

Public Policy Forum

# The “tipping point” in the Alzheimer’s dialogue: It’s all about the messenger

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## Be Heard Here First

### 1. Introduction

May 14, 2008. On first impression, it was one more hearing on Capitol Hill, but I knew intuitively this was not going to be business as usual. Testifying for the first time on the subject of Alzheimer’s disease were two historic figures of unique and compelling stature: Retired US Supreme Court Justice Sandra Day O’Connor, and former Speaker of the US House of Representatives Newt Gingrich, speaking as co-panelists of the recently-formed Alzheimer’s Study Group (ASG).

As an advocate, 14-year veteran caregiver to two Alzheimer’s patients, and former television reporter, I had read their pre-submitted testimony and knew I needed to be there. It was apparent that everyone in the hearing room would be witness to a seminal moment when the battle cry of Alzheimer’s advocates would be echoed and amplified by far more powerful and historic voices that could change the conversation into a movement and mobilize a generation and the nation.

These were individuals who had made history before. Justice O’Connor, the first woman Justice on the Supreme Court, had spent decades finding the rational and sound middle ground for difficult social and political Court decisions. Near the end of her career, she had performed this role while serving as full-time caregiver to her husband John who was struggling with Alzheimer’s disease. Justice O’Connor, now retired, was making her first formal declaration regarding the disease and the country’s response to it.

Similarly, Newt Gingrich was no stranger to historical achievements: an insider with 20 years of leadership in Congress, who had orchestrated some of the most intricate and all-encompassing feats of legislation and outright pol-

itics of his time. As a young, conservative congressman from Georgia, Gingrich conceived of the “Contract with America” which served as the platform for Republicans taking over the majority in the House of Representatives in 1994. Gingrich became Speaker of the House in 1995, one of the youngest Speakers in history, and led the Republican party in its efforts to convince the American people of the benefits of conservative politics, implementing a number of novel pieces of legislation in the process. Speaker Gingrich resigned his office in 1999. He now devotes his time in the private sector to pursuing radical reforms of government, energy policy, and healthcare.

The network morning shows and front pages of the national papers shared my instincts about this hearing. They previewed and covered the story with a level of media attention rarely seen with Alzheimer’s disease.

To the credit of the National Alzheimer’s Association and other dementia patient advocacy groups, momentum had been building all week: a candlelight vigil, release of the prestigious inaugural Leon Thal Symposium meeting report, an early onset Town Hall Meeting, and policy forums. The Association had also arranged for compelling testimony from early-onset Alzheimer’s patient Charles Jackson, caregiver Suzanne Carabone, and Dr. Rudi Tanzi, a pioneer in genetic research from Harvard University.

But the “tipping point,” the game-changing testimony, was provided by the dynamic and open dialogue between the 11 Senators present and Justice O’Connor and Speaker Gingrich. This conversation repositioned the disease from a silent peril trapped in a line of the congressional budget to a national imperative.

### 2. Sandra Day O’Connor: Judicially chosen words from the heart of the epidemic

Justice Sandra Day O’Connor rarely gave interviews during her 21-year tenure. Her quiet, crystal-clear, and frank voice mirrored her reserved demeanor and powerful intel-

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lect. This testimony would be her first and only since her confirmation hearings.

Her courage to speak out made it a day for others to bear witness and reveal that they too had experienced a loved one with this disease. In a gesture of empathy, no fewer than seven of the 11 Senators present made it clear, in their opening remarks, how Alzheimer's disease had affected their own lives: that's 63%, a majority by any measure. Justice O'Connor acknowledged their shared grief and respectfully presented her case. It was what she wouldn't say that would be most telling to every caregiver in the room:

I am here in the position of being a caregiver. My beloved husband John suffers from Alzheimer's. He has had it for a long time now, and he is not in very good shape at present. And so I have some appreciation for the depth of feeling that you have that has generated the interest in the people who are in this room today.

Her companion written testimony provided a bit more insight into this very private woman:

You may remember that in the early days of my husband's illness, I often took him to court with me because he could not be left alone. And, as you know, I retired from the US Supreme Court in 2006 to find a care center for John in Phoenix, where two of our children live. Many caregivers make similarly difficult decisions each and every day. Sadly, these life-changing decisions are simply part of caring for someone with Alzheimer's.

Researchers are now telling us that the disease can also rob caregivers of their health. According to a recent study in the *Journal of Immunology*, people who care for relatives with Alzheimer's are twice as likely as non-caregivers to suffer from depression. They are also more likely to develop a compromised immune system that could shorten their lives [1] . . .

The doctors who take care of my husband tell me that one in two people over 80 are going to have Alzheimer's. Now I'm getting pretty close to 80, so that gets my attention. I think a lot of people will be concerned when they look at it from that standpoint.

In the end, Justice O'Connor's immediate personal struggles and her skills as a policy analyst collapsed into one, as so often happens in a crisis where first-hand experience becomes the voice of real authority:

Clearly, Alzheimer's disease is a family disease. It may directly attack only one member of a family. But every member of that family feels the effects. Every member loses something.

From even the earliest stages, the symptoms of Alzheimer's disease are very difficult to handle. As the disease progresses—often over the course of decades—its symptoms become cruel and punishing.

My own sons have not wanted to go be tested, even though, obviously, with their father in the condition he is they should know, but out of the fear that they would

then be ineligible for insurance. So you have done a wonderful thing in getting that legislation [the Genetic Information Non-Discrimination Act] before us.

I submit to you that until you have actually stared Alzheimer's in the face, as millions of Americans and their families have done, you cannot truly understand the deep sense of frustration, fear, helplessness, and grief that accompany it.

And so her remarkable service to the nation continues.

### 3. Newt Gingrich: The big think and power puncher

Speaker Gingrich's public and private life has focused on large challenges facing the nation. His presence spoke to the enormity of the threat posed by Alzheimer's disease. His reputation as a big problem-solver caused the Senators present to pay special attention to the substance of his remarks. They were well aware of his role as Co-Chair of the ASG, an independent and bipartisan alliance of national leaders which he established with former Senator Bob Kerry in 2007. The ASG intends nothing less than the nation's first *National Strategic Plan* to fight Alzheimer's disease, which they expect to release in early 2009 as a new President is inaugurated.

While testifying, Speaker Gingrich's voice had two tones: one of clear frustration, and the other energized by new ideas and a startlingly fresh perspective about how to revolutionize the nation's response to Alzheimer's disease and, in the process, fix and build a better system that will also more effectively fight other neurologic diseases:

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 10 largest corporations in America. That's the scale and complexity we are talking about here: a Fortune 10 company.

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 and 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 . . .

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.

With a private-sector entrepreneurial perspective, Speaker Gingrich urged the Committee and nation to re-engineer the way we pay for a disease of the elderly at a time when Americans are growing older in increasing numbers and living longer than ever before:

I met with Fred Smith at FedEx to talk about our lack of metrics and our lack of ability to manage large systems. And at one point in our breakfast he said, "Government cannot distinguish between investment and cost." And, therefore, government could never tolerate building FedEx or UPS, because you could never explain why the wireless and the laptop are so central . . .

Now, if you instructed the Congressional Budget Office to design a generational investment strategy—because you know what's going to happen—we're going to run out of money, and we're going to nickel-and-dime truly stupid things to try to save money in Medicare and Medicaid—when if you started right now and had an investment strategy, you might postpone Alzheimer's by 5 years. If you postpone Alzheimer's by 5 years, you save half that money—\$600 billion.

Rattling off multiple strategies on how to manage many aspects of the Alzheimer's crisis, Speaker Gingrich was never at a loss for ideas:

My personal bias strongly favors a tax credit for quality long-term care, and I would even contemplate a tax credit that was in effect a part of what everybody did—almost like FICA, starting when you first went to work, because I think we've got to find a way to quantify and build up resources over a generation, so that the generation starts taking care of itself.

With respect to speeding the translation of basic research into applied cures, Speaker Gingrich first had a plan for the science:

Research on the brain will be one of the most extraordinary areas of explosive new knowledge, because it is the most complex area of science. And we have only had really decent technologies for the last 15 years. It's physics and math, which is the underlying basis of the tools, which allow researchers into the brain to acquire real-time data about living brains. And so it's very important to understand that a truly basic research strategy has to involve the National Science Foundation, as well as the National Institutes of Health.

When moving the basic science to therapeutic research and development, Speaker Gingrich outlined strategies for encouraging private research:

The great engines of translating research into productive use are the private-sector engines. And if we build walls that are too strong, we in fact inhibit the transfer of knowledge in a way that is very, very dangerous . . . I think we need to make the R&D tax credit permanent . . . This will be fairly controversial, but I think you should review the ethics rules to make sure we have not created such solid firewalls at NIH that we in fact inhibit the flow of knowledge back and forth . . .

I would also strongly encourage you to amend the Orphan Drug Act to include all brain research as an orphan drug activity . . . because this is a zone that is very complicated and very hard, and, as a result, pharmaceutical companies aren't going to invest in it. And if you want to maximize the private-sector investment, you want to maximize the possibility of real return, and if all of the work done in Alzheimer's and in Parkinson's and other brain functions was treated as an orphan drug for patent purposes, you would dramatically explode the amount of money being spent.

Now, I understand the countervailing argument, which is that you have the drug on patent longer. Let me just suggest to you, having the drug is precedent to being able to get it to be generic. And if nobody is going to do the research to ever develop the drug, you are never going to get to the generic. And I'd rather spend a few extra years on patent and actually have the drug to save lives.

Regarding the next step in turning pharmaceutical research into available therapies, the FDA was on his target list for reform:

How do we accelerate translating applied research into usable medications? I think that requires FDA reform. I think that particularly in the area of brain science, because a lot of the world that makes perfect sense if you're looking at a normal physical behavior of cancer, or whatever, doesn't make sense when you're dealing with the brain. And I think that you need fundamental rethinking of how the FDA deals with research in the brain.

Clinical challenges solved, Speaker Gingrich moved to better tracking of epidemiology and treatment practices, to learn from the epidemic itself:

Remember that the National Institute of Medicine points out that it takes up to 17 years to adopt a new best practice. I would encourage the National Library of Medicine to help create an electronic internet-based real-time 24/7 learning system for doctors, and recognize that continuing medical education has to be permanent . . . because you want to get the newest breakthrough to your mother's doctor this week, not in 17 years.

At the forefront in fostering the use of information technology in Congress, Speaker Gingrich pushed for Electronic Health Data:

I would also explore a public-private partnership for developing the use of electronic health data. We have over 40 million electronic health records today. They can be used on a depersonalized, anonymous basis with all HIPAA protections that are necessary . . . You ought to bring in the head of eBay and the head of Google and the head of YouTube and the head of Facebook, and people of that caliber and say to them, "What would a public-private partnership look like that allowed us to use the best of IT to create an electronic epidemiology that allowed us to track millions of data points in real time?"

On innovating new care-giving solutions and getting them to Americans faster, Speaker Gingrich stated:

There are technologies that should be designable to modify homes to enable you to take care of Alzheimer's challenges. And all of that modification ought to be a tax credit, because enabling them to stay for an extra year or 2 years will more than pay in avoidance of long-term care facility costs.

So with all this radical reform underway, how would we stay on track? Speaker Gingrich came prepared:

With as much money as Alzheimer's is going to cost in as many different places, I would really urge you to create a White House Coordinator who has reach across the entire Federal Government . . . We have these huge, very expensive things that cost more than any department in the Federal Government, except HHS and Defense. And yet they are totally uncoordinated, and there is no capacity to bring people together and force them to talk to each other and try to get these things done in a way that makes sense.

Will Speaker Gingrich and the ASG succeed in this effort to bring a new process to the old impasses that keep our loved ones from relief and our nation's healthcare system in gridlock? Or, as Speaker Gingrich asked himself in his written testimony:

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?

A fair question. In the closing duet of questions and answers, both Justice O'Connor and Speaker Gingrich ad-

ressed the issue. Speaker Gingrich answered with a call to action:

We need to move now to reinvent and reinforce our fight against Alzheimer's. For the baby-boom generation, this is certainly one of our last chances. This is our current task as we move toward a bold, action-oriented plan next year. We have the nation's future to protect.

Justice O'Connor added:

When the Alzheimer's Study Group releases its final report early next year, I ask you to carefully consider our recommendations . . . The stakes are high. Without a doubt, the future health and well-being of these families—indeed, the health and financial well-being of our entire nation—depends on how swiftly and decisively we act to address this terrible disease.

These final remarks were addressed to the members of the Senate Committee Hearing, but the challenge touched everyone in the room and, through C-SPAN, everyone in the nation.

If it is all about reordering priorities and breaking down institutional barriers to get out of the way of science, it was somewhat ironic that the testimony of Dr. Rudi Tanzi, one of the first investigators to discover a gene that modifies the functioning of the amyloid precursor protein, was the last to be heard in a second tier of witnesses.

By then, only three Senators (Kohl, Smith, and Wyden) politely remained to hear from Dr. Tanzi that there is much cause for hope from new gene discoveries, as he echoed Speaker Gingrich's plea for more basic science funding: "Without it, our drug pipelines will dry up."

Groups like the ASG and efforts like the Annual Leon Thal Symposium (Las Vegas, Nevada, December 7–9, 2008) will focus in tandem and together on translating recommendations into specific public policy and new legislative initiatives, with "stereo instructions" to the next administration on how to implement change.

In this highly charged political year, and out of respect for the future well-being of this nation, our country deserves as thoughtful a debate between our Presidential candidates on the Alzheimer's crisis as the dialogue that occurred in the Senate hearing room. Remember these voices, and vote your mind.

## Appendix 1

### *Leon Thal Symposium Participants*

Zaven S. Khachaturian, Sid Gilman, Ronald C. Petersen, Lon S. Schneider, Peter J. Snyder, Paul S. Aisen, Marilyn Albert, John C.S. Breitner, Neil Buckholtz, Jodey P. Corey-Bloom, Jeffrey L. Cummings, Rachelle Doody, Bill Evans, Steven Ferris, Howard Fillit, Norman Foster, Richard A. Frank, Doug Galasko, Serge Gauthier, Barry Greenberg, Michael Grundman, Bradley Hyman, Claudia Kawas, Jef-

frey Kaye, Ara S. Khachaturian, Edward Koo, Lew Kuller, Richard Mohs, Marcelle Morrison-Bogorad, Tony Phelps, Judes Poirier, Barry Reisberg, Marwan Sabbagh, David P. Salmon, Mary Sano, Dale Schenk, James Simpkins, Stephen Snyder, Ronald G. Thomas, Jacques Touchon, Mark H. Tuszynski, Bruno Vellas, Michael W. Weiner, and Richard J. Wurtman.

#### *Alzheimer's Study Group Panel*

Christine K. Cassel, MD, President of the American Board of Internal Medicine; Meryl Comer, President, Geoffrey Beene Foundation Alzheimer's Initiative; Newt Gingrich, Former Speaker of the House; Steven E. Hyman, MD, Provost and Professor of Neurobiology at Harvard Medical School; Former Senator John Kerrey, New School, NY; Henry F. McCance, Chairman of the Board of Greylock Management Corp.; Sandra Day O'Connor, retired

Supreme Court Justice; James A. Runde, Special Advisor and former Vice-Chairman of Morgan Stanley; David Satcher, MD, Centers for Disease Control; Mark McClellan, MD, PhD, Food and Drug Administration and Centers for Medicare and Medicaid Services; and Harold Varmus, MD, former director of the National Institutes of Health.

Alzheimer's Study Group website: [www.asg.org](http://www.asg.org)

Meryl Comer is the President of the Geoffrey Beene Foundation Alzheimer's Initiative and a member of the Alzheimer's Study Group.

#### **Reference**

- [1] Damjanovic AK, Yang Y, Glaser R, Kiecolt-Glaser JK, Nguyen H, Laskowski B, et al. Accelerated telomere erosion is associated with declining immune function in caregivers of Alzheimer's disease patients. *J Immunol* 2007;179:4249–424.