Alzheimer’s Association and Alzheimer’s Impact Movement Statement for the Record

United States Senate Special Committee on Aging Hearing on “Financial Literacy: Addressing the Unique Just-in-Time Decisions Older Americans and People with Disabilities Face”

January 13, 2022

On behalf of the Alzheimer’s Association and the Alzheimer’s Impact Movement (AIM), including our nationwide network of advocates, thank you for your continued bipartisan leadership on issues important to Americans living with Alzheimer’s and other dementias, and their caregivers. The Alzheimer’s Association and AIM appreciate the opportunity to submit this statement for the record for the Senate Special Committee on Aging hearing entitled “Financial Literacy: Addressing the Unique Just-in-Time Decisions Older Americans and People with Disabilities Face.”

The Alzheimer’s Association is the world’s leading voluntary health organization in Alzheimer’s care, support, and research. It is the nonprofit with the highest impact in Alzheimer’s research worldwide and is committed to accelerating research toward methods of treatment, prevention, and, ultimately, a cure. AIM is the advocacy affiliate of the Alzheimer’s Association, working in strategic partnership to make Alzheimer’s a national priority. Together, the Alzheimer’s Association and AIM advocate for policies to fight Alzheimer’s disease, including increased investment in research, improved care and support, and development of approaches to reduce the risk of developing dementia.

Alzheimer’s is emotionally, physically, and financially draining for individuals and families. It is also creating an enormous strain on the health care system, as well as federal and state budgets. An estimated 6.2 million Americans age 65 and older are living with Alzheimer’s dementia in 2021. Total payments for all individuals with Alzheimer’s or other dementias are estimated at $355 billion (not including unpaid caregiving) in 2021. Medicare and Medicaid are expected to cover $239 billion, or 67 percent, of the total health care and long-term care payments for people with Alzheimer’s or other dementias. Total payments for health care, long-term care, and hospice care for people with Alzheimer’s and other dementias are projected to increase to more than $1.1 trillion in 2050, not adjusted for inflation. These mounting costs threaten to bankrupt families, businesses, and our health care system.

Every illness brings different medical, emotional, and financial challenges for the caregiver. But caring for a person living with Alzheimer’s or another dementia can be particularly expensive. Alzheimer’s impacts a person’s memory, thinking, and behavior. It also impacts their ability to manage money. In fact, studies show that trouble managing bills and other financial problems can sometimes be an early sign of dementia. As the disease progresses, the person living with
dementia will eventually become completely dependent upon their caregiver to manage their money.

**Financial literacy and preparedness**

For individuals living with dementia, their families, and caregivers, making financial decisions can be confusing, which in turn leads to preventable mistakes. This includes a lack of understanding of the disease and future care costs, such as how there are three stages to Alzheimer’s, or even how some individuals can live 20 years or more with the disease. People also tend to assume that financial planning is only for the wealthy, or are too anxious or uncomfortable to talk about money. Additionally, crimes against older Americans are a growing problem, and individuals living with Alzheimer’s are more susceptible to becoming a victim of fraud or financial abuse. Ultimately, many of these mistakes are the result of misunderstandings and can be prevented, which is why the availability of resources or trainings early on during the progression of the disease is so critical.

The Alzheimer’s Association received funding from the Administration for Community Living (ACL) to develop a financial literacy and preparedness education program for dementia and non-dementia caregivers to be delivered in-person or virtually. The Association held focus groups to assess the relevance and usefulness of the curriculum, and finally, we conducted market research with 300 caregivers. The following topics as they pertain to financial literacy and preparedness were identified as being most important to caregivers:

- Costs of caregiving
- Implications of Alzheimer’s disease
- Benefits of planning early
- Avoiding financial abuse and fraud
- Conversations about finances
- Identifying financial and legal needs
- Finding financial support

The program will be available in January 2022 in three formats: online, in-person/virtual, and in Spanish.

**Providing older adults with information**

Providing financial decision information to people living with mild cognitive impairment, Alzheimer’s disease, or other dementia can be done in a variety of ways including collaboration with trusted community partners or gate keepers to help reach those in diverse and underserved communities. It is important that information and materials are culturally sensitive to the community for which it is meant. Additionally, utilizing language that is understandable to people is key. At the Association, we conduct a readability assessment on materials to strive for a 6th grade reading level. Information and materials need to be delivered in a myriad of ways including in-person/virtual programs, online programs, website, brochures, fact sheets, and our Helpline to speak to someone directly 24/7.
Currently available resources
The Alzheimer’s Association currently provides numerous resources and supports as people with mild cognitive impairment, Alzheimer’s disease, or other dementia and their families look to make financial decisions. The Association runs a 24/7 Helpline staffed by specialists and master’s-level clinicians to offer confidential support and information to people living with dementia, caregivers, families, and the public. Additionally, The Association and AARP partnered for a community resource finder which is available at alz.org/CRF.

Specific resources on eldercare and Elder Fraud are available through eldercare.acl.gov and www.fbi.gov/scams-and-safety/common-scams-and-crimes/elder-fraud.

Conclusion
Again, we thank the Committee for holding this hearing on such an important topic and for its commitment to the Alzheimer’s and dementia community. We appreciate the opportunity to comment on today’s hearing, and look forward to working with you and other members of Congress on issues important to Americans living with Alzheimer’s and other dementias, their families, and caregivers including financial literacy.