

Testimony Senate Health Care Committee
Informational Hearing: State Plan for Alzheimer's and Related Dementia
By: Marya Kain, MS, CMC

Good afternoon, Chair Monnes Anderson and Members of the Committee. My name is Marya Kain. I have both professional and personal experience with Alzheimer's Disease and related causes of dementia. 37 years ago, I began my career as a Certified Nursing Assistant in a traditional "convalescent" center, or nursing home. While the staffing and work dynamic at the time was based on the premise or "the lights are on, but nobody is home", as one who actually had the opportunity to work with the people, I quickly saw the people "were home" and I delighted in getting to know the person beneath the manifestation of the dementing illnesses.

Since then, throughout my career, I have held many positions supporting individuals with memory loss and confusion, including administrator, dementia specialist, social worker, activity director and educator. I have facilitated Alzheimer's Support Groups for the Alzheimer's Association since 1993, and have served and continue to serve on several boards and advisory councils. I am a Master Trainer and Class Leader for Powerful Tools for the Family Caregiver, and a STAR-C Consultant.

Currently, I work as a Behavior Consultant and Educator through my business, Power of the Heart: Dementia Care Education and Behavior Coaching, teach additional classes through Oregon Care Partners, and serve as a Certified Aging Life Care Manager (formerly called Geriatric Care Manager) with Interim Health Care.

Though I've worked in the field many years, the whole subject of Alzheimer's disease took a new turn for me when my father, Bill Whitney, was diagnosed in 2012. For several years prior to his diagnosis, he had been experiencing increased confusion and memory loss. In 2006, his doctor had noted "MCI?" ("Mild Cognitive Impairment?") in his record but had not given voice to her concerns. In the Fall of 2011, we began seeking a diagnosis and guidance after he caught his kitchen on fire and drove his car through the garage. My dad was reluctantly agreeable to seeking a diagnosis, as well as to seeking resources. In 2012 we were able to convince him to engage with the programs available through the Alzheimer's Association, and he quickly discovered that the emphasis was on who he was as an artist, a singer, and a human being, not as an Alzheimer's patient. His life opened up again to joy, creating, and relating!

My dad, Bill Whitney, spoke at the press conference, unveiling SPADO, the Statewide Plan for Alzheimer's Disease in Oregon. On September 13, 2012, my dad and I addressed the Human Services Committee of the House of Representatives. My dad felt very grateful for all of the services he and my mom have received, and wanted everyone in Oregon who has dementia, and their family members, to have access to the services that they need. He stated "Instead of living in fear, I live with hope. My desire is for all Oregonians living with dementia, to have the same hope." Bill Whitney passed away on March 2, 2014. I desire to carry on his legacy of hope. I deeply appreciate the opportunity to speak with you today.

As an educator, I have had the opportunity to contribute to fulfilling the goals identified in SPADO, specifically increasing public awareness about Alzheimer's disease. One of the classes I have been teaching is Approaching Alzheimer's: Make Your First Response the Right Response. These classes are greatly appreciated by first responders who often find themselves helping individuals with dementia in moments of heightened agitation. One gentleman in Southern Oregon was found walking down a heavily travelled country road that which is shouldered by deep ditches. He was clothed in his nicely shined shoes and ... his underwear. He was going to work. While his behavior could have been labeled as indecent, inappropriate, and dangerous, his intentions were good. He explained that the new young people at the bank where he worked really needed his help. The officers listened empathetically. They worked with community partners to return the man safely to his foster home. There, I was involved to help devise a plan to prevent future elopement. The most obvious first step is often to place a black mat in front of the door, so it appears that there is a hole there, deterring people from walking over it. In his case, the first step was to remove his shoes in the early evening, so that the caregiver could shine them up and let the shoeshine dry overnight. He readily agreed. The next step was to find ways that he could use his still fairly strong leadership skills in the home where he lived. He began leading the morning meetings, and keeping track of the day's agenda of activities. With this plan in place, there were no future incidents.

Another situation, also in Southern Oregon involved the threat of weapons, and had the officers not been well trained in working with individuals with dementia, the results could have been tragic. Several evenings a week, around 4 pm, the man had begun aggressively kicking his wife out of the house. She would argue with him, explaining over and over again, that she was his wife, tearfully pleading with him to "please remember!" While the man was not aware that his guns had been removed from the home, he would frequently threaten his wife, and the officers who came to help, that he would shoot. By proceeding calmly and respectfully, the officers were able to calm the situation, and worked effectively with the family and myself to come up with solutions. The man had confided to the officers that "this lady thinks she's my wife, but my wife is going to be very upset when she gets home and finds old lady is sitting in her chair." In the short term, we trained the wife to step out and come back in a few minutes later announcing "Honey, I'm home!" to help him frame that this was his wife returning home from work. In the long term, we were able to find him a more supportive living environment, where his wife could enjoy safe visits with him. Officers credit the Approaching Alzheimer's along with crisis intervention training (offered through Jackson County Mental Health), for helping them enhance their skills needed in responding to difficult situations with persons with compromised ability to reason and make sound judgements.

Another class I happily teach, Challenging Behaviors is currently offered through the Oregon Care Partners and it equips family and professional care givers with the same kind of knowledge and tools. Caregivers learn how to communicate effectively, how to help meet underlying needs, improve quality of life and to help the client or loved one to de-escalate when needed. Several additional classes offered through the Oregon Care

Partners address Alzheimer's care staff directly, helping them to create a kind and respectful culture of care for individuals with Alzheimer's Disease and related dementias. The classes are available online and in person, allowing people throughout Oregon to have access to this valuable education. The current funding allows these classes to be offered through June 30th, 2015.

Education for all caregivers and professionals engaging with individuals with dementia was one of the items that my dad Bill Whitney wanted available for all Oregonians. Instead of living in fear, many more Oregonians are living with hope. We deeply appreciate all that you have done to make this happen. And we appreciate your ongoing support for the state plan.

Thank you very much.