# U.S. Senate Committee on Finance
# Subcommittee on Health Care

## *Alzheimer's Disease: The Struggle for Families, a Looming Crisis for Medicare*

**Expert Testimony by**
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Good afternoon, Mr. Chairman, Ranking Member, and members of the committee. I flew here today from Michigan to express my support for the Health Outcomes, Planning, and Education for Alzheimer's Act, also known as the HOPE for Alzheimer's Act, that was introduced by my Senator, Debbie Stabenow. I am currently the Director of the Michigan Alzheimer's Disease Center at the University of Michigan where I am also the Lucile Groff Professor of Neurology and Co-Director of the U-M Protein Folding Diseases Initiative. I am honored to speak on behalf of my colleagues, our patients and their families to express a united vision for comprehensive care and compassion for those who are living with dementia.

As Director of the Michigan Alzheimer's Disease Center, a Center that links the three major research universities in Michigan, I bring with me the support of countless colleagues across our state who provide care for those with Alzheimer's and other forms of dementia. Collectively, we recognize that the comprehensive care planning services provided by the HOPE for Alzheimer's Act will improve the lives of millions of American families confronting dementia. This impact is principally what drives our support: through the HOPE Act, we will provide better care that makes a real difference in the lives of many. By addressing this critical medical need and helping dementia patients and their families navigate the difficult road ahead, the HOPE Act also will reduce federal health care costs associated with this devastating disease by nearly 700 million dollars over the next decade. It's no wonder that this measure has garnered broad bipartisan support. It's the kind of legislation that will inspire a new generation of hope, and I applaud Senators Stabenow and her colleagues for having the vision to craft and support this Act.

Each day, over a thousand Americans receive the diagnosis of dementia. Most often, the specific diagnosis is Alzheimer's, which currently affects more than 5 million Americans. Other related dementias, including Lewy body dementia, frontotemporal dementia, and vascular dementia, affect millions more. As a neurologist who cares for persons with dementia, I have seen the deep fear, anxiety and uncertainty that can accompany this diagnosis. Busy and overworked health care providers may only be able to offer a simple fact sheet about the disease or provide a prescription for a medication. The future brought on by this slowly progressive disease too often remains uncharted and frightening.

To someone newly receiving the diagnosis, the questions come fast and furious:

What does my future hold?

What changes in my life do I need to make now?

How do I prepare for these inevitable changes as my disease progresses?

What kind of medical care do I need and when?

Who will help my family?

How do I connect with others who understand?

To someone caring for a loved one these same questions, and others, surface:

Where can I turn for help?

How will I be able to provide care while also working or managing the household?

How can I possibly cope with the new demands and stresses I’m facing?

What can we do to stay as healthy as possible and close as a family?

Sadly, too often patients and their families never get the chance to consider these questions because the *diagnosis is not provided to them*. Astonishingly, approximately two thirds of seniors diagnosed with Alzheimer’s are unaware of their diagnosis. In no other common disease affecting seniors – cancer, heart disease, hypertension – are so many unaware of their disease. We must do a better job of diagnosing dementia earlier in the course, and making our patients and their family caregivers aware of the diagnosis. Recent evidence shows that early knowledge about the disease improves long-term outcomes for those with cognitive impairment.

The HOPE for Alzheimer’s Act will ensure that patients and families receive answers to these questions, allowing them to work with health care providers to develop a proactive plan to optimize their health and security as they deal with the changes wrought by dementia. I cannot think of anything more pressing for our patients right now. While we in the field are working hard to develop better therapies and ultimately a cure for Alzheimer's, we are not there yet. The HOPE Act will make a difference now.

A few years ago we at the University of Michigan realized that, even at a major research university like ours, newly diagnosed patients and their families sometimes fail to receive all the information they need in a timely manner. Thus, we piloted a new program, the Multidisciplinary Diagnostic Medical Visit -- a "team" approach to dementia that gives patients and caregivers the opportunity to meet with a neurologist, neuropsychologist, nurse practitioner and social worker for a comprehensive appointment during which we discuss test results, diagnosis, and care planning. Our pilot program also shortens the time from first contact to disclosure of a diagnosis. In short, the program has worked very well: Patients and caregivers overwhelmingly support our comprehensive approach, and feel they have a much greater awareness of community support and services as a result. Care planning also allows us to address critical issues that families might not otherwise raise—for example, is it safe for my loved one to keep driving? Or to live alone? In the process, we are continually reminded that each patient is unique. Comprehensive care planning must be customized, taking into account the specific type of dementia, stage of disease, other chronic medical disorders, and family dynamics, among other factors.

Unfortunately, only a small percentage of persons with dementia receive their diagnosis through a major research center such as ours, where we have the privilege to pilot a multidisciplinary approach. That is why the HOPE Act is so important: it will ensure comprehensive care planning for dementia across the country at all types of medical facilities, small and large.

When we think of disease treatment most of us think, first, of medicines. But for dementia, the various components that go into state-of-the-art care extend far beyond medicines. We now know, for example, that non-pharmacologic interventions play a vital role in brain health. Recent studies show that regular aerobic exercise improves cognitive function. Adequate sleep, and the right kind of sleep, may help rid us of the toxic proteins that accumulate in dementia. Cognitive training can make a difference. Careful attention to other chronic illnesses, such as depression, diabetes or heart disease, improves the lives of those encountering dementia. Finally, access to support groups, for patients and caregivers alike, can be a life saver. Access to comprehensive care planning will ensure that these vital components are offered broadly to all of our patients.

I close on a personal note. Throughout my career, I have sought to understand the mechanisms underlying brain diseases so that we might develop cures. When given the opportunity to direct the Michigan Alzheimer’s Disease Center 5 years ago, I jumped at the opportunity. Why? Partly because it’s an exciting time in the field; our understanding of dementia has advanced to the point where we are now testing promising, potential disease-modifying treatments.

Partly because there’s so much we still don’t know, and need to figure out. But mostly because this disease, by affecting millions of Americans, touches us all – whether through a family member, a friend, a neighbor, a colleague. There are so many faces to this disease. I ask you now to think about someone you know who has confronted dementia. I am thinking of a colleague, a brilliant physician loved by his patients, who retired this year when he faced the earliest signs of Alzheimer’s. Like you, I want to make a difference in the lives of those with dementia. Until we have a cure for Alzheimer's and other dementias, we need to provide patients and families with the means to cope and the reasons to hope for a better future. This is precisely what the HOPE Act will do.

Thank you for the opportunity to speak to you today. I am deeply encouraged by the HOPE Act, and personally, I have great hope for the future of those with Alzheimer’s and other dementias. I look forward to getting back to Michigan to continue our work toward that better future and would be happy to answer any questions that the Committee has for me.