

Testimony of Kathryn Carlson, Resident of Gardiner and Director of Community Services and Social Care Coordination, Spectrum Generations

To Joint Standing Committee on Health and Human Services 132nd Maine Legislature, First Regular Session

In Favor of LD 709 (if amended) – An Act to Establish the Respite for ME Program; and

In Favor of LD 815 – An Act to Provide Funding for Respite Care and Supplemental Services Provided by the Family Caregiver Support Program

Delivered in person on March 14, 2025

Honorable Senate Chair Henry Ingwersen and Honorable House Chair Michelle Meyer and all other Honorable Members of the Joint Standing Committee on Health and Human Services Committee,

I am Kathryn Carlson, Director of Community Services and Social Care Coordination at Spectrum Generations and an experienced sandwich caregiver. I'm a single mother with sole custody and financial responsibility for my elementary school aged daughter and was the primary caregiver of my mother who had Alzheimer's. My journey as a sandwich caregiver started when my father was diagnosed with Glioblastoma; an extremely aggressive and deadly brain cancer. Through the stress of caring for the love of her life while watching him lose the ability to walk, to recall everyday words, and to eventually lose his life; the progression of my mother's undiagnosed Alzheimer's was catapulted forward, dramatically.

Being keenly aware of the importance of getting an early diagnosis, I spoke to my mother's PCP, as well as the practice's Social Worker and Nurses, requesting a geriatric assessment and cognitive assessment. My requests were ignored for two years, until my mother needed to be hospitalized, where she was finally assessed utilizing the Montreal Cognitive Assessment and scored a 12 out of a possible 30; dementia was finally confirmed.

With strong familial supports, an understanding employer, Hospice, and the Respite for ME program, we were able to gratefully keep Mom home. She passed away, July of 2024, in the home her grandparents built, surrounded by her sisters, children, granddaughter, and a close family friend.

Why do I share this with you today? The current State Caregiver Respite Program requires a written diagnosis of Alzheimer's, dementia, or related disease in order to qualify for the program. It took me two years to get a diagnosis for my mother, and she isn't the exception.

Many of our caregivers struggle to get a diagnosis, delaying their eligibility and access to resources.

Going into a Memory Care unit or nursing home would have been a fast journey to MaineCare. I want other families to be as successful as we were, and we can support caregivers in Maine by funding LD 815 and amending LD 709 to direct DHHS to collaborate with the Area Agencies on Aging to ensure the eligibility requirements aren't a deterrent for qualifying caregivers and the covered services truly meet the needs of caregivers.