

Thank you very much for the opportunity to speak in support of S.206! My name is Betsey Bianchi and I've been living in Killington, Vermont since 1995. I am joining you today with my Mom, Jennie Craig, who moved to Vermont 6 years ago. She is not the diet lady Jenny Craig but, like that Jenny, my Mom has devoted her life to helping others. During her long career as school social worker, she established new and innovative programs for students with special needs and supported students and their families as they addressed the many challenges thrown their way.

Now S.206 will encourage that same innovative spirit towards supporting those living with Alzheimer's and related dementias, their families and their care teams.

As some background, about 10 years ago my husband and I noticed my Mom's short term memory wasn't as good as it had been, so we encouraged her to ask her primary care physician about cognitive testing. During her next two appointments, her primary care physician in New Jersey dismissed my Mom's requests for testing saying there was no need because there wasn't a cure for Alzheimers. That answer did not sit well with either my Mom or me so when I discovered the Memory Clinic in Bennington, Vermont offered free screenings, my Mom asked me to make an appointment. Her initial screening on May 20, 2014 confirmed she had memory issues but it wasn't until June 23, 2014 after more comprehensive cognitive testing, an MRI and neurological testing that my Mom received a diagnosis of Mild Cognitive Impairment Consistent with Early Alzheimer's. By then she already was so adept at compensating for her memory issues that many friends and family were shocked at her diagnosis.

In 2016 my Mom participated through the Memory Clinic in a clinical trial for Aducanumab but was forced to drop out of the trial when she had an adverse reaction. However, she does not regret being part of the trial because it helped advance the science. In addition, the PET scan which was only available to her through the trial confirmed her brain had the plaques and tangles of Alzheimer's.

At her semi-annual appointments at the Memory Clinic my Mom struggles through the same cognitive tests that were used to determine the functional levels of her students. My Mom hates the testing because it makes her feel stupid. For example, it is very frustrating for her not to be able to remember three common but unrelated words five minutes later. However, it is truly heartbreaking to watch a once avid reader like my Mom struggle to read even a few words or not know where to find her bedroom. It also is challenging to watch a once very independent, world traveler become so dependent on others that she feels anxious when she is left alone for more than 30 seconds.

The Memory Clinic and her new primary care physician in Vermont have provided excellent care far superior to the care she was receiving in New Jersey. However, finding support groups for Alzheimer's patients, geriatric care providers, dementia care specialists and dementia mental health clinicians has been extremely challenging. It also is very clear that there is not nearly enough support and training on caring for dementia patients for primary care physicians and caregivers. For example, primary care physicians may not realize medications for anxiety and

depression often affect Alzheimer's patients very differently because their brains have been damaged by the disease. Understanding more about how those living with Alzheimer's experience the world helps us treat them with the respect they deserve but rarely receive.

Another significant area of concern is the financial burdens placed on the families. My Mom invested very wisely, has a great pension, social security, supplemental medical insurance and an excellent long term care policy but still most likely will not have enough to cover all the costs for her care.

Because my Mom is able to do almost all the activities of daily living by herself as long as someone is there to talk her through them, it has been an uphill battle to convince her long term care insurance company to reimburse for any of her care. Eventually they agreed to reimburse four of the twelve hours a day of care she is currently receiving. Although we would love to be able to reduce the amount of care, if someone is not with my Mom all day to let her know what is happening next, she becomes anxious and her neighbors call the ambulance because her anxiety causes heart palpitations.

As with most other policies, my Mom's long term care insurance does not reimburse for any care provided by family members so it is not financially viable for our family to care for her full time. To make matters worse, for the first year of services, the insurance company did not reimburse for 'At Home Senior Care' Aides because they were not nurses but finally did agree at least to reimburse for their care going forward. In addition, we discovered through trial and error that without changing the total cost or anything about the actual care being provided, long term care insurance reimbursed if the billing was listed as a daily rate instead of as a weekly rate.

It would be wonderful to have more education for physicians, caregivers, and families on how to better support those living with Alzheimers. It also would be very helpful to have support readily available for case management, mental health, insurance reimbursements, care progression planning, networking and identifying helpful technologies so families would not be burdened with those responsibilities too. I would love more help with everything else that comes with being my Mom's care partner so I could just focus on enjoying time with my Mom while she still knows who I am!

If you would like to talk more with my Mom and me about our experiences, please call my cell at 802-353-8029 or email me at [Betsey.Bianchi@gmail.com](mailto:Betsey.Bianchi@gmail.com). Thank you!