

# Alzheimer's: A Disease We No Can Longer Afford to Sweep Under the Rug

Wendy Campbell 23 September 2011

Alzheimer's is a progressive, neurodegenerative disease that destroys brain cells, affecting a person's memory, personality, mood, body function and behavior. It affects men and women, as well as all racial and ethnic groups. It is always fatal. Across the nation, an estimated 5.4 million people are living with the disease, touching one in eight people older than 65.

Ever since German physician Alois Alzheimer discovered the link between these symptoms and microscopic brain changes in 1906, researchers have been searching for a cure or treatment. So far, there isn't even a definitive method to stop the disease from progressing after onset.

Because Alzheimer's remains incurable and has historically received less attention and funding than other, more well-known diseases, such as cancer, heart disease and diabetes, the rate of the disease is skyrocketing. It is also attacking a growing number of people who are just in their 30s, 40s and 50s. Approximately 250,000 individuals in the United States have younger-onset Alzheimer's.

It's growing so rapidly, it is now the sixth leading cause of death in the United States—surpassing diabetes and three other of the nation's top 10 deadliest diseases. During one 8-year time period alone, deaths from Alzheimer's rose 66 percent, while deaths from major diseases like HIV/AIDS, breast cancer and heart disease decreased.

The Alzheimer's Association Delaware Valley Chapter serves a region that has experienced its own share of the disease. As many as 294,000 people in the tri-state area have Alzheimer's. The disease also affects more than just the person living with the disease; at least 600,000 family members care for a loved one who has Alzheimer's disease. The disease lasts an average of eight to nine years, and leaves a devastating impact on a family's emotional well-being and financial resources. Children and other relatives witness the gradual changes in their loved one's ability to remember who they are, their names, and to even recognize him/herself in the mirror. The physical, emotional and behavioral transformations that are associated with Alzheimer's disease can often leave a caregiver feeling overwhelmed and frustrated. Caregivers often report feeling helpless because a loved one with the disease, who was previously easygoing, is now displaying aggressive behavior, or vice versa.

Every year, more than 10,000 people call the Chapter's 24/7 Helpline with a heartbreaking story to tell. Every story is unique to every family, however, because the disease strikes every brain differently. After all, no two

brains are alike. While growing up, everyone learns to read, walk and talk at different times; similarly, the disease does not affect every brain the same way. Perhaps a family member has begun noticing changes in a loved one, like forgetfulness and mood swings and isn't sure whether s/he has Alzheimer's, or is merely having a series of bad days. We all have challenging days, and we all are forgetful from time to time, but if someone is so forgetful that it is interfering with everyday routines and decision-making, it is time to see a doctor – especially if you notice memory changes along with at least one of these other possible Alzheimer's symptoms:

- Challenges in planning or solving problems;
- Difficulty completing familiar tasks at home, at work or at leisure;
- Confusion with time or place;
- Trouble understanding visual images and spatial relationships;
- New problems with words in speaking or writing;
- Misplacing things and losing the ability to retrace steps;
- Decreased or poor judgment;
- Withdrawal from work or social activities; or
- Changes in mood and personality.

Clearly, Alzheimer's is not just a "normal sign of aging." Simply put: If you know your loved one, friend or coworker is always sociable, remembers regularly-scheduled appointments and upcoming special events, and knows to

wear a coat when it's 40 degrees outside, but you begin to notice s/he has been behaving totally differently from how s/he has behaved in the past, it's time to consult a physician.

Now is also the time to recognize that the persistent lack of a cure or an effective treatment, and the increasing rate of onset of the disease among younger generations, makes Alzheimer's disease one of the major public health crises facing the United States. By 2025, Alzheimer's Medicare expenditures alone will equal the 2010 Medicare budget. If no cure or treatment is found, as many as 16 million Americans will have Alzheimer's by the year 2050.

We can no longer afford to sweep this disease under the rug.

Now is the time to do your part and help the federal government develop a National Alzheimer's Plan. In January 2011, President Barack Obama signed into law the National Alzheimer's Project Act (NAPA), after both houses of Congress passed it unanimously. The new law requires the creation of a national strategic plan to fight the rapidly escalating Alzheimer's crisis. Alzheimer's Association chapters across the country have been busy gathering comments and advice from caregivers, people living with Alzheimer's disease and healthcare providers, who get to share their thoughts directly with their members of Congress or their designees at local public input sessions.

The goal is to ensure that U.S. Senators and Representatives return to Washington, D.C. aware of the unique challenges people living with Alzheimer's and caregivers face. For example, the privacy rules mandated by the Health Insurance Portability and Accountability Act (HIPAA) are well-intentioned, but can hinder appropriate care for an Alzheimer's patient. For instance, when a woman living with Alzheimer's disease could not comprehend her primary care physician's instructions, the doctor would not later relay them to her adult daughter, citing HIPAA.

We're hearing calls for exceptions to HIPAA in certain cases, as well as for more awareness among family physicians about how Alzheimer's disease manifests itself.

In the meantime, the Alzheimer's Association Delaware Valley Chapter does its part to meet its mission to eliminate Alzheimer's disease through the advancement of research, to provide and enhance care and support for everyone who is affected, and to reduce the risk of dementia by promoting brain health. The Alzheimer's Association Delaware Valley Chapter has grown a great deal in the last five years, but remains true to its initial roots, when it was founded in 1979 as a collection of support groups for caregivers in Southeastern Pennsylvania. The chapter strives to provide seamless program delivery across the tri-state region, where people regularly cross state boundaries to live, work and vacation.

In the past few years, the Delaware Valley Chapter has evolved significantly, moving to standardize programs across the region and forming key alliances with community organizations and the news media to raise awareness about Alzheimer's disease and the chapter. Most importantly, though, we are leveraging these assets to provide support to the estimated 294,000 individuals with Alzheimer's disease or related disorders who live in our 18-county service area. We offer a broad array of services and support for people living with Alzheimer's or a related disorder and their caregivers, including a 24/7 Helpline, care consultation, early-stage initiatives such as support groups and social engagement programs, advocacy, diversity outreach, educational programs and safety services.

I encourage you to learn more about Alzheimer's and what you can do to help by visiting our website at [alz.org/desjsepa](http://alz.org/desjsepa), or by calling our 24/7 Helpline at, 800.272.3900.

Join the fight, before it's too late.

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