

Working Together: How Community Organizations and First Responders Can Better Serve People Living with Dementia



Working Together: How Community Organizations and First Responders Can Better Serve People Living with Dementia

September 2018

Prepared for

Erin Long, MSW
Administration on Aging
Administration for Community Living
330 C Street, SW #1131A
Washington, DC 20201

Prepared by

Stephanie Hughes, MPP
Katharine Gordon, MSW
Donna Walberg, MBA
Michael Lepore, PhD
Edith G. Walsh, PhD
Elizabeth Gould, MSW
Molly Knowles, MPP
RTI International
701 13th Street, NW, Suite 750
Washington, DC 20005

Contract # HHSP2332009565IWC
Administration for Community Living
U.S. Department of Health and Human Services

Contents

Section	Page
Overview	1
Introduction.....	2
Common Situations Involving People Living with Dementia and First Responders.....	3
Wandering.....	4
Traffic Stops.....	5
Elder Abuse/(Self)Neglect, Exploitation, and Domestic Violence.....	5
Behaviors of People Living with Dementia That Lead to Involvement of Law Enforcement	7
Medical Calls to 911.....	8
Ways for Community Organizations and First Responders to Work Together	9
Providing Dementia Training to Law Enforcement, EMS and Firefighters	9
Preventing and Managing Wandering Incidents	14
Alert systems	14
Voluntary registries.....	15
Electronic tracking.....	16
Education and prevention.....	16
Ensuring the Health and Safety of People Living Alone with Dementia.....	17
Identifying people at risk	17
Safety checks.....	18
Community Paramedicine.....	20
Evaluation.....	23
Challenges in Serving People Living with Dementia.....	24
Program Participation and Implementation	24
Resource Limitations	25
Interagency Communication.....	26
Strategies for Success in Partnering with First Responders	26
Seek Buy-in from Leadership	26
Identify Champions within Agencies.....	27
Build on Existing Relationships.....	28
Meet Their Needs.....	29

Policies and Funding Related to First Responders and Dementia	30
State Plan Mandates for Training.....	30
State Training Standards	30
Federal Patient Alert Programs	31
State-Based Vulnerable Missing Adult Programs.....	31
Project Methodology	32
Resources for First Responders and Organizations Working with First Responders	33
Resource Cards and Brochures.....	33
Training	34
Guides	35
Model Policy for Law Enforcement	35
Public Awareness.....	35
References	37

Acknowledgements

The authors gratefully acknowledge the following subject matter experts who agreed to be interviewed for this guide:

- Nona Best, North Carolina Center for Missing Persons, North Carolina Department of Public Safety
- Jill Cigliana, Memory Care Home Solutions
- Jeff Dostalek, Fitch-Rona EMS
- Jessica Empeno, Alzheimer's San Diego
- Emily Farah Miller, Farah Miller Consulting, LLC
- Michael Knobbe, San Diego County Sheriff's Department
- Mark Odom, Alzheimer's Orange County
- Michael Proffitt, San Diego County Sheriff's Department
- Ronda Randazzo, Alzheimer's Association, Massachusetts/New Hampshire Chapter
- Sharee Rines, State of Georgia, Adult Protective Services
- Molly Schroeder, Wisconsin Alzheimer's Institute
- Shaun St. Germain, Maine EMS
- Heather Strickland, Georgia Bureau of Investigation

The authors also thank Michelle Myers, Loraine Monroe, and Danielle Hennis for editorial and graphic assistance; Mark Howell for help with the literature search; Rebekah MacKinnon for her help in coordinating interviews and taking notes; and Erin Long of the Administration for Community Living for reviewing the content. This toolkit was produced under contract by RTI International through Contract HHSP2332009565IWC, Task Order HHSP23337038T with the Administration for Community Living/U.S. Department of Health and Human Services.

This guide is the work of the authors and does not necessarily express the opinions of the Administration on Aging/Administration for Community Living or the U.S. Department of Health and Human Services.

Overview

The purpose of this guide is to help community organizations collaborate with first responders to better serve people living with dementia as part of a broader community system of care and support.

The guide covers:

- a brief background on the types of situations in which first responders are most likely to encounter people living with dementia;
- common approaches to partnership between community organizations and first responders;
- challenges that community organizations and first responders may experience;
- strategies for community organizations to work successfully with first responders;
- state and federal policies and funding related to first responders and dementia;
- available resources, including training materials, sample policies, tip sheets, and assessment protocols; and
- project methodology.

Although the guide was developed for community organizations conducting outreach to first responders, it has information first responders may also find valuable. The information summarizes current research, reports and resources, and guidance provided through interviews with experts. Three programs are described in detail as case studies.

This guide and many of the programs and initiatives described were developed with funding from United States Department of Health and Human Services Administration for Community Living/Administration on Aging (ACL/AoA). The guide is one of many resources available at the National Alzheimer's and Dementia Resource Center website at <https://nadrc.acl.gov>.

Introduction

Nearly 6 million people in the United States are living with dementia. The majority remain in the community, and as their cognitive functioning gradually declines, they need help staying safe (Alzheimer's Association, 2018a). Behavioral symptoms such as memory loss, confusion, aggression, and agitation are common, and many people living with dementia also experience other chronic medical conditions such as diabetes, hypertension, and congestive heart failure (Alzheimer's Association, 2018a; Bunn et al., 2014). These behavioral and medical issues often bring people into contact with first responders—the law enforcement officers, firefighters, and emergency medical services (EMS) personnel who are charged with keeping citizens and communities safe. Examples of common scenarios are the following:

- People living with dementia might walk out of a store with items they forgot to pay for and face charges of shoplifting.
- They may become lost or get into an accident while driving.
- They may fall and need EMS.
- They may call 911 thinking a misplaced item has been stolen.
- They may become victims of financial abuse by paid caregivers or even family members who take advantage of their diminished cognitive capacity.

First responders increasingly recognize the need for dementia training. They are often uneducated about the signs of possible dementia and may not know how best to respond to incidents involving dementia. In one study, police officers with greater dementia knowledge were better able to recognize behaviors as potentially dementia-related, but researchers also found that additional skills training may be necessary for officers to become truly competent in managing these situations (Sun et al., 2017). EMS providers also typically do not receive dementia training or screen for possible cognitive impairment, even though people living with dementia are significantly more likely than those

without dementia to visit the emergency department (ED) or be hospitalized (Feng et al., 2014; Shah et al., 2011).

Community organizations with dementia expertise play an important role in bridging the knowledge gap for first responders. These service organizations include a range of providers such as Alzheimer's organizations, Area Agencies on Aging (AAAs), social service agencies, offices on aging, and senior services agencies. Other providers such as health care systems or residential facilities may also work with first responders on this topic. In this guide, the term *community organization* refers to all these provider types.

Contact between a community organization and a first responder agency is sometimes limited to a training presentation, but there is potential for the relationship to build over time. A champion within a police department or EMS agency can help make the case for greater time and focus on dementia and may also be willing to serve on an advisory committee or task force. First responders also value community organizations more as they see that the information and services they provide save their agencies time and help them do their jobs more effectively. Eventually, the relationship may entail close coordination of services, with the potential to avoid duplicated effort and to better meet the complex social, psychological, medical, and financial needs of people living with dementia (Payne, 2013).

Common Situations Involving People Living with Dementia and First Responders

First responders may encounter people living with dementia and their families in a wide variety of circumstances. This section covers some of the most common situations. Although evidence on effective approaches is mostly anecdotal, we have included recommended practices based on the literature and practitioner interviews where available. More information about specific interventions, training programs, and ways community organizations and first responders can collaborate to

address dementia is presented in the section on [Ways for Community Organizations and First Responders to Work Together](#).

Wandering

The International Association of Chiefs of Police (IACP) National Law Enforcement Policy Center has developed a [model policy](#) for law enforcement on how to respond to missing persons events involving people living with dementia.

- An estimated 6 in 10 people living with dementia will wander (Alzheimer's Association, n.d., 2).
- Most people who wander on foot remain within a 10-mile radius of home.
- On average, law enforcement agencies spend 9 hours locating a wandering person, costing \$1,500 per hour of investigation (Yang & Kels, 2017).

Wandering can be related to behavioral symptoms such as restlessness or agitation or a response to uncomfortable stimulation, or it can be triggered by an association such as car keys hanging by the door. People living with dementia may become disoriented and lost even in their own neighborhoods, and when they do, they typically behave differently from other people who are lost: they do not take a coherent path, they may try to hide, and they may not respond when called.

They are often unaware of the dangers surrounding them and are at risk of fatal exposure to weather, injurious falls, traffic accidents, and drowning (Petonito et al., 2013). The risk of injury and death increases with each hour that passes; therefore, efficient and appropriate search processes are critically important (IACP, n.d.).

A coordinated interagency law enforcement response and comprehensive training for law enforcement personnel improve the likelihood of locating the person quickly. Voluntary registry systems and electronic tracking also facilitate search efforts (see the section [Preventing and Managing Wandering Incidents](#)).

The IACP policy recommends treating missing persons with dementia as an emergency, providing persons found with appropriate support, and promoting awareness that older adults who appear confused or disoriented may have wandered and not yet been reported lost.

Traffic Stops

People living with dementia are at greater risk of an accident while driving than those without dementia. Impairment may present as:

- driving erratically or failing to obey street signs, traffic lights, or speed limits;
- appearing confused or intoxicated; or
- leaving the scene of an accident unaware of injuries or property damage.

Law enforcement often encounters individuals with dementia who are driving erratically and are lost but have not yet been reported missing. The ability of law enforcement to recognize the signs and symptoms of dementia in these situations is critical for the health and safety of the person and others on the road.

Experts agree that if there has been a driving violation, the driver should be cited instead of issued a warning to create a paper trail for caregivers, medical practitioners, and licensing agencies. This may make it easier for family members or authorities to encourage or require the person to stop driving.

Elder Abuse/(Self)Neglect, Exploitation, and Domestic Violence

Incidents of elder abuse, neglect, and domestic violence including people living with dementia are frequently encountered by law enforcement and Adult Protective Services (APS) staff:

- Estimated rates of self-neglect among people living with dementia range from 14% to 19% (Dong, Chen, & Simon, 2014).
- Having dementia appears to put people at higher risk for multiple forms of abuse by caregivers (Payne, 2013).
- Emergency responders are often the first ones to identify abuse (Payne, 2013).

Abuse can take many forms, including physical injury; verbal abuse or threats; failure to provide a safe environment, proper medical care, or

The University of California-San Diego School of Medicine and Calit2's Training, Research and Education for Driving Safety (TREDS) program has developed a [Driver Orientation Screen for Cognitive Impairment \(DOSCI\)](#) , a brief driving assessment questionnaire for law enforcement and video trainings on how to use that assessment.

The IACP's [Identifying and Helping a Driver with Alzheimer's Disease](#)  helps law enforcement officers assess and communicate with drivers who may have dementia.

food; physical restraints; financial fraud or theft; sexual abuse; or self-neglect (Alzheimer's Association, n.d., 1).

Financial exploitation occurs when a person misuses or takes the assets of a vulnerable adult for his or her own personal benefit (National Adult Protective Services Association, n.d.). Financial exploitation is becoming rampant according to law enforcement agencies. Bankers, doctors, and other mandated reporters often report these incidents to law enforcement or APS. The cases pose tremendous costs to both victims and law enforcement. One elder abuse unit within a law enforcement agency estimated that each case of financial abuse takes 1-2 weeks of staff time to investigate.

Domestic violence may be an existing problem before a dementia diagnosis, or it may occur because of caregiver frustration, behavioral symptoms of aggression or agitation in the person living with dementia, or a combination of both. Although law enforcement is responsible for making sure that all parties are safe from violence, it is also crucial for officers to recognize when dementia may be involved so that inappropriate arrests can be avoided, referrals made to APS and, in some cases, transfer made to an ED for evaluation. In many jurisdictions, there are laws requiring mandatory arrest in cases of domestic violence, which can complicate this process.

Law enforcement also receives calls about unlicensed care homes, which are facilities that claim to be legitimate care homes but are not licensed by the state (Greene et al., 2015; Lepore et al., 2018). In some cases, the operators of unlicensed care homes recruit victims, including people living with dementia, from institutional care settings, such as hospitals. In turn, these homes have been found to lock their victims in unsafe conditions (e.g., in unventilated basements, sheds, or attics with limited access to basic needs, such as food, water, and toilet) and to strip them of resources with financial value, including government social welfare payments, food stamps, and medications which can be sold on the black market (Greene et al., 2015; Lepore et al., 2018). Hospital staff can play a role by confirming that personal care homes are licensed before discharging people to them. In Georgia, an app has been developed in partnership with the Department of Community Health to

list licensed personal care homes in the state, which can be used by first responders and the public to verify care home licensure.

Collaboration across multiple state and community organizations—such as APS, Sheriff’s departments, police departments, state bureaus of investigation, social service, and Alzheimer’s organizations—is critical for addressing issues of elder abuse/(self)neglect, and domestic violence involving people living with dementia. These are people with complex care needs that cannot be addressed by one agency. Having a common language, and understanding of each organization’s role and capabilities, can support these partnerships and help prioritize training needs. Cross-agency partnerships are strongly supported by having champions within upper management at each collaborating agency. Although training first responders about how to work with people living with dementia requires a commitment of resources, experience indicates that it can save tremendous time and money spent on subsequent cases.

Behaviors of People Living with Dementia That Lead to Involvement of Law Enforcement

People living with dementia are at risk of being charged as criminals for actions that stem from their diminishing cognitive capacity. For example:

- Memory loss may cause the person to forget to pay for an item in a store.
- Loss of executive function may lead to socially inappropriate behavior such as indecent exposure.
- Behavioral symptoms such as aggression can result in acts of domestic violence.

These incidents are challenging for law enforcement because the person may not realize that they are acting inappropriately and usually has no intent to commit a crime. Training officers for these types of incidents is critical for avoiding inappropriate responses that can cause further harm to the individuals involved.

“...Sometimes when a person with Alzheimer’s has lost or misplaced an item, he or she may call 911 to report a theft. In many cases, reports of a bure intruder turn out to be an otherwise familiar family member or even a spouse whom the person with dementia has forgotten”

— (Alzheimer’s Association, 2006, p. 3).

As mentioned above, in cases of domestic violence it is important for officers to be able to ensure the immediate safety of those involved while avoiding inappropriate arrests. System-level responses are emerging, such as specially trained teams of law enforcement and APS that respond to urgent situations involving people living with dementia. Through this sort of crisis-based program, officers can contact an APS worker or another dementia specialist directly, 24 hours per day. This type of rapid response helps address urgent needs of the person or caregiver and helps law enforcement resolve a case more quickly by bringing in supportive services.

Medical Calls to 911

- People who are transported by ambulance to a hospital ED are more likely to have dementia than those who arrive via other means (Buswell et al., 2016; Shah et al., 2011).
- People with dementia frequently do not report a dementia diagnosis or medications to EMS providers (Shah et al., 2011).

Implementing dementia-specific training for EMS staff may increase the accuracy of the patient health history reported to ED staff and improve the likelihood of appropriate treatment for people living with dementia. EMS providers who know about cognitive impairment can better gauge the accuracy of patient-reported health status and health history and the patient's understanding of medical instructions if the patient refuses care. Additionally, pre-hospital identification of cognitive impairment by EMS can provide vital information to the larger health care team that may affect hospital admission decisions (Shah et al., 2011). Registry information (see the section on [Voluntary Registries](#)) or medical information posted in the home can supplement information provided by the individual or family.

“Many people have it [dementia] and nobody is being detected. This is likely a huge reason for [hospital] readmissions. [People living with dementia] can’t manage their conditions.”

—Jill Cigliana, Memory Care Home Solutions

Ways for Community Organizations and First Responders to Work Together

First responders and community organizations work together in various ways to enhance the safety of people living with dementia, their families, and the community. Community organizations knowledgeable about dementia can educate first responders to respond effectively to common situations. First responders may develop or tailor services to serve people living with dementia, for instance, through registries or alert systems for wandering, or community paramedicine for people in need of regular health monitoring. They may also seek to identify people at risk, such as those living alone with dementia, and to put in place a network of monitoring and support services.

Providing Dementia Training to Law Enforcement, EMS and Firefighters

The need to provide dementia training for all types of first responders has become urgent as the population with dementia is expected to increase by 51% by 2050 and will have increasing contact with law enforcement, EMS, and firefighters (Hebert et al., 2013). Few first responders know how to recognize and interact with people living with dementia, often compounding already traumatic events. Community organizations can offer dementia training to help first responders find people who wander, reduce inappropriate arrests, promote proper management of domestic situations, and increase connections to community resources with the goal of stemming future emergency situations.

Many resources are available for training first responders on dementia:

- The International Association of Chiefs of Police has two training webinars on dementia for law enforcement.
- The Alzheimer’s Association’s Approaching Alzheimer’s training video covers six dementia topics.

“Understanding the facts of [dementia] does not necessarily transfer to communication skills...additional training...may be needed to make police officers capable of approaching, engaging and helping [people living with dementia]”

—Sun et al. 2017, pp. 7-8.

- Alzheimer's Orange County has 4 brief training videos on dementia for law enforcement.
- The National Council of Certified Dementia Practitioners offers a 6-hour, in-person training for a fee.
- See the [Resources](#) section for additional training materials.

Examples of dementia training programs include the following:

- Massachusetts/New Hampshire Chapter of the Alzheimer's Association

In Massachusetts, Silver Alert legislation was passed that included mandated dementia training for law enforcement and first responders. (Silver Alert is a system of emergency communications used to help locate missing older adults with cognitive impairment.) The Alzheimer's Association worked with the Massachusetts police training committee to identify training needs and create a standard training curriculum.

Using a train-the-trainer model, the Alzheimer's Association provided a half-day training to approximately 90 certified police instructors who then delivered the 4-hour training to their departments over the course of a year. The Association also trained more than 250 police chiefs at their annual conference and provided ongoing coaching and resources to the police instructors and departments, funded by the Association's operating budget. The training was delivered to existing officers statewide and was integrated into classroom training for new cadets.

The 4-hour training program is delivered in 10 modules including Silver Alert, Alzheimer's disease and related dementias as they present in the field, communication challenges and behaviors, driving and traffic stops, wandering and search response, abuse and neglect, firearms and disaster response, and community resources available to law enforcement and to individuals.

Through grant funding from the Tufts Health Foundation, an additional 3-hour training was developed for firefighters and

EMS, including modules on response to urgent scenarios, pain, emergency shelter, and reporting abuse. Massachusetts Office of Emergency Medical Services approved 3 continuing education credits for all levels of EMS personnel completing the training, which has led to high demand from Massachusetts firefighters and EMS personnel and other first responder training conferences. Curriculum has also been developed and provided for Search and Rescue personnel statewide.

- Wisconsin Alzheimer's Institute–Dementia Training for Community Paramedicine Providers

As part of an ACL-funded grant, the Wisconsin Alzheimer's Institute (WAI) at the University of Wisconsin–Madison, in partnership with the Alzheimer's Association and the University of Wisconsin Department of Family and Community Medicine, is providing training to local paramedic service providers in south-central Wisconsin. The paramedic service is tasked with delivering friendly home visits to people living alone with dementia.

Community paramedicine is a relatively new approach to improving health care for people who overuse emergency services, and most programs do not focus on people living with dementia, particularly those living alone. This new project is one of a very few that are beginning to explore this avenue of dementia service delivery. Unlike many community paramedicine programs that provide basic medical care as part of home visits, this project is using non-medical, friendly visits to connect people with other services and resources (See Section [Community Paramedicine](#) for more information about community paramedicine.)

The initial in-person training lasted 3 hours and covered the basics of dementia. A second, 6-hour in-person training is focused on motivational interviewing skills and techniques aimed at encouraging clients to accept case manager support and other services in the home. Two paramedics also attended a separate 1-day “best practices in dementia care” seminar by a national dementia care trainer. WAI has also developed and

delivered a 2-hour training for the paramedics, which includes information on program implementation and data collection. Local senior center case managers have participated in this training to learn more about the program and how to coordinate services with the paramedics, including referral processes between the agencies and service flow from initiation to discharge.

Tips for training first responders:

- Understand that the cultures of first responder agencies, especially law enforcement, can be different from other community groups and different from each other. Ask what situations are causing challenges or questions and tailor training accordingly.
- Keep training short and simple. As one expert suggested, tell them “what to do,” and “what to say.”
- When possible, invite champions within the first responder agency to deliver or help deliver the training. Peer-to-peer presentation can lend great credibility.
- Once you build a relationship with a first responder agency, leverage this connection to establish contacts with other agencies.

First responder training content should include the key signs of dementia and simple tools for assessing cognition that can be used in an emergency. Training can also address special situations that first responders typically encounter. For instance, law enforcement training should include optimal strategies for wandering prevention, the nature of wandering incidents, and best practices in search and rescue for people living with dementia. The [Resources](#) section of this guide contains multiple links to quality training resources, including videos, webinars, and in-person training options.

Case Study #1—Law Enforcement Training

Alzheimer's San Diego, Alzheimer's Orange County, San Diego County Sheriff's Department, Adult Protective Services, Psychiatric Emergency Response Team, other law enforcement agencies

Alzheimer's San Diego and Alzheimer's Orange County are dementia service organizations providing education, support and respite. Each had some experience training law enforcement officers on dementia basics, but an ACL grant awarded in 2015 enabled them to expand their work with first responders.

Their initial goal was to convene safety task groups in each county, update and expand training, develop brief training videos, distribute resource cards on wandering, and help develop an app that would enable first responders to better recognize signs of dementia. Alzheimer's San Diego and Alzheimer's Orange County each convened a safety task group, including representatives from APS, local AAAs, sheriff's departments, and police departments to inform planning and development of trainings and materials.

Both Alzheimer's San Diego and Alzheimer's Orange County have provided extensive training to law enforcement officers, firefighters, and EMS. Alzheimer's San Diego has offered most trainings in person using its own standard content customized to the needs of the agency. More than 1,400 people have been trained. Training has been integrated into the required training for all Psychiatric Emergency Response Team members—specially trained law enforcement officers who are paired with mental health professionals to respond to crisis situations. Alzheimer's San Diego has also provided training to members of the Retired Senior Volunteer Patrol, a volunteer program of the San Diego Police Department that provides safety checks for elderly residents who live alone.

In addition to in-person trainings for local law enforcement, Alzheimer's Orange County has developed a [series of four brief training videos](#) with a total running time of 15 minutes that cover common scenarios: a traffic stop, a wandering event, a 911 call from a distressed caregiver, and a distressed person living with dementia who thinks she has been robbed.

Opportunities to partner with first responders continue to expand. For example, Alzheimer's Orange County is now partnering with an occupational therapist who can advise law enforcement on driving assessments for people with cognitive impairment. Alzheimer's San Diego, in collaboration with the local criminal justice system, is exploring the use of gun violence restraining orders to ensure the safety of people living with dementia and their families when firearms are in the home. The San Diego District Attorney launched an elder abuse initiative that has led to case coordination between APS, the Sheriff Department's Elder Abuse unit, and Alzheimer's San Diego for people in crisis or high-risk situations.

(continued)

Case Study #1—Law Enforcement Training (continued)

Alzheimer’s San Diego is also developing a phone app for first responders in collaboration with the San Diego State University Geriatric Workforce Enhancement Program. The app will give officers and deputies quick access to helpful information when responding to a call involving a person with dementia, including signs and symptoms, common behaviors, communication strategies, home safety tips, and an overview of wandering behavior. Through the app, officers will also be able to make direct referrals to APS, enroll individuals in the Take Me Home program (a local registry for adults with special needs, accessible only by law enforcement), and make a direct referral to Alzheimer’s San Diego for additional support and assistance. The free app will be available on iPhone and Android devices.

Developing relationships with and programs for first responders has involved challenges. One of the biggest difficulties has been adapting to the specific needs of different first responder agencies. Agencies have different processes for arranging training, and informational needs, amount of time allotted, and the physical space also vary. Trainers do not always receive information in advance that enables them to tailor their presentations, so they need to be experienced enough to be able to rapidly adjust to circumstances and needs.

Even with grant funding, comprehensive outreach to all local law enforcement is not possible. Both San Diego and Orange counties are large and contain multiple law enforcement agencies and jurisdictions. Turnover within law enforcement often requires new relationships to be established. The organizations’ growing reputations as effective trainers have facilitated connections with new agencies, while follow-up contact with these agencies has helped build sustainable relationships.

Preventing and Managing Wandering Incidents

First responders and community organizations use several approaches to prevent and manage wandering incidents. Having protocols and technology in place can improve the likelihood of locating the person living with dementia more quickly and safely and can save law enforcement time and resources (Bureau of Justice Assistance, 2014; IACP, n.d.).

Alert systems

Mass communication systems such as mobile phones, digital road signs, or social media can be used to alert law enforcement officers and the public that a person with dementia or other vulnerable adult is missing (Bureau of Justice Assistance, 2014). Silver Alert is the most well-known

“[The] most important thing is to be educated, trained and prepared. When [a person wanders] you have to move fast because the first few hours are the most critical for people with dementia.”

—Nona Best, North Carolina Center for Missing Persons

alert system.

Each state has different policies, but it is common practice for alert systems to require that people reported missing be at least 60 years old and have Alzheimer's disease or some other cognitive impairment. Generally, a missing person report must be filed with law enforcement, and law enforcement determines if requirements have been met to issue an alert. In addition to age and impairment of a missing person, alert programs may have other eligibility criteria, such as determination of a serious risk to the health and safety of the individual. Guidelines in each state determine how broadly the alert is disseminated. States generally absorb program costs within existing agency budgets.

Voluntary registries

Registries give people living with dementia and their families the opportunity to provide law enforcement with information that can help locate the person, prior to a possible wandering event. In addition to people living with dementia, some registries include people with autism spectrum disorders, mental illness, developmental disabilities, or other conditions that might increase the likelihood of becoming lost.

Voluntary registry systems house a variety of data such as recent photographs, locations that hold special interest to the person with dementia like a past home, and information about their impairment. This information can help focus efforts in the first few crucial hours of the search.

Procedures for collecting and accessing registry information vary. Families may fill out a paper form, sign up online, or be interviewed by law enforcement. Law enforcement agencies also vary in the degree of technological sophistication they can employ in accessing this information during a search and rescue call, but even simple applications can provide critical information that saves time in the search process.

The primary challenges to establishing registries include marketing and outreach to elicit participation and maintaining data to ensure that information remains current and useful (IACP, n.d.).

The IACP strongly encourages states and communities to implement voluntary registry systems and connect to national registry systems.

The Alzheimer's Association's [MedicAlert + Safe Return program](#), the Irvine, California "[Return Home Registry](#)," and Polk County, Florida's "[Project Safe & Sound](#)" are examples.

Electronic tracking

A growing number of products are available to help locate someone during a wandering event. Many of these are technologies marketed to family members to be able to track or find their loved ones more easily, but one system, Project Lifesaver International, involves law enforcement agencies as well.

Project Lifesaver uses a wristband that looks like an ordinary watch that cannot be removed by the individual. A law enforcement officer meets with the person and their caregiver monthly to replace the batteries and conduct a routine check-in. If the person wanders they can generally be found within minutes.

Opinions on the ethics and usefulness of tracking devices vary. The IACP National Law Enforcement Policy Center missing persons policy recommends that law enforcement officers encourage caregivers to use tracking devices and other strategies to prevent future wandering. A tracking device may increase personal freedom and provide peace of mind to people living with dementia and their families, but the decision to use one raises ethical issues regarding personal autonomy and privacy (Landau & Werner, 2012; McKinstry & Sheikh, 2013). Some have also suggested that having a location device may lead family members or friends to check in with the person less often (Alzheimer's Society, Canada, 2014). Experts recommend that the person with dementia be involved in decision-making regarding this technology (Landau & Werner, 2012).

Education and prevention

Wandering can sometimes be avoided with basic education and preventive steps by people living with dementia, their families, and first responders. For instance, keeping car keys and purses out of sight and away from the door, installing an alarm on the door, and keeping the person occupied with engaging activities can reduce the likelihood of wandering (Alzheimer's Association, 2018a).

Law enforcement officers are often the only point of contact for families during a wandering event and with the proper knowledge can play an important role in preventing future events. Alzheimer’s San Diego developed a resource card for this purpose; it provides tips on wandering prevention and what to do if someone wanders and is intended to educate law enforcement officers and for officer distribution to families. Law enforcement agencies are often receptive to these resources because they recognize the potential to conserve resources and prevent tragedies.

The [Resources](#) section of this guide includes several training programs and tip sheets focused on preventing and handling wandering incidents.

Ensuring the Health and Safety of People Living Alone with Dementia

Recent data from the National Health and Aging Trends Study indicate that more than 30% of people with dementia live alone (Amjad et al., 2016). Their level of cognitive impairment varies, and some do have support from nearby friends or relatives. However, the potential for injury or self-neglect is real and has led to the development of programs that identify and support these individuals, often through coordination between first responders and community organizations.

Identifying people at risk

Dementia services organizations have recently increased their efforts to identify people living alone with dementia, particularly those without a caregiver regularly checking on them. ACL has identified this as an important service gap and has funded grants to help community organizations address the needs of people living alone. First responders can play a key role in this work.

In Spokane, Washington, Frontier Behavioral Health has partnered with a variety of community “gatekeepers,” including police, fire, and ambulance services, to identify older adults living alone and at risk for harms such as financial exploitation, malnutrition, and inability to perform activities of daily living. Through this program, first responders and others in the community who encounter vulnerable adults, including people living with dementia, can refer them to Frontier

The National Alzheimer’s and Dementia Resource Center’s *[Providing Services to Individuals with Dementia Who Live Alone](#)* offers practical strategies to service professionals working with this group.

The International Association of Chiefs of Police’s *[Identifying and Evaluating the At-risk Older Adult](#)* is a helpful tool for law enforcement to assess drivers or other older adults for possible dementia.

Behavioral Health for an assessment, planning, and establishment of home support services (M. Marcus, personal communication, March 2018).

Safety checks

Home visitor programs and phone check-ins also show promise for supporting the safety of people living alone with dementia. For example, in Lake County, Florida, the Senior Watch program provides daily check-ins for at-risk older adults. Each day, the enrolled person calls to check in with the Senior Watch operator. If Senior Watch does not hear from a participant, a phone call is made to a neighbor or relative, and if contact is not confirmed, someone from the Sheriff's department will come to the home for a welfare check (Lake County Sheriff's Office, n.d.).

In San Diego, the You Are Not Alone (YANA) program operated by the San Diego County Sheriff's Department provides daily telephone checks for enrolled seniors who live alone. Program participants also benefit from one personal visit each week from a Sheriff's department volunteer. If an enrollee cannot be reached during a scheduled check-in, a volunteer patrol member will go to the person's home to check on them (San Diego County Sheriff's Department, n.d.). Through an ACL grant, Alzheimer's San Diego has provided dementia training to YANA volunteers to help them better recognize people with possible dementia who may be able to benefit from additional support services in the community.

Case Study #2—App for Law Enforcement

State of Georgia Adult Protective Services, Division of Aging Services; Georgia Bureau of Investigation; Alzheimer's Association, Georgia Chapter

Law enforcement and APS staff frequently encounter situations where someone appears to have been abused, neglected, or exploited. Unlike Child Protective Services, APS is not available 24 hours a day, 7 days per week, and often, late night calls are made to law enforcement when APS is not available for a consultation.

Previously, the lack of immediate access to emergency services through APS in Georgia was leading law enforcement to take people with dementia to hospitals with a "social admission"—a hospital admission for which no acute medical issues are felt to be contributing. Law enforcement personnel were also more frequently encountering situations where people with diminished cognitive capacity appeared to be wandering or lost. Law enforcement and health care professionals needed quick access to information, screening, and services for these and other urgent situations.

(continued)

Case Study #2—App for Law Enforcement (continued)

The Georgia Department of Human Services, Division of Aging Services (DAS) determined that an app could prove useful for law enforcement, APS, other health care professionals, and the public and commissioned the development of the Georgia Abuse, Neglect and Exploitation (GANE) app. The GANE app specifically provides access (via smart phones and tablets) to resources for law enforcement and other professionals that respond to abuse, neglect, or exploitation. DAS led the app development in collaboration with the Georgia Chapter of the Alzheimer’s Association and the Georgia Bureau of Investigation. The core development team included the former state director of aging, a former investigator for the DA’s office, a former police detective, and a developer with experience creating an app for vulnerable adults living alone. Other contacts in law enforcement served as an informal focus group to identify additional resources to build into the app.

The finished product includes functionality available to the public, health care professionals, law enforcement, and other professionals. Features for the public and health professionals include contact information for various agencies and information on laws related to abuse, neglect, and exploitation. Although originally designed for Georgia, the app can be customized to any state or locale by contacting the app developer, David Cardell from EyeOn App, LLC.

Law enforcement and other elder abuse professionals can obtain an activation code that provides access to:

- screening questions and algorithm for cognitive functioning;
- screening questions and algorithm for determining abuse, neglect, and exploitation;
- screening questions and algorithm for determining financial capacity;
- emergency placement options by zip code and nearest to your location;
- Mattie’s Call (receive and send missing persons alerts; this is Georgia’s version of Silver Alert);
- push notifications of the latest scams.

Training on use of the app for law enforcement was first provided as part of the state’s two-day At-Risk Adult Crime Tactics Specialist Certification course, which is open to first responders including law enforcement and EMS. This training is offered in approximately 20 of the 159 counties in Georgia each year. The IACP Alzheimer’s Initiatives training program conducted in Georgia also incorporates information about the GANE app. The Georgia Bureau of Investigation provides this training in multiple counties each year. The team that developed the app also presents and trains on the app in several Georgia counties each year. Resource constraints within partner agencies have limited dissemination.

The app development and implementation were originally funded through a federal grant from ACL and asset funds acquired through criminal cases. The funds to maintain the tool come from APS’s budget, which is part of the general state funds. It costs \$8,000 annually to host and maintain the app.

(continued)

Case Study #2—App for Law Enforcement (continued)

To date, the app has been downloaded by more than 2,000 unique users. App uptake has faced challenges because some law enforcement officers use BlackBerries and there are no plans to develop an app for that platform. Some local police departments and other providers have been blocked from downloading the app because of firewalls/security concerns. The continued promotion of the app has declined because of staff turnover at the Georgia Alzheimer’s Association and the Georgia Division of Aging Services. The development team must establish relationships with their replacements to keep a positive focus on maintaining and improving the app.

Community Paramedicine

Traditionally, EMS has limited its scope of practice to responding to 911 calls and transporting patients to an acute care hospital ED or transferring patients between hospitals or other care settings.

Community paramedicine (CP) is a relatively new model that uses EMS providers to deliver health care in coordination with other medical providers (Abrashkin et al., 2016). CP care is delivered in a patient’s home and typically targets frequent EMS users, people recently discharged from a hospital because of a serious health condition, and homebound individuals with multiple chronic illnesses. CP programs now exist in most states, although few focus exclusively on people living with dementia (Goodwin et al., 2015; National Association of State EMS Officials, 2018).

Patients are generally referred to CP programs through EMS records of 911 calls, primary care providers, hospital discharge planners, senior centers, and other community service providers. Training for CP providers should include communication strategies and tips on building a relationship. Many older adults are hesitant to accept help because they fear they will be removed from their homes if it is determined that they are unsafe. EMS staff report that with proper training, staff can approach these situations in a way that engenders trust.

Staffing models for CP programs vary. Programs with full-time CP staff can schedule appointments with patients. Other programs use existing EMS staff to conduct CP visits on their “off” time, and emergency calls may interrupt a visit. For people with cognitive impairment, it is preferable for services to be routine and uninterrupted, using dedicated

CP programs for people living with dementia may include a variety of services:

- cognitive screening and diagnostic referral;
- falls prevention and education;
- home safety assessment;
- medication reconciliation;
- administration of medication (e.g., IV line);
- general physical exam;
- assessment of activities of daily living;
- review of advanced care planning; and
- referral to primary care, APS, social services, or other dementia-specific services such as respite.

staff. However, this model is the exception and not the rule because of resource constraints.

Funding for launching and sustaining CP programs is a major challenge. A lack of public and private insurance reimbursement for nontransported paramedic services is one obstacle to growth of these programs (Abrashkin et al., 2016). Typically, programs receive funding from public and private grant sources, private donations, and per member per month fees. Minnesota allows for reimbursement for some community paramedicine services through its state Medicaid program. Commercial health insurance providers, including Anthem Blue Cross and Blue Shield, have also begun to reimburse for some community paramedicine activities. ACL grants have provided funding to launch a few emerging CP programs to serve people living with dementia.

In Wisconsin, a dementia-specific CP program is launching in Dane County. Funded by ACL, it is a partnership between the Wisconsin Alzheimer's Institute, Fitch-Rona EMS, and local senior centers. EMS staff identify people who meet the following criteria: live alone, have a diagnosis of cognitive impairment, and have little or no support. The EMS personnel meet with people in their homes, have regularly scheduled friendly visits, and help transition the person to community services. Specifically, EMS works toward connecting people to case managers at local senior centers. These case managers provide in-home assessments and connect participants with a wide array of services to address their health and safety needs (e.g., home chore assistance, medication management, home-delivered meals, companionship and supervision services, grocery shopping, and personal care assistance).

Case Study #3—Community Paramedicine and Dementia Services

Memory Care Home Solutions, Christian Hospital Community Health Access Program

Health care professionals' limited dementia knowledge is often cited as a significant hurdle to improved outcomes for people with the condition. This was the situation facing the Community Health Access Program (CHAP) of Christian Hospital in St. Louis County, Missouri, when they launched a CP program to fill health care gaps and reduce unnecessary 911 calls, ED visits, and hospital readmissions.

(continued)

The U.K.'s Dementia Partnerships has developed a basic resource manual for EMS staff to understand dementia communication strategies and other topics related to emergency care for people living with dementia: [Dementia Learning Resource for Ambulance Staff](#).

Case Study #3—Community Paramedicine and Dementia Services (continued)

The CHAP program, which employs advanced practice paramedics to identify frequent “over-users” of EMS, found that the highest users were older adults. Often these patients’ challenges were related to undiagnosed cognitive impairment, which hampers the ability to self-manage health situations such as complex hospital discharge instructions. To better serve these patients, CHAP needed to improve its own staff’s dementia knowledge.

The Express Scripts Foundation stepped in with \$175,000 to fund a pilot project partnering CHAP with Memory Care Home Solutions (MCHS), a dementia services provider offering care consultation, caregiver education, home safety assessments, and linkage to community resources. The pilot aimed to improve dementia knowledge within CHAP and improve the quality of the community-based care being offered. With heavily overlapping service areas and similar, low-income clientele with multiple medical conditions, CHAP and MCHS found they were logical partners.

The pilot project began with staff training. MCHS worked closely with the medical director of CHAP to develop curricula for 10 advanced practice paramedics, 40-60 general EMS providers, and all ED case management and social work staff at the hospital. They identified three key topics: (1) prevalence of undiagnosed dementia, (2) use of validated tools to detect dementia, and (3) knowledge of community resources. This core knowledge is critical to the ability of health care providers to serve people living with dementia.

All trainees received a 1-hour training covering basic information on dementia and the Mini-Cog screening tool. Advanced practice paramedics completed a 2-hour training on administering the Mini-Cog and best practices in dementia care. MCHS social workers and occupational therapists did “ride-alongs” with advanced practice paramedics, and the paramedics similarly shadowed the MCHS clinicians on home visits. The in-depth understanding of each other’s work from this shadowing facilitated trust and close working relationships among the MCHS and CHAP team members.

Once training was complete, CHAP began the process of identifying potential community paramedicine clients through 911 calls, referrals from the hospital, and outreach to senior housing providers, who often call 911 for their residents. Potential participants were screened by CHAP using the Mini-Cog; those with a positive screen who were high utilizers of emergency services for non-emergency care were eligible for the paramedicine program; they were also required to have an informal caregiver who was willing to take part in education and care coordination.

(continued)

Case Study #3—Community Paramedicine and Dementia Services (continued)

Enrollees received in-home medical management, with oversight from a medical director, and were referred to community resources by CHAP, while MCHS delivered dementia care education to family members. The MCHS and CHAP teams held case conferencing calls twice a month. This enabled comprehensive case management and avoided duplication of services.

Many of the people who enrolled were more seriously ill than anticipated and needed help determining their end-of-life care preferences. A higher than expected number of enrollees were referred to hospice services through this project. Medical providers often fail to have these difficult conversations with patients about their goals of care, options, and palliative approaches. Referral to hospice was considered a successful outcome because it enabled patients to remain in their homes according to their wishes.

In addition to the poor health of the enrollees, the project encountered other challenges. Navigating family dynamics and engaging family caregivers proved difficult in some cases and required the skills of an experienced MCHS clinician. Families were often in denial and lacked basic knowledge about dementia, which necessitated not only caregiver training but basic dementia education.

Sharing data between CHAP and MCHS was also challenging. Because they were holding case conferences and planning care together, they needed to be able to share data, but each organization also needed to maintain its own records, which required some duplication of data entry. Initially, the project used care coordination software to try to share information, but MCHS workers had personal rather than company-issued cell phones, which created privacy concerns.

The pilot project is officially complete. CHAP and MCHS continue to provide services to clients, but there is no continuing dementia training for CHAP staff, and the MCHS and CHAP teams do not meet to coordinate case management. The relationship that developed between these two organizations over the course of the project remains strong, however, and communication and cross-referrals continue.

Evaluation

Evaluating the impact of first responders' dementia-related activities is critical because it helps organizations make a case to leadership and funders for continuing or expanding programs. The data that are most useful to collect will depend on the program but may include outcomes such as reduced rehospitalization rates; dollars spent or saved; changes in staff knowledge, skills, or attitudes; number of people served; number

of staff trained; and hours spent on various types of first responder calls or cases.

The experts interviewed for this guide commented that it can be difficult to obtain formal evaluation data from dementia training sessions. Training time is often limited, and some first responders are reluctant to complete evaluation forms. In other cases, first responders' databases are not configured to collect and track the most useful information and an initial investment in technology is necessary. For example, community paramedicine programs need to track a different set of measures than typical EMS, such as hospitalization or rehospitalization rates, but although this information is necessary to demonstrate the value of the work, it may take time to obtain the necessary technology.

Challenges in Serving People Living with Dementia

Several challenges are faced by first responders and community organizations when implementing programs to better serve and protect people living with dementia, including program implementation challenges, limited resources, and interagency communication.

Program Participation and Implementation

Enrolling people is sometimes a challenge for programs like wandering prevention registries and community paramedicine.

- Programs attempting to serve high-need people living alone with dementia have found that it often takes a significant amount of time to establish rapport to enable regular visits, and that once participants are enrolled, working with them requires extensive clinical expertise. Families may not recognize that the person has dementia, attributing the person's behaviors to laziness, stubbornness, or being difficult on purpose. This can make it difficult for first responders to engage families or connect them with community organizations that could offer appropriate supports.

- In some communities, lack of trust in law enforcement can also be a barrier to accepting assistance. Conversely, perceptions of their own role as an “enforcer” rather than a “helper” may prevent some law enforcement officers from embracing new approaches, even when agency leadership is on board.
- CP programs may have difficulty getting EMS staff on board because they prefer the excitement of emergency calls to the “nursing” role of community paramedicine. Several programs have addressed this by creating one or a few designated CP positions and inviting other interested staff to volunteer for the role.

Resource Limitations

Staffing and financial resources can also create challenges:

- Staff turnover is a major challenge for numerous reasons. It creates the need to establish new relationships with replacement staff and makes it difficult to keep a positive focus on program maintenance and improvement. Experts commented on the need to recruit new champions when existing champions leave and the challenge of ongoing dementia education to keep pace with staff turnover.
- Resource limitations—including the amount of time staff can spend on dementia-focused interventions and the amount of money available for such programs—are a foundational challenge. For example, many first responders have more than one job, so committing to any additional activities like training beyond their specified shift hours is especially difficult.
- Limited options for reimbursement have posed a significant challenge to CP programs as providers search for the financial resources necessary to provide the service. There is some early exploration of insurance payments for CP services, but to date, funds have mostly come from existing budgets (Abrashkin et al., 2016).
- Training for law enforcement also requires an investment of staff time. Law enforcement leaders suggest that these efforts

can more than pay for themselves in more efficient search and rescue operations and officer time saved through partnership with community organizations.

Interagency Communication

Significant groundwork to develop communication channels is often necessary for collaboration between first responders and community organizations to be successful.

- Agencies may have little understanding of each other's day-to-day responsibilities and roles, not knowing the skills and resources each can bring to the table, and there is often a very different vocabulary used to describe similar situations. Experts emphasized the importance of spending time with different partners and simply learning about each organization and what it does.
- Technology to support interagency communication can also be a challenge. Duplication of data entry was a challenge mentioned by several projects: technology challenges mean that each partner has to enter data in its own system and enter it again in a separate system to share with a partner. Communication technology compatibility can also be a problem; for example, some law enforcement officers use BlackBerries, but many apps are not compatible with that platform.

Strategies for Success in Partnering with First Responders

Experts interviewed for this guide named several factors that can help community organizations and first responders work together.

Seek Buy-in from Leadership

Talk to leaders in local government as a first step. Raising awareness about dementia within the city or county government can greatly enhance success in building community-wide support. Some governments may be more focused than others on these types of issues,

so it is important to be able to demonstrate the relevance to local finances, planning, and resident well-being.

First responder leadership also plays a key role in championing dementia training efforts. Staff are more likely to recognize the importance of this issue if leaders demonstrate a commitment (Alzheimer's Aware et al., 2015). There are a variety of ways to initiate relationships with leaders. A personal connection between a community organization staff member and first responder agency leader may facilitate an initial conversation. Fire chiefs, EMS directors, and police chiefs may also have a family member or friend with dementia, which helps them understand the importance of this issue. One expert interviewed for this guide credited the county sheriff, who is passionate about building community relationships, with making this type of partnership a major focus of his agency.

Getting one leader's support can make it easier to expand to other agencies. For example, in a larger metropolitan area, one local police department may refer a community organization to another area police department, or there may be an opportunity to present to a larger body such as a police chiefs' association. "Word of mouth" is invaluable, as leaders share with their peers the benefit that they have seen from dementia training and community partnerships.

Identify Champions within Agencies

Many interviewees emphasized the importance of identifying champions within first responder agencies—not just leadership. Having an "insider" who understands priorities and procedures makes it easier to introduce new training programs or policies. Often community organizations conduct dementia training themselves, but having an internal training officer or other staff at the first responder agency who can lead or co-lead training is ideal, as peers tend to engender greater trust. Some projects have used a team of trainers, with representation from the community organization, APS, and law enforcement.

Champions may be those whose position relates to dementia or training, such as law enforcement elder abuse units, training officers, or community liaisons. Similarly, within EMS, it is beneficial to have one or two people dedicated to providing community paramedicine. These are often paramedics who volunteer for the role. Identifying those team members who are most committed to the premise of community paramedicine helps build the success of the program.

Champions who have personal experience with dementia can be some of the strongest advocates for training and for building strong partnerships. Having a family member or friend with dementia often enables people to better recognize dementia when they see it in their day-to-day work or even to initiate contact with a community organization for training.

Build on Existing Relationships

Start with what is already happening in your community: regular meetings of community organizations; task forces that are addressing aging, safety, or similar issues; or existing referral networks. Building on existing activities and relationships is time-efficient. Simply introducing an agenda item to an existing meeting can give members an opportunity to learn from each other about what efforts are already taking place, to increase opportunities for cross-referral, and to build the case for focused projects or partnerships.

One community was able to leverage a strong relationship between its all-volunteer EMS service and residents to establish a successful community paramedicine program. Another initiated dementia training for law enforcement as an extension of a county-wide Alzheimer's initiative that had been launched by the board of supervisors. In other examples, existing networks of government, social, and medical service providers have been leveraged to build dementia capability (Shah et al., 2010).

Consider state-level organizations as well. There may be professional associations for first responders that already mandate or provide training to members. Building on this existing structure can greatly expand the reach of your training program or other educational materials.

"We had an officer who found someone who was missing and was trying to get her home. He had a grandmother with Alzheimer's...So many people are affected by this personally, and so often that is what gives them the sensitivity and awareness to want to do something about it and be part of it."

—Jessica Empeno,
Alzheimer's San Diego

"Start with the resources you have. What champion relationships and linkages are already in place? Build on that."

- Emily Farah Miller,
ACT on Alzheimer's, MN

Meet Their Needs

Typically, first responders will not approach community organizations for training or other assistance. Community organizations need to make the case for why this topic is important and how education and tools can help first responders do their work more effectively and efficiently. For example, law enforcement officers tend to understand right away that dementia is an issue, but they may not realize that there is something they can do about it. EMS providers are eager to learn but need more education about dementia. Coming equipped with solutions, statistics, and evidence of positive outcomes can help build the case for involvement. Benefits to emphasize include the following:

- *Potential for reduced costs*

Partnering with community organizations can reduce first responders' costs. For example, providing families with tips on wandering prevention can save law enforcement thousands of dollars in search and rescue costs. Similarly, partnerships between community organizations and CP providers show promise in reducing rehospitalization, which is an incentive for hospital systems that own EMS. Elder abuse units in law enforcement can work more efficiently by partnering with APS and other community organizations to help address an individual's ongoing needs and therefore eliminate crisis calls.

- *Improved morale*

Law enforcement officers interviewed for this project emphasized how proper training and systems for managing dementia-related situations can make their work more fulfilling. Instead of visiting the same home over and over for emergency situations, they can link people with appropriate resources so their needs are addressed proactively.

- *Improved community relations*

First responders are often eager to partner with other organizations to enhance community relations. Working on programs such as wandering prevention or welfare checks for

isolated older adults can demonstrate a commitment to the well-being of community members.

Policies and Funding Related to First Responders and Dementia

Community organizations that want to begin partnering with first responders should become familiar with legislation and policies that may affect program funding and training requirements in their state and local community. Public policies have been established at the state and federal levels to govern how first responders engage with people living with dementia. This includes the development of laws, regulations, and public programs to train law enforcement to locate missing vulnerable adults.

State Plan Mandates for Training

Nearly every state and territory has published a State Government Alzheimer's Disease Plan (Alzheimer's Association, 2018b). The plans for 30 states and the District of Columbia include specific recommendations for training first responders (Alzheimer's Association, n.d., 3). Although these mandates may set an expectation for training, few provide recommendations for curricula, minimum number of hours, or funding to implement these recommendations.

State Training Standards

A 2015 nationwide survey of dementia training requirements for law enforcement, EMS, APS, and ombudsman programs in all 50 states and Puerto Rico and the District of Columbia (Burke & Orłowski, 2015) revealed that:

- 10 states provide some dementia training standards for law enforcement personnel;
- only 1 state mandates such training for EMS; and
- 6 states require dementia training for either APS staff or ombudsman.

The Alzheimer's Association has assembled all states' Alzheimer's Disease Plans at:
<http://act.alz.org/site/DocServer/TRAINING.pdf?docID=4655>

A few states have laws requiring dementia training for law enforcement personnel. Colorado, Maryland, Massachusetts, New Jersey, Oregon, South Carolina, and Virginia incorporated training requirements in their Missing Adult Program mandates. Florida, Indiana, New Hampshire, and Oklahoma have broad-based dementia training requirements for law enforcement; of these, only Indiana and Oklahoma have laws that specify the required number of hours for training.

At the time of the nationwide survey, Connecticut was the only state with a statute requiring dementia training for EMS. EMS providers in Connecticut must complete training that includes a module covering Alzheimer's disease and dementia symptoms and care as part of their 3-year recertification (Burke & Orlowski, 2015).

Federal Patient Alert Programs

Congress authorized funding from FY1996 through FY2015 for the Missing Alzheimer's Disease Patient Alert program under the Violent Crime Control and Law Enforcement Act of 1994. The purpose of the program was to locate and respond to those with dementia who go missing. Congress provided appropriations for the program of \$750,000 to \$2 million annually over the course of the program to the Department of Justice's Bureau of Justice Assistance (BJA) within the Office of Justice Programs. BJA was responsible for administering the funds through grants. Grants were awarded under the program to a variety of entities, including the IACP who used these funds to develop a [guide to state alert systems](#) for missing seniors and adults. Although the program has ended, [BJA's Alzheimer's Aware](#) and [IACP](#) continue to provide many resources related to first responders and dementia.

State-Based Vulnerable Missing Adult Programs

People living with dementia may wander or try to leave their home without a companion; this can happen at any point in the disease and is a safety concern when they are confused about where they are in terms of place or time. See the Section on [Wandering](#) for more information and the Section on [Preventing and Managing Wandering Incidents](#) for interventions to address this problem.

Almost all states have an alert system to help locate vulnerable missing adults, including those living with dementia. An article by Wasser and Fox (2013) indicated that 37 states had “Silver Alert” programs that broadcast alerts to law enforcement when vulnerable adults go missing, or pending legislation to adopt such programs. A search of state government websites found that since that time, most other states have adopted similar alert systems. However, only six states include dementia training requirements as part of their missing person programs (Burke & Orłowski, 2015).

Project Methodology

We used two approaches to gather information for this guide. First, we conducted a literature review of peer-reviewed and gray literature. We identified a total of 36 published articles and determined that 13 were relevant. The gray literature search included professional websites, government agencies, and other nonprofit organizations related to law enforcement, APS and elder abuse, firefighters, and EMS. We identified an additional 11 reports and publications through the gray literature search. The availability of information on this topic is limited, and very few studies or organizations have considered the question of how community organizations and first responders can most effectively partner.

The second way we gathered information was through interviews conducted in June 2018 with 13 subject matter experts. We selected experts who had experience with various projects and partnerships involving first responders and community organizations to better serve people living with dementia. The experts were also chosen to represent diversity of rural/urban areas, regions of the country, and types of first responders involved in their projects. These subject matter experts are listed on the [Acknowledgements](#) page of this guide.

Resources for First Responders and Organizations Working with First Responders

The [National Alzheimer's and Dementia Resource Center](#) provides support to ACL-funded grantees in developing, implementing and evaluating dementia services. Many grants, including several referenced in this guide, have implemented First Responder initiatives. [Information on grant projects](#) is available here.

Resource Cards and Brochures

- [10 Communication Tips](#) —Tips for first responders in dealing with someone who may be wandering. Source: Alzheimer Society Canada
- [10 Warning Signs a Driver May Have Alzheimer's](#) for law enforcement. Source: International Association of Chiefs of Police (IACP)
- [Basics of Law Enforcement/Alzheimer's](#) for law enforcement. Source: IACP
- [Evaluative Questions for Caregivers: Investigating a Missing Person with Alzheimer's Disease or Dementia](#) for law enforcement. Source: IACP
- [Identifying and Helping A Driver with Alzheimer's Disease](#) for law enforcement. Source: IACP
- [Identifying and Evaluating the At-risk Older Adult](#) for law enforcement. Source: IACP
- [Quick Tips for First Responders](#) A brochure with tips on firearm safety, wandering, driving, abuse and neglect, shoplifting, and disaster response. Source: Alzheimer's Association
- [Senior Drivers: Did You Know?](#) for law enforcement. Source: IACP

Training

- [Alzheimer's Disease and Dementia Care](#) 6-hour live seminar for first responders covering many topics including: dementia basics; communication; behavioral symptoms; driving; recognizing abuse and neglect; and diversity and cultural competence. Source: National Council of Certified Dementia Practitioners
- [Approaching Alzheimer's](#) Free online training videos for first responders covering six topics: dementia basics; wandering; driving; abuse/neglect; shoplifting; and disaster response. Source: Alzheimer's Association
- [Driver Orientation Screen for Cognitive Impairment](#) Driving assessment questionnaire and video trainings for law enforcement. Source: TREDs—University of California-San Diego School of Medicine and Calit2
- [MedicAlert Law Enforcement Agency Portal \(LEAP\)](#) Provides training for law enforcement officers on wandering emergencies and free MedicAlert jewelry and services to community members who are at risk for wandering. Source: MedicAlert
- [Certified First Responder Dementia Trainer program](#) This 12-hour, self-led seminar provides certification to train other first responders on dementia. Source: National Council of Certified Dementia Practitioners
- [Training videos for law enforcement](#) The videos consist of four short clips, totaling 15 minutes, which portray law enforcement officers encountering individuals with dementia during standard patrol: (1) a traffic stop; (2) a wandering event; (3) a daughter who has called 911 for help with her very agitated/aggressive mother with dementia; and (4) a woman with dementia who has called 911 thinking someone has tried to rob her home. The four separate videos have been combined into one on this link. Source: Alzheimer's Orange County
- [Training videos and webinars](#) Four videos and two training webinars. Topics include driver assessment, missing person (on

foot or by car), search protocols, three stages of Alzheimer's, and situations in which law enforcement or first responders might encounter someone with Alzheimer's. Source: IACP

Guides

- [Dementia Learning Resource for Ambulance Staff](#) A manual provides EMS staff with basic information on dementia, communication techniques, behavioral symptoms, delirium, and pain. Source: Dementia Partnerships
- [First Responder Handbook](#) Provides information on how to recognize possible dementia, communicate with and respond to various situations such as abuse, hoarding or accidents. Source: Alzheimer Society Canada
- [A Guide to Law Enforcement on Voluntary Registry Programs for Vulnerable Populations](#) For law enforcement: Provides information and resources for starting a voluntary registry program. Source: IACP

Model Policy for Law Enforcement

- [Missing Persons with Alzheimer's Disease](#) Model policy for handling missing people living with dementia for law enforcement. Source: IACP

Public Awareness

- [PowerPoint presentation and script](#) This presentation on wandering can be used by law enforcement to educate the public on wandering. It includes a script, background information for the presenter, a news release, and a guide for caregivers. Source: McGruff Safe Kids
- [Billboard designs](#) Various sizes of billboard designs that can be used by law enforcement agencies, local governments and other community groups. Source: Alzheimer's Aware
- [Encouraging a Community Response to Alzheimer's Disease: Model Local Public Information Campaign](#) This document

provides an outline that can be used to assist in the development of a public information campaign. Source: Alzheimer's Aware

- [Standard website language](#) Provides language that law enforcement agencies can use on their websites to inform the community about dementia and related safety. Source: Alzheimer's Aware

References

- Abrashkin, K. A., Washko, J., Zhang, J., Poku, A., Kim, H., & Smith, K. L. (2016). Providing acute care at home: Community paramedics enhance an advanced illness management program—preliminary data. *Journal of the American Geriatrics Society*, 64(12), 2572–2576. doi:10.1111/jgs.14484
- Alzheimer's Association. (n.d., 1). *Abuse*. Retrieved from <https://www.alz.org/help-support/caregiving/safety/abuse>
- Alzheimer's Association. (n.d., 2). *Wandering*. Retrieved from <https://www.alz.org/help-support/caregiving/stages-behaviors/wandering>
- Alzheimer's Association. (n.d., 3). *State Alzheimer's disease plans*. Retrieved from http://act.alz.org/site/DocServer/STATE_AD_PLANS.pdf?docID=4641
- Alzheimer's Association. (2006). *Safe return: Alzheimer's disease guide for law enforcement*. Retrieved from https://www.alz.org/national/documents/safereturn_lawenforcement.pdf
- Alzheimer's Association. (2018a). *2018 Alzheimer's facts and figures*. Retrieved from <https://alz.org/media/HomeOffice/Facts%20and%20Figures/facts-and-figures.pdf>
- Alzheimer's Association. (2018b). *Alzheimer's Disease state plans*. Retrieved from http://act.alz.org/site/PageNavigator/state_plans.html
- Alzheimer's Aware, et al. (2015). *A guide for implementation of a law enforcement program to address Alzheimer's in the community*. Retrieved from <https://www.bja.gov/Publications/AlzheimersAware.pdf>.
- Alzheimer's Society, Canada. (2014). *Locating devices*. Retrieved from <http://www.alzheimer.ca/en/Living-with-dementia/Day-to-day-living/Safety/Locatingdevices>
- Amjad, H., Roth, D. L., Samus, Q. M., Yasar, S., & Wolff, J. L. (2016). Potentially unsafe activities and living conditions of older adults with dementia. *Journal of the American Geriatrics Society*, 64(6), 1223–1232. doi:10.1111/jgs.14164
- Bunn, F., Burn, A. M., Goodman, C., Rait, G., Norton, S., Robinson, L., Schoeman, J., & Brayne, C. (2014). Comorbidity and dementia: A scoping review of the literature. *BMC Medicine*, 12(1), 192. doi:10.1186/s12916-014-0192-4
- Bureau of Justice Assistance. (2014). *Lost and found: Understanding technologies used to locate missing persons with Alzheimer's or dementia*. Retrieved from <https://www.bja.gov/Publications/PLI-Lost and Found.pdf>.
- Burke, G., & Orłowski, G. (2015). Training to serve people with dementia: Is our health care system ready? Paper 4: Dementia training standards for first responders, protective services and ombuds. Justice in Aging Issue Brief. Retrieved from http://www.justiceinaging.org/wp-content/uploads/2015/08/Training-to-serve-people-with-dementia-Alz4_Final.pdf
- Buswell, M., Lumbard, P., Prothero, L., Lee, C., Martin, S., Fleming, J., & Goodman, C. (2016). Unplanned, urgent and emergency care: What are the roles that EMS plays in providing for older people with dementia? An integrative review of policy, professional recommendations and evidence. *Emergency Medicine Journal*, 33(1), 61–70. doi:10.1136/emmermed-2014-203941

- Dong, X., Chen, R., & Simon, M. A. (2014). Elder abuse and dementia: A review of the research and health policy. *Health Affairs*, 33(4), 642–649. doi:10.1377/hlthaff.2013.1261
- Feng, Z., Coots, L., Kaganova, Y., & Wiener, J. (2014). Hospital and ED use among Medicare beneficiaries with dementia varies by setting and proximity to death. *Health Affairs*, 33(4), 683–690. doi:10.1377/hlthaff.2013.1179
- Goodwin, J., Lane, P., Zavadsky, M., Hagen, T., Hinchey, P., McGinnis, K., Bourn, S. & Myers, B. (2015). *Mobile Integrated Healthcare and Community Paramedicine (MIH-CP)*. National Association of Emergency Medical Technicians. Retrieved from https://www.naemt.org/docs/default-source/community-paramedicine/naemt-mih-cp-report.pdf?sfvrsn=df32c792_4
- Greene, A. M., Lepore, M. J., Lux, L. J., Porter, K. A., & Vreeland, E. E. (2015). *Understanding unlicensed care homes: Final report*. Prepared for Office of the Assistant Secretary for Planning and Evaluation. Retrieved from <https://aspe.hhs.gov/system/files/pdf/200961/Unlicensed.pdf>
- Hebert, L., Weuve, J., Scherr, P., & Evans, D. (2013). Alzheimer disease in the United States (2010–2050) estimated using the 2010 Census. *Neurology*, 80(19), 1778–1783. doi:10.1212/WNL.0b013e31828726f5
- International Association of Chiefs of Police (IACP). (n.d.). *A guide to law enforcement on voluntary registry programs for vulnerable populations*. Retrieved from <http://www.theiacp.org/Portals/0/documents/alzheimers/Alz%20Voluntary%20Registry.pdf>
- Lake County Sheriff's Office. (n.d.). *Senior Watch*. Retrieved from <https://www.lcso.org/bureaus/community%20engagement/communityprograms/seniorwatch/index.php>
- Landau, R., & Werner, S. (2012). Ethical aspects of using GPS for tracking people with dementia: Recommendations for practice. *International Psychogeriatrics*, 24(03), 358–366. doi:10.1017/s1041610211001888
- Lepore, M., Greene, M., Porter, K., Lux, L., Vreeland, E. & Hawes, C. (2018). Unlicensed care homes in the United States: A clandestine sector of long-term care, *Journal of Aging & Social Policy*. doi:10.1080/08959420.2018.1485397
- McKinstry, B., & Sheikh, A. (2013). The use of global positioning systems in promoting safer walking for people with dementia. *Journal of Telemedicine and Telecare*, 19(5), 288–292. doi:10.1177/1357633x13495481
- National Adult Protective Services Association. (n.d.). *What is financial exploitation?* Retrieved from <http://www.napsa-now.org/get-informed/what-is-financial-exploitation/>
- National Association of State EMS Officials. (2018). *State by state Community Paramedicine—Mobile Integrated Healthcare (CP-MIH) status board*. Retrieved from <https://www.nasemso.org/State-CP-Status-Board-and-Map/documents/CP State Status Board CURRENT.pdf>
- Payne, B. (2013). *Physical and emotional abuse of the elderly*. Center for Problem-Oriented Policing (COPS) Problem-Specific Guide Series, No. 71.
- Petonito, G., Muschert, G. W., Carr, D. C., Kinney, J. M., Robbins, E. J., & Brown, J. S. (2013). Programs to locate missing and critically wandering elders: A critical review and a call for multiphasic evaluation. *The Gerontologist*, 53(1), 17–25. doi:10.1093/geront/gns060

- San Diego County Sheriff's Department. (n.d.). *You Are Not Alone (YANA): A San Diego County Sheriff's Department program*. Retrieved from <https://www.sdssheriff.net/documents/yana-brochure.pdf>
- Shah, M. N., Caprio, T. V., Swanson, P., Rajasekaran, K., Ellison, J. H., Smith, K., ... & Katz, P. (2010). A novel emergency medical services–based program to identify and assist older adults in a rural community. *Journal of the American Geriatrics Society*, 58(11), 2205–2211. doi:10.1111/j.1532-5415.2010.03137.x
- Shah, M. N., Jones, C. M., Richardson, T. M., Conwell, Y., Katz, P., & Schneider, S. M. (2011). Prevalence of depression and cognitive impairment in older adult emergency medical services patients. *Prehospital Emergency Care*, 15(1), 4–11. doi:10.3109/10903127.2010.514093
- Sun, F., Gao, X., Brown, H., & Winfree Jr., L. T. (2017). Police officer competence in handling Alzheimer's cases: The roles of AD knowledge, beliefs, and exposure. *Dementia*. doi:10.1177/1471301216688605.
- Wasser, T., & Fox, P. (2013). For whom the bell tolls: Silver alerts raise concerns regarding individual rights and governmental interests. *Journal of the American Academy of Psychiatry and the Law*, 41(3), 421–429.
- Yang, Y. T., & Kels, C. G. (2017). Ethical considerations in electronic monitoring of the cognitively impaired. *The Journal of the American Board of Family Medicine*, 30(2), 258–263. doi:10.3122/jabfm.2017.02.160219