

## **Wendy Campbell, President/CEO DE Valley of the Alzheimer's Association**

Good Morning Ladies and Gentlemen.

As President and CEO of the Delaware Valley Chapter of the Alzheimer's Association I stand before you today on behalf of both Chapters of the Alzheimer's Association and the Pennsylvania Public Policy Coalition. We represent half a million Pennsylvanians with Alzheimer's disease and related dementias and another 1,000,000 + loved ones and caregivers.

We would like to thank Secretary Nora Dowd Eisenhower, the Department of Aging and particularly Governor Rendell and his administration for this opportunity. We applaud their efforts in acquiring community feedback regarding the needs of an ever-mounting and aging population, and particularly the rising demands for dementia specific programs and services.

Alzheimer's disease, a progressive degenerative disease of the brain, is the most common form of dementia. In the United States there are 4.5 million American with Alzheimer's disease. This is projected to grow to 14-16 million by 2050 if no cure is found. It is the 8<sup>th</sup> leading reported cause of death in the US and it is highly under reported. The CDC reports that deaths due to Alzheimer's disease increased 5% from 2000 to 2001, the only one of the top 10 causes to increase. Related neurodegenerative disorders include: frontotemporal dementia (Picks), Lewy Body, Parkinson's disease dementia and vascular dementia.

10% of those over age 65 have AD and 47.5% of those 85 and older have AD. These numbers are staggering. At the same time, Census 2000 reports that the fastest growing segment of Pennsylvania's population is people over the age of 85. By 2010, 25% of Pennsylvania's total population will be over the age of 60, an increase by about 9%. The proposed Plan notes that the age group 85+ will be growing by a huge 33% yet the Plan does not make any reference to the fact that 47.5% of this age group will have AD. Pennsylvania needs to focus on developing special services and community resources for this large and growing need.

Given the significant presence of Alzheimer's disease and related dementias in Pennsylvania, several key issues addressed in the draft State Plan must take their needs and concerns into consideration when developing new policy or changing existing.

**Priority Area 1 - Role of Senior Centers** - A major concern with Senior Centers is that older, well individuals begin to participate in these programs and they inevitably continue to age - becoming less well and able. As a result originally healthy individuals sometimes develop cognitive impairments such as Alzheimer's disease.

In order to address the safety and interpersonal issues that arise Senior Center staff need to have some dementia specific training including but not limited to the following curricula: recognizing the signs of dementia, communicating with individuals with dementia and special programming that promotes independence while building on existing talents/skills to create a sense of accomplishment and worth.

Additionally, Senior Centers should have several policies in place for families and individuals with dementia. At a minimum, the Senior Center should have a policy when it is no longer safe or appropriate to serve someone with dementia. There should also be a referral procedure for families to community supports and services like the Alzheimer's Association, Adult Day Services Centers and other medical services.

**Priority Area 2 - Health & Wellness** – The Alzheimer's Association believes it is important for Pennsylvanians to understand that healthy aging is a process that should begin sooner in life rather than later in order to remain healthy of body and mind for as long as possible. There is increasing evidence that healthy lifestyle habits such as managing your numbers – your blood pressure, cholesterol, and blood sugar levels, as well as your body weight – contribute to healthier aging and may also decrease your risk for Alzheimer's. Because we now know that changes in the brain associated with Alzheimer's disease may begin years before there are any detectable signs or symptoms, it is necessary to assist Pennsylvanians in understanding the benefits of a healthy brain and the potential for reducing the risk for Alzheimer's disease.

The Alzheimer's Association is nationally launching a multiyear, integrated, broad-based campaign, *Maintain Your Brain*, to make brain health a priority. First, we recommend eating right. It is critical to feed your brain with nutrients. Eat foods high in Vitamins E and C. Take a multivitamin that includes folic acid. Include salmon, mackerel or other foods high in omega-3 fatty acids in your diet. Exercise both body and mind – work out, take a class, converse with others, read, play cards, or work on crossword puzzles.

Taking these precautions now can also reduce the risk of other common diseases, such as heart disease, high cholesterol, high blood pressure, type II diabetes, etc. Therefore, we welcome the opportunity to partner with the Department of Aging and other community organizations to expand this message and would be happy to share any information we may have.

**Priority Area 3 – Raising Public Awareness and Marketing Services**

We heartily agree that increasing public awareness and education about all Aging services and agencies including Alzheimer's disease is a top priority for the 5 year Aging plan in Pennsylvania. The Alzheimer's Association has been operating on the premise that education is the best empowerment tool we can give a family. Indeed education must be offered over the

entire course of the disease which may last longer than 20 years. Increasing awareness is clearly a vital first step that must be continuously and creatively addressed if we are to increase service. It will not be accomplished in 5 years. This is a top priority for the Alzheimer's Association Chapters and we welcome partnering opportunities with the Department of Aging.

**Priority Area 4 – Civic Engagement & Volunteerism** - When it comes to aging, research concludes that Baby Boomers want to live their lives to the fullest, redefining the concept of aging. They are determined to keep their minds younger than their bodies healthier. They feel a strong sense of individuality at the same time holding steadfast to collective activism principles.

For these reasons, we encourage and support the Department of Aging to make appropriate changes, particularly engaging interested seniors in philanthropic and other civic responsibilities.

**Priority Area 6 - Expand Home and Community Based Care** – Seven in ten people with Alzheimer's disease and related dementias live at home, making the family caregiver a comprehensive piece of the continuum of long-term care. Hundreds of millions of dollars are spent by Pennsylvania families out of their own pockets to care for loved ones. In fact, families provide 75 percent of care at no cost to the state.

Unfortunately, these figures do not account for the impact of Alzheimer's disease on the caregivers themselves. More than 1 in 10 caregivers become physically ill or injured as a direct result of caregiving and anywhere from 43% to 46% suffer from depression.

Caregivers are often the second victims of Alzheimer's. A study published in the *Proceedings of the National Academy of Sciences* recently concluded that the stress of caring for an Alzheimer's patient at home can prematurely age the immune system, putting caregivers at risk of developing a raft of age-related diseases.

These problems exacerbate state medical expenditures as well as impact businesses. Presently, Pennsylvania businesses spend nearly \$2.6 billion annually on Alzheimer's disease. These costs account for the business share of health and long-term care expenditures for people with Alzheimer's disease and related dementias and also the cost of family caregiving – absenteeism, productivity losses and replacement costs.

Therefore, it is in the best interest of Pennsylvania to provide substantive support for programs that not only maintain people with Alzheimer's in a community setting, but also sustain the

network of family/friend caregivers. Increasing Pennsylvania's investment in caregiver support through respite care, family counseling, and potential tax credits today can result in significant savings for tomorrow.

We recognize and commend Pennsylvania's leadership in the creation of the PA Family Caregiver Support Program. As a pioneer in caregiver support programs, Pennsylvania is a national model for other similar programs, including the National Family Caregiver Support Program. However, we do have several concerns that need to be addressed.

For example, a typical caregiver of an individual with Alzheimer's disease is an adult child who is concurrently raising a family. Under the current PA Family Caregiver Program a household income of \$43,000 - \$46,000 annually only allows for a monthly reimbursement of \$25/month. Twenty-five dollars barely covers the cost of half a day at adult day care or about 1.5 hours of personal care services provided in the home.

Clearly, this is not enough money to provide the quality, reliable support discussed earlier. We recommend revisiting the eligibility requirements as well as the reimbursement rates to, at a minimum, reflect inflation changes since the program's inception in 1992.

Lastly, we share the Department's concern in the availability of home and community based services across the Commonwealth. And we encourage the Department to look at ways to make services available to hard-to-reach populations, particularly rural and multicultural communities.

**Priority Area 10 – Cultural Inclusion and the Aging Network** - As the demographics of Pennsylvania and the entire United States shifts to reflect a rapidly growing older population, the burden of Alzheimer's disease and related dementias will increase substantially for minority populations.

In the interest of supporting efforts to improve access and quality of services for ethnic minority communities experiencing Alzheimer's disease and other dementing illnesses the following should be addressed:

**Acknowledge racial and ethnic disparities and differences:**

- \* Include cross-cultural training in the curricula of all health care professionals.
- \* Recruit health professionals from a diversity of races and ethnicities, as well as language capabilities.

- \* Provide patients with culturally appropriate education programs to know how to access care and participate in decision-making.
- \* Require health plans and federal and state government payors to collect, report and monitor patient care data for treatment disparities and possible civil rights violations.

**Target resources appropriately to vulnerable groups:**

- \* The Alzheimer's Association supports efforts to address and equalize the availability and affordability of health insurance.
- \* Efforts to include greater numbers of diverse populations in clinical trials and studies are strongly encouraged in order to further understand the unique effects Alzheimer's disease and related dementias have on various ethnic groups.
- \* Provide appropriate services, particularly home and community based services as well as prescription drug assistance, reflective of the needs of ethnic populations affected by Alzheimer's disease.

The Alzheimer's Association as partners with the Department of Aging, are recipients of a three-year grant, the Federal Administration's on Aging (AoA) Memory Loss Screening Program.

This program, initiated in 2002, is designed to reach into ethnic communities to provide them with information about dementia, early memory loss screening programs, referral to comprehensive medical care, ongoing services through care management and financial assistance for respite services including adult daycare, in-home support and overnight respite for qualified participants.

Despite severe funding woes, we have been able to reach into Cambodian communities, African American, Vietnamese, Chinese, Korean and several Spanish-speaking populations, including Mexican, Puerto Rican, Peruvian and Dominican.

However we have faced several consistent challenges throughout this project, including: 1.

1. Difficulty or delays in obtaining services
2. Affordability
3. Lack of transportation to service providers
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5. Perception of health status
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7. Illegal alien status
8. Unable to take time away from caregiving responsibilities
9. Lack of understanding and knowledge of AD and related dementia
10. Cultural and individual values and beliefs
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If the Memory Loss Screening Program is funded by the state and able to reach its full capacity, as we are currently advocating for, then at the conclusion of the grant we will be able to produce substantive, quantifiable results that can be shared and hopefully duplicated by the PA Department of Aging and other groups addressing similar issues. We welcome any inquiries about this program and would be happy to share its successes and shortcomings.

The March 24 2003 issue of *Time* magazine stated “every age has its own way of dying. The 19<sup>th</sup> century has consumption, the 20<sup>th</sup> century has the heart attack, and the 21<sup>st</sup> century will be the age of Alzheimer’s disease.”

The proposed plan specifically references Alzheimer’s disease only 2 times in 61 pages. Yet it is clearly one of the major public health issues facing our state, our communities, and our families. The Plan must address building our senior service infrastructure to help prepare Pennsylvania and its caregivers, both family and professionals.

The Medical-Science Advisory Committee of the Delaware Valley Chapter wishes me to include its brief testimony as well.

Department of Aging  
Proposed 5 Year State Plan  
Reading, PA June 23, 2004

At the June 14, 2004 meeting of the Medical-Science Advisory Committee of the Alzheimer’s Association Delaware Valley Chapter, the committee discussed the proposed 2004-2008 plan, The New State Plan on Aging: An Innovative Approach for the Commonwealth of Pennsylvania proposed by the Department of Aging. The Committee, which is composed of 25 of the leading researchers, practitioners and educators from eastern Pennsylvania, southern New Jersey, and Delaware, would like to submit comments regarding Alzheimer’s disease.

There were only two references to Alzheimer's disease in the entire 2004-8 plan. Both were valuable. The committee heartily endorses the Plan's intention to increase awareness of the disease and the services and programs available. The second reference to Alzheimer's specified the need to have transportation available for those with Alzheimer's to transport them to doctor's appointments, day care and other community services with an escort on the vehicle. However **dementia-specific training** is also needed for those escorts and vehicle drivers so they will fully understand the specific needs and safety precautions needed for safe transportation of people with Alzheimer's or a related dementia.

The Plan astutely noted the growth in our 85 year and older population but our plan needs to develop ways to support caregivers and those with Alzheimer's in this age bracket. The Committee suggests that **the plan be expanded to address the specific needs of this increasing population in Pennsylvania** of which 47.5% will have Alzheimer's disease.

The Committee also strongly suggests that **the plan be augmented to address the special needs of the over 60 population who live by themselves**. This group has special needs as they tend to be more isolated and unaware of services and programs. In the case of someone with growing cognitive impairment they may wish to live alone and special community services are needed to help them remain in the community as long as safely possible.

Finally, the committee recommends that the Plan be modified **to reflect the special needs of caregivers** and the importance of keeping senior caregivers healthy and active members of our communities. Whether taking care of an Alzheimer's patient or any other chronic diseases of aging, the caregiver needs support to take care of their health and emotional needs. Caregivers are a vital resource and Pennsylvania needs to strengthen support systems for them.

Alzheimer's disease is a significant Public Health issue facing Pennsylvania and the State Plan on Aging needs to address this issue fully.

Carol F. Lippa, M.D.  
Chair  
Medical –Science Advisory Committee  
Membership List attached

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