Methods for Locating Missing Adults with Dementia

Quantum Units Education

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Executive Summary

Throughout the United States, rarely does a day go by that there is not one media report, or more than one, of a person with Alzheimer’s disease or a related dementia who has gone missing. As the incidence of Alzheimer’s disease continues to increase, it follows that this behavior will rise accordingly—putting more and more of our nation’s vulnerable population at risk of injury or death if not located quickly. Every person with dementia who can walk as well as those who continue to drive are at risk of becoming lost. Beyond directly impacting the person with dementia, this behavior poses widespread implications for other sectors, especially family caregivers, healthcare professionals and law enforcement. Increasing attention is being focused on the fact that behavioral symptoms of Alzheimer’s disease, including wandering and missing incidents, are a major source of caregiver burnout. As well, for law enforcement, this is a serious and costly public safety problem that will only worsen as the disease invades more lives. Strategies are available to cope with—and curb—this potential crisis, as outlined in this report: Educating caregivers and the public about this behavior, including having law enforcement play a leading role in this effort, can help ensure that a person with dementia can be rapidly identified. Programs that alert the public that a senior or disabled adult has gone missing, much like for children, can increase the chances that a Good Samaritan will promptly locate and assist in returning the individual to safety. Emerging technology—whether utilizing radio signals, global positioning satellites or cellular triangulation, or a combination of these technologies—can assist in search and rescue by pinpointing the location of a person outfitted with one of these active tracking systems. Raising awareness of this behavior and disseminating information about available strategies hold the promise of ultimately saving costs and, moreover, lives.

Introduction

The United States is facing an unprecedented crisis related to Alzheimer’s disease. It is estimated that more than five million Americans currently have been diagnosed with Alzheimer’s disease, and every person with Alzheimer’s disease or a related dementia who is not bedbound is at risk of becoming lost. These two facts have serious implications for the communities in which persons with Alzheimer’s disease live and for the law enforcement agencies tasked with locating the missing before they suffer serious injury or even death. As the dementia population increases, as expected, this situation takes on even more urgency.

Wandering is one of the most common, complex, burdensome and costly behaviors of Alzheimer’s disease, and is a safety issue that has significant and far-reaching implications for the person with the disease, the caregiver (family/professional) and the public, including law enforcement and Medicaid/Medicare.

The purpose of this report, “Lost and... Found: A Review of Available Methods and Technologies to Aid Law Enforcement in Locating Missing Adults with Dementia,” is to give law enforcement agencies an understanding of the scope of the problem and practical knowledge about available methods and technologies designed to assist in the rescue and return of individuals with dementia, and to engage law enforcement in the education of caregivers and the community as a whole about the most effective ways to address the problem of wandering. The ultimate goal is to facilitate the prompt and secure return of wanderers and to save lives—to enable all those who become lost to be found.
The Problem of Wandering and Becoming Lost

According to the National Institute on Aging (NIA), as many as 5.1 million Americans currently have Alzheimer's disease, an irreversible, progressive brain disorder that destroys memory and intellectual function. Common symptoms include memory loss, confusion, spatial disorientation, lack of judgment and inability to communicate. Over a period of years, the disease leads to the complete loss of cognitive function, a long period of dependency and, ultimately, death. With no cure in sight, the incidence of Alzheimer's disease is expected to rise significantly as the nation's population ages and life expectancies lengthen. In addition, more and more families and caregivers will bear the physical, financial and emotional toll of this disease. The growing number of people affected by Alzheimer's disease or a related dementia and the rapidly rising costs associated with these disorders will put a heavy economic burden on families, businesses and government.

Dementia is a general term that describes a group of symptoms, such as loss of memory, judgment, language, complex motor skills and other intellectual functions, caused by the permanent damage or death of the brain's nerve cells, or neurons, over a prolonged period. One or more of several diseases, including Alzheimer's disease, can cause dementia. Alzheimer's disease is the most common cause of dementia, representing about 60 percent of all dementias identified at clinical assessment.

The other most common causes of dementia are vascular dementia, caused by stroke or blockage of blood supply, and dementia with Lewy bodies. Other types include alcoholic dementia, caused by sustained use of alcohol; post concussive dementia, caused by head injury; frontotemporal dementia; and many other uncommon diseases.

The incidence of dementia doubles approximately every five years in individuals between the ages of 65 and 95 and by some estimates may reach nearly 50 percent by age 85. Alzheimer's disease is the most common cause of dementia among people 65 and older. Alzheimer's disease is not a normal part of aging; however, age is the greatest known risk factor. And with the older population on the threshold of a boom, dementia is an especially significant issue. As of January 1, 2011, 10,000 people are turning 65 every day—and this incidence will continue for 20 years. By 2030, about one in five persons will be over 65.

The clinical symptoms and the progression of dementia vary, depending on the type of disease causing it, and the location and number of damaged brain cells. Some types progress slowly over years, while others may result in the sudden loss of intellectual function. Experienced clinicians can accurately diagnose the probable cause of dementia 90 percent of the time.

Among the behavioral challenges of the disease, becoming lost is a grave concern—and a very real one. Experts report that 60 percent of people with Alzheimer's disease will wander at some point during the progression of the disease, and half of those will become lost and separated.
from a loved one. Using the incident rate of one critical wanderer per year per 1,000 persons over the age of 65 (1998 Census figures), the expected total of critical wanderer incidents reported to local law enforcement comes to 31,000 cases a year.\(^6\) Research suggests that most people become lost within close proximity to their home.

Every person with dementia who can walk as well as those who continue to drive are at risk of becoming lost, defined as an instance in which the whereabouts of a person with dementia are unknown to the caregiver and the person is not in the expected location. An example would be someone who may take what would normally be a routine walk or drive and then suddenly be unable to find his or her way home. Similarly, a person with dementia who is separated from a caregiver in a shopping center or other busy setting may be unable to locate the caregiver and panic.\(^7\) A person with Alzheimer’s disease or a related dementia can become lost accidentally (for example, by being separated from a caregiver during an outing or leaving the house without a caregiver’s knowledge). Alzheimer’s disease is progressive and at some point, and often at a relatively early stage and without prior warning, an affected individual will become easily disoriented and confused.\(^8\)

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**Commonly-Used Terms to Describe Wandering Behavior by Persons with Alzheimer’s Disease or a Related Dementia**

- During the course of their illness, most people with dementia will engage in some form of wandering. The term “wandering” has been used to describe a range of behaviors, from the relatively safe (but often annoying and challenging for caregivers) behavior of pacing, to the potentially very dangerous behavior of repeatedly attempting to leave a secure environment. Wandering or “wandering around” is not bad per se and can even be beneficial—in terms of relieving anxiety and providing exercise, for example.

- What is a very serious concern for both caregivers and law enforcement is “elopement” or “critical wandering” away from home that can lead to what law enforcement and dementia experts may call a “missing incident.” A “missing incident” is defined as an instance in which the whereabouts of a person with dementia are unknown to the caregiver and the person is not in the expected location. These missing incidents are unpredictable, can happen while the person is doing seemingly normal and routine tasks, and occurs in all care settings, including ones that are professionally staffed.

- In a long-term care setting, the terms “unsafe exiting” or “wandering away” may be used to describe the unplanned and unsupervised departure from the facility by the person with dementia, which could lead to a serious missing incident.

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\(^7\) Meredith A. Rowe, Neil G. Feinglass, and Marnie E. Wiss, “Persons with Dementia Who Become Lost in the Community, A Case Study, Current Research, and Recommendations,” Mayo Clinic Proceedings 79(11) (2004); 1418.

\(^8\) Meredith A. Rowe and Vikki Bennett, “A Look at Deaths Occurring in Persons with Dementia Lost in the Community,” American Journal of Alzheimer’s Disease and Other Dementias 18(6) (2003): 344. It is common for both persons with dementia and their families to engage in denial and ignore early symptoms, and becoming lost is frequently event that triggers a medical evaluation for dementia.
Wandering can be prompted by a person’s desire to “go home”; a response to stress or unmet needs, such as hunger; or a medication side effect. Missing incidents pose a serious threat to a person’s independence and to his or her very life. The challenge is to quickly locate a person before harm occurs, especially because disease symptoms impair a person’s ability to recognize that he or she is in danger or to independently take action to return home safely.

Although the term wandering is routinely used by clinicians, researchers and informal caregivers, the meaning of this term varies depending on the source of the definition and the context in which it is used. Caregivers rarely use the term wandering to label different scenarios that had been previously identified in the literature as wandering. Responses to a survey of 17 wandering experts did not reflect agreement on a definition of wandering. These findings suggest that a broad set of terms should be used to describe this potentially dangerous behavior when healthcare providers communicate with informal caregivers. Improved clarity of the term wandering has the potential to prevent miscommunication in research and clinical settings and to enhance the safety and well-being of older adults with dementia and their informal caregivers.9

“"My great-grandmother went from forgetting small things to forgetting larger things, like when to cut off the stove after she finished cooking. It quickly became a desperate situation. The mail carrier would tell my grandmother that she saw Mama Susie wandering down the street on her own. I remember one time in particular, my great-grandmother stayed over my aunt's house. We didn’t trust her to be alone anymore because we were afraid she would get lost.

"This particular time, my aunt woke up and couldn’t find Mama Susie. Mama Susie had wandered off from the house and walked over five miles to the church that she loved so much. The pastor contacted my grandmother and told her that Mama Susie was there. At that point, it really hit home to me that things were really bad."

Source: Excerpt from essay submitted by Lauren Coleman of Merriam, KS for 2011 Alzheimer’s Foundation of America (AFA) Teens for Alzheimer’s Awareness College Scholarship

The majority of people with dementia live at home, with family members serving as their caregivers. Wandering and the danger of elopement are a major source of stress for caregivers, and it is, therefore, not surprising that the fear that a loved one will become separated from the caregiver or leave the home and become injured or even die often leads to placement in an institutional setting. Placement in a long-term care facility can cause great distress for persons with dementia and their families, and it is very costly to the public because most institutional care is paid for by Medicaid. By working with families and local health and social service agencies to address the problem of wandering and becoming lost, law enforcement can help persons with dementia remain in their communities and defer or even completely avoid placement in a long-term care facility.

Increasing attention is being focused on the fact that behavioral issues, including wandering, are a major source of caregiver burnout. Evident of this, the nation’s historic national Alzheimer’s plan released by the U.S. Department of Health and Human Services (HHS) in May 2012 noted that round-the-clock care can result in caregiver depression and stress, and nursing home placement of loved ones with dementia. The first-ever “National Plan to Address Alzheimer’s Disease” notes that “supporting people with AD and their families and their caregivers requires giving them the tools that they need, helping them plan for future needs, and ensuring that safety and dignity are maintained.”

Instances That Could Lead to a ‘Missing Incident’

In 2011, the Veteran’s Administration and academia from the University of Florida conducted a study on the “Prevalence and Antecedents to Dementia-Related Missing Incidents.” Here are the top reasons that persons with dementia became lost.

- **During Normal Independent Activity:** In these instances, the caregiver left the person with dementia alone after negotiating a period of separation (e.g., a caregiver was doing chores or yard work or allowed the person with dementia to check the mail or go for a walk alone). It was only when the person with dementia took too long to complete the activity that the caregiver realized he or she was missing.

- **Unable to Retain Instructions:** In these cases, the person with dementia was left alone with instructions to wait for the caregiver or meet him or her in a predetermined location, and was unable to retain these instructions and became lost.

- **Independent Awakening:** In these occurrences, the person with dementia awoke independently and made either a “judgmental or way-finding error” and left the home.

- **Agitation:** A person with dementia can oftentimes become agitated with his or her caregiver(s) and can, in response, leave a safe environment.

- **Unusual Situations:** There is no defined set of unusual situations; however, one example could be when a person with dementia is suddenly placed in an electric wheelchair rather than in his or her normal push wheelchair.

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11 Ellen O’Brien, “Medicaid’s coverage of nursing home costs: Asset shelter for the wealthy or essential safety net?” Issue Brief, Georgetown University Long-Term Care Financing Project, May 2005-1.
12 http://aspe.hhs.gov/daltcp/napa/NatlPlan.shtml
The Impact on Law Enforcement

Elopement and becoming lost are also a serious and costly public safety problem that will only worsen as the incidence of dementia increases unless the public is better educated about this behavior, families secure “passive” and “active” systems to identify and locate loved ones, and effective and cost-efficient strategies for law enforcement and first responders are developed and implemented.

Communities across the United States are overburdened by the occurrence of missing incidents. The rising incidence of the disease and the high risk of becoming lost deliver a double punch, with serious implications—practically and financially—for law enforcement agencies tasked with locating the missing before they suffer serious injury or even death. Search and rescue operations typically cost taxpayers $1,500 per hour, and low-tech rescue operations average nine hours—this on top of the $172 billion annual cost of Alzheimer’s disease to society. Although most states do not keep statistics on either the number of cases of missing persons with dementia or the average cost of a search and rescue operation, data from Oregon confirm the urgency of the problem: searches for missing males with Alzheimer’s disease almost doubled in 2009 and have more than tripled since 2006.

Wandering poses a serious threat to the life of the lost individual. Thus, the clock begins ticking when a person with dementia goes missing: Lost events can spark severe driving errors and death for drivers. Research conducted by Robert J. Koester of the Virginia Department of Emergency Services found that 61 percent of wanderers not located within the first 24 hours are found deceased.

Worse, due to their loss of judgment and other symptoms, wanderers themselves do not perceive the risks. Lacking the cognitive ability to be self-protective, persons with dementia not only fail to cooperate with their rescuers, they frequently seclude themselves. This limits the usefulness of standard search methods (such as calling the person by name) and immensely complicates rescue and recovery. With people with Alzheimer’s disease, 94 percent of all subjects will be found within 1.5 miles. Even though most missing persons with dementia are found close to home, some are not found until they are dead of exposure or other causes because they so effectively evade initial search attempts.

14 http://www.projectlifesaver.org/
17 Hunt LA, Brown AE, Gilman IP. Drivers with dementia and outcomes of becoming lost while driving. Am J Occup Ther 64(2): 225-32
18 Koester, Robert, Lost Person Behavior, dBs Productions Charlottesville, VA, 2008.
19 Meredith A. Rowe, Neil G. Feinglass, and Marnie E. Wiss, “Persons with Dementia Who Become Lost in the Community, A Case Study, Current Research, and Recommendations.” Mayo Clinic Proceedings 79(11) (2004); 1418
20 http://www.dbs-sar.com/SAR_Research/Wandering_Characteristics.htm
22 Meredith A. Rowe, Neil G. Feinglass, and Marnie E. Wiss, “Persons with Dementia Who Become Lost in the Community, A Case Study, Current Research, and Recommendations,” Mayo Clinic Proceedings 79(11) (2004); 1419-1420. In this study, 87% percent of those found alive were found within a five mile radius of the place last seen, and 73% of those found dead were found within a half mile of the place last seen.
"I’m writing to let you know about my mother—Helen S. Jacobson—because I feel that knowing about our traumatic and disastrous experience may help someone else.

I was able to retire from teaching to stay home with Mom when she was diagnosed with Alzheimer’s disease. I took care of her for four-and-a-half years and am thankful for the very precious days we spent together.

On January 16, 2011, I woke up at 3 a.m. to find that Mom was not in the house. The temperature was 24 degrees, the snow banks were high, and because we live in the woods and the street light was burned out, the neighborhood was completely black.

We found Mom in a snow bank with nothing on; her nightgown was in the snow beside her. Though the rescue squad got her to the emergency room and the staff tried hard to help her, she did not make it.

For the few months before this happened, we had private nurses come three mornings a week to help with Mom’s shower. Besides having Alzheimer’s disease, she was legally blind... suffered from arthritis... had osteoporosis, was very frail and could not get around without her walker.

The nurses walked with me through our house and said the house was fine for Mom’s needs—and I agreed with them. We did not have extra locks to prevent Mom from getting out because she didn’t move around if she didn’t have to and needed lots of help when she did.

In spite of all this, Mom got out of the house through a storm door and a door with a deadbolt lock so quietly, that neither my aunt nor I heard her leave. She somehow walked alone up a long hill in the snow on a completely black night and collapsed.

In memory of my mother and in the hope of sparing someone else trauma and heartache, I urge caretakers, nurses, doctors, families and anyone involved in the care of people with dementia to recognize that extra out of reach inside locks or at least loud door alarms are always necessary."

Source: Letter sent to the Alzheimer’s Foundation of America by Jean Jacobson of Gloucester, MA and reprinted in the spring 2012 issue of AFA’s care ADVantage magazine
Until now, there has been very limited guidance for law enforcement on how best to address the problem of missing persons with dementia. To fill this gap, in Fiscal Year 2009, the United States Department of Justice's Bureau of Justice Assistance (BJA) awarded three grants under the “Enhancing Law Enforcement: Missing Alzheimer’s Patient Assistance Program.” The grants for national initiatives were awarded to the Alzheimer’s Association, the International Association of Chiefs of Police (IACP) and Project Lifesaver International. Among them, the grant to IACP was to educate and prepare the law enforcement community for a projected increase in necessary intervention to assist people with Alzheimer’s disease and their families. The initial IACP project, in cooperation with Project Lifesaver International, focused on training and the development of a model policy for law enforcement agencies. IACP released this policy at its annual conference in October 2010. Other deliverables of the grant include training tools for officers to readily recognize and interact appropriately with persons in the community who have Alzheimer’s disease; these tools include CDs, roll call cards, posters, podcasts, and a Web site resource guide located at www.theiacp.org.

The grant to Project Lifesaver included conducting a comprehensive review of the effectiveness of existing national programs and local law enforcement methods for locating and returning missing individuals with dementia. This report addresses the following three broad categories of strategies that are currently available to assist in the identification and/or location of missing persons with dementia:

• **Ensuring that a missing person with dementia can be rapidly identified.** Many/most missing persons are found by Good Samaritans—individuals in the community who recognize that something is wrong and assist the person in returning to safety. If the person with dementia is not wearing or carrying some form of identification, there can be a significant delay in reuniting the missing person with a caregiver, thus greatly increasing the stress for both the individual and the caregiver. Multiple forms of identification, identification bracelets, clothing labels with contact information, and registry programs can expedite the process.

• **Alerting the public that a person with dementia is missing in the community.** Programs such as Silver Alert (which are modeled after Amber Alert for missing children) and A Child Is Missing (a national program that uses “robo-calling” technology to place telephone calls to local homes and businesses about missing children and vulnerable adults) can rapidly notify a community that a person with dementia is lost, thus increasing the chances that a Good Samaritan will promptly locate and assist in returning the individual to safety.

• **Using technology-assisted rapid response programs to locate the missing person.** A variety of electronic tagging and tracking systems have been developed for use by caregivers of persons with dementia and other individuals, such as children with autism or Down syndrome, who are also at risk of becoming lost. These systems use radio signals, global positioning satellites or cellular triangulation, or a combination of these technologies, to pinpoint the location of a missing individual who is wearing or carrying a tracking device.

Some of these approaches can be implemented only by law enforcement, some only by caregivers, and some by both. Currently, for the most part, costs for wandering or missing incident management systems are borne by consumers; the devices are not covered by government programs like Medicare and Medicaid, except, as of June 2012, in Florida and Massachusetts, which cover systems to protect against wandering under a Medicaid Home and Community-Based Services waiver.

In each of these three categories, this report reviews the pros and cons, including relative cost of the available methods, programs and technologies, as well as provides recommendations for law enforcement and policymakers. As the discussion will make clear, these methods, programs and technologies are not mutually exclusive, and in almost all cases, using a combination will produce the greatest likelihood that the missing person is found as quickly as possible before he or she suffers serious physical or emotional injury, and that the person can be identified in order to be returned home.

Law enforcement also has the potential to play a leadership role in creating a community safety net for persons with dementia and their caregivers; and, therefore, the final section of the report discusses how law enforcement can take on this responsibility. Although educational efforts about wandering should be directed at all families as a precautionary measure, it is particularly important that law enforcement provide advice regarding prevention and available community resources soon after a successful search. Law enforcement can also help educate the broader community about the risks of elopement and becoming lost, and how to identify and interact with a person with dementia, thus expanding the pool of potential Good Samaritans.24 Finally, local law enforcement agencies can partner with health and social services agencies to create a comprehensive community prevention and education campaign.

One example of a local program where law enforcement creates a relationship with vulnerable individuals in their community exists in Suffolk County, NY. The Suffolk County Police Department’s Community Outreach Bureau, which was established in 2005, acts as a liaison between the police department and the public. The bureau developed a local Silver Alert program that allows persons with dementia and other cognitive disorders to be registered in a local database with the intent that officials will be able to rapidly release this information to officers responding to an emergency situation involving one of these individuals. It also provides a Silver Alert identification bracelet to the individual free of charge. This is just one example of a local program that allows law enforcement to better understand the issues surrounding Alzheimer’s disease by directly recognizing these individuals in the community. The police department educates private, public and county agencies and county residents about the program through presentations at libraries, senior centers, nursing homes, assisted living facilities, nonprofit organizations dealing with people with special needs, other community groups, and health and wellness fairs, as well as via the department’s e-Newsletter and Web site.25

24 Meredith A. Rowe, “People with Dementia Who Become Lost,” American Journal of Nursing 103(7) (2003): 38 (“Only education can remedy the lack of knowledge about dementia among the general public and the consequent failure to realize how helpful Good Samaritans can be.”).
25 http://www.co.suffolk.ny.us/police/communityoutreachSilverAlert.htm
Identification Programs

“Passive” systems that feature identification programs are a critical component in coping with the issue of people with dementia who are lost. Should a Good Samaritan or a member of law enforcement approach or be approached by a person with dementia who has become lost, it might be virtually impossible for the individual to state his or her name and/or address due to memory loss, impairment of verbal skills or other symptoms of the disease. Compounding this, someone who has become lost in a populated area, such as a shopping mall or grocery store, will most likely be confused and scared. Therefore, some form of identification, such as a piece of wearable identification like a bracelet, necklace or clothing label imprinted with general information like an emergency contact number and the person’s diagnosis, can be an immense help in reuniting the person with a loved one.

A simple Internet search can help locate wearable identification at various price points, including some public and nonprofit organizations that provide some forms of identification at reduced or no charge. Each caregiver should take into consideration whether or not this wearable identification will be annoying to the wearer and possibly result in behavioral issues, and, moreover, whether it can be removed by the person with dementia. Depending on the situation, it may be appropriate to choose a product that only a caregiver or other party can remove.

One resource that combines wearable identification with 24-hour nationwide assistance is the Alzheimer’s Association’s MedicAlert® + Safe Return® program. Enrolling someone with dementia in the program requires providing information about the person, which could prove essential to the search and rescue effort. This includes the person’s name, Social Security number, height, weight, eye color, distinguishing marks and other characteristics, as well as a recent photograph. The jewelry is engraved with personalized information and MedicAlert + Safe Return’s 24-hour emergency toll-free response number. If the individual with Alzheimer’s disease or a related dementia wanders and becomes lost, a caregiver, concerned citizen, or a member of law enforcement or other emergency services can call the toll-free emergency response line to report the situation. This will activate a community support network, which includes local Alzheimer’s Association chapters and law enforcement, to help in the search for the individual. As of May 2012, the cost to enroll is $55, plus $7 shipping and handling, and there is a $35 annual renewal fee after the first year.26

Congress originally funded the Safe Return program in 1992 through the Missing Alzheimer’s Disease Patient Alert Program, with principal funding through the U.S. Department of Justice.27 According to the Alzheimer’s Association’s own statistics, in the first decade of its inception, the program had a 99 percent success rate, with 7,500 individuals recovered and returned to their caregivers.28 There are arguably many benefits to register someone with Alzheimer’s disease or a related dementia in a program like Safe Return. Most of all, it enables someone who is found to be identified so he or she can be returned home.

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26 http://www.alz.org/safetycenter/we_can_help_safety_medic_jewelry.asp
28 Wisniewski MD, Thomas M. and Marcin Sadowski MD, PhD. 100 Questions and Answers About Alzheimer’s Disease. Sudbury, MA. Jones and Bartlett. Print. Pg 161
However, it needs to be made clear that this works primarily as a “passive” system; in other words, it does not provide any type of tracking—or “active”—system that could locate a person’s whereabouts. So unless a family member, Good Samaritan or other person finds the individual with dementia, a strategic search would still need to be implemented. For instance, if the individual is lost in a wooded area, a traditional search and rescue method complete with law enforcement officials and possibly volunteers would need to be employed to locate the missing person.

Later on in this report, we will discuss “active” systems that utilize the latest technology, including personal, wearable tracking devices, to assist in the return of an individual with Alzheimer’s disease or a related dementia.

If caregivers find that the person with dementia can too easily remove the selected type of wearable identification, they may want to consider identification bracelets that companies market as “hard to remove.” For example, Never Lost ID markets clear wristbands customized with the individual’s name and emergency contact information that are designed to prevent the wearer’s removal, according to the company Web site. The site illustrates removal by having a third party cut the bracelet off with a pair of scissors, versus the individual with dementia sliding the ID bracelet off his or her wrist. The bracelet is made from a tough silicone product, yet is hypoallergenic, flexible and soft to the touch so as not to cause irritation on the skin. Each bracelet costs $19.95 and can be ordered online or by phone from the company. Like some other identification products on the market, this particular bracelet only provides emergency contact information that would be helpful in identifying someone with Alzheimer’s disease, but it is not connected to a central registry or call center.29

Public Alerts

After many tragic endings to events involving people with dementia who had wandered away and become lost, efforts began in local communities and at the state level to establish coordinated programs to locate missing individuals before they endure suffering or even death. Healthcare statistics show that six in 10 individuals with dementia will become lost at least once during the progression of the disease.30

As the incidence of Alzheimer’s disease increases with the nation’s aging population, the potential for increased cases of wandering rises accordingly. As noted earlier, up to 61 percent will suffer serious injury or death if not found within 24 hours of becoming lost.

Efforts to locate missing adults with dementia mirror more advanced efforts that have been implemented to find missing children. Much like with missing children, notifying the public as quickly as possible could be instrumental in locating a missing adult with Alzheimer’s disease or other cognitive impairment. The Amber Alert for missing children is a voluntary partnership between law enforcement agencies, broadcasters, transportation agencies and the wireless industry to activate an urgent bulletin in the most serious child abduction cases. Taking the lead from that, an initiative popularly called Silver Alert, or similar variations thereof, strives to widely spread or broadcast information that an adult, such as a senior or an adult with dementia, has wandered away and may be lost in order to galvanize community cooperation. Currently, Silver Alert is only being implemented at the state level. As of June 2012, 41 states have formally

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29 http://www.neverlostwristbands.com/default.asp
created alerts that target missing adults, with most specifying a cognitive impairment (see Appendix 2).31

Silver Alert programs use a variety of mediums to distribute an alert regarding a missing adult, including digital roadway signs, television and automated mass notification communication systems. Hi-tech automated emergency notification systems have been gaining ground, replacing low-tech systems such as alarms and buddy lists. Many vendors offer the automated mass communication systems that, in general, are designed to deliver detailed messages immediately, accurately and quickly to a predetermined audience. Depending on the company and/or client’s choice, these messages are relayed via phone, SMS text, e-mail, page, fax and/or TTY/TDD.

One industry leader is REVERSE 911®, an emergency notification system developed by Cassidian Communications, an EADS North America company specializing in mission critical communication and emergency notification. Cassidian’s software application combines mapping and database technologies, which allows public sector agencies such as law enforcement and

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**Missing Man with Alzheimer’s Reappears Next Day in North Carolina**

A man with Alzheimer’s disease who went missing Monday evening from Gainesville was found Tuesday morning hundreds of miles from town in Fayetteville, N.C.

Jack Hill, 83, was last seen in Gainesville at about 8:30 p.m. Monday at the Arby’s on Southwest 10th Street, said Capt. Angelina Valori, public information officer for the Gainesville Police Department.

Earlier that day, he was seen on Bo Diddley Community Plaza at about 6 p.m. and at the McDonald’s at 201 NW 13th St. that afternoon.

When he disappeared, he had last been seen wearing a green shirt, orange jacket, black socks and shoes and a beanie-style hat, according to a GPD flyer posted while he was missing.

After Hill’s family reported he was missing Monday, police issued a Silver Alert that was posted statewide.

This system is used when a person with a cognitive impairment is missing.

Hill had disappeared before a five-day trip a few years ago ended when he was found in Virginia. He took the bus then, so police checked the Greyhound system this time to see if he had purchased any tickets, Valori said.

He had a ticket to Fayetteville from Miami.

Local authorities were at the station when the bus arrived at 9:50 a.m. Tuesday.

“As soon as the bus pulled in, they found him,” she said.

Members of Hill’s family were sent to bring him home.

Police don’t know how Hill made it from Gainesville to Miami after he was spotted at Arby’s on Monday night.

“We don’t know how he got down to Miami,” Valori said. “Somebody probably picked him up and gave him a ride.”

Source: Morgan Watkins, The Independent Florida Alligator Staff Writer | Posted: Wednesday, November 9, 2011 3:45 a.m.

31 www.alzfdn.org
fire/EMS to notify citizens within a certain geographic area of an emergency situation. By subscribing to the REVERSE 911 service, county or city governments can automatically call citizens whose phone numbers are public—usually home-based landlines—and leave a recorded message with details of the emergency situation.\(^32\) For example, in August 2011, a child who was abducted in San Luis Obispo County, CA was successfully rescued after the county sheriff’s office employed the REVERSE 911 system in a localized area four different times in a 12-hour period. The first alert provided the boy’s physical description and asked anyone with information to contact local authorities. Two other alerts kept the public abreast of the ongoing situation, and the last one informed residents that the boy had been found safely. The alerts were instrumental in engaging the public in the search and rescue of this missing boy.\(^33\) One could see how this could also be effectively used in the search of a missing person with Alzheimer’s disease or related dementia.

Other companies in this space include One Call Now\(^34\) and Notification Server.\(^35\) Both are automated notification services that blast out messages to selected audiences, typically on an on-demand or emergency situation, or on a scheduled basis. Subscribers—individuals, government agencies, the private sector and nonprofit organizations—can restrict calls to numbers that are manually pre-loaded into the customer’s personal account database. This list should only include persons who have opted in to receiving such an automatic call, and does not use contact information maintained by any telephone provider or government entity. Some companies transmit messages simultaneously across multiple mediums, like phone, text and e-mail. Users should review the rules and regulations of the federal government’s Do Not Call Registry at www.donotcall.gov to assure compliance with federal law.

In addition, it must be noted that no system should be relied on as 100 percent foolproof. For instance, a message sent to a cell phone would not be immediately heard if the cell phone is shut off. Likewise, a system that relies on cell or GPS could break down in areas where environmental or other factors obstruct or block signal transmission.

The criteria for issuing a Silver Alert vary from state to state. For example, some states, like Arkansas, apply to missing persons of any age with Alzheimer's disease or another cognitive impairment. However, other states, like Texas, limit the alerts to persons older than 65 with a documented impaired mental condition. The latter does not take into account people who have dementia at a younger age, such as the instances of young-onset (also known as early-onset) Alzheimer’s disease, a rare form of Alzheimer’s disease that affects people under 65, including people as young as age 30.\(^36\) Other criticisms of a fragmented state-based system of laws include requirements by some states that documented proof such as prescription medications or medical records must be presented before an alert is even issued—even though time is of the essence.\(^37\)

In 2008, the National Silver Alert Act, which is defined as “a bill to encourage, enhance and integrate Silver Alert plans throughout the United States,” was passed in the U.S. House of Representatives. However, the 110th Congress adjourned before it could be taken up by the Senate; subsequently, it was passed a second time by the House in the 111th Congress and,

\(^{32}\) [http://www.cassidiancommunications.com/](http://www.cassidiancommunications.com/)
\(^{34}\) [http://www.onecallnow.com/](http://www.onecallnow.com/)
\(^{35}\) [http://www.notificationserver.com/](http://www.notificationserver.com/)
again, it was not passed by the Senate.\footnote{38}

Attempts for passage were repeated again in the 112th Congress, with the act introduced both in the House and Senate in 2011; H.R.112 was referred to the Subcommittee on Crime, Terrorism and Homeland Security, and S.1263 was referred to the Committee on the Judiciary. In today’s fragile economic environment, critics are quick to point out costs associated with the implementation of a national plan. The non-partisan Congressional Budget Office estimated in a 2008 report that those costs would be $59 million over a five-year period.\footnote{39} However, it has been noted that the amount does not take into account savings that could occur if states used an existing Amber Alert infrastructure to issue Silver Alerts.\footnote{40} See Figure 1:

Figure 1. Process for Issuing an Alert for Missing Vulnerable Adults

Source: Congressional Research Service.
Note: This diagram is a general depiction of the process for activating an alert and does not represent the exact process in each state.

\footnote{38} “H.R. 6064”. THOMAS Legislative Database, Library of Congress.
\footnote{39} “Cost Estimate, H.R. 6064, National Silver Alert Act”. Congressional Budget Office. September 4, 2008
A nonprofit organization with a national scope that is addressing this issue is A Child is Missing (ACIM). Despite its name, ACIM’s mission encompasses locating the disabled, the elderly and persons with Alzheimer’s disease in addition to missing children. The organization was created in 1997 because no such community-based program existed at the time to serve this purpose. ACIM’s Alert Program incorporates the following steps: A person calls the police department to report a missing child, elderly or disabled adult, or someone with Alzheimer’s disease; the police department calls ACIM’s toll-free number; ACIM records all relevant information about the missing individual; ACIM crafts a recorded message with the information that has been supplied, including the person’s last seen location; ACIM enters the location into the computer and gathers a database of phone numbers of nearby residents/businesses; and ACIM sends out the recorded message to the community by telephone. ACIM also requests a cell phone or beeper number to reach the officer on the scene for additional information and to follow up until the missing person has been found.

ACIM can place 1,000 calls in 60 seconds and process multiple cases simultaneously, and unlike a Silver Alert, can work without jurisdictional boundaries. Its services include law enforcement training as well as refresher training, training videos, brochures and media kits. Financial support comes from special events, sponsorships, private and corporate donations, and state and federal funding. Monetary support from each state is used to help maintain the program in that particular state.41

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Location: Mt. Clemens, MI
Elderly—Recovered May 7, 2012

Story: Macomb County, MI Sheriff’s Office—According to the case follow-up report returned by Dispatcher Hudson, the missing 80-year-old woman was found safe on May 7, 2012 with the assistance of A Child Is Missing Alert. The woman was reported missing when she did not return from a doctor’s visit, and there was concern for her safety because she suffers from dementia. More than 1,400 telephone alerts were sent to residents near both her residence and near the doctor’s office. The agency received six calls with information, but it was the first call that helped deputies locate the woman safe, less than half an hour from the time of activation.

Source: www.achildismissing.com

41 http://www.achildismissing.org/about.asp
Technology-Assisted Rapid Response Programs

Today, there are an increasing number of technological devices on the market to help in the search and rescue of people with Alzheimer’s disease or a related dementia who have become lost, whether from a home, long-term care residence or other location. There are pros and cons to each of these “active” systems, and no one service can guarantee that an individual can be found or found unharmed every time—underscoring the need to deploy all possible prevention methods to stop elopement from occurring in the first place. However, since the majority of people with Alzheimer’s disease will wander away at some point during the disease, possibly despite the best precautions taken, systems should be in place to aid families and law enforcement in the event that a situation mandates a search and rescue.

Approximately 70 percent of people with Alzheimer’s disease receive care at home.\(^2\) Noting the potential market, more companies have been developing technologically-advanced systems aimed at ensuring the safety of the person with dementia and the peace of mind of the family caregiver. Given the importance of ensuring the safety of residents in long-term care facilities as well, these systems—even if not marketed as such—can also be used for persons living in these types of settings.

While most of the available products share some similar characteristics, there can be distinct differences among them regarding:

- underlying location technology (i.e., GPS, cellular, radio; and potential signal transmission problems);
- degree and type of communication (i.e., instant or time-specific alerts; notifications to or access by one or multiple contacts; call, text or e-mail alerts);
- hardware (i.e., hand-held or wearable; size and weight; user-activated; battery life; risk of removal; waterproof/water-resistant);
- location tracking (i.e., constant, regular intervals, emergency-only; consumer/law enforcement involvement);
- involvement of third parties that assist in notification and search and rescue, such as call centers or law enforcement;
- cost (i.e., device, activation fee, monthly monitoring fee, other products like chargers, batteries);
- ongoing support (i.e., call center, affiliation with private company or nonprofit organization that provides training for public/law enforcement, and education or other resources to caregivers); and
- accuracy of location and success rates for search, rescue and safe return.

Some or all of these factors can, ultimately, impact feasibility and ease of use, and, moreover, search and rescue efforts, particularly for the dementia population. It should be noted that not all companies specifically cite the dementia population in their marketing materials. One of the most problematic drawbacks to any system is the potential for weakness of or disruptions in satellite signals or cellular network coverage, which could prevent or delay exact location information as well as prevent or delay an alert to the appropriate parties via phone or Internet. Another point of concern, and consideration, specific to people with cognitive impairment is the

characteristics of the hardware itself. Most notably, the device can prove ineffective if it: relies on activation or interaction on the part of the person with the disease who may lack the required ability or judgment; can be removed or left behind by the user; or does not work submerged or exposed to water (since someone may wander away and fall into a body of water). Therefore, to help make an informed decision about which product or even multiple products to utilize, it is important to understand how these technologies work.

**Global Positioning System (GPS)**—Many of these products utilize the Global Positioning System (GPS). GPS is a utility owned and operated by the U.S. Air Force; in addition to military uses, it is also provided to the public for civilian use. Currently, the GPS system includes more than 30 satellites in orbit 11,000 nautical miles above the earth. A GPS receiver, like the ones that can be used in a car, is required to detect signals from these satellites. In order to pinpoint the exact location of the receiver on the ground, it must connect to at least four satellites orbiting the earth; it has an accuracy of within one meter (approximately 10.7 square feet).  

In relation to this paper, companies have been tapping GPS technology and modifying it to help monitor persons who may have problems with cognition, such as those with Alzheimer’s disease or a related dementia. Depending on the product, these receiver devices can be worn on someone’s ankle or wrist, carried by hand or in a pocket or pocketbook, clipped on a belt or installed in a car.

Using a GPS receiver by itself has its limitations. While it is not reliant on a cellular network, it is dependent on access to satellites. The receiver must have an unobstructed connection with a satellite, meaning it might not work indoors (especially in urban buildings), in heavy brush, in the mountains or under heavy cloud cover.

**Assisted GPS (A-GPS)**—Assisted GPS (A-GPS) combines a GPS receiver with cellular technology. Due to GPS limitations, pairing a GPS receiver with cellular technology, whose signal can travel through solid structures, can prove to be more effective, except in locations, especially rural ones, where a cellular signal may not be available. Therefore, confirming cellular coverage is critical to this system's success. The location of a functional device with this technology can be determined by measuring the distance between cell phone towers in conjunction with data gathered from the satellite GPS system.  

One feature of some systems utilizing GPS or A-GPS that caregivers may find useful is the integration of the technology into a Web-based program and/or call center that can track the individual via telephone or the Internet. For example, some of the newer systems feature a location-based mapping service (LBMS) as well as the establishment of a virtual perimeter or predetermined boundary—a “geofence”; if the individual wearing or carrying the device wanders outside of that set zone, an alert will be sent, depending on the system, to designated parties (i.e., a caregiver) by phone, e-mail or text message. Some systems incorporate established call centers that can also provide timely information to the caregiver and local authorities.  

If used and working properly, these devices can leave a virtual trail, making it easier to locate the individual with dementia in an emergency situation. However, systems relying on cellular

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tracking use the same systems as cellular telephones and are subject to the same loss-of-signal mishaps. In addition, it is important for purchasers to ascertain at what moment (i.e., immediately, set time of day) they would be notified if a geofence is broken, as well as whether the system has a backup feature if an exact location cannot be pinpointed due to signal loss.

Among the systems, the Alzheimer’s Association’s Comfort Zone®, powered by Qualcomm, offers tracking devices that receive GPS and cellular signals to detect a person’s location and integrates it with a Web-based application that helps remotely monitor and locate someone with Alzheimer’s disease or a related dementia. According to the association’s Comfort Zone Web pages, one type of the device can be carried in an individual’s pocket or purse and works much like a cellular telephone; it is not available “to wear.” The other is designed to monitor the whereabouts of a vehicle, rather than an individual (at the time of this paper’s publication, this product was temporarily unavailable due to a product upgrade by the manufacturer).

Once an individual selects a device and a service plan, he or she can use the secure Web-based computer application to establish a “safe zone” for the person carrying the device or whose vehicle it is installed in. If that person travels outside of the pre-set area, the caregiver will receive an alert, such as a text message or e-mail, either, depending on the plan purchased, one to 15 minutes or one to 30 minutes after the barrier is compromised. Comfort Zone also comes with enrollment in the Medic Alert® + the Alzheimer’s Association Safe Return® program, a 24-hour emergency response system that would allow a caregiver to alert a team of professionals who in turn contact the proper authorities with the person’s information and suspected whereabouts.46

One of the obvious benefits of this program is the ability to monitor the person remotely. However, success depends on several very important factors. First, in order to use the Web-based application or to receive alerts by e-mail, the caregiver or person charged with monitoring the individual with Alzheimer’s disease must have access to the Internet. Second, an alert via text message requires cell phone service, which is not always possible, especially when traveling by airplane or in a rural area with poor reception. Since the device is carried, and is not attached to the wrist or ankle of the user, the person with dementia may forget to take the device when leaving home or may misplace it along the way. In this type of situation, the caregiver would not be alerted when the person wandered outside of the safe zone.

Another system that uses a combination of GPS and cellular technology and that can also be used outside the home is MobileHelp™. Marketed as a mobile medical alert system, it features a waterproof necklace pendant or a wrist button. Pressing the “Anywhere Help Button™” activates the device and transmits the person’s location and personal information to a 24-hour emergency response center. At this point, there is amplified two-way voice contact, making the device act much like a regular cell phone on speaker mode. The operator can assess the person’s situation and note the person’s location; protocol calls for sending the closest paramedics, and then calling and sending an e-mail alert to designated family members.47

This system addresses the issue of “wearability” of a device, versus having to remember to take it along. But, although Mobile Help’s Web site does not specifically say the device is designed for

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46 http://www.alz.org/comfortzone/index.asp
47 http://www.mobilehelpnow.com
people with cognitive impairment, the system’s limitation for this target population would be that it relies on the ability of the person to first press the button for help (or have someone else press it), and then ideally to communicate his or her situation. First, a person with dementia may not have the capability to remember or understand how to activate the system. Secondly, a person with dementia may have lost verbal skills or have other symptoms that prevent communication with the operator. In this case, the company’s Web site notes that even if the person cannot speak, the operator can see the person’s location and send first responders. However, hearing a voice through the device might turn into a very frightening and confusing situation for someone with Alzheimer’s disease.

Adiant Solutions markets several locator devices that use A-GPS technology to track individuals with Alzheimer’s disease or a related dementia. One type can be worn (bracelet with or without a locking band); another is belt-clipped or hand-held by the individual; and another can be placed in a car or golf cart. A smaller GPS device that can be placed in a keychain or worn as a pendant will be unveiled in June 2012. Its products address the progression of the disease: for example, tackling the issue of “holding” versus “wearing” a device, the company markets the handheld device as “ideal” for people with mild cognitive impairment; and it pitches the non-locking or locking bracelet for those with cognitive impairment, presumably with the degree of impairment determining the need for the extra feature. Adiant’s locating devices, similar to MobileHelp, rely on an SOS button, which dials a predetermined number to establish two-way communication. The company’s geofence and real-time tracking capabilities are similar to other technologies. The locator devices can allow a caregiver to monitor his or her loved one from outside the immediate environment via an Internet portal or two-way direct communication with the device just like a mobile phone. Designated contacts receive phone or e-mail alerts, or both, if the individual has traveled outside the designated geofence area. The device also includes an accelerometer, which can detect sudden movements or impacts such as a fall. If it detects such a movement, the device will automatically send an alert to the designated contact.48 As an alternative, Adiant Solutions partners with an organization called Centralized Vision to provide 24-hour, real-time monitoring of the individual wearing the device for a monthly fee of $19.95.49

SentrySilver GPS is another company that uses both GPS and cellular technology in its system. It also comes with a Web portal tracking technology, allowing the caregiver to monitor the device from the Internet, via computer or cell phone. The device is hand-held and can easily fit in someone’s pocket. Using geofence tools, the caregiver can also establish “safe” and “forbidden” zones and can opt to receive an e-mail, text or voice message to a designated telephone number when a person with dementia has left a safe zone. The device, the sentryGPSid™, can detect the current location and the last 200 location points collected.50 However, like other systems noted previously, without the capability to attach the device to the wrist or ankle of the person with dementia, the person at some point may forget to take the device when leaving home or may misplace it along the way. In this type of situation, the caregiver would not be alerted when the person wandered outside of the safe zone.

Another locator device using GPS and cellular technologies is being marketed by Breadcrumb LLC, a global leader in location-based services. The company designed and manufactures the Breadcrumb wandering solution, BC300, and developed it in collaboration with the Alzheimer’s

49 http://www.centralizedvision.com/gps_bracelet_monitor.asp
50 http://sentrysilvergps.com/index.php
Foundation of America to meet the specific needs of individuals with dementia and their caregivers. For example, on the exterior of the BC300, there is no on-off switch that could be accidentally turned off by an individual; and there are no flashing lights to irritate or distract an individual. Once fully charged and activated, the wearable, lightweight device is fastened with a heavy-duty band around the ankle or wrist of the person with Alzheimer’s disease; it is designed to be removable only by a third party. Caregivers designate a geofence or digital fence that establishes a “safe” field for an individual to be in; optimal is 800 feet from the location center, 400 feet in each direction.

Trained operators at the Breadcrumb Customer Care Center and up to five designated caregiver(s) can access the wearer's real-time whereabouts around-the-clock on a Google map via an Internet-connected computer and/or smartphones. The device sends the person’s whereabouts to the Breadcrumb Care Center every 15 minutes, and every one minute when someone leaves a designated zone. If the person has broken the geofence parameters, a care center professional immediately notifies the designated caregiver(s) via phone, cell phone text message or e-mail of the location of the device’s last transmission. The operator will remain on the telephone with the caregiver until the person has been successfully located. If necessary, the care center alerts emergency responders.51

With a different twist, GTX Corporation’s Personal Locator Services has devised miniaturized assisted GPS tracking and cellular-location transmitting technology for wearable location devices, including shoes and clip-on devices, and licenses its core technology to consumer brands. Aimed at people with dementia, Aetrex®, a footwear company, is marketing the Aetrex Navistar GPS Footwear System, which has GTX’s tracking technology embedded in the heel. The tech-enhanced leather footwear comes in lace and strap styles for men and women. The wearer’s location is recorded either every 10 minutes or every 30 minutes, depending on the monthly tracking plan purchased. When the person wearing the shoes wanders from a pre-set distance, a caregiver receives an alert on a smartphone and computer, with a direct link to a Google map that plots the person’s location. Like hand-held devices or removable jewelry, the potential shortfall comes when someone wanders away without wearing the shoe, or removes or loses it along the way.52

**Cellular Triangulation**—A system that uses only cellular signals to determine a device’s location is known as Uplink-Time Difference of Arrival (U-TDOA), a type of cellular triangulation technology. This wireless technology can be defined as the process by which the location of a transmitter can be determined by measuring either the radial distance, or the direction, of the received signal from two or three different points.53 U-TDOA is achieved by determining the times at which a cell signal reaches multiple Location Measurement Units (LMUs) installed at the cellular provider’s base stations. It works with all mobile phones. Again, this type of technology works well in areas where cellular service is readily available. Restrictions would occur, especially in very rural parts of the country.54

51 [www.breadcrumbgps.com](http://www.breadcrumbgps.com)
53 [http://searchnetworking.techtarget.com/definition/triangulation](http://searchnetworking.techtarget.com/definition/triangulation)
The locating service, EmFinders®, is one that uses this wireless technology and taps into the existing 911 infrastructure. The individual with dementia wears a watch-like device called the EmSeeQ, available with either a standard or secure-band option. Once the caregiver is made aware that a person has become lost, he or she must call law enforcement to file a missing persons report. Law enforcement will give the caregiver a case number. The registered caregiver then requests remote activation of the device by calling the 24/7 EmFinders Operation Center (EOC). To spare battery life, the device only checks for an activation command every 40 minutes. Once activated, the device places a call to the nearest 911 call center and transmits its location and a recorded message explaining the emergency. The 911 operator can then dispatch a police officer to the location transmitted by the device, while working in tandem with the EOC to share a description of the person who is lost as well as contact information for the caregiver.55

Radio Frequency Identification (RFID)—Another type of technology, commonly used as inventory control at retail stores, is Radio Frequency Identification (RFID). An RFID system consists of three components: an antenna or coil, a transceiver (with decoder) and a transponder (RF tag) electronically programmed with information unique to that tag. The antenna emits radio signals that activate the tag contained in the device. Once activated, the antenna can read and write data to the tag. The reader, which is contained in the same device as the antenna, emits radio waves that create an electromagnetic zone. The size of this zone is determined by the power output of the reader as well as the radio frequency. When the tag passes through the electromagnetic zone, it then detects the reader’s activation signal. The data transmitted by the tag can then provide location information.56

RFID technology uses a localized approach such as a boundary-crossing alarm, which notifies a caregiver that a person with Alzheimer’s disease wearing a device has wandered beyond a set periphery. One such system is Stanley Healthcare Solution’s RoamAlert® wander management, specifically designed for residents of long-term care settings (i.e., assisted living, nursing homes or continuing care settings). Residents are outfitted with a RoamAlert resident tag and strap; the strap is designed “to stay on” with a special clasp to lock it in place and is worn around the wrist or ankle. When a resident wearing RoamAlert approaches an exit or other forbidden location, an alarm is sent with detailed location information to designated pagers. This enables staff on-site to immediately trace the individual down to a specific room. This type of system can also deter falls or other injuries by keeping residents out of dangerous areas.57

Radio Frequency (RF) Telemetry—Radio Frequency (RF) Telemetry is a type of technology that may be best known historically for its use to locate or study migration patterns of wildlife.58 The technology has, however, been modified for optimal use in the human population, specifically for people prone to becoming lost. Telemetry is radio wave signals that have the ability to travel through most walls and objects—thus circumventing the potential signal problems that can impact GPS and cellular systems. However, radio signals can be affected by weather, environmental conditions, terrains and other factors, reducing tracking abilities down to half a mile in a densely-wooded area versus more than a mile in a mowed farm field.59

55 http://www.emfinders.com/how-it-works/faq#what-is-the-typical-emergency-activation-and-recovery-process
56 http://www.aimglobal.org/technologies/RFID/what_is_rfid.asp
58 http://www.michigan.gov/dnr/0,4570,7-153-10370_12143-70426--,00.html
Project Lifesaver International’s PLI-3000 is a rapid search and rescue response system that uses a form of RF Telemetry. The nonprofit organization works in collaboration with law enforcement and public safety organizations nationwide, which are trained and equipped with search and research equipment. Designed for adults with Alzheimer’s disease or related dementias and children with autism or Down syndrome, individuals enrolled in the Project Lifesaver program wear a small personal transmitter around their wrist or ankle that emits an individualized FM radio frequency tracking signal. The caregiver is instructed to notify its local Project Lifesaver agency if a client becomes lost, prompting the trained first responders to immediately begin a search with specialized mobile tracking equipment. The tracking equipment can detect signals denoting the individual’s location from a mile away on the ground to five miles by air. Searches average 30 minutes, compared to hours and days for standard recovery protocol. Additionally, Project Lifesaver assists caregivers in changing the 30-day battery and cutting off the band. It also develops outreach programs, including working with partners like the Alzheimer’s Foundation of America to educate law enforcement and caregivers about wandering and its prevention.

Stamford Police record first documented Project Lifesaver rescue in the state

STAMFORD -- When a loved one is missing, time is of the utmost importance, which is why Project Lifesaver International is such an important tool, says Stamford Police Officer Wayne Macuirzyński.

"When it is zero degrees outside and someone you love goes missing, that is not the best scenario," Macuirzyński. "Finding them as quickly as possible is what you want to do, so having the equipment to do that is crucial."

For the past two years, the Stamford Police Department has been participating in Project Lifesaver International, an organization whose mission is to quickly locate and rescue missing adults and children who wander due to Alzheimer's disease, autism, Down syndrome, dementia and other related cognitive conditions.

Last week, the Stamford Police Department made Project Lifesaver’s first documented rescue in Connecticut, according to police.

Stamford Police Officer Greg Rackoz, the officer who made the rescue, said Project Lifesaver is the reason why he found the missing Stamford resident in under 10 minutes.

"This was an elderly resident who has Alzheimer's disease and has gone missing before," said Rackoz. "The other time we had to find him, the department had around 15 officers out there looking for him for almost two hours. But since his family signed him up for Project Lifesaver, we only needed two officers and found him in under 10 minutes. It’s a great program."

Source: Stamford (CT) Times By Kara O'Conner Times Staff Writer
Posted: Wednesday, October 5, 2011 12:00 a.m.

www.projectlifesaver.org
including typical habits of wanderers and how to approach someone who has become lost.\textsuperscript{60} There are other devices, such as Care Trak, that are similar in nature to the Project Lifesaver system and use telemetry technology. Care Trak International, Inc. sells packages to police departments, fire departments and other public safety agencies that include receivers and training, so that responders can track high-risk individuals who are wearing bands that transmit silent radio signals 24/7. Caregivers purchase bands and batteries, including a new battery that lasts two months. The company also has a home-based perimeter system in which an alarm goes off if someone leaves a specific zone, and a mobile locator tracking unit that can find a lost person up to a mile away from the home. Families must register with a law enforcement agency that has Care Trak equipment.\textsuperscript{61}

These programs are dependent on law enforcement. To participate in Project Lifesaver or Care Trak, a person must be located in an area in which a public safety agency is equipped with the specific receiver equipment to track wanderers.

Deciding on the appropriate wander management solution for a loved one with Alzheimer’s disease or a related dementia requires much due diligence on the part of caregivers. The caregiver should understand how each system and its underlying technology works, and its available services, and weigh the potential benefits and drawbacks. While some points of differentiation may be financial- or structure-related, other key characteristics can be life-saving-related. On the latter, the system should be secure, reliable and efficient. One major variable is the amount of support, such as Web-based tracking or call centers, provided to the caregiver to assist with recovery. For instance, systems like Comfort Zone and the Breadcrumb BC300 can incorporate a call center, while EmFinders, Project Lifesaver and Care Trak involve law enforcement; some others systems put more of the onus on caregivers. Likewise, depending on the system, the time in which a caregiver is alerted when the person with dementia breaches a geofence can span widely—critical since every minute counts in search and rescue. Also of vital consideration is matching a system to a person’s current and future needs as they relate to risk of elopement.

As one can deduce from the preceding discussion on the latest technology, no one system or device can provide a 100 percent guarantee that people with Alzheimer’s disease or a related dementia will not wander from or become lost in their familiar surroundings or be found safely if they do. These are simply tools for caregivers and others that can provide some help in an often challenging, stressful and daunting daily routine. They can provide peace of mind and hopefully increase the odds that family members, law enforcement or private entities can successfully locate these most fragile persons who may lose their way at any moment, at any time of day or night, in any place or in any circumstance—and return them safely to their loved ones. Available wander management solutions plus emerging technology that may further boost reliability and effectiveness offer enormous value in terms of locating individuals before they are in harm’s way. There is no dollar amount that can be equated to a “life.”

\textsuperscript{61} www.caretrak.com
### Sampling of Products Currently Available

<table>
<thead>
<tr>
<th>Product</th>
<th>Location</th>
<th>Transmission Network</th>
<th>Monitoring Service</th>
<th>Device Cost</th>
<th>Monthly Service</th>
<th>Activation Fee</th>
<th>Other</th>
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<td>T-Mobile: ATT</td>
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<td>$249</td>
<td>$29.95/ $34.95</td>
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<td>Breadcrumb BC300</td>
<td>A-GPS</td>
<td>GSM: ATT &amp; T-Mobile</td>
<td>Breadcrumb; CST</td>
<td>$0 on contract, $190 off contract</td>
<td>$43 on contract, $53 off contract</td>
<td>$40</td>
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<td>MobileHelp</td>
<td>Included in periodic cost</td>
<td>$36.95 year/ $39.95 qtr./ $41.95 mon.</td>
<td>$0 annual/ $49 quarterly/ $99 monthly</td>
<td></td>
</tr>
<tr>
<td>SentrySilver GPS</td>
<td>A-GPS</td>
<td>GSM; ATT</td>
<td></td>
<td>$165</td>
<td>$14 basic/ $19 premium/ $40 unlimited/ $64.99 live</td>
<td>$90</td>
<td></td>
</tr>
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</table>
**Prevention Steps**  
*This section was adapted from Robert J. Koester, Chief Executive Officer, dbS Productions LLC*

**Elopedment Prevention**

As noted in this report, wandering itself does not harm the person with Alzheimer’s disease. In fact, wandering may help alleviate anxiety and may provide some often needed exercise. However, “becoming lost,” “critical wandering” or “elopement” that may result in a “missing incident” is a life-threatening problem that must be prevented. The same is true regarding “unsafe exiting” or “wandering away” from a long-term care facility.

While this report has discussed several programs that may help identify and/or locate individuals once they become lost, there are many steps family caregivers, professional caregivers and long-term care facilities can take to help prevent this situation from happening in the first place. Law enforcement can play a critical role for individuals with Alzheimer’s disease and related dementias and their family caregivers in elopement prevention. As the first responders to missing person reports, law enforcement officers have the credibility, and often have established relationships with the families, to initiate a dialogue about elopement prevention tips, and additional prevention resources and programs.

Elopedment prevention may be broken into three major categories: behavioral, inside environment and exit control. Each preventative measure can be implemented in the person’s residence or in a skilled care facility.

- **Behavioral** - Identification of the contributing factors that lead to wandering. This is also sometimes called discovery of agenda behavior.
- **Environmental** - Modification of the inside environment to enable the person to move about in a safe, non-intrusive manner within the structure.
- **Exit Control** - Reduction of unsupervised access to external areas of the premises in an appropriate manner.

**Behavioral Measures**

The first step is to recognize common causes that often trigger elopement. Two studies have been conducted that give similar but slightly different results. The results from Silverstein and Salomns (n=239) are given first and the results from O’Connor, Rosewarne & Bruce study (n=15) are given second. It is expected that differences in results are largely due to differences in the sample sizes. Percentages do not total 100 percent because of some multiple causes or unavailability of information.

Causes that often trigger elopement include:

- Placed in unfamiliar environment (28 percent) (20 percent)
- Saw coat and hat and decided to leave (27 percent) (13 percent)
- Argumentative or confronting situation (23 percent) (47 percent)
- Change in schedule or routine—often first week of moving to a new care facility (23 percent) (27 percent)
• Spent the day in day care (23 percent)
• Had a change in medication (21 percent)
• Was left alone in car (18 percent)

Next, look for the underlying cause of each of these trigger factors. These might include:
• Medication effects
• Stress
• Confusion related to time
• Becoming disoriented to landmarks, familiar people and objects
• Misinterpretation of sights and sounds, resulting in increased anxiety or fear
• Restlessness
• Agitation
• Anxiety
• Past experience pattern (i.e., going to work, looking after a child)
• Memory links (i.e., seeing coat > going outside; seeing doorknob > something to turn)

If a caregiver is unable to recognize an underlying cause or pattern to the wandering, it helps to keep a log of the wanderer’s pattern. The log should list the time, date and events surrounding each elopement event. Over time, it should assist in identifying the possible underlying cause(s). Once a cause of potential elopement has been identified, steps may be taken to reduce the behavior, such as:
• Consult with a physician regarding medication side effects.
• Make sure the person's basic needs (hunger, thirst, temperature, toileting, fear, boredom, etc.) are met.
• Encourage exercise to reduce anxiety, agitation and restlessness. Exercises may include activities such as long vigorous walks, circular walking, rocking chairs, playing with beach balls, dancing or group exercises.
• Empower the person and provide a sense of control by involving him or her in productive daily activities.
• Redirect the person's attention. Offer the person a favorite food or drink. Avoid arguing or confrontation. Instead, focus on a distracting activity.
• Place interesting items the person may engage with near exits.
• If possible, allow the person some control over aspects of his or her life, such as activities or food selection.
• Orient the person to people and place by reminding the person that he or she is in the right place. This should include frequently repeating the name of the person with Alzheimer's disease, or caregiver or staff, and locations of places in the residence. Skilled facilities may consider having staff wear extra-large name tags.
• Let the person look out windows to stay oriented to time of day and season.
• Make sure the person has properly-fitted glasses and hearing aids (if required).
• Reassure the person, if he or she feels lost, abandoned or disoriented. Talk with the
person in a low tone of voice, and use short words and simple phrases. Gently touch the person if words are not understood. It provides reassurance and communicates warmth. Make sure you approach the person from the front and make eye contact first.

- Schedule short-term interesting activities.
- Provide comfortable rocking chairs.
- Provide companionship and one-on-one attention.
- Avoid extended interactions with a large group of people.
- Avoid physical or chemical restraint.

**Environmental Modifications**

- Help the person stay oriented to time by placing clocks and calendars in various spots around the home or facility.
- Remove "trigger" items such as hats, coats, keys, etc. that signal to the person that it is time to leave the structure.
- Place large signs on the bathroom door to reduce wandering in a search to find the toilet. Place a night light in the bathroom.
- Place a picture of the person or a collage of significant pictures on the person’s bedroom door.
- Reduce environmental distractions such as noise levels from television or loud music.
- Provide continuity with the same room assignments and the same furnishings in the room.
- Design a walking path that allows safe wandering with interesting destinations and objects along the way.
- Make the environment more home-like.
- Design a quiet and comfortable place for the person to sit if he or she becomes agitated.
- Assign staff to be responsible for the location of each person.
- Regularly check that doors and gates are securely locked.
- Ensure staff vigilance and observation.
- Assign a companion resident who does not have dementia.

**Exit Control**

- Install fencing or hedges around the home or facility.
- Landscape the outside of each exit with fencing enclosures or hedges.
- Consider placing locks at the bottom of the door or other unfamiliar areas.
- Use child-proof door covers to prevent the individual from turning the knob.
- Set up physical/visual barriers (magnetically locked doors with coded keypads, secured windows, etc.).
- Conceal doors with curtains, posters or other objects that divert the person’s attention away from exiting.
- Paint the door the same color as the wall, and continue onto the door any accent stripping used on the walls.
• Place exit doors along halls instead of at the end of the hall.
• Avoid windows in a door.
• Put a strip of cloth (usually fastened with Velcro) across the door knob.
• Use electronic surveillance to monitor residents in the facility.
• Use visual surveillance (video) on doors that are monitored by staff either directly or indirectly.
• Place alarms on all external doors as an alert if a person is leaving. Reduce the chances of exiting through windows by installing safety latches.
• Lock windows.
• Cover windows to discourage the person from wandering away.
• Place a clearly defined barrier in front of stairs, keeping safety in mind.

Wandering Response Plans
• Develop a wandering response plan. Update the plan at least twice a year. Look over this plan carefully. Make any required modifications. The value of the planning process is not so much the plan, but the preparation and the "what if" mentality that goes into making the plan.
• Conduct a "missing wanderer" simulation, if possible.
• As part of your wandering response plan, be sure to tell your neighbors and/or local businesses of the person’s condition. Ask them to call the emergency contact (caregiver, secondary contact, 911, etc.) if they ever see the person with Alzheimer's disease out alone. Be sure to provide a copy of a photo if needed. Keep a list of their names and phone numbers. Ask if they would be willing to help search if needed.
• As part of your wandering response plan, develop a list of alternative transportation sources. Be aware that the person may not only wander by foot but also by car or by other means of transportation.
• As part of your wandering response plan, keep a list of emergency phone numbers and addresses of the local police departments, rescue squads, fire departments, hospitals and poison control.
• Regularly check fire extinguishers, smoke alarms and other safety equipment to ensure they are working properly. Conduct fire and missing person drills regularly.
• Complete a “Wanderers Information Sheet” (WIS), which can be found online at http://www.dbs-sar.com/SAR_Research/WIS.pdf. Update this sheet at least twice a year. Keep a copy of this sheet handy to give to law enforcement. All searches begin with an investigative component. During this time you will be asked dozens of questions to aid law enforcement and search teams in determining where and how to look. This information is critical to the success of the search. Completion of this form before an incident allows the search to start sooner and assists in collecting more accurate information.
State Listing of Silver Alert Programs

Beginning in 2006, state legislatures across the nation have been approving, and state agencies have been implementing, programs that broadcast alerts when vulnerable adults go missing. Mostly known as Silver Alerts, these programs feature a structured set of criteria and procedures for law enforcement to institute an alert. They may vary in: the eligibility required to activate an alert, such as a specific age and/or diagnosis of cognitive impairment; the eligibility of a person who can file a missing persons report, such as a spouse, legal custodian or agency; the protocol to verify that a person is missing; and how law enforcement implements the alert, such as via media, recorded calls or highway signs. However, the one common thread is the premise behind these alerts: to help locate someone whose disappearance poses a threat to the person’s health and safety, including serious bodily harm or death.

As of June 2012, 41 states have implemented Silver Alert programs. Several others are pending. For more information, contact the state agency responsible for the program’s administration or local law enforcement.

**Alabama**
Name: Missing Senior Alert Plan
Eligibility: senior citizen with dementia or other deterioration of intellectual faculties
Administrator: Alabama Department of Public Safety

**Arizona**
Name: Endangered Person Alert
Eligibility: adult with significant health problem or medically-diagnosed disability (i.e., dementia)
Administrator: Arizona Department of Public Safety

**Arkansas**
Name: Silver Alert
Eligibility: senior or adult with cognitive disorder
Administrator: Arkansas State Police/Arkansas Sheriffs’ Association/Arkansas Association of Chiefs of Police

**Colorado**
Name: Missing Senior Citizen and Person with Developmental Disabilities Alert Program
Eligibility: 60 or older with verified impaired mental condition; person with developmental disability
Administrator: Colorado Department of Public Safety, Bureau of Investigation

**Connecticut**
Name: Silver Alert
Eligibility: 65 or older; 18 or older with mental impairment
Administrator: Connecticut Department of Public Safety

**Delaware**
Name: Gold Alert Program
Eligibility: 60 or older; person with disability
Administrator: Delaware State Police
Florida
Name: Silver Alert
Eligibility: cognitively-impaired adults who become lost while driving
Administrator: Florida Department of Law Enforcement

Georgia
Name: Mattie's Call
Eligibility: adults who are cognitively impaired or developmentally impaired
Administrator: Georgia Bureau of Investigation

Illinois
Name: Endangered Missing Person Advisory Program
Eligibility: seniors with Alzheimer’s disease or other dementia
Administrator: Illinois Department of Aging/Illinois State Police

Indiana
Name: Silver Alert
Eligibility: 18 or older with mental illness, dementia or other physical or mental incapacity
Administrator: Indiana Clearinghouse for Information on Missing Children and Missing Endangered Adults/Indiana State Police

Iowa
Name: Endangered Person Advisory
Eligibility: adults with dementia
Administrator: Iowa Department of Public Safety

Kansas
Name: Silver Alert
Eligibility: person with dementia; 65 or older
Administrator: Kansas Bureau of Investigation

Kentucky
Name: Golden Alert
Eligibility: impaired person with developmental disability; person with physical, mental or cognitive impairment
Administrator: Kentucky Division of Emergency Management

Louisiana
Name: Silver Alert
Eligibility: 60 or older with diagnosed mental impairment
Administrator: Louisiana Department of Public Safety and Corrections

Maine
Name: Silver Alert Program
Eligibility: adults with dementia or developmental disabilities
Administrator: Maine Department of Public Safety
**Maryland**
Name: Silver Alert Program  
Eligibility: 60 or older with cognitive impairment  
Administrator: Maryland State Police

**Massachusetts**
Name: Silver Alert Community Response System  
Eligibility: adult with serious memory impairment  
Administrator: Massachusetts Executive Office of Public Safety

**Minnesota**
Name: Missing Children and Endangered Persons’ Program aka Brandon’s Law  
Eligibility: all ages, including mentally impaired  
Administrator: Minnesota Bureau of Criminal Apprehension

**Mississippi**
Name: Silver Alert System  
Eligibility: 18 or older with dementia or other cognitive impairment  
Administrator: Mississippi Department of Public Safety

**Missouri**
Name: Endangered Person Advisory  
Eligibility: 18 or older  
Administrator: Missouri State Highway Patrol

**Montana**
Name: Missing and Endangered Person Advisory  
Eligibility: person believed to be in danger due to age, health, mental or physical disability  
Administrator: Montana Department of Justice, Division of Criminal Investigation

**Nevada**
Name: Statewide Alert System for Safe Return of Missing Endangered Older Persons  
Eligibility: 60 or older  
Administrator: Nevada Department of Public Safety

**New Hampshire**
Name: Missing Persons With a Developmental Disability and Missing Senior Citizen Alert Program  
Eligibility: persons with developmental disability; 55 or older with verified impaired mental condition  
Administrator: New Hampshire State Police

**New Jersey**
Name: Silver Alert System  
Eligibility: person with cognitive impairment  
Administrator: New Jersey State Police
New Mexico
Name: Endangered Person Advisory
Eligibility: endangered person, including person with degenerative brain disorder
Administrator: New Mexico Department of Public Safety

New York
Name: Missing Vulnerable Adult Alert Program
Eligibility: 18 or older with cognitive disorder, mental disability or brain disorder
Administrator: New York Division of Criminal Justice Services/ Missing Persons Clearinghouse

North Carolina
Name: Silver Alert Program
Eligibility: person with dementia or cognitive impairment
Administrator: North Carolina Department of Public Safety

Ohio
Name: Missing Adult Alert
Eligibility: 65 or older; or adult with mental impairment
Administrator: Ohio Bureau of Criminal Identification and Investigation

Oklahoma
Name: Silver Alert Program
Eligibility: 60 or older with dementia or other cognitive impairment
Administrator: Oklahoma Department of Public Safety

Pennsylvania
Name: Missing and Endangered Person Advisory System (MEPAS)
Eligibility: endangered person due to age, mental or physical disability
Administrator: Pennsylvania State Police

Rhode Island
Name: Missing Senior Citizen Alert Program
Eligibility: 60 or older with impaired mental condition
Administrator: Rhode Island State Police

South Carolina
Name: Endangered Person Notification System
Eligibility: person with dementia or other cognitive impairment
Administrator: South Carolina Law Enforcement Division of Missing Persons/Missing Person Information Center

South Dakota
Name: Endangered Person’s Advisory
Eligibility: person believed to be in danger due to age, health, mental or physical disability
Administrator: South Dakota State Police
**Tennessee**
Name: Senior Alert
Eligibility: 18 or older with dementia or disabled
Administrator: Tennessee Bureau of Investigation

**Texas**
Name: Silver Alert
Eligibility: 65 or older with diagnosed impaired mental condition
Administrator: Texas Department of Public Safety

**Utah**
Name: Endangered Person Advisory
Eligibility: person believed to be in danger due to age, health, mental or physical disability
Administrator: Utah Department of Public Safety

**Virginia**
Name: Senior Alert System
Eligibility: 60 or older with cognitive impairment
Administrator: Virginia State Police

**West Virginia**
Name: Silver Alert Plan
Eligibility: person with cognitive impairment
Administrator: West Virginia State Police

**Washington**
Name: Endangered Missing Person Advisory Plan
Eligibility: person believed to be in danger due to age, health, mental or physical disability
Administrator: Washington State Patrol, Missing Persons Unit

**Wisconsin**
Name: Endangered Missing Person Alert
Eligibility: person believed to be in danger
Administrator: Wisconsin Crime Alert Network/Wisconsin Department of Justice

**Wyoming**
Name: Endangered Person Advisory
Eligibility: person believed to be in danger
Administrator: Wyoming Division of Criminal Investigation

**Pending:** California, Hawaii, Michigan

**No program:** Alaska, Idaho, Nebraska, North Dakota, Oregon, Vermont

*Note: As of June 2012*
Resources

American Silver Alert Coalition
Legislative Updates
www.silveralertbill.com

Eldercare Locator
Local Resources
www.eldercare.gov

International Association of Chiefs of Police
Alzheimer’s Initiatives
www.theiACP.org

U.S. Department of Health and Human Services
Alzheimer’s Disease Information
www.alzheimers.gov

Books

Title: “Evidence-Based Protocols for Managing Wandering Behaviors”
Author: Audrey L. Nelson, Donna L. Algase Ph.D., RN (Editor)

Title: “In Search of the Alzheimer’s Wanderer: A Workbook to Protect Your Loved One”
Author: Mark Warner

Title: “Lost Person Behavior: A Search and Rescue Guide on Where to Look — for Land, Air
and Water”
Author: Robert J. Koester

Title: “Safe Return Home: Crankshaft Inspirational Book for Caregivers of Alzheimer’s”
Author: Tom Batiuk

Title: “The 36-Hour Day: A Family Guide to Caring for People with Alzheimer Disease, Other
Dementias, and Memory Loss in Later Life”
Authors: Nancy L. Mace and Peter A. Rabins, M.D., MPH

Title: “The Alzheimer’s Action Plan: The Experts’ Guide to the Best Diagnosis and Treatment for
Memory Problems”
Authors: P. Murali Doraiswamy, M.D., Lisa P. Gwyther, Tina Adler

DVD

Title: “Wandering...What It Is and What to Do About It”
(Your Time to Care Caregiver Education Series)
Produced by: Alzheimer’s Foundation of America