

**Testimony of Marc Boissoneault, Saco, Maine
In Favor of LDs 709 and 815**

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Live testimony given by Meredith Anderson, Southern Maine Agency on Aging

Good afternoon, Senator Ingwersen, Representative Meyer, and the members of the Committee on Health and Human Services.

My name is Marc Boissoneault and I am testifying in favor of LD 709, which permanently establishes the Respite for ME program, and LD 815, which funds it.

I live in Saco and I am a retired teacher at the Biddeford Regional Center of Technology for over 34 years. I left this position to become a caregiver for my mom when she struggled in her final years of her life with Alzheimer's Disease. In most instances, becoming a caregiver is not a choice. The responsibilities can consume many endless hours, in addition to being overwhelmed by the disease and its progression.

A diagnosis such as Alzheimer's is frightening to the individual as well as the caregivers. How do we meet the challenge? How do you navigate the obstacles of the disease as well as symptoms, behaviors and medication management?

As the journey slowly progressed, I realized that my siblings and I could not manage my mom's care without educating ourselves about the illness and finding available services and resources.

Very slowly my responsibilities as a caregiver needed to include support from outside our family. My siblings and I were supported by a team of individuals who would help navigate my mom's challenges, as well as her caregivers'.

The support team included the following:

- 1) Home health professionals who provided the basic needs in her home. Assistance included: personal hygiene, nutritious meals, and maintaining a clean and safe living space.
- 2) Adult day program at Southern Maine Agency on Aging met the needs of social interaction, daily nutrition, safety, and security from exit seeking, and daily health and well-being observation. The staff reported health and behavior concerns to family and her physician when warranted. The adult day program also involved support from the Family Caregiver Support Program on a monthly basis.

Providing the 24-hour care needed during the last month of my mother's life became extremely difficult for our family. It was the adult day program staff who noticed a change in her physical health. My mom appeared to be jaundiced and days later she was diagnosed with Pancreatic cancer and had only weeks to live.

As her need for care increased throughout the evening and early morning hours, my exhaustion became the obstacle to perform my duties as a son and caregiver. It was a challenge for me to meet her basic needs.

My mom attended the adult day program for several years. As the final days approached, she would ask if she could still attend the day program. It had become her entire social life. The people there had become her dear friends. This desire to spend her last days surrounded by friends is what brought this essential respite for me.

I would call the program director and inquire if my mom could continue to attend. I was always advised to allow her to attend for as long as she had the strength to do so. The days at the center provided the respite I so needed in order to care for her and prepare for those long evening and early morning hours. The respite also provided me additional time for trips to the pharmacy, communicating with hospice services as well as her primary care physician. As the final days approached, my mom labored for each breathe. I took a leave of absence from encore career position to be by her side.

Thanks to the staff, my mom attended this program until several days before she passed. My mom's experience with staff throughout the years was filled with kindness and compassion. Because of this, I have become a volunteer with the Southern Maine Agency on Aging's Adult day program. It is my hope that I can be a small part of that support team for our caregivers who are need it.

When I became certified with the agency as a Direct Support Professional, I became aware that individuals with memory loss and neurological illnesses have a right to choice. My mom's choice was to remain in her home throughout her illness. I'm sure hundreds of Mainers make that choice every day. I am confident, it was a team effort that allowed her to live her final days at home.

It was the assembled team that assisted me and allowed my siblings and I the respite as caregiver we so needed. There are many in desperate need of a supporting team like my family was fortunate to have. The disease was new to us, and we felt helplessness around how to show up and how to manage the changes as they came. The endless hours provided by caregivers are combined with their careers and full-time occupation. During those exhausting months and years, the disease does not stop or end, it continues and progresses, regardless of overwhelming circumstances.

I am confident funds invested in respite care and support for our caregivers in Maine would create a huge savings by supporting Mainers to live their last days at home, whenever possible. It is my hope that our legislators can become part of the caregiver team by supporting legislation for respite services for the most vulnerable in our communities. They face challenges of isolation, neglect, financial exploitation, as well as abuse. Let's not forget our neighbors who served our communities and our country.

Thank you so much for your consideration of the difficult challenges our caregivers and their families face every day. I urge you to support LD 709 and LD 815 for this reason.