



January 9, 2008

Ms. Ann Widger
Presidential Transition Team
Washington, DC 20270

RE: Alzheimer's Association Policy Recommendations to the Transition Team

Dear Ms. Widger:

The Alzheimer's Association appreciates the opportunity to offer policy recommendations to the Obama Administration Team to address the Alzheimer crisis in our country. As the leading voluntary health organization in Alzheimer care, support, and research, our mission is to eliminate Alzheimer's disease through the advancement of research; to provide and enhance care and support for all affected, and to reduce the risk of dementia through the promotion of brain health.

Alzheimer's disease has reached epidemic proportions, taking a tremendous emotional, physical and financial toll on millions of individuals and caregivers while consuming an increasing share of family and government resources. There are 5.2 million Americans living with Alzheimer's, the sixth leading cause of death in the United States. In 2010, there will be an estimated half million new cases of Alzheimer's disease *each* year and a million new cases each year by mid century - unless researchers discover better ways to detect, treat and prevent it. With close to 10 million Alzheimer caregivers today, Alzheimer's does not just impact an individual; its ripple effects can be felt throughout entire families. Yet despite the human and financial costs, the federal government has failed to treat Alzheimer's as the crisis it is.

Attached is a two-page summary of our recommendations for federal action, which include:

- **Developing a Comprehensive National Strategy to Address Alzheimer's Disease**
- **Increasing and Accelerating Alzheimer Research**
- **Addressing Flaws in the Current Health Insurance System that Deny Access to Quality Care for People with Alzheimer's Disease**
- **Improving Quality, Coordinated Care for People with Alzheimer's Disease**
- **Improving Access to Long-Term Care**

If you would like to discuss our recommendations further, please contact Brenda Sulick at (202) 638-8672 or Mike Splaine at (202) 638-8663. We look forward to working with you to improve the lives of millions of Alzheimer families and to saving the lives of millions more.

Sincerely,

Harry Johns
President and CEO

the compassion to care, the leadership to conquer



Action on the Alzheimer's Disease Crisis Policy Recommendations for the Obama Administration Summary Document

Submitted by the Alzheimer's Association
January 2009

Alzheimer's disease has reached epidemic proportions, taking a heavy toll on millions of patients and their caregivers and consuming an increasing share of family and government budgets.

Americans are anxious about this debilitating and incurable disease. One-in-five women and one-in-seven men who reach age 55 will eventually develop the disease or another dementia. Today, as many as 5.2 million Americans have Alzheimer's, and another 9.8 million struggle to care for a family member or friend afflicted by the disease. In just over 20 years, the number of senior citizens with Alzheimer's will have increased by 50 percent to as many as 7.7 million.

Alzheimer's is one of the nation's most expensive medical conditions. Medicare, Medicaid, and businesses now spend at least \$148 billion annually on care for people with dementia. Without breakthroughs, annual federal spending for Alzheimer's will reach \$1 trillion by 2050.

Despite the human and financial costs, the federal government has failed to treat Alzheimer's as the crisis it is. Inaction is cruel to Alzheimer's sufferers and counterproductive fiscally. Government investment today can reduce exploding costs tomorrow.

Action must be taken to develop a comprehensive plan and coordinate government efforts, increase research, fill gaps in health care coverage, and ensure that health care providers are trained to care for Alzheimer's patients.

I. Develop a Comprehensive National Strategy to Address Alzheimer's

There are 20 federal agencies with Alzheimer's and dementia-related initiatives and programs, but no responsible party coordinating their efforts. And there is no federal strategic plan for addressing the Alzheimer crisis.

- A new federal coordinating council on Alzheimer's disease should be created
- A federal strategic plan must be developed to address the multiple and complex burdens Alzheimer's inflicts on patients, families, health care providers, and governments

II. Increase and Accelerate Alzheimer Research

Federal spending on Alzheimer research has actually declined in real dollars in the last five years. In Fiscal Year 2008, only \$644 million was appropriated for Alzheimer research. Had funding kept pace with inflation, the research budget would be \$826 million in fiscal year 2009.

Due to inadequate funding, ongoing research projects have slowed or stopped prematurely, some promising trials have been postponed, and fewer new projects are being funded. Prevention research is one of the most promising areas that demands additional resources.

- An additional \$182 million is needed now to restore Alzheimer research to at least keep pace with medical inflation. This will allow researchers to conduct large-scale trials, determine early markers, facilitate early diagnosis and boost basic science research.
- To ensure progress, steady growth that increases Alzheimer research funding to at least 1.3 billion dollars by fiscal year 2013 should be the target appropriated by Congress.
- Funding partnerships with the Veterans Administration and Medicare should be explored and expanded



- Public health strategies should be expanded to promote healthy brain lifestyles. Implementing the CDC *National Public Health Road Map to Maintaining Cognitive Health* would identify public health opportunities and strategies in the areas of prevention research (such as identifying and controlling known risk factors), communication, policy, and surveillance.

III. Address Flaws in the Current Health Insurance System that Deny Access to Quality Care for People with Alzheimer's Disease

Many of the 500,000 people with dementia under the age of 65 lose their jobs and become uninsured and uninsurable. Before they can become eligible for Medicare, SSDI beneficiaries must endure a complex and cumbersome two-year waiting period.

- Private health plans should be prohibited from denying health care coverage to persons with pre-existing health conditions
- Reforms should make coverage for people with serious, chronic conditions affordable
- The Administration should take steps to end the two year wait for Medicare for SSDI beneficiaries under age 65

IV. Improve Quality, Coordinated Care for People with Alzheimer's Disease

Nearly all Alzheimer's sufferers (95 percent) have another chronic medical condition, which is more difficult and costly to manage due to their diminished cognitive abilities. In addition, a health care system that forces patients to make choices and manage their own care is challenging for patients who are confused, have impaired judgment, and have trouble expressing themselves. Few health care providers identify their patients with dementia and provide them with special assistance, nor are they trained to deal with their unique needs.

- Health plans should identify participants who have dementia or cognitive impairment
- Electronic medical records should include information about patients' cognitive status
- Medicare should pay providers to do geriatric assessments and coordinate care services across multiple settings
- Special training should be required for health and long-term care staff working with Alzheimer's patients

V. Improve Access to Long-term Care

Most Alzheimer patients eventually need home care workers or to move into assisted living residences or nursing homes. Paying for these services for very long is unaffordable for most people with dementia, and private long-term care insurance is not a viable option for them.

- Funding for long-term care should rely on a blend of public and private programs
- Medicaid should serve persons with dementia who cannot pay for their own care or qualify for Medicaid
- Long-term care services should be provided by staff trained to care for people with dementia

The Alzheimer's Association is the leading voluntary health organization in Alzheimer care, support and research. Our mission is to eliminate Alzheimer's disease through the advancement of research; to provide and enhance care and support for all affected; and to reduce the risk of dementia through the promotion of brain health. Our vision is a world without Alzheimer's.

For additional information:

General information – www.alz.org

Facts and Figures -- www.alz.org/alzheimers_disease_facts_figures.asp

CDC/Alzheimer's Association Initiative -- www.cdc.gov/Aging/healthybrain/roadmap.htm