

U.S. Senate Special Committee on Aging
"Until There's A Cure: How to Help Alzheimer's Patients and Families NOW"

Testimony of Robert Egge, Vice President of Public Policy
Alzheimer's Association

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Good afternoon Chairman Kohl, Senator Corker and members of the Senate Special Committee on Aging.

I am Robert Egge, Vice President of Public Policy at the Alzheimer's Association. Thank you for the opportunity to share our current efforts, with particular reference to quality care for those suffering from Alzheimer's disease and other forms of dementia.

It is a privilege to participate in this Forum hosted by a Committee that has distinguished itself through its focus on the scale of and solutions to the Alzheimer's crisis. Both in 2008 and in 2009, the United States Senate Special Committee on Aging hosted important hearings featuring the findings of the Alzheimer's Study Group, an independent, bipartisan taskforce convened to assess the crisis and propose recommendations. I served as Executive Director of that effort, joining the Alzheimer's Association in my current role upon the completion of the Study Group's work.

About Alzheimer's Disease

Since its inception in 1980, the Alzheimer's Association has led the Alzheimer movement: promoting and funding innovative research; speaking out for greater public awareness and the need for increased research, prevention, and care; and actively engaging with the national and local communities to support and expand outreach that ensures greater knowledge, safety, and resources for Alzheimer's patients and their families.

The urgency of the Alzheimer's Association's work is driven by the millions now affected by Alzheimer's. Today, an estimated 5.3 million people suffer from Alzheimer's in the United States¹ and approximately 36 million are affected worldwide.² By 2050, there will be nearly 16 million Americans suffering from Alzheimer's, with a projected global total of more than 115 million.

Furthermore, today nearly 11 million Americans serve as unpaid caregivers for individuals suffering from this disease. According to Alzheimer's Association Facts and Figures, these Alzheimer and dementia caregivers dedicate as many as 12.5 billion hours of care valued at \$144 billion for care for their loved ones. Alzheimer's is a disease that lasts, on average, four to eight years from the time of diagnosis. Because there is no means to stop the progression of the disease, those with Alzheimer's who do not die first of other causes eventually lose the ability to converse with others and respond to their environment, requiring caretakers to provide constant supervision and attentive care.

¹ Alzheimer's Association, *2010 Alzheimer's Disease Facts and Figures*.

² Alzheimer's Disease International, *World Alzheimer Report 2010*

A combination of early detection and preventive or disease modifying medications will likely be needed to overcome this disease. In the meantime, however, much can be done to improve the care and support delivered to those with Alzheimer's and their caregivers.

The Alzheimer's Crisis Today, and How We Should Respond

In March 2009, the Alzheimer's Study Group's report, *A National Alzheimer's Strategic Plan*, was released in the hearing before this Committee. In their testimony co-chairs Speaker Newt Gingrich and Senator Bob Kerrey, ASG member Justice Sandra Day O'Connor, and California First Lady Maria Shriver focused on four elements:

- the scale of the Alzheimer's crisis,
- the need for a comprehensive federal strategy to address the crisis,
- the importance of increasing Alzheimer's research investment, and
- the improvements immediately possible in Alzheimer's care and support.

In my comments below, I would like to briefly revisit these four areas, emphasizing their relevance to today's important discussion.

The Scale of the Crisis

Today, the Alzheimer's Study Group concluded, Alzheimer's is already a grave national crisis. Tomorrow, because of America's rapidly aging population and the fact that age is the greatest risk factor for the disease, the Alzheimer's crisis will rapidly worsen. In fact, given current trends there is good reason to believe it may prove to be the leading U.S. public health crisis of the 21st Century. By 2050 as many as 16 million Americans will have the disease. The corresponding demands on caregivers will grow apace.

The numbers alone do not make Alzheimer's a crisis. What makes this a crisis are these numbers combined with the nature of the disease itself. Alzheimer's is a progressive, degenerative and ultimately fatal disease. It is cruel, and it is a killer. It kills by insidiously clogging and destroying the most vital of organs – the brain. In fact, it is one of the surest killers we know of. If you develop Alzheimer's we can say with absolute certainty that you will either die with it or from it.

Alzheimer's is already the sixth leading cause of death in this country. According to the Centers for Disease Control and Prevention, in 2007 – the most recent year for which data are available – Alzheimer's killed more Americans than diabetes, and more than breast cancer and prostate cancer combined. Further, of the top ten causes of death in America today, Alzheimer's is the only one among them without an identified means prevent, cure or even slow the disease.

The economic factors of Alzheimer's rival the human devastation of the disease. According to the Alzheimer's Association's report, *Changing the Trajectory of Alzheimer's Disease: A National Imperative*, we are spending \$172 billion annually on Alzheimer's and other dementia care in America. \$88 billion of that is for Medicare alone, which is 17 percent of the total Medicare budget. Medicare beneficiaries with Alzheimer's or another dementia cost the system three times more than someone else 65 or older in

Medicare who does not have a dementia.³ For Medicaid, the cost multiplier for someone with dementia is nine times more than a comparable individual.⁴

Alzheimer's also serves as a cost multiplier for other conditions. 95% of Americans with Alzheimer's or other dementia have one or more other serious medical conditions as well. Largely because Alzheimer's strips away an individual's ability to manage these other conditions, such as diabetes or cardiovascular disease successfully, the costs of care for people with these other conditions are far higher when they also have dementia. For instance, average per person Medicare payments for a person with diabetes are \$12,979, but for a person with both diabetes and Alzheimer's or another dementia average annual costs are \$20,655. The same is true for heart disease – those with only heart disease have average Medicare claims of \$14,640, while those that also have Alzheimer's or another dementia have annual costs of \$20,780.

Just as the numbers of those with Alzheimer's will grow sharply in the coming years, so will the costs. The *Trajectory* report also estimates that during the next 40 years, the cost of Alzheimer's and other dementias will exceed \$20 trillion.

The Imperative to Form a Federal Plan of Action

One of the most striking findings to the Alzheimer's Study Group was the mismatch between the dimensions of the crisis as just described, and the lack of a disciplined, strategy-driven federal plan to address it. And so one of their central, immediate recommendations presented before this committee was to embark on a process by 2010 to create a cross-governmental Alzheimer's plan characterized by clearly articulated objectives, accountabilities, and timelines. Updates and progress against this plan were to be reported annually to Congress and to the American people.

Fortunately, thanks to the leadership of members of this committee as well as other members in the Senate and the House, we are close to a major advance on this recommendation. The *National Alzheimer's Project Act* (NAPA), based directly on the Alzheimer's Study Group recommendations and drafted in close consultation with the Alzheimer's Association, is poised for passage into law this year.

This is highly important given the topic under discussion today in this Forum, for this strategic planning effort is not just to be focused on one agency or on one topic, such as biomedical research. Instead, this effort is intended to address all dimensions of the current crisis, and all opportunities to address them. For instance, many Alzheimer's experts make a compelling case that one of the most immediately promising and underfunded areas of Alzheimer's research is in the area of psychosocial interventions. The systematic planning process that will be set in motion by NAPA is designed to expose exactly such shortcomings and to ensure that they are adequately addressed.

Alzheimer's Research and its Critical Relationship to Care and Support

³ Alzheimer's Association, *Changing the Trajectory of Alzheimer's Disease: A National Imperative*; CBO's August 2010 Baseline: Medicare.

⁴ Alzheimer's Association, *2010 Alzheimer's Disease Facts and Figures*.

Alzheimer's impact is so immense in part because there are no treatments that delay onset or slow, let alone reverse or cure, the progression of the disease. This is not a matter that is independent of care. Too often we speak as if the emphases – cure and care – were completely unrelated.

In fact, it is the absence of good therapeutic interventions that makes the provision of care for those with Alzheimer's and other dementias so worrisome. As has been well documented by this committee and elsewhere, one of the looming constraints in caring for those with Alzheimer's compassionately and effectively is the declining geriatrics workforce, and the growing gap between the size of this workforce and the growing demands placed upon it as Alzheimer's cases steadily expand.

One way to close this gap is to increase the size of the geriatrics-capable healthcare workforce. There are excellent proposals today to do just that. Another way to address the gap, however, is on the demand side – that is, by reducing the number of Americans in need of Alzheimer's care through more effective therapeutic options.

To examine this, the Alzheimer's Association worked with the Lewin Group to create a dynamic model that examined the current baseline case where future therapeutic options remain much as they are today, and then contrasted this baseline with two scenarios. In the first, a hypothetical therapy was modeled that delayed the onset of Alzheimer's by five years, much like statins for cardiovascular diseases. In the second, a hypothetical therapy was modeled that slowed the progression of the disease, much as current therapies do in the case of HIV/AIDS.

In both cases, perhaps the most obvious impact was the reduction of healthcare and support costs. For instance, the five year delay in onset scenario reduced costs by almost 50%. But just as remarkable from a care and support perspective, in both cases the number of those with the disease in the moderate and severe stages were dramatically reduced. What this suggests is that with such treatment advances far fewer individuals would require full time attention in a long term care facility, hospital or hospice. Better treatments enable better care.

Improvements Underway in Alzheimer's through Dementia Care and Training

Finally, the Alzheimer's Study Group focused on care and support. And as they did so, they looked to the topic of this Forum, dementia care and training, as an essential key to progress.

For more than 28 years, the Alzheimer's Association has been committed to improving care for people with Alzheimer's and related dementias. The Association has consistently championed dementia care that is safe and respectful for each individual as well as to train providers and caregivers to provide the best possible dementia care.

The Alzheimer's Association Dementia Care Practice Recommendations for Assisted Living Residences and Nursing Homes were developed from the latest evidence in dementia care research and the experience of professional direct care experts. The dementia care practice recommendations and our trainings are based on a person-centered approach to dementia care. This means that care builds on a person's abilities and meets the changing needs of each person as the disease progresses.

The Alzheimer's Association understands the significant strain the aging population will pose on the country's long-term care infrastructure and we believe we can play an important role in building the quality workforce necessary to care for this emerging Alzheimer population. Ensuring appropriate training for all long-term care workers is consistent with the Alzheimer's Association's long standing policy that families must have access to quality care across the spectrum of home and community based care options including assisted living facilities, adult family homes, or state-licensed boarding homes. The recommendations and training reflect the importance of care providers having a good relationship with the person with dementia and his/her family as well as knowing the person's history, abilities, and choices about care. Care providers will be most successful if they have good dementia care training.

With more than 50 percent of residents in assisted living and nursing homes having some form of dementia or cognitive impairment and approximately 70 percent of people with dementia or cognitive impairment living at home, the Association launched several programs which explore different care training models and provide evidence based recommendations for both caregivers and health care providers.

In an effort to empower people with dementia, their caregivers and families to make informed decisions, we have developed the Alzheimer's Association CareFinder™. This interactive online guide is educating consumers on how to recognize quality care, choose the best care options, and advocate for quality within a residence.

Also for families, the Association has developed the *Savvy Caregiver*. This is an educational program for families and caregivers of those with memory loss, dementia, and Alzheimer's disease and has been developed and tested in research at the University of Minnesota.

To increase education among health care and direct care providers, the Association created several programs including:

- **The *Foundations of Dementia Care*.** A classroom training program that is offered by Alzheimer's Association chapters nationwide. The *Activity-based Alzheimer Care: Building a Therapeutic Program* helps professionals that implement activity programming.
- **The CARES training program.** An online dementia care training program for Certified Nursing Assistants (CNAs), supervisors, nurses, social workers, administrators, and other direct-care workers. The *Dementia Care Training for Team Leaders* program provides guidance for individuals who supervise others involved in the care of those with dementia.
- **The *Alzheimer's Association Dementia Care Practice Recommendations*.** Recommendations developed for assisted living residences, nursing homes, and in-home care which were based on the latest evidence in dementia care research and the experience of professional direct care experts.

All of these programs, taken together, have yielded a strong foundation for training and support. However, the Association continues to collaborate with experts such as those participants in today's Forum to constantly improve the programs we offer to care professionals as well as to families.

Looking Forward

This committee, through its recent hearings, has clearly documented the dimensions of the Alzheimer's crisis, and what our country can do to rise to this challenge, as we must. This Forum today follows in that same tradition of leadership. The Alzheimer's Association commends the committee for today's Forum and looks forward to continued work together to do all we can to improve the lives of those contending with dementia, as well as for those who care for them.