

**Statement of
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U.S. House of Representatives**

**Before the
Special Committee on Aging
United States Senate**

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Chairman Kohl, Ranking Member Smith and members of the Committee. Thank you for this opportunity to discuss the growing crisis that Alzheimer's poses to our Nation, and what we can do to accelerate and revitalize our efforts against this terrible disease.

Over the past several years I have steadily increased the time and energy that I have devoted to Alzheimer's, and I have been drawn to do so from several perspectives. This growing focus culminated this past year in my decision to organize a taskforce of national leaders to wrestle with this challenge. I co-chair this taskforce, the Alzheimer's Study Group, with former U.S. Senator Bob Kerrey. I speak to you this morning in that capacity. The Study Group is a remarkable and diverse group of national leaders – leaders such as Justice O'Connor whom I am honored to testify with this morning.

The Alzheimer's Study Group was convened to develop a National Alzheimer's Strategic Plan. We are developing the recommendations in this plan through a focus on five key objectives:

- Encouraging collaboration among researchers;
- Improving Alzheimer's clinical trials;
- 'Rapid learning' from large electronic health datasets;
- Integrating a community-based care model; and,
- Providing better information to policymakers.

I will have more to say about these strategic objectives later in my testimony.

Each of us on the Alzheimer's Study Group no doubt has our own reasons for agreeing to devote a substantial portion of this coming year to grappling with the challenges posed by this disease. But I do believe we hold several reasons in common.

First, the members of the Study Group share a conviction that Alzheimer's is a truly large and momentous challenge to our Nation. We must act now, or we will pay a far, far greater price in the decades ahead.

Second, we share a sense of tempered optimism that America can rise to meet this challenge. America has done so for other diseases; it will not be easy, but we certainly can do so with Alzheimer's as well.

Third, like most every American of our generation, Alzheimer's is simply part of our lives. Some members of the Study Group currently care for loved ones with Alzheimer's. All of us have witnessed its impact on friends, colleagues and relatives. None of this makes us exceptional. Rather, in this respect we are all too typical. Sooner or later, it hits all of us.

I've faced the particular cruelty of this disease at various times over the years. I first encountered Alzheimer's in my 30's when I taught the men's bible study at First Baptist Church in Carrollton, Georgia. I watched with both frustration and sadness as the disease claimed one of my good friends.

Years later, talking with Nancy Reagan during the long process of President Reagan's illness further convinced me that we had a moral obligation to focus on this terrible disease.

Meeting people with Alzheimer's living with my mother at the Homeland Center in Harrisburg, Pennsylvania, over the last years of her life convinced me that most of us live oblivious to its impact on individuals, their families, and our institutions.

At the Center for Health Transformation and through my work as co-chair, also with Senator Bob Kerrey of the National Commission for Quality Long Term Care, it became obvious to me that we could never deal with the fiscal crisis of long term care without substantially improving our capability to treat Alzheimer's successfully.

And now, in my own family, I have watched my sister-in-law care for her mother as she is slowly but irretrievably claimed by the disease.

Most everyone I speak with of my generation can recite a similar list of experiences. Alzheimer's is steadily becoming the uneasily discussed – and often preferably ignored – touchstone of the baby boom generation.

A Crisis Born of Success

In a sense, the Alzheimer's disease crisis is a product of success. Over the past century, clinical and public health advances have added more than 30 years to the average American's life. All of us can anticipate living substantially longer than Americans of prior generations.

But this success, together with the aging of the baby boom generation, means that the number of those with Alzheimer's – already far too high – will increase substantially in the years ahead. The odds of developing Alzheimer's double every five years after 65. It strikes 1-in-8 Americans over age 65 and almost half of Americans over 85. And so Alzheimer's is even now draining this success of its meaning as it robs millions of Americans of their memories, and then their minds.

We now know that just as decades of plaque accumulation and arterial hardening precede heart disease, a decades-long cerebral assault precedes the first recognizable manifestation of Alzheimer's. Many in this room today are even now losing a silent battle against Alzheimer's steady, unrelenting attack – though symptoms of this lost struggle may not appear for years to come.

So far, we don't have any way to block this decades-long descent into Alzheimer's. You will never meet an Alzheimer's survivor – there are none. Alzheimer's always ends in death. Perhaps that's why older Americans fear it more than cancer, heart disease, or any other disease.

Personal Loss; A National Crisis

Alzheimer's is also all too predictable on a national level. More than 5 million Americans currently suffer from this brain-destroying disease. With the aging of U.S. baby boomers, the Alzheimer's Association recently estimated that fully 10 million from my generation will develop the disease in the years ahead.

What's more, because Alzheimer's robs capabilities and independence it's also very expensive. This year the Federal government will spend more than \$150 billion to care for those struggling with the disease. If we did not rely on family caregivers to bear so much of the burden, this figure would be far higher still.

Even so, the government's annual \$150 billion liability is only a foretaste of what awaits our Nation. Under current trends Federal spending on Alzheimer's will increase to more than \$1 trillion *per year* by 2050 in today's dollars. That's more than one tenth of America's current economy. With this amount of money at stake, the government simply will not be able to solve its looming fiscal problems if it fails to address the growing Alzheimer's crisis.

And yet, for all this, as I mentioned earlier there is solid ground for hope. The same impressive pace of innovation that has allowed us to live longer and make substantial progress against so many other diseases may help us defeat Alzheimer's as well. Researchers in academia and industry are steadily unlocking the mysteries of various aspects of the disease. Our great challenge now is to assemble this steady procession of insights from labs and clinics around the country into treatments that will upend these grim projections.

It's important to note that we don't even need to discover the Holy Grail – The Cure – to substantially blunt Alzheimer's future toll. According to a Lewin Group analysis commissioned by the Alzheimer's Association, a research advance that delayed the onset of Alzheimer's by just five years would translate by 2050 into a 5.3 million person (40%) reduction in disease prevalence and roughly \$515 billion (44%) in annual savings for the Centers for Medicare and Medicaid Services (CMS).

A Lesson from the World that Works: Start with a Strategy

So, are we doing all that we can to speed such breakthroughs and to bring some measure of relief to families already contending with this disease?

The sad but undeniable fact is that we have been entirely too complacent in the face of this growing crisis. Nowhere is this clearer than within the Federal government itself.

You might expect me to back that charge with a critique of the current National strategy. But that's just the point. There is no National strategy. It doesn't exist.

To be sure, there are strategic Alzheimer's plans within some of our health agencies and institutes. In fact, some of these plans contain very thoughtful and promising strategies – strategies that have yielded world-class programs like the Alzheimer's Disease Neuroimaging Initiative (ADNI).

What's missing, however, is critical: an overarching strategy for the Federal government as a whole. There is no strategy that articulates Washington's overarching goals, objectives, strategies and metrics, or that serves to coordinate and maximize the sum of the activities underway across all the various Federal agencies.

Do we really need such an overarching strategy? Or would that just be a triumph of process over practice; a distraction from the work that needs to be done, and little more?

To answer that question first consider that, taken on its own, the \$150 billion that the US federal government will spend this year on Alzheimer's would place it among the ten largest corporations in America. That's the scale and complexity we are talking about here – a Fortune 10 company.

Now, if you were to ask the CEO of any of those ten largest US companies to describe how important a clear, coherent, carefully implemented strategy is to their success, he would tell you that such strategic planning is essential. On what grounds do we assume that a clear, organizing strategy is any less important for our nation's battle against Alzheimer's? After all, not only are similar dollars at stake but – much more importantly – millions of lives hang in the balance as well.

Some would likely object that our government simply can't afford to craft an individual strategy for a specific disease. Instead, they would say, we should just let the National Institutes of Health (NIH), the Food & Drug Administration (FDA), the Centers for Disease Control and Prevention (CDC) and other agencies do their own thing. That's the conventional wisdom in Washington. But that thinking would be met with astonishment in the board rooms of our Nation's best run organizations.

Imagine, for instance, if Richard Wagoner, the CEO of General Motors, announced that GM will no longer develop distinct strategic plans for its pickups, sports cars, luxury vehicles, or sub-compacts. No need for distinct strategies; after all, they are all vehicles.

Imagine, further, that Mr. Wagoner announced instead that GM will just let its individual operating divisions – manufacturing, finance, marketing and so on – make their own decisions regarding each car model without coordinating with any of the other divisions.

Clearly that example is absurd – almost too absurd to imagine. But someone from the Federal government needs to explain to this committee why it is any less absurd for the Federal government to assume that there is no need for a distinct federal strategy for Alzheimer's or to not insist on careful coordination among the various Federal health agencies.

By contrast, consider the intellectual energy and time that the leadership of America's best run public and private organizations put into strategic planning and execution. Is this wasted effort? A triumph of process over practice? Consider how much effort executives at leading companies like Fed Ex, GM or Microsoft devote to analyzing, planning, and monitoring to ensure figures much smaller than \$150 billion are spent with maximum effect – so that waste is minimized and benefits are maximized. This is how our Nation's most successful organizations approach issues of this magnitude. They sweat over it.

The Signs and Consequences of Strategic Drift

So if this is right, we should be able to point to how this lack of a strategy is leading to bad outcomes. In fact, that's exactly what we can do.

Take the example of our Federal investment in the search for disease-modifying treatments. For every dollar the Federal government now spends through Medicare and Medicaid to care for those with Alzheimer's, it invests *less than a penny* to accelerate the discovery and development of effective therapies through the work of NIH and FDA.

This penny-on-the-dollar approach toward Alzheimer's is about as good an illustration of a "penny wise, pound foolish" policy as one could imagine. The government under-invests in accelerating the search for effective therapies based on the argument that there's simply no more money. They ask, how can we afford to do more?

However, each day we go without such treatments leads the government to spend many, many times more than the total devoted to Alzheimer's at NIH and FDA in order to cope, as best it can, with Alzheimer's devastating impact. A strategic perspective on such imbalances would immediately lead us to the right question: How can we afford *not* to do more?

Because we have framed this issue without a strategic reference, the investment gap grows wider each year. Federal funding for Alzheimer's research has remained flat for years – declining, in fact, when accounting for inflation. All the while, the cost of caring for those with Alzheimer's increases.

Consider another example: the Administration on Aging's Alzheimer's Disease State Matching Grants program. The intent of the program is to support state innovations to enhance care for individuals with Alzheimer's and their families, especially in minority, low-income and rural communities. For several consecutive years, the Bush administration's budget has proposed eliminating the program's funding. And in each of these years, as it has since 1992, Congress has acted to keep its funding intact.

Should this program be funded? Perhaps the Administration has a compelling case for canceling the program. But making a convincing, thoughtful case would require, almost by definition, some reference to the Administration's overall Alzheimer's strategy. Absent that, how can Congress know how the Administration intends to support the millions of families caring for those with Alzheimer's, and how this particular program does (or does not) contribute to that goal?

Referencing the \$11 million in immediate cost savings is not, in itself, a sufficient justification for cancelling the programs either. After all, strong evidence from carefully conducted trials shows that support for caregivers can delay nursing home admissions and bring many other benefits. It's entirely possible that, scored correctly, these expenditures save the government far more than their cost in savings to Medicare and Medicaid.

These are not just academic questions. We have spoken with leading researchers that have pleaded for a clear national policy with regard to caregiver support. Currently they have to try to work with an array of agencies and a patchwork of programs – with each unsure of their own mandate and long-term support for such work.

Questions like these are fundamental. They are the kinds of questions that surface within the first hours of serious deliberation – as indeed they have for the Alzheimer's Study Group. This is an example of precisely the kind of overarching strategic discussion that has been missing far too long and that we cannot afford to neglect any longer.

Real Change Requires Real Change

The Alzheimer's Study Group was organized to address this lack of strategic planning. Our charge is to develop a National Alzheimer's Strategic Plan. Our intention is to spur the strategic conversation and planning that has been neglected for far too long.

The Study Group does not aspire to propose small adjustments to the status quo. Simply doing a little bit more of what we are already doing or doing it in a slightly better way will not bring us to where we need to be. If we want to see a real change in the impact of this disease upon our country, we need to embrace real change in the way we seek to overcome it.

That, in turn, begins with bold but disciplined strategic planning. The Alzheimer's Study Group is working to anticipate emerging trends and capabilities. Our aim is to capitalize

on them as quickly as possible to dramatically speed our current pace of discovery, development and delivery of better treatments and care practices.

Toward that end, the Study Group has selected five key areas that we will focus on as we craft our recommendations.

- *Encouraging Collaboration among Researchers.* Scientific researchers from academia, government, and industry need the tools and incentives to scan the growing body of Alzheimer's research for relevant breakthroughs. They also must be encouraged to more efficiently collaborate on solutions, regardless of organizational boundaries.
- *Improving Alzheimer's Clinical Trials.* Alzheimer's clinical trials must be better supported and coordinated to reduce delays, improve efficiency, and ultimately allow the faster identification of promising new treatments.
- *'Rapid Learning' from Large Electronic Health Datasets.* Cutting edge "data mining" tools and methods have the potential, if paired with the right information, to revolutionize how we prevent, treat and care for Alzheimer's. Our vision is of a bold, 21st century version of the Framingham Heart Study.
- *Integrating a Community-Based Care Model.* Innovative approaches to care have been proven to make a tremendous difference for those with Alzheimer's and their caregivers. Better ways to support patients and families, and help managing the cost of care must be developed from best case practices, and then made available to all Americans.
- *Providing Better Information to Policymakers.* Government leaders must be given meaningful and timely information on the mounting impact and potential responses to Alzheimer's if they hope to assess progress, set funding priorities, and exercise strategic oversight.

The Study Group has established working groups to develop recommendations based on each of these areas. Far from working in isolation, we have already worked with over a hundred leading Alzheimer's experts to assess where we stand today. We will continue to collaborate with these leaders and many others in the work that lies ahead.

We anticipate releasing our plan in early 2009. We request that you and your colleagues work with us to shape these recommendations and partner with us in their implementation.

Conclusion

I would like to conclude by thanking you again for this opportunity to speak with you about Alzheimer's disease, and the path we must embark upon to overcome it.

Alzheimer's is a crisis that mounts by the day. We have let too many of these days slip by without bold, decisive action to deliver meaningful relief to the millions of Americans struggling with this terrible disease. Together, we can end this sad legacy and replace it with a much better future for millions of Americans and our Nation as a whole.