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Identifying and Meeting the Needs of Individuals With Dementia Who Live Alone

Report

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EXECUTIVE SUMMARY

A substantial portion of people with dementia live alone. Data analyzed for this report indicate that in 2011, 13 percent of people with dementia who were living in the community were living alone. People with Alzheimer's disease or dementia commonly require some care or help to maintain a safe and healthy life because these conditions cause substantial and progressive functional impairments. People with dementia who live alone are potentially at risk for adverse events because of their cognitive impairment. Unfortunately, in some cases the needs of people living alone are unmet and are not identified until there is an emergency.

Like other older adults who live alone, many people with dementia prefer living alone to the other options available to them. However, people with dementia who live alone are at high risk for self-neglect, malnutrition, injury, medication errors, financial exploitation, unmet care needs, and nursing home placement. Managing personal needs and daily activities is a primary challenge for people with Alzheimer's and other dementias who live alone, particularly in the areas of looking after the home, accessing and preparing food, providing self-care, doing laundry, and managing medications. Among this population, dangerous self-medication errors have been found to occur in administering the medication, modifying the medication regimen, and not following clinical advice about medication use.

Identifying individuals with dementia who live alone is a primary challenge to meeting their needs. This report highlights indications that a person with dementia living alone is not able to adequately manage his or her personal care needs and daily activities, such as frequent emergency medical visits, little or no food in the home, unkempt appearance, dirty clothes, and weather-inappropriate clothing. Intervention strategies to serve this population also are addressed, including referral for pharmacist or nurse medication reconciliation, home-delivered meals, arranging for home care services, notifying the police and fire departments of the person's condition and providing contact information.

Finally, this report describes several evidence-informed innovative practices that are implemented in a variety of locations to support people with Alzheimer's or dementia to safely live alone. Example practices include friendly visitor, gatekeeper programs, home care services, and police programs. Gatekeeper programs recruit mail carriers, utility meter readers, ministers, pharmacists, and other individuals who interact with many people in the course of their daily work and train them to identify isolated older people who may need assistance and refer those people to a central agency. A home care services provider in the Washington, DC, area contracts with Adult Protective Services (APS), the Department of Veterans Affairs, and local government funding to provide services to individuals with dementia who live alone. In addition to describing these programs and providing guidance on a variety of resources for helping to meet the needs of individuals with dementia who live alone, this report also addresses the importance and challenge of supporting both the safety and the autonomy of this population.

INTRODUCTION

A substantial portion of people with Alzheimer's disease or dementia live alone, and many require some care or help to maintain a safe and healthy life because these conditions cause substantial and progressive functional impairments. People with dementia who live alone are potentially at risk for adverse events because of their cognitive impairment. Unfortunately, in some cases the needs of people living alone are unmet and are not identified until there is an emergency.

This report provides information on what is known about the prevalence of people living alone in the community and summarizes strategies for identifying and providing services to this population. The first section of the report summarizes available information about the proportion and characteristics of people with Alzheimer's and other dementias who live alone. Later sections provide information from published studies regarding areas of unmet needs, ethical and legal issues encountered by providers such as respecting the person's autonomy and risk tolerance, person-centered services, and intervention strategies as well as innovative programs informed by expert interviews and provider resources.

METHODOLOGY

This report relies primarily on three sources of information. First, we analyzed data from the National Health and Aging Trends Study (NHATS) to determine the prevalence of individuals with dementia living alone. Second, we reviewed research literature to identify what is known about people with Alzheimer's and other dementias who live alone. Third, we report information collected during two sets of interviews: interviews conducted in 2010 with persons with dementia who live alone, caregivers, and health care and social service professionals who work with this population as part of another project; and interviews conducted in 2015 with service providers about intervention strategies and innovative programs.

National Health and Aging Trends Study

Data for these analyses are from Round 1 of the NHATS, collected in 2011. NHATS includes a nationally representative sample of 8,245 older adults who are current Medicare enrollees.¹ The three-stage sample design identified older adults by geographic location of residence, targeting persons who were age 65 or older by September 30, 2010 (Montaquila et al., 2012). Data were obtained through a 2-hour, in-person interview with the sample member or a proxy.

These analyses targeted a subset of NHATS sample members who reported or their proxy reported that the sample member was living in a private residence. *Private residence* was defined as a freestanding single house, single house attached to others, mobile home or trailer, or multi-unit building. Nursing home residents and sample members living in retirement or senior housing, group homes, board and care homes, assisted living facilities, and religious group quarters were excluded.

¹ Ninety-six percent of people age 65 and over in the United States are enrolled in Medicare (Montaquila et al., 2012). Thus, the NHATS sample represents almost the whole U.S. population in that age group.

NHATS did not conduct a comprehensive diagnostic evaluation to determine whether sample members had dementia. Instead, sample members were classified as having *probable dementia*, *possible dementia*, or *no dementia* based on three criteria (Kasper et al., 2013): (1) the response of the sample person or the proxy respondent to a question about whether a doctor had said the sample person had dementia or Alzheimer’s disease; (2) five brief cognitive tests completed by the sample person; and (3) answers to a brief questionnaire completed by a proxy. Sample members were classified as having probable dementia if (a) the sample person or proxy reported that a doctor had said the sample person had dementia or Alzheimer’s disease or (b) the proxy provided affirmative responses to at least two of the AD8 Dementia Screening Interview questions (Galvin et al., 2005). Additionally, sample members were classified as having probable dementia if their responses were equal to or more than 1.5 standard deviations below the mean in two of the three NHATS cognitive interview domains: orientation, memory, and executive functioning. Respondents were classified as having possible dementia if their responses were equal to or more than 1.5 standard deviations below the mean within one of the three NHATS cognitive interview domains. All other sample members were classified as having no dementia. All analyses were completed using STATA (v. 13.1), including the STATA programming statements for dementia classification (Skehan & Spillman, 2013).

As with any dataset, limitations exist that may affect overall findings. First, NHATS data are self-reported, meaning data include a degree of response bias based on sample members’ or proxies’ individual perceptions and personal knowledge. However, the use of in-person interviews for data collection allowed interviewers to provide additional information where appropriate, thus improving data quality. Individuals living alone were defined using a series of separate questions regarding household composition and the residential settings.

Literature Search

Project staff performed literature searches in the following databases: PubMed/Medline, CINAHL, PsychInfo, and ScienceDirect.² To access other grey literature, Google and Google Scholar were searched using the above natural language syntax queries along with the phrase “people with dementia living alone.” A total of 494 articles were found, 298 since 2010. The abstracts of these articles were reviewed to determine their potential relevance to the topic of living alone with dementia; 126 articles were identified as potentially related to this topic and 60 were used for this report. The literature review identified several issues related to people with dementia living alone, including risk assessment and capacity to live alone, decision-making capacity, self-neglect, functional performance and unmet care needs, assistive technology, safety

² The following search terms were used singularly and in combination: Dementia; Family Characteristics/One-Person Households; Independent Living/Psychology/Delivery of Health Care, Integrated/Trends/Utilization/Quality Assurance/Patient Care Planning/Standards/Ethics; Aging in Place/Population Characteristics; Social Isolation/Population Characteristics/Population At Risk/Self Care/Psychology/Healthy People Programs; Personal Autonomy/Self-Help Devices/Trends/Utilization/Ethics; Telemetry/Remote Sensing Technology/Telemedicine; Therapy/Computer Assisted; Electronics, Medical; Mental Competency/Legislation & Jurisprudence/psychology; Elder Abuse/Prevention & Control; Legal Guardianships/Legislation & Jurisprudence. Natural language syntax queries were also used: Dementia and Live Alone; Dementia and Community-Dwelling; Dementia and Assistive Technology/Assistive Devices; Dementia and Smart Environment; Dementia and Competency.

issues, financial exploitation, social isolation, risk assessment and providing person-centered services.

The available information about people with Alzheimer's and other dementias living alone is limited. There are many published studies about people living with these conditions and some published studies about older people who live alone, but very few studies have addressed the intersection of these groups. It is especially difficult to find information about people with Alzheimer's and other dementias who live alone and lack an involved family member or other informant. Several of the more promising studies are quite old, reporting data from the mid to late 1990s. Presently, new research on individuals with Alzheimer's and other dementias who live alone is being conducted in the United States and internationally.

Interviews

Two sets of interviews inform this report. For an earlier paper (Gould et al., 2010), interviews were conducted by the Alzheimer's Disease Supportive Services Program National Resource Center (the previous name of the National Alzheimer's and Dementia Resource Center) in June–August 2010. A total of 13 persons were interviewed, including persons with dementia who live alone, a family caregiver, a professional caregiver, geriatric medicine professionals, APS personnel, geriatric care managers, home care providers, an adult day care provider, and an expert on hoarding. The individuals interviewed resided in California; Idaho; Illinois; Massachusetts; Nebraska; Texas; and Washington, DC. Professional interviewees represent for-profit and not-for-profit organizations and serve diverse, low- to high-income communities in rural, suburban, and urban areas. The interviews covered the following topics: functional abilities of people living alone; unmet needs, service use, and services needed; support system; barriers to accessing services; role of assistive technology; future health and long-term care planning; home safety; and challenges with living alone. The content of those interviews is reflected in quotes throughout the paper.

Telephone interviews addressing intervention strategies and innovative programs that serve people with dementia who live alone with service providers were conducted between May and August 2015.

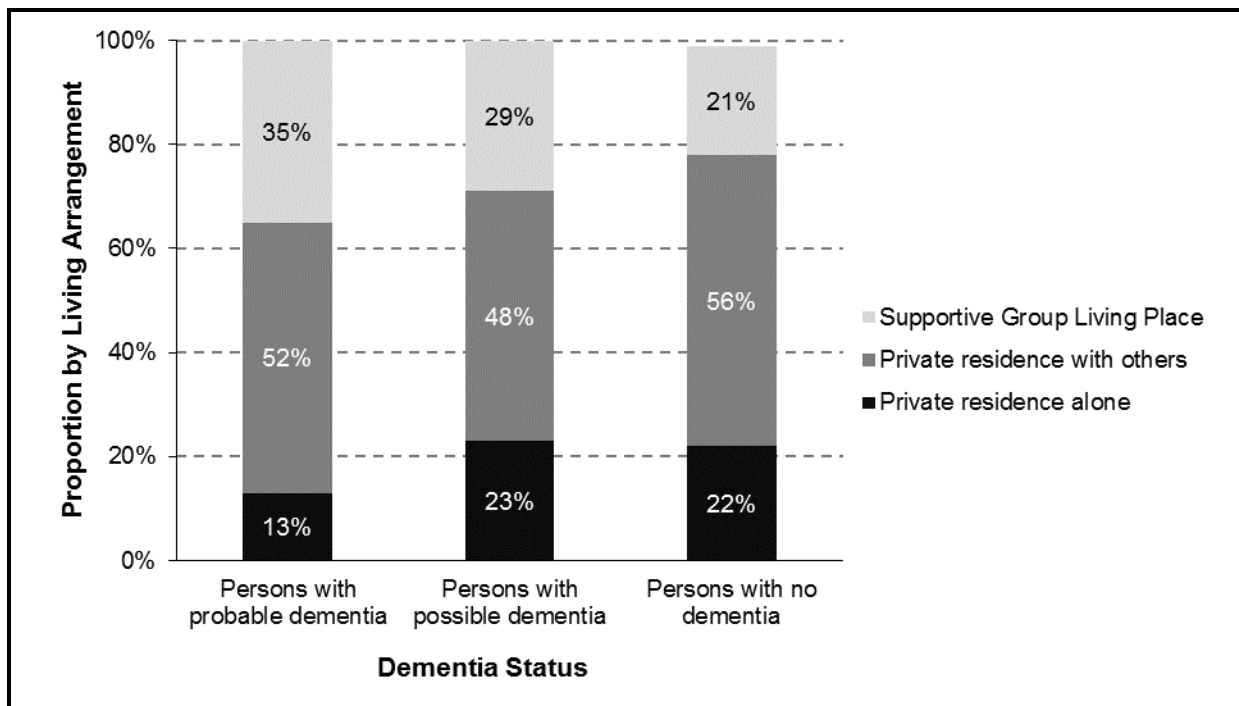
BACKGROUND

Prevalence of People With Dementia Living Alone

Although estimates vary, the available national and regional data indicate that a significant number of people with dementia live alone. Data from NHATS indicate that in 2011, 9.7 percent of the non-nursing home U.S. population age 65 and older, about 3.6 million people, had probable dementia (Kasper et al., 2014). Of the 3.6 million people with probable dementia, 13 percent were living alone in a private residence (Figure 1). The 13 percent represents about 468,000 individuals. Another 52 percent of people with probable dementia, about 1,872,000 individuals, were living in a private residence with one or more other people. The remaining 35 percent, about 1,260,000 individuals, were living in a diverse array of other supportive group living places that provide some level of support or care for their residents. Supportive group living places include retirement communities, senior housing facilities, adult family care homes, personal care homes, board and care facilities, and assisted living facilities.

As shown in Figure 1, people age 65 and older with probable dementia were, on average, less likely than people age 65 and older with possible dementia or no dementia to be living alone in a private residence (13% vs. 23% and 22%, respectively). They were more likely than people with possible dementia but less likely than people with no dementia to be living with others in a private residence (52% vs. 48% and 56%, respectively). Lastly, people with probable dementia were more likely than people with possible dementia and people with no dementia to be living in a supportive group living place (35% vs. 29% and 21%, respectively).

Figure 1. Living Arrangements of Persons With Probable Dementia, Possible Dementia, and No Dementia, Age 65+, National Health and Aging Trends Study, United States, 2011, n = 7,837



Source: Unpublished analyses of NHATS data conducted by RTI International, 2015.

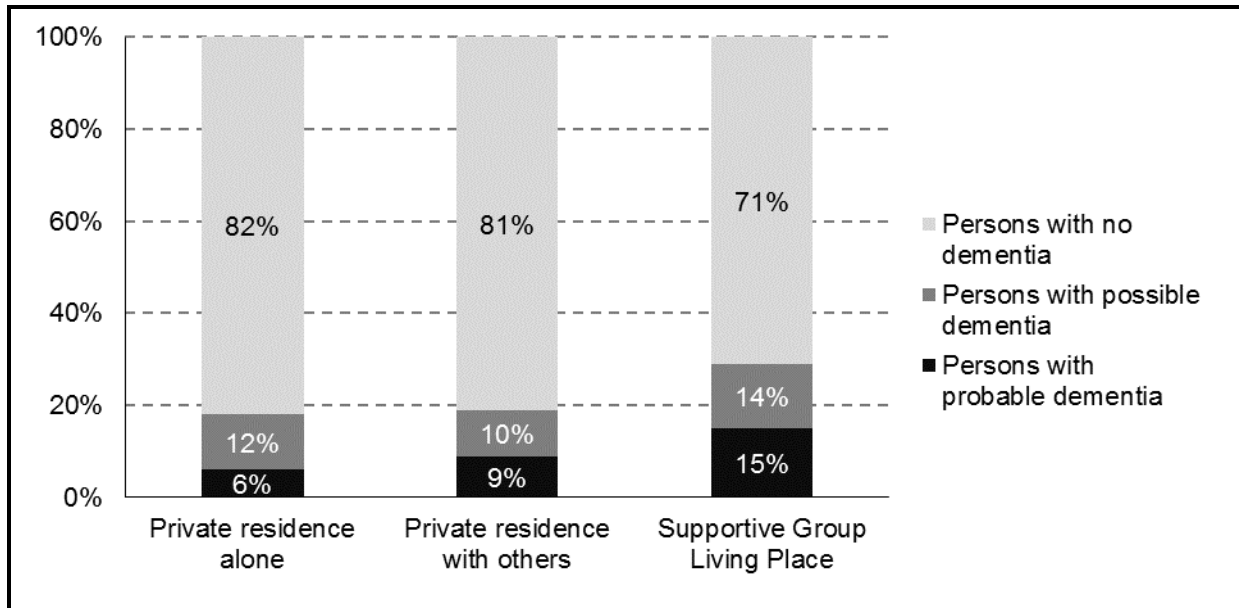
Previous studies conducted in nationally representative samples of the U.S. population have found somewhat higher figures for the proportion of older people with dementia living alone. Findings for 2008 from the Medicare Current Beneficiary Survey (MCBS) show that 25 percent of sample members age 65 and older who reported (or their proxy reported) that the person had been diagnosed with Alzheimer’s disease or dementia were living alone in a private residence (Alzheimer’s Association, 2012).³ It should be noted that the 25 percent figure may underestimate the true proportion of older people with dementia who live alone, because many people with dementia have not been diagnosed.

³ The MCBS uses a nationally representative sample of Medicare enrollees.

Findings for 2000 and 2002 from the Aging and Demographics and Memory Study (ADAMS) show that 32 percent of sample members age 71 and older who met the diagnostic criteria for dementia were living alone (Okura et al., 2011).⁴ The 32 percent finding from ADAMS is not directly comparable with the 13 percent finding from NHATS or the 25 percent finding from MCBS because the ADAMS sample is older (age 71 and older vs. age 65 and older). In addition, the ADAMS category of people with dementia who were living alone included some people with dementia living in a supportive group living setting.

According to the 2011 NHATS, people with probable dementia account for a small proportion of all older people living alone. The data indicate that in 2011, people age 65 and older with probable dementia accounted for 6 percent of all people in that age group who were living in a private residence alone (see Figure 2). They accounted for 9 percent of all people age 65 and older who were living in a private residence with others and 15 percent of all people age 65 and older who were living in a supportive group living place. People with possible dementia accounted for 12 percent of those living in a private residence alone, 10 percent of those living in a private residence with others, and 14 percent of those living in a supportive group living place. Lastly, people with no dementia accounted for 82 percent of those living in a private residence alone, 81 percent of those living in a private residence with others, and 71 percent of those living in a supportive group living place.

Figure 2. Dementia Status of Persons Living in a Private Residence Alone, in a Private Residence With Others, or in a Supportive Group Living Place, Age 65+, National Health and Aging Trends Study, United States, 2011, n = 7,837



Source: Unpublished analyses of NHATS data conducted by RTI International, 2015.

⁴ ADAMS used a stratified random sample drawn from the nationally representative samples assembled for the 2002 and 2002 waves of the Health and Retirement Study.

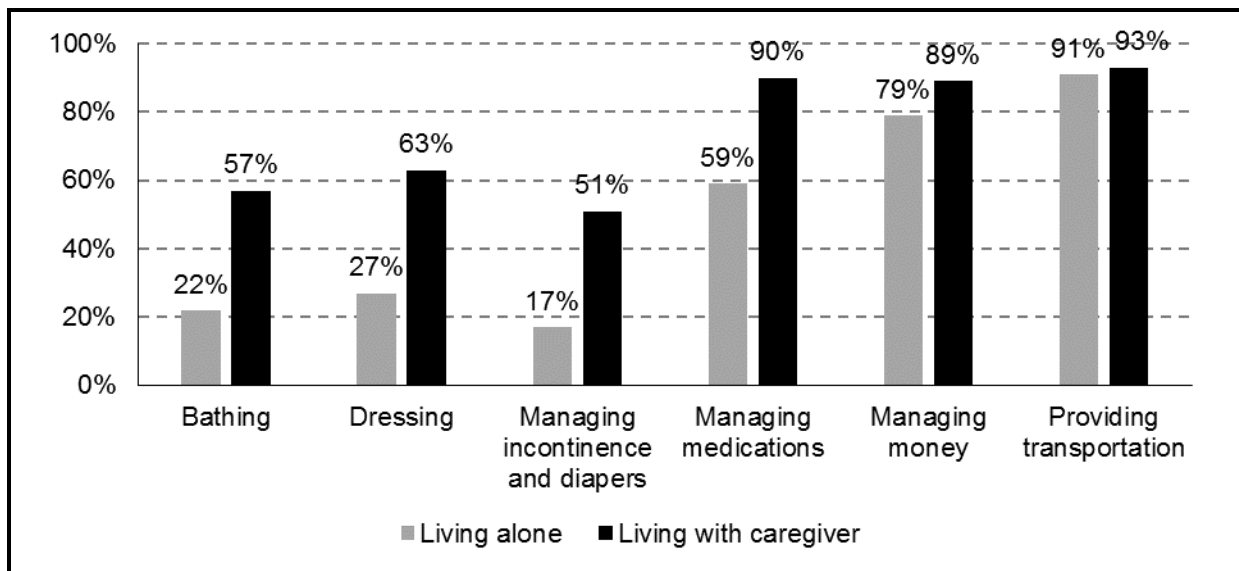
Finally, it should be noted that no information is available about the proportion of nonelderly people with dementia who live alone. The number of nonelderly people with dementia is much smaller than the number of elderly people with the condition. However, nonelderly people with dementia constitute an important subgroup that should not be ignored as program planners, administrators, and service providers try to estimate the total number of people with dementia in their service area.

Availability of a Family Caregiver for People With Dementia Who Live Alone

Many people with dementia who live alone in a private residence have one or more caregivers, including relatives, friends, and neighbors, who provide various kinds of assistance. A 2009 telephone survey of a nationally representative sample of Americans aged 18 and older who identified themselves as family caregivers found that 28 percent of caregivers of community-dwelling people with Alzheimer’s and other dementias said the care recipient was living alone (NAC/AARP, 2010). Another 25 percent said the care recipient was living with the caregiver, and the remaining caregivers said the person with dementia was living with other relatives or friends. People with dementia who do not have a caregiver are not represented in the survey findings.

The 2009 telephone survey found that caregivers of people with dementia who lived alone were less likely than caregivers of people with dementia who lived with the caregiver to be providing help with various personal care and other daily activities (NAC/AARP, 2010). Still, substantial proportions of caregivers of those who lived alone were providing help with the activities. Figure 3 shows the proportions of caregivers who said they provided help with six activities for people with dementia who lived alone versus people with the condition who lived with the caregiver.

Figure 3. Proportion of Caregivers of People With Dementia That Report Helping the Person With Specified Activities by Living Arrangement, 2009



Source: NAC/AARP, 2010.

UNMET CARE NEEDS FOR PEOPLE WITH DEMENTIA WHO LIVE ALONE

People with Alzheimer’s and other dementias who live alone have care needs that differ and that are dependent on factors including the extent of their cognitive and functional abilities, availability of a caregiver, access to adequate care and services, and coordination of care. People with dementia generally report fewer unmet care needs than their caregivers. The number of reported unmet care needs is related to the severity of their dementia and their living situation. Some reasons for unmet needs in community-dwelling people with dementia, including those living alone, are lack of knowledge of existing services and that some of the services are insufficient and not customized to the person’s needs or preferences (Van der Roest et al., 2009).

I am never sure when to step in. I don't want to rob her of her independence.

—Caregiving daughter

Many people with dementia who live alone are at risk for self-neglect. Self-neglect is when a vulnerable adult is unable to practice basic self-care, including but not limited to provision of food, clothing, or shelter, and management of health care needs; physical and mental health maintenance, emotional well-being, and general safety; or manage financial affairs. Signs of self-neglect include dehydration, malnutrition, untreated medical conditions, poor personal hygiene, unsafe or unsanitary living conditions, inappropriate or inadequate clothing, and inadequate housing or homelessness (National Center on Elder Abuse, 2015). In a survey conducted by the National Association of Professional Geriatric Care Managers (PR Web, 2014), 92 percent of care managers said that elder self-neglect was a significant problem in their community and 94 percent of care managers indicated that elder self-neglect is a largely hidden problem with cases frequently going unreported. According to a national survey on vulnerable adult abuse conducted by the National Center on Elder Abuse (Teaster, 2004), self-neglect is the highest category of abuse investigated and substantiated by APS.

Self-neglect in older adults includes both medical and social care needs and has implications for public health (Pavlou & Lachs, 2008). Cases of self-neglect can be among the most difficult to address and manage. At times, a person will resist interventions, deny or underestimate the severity and importance of his or her cognitive deficits (Tierney et al., 2004; Wilkins et al., 2014), and have little or no awareness regarding his or her circumstances (Dong et al., 2010; Lehmann et al., 2010; Wilkins et al., 2014) thus placing them at greater risk for adverse outcomes. Service providers working with these individuals are presented with the ethical dilemma of balancing efforts to support individual autonomy with efforts to ensure safety, with the understanding that there is “no perfect environment” for someone with dementia living alone and that “a certain amount of risk is inevitable” (interview with Lisa Gwyther conducted on May, 19, 2015, and personal communication with Geri Hall on May 19, 2015).

People are more vulnerable when they live in their own homes and they need more protection.... The reports are going up while staffing is going down.

—Adult Protective Services professional

People with dementia who live alone may underuse needed long-term services and supports (Lehmann et al., 2010). In a study of African American older adults with dementia

living in the community, social workers rated 61 percent of the persons with dementia living alone as receiving inadequate support and supervision, compared with 25 percent of persons with dementia living with others (Edwards & Morris, 2007). A recent study from Sweden indicated that a large number of people with Alzheimer's disease or other dementia living alone had severe cognitive and functional impairment, but use of home help services did not match the severity of cognitive impairment (Wattmo et al., 2014).

Ability to Manage Personal Care Needs and Daily Activities

Among individuals with dementia, the ability to live alone is dependent on their physical ability and cognitive capacity to perform daily activities independently. Miranda-Castillo et al. (2010) reported that individuals with dementia who lived alone had significantly more unmet needs than those living with others, particularly in the areas of looking after home, food, self-care, and accidental self-harm. One study indicated that activity of daily living impairment was more common among subjects who lived with others but nearly half of the individuals with dementia living alone were found to have two or more impairments in instrumental activities of daily living (Lehmann et al., 2010).

People living alone with dementia are also at greater risk for malnutrition than those living with others (Nourhashemi et al., 2005). A study of individuals with dementia and their caregivers (about half of whom lived separate from each other) showed that the nutritional status of older people with dementia is strongly and positively associated with the nutritional status of caregivers (Rullier et al., 2013). Accordingly, it is recommended that nutritional interventions in the context of dementia should address the caregiving dyad and not strictly the person with dementia (Rullier et al., 2013).

Medication nonadherence is a complex problem with various risk factors, particularly in older adults living alone. Accidental injuries from errors in medication self-administration are more likely for people with dementia than injury from fires/burns and wandering (Douglas et al., 2011). According to one study, the majority of self-

Right now, I do my own cooking, cleaning, laundry, and shopping. I will do the checkbook and then my son will verify that it is correct. If I get goofed up, my friends and family don't give me a hard time.

They understand.

—Person with dementia

Making decisions has become increasingly difficult. She needs help with picking clothes to wear and she doesn't know how to dress properly for the weather.

—Professional caregiver

Meals on Wheels is a fantastic program but it doesn't work so well when the person won't open the door, or when they won't open the food, eat the food, or store the food that is delivered. We've gone into houses where food has sat on the counter because the person wasn't hungry or they didn't recognize that they were hungry, and now it is 2 days later and it is inedible, but it is being consumed anyway.

—Expert on hoarding

medication errors occurred in administering the medication, modifying the medication regimen, or not following clinical advice about medication use. These errors were attributed to cognitive deficits, sensory or physical problems with dispensers, or the complexity of the regimen (Douglas et al., 2011).

In a study of 339 elderly participants with cognitive impairment who lived alone and took at least one medication, 17.4 percent had at least one report of medication nonadherence. The most frequently occurring medical consequences were essential hypertension (13.0%), exacerbation of diabetes mellitus (13.0%), complications of heart disease (8.7%), constipation (8.7%), and edema (8.7%). Eleven (47.8%) of the 23 who had a medical consequence also required an emergency medical service (Thiruchselvam et al., 2012).

Indications that a person with dementia living alone is not able to adequately manage his or her personal care needs and daily activities include frequent emergency medical visits, little or no food in the home, unkempt appearance, dirty clothes, and inappropriate clothing for the weather. Intervention strategies include referral for pharmacist or nurse medication reconciliation, home-delivered meals, arranging for home care services, and notifying the police and fire departments of the person's condition and providing contact information.

Home Safety Issues

Alzheimer's and other dementias result in deficiencies that can reduce an individual's ability to remain safe at home, such as impairments in balance and mobility, judgment, sense of time and place, orientation and recognition of environmental cues, and changes in vision or hearing. As a result of impaired judgment, visual and spatial perception deficits, and disorientation, cognitive impairment increases the risk of falls by almost two-fold (Rubenstein & Josephson, 2006). Falls are the most common source of in-home accidents leading to morbidity and mortality. Falls are also the leading source of in-home injury in dementia (Douglas et al., 2011). Signs that a person is at risk for falling include confusion, poor balance and unsteady gait, and four or more prescription medications (National Institutes of Health, 2013).

Compulsive hoarding or extreme clutter and debris in the home can contribute to an

The most common problems of my clients who have dementia and live alone include not taking medications or not taking them properly, poor grooming/odor, not dressing for the season or the temperature, missing doctor's appointments, not seeing the doctor for a year or more, and suspected financial abuse.

—Home care professional

The most common time my agency is contacted to help a person with dementia who lives alone is after a fall or hospitalization.

—Geriatric care manager

I did some organizing around the house and got rid of a lot of clutter. I simplified my wardrobe to make it easier on myself. I put labels on the kitchen cupboard so that I am able to find things easily. I try to keep it simple.

—Person with dementia

individual's inability to manage his or her own daily activities and self-care. Food preparation becomes difficult if the person cannot access cooking appliances or even cupboards where food is stored. A significantly cluttered environment can lead to unsanitary living conditions and poses safety risks such as fire or falls/trips hazards. The living conditions affect not only the individual and family members but also neighbors and can become a public health concern (National Center on Elder Abuse, 2015).

Safety considerations and adaptations to the home to reduce safety risks include removal of throw rugs that may be a trip hazard, placement of latches on kitchen cabinets and drawers to keep knives and cleaning products out of reach, monitoring the environment for rearranging or removing furniture, removal of clutter and organization of areas of the home, installation of a ramp and grab bars in the bathroom, and widening doorways (Alzheimer's Association, 2015a; Gitlin & Corcoran, 2000). Various types of assistive technology can also be used to prevent injuries in the home such as gas detectors, room air temperature monitors, and devices that monitor water levels to prevent accidents and damage from flooding. Technology is available to alert a caregiver or emergency response system when the person with dementia has fallen. These systems may monitor for activity in the home or may detect falls through a floor impact sensor (O'Keeffe et al., 2010).

We worked with a man who had dementia and lived alone. He spent years after his parents died picking through the neighbors' garbage cans and bringing home their garbage until his townhouse was so completely filled on every level that he could no longer enter the home. He ended up living in his back yard and eventually he was placed into long-term care by the Public Guardian. Because it was a townhouse situation, the neighbors were directly affected by the rodent and insect infestation as well as the constant potential danger of a fire which could have cost lives as well as property.

—Expert on hoarding

Wandering

Wandering is a serious safety risk for people with dementia living alone because the likelihood of a person returning home safely largely depends on others recognizing that the person is missing or that something is unusual and reporting it to the appropriate authorities. Rowe and Glover (2001) define "unattended wandering" as forays into the community without the supervision of a caregiver. The professionals interviewed indicated that those at greatest risk are individuals with dementia living alone or living with a caregiver who leaves them alone while attending to other family or job responsibilities.

I take more precautions when I am not feeling physically well and I let people know if I am feeling disoriented.

—Person with dementia

The Alzheimer's Association (2015b) suggests that families make a plan if someone with dementia goes missing. Strategies include keeping a list of people to call on for help, a recent close-up photo, a list of places where the person may wander, and enrolling the person in an

identification program. A missing persons report should be filed immediately so that police can begin to search for the individual.

Global positioning systems (GPS) and other assistive technologies are being used to monitor and locate people with dementia at risk of wandering. A person can wear a location device as a watch or pendant, carry it like a mobile phone, or even mount it to the car (McKinstry & Sheikh, 2013). As the technology advances, people with dementia are being engaged in the process of design with the hope of leading to devices that are more acceptable, user-friendly, and relevant to their needs (Arntzen et al., 2014; Robinson et al., 2009). There are some limitations to using these devices. GPS and other assistive technologies are dependent on transmission and reception capability to be effective and buildings or other objects can impede signal transmission. In addition, a person with dementia may not like wearing or carrying a device and may remove it (O’Keeffe et al., 2010).

Although a location device may increase personal freedom and provide peace of mind to the person with dementia and those close to him or her, 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 have also suggested that the person with dementia be involved in decision-making and that this decision should be made in a formal structured meeting facilitated by a professional team (Landau & Werner, 2012).

Ability to Respond to Emergencies

The ability of persons with dementia to respond to crisis situations in the home is another important safety concern. One study found that older people who die as a result of a fire are more likely to be living alone than other older people (Elder et al., 1996). Another study of 38 people with dementia who are living at home demonstrated that those living alone were perceived to be more at risk than those living with someone, and the most commonly reported risks included fire, nutrition, and medication management (Bourgeois et al., 2009). Dementia increases the risk for fire-related death (Douglas et al., 2011). Alden et al. (2005) found that the majority of persons with burn injuries among persons with dementia were unsupervised at the time of injury and were burned while performing routine activities of daily living, such as cooking or bathing. The causes of burn injuries were predominantly bathroom or kitchen scalding and flame burns, suggesting that routine cooking and bathroom activities are of concern when an individual with dementia is alone.

Living alone with dementia increases the risk of mortality associated with accidental injuries because of impaired insight and problem-solving ability (Cooney et al., 2004), the absence of a caregiver and delayed medical help (Kibayashi et al., 2007). Difficulties in using the telephone are common among individuals with dementia living alone (Nygard & Starkhammer, 2003), so when emergencies do arise calling for help may not be possible.

Home and community-based services providers need to understand how to respond in an emergency, to the unique needs of someone with dementia who lives alone. Emergency personnel at the time of the crisis situation should have access to concise, accurate information

about the person's medical conditions, medications and dosage, and other important information. Home and community-based services providers should be trained on working with first responders such as fire personnel or police to assist with finding individuals in emergency situations, effective communication strategies for people with dementia, and effective approaches when offers of assistance meet resistance (interview with Amanda Burstein, International Association of Chiefs of Police, July 28, 2015).

Financial Exploitation

According to the National Elder Abuse Incidence Study, financial exploitation is one of the most common reported types of elder abuse in people with dementia living alone (National Center on Elder Abuse, 1998). The perpetrators are often friends or family members who have a relationship of trust with the victim. The National Association of Adult Protective Services Administrators recommends that all professional financial service providers receive special training on identifying and reporting financial exploitation (National Association of Adult Protective Services Administrators, 2003).

Marson (2013) defines financial capacity as the ability to independently manage one's financial affairs in a manner consistent with one's personal interests and values. Further, he notes that financial capacity has both a performance aspect and a judgment aspect. The person must be able to perform a variety of tasks and skills to meet his or her financial needs such as recognizing money and its value when paying for things at the store or understanding basic financial terms and concepts such as a mortgage, will, or annuity. In addition, the individual must be able to use appropriate judgment and decision-making regarding household budget and financial investments.

Individuals with dementia are at risk for financial exploitation or money mismanagement when they are unable to get to the bank without assistance; have multiple care providers; repeatedly targeted by cold callers and scams; or leave money, bills, and other financial information around the house. An individual with dementia is also at risk if they are socially isolated and have a propensity to talk about their financial situation with strangers; or feel pressured by family or

I have a special needs child and the local (suburban) fire department has a system for people with special needs like my daughter where you can put a red dot in the doorway so when the door is opened, it is visible to fire personnel to know to look on the refrigerator for medical information in a plastic pouch. This is a quick and easy way for the emergency responders to get medications, illnesses, allergies, emergency contacts, etc., especially when there is a lot of information (such as with an illness or disability). When I asked about something similar for my mom with the city fire department where she lives, I was told that there wasn't anything that met this need. A system similar to this could be very beneficial for a person with Alzheimer's, especially one who lives alone.

—Caregiving daughter

I had a client living alone with dementia who paid a family member \$30,000 to help clean out the house.

—Expert on hoarding

friends for money (Alzheimer’s Society UK, 2011). Care providers and family members can reduce risk of exploitation by removing the person’s name from telemarketer lists, checking their credit report yearly, enrolling in automatic bill payment, and notifying shopkeepers, bank tellers, and others of the person’s difficulty with financial transactions. Appendix A contains additional tips on fraud protection.

Social Isolation and Loneliness

Relationships with others and having the support of family and friends are important to sustain people with dementia who live alone. In a qualitative study of 15 people with dementia who live alone, the participants indicated that having a strong social support network was the most important factor for helping them cope with living alone (Harris, 2006). The study participants were concerned about maintaining their independence, continuing to drive, and being involved in decision-making for as long as possible. Most were comfortable living alone but they did experience feelings of loneliness. The author suggests that services for people with dementia living alone need to be sensitive to the person’s needs and wishes, and not just about responding to safety concerns.

A more recent study found that people with dementia who live alone with an unmet care need did not manage everyday life when they felt lonely (Svanstrom & Sundler, 2015). Feelings of loneliness may negatively impact a person’s ability to act and engage in everyday activities. The presence of a home care worker, for the purpose of performing a task, did not relieve feelings of loneliness. One of the participants in the study described the home care worker as being rushed and expressed a wish for a longer visit to allow for companionship and conversation. The authors also found that without the presence of others, the person with dementia seemed to lack initiative and experienced difficulties in managing everyday life. The authors highlight the importance of the presence of caregivers for those who live alone with dementia that address needs for socialization and not solely focus on specific tasks or physical needs.

If there is no one in the home to observe changes in the person’s cognitive and functional abilities, the progressive decline associated with Alzheimer’s or a related dementia may go unnoticed until it is a problem (Soniati, 2004). Changes in the ability to plan, organize, and follow through with daily activities and personal care needs are likely to lead to self-neglect because of the individual’s lack of insight and poor judgment (Wilkins et al., 2014).

Often the needs of my patients with dementia who live alone are less about their medical condition and more about being connected to others as a way to avoid further decline in physical and cognitive health.

—Geriatric nurse practitioner

The isolation of a person with dementia leads to increasing confusion and the person withdraws even more. They are more vulnerable to a scam artist or new “best friend.”

—Adult Protective Services professional

Even when someone who lives alone gets support from family and friends, it may not be enough to manage all of his or her daily needs. One study found that persons with dementia living alone had significantly more unmet needs than those living with others in the areas of looking after home, nutrition, self-care, daytime activities, companionship, psychological distress, eyesight/hearing, and accidental self-harm (Miranda-Castillo et al., 2010). Another study that assessed African Americans with dementia living alone found that neighbors and friends were more often the primary care providers. Neighbors and friends, when compared to caregivers living with the person, were less likely to help with tasks that were time-consuming or required more intimate care (Edwards & Morris, 2007).

Soniat and Pollack (1993) describe nontraditional support systems for individuals with dementia who live alone with no close family as “makeshift networks of neighbors and agencies.” Those involved in helping a person stay in the community may have narrowly defined roles and the various members of the network may not even know each other or coordinate the care they provide. When there is no relationship history, as with a family member or close friend, the support person may not have any emotional ties or commitment to the individual with dementia that keeps them involved in caregiving. The caregiving relationship may end when the support person gets frustrated and decides to move on.

ENSURING SAFETY AND SUPPORTING AUTONOMY

Like other older adults who live alone, many people with Alzheimer’s disease and other dementias want to remain independent and prefer living alone to the other options available to them (DeWitt et al., 2009; Harris, 2006). However, the symptoms of Alzheimer’s disease and other dementias can create serious risks for individuals who live alone. Home and community-based services professionals may be asked to determine whether an individual has the ability to live alone and manage daily activities without assistance. Although an individual’s freedom to choose where and how to live is one of the most important rights in our society, the value of his or her autonomy comes into question when it involves potential danger. The service professional has an ethical and legal obligation to carefully assess the individual’s capacities and ensure that the individual’s civil rights are not violated (Kane, 2001).

I don’t really have anyone in my life who could check in on me regularly when I need more monitoring. I am interested in maybe getting something like a location management system and I also like the idea of a home check-in through the TV or a videophone by a care manager or a social worker.

—Person with dementia

People in our town will come to someone’s aid if they know that the person with dementia doesn’t have support from family or friends until they get tired of doing it.

—Home care professional

The “perfect storm” is when there is no plan, there is a crisis, the person lacks decision-making capacity, and the family doesn’t communicate.

—Adult Protective Services professional

As a professional weighs concerns regarding safety and respect for autonomy, it is important to understand an individual's capacity to make everyday decisions and carry out those decisions in light of his or her own values. The Duke Family Support Program provides questions for professionals and others to guide decisions about the safety of someone with dementia living alone (Gwyther & Ballard, 2002, Appendix B). Assessment of decision making capacity includes asking the individual to state the risks and benefits of a particular decision, make a choice, and explain the reasons for that decision (Wilkins et al., 2014). Assessment of decision-making capacity is complex and requires proper training because an individual's capacity can fluctuate over time, even in the course of one day (Kane, 2001).

APS is charged with responding to concerns regarding the safety and well-being of older adults and adults with disabilities, including individuals with dementia living alone. Many social service professionals and health care providers are mandated to report suspected abuse or self-neglect. The National Center on Elder Abuse lists warning signs of what to look for and when to report (<http://www.ncea.aoa.gov/faq/index.aspx>). APS is a social service program provided by state and local government that provides assistance to individuals who may be vulnerable to abuse, neglect, self-neglect, or exploitation (National Adult Protective Services Association, 2015).

There may be scenarios in which social service professionals, health care providers, or concerned family members will petition the court for guardianship on behalf of a person with dementia living alone. Guardianship is the most restrictive option for protecting individuals and their property and allows the courts to appoint a substitute decision-maker to make financial, personal, legal, and health care choices for the individual depending on the type of guardianship the court imposes. Currently, all states have guardianship provisions and full guardianship may deny the individual his or her right to "vote, marry, travel, drive, be employed, enter contracts, manage property, consent to medical treatment, choose a residence, or even pursue a social life" (Kane, 2001, p. 93). Courts are also able to appoint limited guardianships, which may allow individuals to retain some of their rights and articulate care preferences. Limited guardianships support the individual in maintaining his or her civil rights for as long as possible (Kane, 2001).

While respecting individual autonomy to the extent possible, professionals will recognize that some people with dementia are not in danger of harm or loss and for those who are at risk, there are alternatives to guardianship to consider (Kane, 2001). Most people with mild to moderate-severe dementia can express a choice (Lai & Karlawish, 2007). For example, a person may lack capacities to drive or handle his or her financial affairs but retain the ability to make decisions about where he or she wants to live (Alzheimer's Association, 2011). Balancing safety and autonomy for individuals with dementia living alone requires professionals to seek the least restrictive alternative and mobilize available supports within that individual's community. Often the involvement of family and friends precludes the necessity of guardianship and advance planning (i.e., appointing a representative payee or durable power of attorney) ensures that the person's values and beliefs are honored (Kane, 2001).

PROVIDING PERSON-CENTERED SERVICES

Person-centered services emphasize the importance of the individual by building on remaining strengths and involving the individual in decision-making. Collaboration and

meaningful connection will aid in building trust and sustaining the caregiver relationship over time.

Sometimes, an individual with dementia living alone does not want help. It is important for the health care provider to be sensitive to religious or cultural beliefs that may influence decision-making (Pavlou & Lachs, 2008). In a small Australian study of 19 older people who live alone with cognitive impairment or early stage dementia, participants were emphatic in their desire not to receive what they determined was an unnecessary level of support, choosing instead to complete their own daily living tasks to maintain their independence (Duane et al., 2013). Physicians and other providers sometimes become frustrated by people with dementia living alone who do not want help (Pavlou & Lachs, 2008). Consultation with fellow team members can be beneficial in understanding an individual's decision not to accept help and developing the most appropriate response (Wilkins et al., 2014).

You need to take baby steps—you can't do it all at once. Be a friend first, then check in once a day, maybe bring food to the person, offer to join them for a meal, maybe have them attend the adult day center for a couple of hours and then half a day and so on.

—Home care professional

Home and community-based services professionals can ensure that the person with dementia has a voice in the care planning process by starting with his or her main concerns (Lisa Gwyther, interview May 19, 2015). Family meetings can help to clarify areas of concern and establish consensus on ways to intervene (Wilkins et al., 2014). A family meeting, facilitated by a care manager or another professional, can be the basis for family discussion and collaboration around possible solutions to the findings of a home visit/risk assessment (Geri Hall, personal communication on May 19, 2015; Wilkins et al., 2014).

Communication between community service providers and physicians is an important strategy to fill gaps in understanding the needs of individuals with dementia who live alone (Newhouse et al., 2002). Interdisciplinary/interagency teams encourage collaboration and service coordination across government agencies and community-based service providers to ensure quality care and cost-effective service delivery for people with dementia living alone.

INNOVATIVE PRACTICES

Some community agencies in the United States have developed innovative practices to help people with Alzheimer's and other dementias who live alone. These initiatives aim to identify individuals with dementia who live alone, increase public awareness and community support, provide specific services for people with dementia who live alone, and mobilize local networks of support.

Friendly Visitor Programs

Friendly Visitor programs engage volunteers or paid home care workers who can provide companionship to people with dementia who are socially isolated. In the United Kingdom, the Alzheimer's Society has a model for volunteer "befrienders" who support individuals in their homes or during outings and activities in the community by helping them to carry out regular

activities such as shopping, hobbies, and personal interests (Alzheimer’s Society, UK, 2015). Catholic Community Services in Australia has a dementia-monitoring program that serves clients at risk of social isolation by increasing each client’s social networks and participation in meaningful activities. The paid provider assists with a variety of activities including the preparation of meals, outings and day trips, letter writing, minor garden and home maintenance, or regular telephone contact (Catholic Community Services, 2014).

Gatekeeper Programs

Gatekeeper programs recruit mail carriers, utility meter readers, ministers, pharmacists, and other individuals who interact with many people in the course of their daily work and train them to identify and refer isolated older people who may need assistance to a central agency (Raschko et al., 1991). Gatekeepers provide “discreet surveillance,” monitoring for any unsafe behaviors without being invasive (interview with Lisa Gwyther, May 19, 2015).

Through an Alzheimer’s Disease Demonstration Grant to States (ADDGS) grant, the University of Iowa worked with the Iowa Department of Elder affairs to train six registered nurses to be gatekeepers for one or more rural counties. The nurses held community meetings for health professionals and service providers such as bankers, plumbers, and electricians to increase awareness of the signs and symptoms of dementia and to get people with dementia and their families needed services. Early on in the grant, the project team recognized that a significant number of people with dementia in rural areas were living alone, which posed unique challenges to the individual with dementia and the family. When the nurse made a recommendation for increased support in the home, families wanted to know the basis for the recommendation and how soon intervention was necessary. In response to this finding, the project team developed a risk assessment for individuals with dementia living alone (Hall et al., 2001; see Appendix C). The nurse would use the risk assessment as a timeline and a guide for families to assist with making decisions (personal communication with Geri Hall, August 15, 2015).

Faith communities have a higher concentration of older adults in their congregations. Members of a person’s faith community are able to provide meaningful insight on changes seen in a longtime member, making them ideal gatekeepers (interview with Marla Lahat, July 20, 2015).

We are in a small rural community of 3,500 people and people know our agency. We have gotten calls from the grocer saying, “Can you help this person?”

—Home care professional

Resident managers of apartment buildings such as senior housing complexes are a valuable referral source. Individuals in such roles may be aware of home safety issues, neighbor complaints, squalid living conditions, unsafe wandering, and missed rent payments or eviction notices. They can offer valuable information to a case manager conducting an in-home assessment and can be an integral part of a person’s ongoing support system (interview with Marla Lahat, July 20, 2015).

Mail carriers have a unique perspective as gatekeepers, because they come to an individual’s home every day and may observe signs of changes in capacity. The Erie County

Aging and Disability Resource Center (ADRC) in New York uses the gatekeeper model in its Carrier Alert Program. The program is a partnership between the local post offices, AARP, and the Erie County Department of Senior Services. The post offices train carriers on warning signs such as neglected mail that is piling up and lack of response when the postal carrier attempts to deliver a package. Individuals can enroll if they would like to have their mail carrier monitor for their safety and well-being. Once a person is enrolled, the Erie County ADRC enters the individual's information into its database. The program provides a color-coded sticker for the mailbox that indicates to the postal carrier that the person is enrolled. If a postal carrier has some concerns, he or she can refer the person to the ADRC for home assessment which may result in ongoing care management (interview with Dan Szeck and Miriam Callahan, May 21, 2015).

Home Care Services

Home care services can help an individual remain at home, in the community, by supporting activities of daily living that are no longer manageable. Home care agencies are sometimes reluctant to serve an individual with dementia living alone because he or she is unable to follow through with a plan of care and perceived to be too great of a liability. A person with dementia living alone also may not understand the reason for a home-care provider visit and may not allow that person into his or her home. The Alzheimer's Association (2009, Appendix D) has tips for home-care professionals that address the importance of building rapport and trust.

In the mid-1980s, Home Care Partners, a nonprofit organization providing nonmedical home-care services in the Washington, DC, area initiated a special program to serve people with Alzheimer's disease and other dementias. After 5 years, social workers and community case managers asked the agency to serve people with dementia who live alone. The agency received an ADDGS grant in 1992 to expand its program, which required targeted recruitment and specialized staff training. "At that time, we knew that we were not going to make things perfect but if we could make things better for the individual, we could make a difference in that person's quality of life," shared Marla Lahat, Executive Director. Home Care Partners does not provide Medicare- or Medicaid-funded services nor does it provide heavy-duty medical or physical care. Home care aides are able to support an individual with homemaker or personal care services and generally provide 6–9 hours per week. The initial client assessment is conducted in the home by a case manager (licensed social worker or nurse) and the client participates in development of the plan of care. The case manager then oversees and coordinates home care aide services and makes referrals to community programs for services the agency does not provide.

Occasionally, Home Care Partners discharges clients because of safety issues. Clients may be discharged as a result of issues that cannot be safely managed outside the time the aide is in the home including wandering outside of the home or threats of violence or significant physical care needs such as incontinence or severe malnutrition. The agency emphasizes flexibility in serving clients with unique care needs and preferences and tries to accommodate the individual as much as possible (interview with Marla Lahat, July 20, 2015).

Law Enforcement

Law enforcement personnel encounter people with dementia in a variety of situations including reports of missing persons, neighbor complaints, traffic violations, claims of fraud or theft, suspected elder abuse, and domestic violence. Progressive memory loss and cognitive

changes because of dementia pose significant challenges and can affect an individual's ability to think clearly and respond appropriately, especially in a crisis. When an individual with dementia lives alone, the responding officer may be challenged to understand and resolve the situation without input from others close to the person.

With funding from the U.S. Department of Justice, the International Association of Chiefs of Police (IACP) developed a 1-day training available to police departments anywhere in the country. The IACP Alzheimer's Initiative provides training on effective intervention strategies that includes statistics and characteristics of individuals living alone with dementia. The training curriculum consists of four modules that address learning about Alzheimer's disease and related dementias, approaches for interacting with individuals who have dementia and warning signs, search and rescue techniques specifically tailored for people with dementia who are missing, and local community services that can provide follow-up support. The IACP also hosts a website with resources and materials for educating law enforcement that includes online roll call training videos and a discussion guide, identifying at risk drivers, and evaluative questions to ask caregivers.

Police departments are encouraged to partner with their local community organizations and participate in events such as Alzheimer's walks, senior center programs, Boys and Girls Club activities, public library offerings, and locally sponsored National Night Out events where community residents can meet their police officers. Building relationships with local community organizations will help police connect individuals living alone with dementia to services (interview with Amanda Burstein, July 28, 2015).

Fifteen years ago, the Lake County Sheriff's office in Lake County, Florida, implemented the Senior Watch Program, a program intended to monitor older people who are living alone and have no one to check on them daily, including people with dementia. The person must register and provide some personal details, such as age, medical conditions, and contact information for neighbors or nearby relatives. The program participant is supposed to check in with the Senior Watch telephone operators every morning. If the operators do not receive a call from the participant, a call is placed to the person, and if there is no answer, a neighbor or relative is contacted to check on the person. If a timely contact cannot be made, a Deputy Sheriff is dispatched to the home (interview with Lake County Sheriff Dispatch, July 29, 2015).

CONCLUSION

Despite the large proportion of people with Alzheimer's and other dementias who live alone, few evidence-based programs or practices exist to support their living safely and autonomously. Notably, these individuals commonly have unmet care needs and have a high level of risk for self-neglect, financial exploitation, malnutrition, and dehydration, and may be particularly prone to adverse outcomes from accidents in the home. As detailed in this report, some promising programs and practices have been employed with this population and provide helpful guidance to identifying and serving people with Alzheimer's and other dementias who live alone.

People with dementia who live alone face obvious risks. Many receive help from family members, neighbors, and friends, and some may not need additional help at any particular point

in time. On the other hand, Alzheimer's and most other dementias are progressive, and all individuals with these conditions will need more help over time. Family members, friends, and neighbors who visit or check in with the person regularly can monitor the person's increasing cognitive and functional impairments and may be able to provide or arrange for needed services. Impairments in judgment and ability to plan and carry out activities, and lack of awareness of cognitive and functional impairments, mean that many people with dementia are unable to recognize their increasing need for help or plan for or arrange needed services. Even those who have someone who visits regularly are at risk for serious injuries associated with falls, wandering and getting lost, medication errors, and cooking accidents that result in life-threatening burns and require an immediate response.

As the prevalence of Alzheimer's and other dementias continues to rise, the needs of people with dementia living alone will also increase. Community and government agencies and others in the aging services network can test and share innovative practices in an effort to develop services that are responsive to the needs of people with Alzheimer's or other dementias living alone.

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APPENDIX A: FRAUD PROTECTION FOR ELDERS LIVING OR STAYING ALONE

- Remove the person's name from telemarketer lists and junk mailings.
- Set up a P.O. Box for mail delivery and screen mail.
- Arrange with the bank to allow access only to predetermined amounts of money. Ask the bank to call you if a request for a large withdrawal is made.
- Limit credit card access.
- Look for unusual activity and bank accounts, bounced checks, "maxed out" credit.
- Look for checks or documents with signatures that appear forged.
- Screen phone calls.
- Be sure the person's Social Security number does not appear on checks.
- Check the person's credit report yearly.
- Look for unpaid or overpaid bills.
- Be aware if someone isolates the person or talks excessively about finances.
- Notice if a new acquaintance expresses inordinate affection and loyalty.
- Look for changes in the will, deed, or Power of Attorney if the person is not able to comprehend such changes.

Gwyther, L. P., & Ballard, E. L. (2002). *Working with family caregivers of people with memory disorders: A North Carolina information & assistance toolkit*. Durham, NC: Duke Family Support Program.

APPENDIX B: CAN A PERSON WITH ALZHEIMER'S LIVE ALONE?

The following questions may guide decisions about the safety of someone with a memory disorder living alone. It's best to observe the person doing these things rather than rely only on the person's report. Use only the questions that apply to your situation, for example, safe use of power tools may not be an issue for a woman living alone. Some of these questions apply to persons who are left alone during the day. If there are many yes answers, the person may need more supervision, support, or a change in living situation.

Safety Concerns/Does the person:

- Have driving accidents, even minor ones?
- Get lost driving or walking?
- Burn pots or forget to turn off burners or oven?
- Forget to extinguish cigarettes?
- Let strangers into the house?
- Lock him- or herself out often?
- Forget to secure the house at night?
- Have mood swings and suspicious behaviors?
- Leave the house and get lost?
- Know there are firearms or dangerous tools in the house and how to use them safely?
- Know how to operate the thermostat and judge temperature appropriately?
- Know what to do in case of emergency?
- Have a recent history of being a victim of fraud, telemarketers, or a crime?
- Risk injury from falls, vision, or balance problems?

Personal Care/Other/Is the person able to:

- Eat well-balanced meals and drink enough fluids?
- Dress appropriately for the weather?
- Bathe and use the toilet when needed?
- Keep up with housekeeping and home repair?
- Pay bills on time, handle the checkbook, credit cards?
- Shop for, store, and cook food correctly?
- Use the phone or answering machine?
- Take medicine on time and in the right amount?
- Know current address and phone number?

Gwyther, L. P., & Ballard, E. L. (2002). *Working with family caregivers of people with memory disorders: A North Carolina information & assistance toolkit*. Durham, NC: Duke Family Support Program.

APPENDIX C: LIVE ALONE ASSESSMENT

The following conditions may indicate when a person with dementia is no longer safe to live alone or will require more services, assistance or placement. Place a check by each statement that is known or observed. Calculate scores in each section and utilize recommendations from Boxes A–C.

GRADE			
A = Emergent Only <u>one condition</u> needs to be present. Immediate help or placement is required.	A / B Emergent/ Semi-Emergent Can be either A or B depending on the cause, severity, and the person's response to the situation.	B = Semi-Emergent > <u>2 conditions</u> indicate that there are safety concerns that must be addressed and remediated.	C = Non-Emergent > <u>3 conditions</u> are present. Additional help will be beneficial. Re-evaluate monthly.
OBSERVED OR REPORTED CONDITIONS			
<ul style="list-style-type: none"> <input type="checkbox"/> Weight loss of > 6 pounds or 10% body weight in 6 months, evidence of protruding bones <input type="checkbox"/> Presence of paranoia, hallucinations, delusions, aggression or thoughts of suicide <input type="checkbox"/> Threatens violence with/without weapons <input type="checkbox"/> Evidence of caregiver injury/domestic violence <input type="checkbox"/> Repeated ER visits, hospitalizations <input type="checkbox"/> Evidence of substance abuse <input type="checkbox"/> Frequent calls to police or emergency services <input type="checkbox"/> Wandering outside the home <input type="checkbox"/> No food/rancid food in the home <input type="checkbox"/> Lack of safety with stove, power tools, yard <input type="checkbox"/> Unable to take medications correctly <input type="checkbox"/> Live stock/other animals receive inadequate care <input type="checkbox"/> Eviction notice served 	<ul style="list-style-type: none"> <input type="checkbox"/> Malfunctioning plumbing <input type="checkbox"/> Thermostats not set appropriately for weather conditions <input type="checkbox"/> Chronic anxiety, panic attacks, worry or depression is present <input type="checkbox"/> Unsafe driving or refuses to stop driving <input type="checkbox"/> Neighbors calling police 	<ul style="list-style-type: none"> <input type="checkbox"/> Not able to manage bowel/bladder care <input type="checkbox"/> Repeated calls to family/others asking what to do next <input type="checkbox"/> Dirty/infested household <input type="checkbox"/> Garbage accumulation <input type="checkbox"/> Food stored inappropriately <input type="checkbox"/> Taken advantage of by family, friends, neighbors <input type="checkbox"/> Refuses personal care for prolonged period of time 	<ul style="list-style-type: none"> <input type="checkbox"/> Phone calls from community members advising help is needed <input type="checkbox"/> Vegetative or socially isolated behavior (sitting all day with TV on or off) <input type="checkbox"/> Missing belongings, hiding things <input type="checkbox"/> Poor grooming, wearing the same clothing all the time, soiled appearance
Total A:	Total A/B's:	Total B:	Total C:

Adapted from the University of Iowa, 2004

APPENDIX D: CONSIDERATIONS FOR THOSE WITH DEMENTIA WHO LIVE ALONE

It is especially important to build rapport and develop effective communication with the person with dementia living alone. Frequently, individuals with dementia who live alone have a strong sense of independence, so building rapport may take time.

- People who live alone can be described by one of the following general categories:
 - They live alone but receive frequent support from relatives and friends living nearby.
 - They live alone with support from long-distance caregivers, usually adult children or siblings.
 - They have no close family members or friends to provide monitoring or assistance—this is the most vulnerable group.

Note: People with dementia who live alone are at high risk for self-neglect.

- Some general guidelines for working with individuals with dementia who live alone include the following:
 - Always introduce yourself and mention the name of a family member or friend to help the person understand why you are there. If possible, arrange for a family member, friend, or home care provider with whom the individual has a relationship to introduce you to the person the first time you visit.
 - Allow sufficient time to build trust. Be prepared to participate in friendly conversation while the person gets more comfortable with you.
 - If the person is suspicious, a call from the agency (to confirm that the provider is there to help) or from a family member (to verify that it is all right to let the provider in) may be enough to gain entrance.
 - If the person will not open the door, sometimes leaving and attempting to visit again later the same day or another day is an effective approach.
 - Build rapport by learning about the person’s interests, history, favorite memories, family, and friends.
 - Monitor food and fluid intake. If meals are being delivered, check to see that they are being eaten. Serve water and other liquids during visits. Dehydration is a serious risk.
 - Check for fire and other safety risks as part of every visit, including food left cooking on the stove, evidence of small fires, burns on the person or on furniture, and frayed or loose wires.
 - Provide support to help the person with dementia maintain as much independence as possible.
 - Anticipate and avoid crisis situations.

Reprinted with Permission. Alzheimer’s Association. (2009). Dementia care practice recommendations for professionals working in the home setting. pp 53–54.