United States Senate Special Committee on Aging

Finding a Cure: Assessing Progress Toward the Goal of Ending Alzheimer’s by 2025

Testimony of Lisa Baron, JD

Executive Director, Memory Care Home Solutions

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Thank you Chairman Collins, Senator Claire McCaskill, Ranking Member and distinguished members of the Senate Special Committee on Aging. Thank you for the opportunity to highlight the importance of the role of the caregiver as part of this discussion. My name is Lisa Baron and I am honored to lead a non-profit that I founded named Memory Care Home Solutions.

Every day our team sees first-hand the devastation created by Alzheimer’s and dementia. It affects not only the person afflicted with the disease, but also the caregivers who are devoting untold resources and energy.

We are facing a national crisis caused by Alzheimer's and dementia. Increased funding for Alzheimer’s research is critical to avert this crisis for our nation and to find a cure by 2025. However, it is also important to recognize the work that can be done today to ease the pain for the millions dealing with this deadly disease. The majority of individuals suffering from Alzheimer’s today live in the community, either with family or alone. There are 15 million unpaid dementia caregivers who need help today.

I am here to talk about a bright spot, a ray of sunshine in the dark landscape that is Alzheimer’s. I founded Memory Care Home Solutions 16 years ago as a result of my own family experience. At Memory Care Home Solutions, we directly intervene to help caregivers and those with Alzheimer’s and cognitive impairment. We serve low-income families struggling to live with this disease. Fifty-four percent of those we serve have annual incomes of $20,000 or less and we offer this service free of charge thanks to generous foundation and donor support.

My mother-in-law Betty Baron began experiencing signs of Alzheimer's in 1997. Our family was blessed with educational and financial resources, yet nothing prepared us for Alzheimer's disease. It was a nightmare. If my family struggled and felt absolutely unprepared, you can only imagine the struggles most American families are experiencing. For our family, we were most concerned with my father-in-law who assumed the role of caregiver for his wife Betty. Was he sleeping enough? Was he eating enough? Was he isolated? No one in our family escaped the effects of this devastating disease.

Betty and Charles lived in a wooded area of St. Louis. One night my father-in-law was making dinner and Betty left the house undetected. After a traumatic night of panic and searching, the fire department found her at the bottom of a window well where she had fallen and was miraculously unharmed. At this moment, I knew I had to take action to improve the lives of families like my own who are facing the destruction of this disease. Memory Care Home Solutions helps families prevent crises like the one our family experienced.

I did not know where to start. I reached out to local researchers at the Knight Alzheimer's Disease Research Center at Washington University in St. Louis and began connecting with experts. They directed me to the growing body of evidence on non-pharmacological treatments for dementia.

I was amazed to learn there are tested and proven interventions to help people like Betty stay safe at home and functioning on the highest level while making life less stressful for the caregiving family. I was stunned to learn there was no organized system in place to help families deal with this chaos. Everyone is left to figure it out on his/her own. The Memory Care Home Solutions team went to work using this evidence as a foundation to create a home- and community-based intervention for families confronted with dementia.

I share this story to highlight the important connection between research and community health. Without this prioritization and funding of the federal government we would not have:

- a body of knowledge from which to draw and inform our program,
- a shared vision of the National Alzheimer's Project Act (NAPA), or

- the focus on "expanded supports for people with Alzheimer's disease and their families" specifically called for in NAPA.

While pushing aggressively forward for a cure, we must get quality, proven interventions to the caregivers of the 5.4 million people currently dealing with this disease. Our program is a model that can be replicated throughout the United States.

The Memory Care Home Solutions program consists of behavioral approaches to manage the symptoms of Alzheimer's and dementia, environmental modifications to support function in the home combined with caregiver education and training. Social workers and occupational therapists from our staff meet with families in their homes to uncover their most problematic issues. We immediately help the family implement safety measures and teach them dementia care strategies. We practice these techniques with family caregivers to teach them the skills needed to cope and find quality of life, despite this diagnosis. We also educate the family on prevention of common Alzheimer's complications like urinary tract infections, falls and dehydration. In the case of my family, Memory Care Home Solutions could've provided a door alarm to alert my father-in-law that Betty was attempting to leave the house, and taught strategies to engage Betty in meaningful activities so she would not wander.

This focus not only helps patients and families deal with the physical and emotional burden of this disease, but it can help avoid billions of dollars of cost for caregivers, health systems, and the Medicare and Medicaid programs. In 2015, the national estimated cost for Alzheimer's and other dementias reached $236 billion annually. Up to half of older adults with dementia make at least one visit to the emergency department annually, which is 25% higher than those without dementia. Of those, 40% are ultimately admitted to the hospital. Over 58% of people with dementia, who make a visit to the emergency department, return within 30 days. This high utilization rate clearly underscores the need for education - and we have proven that providing education has a significant positive impact! Memory Care Home Solutions’ program results in **a two thirds** reduction in 911 calls, emergency room visits and hospital readmissions.

Programs like ours create a win-win: a significant increase in quality of life for those impacted with the disease, combined with a significant decrease in costs for insurers, Medicare and

Medicaid. Most of our program participants already meet the criteria for nursing home care as they are dependent in two or more activities of daily living. However, 91% of our clients remain in the community with their family rather than transferring to a nursing home. In Missouri, this translates into cost savings of over $30 million dollars to the Medicaid program.

Unfortunately, most families across our country do not have access to this type of care. I urge the Committee to allocate the funding and resources necessary to equip all families in the United States with effective non-pharmacological treatments for dementia. According to Laura Gitlin, a leading researcher in the field, “There are over 200 proven behavioral interventions for family caregivers, yet less than 3% of these interventions have been submitted for translation into real practice settings.” Memory Care Home Solutions is proud to implement this evidence into community practice for the benefit of caregivers.

I'd like to close with a quote from Dr. Covinsky of UCSF cited in the Administration on Aging’s white paper on this subject that highlights the importance of these types of treatments - "if these interventions were drugs, it is hard to believe that they would not be on the fast track to approval. The magnitude of benefit and quality of evidence supporting these interventions considerably exceed those of currently approved pharmacological therapy for dementia.”

I thank you for this opportunity and I urge you to think about the families of those with Alzheimer's who are in desperate need of our help.