuals who have Alzheimer's.

For many years I was your average caregiver -- part of the "sandwich generation" -- the oldest daughter, single-parent, raising a child, working full-time, and caring for an independent aging parent.

In 2011, due to a series of events, I was in jeopardy of becoming homeless. Fortunately, I discovered a program called "Project Home Share." I submitted my application and stated on it that I was willing to live with anyone, except someone with Alzheimer's. This disease frightened me!

I received a call from a woman seeking someone to live with her mother -- someone who could be available in the evening and overnight -- in exchange for housing. However, her mother was in the early stages of Alzheimer's.

I reflected upon my past experiences when I had taken risks outside my comfort zone. Those experiences taught me so much about myself. So, I chose to embrace this opportunity with a spirit towards seeking personal growth, discovery, and development.

We decided to try it for a month. Although Elizabeth had been living independently, I requested that she be evaluated to ensure that she would be safe being home alone during the day. The evaluation revealed Elizabeth required 24/7 (168 hrs/wk) supervision. As our arrangement was working well and my position was ending, her daughter offered to pay me to care for her mother. After all, she needed to pay someone, why not me? That's how I became a live-in caregiver.

We created a mutually acceptable agreement. I became an employee; IRS's rules. I had unemployment and workman's compensation benefits as well as a temporary housing agreement for the day when Elizabeth's illness would become too difficult for me to manage or if she passed.

Knowing very little about this illness and being entrusted with the care of another, I educated myself. My first call was to the Alzheimer's Association. I sought training, support groups, lectures, seminars, videos, and conferences as I am an audio-visual learner.

Beth, from our Alzheimer's Support Group, shared books from her personal library such as: "Learning to Speak Alzheimer's," "The 36-hour Day," "Creating Moments of Joy," etc. Other resources I obtained through inter- and intra-library loans as my local library had few resources.

The support that I received through the Alzheimer's support group was critically important. The group provided care for Elizabeth so that I could attend. Otherwise, I would not have been able to participate. Agencies in my rural area charge approximately \$25 - \$35/hr for hands on care, and few, if any, employees had dementia training. A 4-hour respite would cost \$100 - \$140. Medicaid's daily rate was \$240/day for 24 hours worth of care. Adult Day Care programs close at 5:00/6:00 p.m. Hiring someone privately imposes additional burdens – learning everything associated with being an employer -- taxes, training, finances, record keeping, etc. As if the "sandwich generation" caregiver is not juggling enough.

The wisdom that I gained from the stories, challenges, and struggles shared in these resources provided me with a unique understanding of potentially what lie ahead. I no longer feared the disease and the unknown. Therefore, I could focus my attention on Elizabeth's needs versus the disease itself.

It was easier for me to care for Elizabeth versus her daughter as I had no knowledge of who Elizabeth was before her illness or what she was capable of doing. This lack of knowledge allowed me to approach the situation with an eye for discovery. Who was she now? What was she capable of doing herself? How could we maintain her sense of autonomy and independence while keeping her safe? How was her brain interpreting her experiences? As a result, we were able to adapt to "what is" versus "what was."

Elizabeth enjoyed being physically active, being outdoors, watching and playing with animals, socializing with people, and admiring art. So, we spent our days walking the airline trails, picnicking, and conversing with pet owners who shared their pets with us. We spent hours observing nature, animals, flowers, etc. We engaged in yoga classes and activities with the Senior Friends of Hebron. They welcomed Elizabeth with warm hugs and embraces. We spent time with family and friends and went to museums (obtaining free/low cost tickets through the libraries), etc.

Elizabeth died in November 2013. Although caring for her 24/7 for 2 ½ years was challenging, I was learning from her how to live in the moment; and I experienced one of the most precious gifts -- unconditional love. I shall be forever grateful that she was a part of my life!

I submit this testimony to speak about the importance of expanding dementia (neurocognitive) training so many more individuals like Elizabeth can live safely in their homes. I also want to express how unique Alzheimer patients' needs are and the extra care that is required. The reward of caring for these individuals is enormous. Thank you for allowing me to speak in support of Raised Bill No. 179.