

Testimony

Relating to

L.D. 709, An Act to Establish the Respite for ME Program

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Senate Chair Ingwersen, House Chair Meyer, and members of the Joint Standing Committee on Health and Human Services:

My name is Jill Carney, Director of Maine Public Policy for the Alzheimer's Association, and a resident of Cumberland. The Alzheimer's Association urges the Committee to support L.D. 709, which would establish a singular program, called Respite for ME, aligned with the National Family Caregiver Support Program to provide respite care and supplemental services for family caregivers and older relative caregivers, including those caring for people living with dementia.

Overview of the Alzheimer's and Dementia Public Health Issue

Alzheimer's is a progressive, fatal disease affecting 29,600 Mainers aged 65 or older. In addition, there are more residents who are living with other forms of dementia or who have younger onset Alzheimer's (when Alzheimer's occurs in individuals under the age of 65). In Maine, the Alzheimer's Association estimates that 51,000 caregivers provide 87,000,000 hours of unpaid care for people living with Alzheimer's at a total value of \$1.9 billion. As people live longer and the population ages, the prevalence of Alzheimer's will rise significantly in the coming years, nearly doubling by 2050, and with it, the need for and demands on unpaid caregivers.

Overview of the Impact of Dementia Caregiving

Unpaid caregivers provide extensive, sometimes all-encompassing care for people living with Alzheimer's or other dementia, comprising a significant amount of unpaid labor each

year. Dementia caregiving involves many hours over a long period of time, with more than one quarter of these caregivers providing full-time care (40 hours or more per week). This can have a negative impact on employment, income, and financial security.

- More than 40 percent of dementia caregivers have annual household incomes below \$50,000. In 2021, dementia caregivers bore, on average, \$12,388 in out-of-pocket costs on behalf of the person with dementia.
- Among employed dementia caregivers, 57 percent report having to go in late, leave early, or take time off to fulfill their caregiving duties.
- Nearly one in five had to reduce their hours of work.
- Among those who provide dementia care and/or assist with expenses, 48 percent cut back on other spending and 43 percent cut back on savings.
- Nearly 40 percent report food insecurity – running out of food and not having money to buy more.

Finally, the demands of dementia caregiving often result in physical and mental health problems among caregivers themselves, which underscore the need for early intervention with education and support services.

Establishment of Respite for ME in L.D. 709

Currently, Maine's dementia caregivers are served through the federally funded National Family Caregiver Program and the state-funded, dementia-specific Caregiver Respite Program, with more caregivers accessing support through the Respite for ME pilot project during the period of its implementation.

L.D. 709 would streamline these disparate programs into one unified program under the title of Respite for ME. This would create efficiencies for program administration and simplify the process for caregivers seeking support. In addition, it would update eligibility requirements to expand access to a greater number of caregivers, including more dementia caregivers, and provide more flexibility in the services and supports that funding would be used for based on a comprehensive assessment and care planning process. The success of this updated approach to respite care is outlined in the final evaluation report of the Respite for ME pilot. In addition to traditional respite services, caregivers used funding for self-care items, such as fitness classes or memberships, home modifications, chore services, and personal supplies. Caregivers reported that this flexibility significantly reduced stress and enabled them to better manage their own needs as well as the needs of their care recipient.

Importantly, while the dementia-specific Caregiver Respite Program would cease to be its own entity under Respite for ME as proposed in L.D. 709, the new program would align with

the National Family Caregiver Program, which by law requires prioritizing support for dementia caregivers. This is crucial, as dementia caregivers often provide more complex care for more hours per week over a longer period of time than non-dementia caregivers. We look forward to engaging with the Department through the rule-making process to ensure a process that appropriately prioritizes delivering care to those with the greatest social and economic needs.

Need for Additional Funding Not Included in L.D. 709

Given that L.D. 709 would remove a source of funding dedicated to dementia caregivers, however, we are disappointed that the Department's bill does not propose additional funding to account for the broader access this new program would provide. Putting aside the Respite for ME pilot project, available funding for respite support programs has remained stagnant for many years and has not kept pace with the increasing number of dementia caregivers. Waitlists for support are common. The Respite for ME pilot demonstrated a strong demand for additional support from dementia caregivers, as nearly two-thirds (63 percent) of caregivers reported that they were caring for a loved one with Alzheimer's disease and related dementia or memory issues. A separate bipartisan bill, L.D. 815, would provide this additional funding, and we encourage the Committee to support both bills to ensure a comprehensive update to Maine's respite program that would increase efficiency and effectiveness, as well as reach more caregivers in need.

Early intervention with care assessment and coordination, respite services, caregiver support, and caregiver education is critical to helping people living with dementia live as independently as possible, delaying more costly residential care or emergency incidents. Increasing support for caregivers is a crucial component to ensuring the strength of the entire continuum of care for people living with dementia, from home and community-based services to residential or nursing home care.

Thank you for your consideration of L.D. 709. Again, we urge the Committee to support this critical legislation.

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