

**Healthcare Advisory Committee  
Brian Flynn for Congress**

**Alzheimer's Disease  
PRELIMINARY DRAFT**

**Key Points**

- Alzheimer's disease is common: the most common cause of dementia and the second most common cause of death in people over 65. There are a third more people over 65 in the 19<sup>th</sup> Congressional District than in the US as a whole.
- It is a financial burden: average out-of-pocket costs for families are over \$10,000 a year and the unpaid care they provided in 2017 was valued at over \$230 billion.
- We can decrease costs: people with Alzheimer's disease are hospitalized 5 times as often as those without the disease at 25% of admissions are preventable.
- Some unnecessary expenses are caused by people getting care only when they have to or where they can get it paid for: ensuring health insurance for all and expanding coverage to include home care and nursing home care will reduce unnecessary expenses.
- Better use of programs that help caregivers and that use expert teams to coordinate care can reduce unnecessary hospital admission and lower costs.
- We need to fund research on prevention to reduce the increasing burden of Alzheimer's disease on the people.
- The tools learned from improving the lives of people with Alzheimer's disease and their caregivers can be applied to other chronic diseases.

**Executive Summary**

Alzheimer's is a devastating disease which profoundly impacts patient's and loved ones. It is the most common cause of dementia and the second highest cause of death in people over the age of 65. Since 2000, deaths from Alzheimer's have increased more than six times as much as deaths from heart disease. There are 5.7 million people in the U.S. with Alzheimer's disease and that number is expected to increase to 13.8 million by 2050. Yet there is barely one specialist in geriatrics for every 2,000 Americans over 65 in need of care. Few nurses, social workers and pharmacists specialize in the care of the elderly.

People with Alzheimer's disease and other dementias have five times as many hospital days as people without dementia. Twenty-five percent of these hospitalizations are preventable. The disease can cause an enormous burden for caregivers. Many caregivers for people with Alzheimer's disease and other dementia report that their health has gotten worse due to care responsibilities (35%). And out-of-pocket costs for Medicare recipients with Alzheimer's disease and other dementias average over \$10,000 a year. In 2017, caregivers provided about 18 billion hours of unpaid care valued at over \$230 billion. That's almost 9 times as much as McDonald's total revenue in 2016. National healthcare expenses are also much higher for Alzheimer's disease than for other

patients. Medicare costs are over 3 times higher and more than twice as many beneficiaries with Alzheimer’s disease are on Medicaid as other Medicare enrollees.

Inpatient hospital expenses are responsible for about one-fourth of healthcare expenditures for people with Alzheimer’s disease. And one-fourth of those hospitalizations are preventable. With so much assistance dependent on unpaid care and so few professionals who specialize in caring for these individuals, this should not be surprising. Our healthcare system is not set up to manage a chronic disease of this proportion. Most insurance does not cover the long-term nursing care that most individuals require as the disease advances and can cost up to \$100,000 a year. And our fragmented system does not foster the coordination of care that is needed to prevent complications and the unnecessary expense of emergency room visits and repeated hospital stays.

Programs that have been shown to improve the skills of caregivers and reduce their stress will help keep people with Alzheimer’s disease from developing complications and allow them to stay at home, avoiding more expensive care in nursing homes and hospitals. Programs that use professionals trained to help individuals with memory problems and to work as a team have been shown to reduce hospitalizations with dramatic cost savings. These programs need to be supported and expanded. Further research for other promising strategies needs to be supported.

Most importantly, health insurance for all must be ensured and benefits must be expanded to include coverage for long-term care, home health care and personal care at home to relieve the enormous financial burden on caregivers of individuals with Alzheimer’s disease, reduce the informal costs of the disease and allow more individuals to stay home and utilize less expensive care, reducing emergency room visits and hospitalizations, lowering overall national healthcare expenditures. Resources need to be allocated to identify other effective and cost-efficient models of care integration.

It is also crucial to increase Federal funding for research through the National Institutes of Health research budget. We cannot afford to leave research primarily in the hands of private industry and profit motives.

Alzheimer’s, like other degenerative brain diseases, such as Parkinson’s disease, is due to accumulation of abnormal proteins in the brain. The process starts long before the symptoms occur. Clinical trials based on removing these proteins from the brain have been disappointing so far. However, trials are underway to test if this will work if started earlier, long before symptoms of dementia can be detected. To do this, we need to perfect our tools for diagnosing the disease before symptoms develop. And we must fund research on the best methods of this kind of pre-symptomatic treatment.

Most cases of Alzheimer’s are sporadic, but several genetic forms have been identified. The interplay between genetics and the environment in Alzheimer’s disease is being actively studied. This is another important area of research that needs to be promoted. Finding ways to decrease the risk of developing Alzheimer’s disease or other dementias

or slowing their progression could reduce their burden on patients, caregivers and national healthcare expenditures.

The Genetic Information Nondiscrimination Act privacy protection should be strengthened and extended to other forms of insurance like life insurance, long-term care, and disability insurance. Genetic-based discrimination in schools, mortgage lending, or housing should be prohibited. Genetic information may prove to be the most important piece of our personal information that we need to safeguard.

We cannot afford to be passive as we face a looming public health crisis. As life expectancy rises and birth rates drop we will have an older population, with more people living with chronic diseases and fewer healthy people to take care of them. Alzheimer's and other chronic conditions will exact an increasingly heavy cost to our society. We have an obligation to act. By improving how we pay for and deliver care, and nurturing biomedical research, we have an opportunity to make lasting positive change that will help this generation and future generations.

Brian Flynn for Congress - Preliminary Draft