

**2008-2012  
STATE PLAN ON AGING  
WRITTEN TESTIMONY**

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**alzheimer's  association™**

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## INTRODUCTION

*FACT: Alzheimer's disease alone affects an estimated 280,000<sup>1</sup> Pennsylvanians today; factoring in related dementias brings the total to over 400,000.*

In a recent survey conducted by Hart Research, results showed that Americans are more afraid of developing Alzheimer's disease (69%) than becoming a victim of a natural disaster, such as a wildfire or hurricane (42%).<sup>2</sup> Yet, in a recent conversation, an elderly woman stated that her daughter "hopes she gets Alzheimer's, so she doesn't know she's suffering."

Clearly, a huge gap exists between what people know on a surface level about Alzheimer's disease (AD) or other dementias, and what people truly understand about the impact of the disease. Many, like the woman mentioned above, believe that it ensures a "blissful ignorance" or "quiet way out", rather than suffering the physical and emotional ravages of cancer, for example. Many still believe the myth that AD/dementia is a normal part of aging – senility, perhaps, or "old-timers" disease. Both of these ideas are false. Early-onset Alzheimer's currently affects almost 500,000 Americans, some of whom are diagnosed in their late thirties. While age is still the most common risk factor (nearly half of persons over age 85 have Alzheimer's), it cannot be dismissed simply as an old person's disease, and any AD caregiver can verify that it is certainly not a "quiet way out".

As stated above, Alzheimer's disease alone affects an estimated 280,000<sup>3</sup> Pennsylvanians today; however, factoring in related dementias brings the total to well over 400,000. Regardless of the exact number, the scope of this disease touches more than just the afflicted. An equal number of Commonwealth citizens – serving as primary caregivers – struggle with the immense challenges of these devastating conditions every day. It is nearly impossible to recognize the needs of the afflicted without also bearing in mind the needs of the caregivers, who may be family members, friends, or professionals. And, because Pennsylvania is an aging-in-place state, many of these caregivers are also frail elders.

The caregiver is often referred to as the "second victim" of AD/dementia, as more than 80% of Alzheimer caregivers report that they frequently experience high levels of stress, and nearly half say they suffer from depression.<sup>4</sup> This vulnerable population provides 75% of the individual's care at no cost to the state, the value of which is estimated at **\$3.9 billion dollars**.<sup>5</sup> This astonishing total lands Pennsylvania 5<sup>th</sup> on the list in the amount of unpaid care it provides, following California, Texas, New York, and Florida.<sup>6</sup>

Alzheimer caregivers spend a robust amount on out-of-pocket expenses, even when the person with dementia is not the caregiver's dependent for tax purposes. Among non-spouse caregivers, nearly half (49%) provided financial assistance averaging \$218/month.<sup>7</sup> In addition, there are dramatic costs to businesses whose employees are also Alzheimer caregivers – on a national scale, lost productivity, missed work and costs to replace those who leave their jobs to take on full-time caregiving responsibilities totals **\$36.5 billion**. In 2002, Alzheimer's disease cost American businesses more than \$61 billion – the equivalent of the net profits of the top ten Fortune 500 companies.<sup>8</sup> Given the increase in prevalence of the disease over the past six years, even that immense total - \$61 billion – has likely increased dramatically since the publication of the original report.

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<sup>1</sup> *2008 Alzheimers' Disease Facts & Figures Report*, March 2008, Alzheimer's Association

<sup>2</sup> "New Survey Shows Confronting Alzheimer's Disease a Key Issue in 2008 Presidential Election", Dec. 2007, Alzheimer's Association

<sup>3</sup> *2008 Alzheimers' Disease Facts & Figures Report*, March 2008, Alzheimer's Association

<sup>4</sup> "With Alzheimer's, the Caregiver is a Patient Too", <http://healthlink.mcw.edu/article/1031002313.html>, Nov. 2003

<sup>5</sup> *2008 Alzheimers' Disease Facts & Figures Report*, March 2008, Alzheimer's Association

<sup>6</sup> *2008 Alzheimers' Disease Facts & Figures Report*, March 2008, Alzheimer's Association

<sup>7</sup> *Families Care: Alzheimer's Caregiving in the United States 2004*, Alzheimer's Association

<sup>8</sup> *Alzheimer's Disease: The Cost to U.S. Businesses in 2002*, Prepared for the Alzheimer's Association by Ross Koppel, Ph. D., University of Pennsylvania

Understanding the fiscal implications of caring for those with Alzheimer's is only one piece of the puzzle. There are tremendous emotional and physical costs that cannot be adequately quantified. Caregiving also takes a large personal toll on the dementia caregiver and her/his family: 55% have less time for other family members; 49% give up vacations, hobbies or social activities; 30% get less exercise than before. Over 40% report high levels of emotional stress. One in five dementia caregivers are in fair or poor health and 18% say that caregiving has made their health worse.<sup>9</sup>

These caregivers are not only taking on enormous responsibility at great personal cost, they are doing it without the help and support they need. While many caregivers get help from other family members, only about half use any paid help or supportive services. Three out of four Alzheimer caregivers have unmet needs. One in three say they need time for themselves, help in balancing work and family responsibilities, and help in managing stress, but only 9% use respite services and only 11% participate in support groups.<sup>10</sup>

### **THE IMPACT ON THE COMMONWEALTH**

*FACT: Only California (440,000), New York (330,000), and Florida (360,000) have higher incidences of Alzheimer's than Pennsylvania.*<sup>11</sup>

According to the 2007 Older Pennsylvanians report, five causes of death (CLRD, Alzheimer's, Influenza/Pneumonia, Nephritis/Nephrosis, and Accidents) had higher numbers and rates in 2003-05 compared to 2000-02. Alzheimer's disease experienced the **largest increase in the number of deaths** over time (2000-02 compared to 2003-05). There were 1,466 more deaths in 2003-05, 18.2 percent higher than 2000-02.<sup>12</sup> Clearly, this is a disease whose incidence is on the rise, and its impact cannot be ignored.

While many more reports, studies, and surveys could be referenced to support the dramatic impact of Alzheimer's in the Commonwealth, the State Plan on Aging Discussion Guide mentions dementia once (as a contributing factor for elder abuse/exploitation) and Alzheimer's twice (only in the context of prevention). But prevention alone does little to help the nearly 1 million Pennsylvanians either afflicted or impacted as caregivers – along with the tremendous costs to the state treasury. By 2010, the Commonwealth is expected to spend over **\$6 billion** in Medicare/Medicaid funds for individuals with AD. At a time when federal and state budgets are experiencing greater strain, this does not bode well for the future stability of these programs and their vulnerable recipients.

Therefore, we believe that there are a variety of issues surrounding Alzheimer's and related dementias that the Department needs to address, given its responsibility of serving older Pennsylvanians. We also believe that there are a variety of creative solutions to approach the challenge.

### **RECOMMENDATIONS**

*FACT: Delaying nursing home admissions for people with Alzheimer's disease by just one month could save Pennsylvania, on average, \$1,863 per patient.*<sup>13</sup>

With this in mind, it would behoove the Department to expand options for supporting people with Alzheimer's in community-based settings for as long as possible. Research affirms that 70% of those with AD/dementia are cared for at home by family and friends.<sup>14</sup> However, we know that these caregivers are strained by the financial, physical, and emotional costs to care, making them nearly as vulnerable as the care recipients.

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<sup>9</sup> *Families Care: Alzheimer's Caregiving in the United States 2004*, Alzheimer's Association

<sup>10</sup> *Families Care: Alzheimer's Caregiving in the United States 2004*, Alzheimer's Association

<sup>11</sup> *2008 Alzheimers' Disease Facts & Figures Report*, March 2008, Alzheimer's Association

<sup>12</sup> *Older Pennsylvanians 2007*, Bureau of Health Statistics and Research, PA Department of Health

<sup>13</sup> *Alzheimer's Disease & Related Dementias in PA: A Growing Crisis, A Model for Change*, PA Public Policy Coalition, Alzheimer's Association

<sup>14</sup> *2008 Alzheimers' Disease Facts & Figures Report*, March 2008, Alzheimer's Association

Therefore, the Alzheimer's Association believes the following list highlights initiatives that would be beneficial and essential to ensuring that Pennsylvania is prepared to support its aging caregivers and care recipients both at home and in various other LTC settings:

- Increase availability of diagnostic services, adult day care & adequate, "arm-in-arm" transportation for those with dementia (especially in rural areas)
- Recognize the past success of Administration on Aging-partnered demonstration projects and seek future funding opportunities (i.e. rural/multi-cultural outreach, memory loss awareness screenings, care coordination and respite)
- Encourage the expansion/provision of family and professional caregiver training/education
- Foster development of additional ADRC partnerships
- Improve the quality of/access to long-term care (residential and HCBS settings) for those with dementia
- Ensure thorough methods are in place for quality control/assurance of dementia care in various LTC settings through regulatory compliance and other established programs (such as Ombudsman program)
- Promote the importance of research (perhaps through the avenue of the Jonas Salk Legacy Fund), which is critical both in terms of prevention and cost-savings
- Advance awareness and public education campaigns on issues regarding Alzheimer's and related dementias and existing programs that provide necessary help, such as the Pennsylvania Family Caregiver Support Program
- Develop a Disaster Preparedness Plan that integrates strategies for dealing with vulnerable populations (in conjunction with the Alzheimer's Association Safe Return + Medic Alert® program)
- Expand Medicaid coverage (i.e. inclusion of an Alzheimer's-specific waiver and coverage for those diagnosed under age 60)
- Provide dementia-specific training for the Older Adult Protective Services department

## **CONCLUSION**

While the list above is not exhaustive, it provides a framework for programs and services that the Department should consider expanding, initiating, and implementing to better meet the needs of all of our citizens struggling with the far-reaching impact of Alzheimer's and related dementias. Until we can cure or fully prevent the disease, our nation, and the Commonwealth of Pennsylvania, must be prepared to deal with the challenges and burdens that this devastating disease presents. Our Chapters are willing and able to partner with the Department to meet these goals and look forward to seeking creative ways to work together and achieve success. In the meantime, we will continue to advocate among members of the General Assembly and the Administration for immediate action and positive outcomes for those many citizens already afflicted.

## WORKS CITED

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