

The Alzheimer's Association National Policy Agenda

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The evidence presented in Donald Taylor's Issue Brief is a compelling call for action.¹ The Alzheimer's Association has a plan that includes a major mobilization of people and significant new resources. The Association is prepared to lead the fight, but the nation needs the leadership of the President and the Congress as well. We call upon Congress and the Administration to take action in three key areas:

- (1) Increase funding for Alzheimer's research at the National Institutes of Health (NIH) to \$1 billion annually as quickly as possible;
- (2) Protect Medicaid funding levels and improve quality of long-term care; and,
- (3) Implement the new Medicare Modernization Act in ways that meet the needs of people with Alzheimer's disease and improve the Medicare program so that it better meets the needs of people with dementia and other chronic conditions.

Research Funding

In 1983, when President Ronald Reagan first designated November as National Alzheimer's Disease Month, the extent of the disease was not widely known. At that time, a definitive diagnosis could be confirmed only via an autopsy and there was no infrastructure for Alzheimer's research. Twenty years of investment in research through NIH has resulted in steady scientific progress and advances no one would have imagined in 1983. We are well into an era of discovery that has already brought us tangible benefits.

It is now possible to diagnose Alzheimer's with more than 90% accuracy. Understanding of the fundamental neurobiology of the disease and its impact on the brain is developing rapidly. Identification of

potential points of therapeutic intervention has accelerated the search for new treatments. Several animal models mimicking some aspects of the disease are available to researchers, enabling scientists to narrow the targets for prevention and speed effective drugs to market. Five prescription medicines specifically approved to treat Alzheimer's are available in pharmacies. Three genes that cause rare, early-onset forms of the disease, and one risk gene for the more common, late-onset form, have been identified.

Current research is focused on the importance of identifying and treating Alzheimer's disease at much earlier stages, before the symptoms of the disease emerge. Additional strategies for slowing the progression of the disease process—to postpone onset of and hopefully prevent full-blown Alzheimer's—are under investigation. Advanced technologies, including neuroimaging techniques such as magnetic resonance imaging (MRI), functional MRI, and positron emission tomography (PET) are expanding possibilities for early detection and intervention.

The best treatment, for individuals, for the healthcare system and for the public health system, is prevention. If science could delay the onset of Alzheimer's by even five years, the number of individuals with the disease could be reduced by as much as 50% over time. The key to realizing a future without Alzheimer's disease is finding a way to prevent the disease. Scientists are closing in on this goal because of the past investment in research by the federal government, private funders like the Alzheimer's Association, and the pharmaceutical industry.

To ensure that rapid progress continues, additional resources are needed in all sectors, but especially at the NIH. If current federal funding for Alzheimer's research were increased to \$1 billion annually, substantial progress could be made on the most promising leads in basic science, risk factors, early markers, and clinical trials to develop new treatments and prevention.

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The National Institute on Aging (NIA) has undertaken two promising efforts, among many others, on genetics and imaging. While we maintain hope about our ability to slow the progression of and one day prevent Alzheimer's disease, we must also invest in research that will speed the discovery of risk-factor genes for late-onset Alzheimer's, the most common form of the disease. Discovery of risk-factor genes will help illuminate the underlying processes of Alzheimer's disease, open up novel areas of research, and identify new targets for drug therapy. NIA and the Alzheimer's Association are in the process of recruiting at least 1,000 families over the next three years to create the nation's largest repository of genetic material from families affected by late-onset Alzheimer's disease.

NIA, in partnership with the pharmaceutical industry, the Alzheimer's Association and the Food and Drug Administration (FDA), is also engaged in a new initiative using imaging technologies to monitor changes in the brain that indicate progression of Alzheimer's disease and to provide accurate, early diagnosis. We are hopeful that this initiative will lead to better diagnostic techniques. More importantly, the imaging initiative may help speed up the process of discovering new, more effective treatments and preventive agents for Alzheimer's disease by allowing scientists to detect the effects of interventions on brain function much more quickly than traditional clinical trials without the use of imaging.

A significant, immediate investment in Alzheimer's research could save lives and money. Increasing funding for Alzheimer's research will increase the pace of discoveries that can delay the onset of the disease and slow its progression. If annual research funding of \$1 billion for the next five years resulted in modest delays in onset and slowing of progression of AD by 2010, the return on investment in 2015 could be as high as \$13 for each federal dollar spent on research. By 2025 the return could be as high as \$28 to \$1 and by 2050 it could be \$100 to \$1. Under this scenario, annual Medicare savings could reach \$51 billion and saving in Medicaid spending on nursing home care could be \$10 billion by 2015.²

Only Congress and the President, through a significant addition of new funding, can assure that we realize the opportunities in Alzheimer's research. Minimal increases in funding for the NIH are not enough to support additional clinical trials and maintain the momentum of basic scientific discovery. Inadequate funding increases mean that less money will be available to support new research grants and clinical trials, delaying scientific discoveries, and resulting in lost opportunities.

Medicare

Because of their impaired memory, judgment, and reasoning ability, Medicare beneficiaries with advanced Alzheimer's disease or other dementias cannot completely manage or direct their own care. As Alzheimer's progresses, individuals with the disease cannot follow the medication instructions or nutritional regimes prescribed by their doctors, nor can they recognize symptoms that their condition may be getting out of control. Individuals with dementia need ongoing care management to monitor their health status and prevent the acute care crises that are driving up Medicare costs today.

Alzheimer's disease is a major contributor to rising Medicare costs. Ninety-five percent of all beneficiaries with dementia have at least one other chronic health condition common in the elderly—30% have coronary heart disease, 28% have congestive heart failure, and 21% have diabetes. Medicare costs for beneficiaries

with dementia and other chronic conditions such as coronary heart disease, congestive heart failure, or diabetes are twice as high as costs for beneficiaries with chronic conditions who do not have dementia.

One of the most effective ways to restructure Medicare in the short term is to establish a care coordination benefit targeted to individuals with complex chronic conditions, including Alzheimer's or other dementia. A Medicare chronic care benefit should include: payments to the beneficiary's primary health-

care provider for an initial assessment of health status; development of a coordinated care plan; and care management activities including coordination of clinical care across providers, medication management, multidisciplinary care conferences, and ongoing consultation with the beneficiary and his/her caregivers.

Care coordination is very different from disease management programs that focus on managing only one aspect of an individual's overall health status at a time. Care coordination focuses on managing an individual's care needs across various healthcare settings and among different providers to avoid adverse medical events exacerbated by the presence of multiple chronic conditions.

Passage of the *Medicare Prescription Drug & Modernization Act* will, for the first time, provide Medicare beneficiaries with Alzheimer's disease critically needed coverage for prescription drugs. This is an historic accomplishment that provides both up-front and catastrophic coverage of prescription drugs and offers subsidies to help protect low-income Medicare beneficiaries. The Alzheimer's Association believes that the addition of

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the prescription drug benefit moves the Medicare program in the right direction. The Alzheimer's Association, however, will be vigilant in overseeing the implementation of this new benefit in an effort to make sure this benefit meets the needs of people with Alzheimer's disease.

Medicaid

Medicaid is the single largest public payer for long-term care services in the United States and a last resort for persons with Alzheimer's who have no other way to pay for the help they need. Half of all Medicare beneficiaries with Alzheimer's also received Medicaid to help pay for long-term care, prescription drugs and other medical care because they have exhausted their own resources and qualify for assistance. In 2000, Medicaid spent an estimated \$19 billion on nursing home care for people with Alzheimer's. Medicaid nursing home expenditures for persons with Alzheimer's are projected to rise to \$118 billion by 2050—a more than six-fold increase over current spending.²

In the absence of a better national long-term care program, Congress and the President must preserve the long-term care safety net that Medicaid provides. This includes maintaining or improving the federal entitlement to benefits, and preserving existing nursing home quality standards as well as protections

against spousal impoverishment. Reform proposals that cap Medicaid funding as a method of giving states more flexibility regarding benefits and services will leave many of society's most vulnerable citizens in jeopardy.

Conclusion

Without a cure, the number of Americans with Alzheimer's—4.5 million today—will increase to between 11.2 million and 16 million by 2050. Without a cure, the incalculable human costs will continue to rise—the pain of seeing loved ones suffer and the lost contributions of millions of older Americans who would otherwise enrich us as a people. The time to act is now.

There is real hope for a future without Alzheimer's disease. Greater understanding of the disease, improved care and treatment, and unprecedented scientific opportunities for delaying onset and preventing the disease can all lead to a future where Alzheimer's is just a memory. By investing in Alzheimer's research, President Bush and Congress can ensure that the scientific opportunities that lie before us are realized. And by improving the Medicare and Medicaid programs, Congress will help the 4.5 million people living with Alzheimer's get the care they need. **NCMJ**

REFERENCES

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- 2 Saving Lives, Saving Money: A Report of the Lewin Group to the Alzheimer's Association. June 23, 2004.