

# NO TIME TO WASTE

Recommendations for an Integrated National Plan  
to Overcome Alzheimer's Disease



Alzheimer's Foundation of America  
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**The Alzheimer’s Foundation of America (AFA)**, based in New York, is a national nonprofit organization that unites more than 1,600 member organizations nationwide with the goal of providing optimal care and services to individuals confronting dementia, and to their caregivers and families. Its services include counseling and referrals by licensed social workers via a toll-free hot line, e-mail, Skype, and live chat; educational materials; a free quarterly magazine for caregivers; respite care grants; and professional training.

Advocating for meaningful public policy on behalf of individuals with Alzheimer’s disease and related illnesses and their family caregivers is an important part of AFA’s mission. AFA has been active in efforts such as advising on the “Caregiver Initiative” included in the February 2010 annual report for the Middle Class Task Force, chaired by Vice President Joe Biden; successfully advocating for a doubling in federal appropriations for the Missing Alzheimer’s Disease Patient Alert Program; organizing more than 100 national and local organizations in support of the National Alzheimer’s Project Act (NAPA); and co-facilitating public policy activities for Leaders Engaged in Alzheimer’s Disease (LEAD), a network of more than 40 members and organizations dedicated to increasing awareness of Alzheimer’s disease and accelerating solutions to the Alzheimer’s disease crisis.

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## Introduction: Voices From Around the Country

The Alzheimer's Foundation of America (AFA), our 1,600+ member organizations and the millions of families they serve, as well as AFA's national partners were honored to play a significant role in the passage—and now implementation—of the National Alzheimer's Project Act (NAPA). AFA organized 14 national organizations and more than 90 state and local organizations in nearly 30 states to actively support NAPA. In addition, AFA worked with legislators to ensure that a national voice representing various local organizations would have a place at the table on the Advisory Council on Alzheimer's Research, Care and Services (Advisory Council).

Millions of Americans who have been touched by Alzheimer's disease and related dementias view NAPA as a once-in-a-lifetime opportunity to change the conversation about a mentally, physically, emotionally and financially devastating illness to one about comprehensive support services, quality care, cost effectiveness, a robust research environment and an eventual cure. As a nation, we must do better, and NAPA is the vehicle to meaningful transformation—but only if we do it right.

In the nearly nine months since NAPA was signed by President Obama, AFA has consistently heard from family caregivers, clinicians, researchers, long-term care professionals, direct care professionals, law enforcement officers, policymakers and the general public about their personal and professional experiences with Alzheimer's disease, their recommendations for change, and their hopes that this process goes beyond a “check the box” exercise. We have heard from them in the field, by organized conference calls, and through their many e-mails, letters and calls to our office.

This report is a compilation of their voices shared with AFA and our own beliefs regarding the necessary components of what the NAPA statute defines as “an integrated national plan to overcome Alzheimer's.” Many of these recommendations will take time to develop and implement, but some can be started today.

The one idea that we can all agree on is that there is no time to waste.

## Be Bold and Be Practical

One of the themes that emerged from the first meeting of the Advisory Council on September 27 is that we must stop the current incremental approach to solving the Alzheimer's disease crisis and instead advance a bold and transformative strategy. To be clear, AFA is very supportive of setting ambitious, benchmark-specific goals and formulating solutions within—as well as outside of—current government programs to ultimately “defeat” Alzheimer's disease.

However, AFA also believes that defeating Alzheimer's disease cannot be done in one fell swoop. It will likely happen in a series of small victories. We had a victory when NAPA passed. We earlier had a victory in getting the “detection of any cognitive impairment” included in the new Medicare Annual Wellness Exam—and hopefully we will be victorious in the future in requiring the use of a cognitive screening tool as part of the exam. **We are also engaged in other pressing issues right now that we must make a concerted effort to address. They include: FY 2013 budget planning that will impact dollars for Alzheimer's disease research and programs; and deliberations by the Joint Select Committee on Deficit Reduction to potentially overhaul future Medicare and Medicaid benefits that would financially squeeze our population even further.** We must engage in these issues together—and press the White House for accountability on them—as we seek a bold solution to Alzheimer's disease.

## Change Starts with Public Awareness

Public awareness of Alzheimer's disease is unfortunately similar to where cancer and heart disease were decades ago. **An integrated national plan to overcome Alzheimer's disease must include public awareness campaigns to educate the public, press and policymakers about the true prevalence of this disease; its social and economic impact on families, government and society; signs and symptoms of cognitive problems in general, and Alzheimer's disease and related dementias specifically; how healthcare professionals should screen, diagnose and treat cognitive problems; services and supports available for individuals with Alzheimer's disease and all members of their families, including children and young adults; and the dire need for more private and public funding for both research and care-related services.**

As with breast cancer, HIV/AIDS and other diseases, Alzheimer's disease and related dementias carry a tremendous stigma. Most people are not inclined to discuss memory concerns with their healthcare providers, often because of fear or shame. A survey conducted during AFA's annual National Memory Screening Day in 2007 found that 68 percent of respondents had concerns about their memory. However, while more than 44 percent had visited their primary care physician within the last six months, fewer than one in four of those with self-identified memory problems had discussed the issue with their physician.<sup>1</sup> Similar results among family members were found in a survey conducted on behalf of the Alzheimer's Disease Screening Discussion Group.<sup>2</sup>

There are additional barriers<sup>3</sup> to early detection<sup>4</sup> of dementia:

- Individuals are often unaware, deny or minimize the severity of symptoms.
- Access to quality care is a key issue for all individuals with dementia and for those of minority racial and ethnic backgrounds in particular.
- Clinician evaluation may be time-consuming and not well reimbursed.
- Many, especially minority populations, believe that memory loss and cognitive decline are a normal part of aging.

For racial and ethnic minorities, the barriers to early detection are often magnified. One survey found that African-American and Hispanic caregivers were significantly more likely (37 percent versus 33 percent) than caregivers of other races (23 percent) to believe that Alzheimer's disease is a normal part of the aging process. About one-third (33 percent) of overall respondent caregivers reported that their loved one's concern about stigma delayed diagnosis, while about a quarter (26 percent) indicated that their own concern about stigma was a reason for the delay. African-American caregivers were significantly more concerned about stigma (36 percent) than Hispanic (22 percent) and other race

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<sup>1</sup> Powers RE, Hall E, Ashford JW, Howard G. Self reported features of 2178 respondents undergoing memory screening during National Memory Screening Day in 2007 as sponsored by the Alzheimer's Foundation of America. 2008 ICAD Poster Session. June 30, 2008.

<sup>2</sup> Alzheimer's Disease 2008: Current Attitudes and Perceptions Survey, Harris Interactive Survey on behalf of the Alzheimer's Disease Screening Discussion Group, released September 24, 2008.

<sup>3</sup> Solomon PR, Murphy CA. Should we screen for Alzheimer's disease? A review of the evidence for and against screening for Alzheimer's disease in primary care practice. *Geriatrics*. 2005, 60(Nov): 26-31.

<sup>4</sup> Knopman D, Donohue JA, Guterman EM. Patterns of care in the early stages of Alzheimer's disease: impediments to timely diagnosis. *J Am Geriatr Soc*. 2000 Mar;48(3):300-4.



(18 percent) caregivers. Other reasons for the delay in diagnosis included not wanting to face the possibility of something being wrong, fear of the responsibility of caregiving, not being offered a memory screening and resistance to visiting a doctor.<sup>5</sup>

Much of the public fear of Alzheimer's disease is based on observed behaviors exhibited on the part of the individuals with the disease, coupled with the helplessness that people feel to effect change. It will be necessary to humanize these behaviors and shift the focus from fear to acceptance of the disease. Lessening the social chasm between "us and them" will be a huge step toward ameliorating the stigma.

**Public awareness campaigns are essential to spark an impactful and long-lasting national dialogue about Alzheimer's disease and to effect change. First, all levels of government, which includes federal agencies as well as the White House, must develop and roll out wide-scale public awareness campaigns.** The White House has waged campaigns against many diseases and chronic conditions, from breast cancer and HIV/AIDS to autism and obesity. Such campaigns not only educate, they generate additional interest from the public and private sectors to invest resources and time. In addition, public-private partnerships with national and local Alzheimer's disease organizations, industry, and corporate interests will be the key to successful public awareness.

AFA supports the perspective that there is value in knowing whether someone's cognitive impairment is different from normal aging, and that individuals have the right to information to help them make educated choices.

No one entity "owns" the Alzheimer's disease issue or has the answers to address every need. AFA has been, and always will be, about working with as many constituencies as possible to influence meaningful change. AFA looks forward to working further with government, non-profit and corporate partners and others in the months and years ahead on public awareness campaigns that change the conversation about Alzheimer's disease in the United States.

## Don't Reinvent the Wheel

It is no secret that the United States is nationally behind the curve of seven countries<sup>6</sup> and more than 25 states in our nation that already have Alzheimer's disease plans in place. We have much work ahead of us, but we can learn from what has already been done overseas and in our own country at the state level—both in planning and in political commitment.

The federal government should review existing state plans to learn more about needs as well as innovation at the local level that may be replicated nationally. In states where funding for local implementation has been an issue, the federal government should consider appropriating support.

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<sup>5</sup> ICAN2: Investigating Caregivers' Attitudes and Needs. Harris Interactive for the Alzheimer's Foundation of America. February 9, 2007, [www.alzfdn.org](http://www.alzfdn.org).

<sup>6</sup> <http://www.alz.co.uk/alzheimer-plans>

In addition to a comprehensive review of existing state plans, the next crucial step is to convene an international meeting by the second quarter of 2012. AFA would be honored to serve as an NGO supporting partner in such an effort and would be glad to work with Alzheimer's Disease International (ADI) and others. In AFA's view, the international meeting would ideally consolidate how other countries have approached their plans and would produce a compendium with common threads. Such a meeting would help us craft our national strategy and help us begin to flesh out a global approach to this pandemic.

The meeting would also include a day or more of panel discussions on established policies and innovative care programs abroad as well as insight into the many effective programs in the United States. There is little doubt we can get there faster by reviewing what has already been done, what has been successful, and what to avoid.

Representative Chris Smith (R-NJ), a co-chair of the bipartisan Congressional Task Force on Alzheimer's Disease, has led the charge in Congress on this idea. In June of this year, Chairman Smith convened an historic hearing on "Global Strategies to Combat the Devastating Health and Economic Impacts of Alzheimer's Disease" before the United States House of Representatives Committee on Foreign Affairs Subcommittee on Africa Global Health, and Human Rights.<sup>7</sup> Representative Smith and Representative Ed Markey (D-MA), the co-chair of the Task Force, as well as AFA, called for an international meeting between the United States and countries with existing Alzheimer's disease plans. **AFA supports Representative Smith's effort to include \$750,000 in the State, Foreign Operations, and Related Programs in FY 2012 Appropriations for the United States to organize and host a high-level meeting of leaders from nations with existing Alzheimer's disease plans by June 30, 2012.**

Representatives Smith and Markey, as well as 28 other Task Force members, also called on the United Nations General Assembly to include Alzheimer's disease in its September 2011 high-level summit on the prevention and control of non-communicable diseases.<sup>8</sup> Due to these efforts, the United Nations specifically identified Alzheimer's disease as an important cause of death and contributor to the global non-communicable disease (NCD) burden. The United Nations declaration states, in part, that General Assembly members "recognize that mental and neurological disorders, including Alzheimer's disease, are an important cause of morbidity and contribute to the global NCD burden for which there is a need to provide equitable access to effective programmes and health care interventions."<sup>9</sup>

## Framing and Categories

There was discussion at the first meeting of the Advisory Council on September 27 about how to frame a national plan and what categories or "buckets" to use when making recommendations. AFA believes that the framework should include a timeline, with short-term (i.e., within a year of release of the final plan) and long-term (i.e., longer than one year) goals.

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<sup>7</sup> [http://foreignaffairs.house.gov/press\\_display.asp?id=1879](http://foreignaffairs.house.gov/press_display.asp?id=1879)

<sup>8</sup> [http://chrissmith.house.gov/UploadedFiles/6\\_15\\_11\\_Final\\_letter\\_to\\_UN\\_Pres\\_Deiss\\_re\\_Alzheimers\\_w\\_signatures.pdf](http://chrissmith.house.gov/UploadedFiles/6_15_11_Final_letter_to_UN_Pres_Deiss_re_Alzheimers_w_signatures.pdf)

<sup>9</sup> [http://www.un.org/ga/search/view\\_doc.asp?symbol=A%2F66%2FL.1&Lang=E](http://www.un.org/ga/search/view_doc.asp?symbol=A%2F66%2FL.1&Lang=E)

The existing categories for recommendations in research, clinical care and long-term care are a solid framework. However, AFA recommends that each category should include:

- a public awareness strategy as described above (e.g., a campaign on clinical trial recruitment for research, including strategies to increase ethnic minority recruitment; a national conversation on exactly what Alzheimer’s disease is and what to expect with a diagnosis; and programs and resources available for family caregivers of all demographics);
- a funding strategy, including promotion of public-private partnerships;
- a public safety and legal system strategy that addresses issues such as falls; medication adherence; driving; becoming lost; neglect, abuse and exploitation; and competency for medical and legal decision-making;
- an early-onset strategy that addresses the needs of younger individuals with Alzheimer’s disease;
- a “co-morbid and related dementias” strategy that targets vascular dementia, caused by stroke or blockage of blood supply; alcoholic dementia, caused by sustained use of alcohol; post concussive dementia, caused by head injury; frontotemporal dementia; Lewy body dementia; and other uncommon diseases;
- an education and workforce strategy (e.g., mandatory dementia care training for all healthcare and long-term care professionals who have direct access to persons with dementia); and
- a data collection strategy to better inform policy (e.g., number of families served by existing Administration on Aging programs).

## Research

### *Recommendation One: Raise the Budgets of the National Institute on Aging and the National Institutes of Health in FY 2013*

We cannot create a comprehensive national plan to defeat Alzheimer’s disease without addressing public funding, particularly in a challenging economic environment where private sector resources are also limited. AFA has heard President Obama’s call for continued strategic investments into basic medical research, and we echo that appeal.

The National Institute on Aging (NIA) is the primary agency at the National Institutes of Health (NIH) responsible for Alzheimer’s disease research and receives nearly 70 percent of the NIH Alzheimer’s disease research funding. As the lead NIH institute on related genetic, biological, clinical, behavioral, social and economic studies, the NIA will not be able to move toward a breakthrough toward the prevention, treatment, cure and care of Alzheimer’s disease without a substantial investment in Alzheimer’s disease research.

In 2010, total Alzheimer’s disease care costs to all payers in the United States were estimated at \$172 **billion**, but the institute-wide federal investment at NIH in Alzheimer’s disease research is estimated to be only \$469 **million**.<sup>10</sup> The anticipated growth in the affected population over

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<sup>10</sup> Lewin Group for the Alzheimer’s Association, Changing the Trajectory of Alzheimer’s Disease: A National Imperative, May 2010; National Institutes of Health Office of the Budget <http://report.nih.gov/rcdc/categories/>.

the next 10 years will widen the cost to research investment discrepancy. While the current dollars appropriated to NIA seem to have risen significantly since FY 2003, when adjusted for inflation, they have gone down almost 18 percent in the last nine years. According to the NIH Almanac, out of each dollar appropriated to NIH, only 3.6 cents goes toward supporting the work of the NIA—compared to 16.5 cents to the National Cancer Institute, 14.6 cents to the National Institute of Allergy and Infectious Diseases, 10 cents to the National Heart, Lung and Blood Institute, and 6.3 cents to the National Institute of Diabetes and Digestive and Kidney Diseases.<sup>11</sup>

**AFA urges the President to work with Congress to raise NIH and NIA funding based on the Biomedical Research and Development Price Index (BRDPI, also known as “birdpie”) as opposed to gross domestic product (GDP).** The annual change in the BRDPI indicates how much the NIH budget must change to maintain purchasing power. The BRDPI was developed and is updated annually by the Bureau of Economic Analysis at the Department of Commerce under an interagency agreement with the NIH. The projections for future year values are prepared in the Office of Science Policy at NIH.<sup>12</sup>

**AFA urges the Administration to include \$1.4 billion at a minimum—an increase of at least \$300 million from FY 2011—for NIA in the President’s proposed FY 2013 budget.** This funding is essential to increase the NIA’s baseline to a level consistent with comparable research initiatives conducted under the auspices of the NIH and to support additional research into Alzheimer’s disease and related dementias.

#### *Recommendation Two: Fund the Cures Acceleration Network*

The health reform law established the Cures Acceleration Network (CAN) within the Office of the Director of the NIH. CAN seeks to cut the time between discovery and development of drugs and therapies through new grant-making mechanisms at NIH. A board of 24 diverse members from several fields, including research, FDA, venture capital and patient advocacy, will oversee CAN. In addition, CAN will work with the FDA to coordinate approval requirements with the goal of expediting the development and approval of safe and viable new products. The Senate Appropriations Committee included \$20 million to initiate CAN in FY 2012, and its report stated, “The average length of time from target discovery to FDA approval of a new drug is 14 years, a delay that is costing lives and prolonging human suffering.”<sup>13</sup> Funding for this initiative is critical to appropriately engage the private sector and aid in speeding the translation of basic scientific discoveries into treatments for diseases such as Alzheimer’s.

#### *Recommendation Three: Increase Resources for the Food and Drug Administration*

Drug development is a crucial component of research. In order to maintain robust investment in Alzheimer’s disease from the private sector, new approaches are needed to accelerate therapeutic development and create corresponding incentives for innovation to produce better treatments that will prevent and cure this disease. It will be critically important that the FDA has sufficient funding to carry out these approaches.

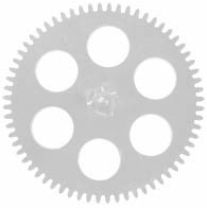
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<sup>11</sup> <http://www.nih.gov/about/almanac/appropriations/index.htm>

<sup>12</sup> <http://officeofbudget.od.nih.gov/gbiPriceIndexes.html>

<sup>13</sup> <http://www.gpo.gov/fdsys/pkg/CRPT-112srpt84/pdf/CRPT-112srpt84.pdf>





Recent annual increases in the FDA's budget have been essential in strengthening the agency. Nonetheless, there remains an extraordinarily large gap between the FDA's responsibilities and its resources. Every year, the agency's responsibilities become scientifically complex and more difficult to implement. Congress enacts new laws affecting the FDA with some regularity, further straining the FDA's ability to meet the expectations of Congress and the American people.

AFA recommends a \$495 million increase or more for the FDA in the President's proposed FY 2013 budget. This is the amount we believe is needed to make further progress against existing responsibilities. Any new legislation must come with the assurance that there will be larger "budget authority" appropriations to cover the cost of the additional work.

According to the Alliance for a Stronger FDA:

FDA's annual appropriation is quite small, especially when matched against its jurisdiction over one-quarter of consumer spending, 80% of the food supply and all of the drugs, biologics, medical devices, animal drugs, cosmetics and dietary supplements used anywhere in the United States. FDA must also deal with the food and medical products that are sourced from overseas. Despite three years with appropriations above the break-even point, the FDA still gets only \$2 billion per year. There cannot be many agencies in the US government that have such a vast scope of responsibilities and so few dollars to get the job done.<sup>14</sup>

#### *Recommendation Four: Balance Basic Research With Clinical Research*

Consensus feedback to AFA includes a strong call for an increased focus on clinical research. It was striking to hear in NIA Director Dr. Richard Hodes' September 27 overview of federal research funding that only about \$30 million of the \$469 million devoted to Alzheimer's disease research at NIH goes toward clinical research in Alzheimer's disease care, training and support. While we are all hopeful about finding an eventual cure for Alzheimer's disease, we must also keep clinical research needs in mind for people who currently have the disease as well as individuals who will be diagnosed in the years to come. Continued and expanded research is needed in earlier diagnosis and prevention; better treatments; safety issues; non-pharmacological behavioral interventions; end-of-life care; and support and dementia care training for family caregivers of all ages and ethnic backgrounds, clinicians—including primary care physicians, and direct care employees.

## **Clinical Care**

#### *Recommendation One: Promote Earlier Detection Through Cognitive Screening*

Unfortunately, there are serious deficiencies in the healthcare system's ability to recognize dementia. A 2009 article in the American Journal of Geriatric Psychiatry found that general

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<sup>14</sup> "Written Testimony of the Alliance for a Stronger FDA," March 26, 2010, <http://strengthenfda.org/resources/>

practitioners miss about half of all dementia cases.<sup>15</sup> Persons with dementia cannot rely simply on relatives and friends, with whom they may have limited contact, to notice or be educated about memory problems. Physicians must play a greater role in discussing memory problems and in case identification. **In addition, it will be vital to have Administration support for a public awareness campaign to drive earlier detection.**

The NIA recognized in its 2008 report entitled "Alzheimer's Disease: Unraveling the Mystery" that "it is best to find out sooner rather than later," because there are important medical and practical benefits to early detection. As NIA noted: "The drugs now available to treat AD can help some people maintain their mental abilities for months to years;" and "the sooner the person with AD and the family have a firm diagnosis, the more time they have to make future living arrangements, handle financial matters, establish a durable power of attorney and advance directives, deal with other legal issues, create a support network, and even consider joining a clinical trial or other research study."<sup>16</sup> The value of knowing includes supporting the individual's right to information to make the best healthcare and support choices.

The success achieved in including "detection of any cognitive impairment" in the new Medicare Annual Wellness Exam needs to be taken a step further. AFA strongly suggests that the Centers for Medicare and Medicaid Services (CMS) revisit its definition of "detection of any cognitive impairment" in the annual wellness visit. Currently, the definition is based on observation and patient and third party reporting. Unlike heart disease, breast cancer and high blood pressure, there is no screening test for dementia included in the wellness visit. **AFA strongly believes that the Medicare annual wellness visit should include a cognitive screening.**

A cognitive screening is a simple and safe evaluation tool that assesses memory and other intellectual functions and indicates whether additional testing is necessary. It is important to note that screening is neither a diagnostic nor case finding process. Screening tests in general simply help determine whether diagnostic tests should be considered. A "positive" result from a cognitive screening should never be interpreted as a diagnosis of Alzheimer's disease or a related illness or other illnesses—no more than a "positive" mammogram means an individual has breast cancer.

Multiple screening instruments are available to assess individuals for cognitive decline.<sup>17-18</sup> The length of the screening test ranges from less than five minutes for the Brief Alzheimer's Screen (BAS) to approximately 15 minutes for the Mini-Mental Status Examination (MMSE).<sup>19-20</sup> A broad range of instruments, such as the GPCOG, Mini-Cog and MIS, are

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<sup>15</sup> Pentzek M, Wollny A, Wiese B, et al. Apart From Nihilism and Stigma: What Influences General Practitioners' Accuracy in Identifying Incident Dementia? *Am J Geriatr Psychiatry*. 2009 Nov;17(11):965-975.

<sup>16</sup> National Institute on Aging, National Institutes of Health, "Alzheimer's Disease; Unraveling the Mystery," September 2008, 48-49, available at [http://www.nia.nih.gov/NR/rdonlyres/0FA2EE06-0074-4C45-BAA3-34D56170EB8B/0/Unraveling\\_final.pdf](http://www.nia.nih.gov/NR/rdonlyres/0FA2EE06-0074-4C45-BAA3-34D56170EB8B/0/Unraveling_final.pdf).

<sup>17</sup> Burns A, Lawlor B, Craig S. *Assessment scales in old age psychiatry*. London: Martin Dunitz Ltd, 1999.

<sup>18</sup> Ashford JW. Screening for Memory Disorder, Dementia, and Alzheimer's Disease. *Aging Health*. 2008 4(4):399-432.

<sup>19</sup> Mendiondo MS, Ashford JW, Kryscio RJ, Schmitt FA. Designing a Brief Alzheimer Screen (BAS). *J Alzheimers Dis*. 2003 Oct;5(5):391-8.

<sup>20</sup> Folstein MF, Folstein SE, McHugh PR. "Mini-mental state." A practical method for grading the cognitive state of patients for the clinician. *J Psychiatr Res*. 1975 Nov;12(3):189-98.



available with acceptable levels of sensitivity and specificity as well as interrater or rater reliability.<sup>21-22</sup>

Several distinct methodologies include face-to-face screening, telephone-based screening and computer-based screening of at-risk persons. Many dementia screening tests have been developed and studied in numerous populations, using both prospective and retrospective analyses, and have been recommended for consideration.<sup>23-24-25-26-27-28-29</sup>

**It is not necessary for CMS to be prescriptive about the specific instrument, except that the instrument has well-established psychometric properties that would make it suitable for the purposes of the wellness exam.**

Several screens have adequate sensitivity and specificity to serve as routine, cost-worthy evaluations. In fact, cognitive screening instruments demonstrate 80 percent to 90 percent or higher sensitivity and specificity in reviewed studies<sup>30</sup>—similar to other established screening tests such as a mammography<sup>31</sup> and Pap smear.<sup>32</sup>

Screening tests may be short cognitive tools administered to individuals, high-sensitivity questions asked of individuals themselves, questions asked of family members, or some combination of all of these approaches. Several comparative reviews on the application of screening tests for Alzheimer's disease and other dementias are available.<sup>34-35</sup> The qualifications of the healthcare professional depend upon the screening instrument used, but

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<sup>21</sup> Brodaty H, Clarke J, Ganguli M, Grek A, et al. Screening for cognitive impairment in general practice: toward a consensus. *Alzheimer Disease and Associated Disorders* 1998;12(1):1-13.

<sup>22</sup> Burns A, Lawlor B, Craig S. *Assessment scales in old age psychiatry*. London: Martin Dunitz Ltd, 1999.

<sup>23</sup> Borson S, Scanlan JM, Watanabe J, et al. Simplifying detection of cognitive impairment: comparison of the Mini-Cog and Mini-Mental State Examination in a multiethnic sample. *J Am Geriatr Soc*. 2005 May;53(5):871-4.

<sup>24</sup> Brodaty H, Pond D, Kemp NM, Luscombe G, et al. The GPCOG: a new screening test for dementia designed for general practice. *J Am Geriatr Soc*. 2002 Mar;50(3):530-4.

<sup>25</sup> Buschke H, Kuslansky G, Katz M, et al. Screening for dementia with the memory impairment screen. *Neurology*. 1999 Jan 15;52(2):231-8.

<sup>26</sup> Mendiondo MS, Ashford JW, Kryscio RJ, Schmitt FA. Designing a Brief Alzheimer Screen (BAS). *J Alzheimers Dis*. 2003 Oct;5(5):391-8.

<sup>27</sup> Shankle WR, Romney AK, Hara J, et al. Methods to improve the detection of mild cognitive impairment. *Proc Natl Acad Sci U S A*. 2005 Mar 29;102(13):4919-24.

<sup>28</sup> Ashford JW. Screening for Memory Disorder, Dementia, and Alzheimer's Disease. *Aging Health*. 2008 4(4):399-432.

<sup>29</sup> Milne A, Culverwell A, Guss R, et al. Screening for dementia in primary care: a review of the use, efficacy and quality of measures. *Int Psychogeriatr*. 2008 Oct;20(5):911-26.

<sup>30</sup> Solomon PR, Murphy CA. Should we screen for Alzheimer's disease? A review of the evidence for and against screening for Alzheimer's disease in primary care practice. *Geriatrics*. 2005, 60(Nov): 26-31.

<sup>31</sup> National Cancer Institute. Breast Cancer Screening Modalities. <http://www.nci.nih.gov/cancertopics/pdq/screening/breast/HealthProfessional/page5>.

<sup>32</sup> Kulasingam SL, Hughes JP, Kiviat NB, et al. Evaluation of human papillomavirus testing in primary screening for cervical abnormalities: comparison of sensitivity, specificity and frequency of referral. *JAMA*. 2002 Oct 9;288(14):1749-57.

<sup>33</sup> Ashford JW, Borson S, O'Hara R, et al. Should older adults be screened for dementia? *Alzheimer's & Dementia*. 2006;2:76-85.

<sup>34</sup> Shulman KI, Herrmann N, Brodaty H, et al. IPA survey of brief cognitive screening instruments. *Int Psychogeriatr*. 2006 Jun;18(2):281-94.

<sup>35</sup> Lorentz WJ, Scanlan JM, Borson S. Brief screening tests for dementia. *Can J Psychiatry*. 2002 Oct;47(8):723-33.

registered nurses, and sometimes trained office staff, can perform most brief screening tests.<sup>36</sup> After receiving and reviewing the results, primary care providers have the opportunity to discuss the findings with screened individuals during an office visit.

### *Recommendation Two: Require Geriatric Competencies and Dementia Training*

One of the main concerns we hear from our member organizations and from family caregivers is that clinicians do not spend enough time explaining what to expect after a diagnosis of Alzheimer's disease, including care options and issues to consider as the disease progresses. One of the most telling comments came during a national call organized by AFA. "What we are proposing is a culture shift," said a caller from Tyler, TX. "One barrier of reaching professionals is that dementia has been around a long time; therefore, people think they don't need to learn anything new, even though we know so much more about Alzheimer's disease and dementia now."

As the baby boom generation has begun to turn 65 in huge numbers each year and the corresponding numbers of people with Alzheimer's disease increases, dementia training will prove to be more important than ever. It is incorrect to assume expertise in geriatrics or dementia based on a physician's patient load of older people. Many primary care physicians and non-physician providers have little or no exposure to formal instruction in specialty areas such as geriatrics, geriatric psychiatry/psychology or neurology that train in dementia diagnosis and care, and medical students are generally not required to complete rotations in these areas. In addition, incentives must be developed so that those clinicians who obtain training are better reimbursed for the dementia services they provide.

#### **AFA believes that adequate education of and reimbursement for primary care clinicians and staff are essential to improving earlier detection, treatment and care for people with Alzheimer's disease—as well as supporting family caregivers.**

Inadequate primary care training in geriatrics, chronic care management and long-term care leads to misdiagnoses, medication errors, increased institutionalization, poor care coordination and unnecessary stress on family caregivers—resulting in substandard care and higher costs. Training must take into account that people under age 65 can have Alzheimer's disease as well (known as young-onset or early onset). Training must also include a focus on the identification and management of behavioral issues that may accompany dementia. Behavioral issues are a main reason that clinicians prescribe psychoactive medications in long-term care settings, which may result in increased confusion, falls and mortality.

CMS should require all healthcare professionals who treat persons with Alzheimer's disease to have certification and training in geriatrics and/or dementia: Physicians who treat people with Alzheimer's disease and related dementias should be able to demonstrate either Geriatric Board Certification or evidence of adequate continuing medical education (CME) in Geriatric Medicine; nurse practitioners should either have Geriatric Certification or CME in Geriatrics and Dementia Care; physician assistants should have CME in Geriatrics and Dementia Care; social services/case management staff should be required to have Dementia Certification; and nursing staff (RNs and LPNs), medical assistants and utilization review staff should be required to have dementia training.

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<sup>36</sup> Solomon PR, Murphy CA. Should we screen for Alzheimer's disease? A review of the evidence for and against screening for Alzheimer's disease in primary care practice. *Geriatrics*. 2005, 60(Nov): 26-31.

## Long-Term Care

### *Recommendation One: Expand and Promote Family Caregiver Training and Support Across the Continuum of Care*

The Resources for Enhancing Alzheimer’s Caregiver Health (REACH) program includes proven strategies, such as skills training, environmental interventions and behavior management, for helping family caregivers manage the stress and emotional burden of caring for people with dementia. Studies about the program show that it produces a significant improvement in caregivers’ sense of burden, social support, depression and health, as well as in the care recipients’ behavior problems and mood.<sup>37</sup> **REACH is now implemented at all facilities operated by the U.S. Department of Veterans Affairs, and it should also be implemented system-wide for Medicare and Medicaid beneficiaries by CMS through the Center for Medicare and Medicaid Innovation, known as the Innovation Center.**

We need new ideas for supporting younger family members who may be helping with care, such as teens and young adults. This is especially critical when parents of children and young adults are living with young-onset Alzheimer’s disease. Results from the 2008 AFA “ICAN: Investigating Caregivers’ Attitudes and Needs” survey suggest that Alzheimer’s disease care is a family affair. Most “sandwich caregivers”—the parents or guardians of children under 21 who also care for an aging parent, other relative or friend with Alzheimer’s disease—said their children were assisting with caregiving responsibilities that range from attending doctors’ appointments to feeding and dressing their loved ones. Among children, ages 8 to 21, who are involved in caregiving, many are reported as taking on significant tasks: about one-third of young adults (18 to 21) assist with doctors’ appointments; 42 percent of young adults assist with transporting loved ones with Alzheimer’s disease; and about one-quarter of young adults and teens (13 to 17) assist with activities of daily living, such as feeding and dressing.<sup>38</sup>

Family caregivers, particularly women and members of low-income families, are faced with tremendous stress. Families and friends who provide this unpaid care often do so at the expense of their own physical and mental health and financial well-being. Business productivity losses related to family caregiving in the United States have been estimated as high as \$33.6 billion per year.<sup>39</sup> Many caregivers get caught in a difficult spiral of negative consequences. They are forced to take time off from work, forgo promotions and maybe even drop out of the workforce altogether to care for relatives. Consequently, they work less and

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<sup>37</sup> <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2577188/>

<sup>38</sup> <http://www.alzfdn.org/Publications/surveys.html>. Founded in 2002 by a teenager, AFA Teens seeks to mobilize teenagers nationwide to raise awareness of Alzheimer’s disease and to engage teenagers in the cause. The award-winning program is aimed at teens with family members affected by the disease and those purely interested in the cause. AFA Teens’ dedicated Web site, [www.afateens.org](http://www.afateens.org), creates an online community for teens, giving them support from experts and the opportunity to share experiences and connect with each other through a bulletin board and blog. AFA Teens awards a \$5,000 college scholarship to a college-bound student each year. The scholarship is designed to provide an outlet for teenagers to express their thoughts about Alzheimer’s disease and to engage the younger generation in this cause.

<sup>39</sup> Feinberg, Lynn, Reinhard, Susan C., Houser, Ari, Choula, Rita. “Valuing the Invaluable: 2011 Update The Growing Contributions and Costs of Family Caregiving,” AARP Public Policy Institute.





earn less, which reduces the Social Security and pension benefits they receive. And women, who generally live longer than men, must stretch their meager resources much further.

**We need to work on multiple solutions to help family caregivers aid the ones they love, including:**

- family friendly workplace policies;
- tax credits for individuals with substantial long-term care needs or for their family caregiver(s);
- parity for home- and community-based care with the Medicare and Medicaid eligibility levels for nursing home care;
- full funding for existing programs that seek to reduce family caregiver burden and reduce institutionalization, including the Lifespan Respite Program, the National Family Caregiver Support Program, and the Alzheimer’s Disease Supportive Services Program; and
- Medicare and Medicaid coverage for adult day and respite services, including post-acute services and non-medical service models.

AFA has received overwhelming feedback that presses the point of family support services. A recent AFA conference call participant from West Palm Beach, FL noted, for example: "This is a family disease. Whatever type of funding, the service needs to always incorporate the caregiver and the patient."

Among other points that would assist family caregivers, participants stressed the need for uniform dementia training and certification for healthcare workers, including primary care doctors; training for law enforcement who interact with people with dementia who have gone missing; funding for recreational therapies for individuals with dementia; more services for people with young-onset Alzheimer's disease; and greater collaboration among federal, state and local agencies that provide resources to family caregivers and people with Alzheimer's disease.


*Recommendation Two: Make Care Coordination Systemwide*

**Proven pilot and demonstration programs such as Independence at Home (IAH) and other care coordination models should be implemented systemwide by CMS.**

Numerous studies show that IAH and other CMS-tested care coordination programs for high-cost Medicare beneficiaries with two or more chronic conditions—including Alzheimer’s disease—reduce healthcare expenditures, improve quality of care and enhance health outcomes.

IAH is a unique clinical, financial and legal healthcare delivery model, compatible with other models, that will be tested under Medicare in a demonstration beginning January 1, 2012 and is being implemented by Medicare Advantage, Medicaid and private health plans to reduce healthcare costs “where they are the highest and improve outcomes where they are the worst.”

IAH focuses on the 5 percent to 25 percent of people who account for 43 percent to 85 percent of costs and receive the worst care. IAH takes primary care to the person in the home, tailors the care team to the individual’s needs and coordinates care across all treatment settings on a 24/7 basis. Practitioners are strictly held accountable for a minimum savings of 5 percent annually, positive outcomes and patient/caregiver satisfaction. Funding for IAH is entirely from the savings it achieves, and savings sharing will permit reinvestment in three types of technology (health information technology, telemonitoring, and mobile miniaturized



diagnostics) that will allow even more people to avoid unnecessary hospitalizations, emergency room visits and nursing home admissions in the future. IAH has proven effective in hundreds of programs that have operated in every state and the District of Columbia for decades.

### *Recommendation Three: Expand the Geriatrics Workforce*

Many of the healthcare professionals who reached out to AFA with suggestions emphasized the importance of expanding the eldercare/geriatrics workforce. Our nation faces an impending healthcare crisis as the number of older individuals with Alzheimer's disease and other complex health needs increasingly outpaces the number of healthcare providers with the knowledge and skills to adequately care for them. If current workforce trends do not change, we will continue to fail to ensure that every older American is able to receive high-quality care. The Institute of Medicine's (IOM) April 2008 report entitled "Retooling for an Aging America: Building the Health Care Workforce" calls for immediate investments in enhancing the geriatric competencies of the entire workforce, increasing the recruitment and retention of geriatric specialists and caregivers, and improving the way that care for older adults is delivered.<sup>40</sup>

The Eldercare Workforce Alliance<sup>41</sup> (EWA), a group of 28 national organizations (including AFA) that joined together to address the immediate and future workforce crisis in caring for an aging America, recommends several significant policy changes to expand the eldercare workforce. Direct-care workers provide critical support to older adults in need of long-term care, providing eight out of every ten hours of paid service delivered.<sup>42</sup> This field, which is increasing at three times the rate of other jobs within the United States economy, provides the best opportunity for caring individuals to obtain vital employment positions.<sup>43</sup> **To ensure that all direct-care workers are able to provide the highest quality care to all long-term care consumers, these positions should offer comprehensive training, certification and career advancement opportunities; livable, family-sustaining wages; affordable health insurance and other benefits; full-time hours, if desired; and balanced workloads.**

EWA also notes that there is also a significant shortage of health professionals and direct-care workers with specialized training in geriatrics and an even greater shortage of the geriatrics faculty needed to train the entire workforce. Title VII Geriatrics Health Professions programs are the only federal programs that increase the number of faculty with geriatrics expertise in a variety of disciplines and offer critically important geriatrics training to the entire healthcare workforce. Title VIII Geriatrics Nursing Workforce Development Programs are the primary source of federal funding for advanced education nursing, workforce diversity, nursing faculty loan programs, nurse education, practice and retention, comprehensive geriatric education, loan repayment and scholarship. **AFA believes these programs are essential in order to have the faculty needed to train providers.**

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<sup>40</sup> <http://www.iom.edu/Reports/2008/Retooling-for-an-Aging-America-Building-the-Health-Care-Workforce.aspx>

<sup>41</sup> [www.eldercareworkforce.org](http://www.eldercareworkforce.org)

<sup>42</sup> C.A. McDonald, "Recruitment, Retention and Recognition of Frontline Workers in Long-Term Care," *Generations: Journal of the American Society on Aging* (Fall 1994), Vol. XVIII, No 3).

<sup>43</sup> Paraprofessional Healthcare Institute, *Direct-care Health Workers: The Unnecessary Crisis in Long-Term*. The Aspen Institute, January 2001.

Even if more students enter geriatrics training, incentivizing them to stay will require loan forgiveness options. In May, Senator Barbara Boxer (D-CA) introduced S. 1095, the “Caring for an Aging America Act” that would amend the National Health Service Corps (NHSC) requirements to permanently add geriatrics and gerontology to the eligible fields for loan forgiveness. This small change in the language governing eligibility for NHSC loans would mean that geriatrics and gerontology specialists would always be eligible for NHSC loans as opposed to the current situation in which these specialists can only participate in the program if the HHS Secretary so designates it. An additional advantage is that the loan forgiveness would be fully funded through the NHSC. **AFA supports passage of S. 1095, the Caring for an Aging America Act.**

Finally, EWA estimates that by 2030, our nation will require 3.5 million additional healthcare professionals and direct-care workers to fulfill the growing demand for care. The National Health Care Workforce Commission, established by the Affordable Care Act, will play a central role in formulating a national strategy for bolstering the healthcare workforce in order to meet the needs of the escalating number of older Americans.

#### *Recommendation Four: Preserve Medicaid Benefits for Those in Need*

Few individuals with Alzheimer’s disease or other types of dementia and their families either have sufficient long-term care insurance or can afford to pay out-of-pocket for long-term care services for as long as the services are needed. Medicaid is the only federal program that will cover the long nursing home stays that many people with dementia require in the late stages of their illness—and, according to CMS, nearly half of nursing home residents have a diagnosis of Alzheimer’s disease or other dementia. Medicaid is also a growing source of financing for home- and community-based services for people with Alzheimer’s disease, such as home health, personal care and adult day services.

A majority of people with Alzheimer’s disease rely on help from family caregivers, who provide more than \$200 billion annually in unpaid care. However, many others do not have children, spouses or others to take care of them, or these relatives are unable to provide such care. With the annual cost of caring for one individual with Alzheimer’s disease ranging from nearly \$18,500 to more than \$36,000 depending on the stage of the disease, many individuals and their families are already being forced to deplete all of their assets to pay for this type of care. Medicaid plays a critical role for people with dementia and their families who can no longer afford to pay for long-term care expenses on their own.

**AFA believes that a blended rate may lead to deep reductions in Alzheimer’s disease care under Medicaid.** Under a blended rate proposal, states would have to resort to such strategies as requiring higher cost-sharing from already low-income individuals. States would also be very likely to cut or eliminate specific benefits, especially for home- and community-based services—which are particularly valuable to people with Alzheimer’s disease. For instance, states may cut the number of hours a home health aide may assist a beneficiary. Reducing basic Medicaid services such as annual exams and home health services will only balloon Alzheimer’s-related Medicare and Medicaid costs in the near future for acute care needs such as broken hips, undiagnosed or untreated bed sores or diabetic ulcers, or exasperation of other co-morbidities such as diabetes, hypertension, or coronary heart disease because beneficiaries did not remember to take their medications.

We recognize that cash-strapped states are urging Congress to give them flexibility in how they manage the program. However, **AFA strongly opposes efforts to eliminate “maintenance of effort” (MOE) rules that curb enrollment limits.** Eliminating MOE will mean many people with Alzheimer’s disease would have less access to Medicaid.

In addition, cuts to Medicaid benefits would mean cuts to the eldercare workforce. With the direct-care workforce totaling more than 3 million in 2008, employment projections predict the need for an additional 1.1 million direct-care jobs by 2018.<sup>44</sup> Medicaid is the primary source of funding for these jobs. If Medicaid reduces payments for long-term services and supports, the workforce will shrink, thereby increasing unemployment, hurting local communities, and limiting access to the long-term services and supports that many older adults and people with disabilities need to live in dignity in their homes and communities, rather than in institutions.

The delivery of home- and community-based services is much less costly than institutional care. Forcing older adults and people with disabilities to receive care in institutions, due to cuts in home- and community-based services under Medicaid, will negate cost savings.

We recognize the financial situation our government currently finds itself in; however, any solutions to our budget deficit or long-term debt problems should not come about at the expense of low-income older adults and Americans with high-cost diseases like Alzheimer’s.

## Conclusion

The Alzheimer’s Foundation of America (AFA) brings a unique, pragmatic perspective to its recommendations for a national plan. We have many struggles ahead in our effort to defeat Alzheimer’s disease, and AFA looks forward to working with the U.S. Department of Health and Human Services (HHS), other government agencies and the White House, as well as our partners and member organizations each step of the way. Public awareness will need to play a central role, as will review of existing plans both at the state and international levels. Educating the public, press and policymakers about the scope of Alzheimer’s disease and related dementias must be an integral part of any national plan.

In addition, several issues cut across all three categories of research, clinical care and long-term care, and strategies should be developed to incorporate them. With the following recommendations, it is possible for HHS to develop a comprehensive and meaningful integrated national plan to overcome Alzheimer’s disease:

### Research:

- AFA urges the President to work with Congress to raise funding for the National Institutes of Health (NIH) and National Institute on Aging (NIA) based on the Biomedical Research and Development Price Index (BRDPI, also known as “birdpie”) as opposed to gross domestic product (GDP).
- AFA urges the Administration to include \$1.4 billion at a minimum—an increase of at least \$300 million—for NIA in the President’s proposed FY 2013 budget.

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<sup>44</sup> <http://www.directcareclearinghouse.org/download/NCDCW%20Fact%20Sheet-1.pdf>

- AFA urges the Administration and Congress to fund the Cures Acceleration Network to engage the private sector and aid in speeding the translation of basic scientific discoveries into treatments for diseases such as Alzheimer's.
- AFA urges the Administration and Congress to significantly increase resources for the Food and Drug Administration.
- AFA urges HHS and NIH to balance basic research with clinical research in earlier diagnosis and prevention; better treatments; safety issues; non-pharmacological behavioral interventions; and end-of-life care.
- AFA urges HHS to support dementia care training for family caregivers of all ages and ethnic backgrounds as well as for clinicians—including primary care physicians, and direct-care employees.

#### **Clinical Care:**

- AFA urges Administration support for a public awareness campaign to drive early detection.
- AFA urges the Centers for Medicare and Medicaid Services (CMS) to include cognitive screening in the Medicare Annual Wellness Exam.
- AFA urges CMS to require geriatric competencies and dementia training for primary care clinicians and staff to improve detection, treatment and care for people with Alzheimer's disease.
- AFA urges CMS to expand and promote the Resources for Enhancing Alzheimer's Caregiver Health (REACH program) systemwide for Medicare and Medicaid beneficiaries through CMS' Innovation Center.
- AFA urges CMS and the Administration on Aging (AoA) to develop new ideas for supporting younger family members who may be helping with care, such as teens and young adults.
- AFA urges the Administration and Congress to work on multiple solutions to help family caregivers aid the ones they love, including:
  - family friendly workplace policies;
  - tax credits for individuals with substantial long-term care needs or for their family caregiver(s);
  - parity for home- and community- based care with the Medicare and Medicaid eligibility levels for nursing home care;
  - full funding for existing AoA programs that seek to reduce family caregiver burden and reduce institutionalization, including the Lifespan Respite Program, the National Family Caregiver Support Program, and the Alzheimer's Disease Supportive Services Program; and
  - Medicare and Medicaid coverage for adult day and respite services, including post-acute services and non-medical service models.

#### **Long-Term Care:**

- AFA urges CMS to implement systemwide proven pilot and demonstration programs such as Independence at Home (IAH) and other care coordination models.
- AFA urges the Health Resources and Services Administration (HRSA) to provide immediate investments in enhancing the geriatric competencies of the entire workforce, increasing the recruitment and retention of geriatric specialists and caregivers to improve the way that care for older adults is delivered.



- AFA urges the Administration to ensure that direct-care workers are able to provide the highest-quality care to all long-term care consumers by requiring employers to offer comprehensive training, certification and career advancement opportunities; livable, family-sustaining wages; affordable health insurance and other benefits; full-time hours, if desired; and balanced workloads.
- AFA urges the Administration and Congress to support full funding for Title VII Geriatrics Health Professions Programs and Title VIII Geriatrics Nursing Workforce Development Programs.
- AFA urges Congress to pass S.1095, the Caring for an Aging America Act.
- AFA urges the Administration to implement the National Health Care Workforce Commission to formulate a national strategy for bolstering the healthcare workforce in order to meet the needs of the escalating number of older Americans.
- AFA opposes efforts to eliminate "maintenance of effort" (MOE) rules that curb Medicaid enrollment limits or to promote blended rates, both of which would result in cost shifting to Medicaid beneficiaries.

*The Alzheimer's Foundation of America is honored to have a seat at the table to advise HHS on the formulation of a national plan to combat Alzheimer's disease. On behalf of the millions of Americans with Alzheimer's disease and their family caregivers who AFA represents, we bring with us a sense of urgency, but also stress the importance of getting this right, not only to ease their struggle, but also for the overall strength and health of our nation.*



*"Caring for the Nation...One Person at a Time"*

