

Testimony by Christine DiLeone on Raised Bill #900-AN ACT INCREASING FUNDING FOR AGING IN PLACE INITIATIVES.

Submitted to the Aging Committee

February 23, 2021

Senator Slapp, Representative Phipps and members of the Aging Committee, my name is Christine DiLeone. I am a nurse and faculty member at UCONN and a volunteer Community Educator and Advocate for the Alzheimer's Association CT Chapter. I am speaking out today **in support of Raised Bill #900-AN ACT INCREASING FUNDING FOR AGING IN PLACE INITIATIVES** which would expand access to the Alzheimer's Respite Program by adding additional funding.

On a personal level, my mom was one of 15 children. She passed about 3 years ago with AD. 7 of her siblings suffered with AD, one continues to suffer with it, one passed with COVID a couple weeks ago. My family has suffered with the challenges and struggles this disease brings. My mom was a real estate broker in upstate NY and owned her own business, until she started forgetting important details on contracts and appts to show homes. This began and almost 11-year journey of decline. I moved her into my home in the early stages of the disease, in CT. I was able to maneuver the health care system as a nurse, but I was not able to care for myself, or get the much-needed respite I needed. I was a walking anxiety attack, working and going to school for a masters degree along with mom's care.....I didn't get a break. The grief of watching my mom fade away from me and the anxiety that accompanied it led to me being unable to work for 6 months. The decline in my own well-being caused me to make a difficult decision to move her into assisted living and later into long term care. Had I had the benefit of respite; I may have been able to keep her at home with me.

In 2020, caregivers of people with Alzheimer's or other dementias provided an estimated 18.6 billion hours of informal (that is, unpaid) assistance, a contribution to the nation valued at \$244 billion. One of the main reasons caregivers provide care and assistance to a person with Alzheimer's or another dementia are the desire to keep a family member at home (65%). They want to keep the family member at home.....but, the stress of caregiving takes it toll on their mental and physical health. Increasing funding to this important program so they are provided respite is a big step in helping them do that. Forty-one percent of caregivers have a household income of \$50,000 or less. How can they get respite at that income level without your help? one-quarter of dementia caregivers are "sandwich generation" caregivers — meaning that they care not only for an aging parent, but also for a child. This speaks to the degree of responsibility they have. By providing unpaid care at home and not in long term care, for example, family caregivers are also saving the

government billions of dollars. But the level of care increases as the disease progresses and is not something that is easy maintained.

As a researcher and faculty at UCONN SON, my PhD dissertation research last year, focused on daughters caring for a parent with AD at home. I can tell you these women are suffering. Their blood pressure is high, they are on anti-depressants and in counseling. Not to mention the grief they are dealing with watching their parent fade away from them. They are not getting the help they expected from family members, are trying to keep their family member safe at home, safe from taking the wrong medications, safe from doing damage to the home, and from wandering outside the home. They have lost friends and their social life. Their own life goals and plans are put on hold and their jobs are affected. One daughter installed cameras in her home and work office so she could watch her mom when she came home from adult daycare. My next study will focus on the experiences of sons caring for their parents in the home with AD, as I suspect there are unmet needs and a need for respite in this population as well.

The caregiver's subjective sense of well-being needs to be preserved and increasing funding for this very important program can help do that. It provides a lifeline to the family caregivers and supporting this legislation will allow more older adults to live safely in their homes and communities. Thank you for your time.