



IACP NATIONAL LAW ENFORCEMENT POLICY CENTER

Missing Persons with Alzheimer's Disease

Concepts and Issues Paper

April 2011

I. INTRODUCTION

A. Purpose of Document

This paper was designed to accompany the *Model Policy on Missing Persons with Alzheimer's Disease*. Alzheimer's disease and related dementias (AD/D) is a community issue, especially when a person with AD/D is missing. Searches are exhaustive, expensive, and not always successful. As the population of persons with AD/D grows, so too will the demand for law enforcement and community resources for those with AD/D. This paper addresses best practices, response challenges, and specific search-and-rescue protocols for the AD/D population. It is anticipated that this material will be of value to law enforcement executives in their efforts to tailor the model policy to the requirements and needs of their agencies and communities.

B. Background

Currently over five million Americans have AD/D, and it is projected that seven million people will have AD/D by 2030.¹ Approximately seven out of ten persons with AD/D are cared for at home by almost 11 million unpaid caregivers.² It is important to note that while AD/D most commonly strikes older adults, there is a growing percentage of cases of early-onset Alzheimer's disease

beginning as early as age 35. Therefore, it is important to approach all encounters with persons with Alzheimer's with this in mind.

AD/D is a progressive brain disorder that damages and eventually destroys brain cells and leads to tissue loss throughout the brain. Over time, the brain shrinks dramatically, affecting nearly all bodily functions.³ Alzheimer's is not a part of normal aging, but results from a complex pattern of abnormal changes starting in the region of the brain that affects recent memory and then gradually spreads to other parts of the brain. It usually develops slowly and gradually gets worse as more brain cells are damaged or destroyed. When interacting with an individual with AD/D, law enforcement and first responders should consider this person as a diseased individual rather than an individual having a psychological mental health issue. As a result, an AD/D person should be taken to a hospital not a mental health facility.

Persons with AD/D present unique and considerable challenges to law enforcement. AD/D is hallmarked by progressive memory loss and disables a person's ability to think clearly; to recognize persons, landmarks, or other familiar objects; to remember the names of objects; to safely operate a vehicle; and, often, to react rationally under what most people would consider normal situations. Persons with AD/D may display poor situational or contextual awareness. When taking a report of a missing person with AD/D, consider that the AD/D mind is not logical and the missing person is lost both physically

¹ The Alzheimer's Association, *2010 Alzheimer's Disease Facts and Figures*, Alzheimer's & Dementia, vol. 6 (2010), http://www.alz.org/documents_custom/report_alzfactsfigures2010.pdf (accessed October 14, 2010).

² Ibid.

³ Ibid.

and mentally. Lost persons with AD/D most often do not consider themselves lost.

Reports of missing persons with AD/D should be treated as emergencies, beginning with an exhaustive search of the home and premises as soon as reasonably possible. Studies have proven that those missing with AD/D tend to hide or seclude themselves early in the process, so swift action is imperative. The first six hours are the most critical; of those individuals found alive, about 60 percent were found within the first six hours of being missing and about 30 percent within six to twelve hours.⁴

The initial response to a missing person with AD/D is perhaps the most crucial component of the investigation. The manner in which law enforcement officers respond to the initial call often determines whether the person is found quickly and returned home safely, remains missing for an extended period of time, or is never found. Questioning, report-taking, investigation, and search considerations should be expanded beyond a standard missing person's case since lost persons with AD/D may not think they are lost or missing, rather they have established a mission to go somewhere, even if it is a faulted mission. Furthermore, AD/D persons won't likely respond to anyone calling for them, nor will they ask for help. They likely don't understand that you are searching for them, consequently, making search considerations for them greatly different from most typical missing person's cases.

C. Wandering as a Symptom of AD/D

The term "wandering" is actually misleading, as the majority of missing persons become disoriented while they are engaged in a routine activity. Persons with AD/D most often have an intended mission, whether it is real or imagined. Wandering is a result of the diseased brain being unable to recall familiar surroundings or routes, problems with way finding and spatial orientation, and the brain's inability to problem solve. It is estimated up to 70 percent of persons with AD/D wander away from their caregivers or care settings at some point in the illness. Wandering is arguably the most dangerous of AD/D symptoms.⁵ Unlike other forms of dementia, Alzheimer's sufferers commonly experience neurological and sensory impairments so that the missing individual may not recognize the body's signals to stop, including pain, dehydration, and hunger. This is why a missing person with AD/D is capable of walking farther than his or her physical condition might indicate, hide in difficult terrain, or continue without stopping for sustenance or restrooms.

⁴ Meredith Rowe, "People with Dementia Who Become Lost," *American Journal of Nursing* 103, no. 7 (July 2003): 32-39.

⁵ Ibid.

II. CATEGORIES OF MISSING PERSONS WITH AD/D

Missing persons with AD/D fall into three categories:

1. *Individuals who seem coherent and oriented during encounters with law enforcement and other persons and may not be classified as missing, but upon further investigation their behaviors suggest that they are lost or at risk of becoming lost.* This includes individuals who are en route to regular outings (such as the grocery store, bank, or doctor's office), but instead become disoriented, sometimes requesting assistance of law enforcement personnel. Such encounters with law enforcement might include directional or roadside assistance; responding to reports of the person unknowingly shoplifting; items reported stolen by the AD/D individual (which may or may not be truly stolen); and traffic stops related to the person's poor memory and inability to comprehend the "rules of the road."

One significant aspect of such encounters is that the person can often navigate a casual conversation that is devoid of facts or specificity. For example, if asked his or her name the person might say, "Oh, didn't I tell you that already?" or if asked where they are going, the person might respond, "Oh, just around the corner." Vague responses such as these should be considered with caution. Such instances should be viewed by law enforcement personnel as an opportunity to prevent a missing person case. Officers should treat encounters with all older adults with special considerations and ask evaluative questions in an effort to determine the person's ability to understand the situation.

2. *Those who are missing, but have not yet been reported missing by caregivers.* This primarily refers to those with AD/D who leave their homes or care facilities, or those, from the first categories, who have raised the suspicions of those around them, but have not yet been reported as missing. Most often someone encounters the person, knows or senses the person is lost, and secures the person until family or law enforcement is contacted.

Law enforcement should also take into consideration that many persons with AD/D are undiagnosed and may not have a formal caregiver. Sixty-one percent of caregivers report that a diagnosis of AD/D came one to two years after symptoms first appeared.⁶

3. *Those who are reported missing by caregivers or the care facility.* Often by the time the report is made, the person has been missing for some length of time. This delay can be the result of a variety of circumstances, including caregivers searching in vain on their own, the person going missing while the caregiver is sleeping, the

⁶ The Alzheimer's Association, 2010 *Alzheimer's Disease Facts and Figures*.

caregiver hoping the person will return, or the caregiver's embarrassment. For these reasons, law enforcement personnel should assume they are already working with significant time already lapsed.

Each category presents unique opportunities for law enforcement intervention that are specific to persons with AD/D. Indicators of a person with AD/D who may be disoriented or lost include the following:

- Inappropriate clothing for weather
- Inappropriate social behavior for the setting
- Inability to navigate crosswalks or sidewalks
- Aimlessness
- Walking in the street or on the side of the road
- Difficulty interacting with others in proximity

A. Challenges to Law Enforcement

Missing persons with AD/D present challenges to law enforcement including the following:

- They may not take a coherent path—searchers must redirect thinking of likely or logical routes and appropriately modify traditional missing persons protocol.
- They often try to seclude themselves in natural areas, such as lakes, ponds, brush, or woods, early in the event. Once secluded, they are likely to remain in that location or nearby.
- They likely will not respond to anyone calling for them, ask for help, or understand that they are the subject of a search.
- In their broken logic, lost AD/D persons may seek to evade searchers if they suffer from paranoia or delusions, think they are “in trouble,” know they are doing something that is prohibited, or are simply scared of their unexpected surroundings.

III. PROCEDURES

A. Identifying the At-Risk Older Adult and Preventing a Missing Person Case

Often an older adult, who, while initially coherent, is subsequently recognized as being confused and disoriented, will encounter law enforcement for a variety of reasons. Upon further questioning, he or she may provide vague answers without factual basis, display poor communication skills, be unable to follow instructions, or demonstrate other markers of AD/D. Often the individual is aware of his or her memory deficiency and will try to negotiate the conversation with casual conversation as previously discussed.

Every effort should be made by law enforcement personnel to question older adults to ensure their safety and to safeguard them in the event that an officer's suspicions

are raised about the mental capability of the older individual. In traffic stops, if there is a witnessed violation, it is recommended to cite the driver instead of issuing a warning, as this will create a paper trail for caregivers, medical practitioners, and the licensing agency for follow-up. In instances where an officer becomes suspicious about an older person's mental capabilities, the person should be secured at his or her present location and efforts should be made to locate family or a care facility. If reasonable efforts are not successful, the person can be taken to a local hospital. The vehicle should be safeguarded per agency standards.⁷

In both suspected and reported cases, law enforcement personnel should check if the person has a tracking or identification device.⁸ Devices are usually visible on the wrist, neck, or ankle.

B. Reporting/Classification of Missing Persons with AD/D: Call-Taker and First Responder Responsibilities

The model policy indicates there should be no waiting period to respond to a missing person's report when AD/D is known or suspected. Persons who know the behavior patterns and character of the individual involved, such as caregivers, guardians, or personal friends, are often the best sources of information for the individual's whereabouts.

The most critical role in any missing persons case is that of the first responder. It is this officer who initially establishes the seriousness of the complaint about a missing person with AD/D, safeguards the scene, gathers crucial facts, and conducts preliminary interviews of witnesses. All law enforcement personnel need to be trained to respond to such calls efficiently, compassionately, and professionally—completing the aforementioned tasks, while simultaneously calming and reassuring the caregivers or guardians of the missing person. For this reason, officers must be as thorough as possible in responding to such reports. Assumptions about such cases must be avoided, as they may lead officers to overlook crucial information, evidence, and clues to the missing person's whereabouts.

Before arriving on scene. Before the responding officer arrives on the scene, information about the missing person should be relayed from the dispatch or

⁷ An assessment tool has been developed to help evaluate older adults, *Cited Driver Worksheet* (Missouri State Highway Patrol, February 2010).

⁸ Examples of these devices include the Alzheimer's Association's MedicAlert + SafeReturn and Project Lifesaver. MedicAlert + SafeReturn is a registry program in which the individual's emergency and medical information is accessible through the missing person's identification bracelet number. Project Lifesaver is a two-way radio system in which the wearer's bracelet emits signals that assist law enforcement in locating the missing person.

Emergency Operations Center (EOC) to the responding and assisting officers. EOC operators, working with a standard list of predetermined questions, should gather pertinent information from the caller and relay it to the responding officers. Once the EOC operator has calmed the caller, basic facts and information can be gathered to help responding officers, including a brief description of the missing person and any other known information. EOC personnel should, to the degree possible, also provide responding officers with an overview of any agency records concerning the missing person, such as the person's history of wandering episodes and other locations the person has previously been found; fears of crowds, law enforcement officers, or other persons in uniform; access to cars, money, and other resources; knowledge of public transportation; favorite locations; and access to weapons.

Such information could disclose many things: potential locations the person might go, how far the person could travel with the resources available, and any potential threats to officer safety or that of civilians who may encounter the individual.

Agency policy should provide for a city- or countywide radio alert to all other patrol units and all neighboring law enforcement agencies, as soon as reasonably possible. These radio broadcasts often result in prompt, safe recoveries, particularly when the person has simply wandered away from home and is in the immediate area. Any information about tracking or identification systems should be relayed and the corresponding organization contacted immediately.

Once on scene. Once on the scene, the responding officer should do the following.

Interview the person who made the initial report to the EOC. After ruling out foul play, the officer should interview the reporting party. This interview should be conducted in an area where interruptions are minimal and preferably in private. The purpose of the interview is to obtain substantive information necessary to report to searchers. The officer should seek a recent photo and ascertain to what extent a search has already been conducted.

Information obtained from the interview should include a full physical description, including clothing last seen in; the relationship of the reporting party to the missing person; the time and place of the last known location; and who was the last person to see the missing person. Additional information may include whether the person left on foot or by car and, if by car, how much gas was in the tank. Inquiries should be made regarding plans, habits, routines, and personal interests of the individual including places frequented or locations of particular personal significance. The officer should also determine which door

or exit the person left from, as it often provides valuable clues to the missing person's path.

Additional helpful questions for investigating missing persons with AD/D include the following:

- Would the person recognize and respond to police officers or someone in uniform?
- Would the person be fearful of police or those in uniform for any reason?
- Could the person have gone to a former residence, workplace, church, and so on?
- What is the person's general daily routine?
- Is the person able to use money, and is it likely the person is carrying any money?
- What neighbors does the person know well?
- Are there activities the person seeks out or enjoys? What would the person find interesting?
- Does the person know how to use public transportation, or use it regularly?
- Does the person still remember a home address or telephone number?
- Is the person drawn to certain landmarks, buildings, or objects?
- Does the person have fears of crowds, strangers, and so forth?

The last person to see or have contact with the missing person should be carefully interviewed if he or she is not the reporting party. If there are several people at the scene, each person should be interviewed separately. Witnesses should not be interviewed in the presence of other witnesses, since there is a tendency on the part of some to go along, either consciously or unconsciously, with a description given by another witness. As most officers know, the perception and recall of witnesses can be faulty, and, when they use one another to fill in missing details in their memories, important details may be lost.

Complete a thorough search of the home and premises. Those with AD/D are known to hide in unusual locations. Responding or assisting officers should conduct an exhaustive search of the home or care facility and surrounding premises as soon as reasonably possible. Every part of the home should be searched, including under beds, in locked rooms, closets, crawl spaces, attic/loft areas, cars, false ceilings, air-conditioning venting, toy boxes, under sinks, and in exterior shrubs. An ensuing search of neighbors' yards should also be conducted. Officers should never assume that searches conducted, often by distraught caregivers or others, have been performed in a thorough manner.

Preserve the place last seen. The place where the person was last seen should be secured as a crime scene and treated accordingly with barrier tape, photos, preservation of foot prints, and so forth.

Evaluate any complicating factors. Does the reporting party know if the person would have been wearing weather-appropriate clothing? What is the current physical condition of the subject? Does the missing person have any other medical conditions? If the person takes prescription medication, when was the last dose and how long can the person function without taking the next dose? Does the missing person have familiarity with and/or access to weapons?

Initiate a Silver Alert, Endangered Persons Alert, or similar alert. If a thorough search of the home and immediate area does not result in the missing person being located, a formal search should be initialized. Upon verification of a missing person, a “missing–critical” or endangered missing persons report shall be completed, and an alert should be initiated if a Silver Alert, Endangered Persons Alert, or similar system exists in the area or jurisdiction where the person has been reported missing. Appropriate entries should be made in state and national information databases in accordance with established procedures (for example, adjacent jurisdictions, department of public safety, National Crime Information Center, LEADS, and fusion centers). Requesting or assigning a specific dispatcher to handle calls in relation to this case is recommended if practical to establish a consistent flow of communication.

Advise the public not to approach the person if found. Since media, social networks, and other civilian avenues may be used to distribute information, a directive should be included that anyone locating the missing person should not approach the individual unless he or she is in imminent danger or is creating a danger to others. Doing so may startle or provoke someone who is already scared or agitated. The missing person should be observed until law enforcement arrives to secure him or her.

C. Search and Operational Considerations and Guidelines

Standard grid-style searches may not be useful when dealing with a missing AD/D person. While this approach is both logical and practical with the random wanderer, alone it does not help identify the victim’s behavior within the search area. Information about previous work habits, likes and fears, as well as types of environments that might stir interest or activate old memories can help fine-tune the grid search. The missing person may perceive that they are in trouble and further hide or seclude themselves.

An Incident Command Center should be established and the Incident Command System implemented.⁹ Notifying other people or organizations in the community may also prove helpful, such as governmental/contracted

⁹ For more information on this procedure, please consult the IACP *Model Policy on Incident Command*.

employees with radios and vehicles such as parks/facilities, road crews, waste management, and so forth.

If the person left on foot. Leaving on foot is most common, occurring in about 75 percent of missing persons with AD/D cases.¹⁰ This is helpful if the person follows the statistical pattern, the person will likely remain within a few miles of the place last seen. However, this does not make the situation any less dangerous, as most of those found deceased are found within 1.5 miles of the place last seen, and more than 50 percent are found within one-half mile.¹¹ The deceased were most commonly found in secluded areas such as thick brush or vegetation; in or near bodies of water (including ravines, sewer drains, and other shallow bodies); or in populated but abandoned areas such as vacant lots, building rooftops, and empty buildings. Because persons with AD/D most likely will not respond to calls, if searchers do not physically locate them, they may be easily overlooked even in a search that includes their location.

Additionally, leaving on foot leaves open the risk of the person accepting a ride from someone, taking public transportation, or hiding “in plain sight” meaning walking among crowded, populated areas. All of these scenarios come with inherent risks both to the missing person and to the search efforts.

If the person left by car. Adjacent jurisdictions should be notified as soon as reasonably possible, as only about 40 percent are found in the county of residence.¹² Proportionately, men tend to leave by car more than women. The amount of gas that was in the tank should be ascertained to establish a drivable radius. Many persons with AD/D will only drive the limits of the gas tank without thinking to refill the tank. However, establishing the limits of the person’s ability to travel is only helpful to a certain extent, as running out of gas has its own risks for a person with AD/D. The person may seclude himself or herself in the car versus seeking help, often with deadly consequences, or continue on foot once stopped.

D. Ongoing Investigation

The active investigation should include reworking the same search areas if the person left on foot, beginning with the first 1.5 miles and expanding to 5 miles, then 10 miles. This procedure should be reevaluated every few hours, using daylight and weather conditions as guidelines. One suggested timeline is to begin with the first half-mile and increase by one mile each hour. At the 5-mile mark, searchers should be split into two groups; one to pursue

¹⁰ The Alzheimer’s Association, *2010 Alzheimer’s Disease Facts and Figures*.

¹¹ *Ibid.*

¹² *Ibid.*

the 5- to 10-mile radius, and the other to search the initial 1.5 miles again. It is recommended that searches continue during nighttime hours as this is the most dangerous time for missing persons with AD/D. About 20 percent of those found are rescued during nighttime hours.¹³

The Incident Commander (IC) should request checks of local hospitals and coroner's offices for persons fitting the description and request fingerprints of the missing person and dental records if deemed necessary. The IC should remain in constant contact with the missing person's closest relative (or the point of contact left at the missing person's home or care facility) and the assigned dispatcher concerning progress of the investigation.

Long-term cases should be evaluated according to the agency's standard missing person's policy with regards to following leads, investigation, and so on.

E. Rescue/Recovery of Missing Persons and Case Closure

The model policy outlines steps to be taken to report and close the case. Two items are of special importance: (1) the reunification procedure and (2) incident reporting. After notifying all involved parties and jurisdictions that the person has been located, follow-up and close-out procedures are especially important to document unusual circumstances, identify abuse or neglect, review department procedure and lessons learned, and prevent future missing persons.

Reunification. After returning the person safely to his or her care setting, it is important to carefully interview all interested parties and document the circumstances surrounding the disappearance. The formerly missing person should be interviewed to provide any information about his or her previous whereabouts and activities. Interviews should be conducted in separate settings. Documenting how the person came to leave the care setting, which exit was used, and how the person left unnoticed will be helpful to prevent future events. It is most important to look for patterns such as repeated events, especially in the case of missing persons from professional care facilities that may indicate negligence.

Incident reporting. Repeated events from professional care facilities can indicate poor facility security, understaffing, and abuse or neglect, as well as pose the risk of violating the professional accreditation of the facility. Law enforcement should carefully document and report each instance of missing persons from care facilities. Proper reports should be filed to the facility's chain of command, including state accrediting agencies, corporate

¹³ "Alzheimer Disease: Nurse Researcher Identifies Search Criteria for Wandering Patients," *Pain and Central Nervous System Week*, 5 (citing Meredith Rowe study) November 5, 2001.

offices, and insurers, and the facility should take proper precautions to prevent future incidents. Where indicated, follow-up action includes filing an abuse and neglect report with the state aging agency. If necessary, criminal charges should be filed with the prosecutor's office.

In cases where the person went missing from a home care setting, repeated events can signal an overwhelmed caregiver, poor supervision, or abuse or neglect. It is important to remember the person with AD/D can be the abuser. Investigate for other signs of abuse or neglect in the home from both parties.

Abuse and neglect. Abuse is the infliction of physical or psychological harm or the knowing deprivation of goods or services necessary to meet essential needs or avoid harm. Neglect is a failure to perform caretaking duties essential to the safe care of a person, within the context of persons with AD/D or other medical issues. Neglect can be purposeful but can also happen when the caregiver is simply overwhelmed.¹⁴

In responding to home care settings, officers should be prepared with resources (referrals, handouts, etc.) to provide the caregiver with ways to prevent future episodes.

Media. Care should be taken when interacting with the media, regardless of whether the individual is found alive or deceased. For many families of those with AD/D, the disease carries a stigma of mental illness because they cannot control or prevent their loved one's behavior. However, bringing the issue to light helps remove that stigma and asserts AD/D as a community issue. Raising awareness of the inherent dangers presented to those with AD/D and the caregiver component can prompt families of those with AD/D to prepare for such instances and may benefit all parties in future missing persons events.

Internal follow-up. Agency case closure should include a complete report on the known whereabouts, actions, and activities of the missing person. It should also include a similar report of the agency's actions and efforts during the search. A post-incident briefing should be conducted to establish lessons learned and after action reports (AARs). When the person left from a care facility, it is particularly important to report and notify the facility's insurer and/or accreditation authority to help them identify patterns of security breaches.

F. Prevention Strategies and Suggested Community Outreach

Since searches for missing persons with AD/D are expensive and exhaust many resources at once, it is advisable to implement prevention techniques within the community. Agencies should train and prepare to

¹⁴ The Alzheimer's Association, "Monitoring Abuse," http://www.alz.org/living_with_alzheimers_monitoring_abuse.asp (accessed April 20, 2011).

respond to AD/D in their communities by having materials available for officers; utilizing this document for roll call training and continuing education; and establishing a list of community resources to provide to families, such as local social services, contact information for the local Alzheimer's Association chapter, Neighborhood Watch, and Volunteers in Policing program.

RESOURCE GUIDE

- **International Association of Chiefs of Police**
www.theiacp.org/alzheimers
- **The Alzheimer's Association**
www.alz.org
- **National Institutes of Health, National Institute on Aging**
www.nia.nih.gov
- **Project Lifesaver**
www.projectlifesaver.org
- **Volunteers in Police Service**
www.policevolunteers.org
- **Caring.com**
www.caring.com
- **The Alzheimer's Foundation of America**
www.alzfdn.org
- **National Care Planning Council**
www.longtermcarelink.net/eldercare/medicaid_long_term_care.htm

Every effort has been made by the IACP National Law Enforcement Policy Center staff and advisory board to ensure that this document incorporates the most current information and contemporary professional judgment on this issue. However, law enforcement administrators should be cautioned that no "model" policy can meet all the needs of any given law enforcement agency. Each law enforcement agency operates in a unique environment of federal court rulings, state laws, local ordinances, regulations, judicial and administrative decisions and collective bargaining agreements that must be considered. In addition, the formulation of specific agency policies must take into account local political and community perspectives and customs, prerogatives and demands; often divergent law enforcement strategies and philosophies; and the impact of varied agency resource capabilities among other factors.

This project was supported by a grant awarded by the Bureau of Justice Assistance. The Bureau of Justice Assistance is a component of the Office of Justice Programs, which also includes the Bureau of Justice Statistics, the National Institute of Justice, the Office of Juvenile Justice and Delinquency Prevention, the Office for Victims of Crime, and the Office of Sex Offender Sentencing, Monitoring, Apprehending, Registering, and Tracking. Points of view or opinions in this document are those of the author and do not necessarily represent the official position or policies of the U.S. Department of Justice or the IACP.

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