

Steven Sepe

From: Nicki Trilling <ntrilling@gmail.com>
Sent: Tuesday, March 18, 2025 7:40 AM
To: House Health and Human Services Committee
Cc: Meredith Sheehan; Rep. McGaw, Michelle E.
Subject: H.5619: AN ACT RELATING TO HEALTH AND SAFETY - RHODE ISLAND PROGRAM TO ADDRESS ALZHEIMER'S DISEASE

Representative Susan Donovan
Chair, House and Human Services Committee

Dear Representative Donovan and members of the House Health and Human Services Committee,

As an older adult and Alzheimer's Association volunteer, I am writing in support of House bill H.5619.

After losing five family members to Alzheimer's and other dementia's over close to a 50 year period, I have experienced the struggle to care for and make decisions for loved ones suffering from this devastating disease. This included my mother who died in 2007, her mother (1981) and her sister in 2018. When my aunt died from complications due to Alzheimer's Disease (AD), the knowledge learned as a caregiver to my mother and her mother, translated into end of life care decisions for both her and my uncle while they were well. This benefited my cousins in the end of life decisions when they lost each of their parents within a two year period. Sadly, as is often the case with primary caregivers, my uncle's vascular dementia was not diagnosed until after my aunt's death.

Losing a parent gradually to a dementia is not easy and in fact still makes me cry as I write this, all these years later. My mother lost her ability to communicate the last few years, so when end of life decisions arose, there were disagreements that could have left a permanent divide in our family. Fortunately, it did not. In my volunteer work with the RI Chapter of the Alzheimer's Association as a fundraiser, community educator and advocate, I have met many people who not only lost someone to this disease, but also lost other family members due to care disputes.

Now with early detection methods and treatments available to delay symptoms, it is even more important that early detection takes place.

With a history of this disease in my family, I initiated conversation with my former primary care doctor and was astounded at the outdated and incorrect knowledge about this disease (*e.g. AD can only be diagnosed after death*) and the treatments available. And as my father-in-law began displaying symptoms during COVID, his primary care doctor attributed it to regular aging...it was not. We lost him to vascular dementia in 2023.

Please pass this important legislation to ensure increased public awareness and healthcare provider education takes place. This is urgent. Alzheimer's is a public health crisis in Rhode Island. As reported in the 2024 Alzheimer's Disease Facts and Figures report, over 22,000 Rhode Islanders are living with Alzheimer's. This represents approximately 11% of all Rhode Island seniors. This number is expected to increase by 12.5% by the end of 2025.

Thank you.

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