

November 20, 2015

TO: The Legislators of the Children and Families Interim Committee

FROM: Kathleen Burke, 1590 Babcock Blvd, Billings, MT 59105

Committee members, individuals who recommended my participation, fellow panelists, and audience members, thank you for participation in this **vital** committee hearing. I appreciate the committee considering the challenging issues faced by family caregivers for people who have Alzheimer's and dementia, especially since November is National Alzheimer Disease month, National Brain Awareness month, and also National Family Caregivers month. It is with a humbling sense of responsibility that I hope to bring a **common face** to the 48,000 family caregivers of the current 19,000 Montana Alzheimer's patients. Projections for Montana Alzheimer's patients are for an increase of 50% by 2025. This is a **startling** forecast for which we need to plan. I have a family history of Alzheimer's and related brain disorders on both sides of my family for at least two generations, including grandparents, both parents, aunts, and uncles. I helped my maternal grandparents in the 1970s. I resumed caregiving when my mother was diagnosed with Alzheimer's in 2002 and my father in 2010, both of whom died within the last two years. In addition, I have been involved with caregiver support groups here in Billings for 13 years, so I interact with many people who face the challenges of being family caregivers. I am also a member of the Montana Alzheimer's/Dementia Work Group preparing a state plan to present to the Governor.

From a caregiver's perspective, here are some **themes** I want you to think about:

- **Education and training about Alzheimer's is needed for everyone, even medical personnel.**

Caregivers beg for education and training on the disease. Much of the time none of this is provided with the diagnosis. It would be beneficial to have some type of **certified care manager**, like is used after a diagnosis of diabetes or breast cancer.

Caregiver support groups are desired with strong components of education and training. On one occasion I had to move my car from the two hour parking zone when Mom was put into the hospital during a regular medical appointment. She was very confused, so I stopped at the nurses' station to remind them to watch her while I was gone so that she did not remove the IV or pull off the chest leads for the 24 hour 12 lead ECG. When I returned after less than 10 minutes, no one was with her, she was bleeding from where she had pulled out the IV, and had several of the leads removed. On December 23 I had to stay in the chair next to her bed all night to prevent her from interfering with overnight testing when the hospital was unable to provide the care they promised. I went directly from the hospital to my regular eight hour job. When Mom moved into the nursing home, I was concerned with her walking in unfamiliar surroundings at night. I was not happy that the bed had no safety railings, but was given the explanation that the bed would be lowered with a pad placed on the floor on which to land if she fell out of bed. The second night the wheels on the bed were not locked, she fell out of bed onto the hard floor between the bed and the wall where there was no pad, suffering a cut on her arm. She could not get up and staff did not find her for approximately two hours. Mom's increased confusion in unfamiliar surroundings, coupled with lack of Alzheimer's knowledge on the part of medical personnel, resulted in injury. Once at MSUBillings I had to interrupt a class to deliver a message to a student about his family in Great Falls. His Alzheimer's afflicted father had beaten his mother so severely that she was taken to the hospital and his father was arrested by responding police instead of being taken to a medical facility. These instances point out that **Alzheimer's education is needed for everyone** to meet the needs of these patients.

- **People want to remain at home as long as possible.**

This desire was **paramount** at all town hall meetings and is often voiced at caregiver meetings. I wanted to help my parents stay at home as long as possible because they had long discussed not wanting to be in a nursing home. I agree with much research showing patients do better at home with support, since unfamiliar places and different routines can add to their **confusion**. My parents found it

increasingly difficult without financial oversight, medication management, appointment coordination, cooking, housekeeping, shopping, and help with personal hygiene. My brother and I did everything we could to help out, but even we could not easily cover all their needs while working full time. After much detective work, I enrolled them in a wonderful Medicare/Medicaid program available in over 30 states for approximately 40 years called the **Program of All-inclusive Care for the Elderly (PACE.)** Since both of my parents were WWII veterans, the Veterans Administration paid for them. It met my parents' care needs with services both at home and with medical partners so they didn't have to go to a nursing home. They participated for the last five months of the two year Montana program, which was then eliminated. When the PACE program ended, I knew of people who, due to lack of in-home support, had to go into a nursing home where they rapidly declined. The nursing home cost to Montana was also substantially higher than providing services to allow them to stay at home. It reminded me of the old Fram oil filter TV commercial in which the mechanic held up the filter and said, "You can pay me a now or you can pay me later." I recommend that this committee do all you can to provide services to families to help patients stay in their homes, where **77%** currently reside.

- **Caregivers need a break or they will not be able to provide care.**

Caregiver burn out is a serious problem. **73%** of caregivers report concern about maintaining their physical health, while **40%** suffer depression compared to **5-15%** of non-caregivers of similar ages. At almost every caregiver support meeting I have attended in the last 13 years, including three this week, caregivers were crying, as they were at the town hall meetings. Caregivers need some kind of respite for their own health, even if for only a few hours. When my Dad had a brain abscess in 2007, I had to take **Mom to work with me** because I could **not safely leave her alone** and there were work deadlines. As my mother's disease progressed and my father was trying to take care of her at home, my brother was concerned about the toll it was taking on Dad's health. It was difficult to find senior day **care** in Billings **then**, it is still **limited**, and may require a **contract** as opposed to meeting drop-in needs. The client has to be quite **independent**, but it

is much cheaper per day than in-home care, another good respite option if the town has it. Many parts of Montana have neither option. It is common for a spouse in their 80s to be stressed out due to providing virtually all of the caregiving by themselves. People of this generation and many Montanans were brought up to be self-reliant, don't feel they should seek any help for themselves, and are afraid of how the patient will respond to it. When in-home help is suggested, many say they cannot afford the \$20-\$30 per hour. One family, with only one elderly caregiver, was told that their income was \$50 per month over the financial eligibility guideline to get state help. Many middle aged caregivers are the **sandwich generation**, trying to care for both their own children and their parents, in addition to working full time. On a positive note, I have been very pleased to see the recent public service ads on television about the Montana Lifespan Respite Coalition. I hope these increase both awareness and usage.

- **Caregivers need to be recognized and included more by hospitals and doctors.**

Many caregivers feel strongly that a responsible caregiver should be designated at the time of diagnosis and be at all subsequent medical appointments. Not all medical personnel are receptive. Official paperwork is required due to privacy issues. During an Emergency Room trip, I explained to the doctor who I was and about Mom's dementia, but he did not want me to answer questions for her. He finally asked Mom who I was. She looked at me, hesitated, and said, "She is a very good friend," but gave no name or relationship. At that point the physician accepted my answers. On three other appointments my permission paperwork was misplaced at medical facilities, so my parent's appointments were delayed while I was sent to various departments where they looked for the papers they misfiled. I hope all facilities finish computerization to help the recognition of this caregiver responsibility. Caregivers are also vital in understanding and implementing hospital discharge orders.

- **Caregiving is stressful and caregivers need more support from employers.**

56% of Montana caregivers reported high to very high emotional stress.

Caregiving alone is challenging, but balancing work and caregiving is tough. At one point I was concerned about forgetting things at work, so I underwent testing and was told my memory problems were related to work and caregiver stress, not my family history and five concussions. I had much vacation time that I used for caregiving and was able to work some flexible hours to balance full-time work demands and caregiving. With the number of small employers in Montana, that is **not the case with many caregivers**. I was surprised and disappointed upon hearing about a social worker, who had to find a different employer when her parent needed increasing caregiving from her and her employer was unwilling to find a workable solution. Social work is supposed to be a **caring profession**, but even here the employer did not understand the disease and the caregiving needs. Maybe Montana could recognize designated caregivers as a protected class so employers would be required make Alzheimer's and dementia caregiver accommodations.

I'll end with a personal stress story: At the end of their 68th wedding anniversary celebration in the nursing home on July 4, 2013, Mom pushed Dad away when he bent over to kiss her good bye, saying that her husband would not like that. It was difficult for me to see, but probably worse for him since he would not talk about it. He was diagnosed with pancreatic cancer in August and didn't visit her after that. Knowing that she would not understand, it still hurt not to tell her that her husband died of pancreatic cancer or that his funeral was one day before her 91st birthday on September 28. This was a stressful time for all family members, who had to change from being sad to happy in a 24 hour period to celebrate her birthday.

My faith has helped me cope with this disease. I think God has a sense of humor, realizes that patience is not one of my better virtues, and provided multitudinous Alzheimer's opportunities for me to work on that virtue.

In closing, thank you Committee members for being public servants in the Montana Legislature and allowing me to testify. I hope you can find ways to help families cope with these devastating diseases before the terrible Montana **forecast** becomes a reality.