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Before the Senate Special Committee on Aging  
March 25, 2015

Good afternoon Chairman Collins, Ranking Member McCaskill and Distinguished Members of the Senate Special Committee on Aging, my name is Doctor Heidi Wierman, and I am appreciative of the opportunity that you have provided for me to share with you my experience treating patients with dementia, including Alzheimer's Disease, and to offer my support for continued investments in research and treatment.

I am a Geriatrician from Maine, though I am from Oregon originally and will always be considered from "away", where I am the Division Director for Geriatrics at Maine Medical Center and the Medical Director for Elder Care Services at MaineHealth. I am also a founding member of our local chapter of the American Geriatrics Society with a goal to help health practitioners across our state meet the needs of older adults. My clinical work is focused on dementia – evaluating individuals with cognitive issues at our outpatient Geriatrics Center and working in the hospital as the Medical Director for the Hospital Elder Life program trying to prevent delirium for hospitalized older adults, which can be particularly devastating for individuals with dementia.

Dementia is a looming crisis for our state and the nation, with Alzheimer's being the most common. Maine has the oldest median age – nearly 6 years older than the average median age in the U.S. and we have fewer working aged individuals than most states to care for our aging population formally as paid caregivers, but also as informal supports. Projections for Maine are that 65+ is the only population to increase in the next 10 years, even as our total population remains flat (Nielson, 2014) . Of Maine's 1.3 million residents, approximately 37,000 have been diagnosed with dementia, and this number is projected to increase by nearly 50% to 53,000 diagnoses in the next 5 years... Dementia is an epidemic that will have dire consequences on our economy, our health system and our family structures if we do not act fast.

Dementia stresses our state in many ways including increased burden placed on caregivers both paid and unpaid, a lack of safe housing, needs for transportation, and a health care system that is overburdened to begin with. In Maine, about two-thirds of patients with dementia die in nursing homes (State Plan for Alzheimer's Disease and Related Dementias in Maine, 2012). Fewer young people mean fewer formal and informal caregivers to help our aging population, and particularly those with cognitive impairment. Within the MaineHealth System, we are experiencing significant challenges finding suitable placement for hospitalized patients with dementia when they can no longer be cared for at home. The results are patients remaining at the wrong level of care in an environment that is not designed for dementia care, stressing the patients and their families and creating a financial burden for all.

Diagnosis and treatment of patients with dementia is not a part of clinical training for most providers and staff in many care settings. It is critical that our primary care system become prepared to deal with cognitive assessment and care planning for patients with dementia and their families to try to avoid these crises. Dementia is a chronic, terminal illness and we need to prepare our health care system and

communities to provide planning and support to patients once diagnosed. As one of our primary care providers in a rural community told me, “geriatrics and palliative care should be spread over primary care like peanut butter.”

In my own house, I talk with my children about what they should do if I develop Dementia. I tell them that I hope I will be pleasant and agreeable with their plans. That I will try to be happy when I need to move and accept help. I tell them which music makes me happy and which music will likely make me strike out (a particular tune that always reminds me of my son’s Karate that will probably get me kicking – not in anger or frustration but in memory of the many hours I watched his classes). I talk with my family about their wishes and pray that my father at 6 foot 9 does not develop dementia or really the behaviors of dementia that are often the most challenging. Really, it is not the memory loss I fear so much but the behaviors that evolved as part of the memory loss. Even as we search for a cure for the disease, we need support for caregivers now in researching ways to keep them coping and helping their loved ones. We need studies that help us identify the best ways to treat the behaviors of dementia that does not include tying people down and giving them medications until they can no longer interact. We need increase emphasis on advanced care planning and implementation of tools to facilitate this.

I want to share a few stories, of patients and families I have cared for that illustrate the challenges of dementia and I hope emphasize the need for increased funding to find a cure, but also the need for funding to help those suffering with the disease now. I first met Mr. and Mrs. Keller about 10 years ago when I diagnosed Mr. Keller with Mild Cognitive Impairment. Sadly, he progressed to dementia. Over the next several years, he had a gradual decline and developed issues walking and swallowing. Eventually, he began having more issues with eating and frequent pneumonia. I began visiting him in the home as it was just too challenging to come to the office. Support was provided by his wife and hired caregivers. Eventually we involved hospice and he was able to die in his own apartment with the support of his wife and family.

During this time, I got to know Mrs. Keller well – a very active woman, involved in her senior community, who became increasingly anxious as her husband’s disease progressed. She had her own counseling and after her husband passed away, I did not see her for a year. She then appeared in my schedule as a patient – she had started to show evidence of memory loss. She no longer had a spouse her children were supportive, but they did not live close by. Mrs. Keller utilized increasing support in the home through paid caregiving and eventually moved to assisted living. She did not transition well – she fell, experienced a head injury and has continued to decline. She and her husband had tried to plan financially, but paying private caregivers is very expensive, and her funds have not lasted. Recently, Mrs. Keller was forced to move to a nursing home– not one of her choice, but one that takes Medicaid. Her children feel guilty that they are not able to provide the same support for their mother that allowed their father to die at home. But the resources are simply not there. More flexibility in funding caregiver support and alternative options for housing to care for individuals with dementia could have improved this outcome.

I have another patient that resides with her daughter and son-in-law. Her daughter had to give up her job to care for her mom and remains determined to keep her mom at home despite the challenges to their family. Her daughter recently utilized a respite service so she and her husband could go and visit her son at college. Her daughter felt very guilty about taking this time away from her mother for her family. This same daughter is forced to work as a bar tender a couple of nights a week and has a side

business in helping people be organized just to make ends meet. She is tired, stressed and not sure how long she can continue to do this while maintaining her marriage. Caregiving is hard work and it takes an emotional and financial toll on families.

In my own neighborhood, I was out in the late afternoon in the autumn a couple of years ago when a woman went walking by in her slippers and a robe. It was 35 degrees. I tried to talk with her – she could not tell me where she lived or her name. She would not come into my house and would not stop. I called the police as I followed from behind – they knew who she was and I asked if they would please have her family call me. Her son did call me – he was very stressed as he had been caring for his mom for several years. He worked and it was obvious that she was no longer safe at home – this was the first time she wandered and fortunately, it was not the winter.

While these stories illustrate the daily challenges I see as a geriatrician, I have also seen the challenges of dementia from the perspective of being a family member prior to my induction into the health care community. My grandmother had vascular dementia and resided with our family when I was growing up, and I was cognizant of the strains this caused as family members tried to keep her both happy and safe. As a college student, I also recall a very frightening drive with my grandfather as he entered the early stages of cognitive dysfunction and refused to allow me or my now husband to drive. ...It was terrible not knowing what to do with this information. Now, I am also a health care provider. This disease challenges families and our communities – currently we know that once diagnosed, dementia will worsen and the needs of individuals will get more intense over time. We are working actively in our communities to identify individuals earlier so that there can be meaningful planning for the inevitable decline, but my real hope and dream is that we can identify a cure.

Thank you for taking the time to hear some stories. I implore you to support continued and increased funding to support caregivers of and individuals with dementia now, to support alternative housing options and creative community supports for individuals with dementia. Ultimately of utmost importance is an increase in funding to identify ways for prevention and cure of this devastating disease.