

**Testimony of Mary Dysart Hartt**  
**Alzheimer's: New Directions in Biomedical Research and Caregiving**

**Special Committee on Aging**  
**United States Senate**

**April 2, 2019**

Chairman Collins, Ranking Member Casey, and members of the committee. Thank you for the opportunity to testify before the committee about my experiences as a caregiver for my late mother, and now my husband Mike, who is currently living with Alzheimer's disease. He was diagnosed at 62. My hope is that, in sharing my story, others who are impacted by this disease will feel less alone and understand that with proper supports, there is life after diagnosis.

Mike was 58 when I started noticing that things did not seem quite right. After living on our family farm since 1977, daily tasks like running the tractor became a challenge and fender benders became more frequent. During that same time, I was part of a family care team caring for my mother who was living with dementia. She was a brave woman who was never afraid to forge her own path. She started our family-owned business, Dysart's, with my father 52 years ago and my two brothers and I are very proud to have carried on our parents dream into the third generation. You may have heard of our famous "Purpleberry Pie" which has raised over \$25,000 for Alzheimer's Association, Maine Chapter. I began to see similarities in the challenges they were both facing and decided to reach out to our family doctor who agreed to help me monitor Mike for changes. For four years we continued on this path, with things coming to a head when Mike was 62.

When Mike was 62, he agreed to be tested. We turned to a hospital in Bangor for help and a diagnosis. After enduring test after test, Mike was diagnosed with frontotemporal dementia, or FTD, and given five years to live. In an effort to understand the diagnosis and what lay ahead, we contacted our insurance provider who referred us to Massachusetts General Memory Clinic in Boston. We are so thankful for the care we received at Mass General where after more tests, his diagnosis was changed to younger-onset Alzheimer's disease. Following the diagnosis, life changed significantly. We sold our farm where we had lived for nearly 40 years and condensed our life. At 63, Mike volunteered to give up driving, a freedom that was too dangerous to continue.

Before Mike was diagnosed, we were not familiar with younger-onset Alzheimer's disease, but had some knowledge of Alzheimer's and dementia through the experience of caring for my mother. One common assumption about this disease is that life stops completely. While we've faced unique challenges as we've tackled this disease, we continue to move forward with our life as best we can. It has been important to both of us for him to retain his dignity. Mike was president of his family's trucking business, Hartt Transportation, and also owned a business that manufactured log homes — he was our primary breadwinner. He always managed the money, so when we go out, he has money in his wallet. I help him keep an eye on it, but he has control

over it. In a disease that robs you of simple freedoms, it's important to feel grounded and in control of the aspects that are manageable.

In just two weeks I will be running my 41st marathon in Boston, Massachusetts. I am running to help rid the stigma of this disease. Too often, Alzheimer's is only talked about in terms of cognition and memory, but it is so much more. In my husband, I see it affect his emotions and temperament with agitation, apathy, anxiety. If someone is diagnosed with cancer, people automatically rally around to offer support and guidance. An Alzheimer's diagnosis is sadly not the same — but there's nothing to be ashamed about. We cannot hide behind a diagnosis if we want to make progress.

The staff at Mass General made clear that this disease is something that is meant to be taken day by day — to be approached with humor and a grasp of reality. Our doctor told us “don't worry about tomorrow, enjoy today.” That's how we've chosen to live our new life. Thanks to our providers and the support we received at the Alzheimer's Association, Maine Chapter, we've begun fulfilling wishes on our “bucket list”. Lucky for Mike, most of them are fishing adventures. Following more than 40 years of marriage, I took my first class at his fishing club, 'Fly Fishing 101.' We've made trips all over the world, including to Alaska, Iceland, British Columbia, the Yukon, and more. Mike can still out fish everyone on the river.

However, I know these adventures aren't typical for everyone — especially for those without a care plan. For us, this plan came in pieces and with the help of our team of care providers at Mass General. According to the Alzheimer's Association, today only about half of those living with Alzheimer's have been diagnosed, and of those only 33 percent are aware of their diagnosis. One of the reasons physicians do not diagnose — or do not disclose a diagnosis once it is made — is because of the lack of time and resources to provide information and support to patients and caregivers. But a diagnosis allows people to work with their family and physicians to engage in care planning, address financial decisions, and access support services. Mike's diagnosis at 62 was a shock, but working with the team of care providers at Mass General gave us time to talk through the reality of the situation and plan for the challenges that lie ahead.

Having a care plan has been critical to managing these new challenges and to living well with Alzheimer's. Care planning allows both the person living with the diagnosis and caregivers to learn about medical and non-medical treatments, clinical trials, and support services available in their community. It can mean fewer hospitalizations and ER visits and a better quality of life. Fortunately, Medicare now covers care planning for individuals with cognitive impairment and has made it easier for physicians to provide the care and support services that people affected by Alzheimer's need. I believe that our quality of life would be significantly different had we not been made aware that a care plan was vital to our future. However, patients and their providers are often unaware that these services are available.

Legislation like the Improving HOPE for Alzheimer's Act would help educate clinicians on Alzheimer's and dementia care planning services through Medicare and give them the

knowledge and tools to better help patients and families. For example, as part of our care plan, Mike and I met with a social worker who helped us to access speech pathology services--these have been enormously helpful. We continue to have regular visits to Mike's team of care providers and at our last appointment, we had the conversation about giving me power of attorney — something I would have never thought to seek but was part of our plan. Thank you Chairman Collins for introducing this important legislation that will make a difference in the lives of people living with Alzheimer's disease and other dementias and their families.

Mike is 66 now and quieter than he once was. An avid outdoorsman, he is no longer able to drive to his camp in the North Maine Woods — which he enjoyed for over 30 years. Once a larger than life character who used to joke and tell stories, he now listens respectfully and smiles to let you know he hears you. He can read but does not enjoy it as he once did. And while his memories seem to be mostly intact, we're re-learning how to do every day, routine tasks like turning on the T.V.

I think a lot about how lucky we've been in our life to be able to care for ourselves in this next phase. For many with the younger-onset diagnosis, that is not their reality. The services and supports that are there for those 60 years and older are vast compared to those available to the population in the Alzheimer's and dementia community who have not yet reached retirement age. Under the Older Americans Act, individuals and families are able to access programs related to support services, the long term care Ombudsman program and the National Family Caregiver Support program. These programs would make a huge difference in the lives of individuals living with younger-onset Alzheimer's disease who don't have support services available to them. The Younger-Onset Alzheimer's Disease Act, introduced by Chairman Collins, Ranking Member Casey, Senator Jones and Senator Capito, would make these Older Americans Act programs available to this population. Thank you for being leaders on this impactful legislation.

Throughout the past few days, Mike and I have joined our Alzheimer's Association, Maine Chapter, along with over 1,200 advocates from across the nation to make a difference in our nation's capital. We are here to advocate for the 5.8 million Americans living with Alzheimer's, 200,000 of whom are under the age of 65 and living with younger-onset Alzheimer's disease, and the more than 16 million people caring for them. Alzheimer's is the only leading cause of death in the U.S. that cannot be prevented, cured, or even slowed, but through the power of advocacy we have quadrupled the funding for Alzheimer's disease research at the National Institutes of Health since 2011, where the scientific community is tireless in their efforts to identify medical breakthroughs to change that dire sentence.

I am here today because I am the wife, caregiver, friend, and daughter of Alzheimer's. We all are. And we must remain a strong and resilient voice for those who may have lost theirs. I am honored to be the Alzheimer's Ambassador to Chairman Collins who has been a champion for individuals living with Alzheimer's disease and other dementias - especially for her leadership on the Building Our Largest Dementia (BOLD) Infrastructure for Alzheimer's Act which became law at the end of last year. I respectfully ask Congress to continue to make Alzheimer's

research a priority and to work together to pass critical legislation like the Improving HOPE for Alzheimer's Act (S.880) and the Younger-Onset Alzheimer's Disease Act (S.901) to help other families like Mike and me receive the support and services we all need and deserve. Thank you for inviting me to speak, listening to our story, and for all you have done. Please continue to join us in the fight to end Alzheimer's for generations to come.