Kimberly R. Kelly Falconer, *Founder and Executive Director*

Project Far From Home
P.O. Box 2292
Ramona, California 92065

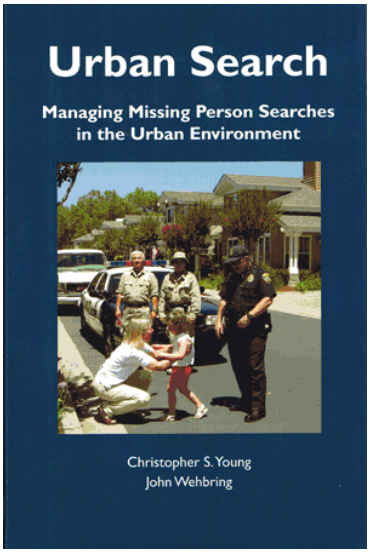
760.315.1895
kimberly@projectfarfromhome.org

Part III b - Special Challenges

Alzheimer's Disease

The following contribution to this book is from the presentation **"Missing at Risk – Understanding and Managing the Search for the Missing Alzheimer's Subject"** by Kimberly R. Kelly Falconer. Kimberly is the founder and executive director of "Project Far From Home", a national training program designed to educate law enforcement, search and rescue, fire, EMS, and others who may search for missing at risk elders.

The information in the pages that follow are condensed from material presented in **"Urban Search: Managing Missing Person Searches in the Urban Environment"** by Christopher S. Young and John Wehbring, with additional contributions by Kimberly R. Kelly Falconer, Michael St. John, and Robert Koester. It is available through dbS Productions, www.dbs-sar.com.



Note: All examples used in the following are based on real persons, or real incidents, however, certain details or information have been altered or fictionalized to protect the identity and privacy of the subject and their family.

"911...what is your emergency?"

"My mother is gone! She has Alzheimer's disease and wandered away," the voice is frantic. "Please, send someone quickly!"

Every day across the United States, as well as in countries throughout the world, this scenario is played and re-played by law enforcement officers who respond to missing persons with Alzheimer's and dementia who are at-risk. Yet, while this type of call has become more and more commonplace, many people underestimate the severity of danger that a missing person with Alzheimer's faces.

In the United States, there are currently more than 5 million Americans with Alzheimer's disease. It is estimated that our current Alzheimer's population will bloom to more than 14 million and perhaps as many as 16 million people with Alzheimer's disease by the year 2050.

Because of the changes that occur within the brain, wandering is a common, and dangerous, effect of the Alzheimer's disease process. More than 70% of all people with Alzheimer's disease will wander away at least once during the course of their illness.

In urban settings, more than 25% of all missing persons that come to the attention of law enforcement and/or search and rescue personnel have Alzheimer's or dementia.

Further, while many search and rescue teams report a global decrease in the number of their missions, many teams also report that they are increasingly being called out on search missions for missing persons with Alzheimer's disease.

As such, this chapter is devoted to providing search and rescue personnel with an understanding of Alzheimer's disease and suggested tactics necessary to locate persons with Alzheimer's (and related dementias) who have wandered and become lost.

What is Alzheimer's disease?

Most people are familiar with the term "Alzheimer's disease" (AD), even if they do not fully understand the diagnosis. Pronounced as "Alz-hi-merz", it is named for the German neuropathologist Alois Alzheimer (1864-1915), who first recognized the disorder as a true disease in 1906. Most people in the United States, however, first heard about Alzheimer's disease when President Ronald Regan first disclosed his own diagnosis in 1984.

Alzheimer's disease is one of nearly 70 of diseases that fall into a category known generally as "dementia". Dementia, derived from Latin meaning "*mind*" and "*away*", is a term used to indicate a loss or reduction of mental capacity severe enough to interfere with daily functioning. It does not mean or signify stupidity, insanity, or retardation.

Dementia refers to a variety of symptoms, but is not a disease in itself. Dementia symptoms include memory loss or confusion, a reduction in cognitive abilities, difficulty with language, perception, personality, judgment and coordination. There are four major types of dementia: Alzheimer's disease (AD); vascular dementia (VAD), which includes Multi-Infarct dementia (MID) and Binswanger's disease; fronto-temporal dementia (FTD) and, finally, diffuse Lewy body dementia (DLBD).

Alzheimer's disease is the most prevalent type of dementia: approximately 50% of people who have dementia are diagnosed with Alzheimer's. Alzheimer's disease combined with vascular dementia accounts for another 20%.

It is important to note that because AD is the common type of dementia, we will be referring primarily to Alzheimer's during the course of this chapter. However, many families often will not disclose a diagnosis of Alzheimer's disease or any of the related dementias because of fear of stigma, embarrassment, supposed protection of the missing person, denial or simply because they may not know.

How Is AD Diagnosed?

Alzheimer's disease is distinguished from other forms of dementia by characteristic changes in the brain. These changes include a 50% reduction of acetylcholine, a necessary brain chemical, and the formation of plaques and tangles. These plaques and tangles are abnormal growths or accumulation of certain proteins that build within and surrounding the brain cells. As a result of these changes, brain cells are damaged, and eventually destroyed, which results in the previously described symptoms of dementia.

AD is considered to be a disease of exclusion; this means that all other possible causes, such as infection, disease, alcohol/drug abuse, and mental illness, must be ruled out before any probable diagnosis of Alzheimer's is given. This is accomplished by undergoing a complete physical, neurological and psychological examination.

However, due to the very nature of the disease, a diagnosis of AD can only be confirmed by autopsy of brain tissue after death.

Progression of the Disease

The American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders* (1987) characterizes Alzheimer's disease as a chronically "progressive, global, cognitive loss". The affected individual suffers a loss of thinking or learning capabilities of sufficient impairment to affect their daily life, whether it is social or occupational functioning.

Changes are often slow to progress, and thus difficult to detect in the early stages. These symptoms may include short-term memory loss, anxiety or irritability, difficulty in conversation, or inability to complete involved processes, such as balancing a checkbook or map orientation.

Example*: Ms. Deborah Melvin reports an incident that occurred in January, approximately three days prior to her father John Melvin's disappearance. While at a bank's automated teller machine with her, Mr. Melvin forgot his personal identification number (PIN). He was adamant that the last four digits embossed on the card were the appropriate PIN. Deborah stated that Mr. Melvin became increasingly frustrated, and repeatedly tried that incorrect number.*

Eventually, as the disease progresses, impairment becomes more severe and obvious. The person makes glaring mistakes in his work, repeats conversation or questions over and over, and loses more and more of his ability to remember persons, places, or events. Short term memory loss deteriorates into severe memory problems. Impaired judgment and radical personality changes can also be evident.

Example: *Christopher Allen states that his mother's "short term memory is going". Christopher also reports changes in his mother's personality and abilities. He reports that she has become obsessed with a morning routine of waking, eating breakfast, and taking her medication. Once that routine is completed, however, Mrs. Allen apparently becomes without direction or purpose for the rest of the day.*

Moderate stages include obvious functional declines. Traveling alone, even in familiar environments, is often difficult. Complicated tasks are more difficult. Memory of recent events is

clearly impaired. Personality changes often begin to appear: flat affect, loss of inhibition, tact, social grace, and judgment. Changes in sense of time and place, as well as short- and beginning of long-term memory impairment also occur (Bales, 1982).

Severe stage memory begins generally when an individual can no longer care for themselves, or survive without assistance. They begin to lose relevant facts such as current addresses, phone numbers, or close family members. Personality and emotional changes often become more pronounced, and patients can become agitated, delusional, and/or paranoid in their behavior (HHS Secretary's Report, 1984).

Such losses of ability can lead to further problems, such as anxiety, paranoia, hallucinations, frustration or irritability, anger, aggression or violence, withdrawal, pacing, and wandering.

In addition to the changes that occur to memory and cognitive abilities, Alzheimer's patients also experience significant impairment to visual, speech, and motor skills. Those skills and the resulting deficits (agnosia, aphasia, apraxia) are described in the sections below.

It is important to note that for a diagnosis of Alzheimer's disease to occur, in addition to the presence of confusion and lack of cognition, at least one of the three conditions must occur. Most Alzheimer's subjects have some form of all three.

Further, when the Alzheimer's subject becomes dehydrated, injured, ill, stressed or lost, signs and symptoms of agnosia, aphasia, and apraxia often become much more obvious and severe.

Agnosia

Agnosia is the loss or reduction of the brain's ability to interpret images transmitted by the eyes.

Example*: Kayla Hardin recounts an incident, in regard to her grandfather, and provides an unmistakable example of agnosia: Grandpa Hardin was standing outside the house, on the back patio, and pointed to an object in the distance. Grandpa Hardin stated the "man in the boat" appeared to be having difficulty. After Kayla pressed as to "what man, where?", it was finally determined that Grandpa Hardin had misidentified one of his neighbor's wind socks, blowing in the breeze, as a man in a boat.*

The eyes do not actually "see"; they merely transmit images to the brain, which must then orient those images into something familiar or known. It is quite common for an Alzheimer's subject to be able to clearly and accurately describe their home, or a family member, but, at the same time, be unable visually recognize the said house or person in front of them.

With Alzheimer's disease, this interpretation process becomes altered. Even though the information being transmitted remains the same, and the eyes and optic nerve suffer no injury, the brain will no longer process that information in the same way. Grandma may misrecognize her grandchildren as her children. Auntie may no longer recognize her home, car, spouse, children or beloved pet.

This is particularly important for the law enforcement officer or search and rescue worker to know. Many times, a missing person with Alzheimer's has disappeared while on a routine errand, a customary walk, or from a familiar place. It is important to realize that as agnosia develops, a person will lose the ability to record or recognize changes, even when it occurs slowly.

However, even with agnosia, it is typical and normal for people with Alzheimer's disease to be encouraged to walk, maintain their own independence, or seek outdoor experiences. Walking and maintaining independence can be very therapeutic. The caregiver and the subject quite often

agree to a pattern of travel or behavior; i.e., "don't leave the house", "always stay within the neighborhood", or "don't cross Fifth Street".

Additionally, family members will often tell the interviewer that the person will not cross a certain street. As a result, it is quite common for the Incident Commander or Operations Chief to set up boundaries along these given barriers. It is a dangerous fallacy to believe that a person who has agnosia, who does not recognize friends or family, will somehow recognize that they should not cross a certain street.

Unfortunately, with such boundaries in place, caregivers often feel falsely secure. With this false sense of security, however, come dangerous assumptions, and if those assumptions are followed by the search manager, the results may be disastrous.

Example: *Mary always walks along Fifth and Vine; however, road construction has started, and she is forced to walk on the opposite side of the street. Even though Mary walks the same route every day, she now must view the street in an entirely different manner. Her route is no longer familiar, and she wanders out of her normal area. People are used to seeing her walking, however, and no one stops to offer her assistance.*

An Alzheimer's subject with agnosia will not see the same things searchers see. They may not recognize a highway, road, train track, or environmental hazard such as blackberry patches, thick manzanita, cactus, or bodies of water as dangerous. They may very well walk, fall, crawl, drive, or otherwise become trapped in such.

This is important for the search manager to recognize, and understand for a number of reasons. Just as it is common for family members, or nursing home staff, to say, *"he will not ever cross the street", or, "there is no way he could climb a fence"* , it is equally as common for searchers to declare *"there is no way that guy went in there*", or, "*no one would ever go into that…*"

Search records, and the accompanying mortality rates show that Alzheimer's subjects who get "stuck" in such dangerous hazards are most often unable to extricate themselves. Searchers must be cognizant of, and thoroughly search, these areas.

Agnosia and Driving

An Alzheimer's subject who still drives may not recognize a red light and drive into the intersection, or, may not recognize a highway off ramp as such, and enter a highway into oncoming traffic.

Although a subject may not have left in his own car, searchers should still be alert to driving history and vehicle availability. Are there other vehicles (garden tractors, golf carts, neighbor's cars) that can't be accounted for? Would, or could, the subject take a bus? A taxi? Could they hail such a vehicle on their own? Would they get on a bus, or in a taxi, if someone else helped them? Lack of bus or taxi fare should not be considered a hindrance; it is all too common for a Good Samaritan to pay the subject's way.

Interviewers must ask if there have been previous instances in which the missing subject drove away, or become lost while driving. Pay special attention to driving history, and mechanical experience. Many times, family members will hide car keys, or disable a vehicle (remove distributor caps, unhook batteries, remove tires) in order to prevent their loved one from driving. That has not always worked, as sometimes, subjects with mechanical experience simply fix the disabling device, and drive away.

Agnosia and Additional Concerns

A person with agnosia may misunderstand a person's body language, facial expression, law enforcement or SAR uniform, or other visual cue as a threat, and react inappropriately, even violently. A person with agnosia may misinterpret searchers' actions, and or search dog behavior, in the field.

Searchers must be aware of a subject's likes, dislikes, attractions and fears. Knowing the purpose of why the person went wandering can also help teams formulate search patterns, methods, equipment, and best approach when finding the missing subject.

Example*: Peter K. is a 72 year old man with Alzheimer's disease. He is a generally happy person, however, can be very afraid of strangers. He walks with a pronounced limp, and has severe arthritis. He has been missing for more than 14 hours when local SAR was activated. Searchers quickly find his track, and begin following sign. A helicopter unit with FLIR is brought in, and a heat source believed to be Peter is located. As searchers move into the foothills in his direction, the helicopter turns its spotlight on, and activates its public address (PA) system, calling for Peter. Searchers discover that Peter's track pattern has changed from walking to erratic running, in a direction away from search teams. They also discover sign that indicates he has fallen at least twice. When Peter's body is located the following day, searchers and management estimate he has run at least twelve miles from where he was originally spotted.*

Information later developed from in-depth interviews from family reveal that Peter K. had served in World War II, where he was taken prisoner of war and was incarcerated in a Russian POW camp. It is assumed that Peter ran to his death, believing the searchers that were there to rescue him, were in fact, there to harm him.

Aphasia

Aphasia is the loss or reduction of the brain's ability to interpret and formulate language.

Usually, the first evidence of language difficulty appears in naming objects or persons in normal speech or in naming tasks. A person may show significant pausing, or strange word substitutions. Additionally, in the early stages, the person is aware of their worsening speech, and may develop methods of hiding the difficulty. They may ramble on or abruptly change the topic.

A person with aphasia may drop, or inappropriately add words during the course of conversations such as "I you go store with you?" They may substitute similar words for more common terms.

Example*: Instead of the more appropriate phrase "middle aged", they may say something like "light years" or "medium aged."*

Frequent usage of vague terms such as "*thing*," "*there*," "*that*," or nonspecific naming, such as "*he*," "*she*," or "*it*" may also demonstrate language deterioration.

Example*: Mary Ellen has Alzheimer's disease. She becomes increasingly frustrated when she is unable to name her needs: "I want that thing over there." Her caregiver responds, "What thing? The watch? The book?" Mary Ellen: "That thing!" Caregiver: "Where? On the dresser? On the table?" Mary Ellen: "THERE!"*

In moderate Alzheimer's disease, the speaker begins to show significant errors, both in speaking and comprehending conversation. He or she may not be able to appropriately answer questions, has difficulty in naming items or persons, and may answer nonsensically.

In the later stages of Alzheimer's, a person can be severely impaired in his or her naming abilities, expressing themselves verbally, may use incoherent jargon, and may not be able to comprehend speech at all. In severe cases, all ability to use or understand verbal communication is lost.

Furthermore, persons with Alzheimer's may become responsive only to certain terms or phrases. Alzheimer's disease, and aphasia, can affect the way a person thinks of themselves, or responds. Nicknames from childhood, pet names, may begin appearing. A married woman may revert to her maiden name, or a previous married name.

***Example**: Franklin will only respond to being told, "Mrs. Barnes wants to see you", or Kathryn will only come when she hears "here, kitty, kitty, kitty!", an apparent nickname from her childhood.*

***Example**: Marjorie Simpson has been married to Joseph Simpson for 11 years. Prior to this marriage, Marjorie was married to Gordon Graham for 27 years, until he passed away. Marjorie has Alzheimer's disease. She was reported to SAR, and a search initiated after she walked away from her residence. Unbeknownst to SAR teams and law enforcement, a Good Samaritan found her wandering an industrial district, and took her to a local emergency room, when Marjorie identified herself as Marjorie Graham. Hospital staff did receive a police notification about Marjorie Simpson, but they have nothing to connect Mrs. Simpson with the woman now sitting in their emergency department, and thus, a fruitless search continues.*

Aphasia can take many forms from minor (breaks in speech, forgetting obscure words) to severe (complete loss of language). Anomic aphasia, the misidentification or misnaming two or more objects, can occur.

***Example**: When told to get his jacket, Jim repeatedly gets a shirt.*

Aphasia can also manifest in the use of sexually explicit, profane, socially inappropriate language, or communication that would be atypical of their past use of language.

***Example**: An elderly white person with Alzheimer's encounters an officer or searcher of color. She is not likely, as her language regresses, to refer to the rescuer as a person of color, or an "African American" or black officer. Instead, she is more likely to use one of the several offensive terms more commonly used historically. By understanding that this may simply be part of her aphasia progression, the responding individual is less likely to react and escalate an already tenuous situation.*

Understanding this process is extremely important for the search team members and Incident Commander. Without a clear picture of how the subject communicates verbally, searchers may miss important clues in the field. Searchers may miss the subject entirely if they rely on him calling out, or answering shouts for him.

***Example**: Border Patrol's Search, Trauma, and Rescue (BORSTAR) team is assisting local law enforcement in a search for David, a 67 year old man with Alzheimer's disease. As Team 1 takes a hill as their assignment, and Team 2 is deployed to a connecting ridge, all begin calling for David. As they shout for David, they hear what sounds like another searcher also calling for David. However, they know that no one else is deployed in their sector. Listening carefully, they begin moving toward the voice – and find David, trapped in a rocky area, calling his own name out, echoing the searchers. Had BORSTAR not been cognizant of this situation, David may not have been found in time, or at all.*

Some persons with Alzheimer's will lose all ability to use spoken language; however, there is nothing physically wrong with their vocal cords. They may not speak at all, but sing perfectly on key with the appropriate words. Even as they are normally silent, they still may sing, scream, moan, shriek, bark like a dog, or make other sounds.

While a person who wanders is sometimes able to recognize, and verbalize, that he requires assistance, most are unable, or unwilling, to do so. A pioneering review of 46 search mission records from Virginia shows that in no case did a person with Alzheimer's ever call out for help, nor answer to calls shouted by field personnel [Koester and Stooksbury, 1992, 1995]. Those records do not reflect, however, how many of those subjects suffered from aphasia, so it is difficult to know whether or not the subjects chose not to ask for help, or could not ask for help.

It is important to note here that persons who speak two or more languages may begin using words from the primary language when they forget the word in English (*example*, "pass me that, that, that naranja!"). As aphasia progresses, the speaker may use more and more of the primary language, combining a form of the two (or more) languages. Ultimately, the speaker may revert to the primary language totally, becoming completely non-responsive in English.

Example*: Amparo de Gonzales, a resident of Nebraska, is by heritage Cuban. Her normal daily use language is English, however, her birth language is Cuban. Her husband reports that Ms. De Gonzales has begun using more Cuban phrases and words in her speech. Additionally, within the past few weeks, she told her husband that he has begun dreaming in Cuban. She does not speak, read, or understand any other language.*

A multilingual subject may not respond in any way to searchers calling in English, but may be completely coherent and responsive in Italian or German. The missing person report and interviews MUST address language issues. All languages that are read, spoken, or understood must be detailed, even if that person has not used that language in years.

It is most important for the search and rescue personnel or law enforcement officer to recognize that symptoms may seem mild when at home, where the person is well fed, cared for, warm and comfortable. Under the stress of becoming lost or disoriented, dehydrated or injured, a person with aphasia will have more severe language difficulties, making verbal communication that much more difficult (or impossible).

Therefore, it is critical that field teams understand that the Alzheimer's subject may not be responsive to searchers, or may not respond in a manner that a searcher would ordinarily expect.

Apraxia

Apraxia is the loss or reduction of the ability to coordinate fine and gross motor skills. A significant warning sign of Alzheimer's disease is a change in gait or locomotor patterns.

A person with apraxia will have difficulty with basic life skills, such as dressing themselves, making a sandwich or eating, bathing, brushing their teeth or performing other basic hygiene.

The person may look disheveled and unkempt and have the appearance of a homeless person. Coupled with aphasia and/or agnosia, apraxia may cause law enforcement to misinterpret a contact with the person as just another homeless encounter and actually transport the person with Alzheimer's to a shelter or County Mental Health. Historically, it was not uncommon for police to transport persons with Alzheimer's to jail, having failed to recognize the disease and its manifestations.

Example*: a 75 year-old male comes to the attention of law enforcement for exposing himself to a woman in a park. The man comes out of a public bathroom with his pants unzipped and exposed. He approaches a woman, stands in front of her without saying anything, but gesticulating at his pants.*

Further investigation reveals the gentleman to have Alzheimer's disease, suffering from moderate agnosia and apraxia, with severe aphasia; he had wandered away from his home. His primary caregiver is his daughter, whose hair coloring resembles that of the woman in the park. The gentleman can take himself to the bathroom, but cannot reassemble himself after toileting. It is habit, in his home, to toilet by himself, and then come to his daughter for help in re-dressing.

SAR interviewers should ask a variety of questions about the AD subject's abilities. Although it may seem inconsequential to ask how a subject dresses, the responses can give much insight to the subject's field capability.

A subject who can pick out his own clothing and be appropriate for the weather will have better ability to recognizing potential dangers in the field, than a person who dresses in a sundress in winter, or a heavy coat in summer.

A subject who must have her husband assist her dressing, and who must sit in order to place the pants over her feet, will have a harder time navigating difficult terrain.

A subject who must wear clothing that cannot be easily removed will have a very difficult time in public using a restroom facility, or, "finding a bush" in the field. A subject who had an incontinence accident because they could not get their clothing removed in time may deliberately hide from searchers out of embarrassment.

Searchers should be aware that when a subject is reported as "a strong walker", it is important to follow up with questions about what types of surfaces the subject usually walks on. If he usually walks on firm surfaces, walking on sand, river washes, or hilly terrain will significantly tire him more so. The more an exhausted Alzheimer's subject tires, the worse their symptoms appear.

With subjects already experiencing fine motor deficits, it is logical to anticipate gross motor deficits early in the search. Searchers should be clue aware for worsening gross motor skills, worsening gait patterns, shuffling prints, and foot dragging marks.

Cognitive Mapping

Cognitive mapping is the brain's ability to memorize patterns and locations. This is the ability that gives an individual the capability to locate the bathroom in the middle of the night, with the lights off, use the toilet, and return to bed without requiring conscious thought, turning on lights, or using a map.

People with Alzheimer's disease lose this ability. A person with Alzheimer's disease, who gets up in the middle of the night to use the restroom, may find themselves locked in a utility closet by accident. A man with AD who uses the elevator may instead find himself in a service elevator; without the proper codes to activate action, the elevator simply sits idle, with the subject standing inside. A woman who habitually walks to the grocery every day becomes lost and confused as the route, once comforting and familiar, is no longer so.

Example*: Mr. Voight, a 72 year old Canadian citizen with Alzheimer's disease, becomes lost while vacationing with his family in Arizona. While Mr. Voight appears to still be able to navigate his own home at this time, he has now twice become lost while on holiday. His inability to map his surroundings will significantly hamper his ability to find his way back to the vacation home.*

Searchers should be aware that it is quite common for wandering Alzheimer's subjects to find a home, any home, and try to get in, particularly in developments in which most of the homes look alike or follow a similar design pattern.

Searchers should not rule out other homes in the area, particularly vacant homes. Be alert for broken windows or locks, doors ajar, rifled gardens. Look for hoses that may have been left running, where someone has made an attempt to drink. Law enforcement in the area should be notified, and be alert for reports of returning homeowners who find something amiss, or complaints of vandalism.

Sundowning

Sundowning, or sundown syndrome, is a pattern of delirious behavior; a condition that has been historically documented in Hippocrates' own medical writings. It affects many persons with dementia (all dementias, not only Alzheimer's disease), and manifests in the hours of sunset, hence its peculiarly appropriate name.

During the hours of sunset, a person with dementia, including Alzheimer's, often experiences a significant increase in confusion, agitation, aggression, paranoia, violence, obsessive behavior, and wandering. Significant decreases in physical capabilities, thinking and speech, as well as other sensory deficits can also occur.

In essence, a subject with Alzheimer's disease and experiencing significant sundowning, lost in the field during the hours of sunset is more likely to be agitated and afraid, and less rational, less able to hear, see, or maintain their balance. Persons in this state commonly will not bunk down for the night, and tend to push harder because of their altered perceptions. The result of this is often blindly barging into areas such as dense brush, thick vegetation, or into hazardous terrain. They are less likely respond to searchers who shout, call, or try to approach. They may often purposely evade or hide from search teams.

Example*: In our phone interview, Michaela Morey indicated that her mother seemed worse in the evenings, and that that deterioration in her behavior and agitation began around 5:00 pm each day. Ms. Morey states that her mother's agitation and fearfulness becomes even more extreme when she misses her daily nap. Further, she states that the recent Daylight Savings Time switch seems to have made her mother's condition worsen, and that she struck at Michaela, out of frustration and fear, last week for the first time.*

When a subject is found, the risk of violence is usually highest during this period. Do not underestimate the capability of an elderly and apparently frail Alzheimer's subject. Search teams should be aware of, and prepared for, signs of a subject lashing out.

Dysphagia

Dysphagia is the loss or reduction of the ability to swallow. This is an unfortunate progression of Alzheimer's disease, and often leads to pneumonia, aspiration, choking, spitting, and/or difficulty eating or drinking.

Searchers need to be particularly aware of dysphagia in combination with a subject's lack of gross motor skills. Often, when an Alzheimer's subject falls, whether in the field or in a home, the lack of ability to swallow and the inability to right oneself to their feet leads to aspiration pneumonia. It also inhibits the subject's ability to call for assistance.

Searchers must also be aware that even if a missing or wandering Alzheimer's subject has food or water with them, or has access to such, they may not be able to consume it.

It is important for the SAR interviewer to ask about the subject's eating habits. A subject who is regularly provided meals and fluid may not actually be able to swallow, or ingest those foods. Do not assume that your subject is always well nourished, nor well hydrated.

Further, it is important for the SAR interviewer to ask whether or not the AD subject wears dentures. Many do, and because of dysphagia swallowing issues, proper dental fit and usage can be difficult. It is important to know whether or not a subject may remove their dentures for comfort.

Example*: Mary does not like wearing her dentures. She states that they are uncomfortable, and rub. She has had repeated fittings and alterations, without success. No specific problem can be pinpointed however Mary has dysphagia. Because her swallowing problems have progressed so, she now takes her dementia and other necessary medications in liquid and capsule form, so that they can be swallowed in applesauce or pudding for ease. Dry mouth is also a side effect of some of her prescription medication, and contributes to her swallowing problems. Mary will wear her dentures when entertaining company, but otherwise, she will keep them in her sweater-coat pocket, wrapped in a paper napkin or Kleenex. As a result, she has often dropped her dentures, lost them in restaurant garbage, or misplaced them in her residential nursing care facility. Mary will not answer nursing staff, or see her family, however, if she does not have her dentures in. As a result, it is logical to believe that Mary will hide from searchers in the field, if she has dropped, or does not have her dentures.*

Combine apraxia (loss or reduction of fine and gross motor skills) with dysphagia (loss or reduction of ability to swallow), and often the result is a person who falls and chokes or aspirates. Searchers must be aware that their subject with Alzheimer's disease is at increased risk of aspiration and pneumonia, and even more so if they lay, fallen and prone, in the field. These subjects are even less likely to be able to call out for rescuers or aid.

Wandering

Alzheimer's patients often come to the attention of law enforcement officials because of wandering. As the afflicted AD sufferer loses more and more of his memory, he will often go in search of a particular item, person, or place. These persons are not easily distracted idiots who have simply gotten lost. The brain changes in memory, thinking, personality, visual and other sensory impairments that occur in Alzheimer's patients cause an irrepressible urge to wander, walk, or to go seek something or someone in particular.

Wandering has proven such a common behavior that Alzheimer's experts predict that nearly 70% of all AD sufferers will wander away from safety at least once during the course of their illness. Many will wander an average of 6 to 8 times before the victim is placed into a residential facility or an outside, qualified caretaker/nurse is brought into the home to help. Some, no matter how many times they wander, will never be placed into a secure facility because the caretaker assumes that since the subject has always been found and returned, that will always be the positive outcome.

Generally accepted statistics used by the Alzheimer's Disease and Related Disorders Association (ADARDA) show that one in ten persons aged 65 and over, and nearly 50% of all persons aged 85 and over, have Alzheimer's disease.

It would be easy, then, for a SAR IC to assume that ten percent of all his searches for persons 65 and older are for persons with Alzheimer's (and along that same reasoning, half of all his searches for persons 85 and older). This would be a fallacy, and dangerous to assume. The reality is that a much higher percentage of SAR call outs for wandering or missing elderly are people with Alzheimer's; a person with normal cognition, even at age 85, is not likely to get up and wander at 2 a.m.

Search records, and anecdotal history from law enforcement officers, show that even when wandering Alzheimer's subjects do encounter public citizens, they are often ignored, considered "homeless", or given aid, but are not reported to responsible agencies. In areas of high poverty or with a transitory or nomadic population, the likelihood of receiving aid is even less.

Additionally, Medic-Alert, Care-Trak, Project Lifesaver, or "Memory Bracelets" like those issued by the Alzheimer's Association's *Safe Return* program, while certainly encouraged, are not a guarantee that the public will recognize or report people who are wandering.

Search team interviewers must be certain to ask whether the subject is, or has ever been enrolled in a wandering or medical alert program. If the subject has been enrolled in such, it is vital to follow up with those organizations – they may hold crucial information, or clues, that prove helpful in the current situation.

It is also recommended best practice to notify Safe Return, or local Alzheimer's disease support chapters, regardless whether or not the subject is, or has ever been enrolled. If the subject is found by a member of the public, or the chapter/Safe Return is familiar with the subject, reunification with the subject's family will be that much swifter and easier.

SAR teams should, however, also as best practice, notify those same persons or chapters when the AD subject is actually found, so that ongoing efforts are not made fruitlessly. Such effort continuing after the subject is found is a waste of energy and resources, and leads to detrimental, negative feelings when future incidents arise.

Family Reporting Incidents of Past Wandering

In discussion and interviews with caregivers or family members, many initially report no previous history of the subject "wandering" or becoming lost. Many become downright adamant; "*he's never done this before!"*

However, when further queried or questioned by a skilled interviewer, many do then recall an incident or occasion when the subject has become lost or disoriented.

Example*: Traditional Interview –*

Interviewer: "Has this ever happened before?' – The interviewer means, *"has your loved one ever wandered away before?"*

Reporting Family Member, *looking at the deputies going down the hallway, the search dogs in the laundry room, the mounted SAR member combing the backyard, the helicopter with FLIR overhead, and the media in the driveway, responds, honestly and truthfully*: "No, *THIS* has never happened before."

This is incredibly important for SAR interviewers to recognize, and understand. Often, better answers come when the skilled interviewer opens dialogue that is both reassuring and non-blaming. Further, more detailed information comes when a family member or reporting party understands exactly what is being asked.

Example*: Better Interview –*

Interviewer: "I would like to talk to you about your father. I know how scary and confusing this can be, so I want to make sure that you are comfortable, and understand what I am asking. No one is blaming you; wandering is a part of Alzheimer's disease, and is often uncontrollable. I really need you to be as open and honest with me as possible so that we have the best shot at finding your father. No one will think badly or poorly of you, or your dad. I'd like to ask you about previous wandering incidents. Has your dad ever turned up someplace you didn't expect him to be? Has he ever NOT been where you did expect him to be? I'd like to give you an example, have you ever been in the store, talking to your Dad, and as you were talking, you realized he was no longer there? We would consider that "wandering"."

Reporting Family Member: "Okay, I understand. No, my dad's never wandered before, but this one time, we were in downtown San Francisco. He saw a man drop a gum wrapper on the ground. My dad went over, picked up the trash, and followed this man many blocks into Chinatown, before catching up. He gave the man his wrapper, and then didn't know where he was."

The interviewer thought the family member was finished, however, the family member then continued on to provide several more incidents. It is important to note that none of these incidents had been considered "wandering" since the family had always found the subject safely and within a reasonable time period. They "just didn't know where he was".

This real life example illustrates that quite often an Alzheimer's subject has a history of wandering - a history that may be extremely relevant to the current circumstance - and yet, the family will not recognize wandering for what it is. Many family members, caregivers, or reporting parties feel that if/since a wandering subject had found his way home, he wasn't really lost to begin with.

Using the current situation as an example, the skilled SAR interviewer can educate the reporting party that a subject's merely finding one's way home, or discovering one's location, doesn't negate being lost in the first place.

***Example**, SAR Interviewer: "Mrs. Ukrainetz continued to insist that her father had never wandered before, never been lost, that the few times she didn't know where he was, he always turned up. "See? He wasn't lost, he just wasn't where I thought he was." I then asked Mrs. Ukrainetz that if we were to find her father today, and found that he had been safely secured in an abandoned home, would that mean he hadn't been lost for the past ten days? She then understood, and was able to relate other several other instances in which her father became separated from her mother, walked away from home, or became disoriented, such as at the grocery store or in parking lots."*

Lost in the Labyrinth

People with AD who wander rarely find their own way home; when they are located in or near a home, the likelihood is greatest that they hadn't wandered far to begin with.

Many become lost or disoriented from their own home or care facility, but an increasing number of people with AD are being reported missing from malls, parks, zoos, and other public arenas. These persons, already in an unfamiliar environment, are particularly unlikely to be able to navigate themselves to safety.

Search records and anecdotal history from law enforcement officers and SAR records often reflect, once a subject has been found, a variety of items that cannot be explained by the subject.

***Example**: In a 1997 case in Escondido, California, a subject named Audrey, a 73 year-old woman, was last seen at her care facility wearing pink pajamas, slippers, and carrying her wig. When located nearly nine hours later, Audrey was found to have four separate canceled bus pass tickets on her person. As she left without money, it became obvious that Audrey – dressed in pajamas and carrying her wig – encountered persons who purchased bus fare for her. None of these people reported her missing, and no one called law enforcement or for medical aid. Audrey's case is not unusual.*

Additional Risk Factors

Law enforcement officers, search incident commanders and search teams need to be aware of how a person with Alzheimer's will react in a particular environment. Again, knowing the missing person's history and experience will help you to define and determine a behavior profile.

As the disease progresses, eventually the person with AD will succumb to more devastating and debilitating brain dysfunction that will lead to eventual death of the patient. These include:

Catastrophic Reaction—often described as a "super anxiety attack," a catastrophic reaction is generally a hyper-response to a stressful situation that may cause injury to self or others. The person with AD will break objects, scream, cry, take off clothing, kick, bite, moan, rock, withdraw, lock themselves into a room or hide, etc. This could be the trigger that causes wandering or the behavior may be triggered because of wandering.

Example*: During the course of Ashley's third birthday, she fell off the trampoline and severely broke her arm. 911 was called, and both mother and father accompanied Ashley in the ambulance to the hospital. Carmela and Wilfred, Ashley's great-grandparents, both of whom suffer from Alzheimer's disease, were left behind. In the noise, confusion, ambulance sounds and lights, Carmela disappeared, and SAR was activated to look for her. Wilfred was found sitting alone at the kitchen table, rocking, picking and eating the leaves off the fern centerpiece.*

Violence: When a person with AD realizes that they cannot control their environment or that they are uncomfortable and have a need they cannot communicate, they may be resistant or even violent. These behaviors can be unpredictable. Once the person is found, it is important to approach them calmly. When transporting a subject with Alzheimer's disease, do not place them in the front seat where they could suddenly grab the steering wheel or hit the driver. Some persons with Alzheimer's have been known to open the door and step out of a moving vehicle.

Further officer and SAR field team safety measures must also be considered. A 1999 study found that 60.4% of all homes with a family member who suffers from Alzheimer's disease or dementia have a firearm, or gun, present in that home.

44.6% of all those homes that had a firearm present, reported that the weapon was kept loaded.

Another 38% stated that they did not know if the weapon was kept loaded or not.

It is absolutely imperative for SAR interviewers to discover whether or not the AD subject has, or previously has had, a gun in his home, or available to him. It is further critical to discover whether or not that weapon, can be accounted for. If it, or any weapon, cannot be located or accounted for, then teams must assume that the subject has it with him, and proceed with due caution.

The skilled SAR interviewer needs to thoroughly explore any possibility or history that pertains to safety in the field, both that of the subject and that of the team. Examine military experience, law enforcement history (either as an officer, or as an offender). Discover likes and dislikes, preferences and fears.

When teams discover a subject, particularly one who may be hostile, it is often best to send forth one person. If the subject is known to dislike women and dogs, it is clearly obvious that the contact person should not be a female canine handler. On the other hand, if the subject is looking for his daughter, a male might not be the first choice.

Searchers must keep in mind the effects of agnosia (the loss or reduction of the brain's ability to interpret images) on the subject's ability to perceive help in the field. A searcher approaching the

subject may be perceived as a threat, or a savior. If the subject is known to be afraid of law enforcement, or hostile to persons in uniform, a command decision to wear “subdued” clothing may be wisest.

Example*: William has Alzheimer’s disease. He lives at home, and is cared for by his wife, Edith. When their daughter, Anne, had not been able to make contact for several days, she went to their home. The front door was barricaded, and the family vehicle was gone. Edith’s purse was spilled across the kitchen. William served in World War II and in Korea. He received several war injuries, including being shot in the leg, and losing part of his left hand. As his Alzheimer’s disease has progressed, his nightmares of war have returned. He believes “the enemy is coming for him”. When Anne searched the house, she discovered than an antique .22 was missing. Law enforcement was notified, and a search began. William and Edith were later found deceased, both of gun shot wounds.*

Ultimately, if a subject is known to be hostile, and is reported to be armed, a decision must be made as to whether volunteer SAR teams are the best choice in searching.

Incontinence: As Alzheimer’s disease progresses, it also robs the person of bladder and bowel control. The bladder is essentially a large muscle, and as the person loses recognition of the urge to urinate, the bladder will continue to fill until it spasms and voids. When this occurs often enough, the bladder muscle loses tension, and control, which often leads to leakage. Additionally, because of the infectious waste associated with loss of bladder and bowel control, people with Alzheimer’s often develop urinary tract and bladder infections. These infections only serve to further reduce bladder and bowel control.

Additionally, it is often an undiagnosed, undetected, or untreated bladder or urinary tract infection which can cause, or trigger, a person to wander.

This is of particular importance to the patrol officer, who is often called to transport a person with Alzheimer’s who has been found.

Many officers, in an effort to comfort this “nice old lady who was out wandering” will place the subject in the front of a patrol car. This is unsafe for a variety of reasons, including but not limited to the subject’s ability to open the door while in transit, as well as reach the officer’s weapon, radio, or the steering wheel. The wandering subject is most often best placed, securely, safely, respectfully in the back of a patrol car.

Incontinence is yet another reason to safely place the person with Alzheimer’s in the back of the patrol vehicle, because the seats are often an easy to clean, one-piece plastic bench. Loss of bowel and bladder control can produce what is considered a hazardous material spill incident (HazMat), which will require special clean-up services.

Cleaning of such a spill on a fabric seat can take considerable time and often ends up with that patrol vehicle out of service for the rest of its shift. If there is no other alternative, and incontinence is an issue, the person may literally be transported sitting on or with a plastic garbage bag tied around their waist.

A Death March

In order to understand how the missing at risk Alzheimer's subject may behave or react to his environment, search managers must understand Alzheimer’s disease. Without understanding the impairments in thinking, logic, emotion, vision, and other critical areas of the brain, searchers may be less likely to attach a significance of risk to these persons. The result, quite often, is that searchers overlook important clues, thus reducing the likelihood of finding the subject.

This illustrates the point the person may not be aware and therefore unable to ask for help. Because of the impairment to judgment and logical thinking, many persons with AD are unable to recognize a danger to themselves. They may wander across roads or highways, fall into bodies of water, or become entrapped in heavy brush.

This is extraordinarily important to realize, since many law enforcement agencies do not consider a missing person with Alzheimer's to be at risk. Some departments do not consider a person over the age of eighteen to be missing until after twenty-four hours. Some departments still require a mandatory 48 hours, or worse, 72 hours since last seen. Wandering Alzheimer's persons do not have the luxury of time.

Studies by Robert Koester and David Stooksbury (1992, 1995) show that wandering persons with Alzheimer's lost in Virginia faced a 46% mortality rate, if not found within 24 hours.

Information provided by the Emergency Services Council of British Nova Scotia reported death incidents of 70% for Alzheimer's subjects not found within 24 hours.

Records by the Rim of the World Search and Rescue team, 1968-1994, showed 100% mortality rates for persons over the age of 60 who were not found within 24 hours (no distinction made for person's with Alzheimer's versus elder persons; "Operations of the Rim of the World Search and Rescue Teams from 1968 to 08/30/94", Michael M. Dest, Captain James Nunn, Commander Gary Steffens).

Unfortunately, many persons with Alzheimer's disease who wander will succumb to personal or environmental hazards. The three leading causes of death for persons who wander are heart attack or stroke, exposure to the weather, and drowning. Rates appear to remain the same for those who wander and become lost in both urban and rural areas, as well.

"So That Others May Live…"

Originally the United States Air Force Pararescue Airmen teams' creed, *"This We Do, So That Others May Live"*, or more simply, *"That Others May Live"*, many SAR teams across the world have also adopted both the motto and attitude.

While many people think that slogan only really belongs to teams who go after injured climbers on Mt. Hood, or trekkers in Nepal, the reality is that searchers are often the difference between living, and dying, for a missing at risk Alzheimer's subject.

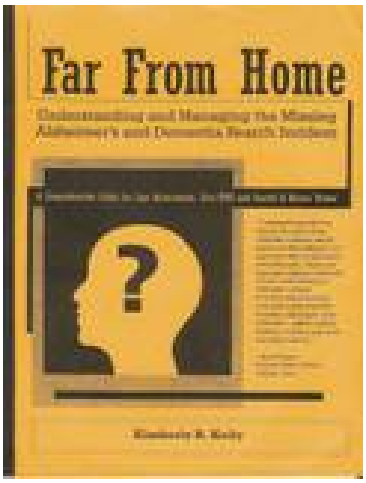
There are many areas of SAR where teams can rely on past history for current search management. Examples include knowing where planes typically get caught in swirling winter wind patterns, and that they usually crash in a fairly predictable pattern or area. Or knowing that people often walk a particular hiking trail in a certain pattern, following a map in a local guide book – fortunately, local SAR recognizes the guide book map is misleading, and generally finds their subjects in the same vicinity.

However, in searching for, or managing the search for missing at risk Alzheimer's subjects, we simply cannot rely on methods that work so well in other types of searches. We generally do not have subjects from a plane crash who deliberately hide from teams. We do not have overdue hunters who sit calling their own name back to searchers. And, we do not have injured or stuck climbers who only respond to assistance if told, "Mrs. Barnes wants to see you".

It is critical, then, that we, field searchers and managers alike, understand Alzheimer's disease and it's affect on the subject. It is imperative that SAR understands agnosia, aphasia, apraxia, and how those changes affect field behavior.

As our society ages and as people with Alzheimer's disease continue to wander, the toll on our law enforcement, and SAR missions, will only increase. No one person or single team alone will be able to solve the problem of missing Alzheimer's subjects. However, together, by educating the public, the Alzheimer's family and caregiver, the SAR member, SAR team, SAR manager, responding law enforcement officer, and other first responders, we can reduce the number of repeat searches, the time and resources required for searching, the subject injuries incurred, and most importantly, the lives lost to both this devastating disease, Alzheimer's, and our lost subject.

"You found him, you found him. I am so happy. I am just so happy…"
- the family member of a lost Alzheimer's subject, Hawaii, 1996, to joyous searchers



For more information, material, presentations, additional use request, or for assistance with your missing person's case, please contact:

Project Far From Home
P.O. Box 2292
Ramona, California 92065
(760) 315.1895
info@projectfarfromhome.org

Biographical Information:

Ms. Kimberly R. Kelly Falconer is the founder and executive director of **Project Far From Home**, www.projectfarfromhome.org, a national law enforcement educational program designed to teach law enforcement and search and rescue teams about missing at risk Alzheimer's and dementia subjects.

Ms. Kelly Falconer also serves her community as a search and rescue specialist, donating her time to the non-profit international search and rescue team, 1SRG: First Special Response Group, www.1srg.org, as well as instructor

Ms. Kelly Falconer is a retired law enforcement reserve and SAR volunteer with the San Diego County Sheriff's Department. Ms. Kelly Falconer served as Lieutenant of the Training Unit, and Search and Rescue Academy, San Diego County Sheriff's Search and Rescue Team. She has previously served as training sergeant for the mounted, training and underwater search and recovery units, acting lieutenant for the training unit, as well as certified as a technical rescue specialist and medical unit support personnel.

Ms. Kelly Falconer is the author **of "Project Far From Home: Understanding and Managing the Search for the Missing at Risk Alzheimer's and Related Dementia Subject**", available through Project Far From Home, www.projectfarfromhome.org.

She is a contributing author to Mark L. Warner's celebrated workbook, **"In Search of the Wanderer: A Workbook to Protect Your Loved One"**, available through Purdue University, www.thepress.purdue.edu, and book retailers such as Amazon.com. "In Search of the Wanderer" was designed for the Alzheimer's caregiver and family to assist in their efforts to care for, and protect, the at-risk Alzheimer's subject.

The information contained in the preceding pages authored by Kimberly R. Kelly Falconer, and appear in **"Urban Search: Managing Missing Person Searches in the Urban Environment"** by Christopher S. Young and John Wehbring, with additional contributions by Kimberly R. Kelly Falconer, Michael St. John, and Robert Koester. It is available through dbS Productions, www.dbs-sar.com.

Ms. Kelly Falconer and Project Far From Home have been recognized by President George Bush for her volunteer work, education, and training; California Office of Emergency Services (CA OES); Placer County Sheriff's Department; New Mexico State Search and Rescue Council; the Thousand Oaks, California, Disaster Response Teams; Oregon's Marion County Sheriff's Department; the Alzheimer's Association chapters of Oregon, Washington, and Idaho, as well as San Diego chapter; San Diego County Sheriff's Department, "1996 Reserve Deputy of the Year", San Diego Union Tribune ("Making a Search a Success"); the 1997 Do Something Foundation and Blockbuster's "Brick Award Finalist"; Channel 10 "Leadership Award"; North County Times "Woman of Merit"; Palomar Pomerado Health Systems "Unity Award Finalist"; as well as receiving the San Diego County Sheriff's Department "Medal of Meritorious Service".

For more information about **Project Far From Home**, or **Kimberly R. Kelly Falconer**, to schedule presentations or training, or for assistance on your missing person's case, please contact:

Kimberly R. Kelly Falconer, *Founder and Executive Director*
Project Far From Home
P.O. Box 2292
Ramona, California 92065
Kimberly@projectfarfromhome.org, info@projectfarfromhome.org
(760) 315.1895