

Testimony of Tiffani Chambers, Family Services Coordinator
On behalf of



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Madame Chair, Mr. Vice-Chair and members of the House Aging and Older Adult Services Committee, I welcome this opportunity to provide testimony on behalf of individuals and caregivers touched by Alzheimer's disease or a related dementia and the Alzheimer's Association's Pennsylvania Public Policy Coalition regarding legislation to implement a state Silver Alert System.

The Association continues to support the creation of a Silver Alert system that are sensitive and responsive to the needs of persons living with dementia and their families and effectively communicates with appropriate local law enforcement and community support networks such as ours.

As we have the same goal at heart which is the safe return of individuals who wander to their families or care settings, I wish to reiterate the seriousness of wandering by sharing the following incident.

An 89-year-old Pittsburgh woman who suffered from dementia and heart problems was found dead on the roof of a large metropolitan hospital. This woman wandered unnoticed from her 12th-Floor room on Tuesday, December 2, 2008, and made her way to the roof. Her body was found by maintenance workers on Wednesday morning. Overnight temperatures dipped to 23 degrees and she was dressed only in a hospital gown and slippers. Authorities believe she went through a fire exit about 5 feet from her room. When the alarm did not sound, she went up two short flights of stairs, through a boiler room and onto the roof. The roof door did not lock.

Six out of 10 people with Alzheimer's disease will wander. This can happen within any stage of the disease and frequently occurs by foot, but can happen by car or via other forms of transportation. It only takes a moment for someone to wander. This is just as true at home as it is at the mall or at the grocery store. Most people with Alzheimer's disease who wander are found within 1.5 miles of home, and up to half of individuals who wander will suffer serious injury or death, if not found within 24 hours.

An 85 year old Philadelphia man who suffered from dementia wandered away from his home on a cold February night in 2004. Still functioning well in the home, his family was not concerned about leaving him unattended for short periods of time and usually kept a close eye on him. However this time was different. He never returned home. After an intensive five-week search, his body was found in a backyard, about a mile and a half from his home. Authorities placed likely time of death the first night he was gone.

As we've also testified in previous hearings, Pennsylvania sits at 'ground zero' with its sizable aging-in-place population and upwards of 400,000 of its citizens currently afflicted with Alzheimer's or a related dementia.

Wandering and becoming lost is a dangerous situation for an individual with dementia, as it is often difficult for them to recognize when they are in danger and their ability to think through safety issues is decreased or not present at all. This often results in persons doing things that are dangerous as demonstrated in the story above, quickly turning wandering into a life threatening situation. Exposure and other environmental dangers also pose serious threats to people with Alzheimer's disease because they may lose their cognitive ability to remember when to eat and drink and the ability to protect themselves from extreme weather. For these reasons, a timely, local search response to wandering incidents is crucial.

In thinking about Alzheimer's disease or related dementias, we also need to consider that the face of dementia is changing. It is no longer a "disease of the elderly." Younger Onset Alzheimer's disease and other dementias like Lewy Bodies or Frontotemporal Dementia affect people who are under the age of 65. Many individuals are in their 30's, 40's and 50's. In 2009, as many as 5.3 million people were living with Alzheimer's disease nationwide. This includes as many as 200,000 people under the age of 65 with younger onset Alzheimer's disease. Dementia does not have an age threshold and neither should an all-inclusive Silver Alert program.

The Alzheimer's Association is a leading source of information, education and support for millions of individuals, caregivers and care professionals who face dementia every day. Silver Alert legislation can enhance current, successful protocols, such as our MedicAlert® + Safe Return® program.

The Alzheimer's Association Safe Return program was initiated in April 1993 in partnership with the Department of Justice to create a nationwide network to specifically address the safety needs of people with dementia who wander. In November 2007 we partnered with MedicAlert Foundation International to launch the MedicAlert® + Safe Return® (MASR) program. This enhanced service provides the same benefits of the Safe Return program with the added benefit of a vital medical history. Since 1993 over 160,000 people are enrolled, and the program has facilitated over 16,000 safe returns nationwide. The MASR program boasts a nearly 100% recovery rate for those enrolled.

The MedicAlert® + Safe Return® program works in one of two ways: either a person is reported missing by his/her caregiver, or a person is reported found by a law enforcement officer or a good samaritan. MedicAlert® + Safe Return® notifies local law enforcement and the local Alzheimer's Association chapter to assist in locating the missing individual. By working hand in hand with local law enforcement and offering dementia specific training of public safety personnel, the program operates successfully nationwide. Additionally, the program provides first responders with an adult wanderer's vital medical history.

The Alzheimer's Association is committed to working with lawmakers to ensure that a Silver Alert System is comprehensive and will grow with the increasing and ever-changing population of individuals touched by some form of dementia. Based on our earlier testimony, upwards of 240 thousand Pennsylvanians with dementia will wander at some time during the disease process, some, multiple times. Although we have a functioning mechanism to respond and assist individuals with dementia and their caregivers, we know that we are not yet reaching the 'silent majority' of afflicted families dealing with this grave hazard.

A program such as Silver Alert has the potential to increase human interest and awareness of people who are at risk and offer the community a positive solution to a problem that occurs daily. It is an appropriate way to provide support to families and help them work with law enforcement and community services. Many times families don't report their loved one missing immediately, for fear

of being perceived as a bad caregiver or negligent. Others hesitate to contact local law enforcement because of worrying about wasting their time. The reality is that time is crucial in the first hours of a missing incident and it is imperative that searches begin immediately. It is necessary for the state to move forward to join the efforts to support and educate communities about persons living with the effects of dementia.

The most effective system will foster a relationship between families, law enforcement, local government and organizations like the Alzheimer's Association. We feel a successful program will at minimum:

- Support interoperability with the existing Medic Alert® + Safe Return® program and include a mechanism to enroll individuals in the program. The Alzheimer's Association can act on a referral basis to work with families to prevent future incidents and provide information about local resources and services through their local chapter; it may also be appropriate to help families improve communication or environmental issues that could contribute to agitation and wandering.
- Include dementia-specific training for first responders and involved organizations, which would include information at minimum about wandering behaviors. A first responder who is more equipped to recognize and manage wandering behaviors can be a vital resource where time and efficiency are of the essence.
- Not have an age threshold and be tailored to the needs of individuals with Alzheimer's or other dementias who wander.
- Not require official proof of diagnosis, instead require a caregiver statement.
- Use a 'tiered' approach that emphasizes local searching first, only escalating to regional or statewide if a person has left the immediate area.
- Allow local searching to begin within 24 hours of the reported disappearance.
- Collect data on Silver Alert usage and evaluate program operation.

The Alzheimer's Association welcomes the opportunity to assist Pennsylvania in joining 13 states, most recently New Jersey, that have successfully enacted Silver Alert legislation.