



53 Baxter Boulevard, Suite 202 | Portland, ME 04101  
Phone: 866-554-5380 | Fax: 207-775-5727 | TTY: 877-434-7598  
aarp.org/me | me@aarp.org | twitter: @aarpmaine  
facebook.com/aarpmaine | instagram.com/aarpme

May 7, 2021

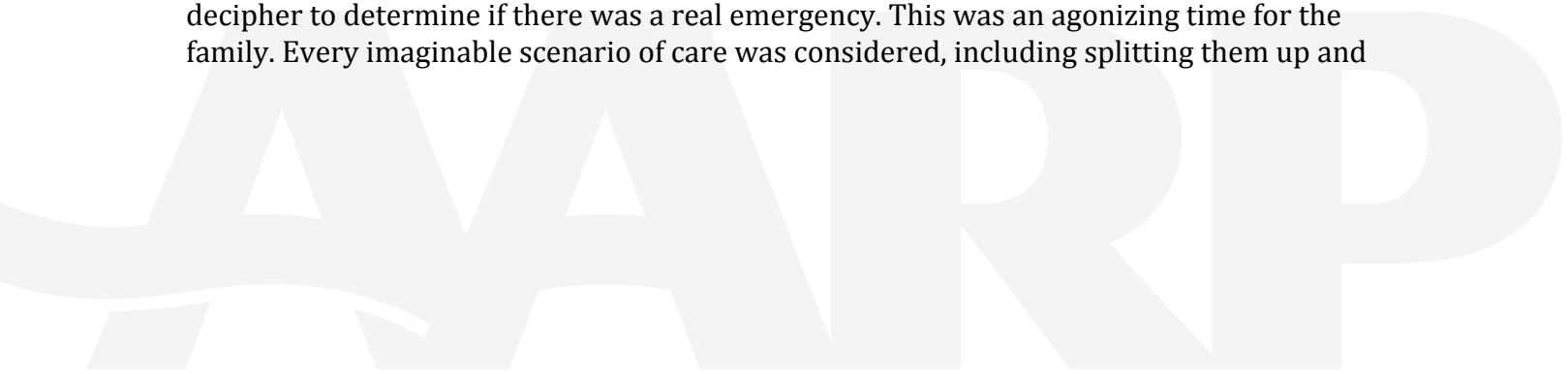
**LD 1559: Resolve, To Create the Commission to Develop a Paid Family and Medical Leave Benefits Program**

Dear Chairs Senator Hickman and Representative Sylvester, and members of the Joint Committee on Labor and Housing. Thank you for your time and attention in listening to those who are compelled to testify today. My name is Melissa Huston, I live in Bangor and I find myself with a new title: caregiver. I offer the testimony below in support of LD 1559.

Each year 181,000 family caregivers in Maine provide critical care to their loved ones. This includes family members caring for older relatives and helping them remain close to their family. This is my current situation.

I am originally from out of state but have been blessed to marry into a loving family of Mainers. Mainers who are hardy and fiercely independent. At 91, my father-in-law Ave, a retired colonel in the Army, was still mowing his own lawn, painting his camp and traveling to Florida for the winter months. He was also shouldering the burden of his wife's early stages of Alzheimer's. At 78, my mother-in-law Sandy, who was always a fabulous cook, was no longer able to prepare their meals. Despite the family bringing over casseroles and soups to stock their refrigerator each week, the simple task of heating up items in a microwave was now beyond her ability. Ave, starting to feel his own slowing down and subsequent isolation, did not have much of an appetite and preferred a stiff scotch over the fuss of a meal. After a couple of falls and increasing signs of heart failure, the family was able to persuade Ave that it was time to move out of their home and into an independent senior living facility in December of 2019. This provided enough initial support – namely, a dining room that served three meals a day and an elevator instead of stairs – but still the independence to come and go as they pleased. All sounded great. Who knew a pandemic was coming?

The move itself turned out to be very traumatic for them both. Compounded by three months of strict quarantine, both of their cognitive abilities dramatically declined, and Ave grew very frail physically. He developed dementia and full-blown Sundowners Syndrome. He became disoriented and started hallucinating. His days and nights were reversed, which resulted in many middle-of-the-night phone calls from him that were impossible to decipher to determine if there was a real emergency. This was an agonizing time for the family. Every imaginable scenario of care was considered, including splitting them up and



bringing them into our homes, but the layout of our homes and our own work commitments could not accommodate their individual needs. Ultimately, professional caregivers were hired to provide around-the-clock supervision beyond what the family could offer. However, this was very expensive and far from ideal. Managing a schedule of three to four home health aides, which required an awake overnight shift, was challenging to Sandy and Ave, who both found it very intrusive to have a parade of “strangers” in their home. The stress of coordinating their daily care, shopping for their groceries, arranging their ever-increasing doctor’s appointments and prescriptions and still navigating COVID was exhausting to the family. Not to mention the grief that we were all starting to experience as Ave’s health continued to decline. Ultimately, a hospice team gently guided us through his final months and facilitated a move to a hospice home. We moved him on a Thursday and he passed that Sunday. He was finally at peace and the family could now devote our energy to caring for Sandy.

My husband (their oldest son) and I brought Sandy into our home to provide some comfort during her husband’s transition and to assess what she needed for care. We already knew she could not live independently and would require a different setting than the one she had shared with Ave. Alzheimer’s is a heartbreaking disease to witness up close. We thought we understood her limitations, but we were naive. She clearly benefitted from the caregivers coming and going to check on Ave and took many cues from them. After a week or two of her living with us, it was apparent that she would be completely lost in a facility and would be at the mercy of their staff to guide her through each step of the day. Most upsetting was the realization that her ability to recognize family and friends would be lost without daily and continued reinforcement from the family.

My husband and I began to contemplate her living with us. Could we make modifications to our home? Could she manage alone for a few hours a day while we tag-teamed and went to our jobs? Could we manage the additional stress on top of both of our own demanding professional careers and small business that we own and operate? The answer was yes, but at what cost? Our own mental health being stretched too thin was a valid concern. Could we be productive employees under this stress? Could we manage financially if one of us quit our job to stay home and care for her? The answer was yes, but at what cost? We could muddle through day-to-day expenses, but what was this going to mean in lost contributions to our own retirement fund? If short-term, would we be able to re-enter the workforce at the same level? Let’s face it, at our ages of 57 and 58, would we even be a desirable candidate among younger applicants that could be hired at a lower salary?

While other siblings were also willing to have her live with them, my husband and I had the most flexible jobs. I had every intention of continuing to work but soon learned it was overwhelming to manage both. My job was coming back strong after the pandemic and was going to require 150 percent of my energy. I felt like my home life was also now going to require 150 percent of my energy and I had about 50 percent left to give anyone after the year we had all just climbed out of. My employer had been very patient and provided generous personal time off – but it was not going to be enough for our situation nor could they guarantee a comparable position would be available if I were to take a leave of absence or extended time off under the Family and Medical Leave Act.

Ultimately, I quit my job and am now Sandy's full-time caregiver. Time is all you have to offer someone with Alzheimer's. It will reach a point where her needs are beyond what we can manage. At her age and given her healthy physical status, she may need intensive care for many years. Having her live with us is also strategic in stretching her resources that will undoubtedly come into play. We are taking it one day at a time.

Because of the pandemic, this past year has been uniquely challenging for caregivers – but it has also helped highlight what so many Mainers who are caregivers have had to juggle all along. Mine is only one story that pales in comparison to many others who are shouldering a much heavier burden. However, all our stories share the common thread of lovingly and compassionately caring for our families as best we can. Whether at end of life, beginning of life when developmental foundation is laid or during disruptions in life that can unravel the whole family unit, families need time to take care of their loved ones – and themselves.

I am grateful to the committee and the members of the proposed commission for examining this issue. I am confident that their findings will prove to be not only compassionate for the care receivers but economically prudent for Maine.

Thank you for the opportunity to testify today. I respectfully ask you to vote in favor of LD 1559.

Melissa Huston  
Bangor