

April 2, 2019

To the Oregon Senate Human Services Committee:

My name is Tera Stegner and I am a Co-Director of Grace Center for Adult Day Services. I am writing to tell you why I support SB 1035. Grace Center is a specialized day center in Corvallis that has been providing respite to family caregivers in Linn, Benton, and Polk counties since 1983. For over 35 years, we have had a front row seat at Grace Center to the ever growing need of respite services for people in our tri-county community who are caring for their elderly or disabled family members. The ever increasing need for respite in Grace Center's service area is reflective of the growing need for respite services across the state.

As one of my roles as the Director of Community Relations, I have overseen the admissions process at Grace Center for the last 8 years. Over and over again caregivers tell me, "I wish I knew about your program earlier!" Or, equally as common, "I wish I could afford to use you more often!" Many participants and their families cannot afford the respite services they need even though adult day services are, on average, *half the cost* of in-home care and a quarter of the cost of long term care facilities. **The need for respite is great but the access to respite services and supports for family caregivers is low, often because of financial constraints**. So many caregivers feel isolated, alone in their journey of caregiving without the supports they so desperately need. I served on the Oregon Caregiver Respite Work Group because I see the urgent need in Oregon for a program to support the family caregivers found in every community across the state.

Respite services are the life raft keeping many family caregivers afloat while they carry out the important and valuable work of caring for their loved ones who can no longer care for themselves and/or be left home alone. A 24/7 job, caregiving can often be taxing emotionally, financially, physically and/or psychologically. I would like to share with the Senate Human Services Committee several stories of some family caregivers I have encountered at Grace Center and how respite services impacted their lives.

Board Members

Dave & Carol

Carol and her husband Dave recently celebrated 60 years of marriage. Their partnership in life has included travel, photography, art, and community involvement. They raised three children together and have nine grandchildren. Dave worked for OSU as a professor in the Department of Botany and Plant Pathology and Carol worked as secretary in OSU's Department of Agriculture Engineering as well as the Athletic Department and later for the Department of Parks and Recreation. They have lived in Corvallis community for 50 years.

In 2005, Carol was diagnosed with Alzheimer's disease at the age of 67. At first there was not much noticeable change. Life went on and Dave and Carol continued in their hobbies and daily routines. But as the years went by, Carol's ability to engage with the world around her diminished and frustration was almost constant as activities of daily living became puzzles often too hard for Carol to solve.

Dave's role in his wife's life, after 40 years of marriage, was dramatically changing. She needed him to be her memory; she needed his voice to speak for her; and she now needed help with almost every part of her day to day life.

In 2010, their daughter began researching services in the community. Dave had to have open heart surgery and family was realizing that he needed help caring for Carol. Dave's hope was to continue to care for Carol at home for as long as possible but he was going to need access to respite services to do so. That is when Grace Center entered the picture.

Carol began attending Grace Center three afternoons a week. Due to her mid-stage Alzheimer's disease, she was very reluctant about being in a new environment and showed signs of anxiety through anti-social and sometimes aggressive behavior. Grace Center immediately began to work on creating a calming environment which worked specifically for Carol and her needs. Once this was accomplished, it allowed for staff to then introduce creative care techniques with Carol which helped her gradually grow to not only accepting her surrounding environment but also enjoying and positively interacting with it.

Carol continued to attend Grace Center for 3 years. Over time, Carol's attendance increased to 4-hour half days, every day of the week, with daily showers provided. Because of Grace Center's services, Dave and Carol were not separated by Alzheimer's disease; they were able to continue to live together in their own home. Without such respite services, Carol would likely have been prematurely placed in a nursing home or another long term care facility.



Colleen & Marilyn

Herb and Marilyn recently moved in with their adult daughter Colleen after Herb was diagnosed with Alzheimer's disease. At first, in the early stages of the disease, it was not a problem for Marilyn to care for and keep an eye on Herb at home while Colleen was at work on week days. It wasn't very many months though before Herb began to progress into mid-stage Alzheimer's disease and his needs began to increase. He became confused and agitated, often trying to leave the house thinking he wasn't where he was supposed to be, not recognizing his surroundings. Herb's balance began to be an issue too as the disease progressed and he started to fall at home, not being able to get back up without assistance. Marilyn, a senior herself with limited strength and energy, began to be concerned that she could not safely care for Herb while Colleen was away at work. Even when Colleen was at home from work, caring for Herb was a challenge because he would often get up several times in the night, making noise around the house at all hours, thus disrupting both Colleen and Marilyn's sleep on a regular basis.

Marilyn and Colleen arrived at Grace Center for Herb's admission appointment looking tired, sleep deprived and stressed. At this point Colleen had to take time off of work to assist her mom with caring for her father but she needed to get back to work. They knew that, in his current state, Herb would be extremely resistant to moving into a memory care facility and they wanted to avoid it at all costs. Herb started coming to Grace Center several days per week and eventually nearly every day per week, for full days.

As the months progressed and Herb continued to come to Grace Center, I watched a transformation occur in Marilyn. While Herb was at Grace Center for 8hrs a day, Marilyn was able to take naps; she was able to see friends and volunteer at her church; she had time to clean the house and go to her doctor appointments; she didn't feel guilty any more about burdening her daughter because Colleen was able to go back to work. With all these new opportunities and changes in her caregiving situation, Marilyn began to appear more energetic. She was happier! She looked healthier each month that went by. Instead of arriving with Herb each day looking anxious and exhausted, she started to come in with a smile on her face. She laughed more and joked with staff. Eventually Herb progressed into late state Alzheimer's disease and Marilyn and Colleen decided it was time to move him into memory care. At this point, Herb was calm and past the point of knowing the difference between home and anywhere else. He made the transition to memory care smoothly and Marilyn came back to Grace Center on several occasions wanting to tell all of our staff how incredibly helpful we were to her and her daughter and how Herb's transition would have not been smooth at all if they hadn't had our respite services to use when he was only in mid-stage Alzheimer's. She said in her exit interview, "Grace Center was a real life saver for us and I don't know what we would have done without it."

Board Members

Ed & Judy

The following is testimony from one of the family caregivers we served at Grace Center: "For many years my husband and I drove or walked by Grace Center. We probably each had an idea of the service provided but certainly not the scope of the services offered. In 2011 my husband (Ed) fell and fractured his hip in four places. He had been dealing with Parkinson's disease for about 10 years. When he returned home after surgery and rehab, the physical therapy working with him suggested we look into his going to GC to continue his rehab. We visited GC and learned about the exercise program and the other services it provided. He began coming to GC three mornings a week, and later, as the disease progressed, five mornings. At the time Ed started at Grace Center, he was using a wheelchair and required assistance in transfers. With the support of the staff, Ed was able to develop strength and move from using a wheelchair to that of a walker within two months. This happened gradually as the staff helped him take a few steps to walking down the length of the hallway using his walker. Ed's neurologist had counseled us that he might not be able to walk again and she gives GC, as do I, credit for his improvement in mobility. And with the increase in mobility, our life became easier at home.

Grace Center is also a benefit to those of us who are caregivers. The staff helped me to understand how best to work with Ed and answered questions that arose regarding his care. When he was at GC, I was able to do things for myself with the knowledge that I did not need to worry about leaving my husband at home alone. While Ed was at GC, I was able to run errands and even continue to volunteer on a limited basis which helped me to handle the depression I often felt. Again, when I was having a difficult time, the nurse and other staff at GC helped me to deal with the issues I faced in being a caregiver for my husband. If you take the GT (i.e. Gazette Times, the local newspaper), you may have read a letter from a husband whose wife was at GC for a couple years. He praised the staff for his wife's care which allowed him to keep his wife at home for 'two precious years.' I felt the same way as he did and was grateful for all the care and support given, not only to my husband, but also myself."

Thank you, Chair Gelser and committee members, for your consideration and support of family caregivers in Oregon and for recognizing the importance of the availability and accessibility of respite services in every community.

Sincerely,

Jers Stegner

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