

Handbook for Helping People Living Alone with Dementia Who Have No Known Support



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This handbook is dedicated to Joshua Wiener whose commitment to quality dementia care spanned several decades. During his career, Josh influenced the delivery of dementia care services and long-term care financing, policy, and research. Since 2004, Josh directed the National Alzheimer's and Dementia Resource Center, and he consistently pushed for the highest quality products from the Resource Center. He was generous with his time, a real stickler with editing, and a mentor for all Resource Center staff. His guidance had a great impact personally and professionally on many, and his influence is greatly missed.

How to Use This Handbook

The purpose of this handbook is to provide practical strategies that can be used to address challenges that medical, legal, and social services professionals face when working with individuals with dementia who live alone with no known support. Although the legal guidance is written for a U.S. audience, the handbook has valuable information applicable to social service, legal, and medical professionals internationally. The handbook builds on the 2015 report *Identifying and Meeting the Needs of Individuals with Dementia Who Live Alone* (Gould et al., 2015) and the 2017 guide *Providing Services to Individuals with Dementia Who Live Alone: A Guide of Practical Strategies* (Knowles et al., 2017), authored by the National Alzheimer's and Dementia Resource Center. This resource provides specific strategies for how home and community-based service professionals can work with individuals with dementia living alone in the community.

In the sections outlined below, the handbook guides users through the challenges of working with individuals with dementia who live alone with no known support network:

- Assessing risk
- Determining whether there is a support system
- Evaluating decision-making capacity
- Screening for elder abuse, neglect, and financial exploitation
- Working effectively with Adult Protective Services
- Enhancing safety
- Managing money
- Managing health

- Basic estate planning and funeral arrangements
- Reviewing decision making options
- Guardianship

Quotes from the Field that capture the experience of Administration for Community Living (ACL) grantees serving people with dementia living alone and with no known supports are a feature throughout the Handbook. The quotes illustrate lessons learned and successful strategies that may be useful to others interested in this work.

Introduction

As dementia progresses, individuals experience an increasing need for support as a result of declines in memory, cognition, and decision-making. Studies indicate that 28 to 34 percent of people with dementia live alone (Amjad et al., 2016; Ebly et al., 1999; Nourhashemi et al., 2005; Wattmo et al., 2014). People living alone with dementia are at high risk for self-neglect, malnutrition, injury, medication errors, financial exploitation, social isolation, and unattended wandering (Acierno et al., 2010; Bourgeois et al., 2009; Douglas et al., 2011; Evans et al., 2016; Gould et al., 2010; Harris, 2006; Miranda-Castillo et al., 2010; Nourhashemi et al., 2005; Peterson et al., 2014; Rowe & Glover, 2001; Wattmo et al., 2014). Although many people living alone have a caregiver nearby, some do not.

There are several explanations as to why people with dementia may be alone. Living alone may be a personal choice, a circumstance of outliving all family and friends or possibly a result of others choosing to discontinue contact. A recent study (Evans et al., 2016) presents other circumstances that may result in a person living with dementia living alone without support:

- living alone for a short period of time while the caregiver is hospitalized or some other temporary situation, or
- living alone unexpectedly because of the death or nursing home placement of the caregiver.

Another possible challenging scenario would be that of a person living with dementia residing with someone who cannot provide meaningful support, supervision, or companionship such as an adult child who has a drug or alcohol addiction.

People with dementia who live alone are much less likely than people with dementia who live with others in the community to have been diagnosed with the condition (Lehmann et al., 2010), and because individuals living alone are less likely to recognize their own limitations, they are unlikely to seek the help they need. A recent study found that lower cognitive ability actually predicted fewer hours of home help service, which suggests that these individuals were not able to request the assistance they needed (Wattmo et al., 2014). Additionally, people with dementia who live alone do not manage daily activities as well or at all when they feel lonely (Svanstrom & Sundler, 2015). In the absence of readily identifiable informal supports (e.g., unpaid assistance from family or friends), the person will need to rely on social services, medical, and legal professionals for assistance to remain safe in their home.

The goal of this handbook is to be an action guide for social services, legal, and medical professionals to help a person living with dementia who has no known informal supports. The handbook includes strategies for assessing risk, identifying individuals willing to help (including family and friends), determining decision-making capacity, options for helping the person maintain their independence, and the basics of guardianship or conservatorship.

Assessing Risk

Adults may voluntarily choose to live in unsafe conditions as long as they understand the risk of their choice and their behavior does not present a substantial risk of safety to others. An assessment of safety should be done when first encountering a person with suspected dementia living alone, and ongoing assessments should be done as the person's illness progresses. As a person's ability to protect

themselves from harm diminishes, the need for intervention increases.

Professionals working with these individuals are presented with the ethical dilemma of balancing efforts to support individual autonomy with efforts to ensure safety, understanding that there is “no perfect environment” for someone with dementia living alone and that “a certain amount of risk is inevitable” (L. Gwyther, personal interview, May 19, 2015). If there are no family members or friends to take the lead in assessing, intervening, and monitoring the person’s health and safety, it will fall on health and social service providers to carefully consider options and creatively explore how to address needs and add safeguards in the least restrictive way possible. The individual’s agreement with any suggested interventions is necessary for both practical and legal reasons. If an individual appears to lack the ability to understand, make, or implement decisions regarding their self-care and refuses help, a report to Adult Protective Services is necessary.

Socially isolated individuals are at increased risk for abuse and financial exploitation. Agencies providing services to a person living with dementia should strive to adopt oversight methods to reduce the risk of abuse and increase the likelihood that abuse is reported if it occurs. Having more people engaged with a person living alone with dementia increases the likelihood that abuse will be detected. The best protection against any kind of abuse is ongoing monitoring of risk areas, including regular monitoring and reporting of financial matters. Enhanced financial reporting should be included in contracts and powers of attorney, requiring sharing records of all transactions with a trusted third party. It is also important to monitor credit and debit card activity. For example, banks can

Quotes from the Field

Serving people with dementia who are living alone requires time and patience to build trust, understand their needs, and develop a support system. Helpers must be willing to do things differently, rather than trying to hustle the person along or shortcut the process.

—ACL grantee

e-mail copies of statements for review by a third party. Additional information on financial management is in the Money Management section.

Determining Whether There is a Support System

In both community and inpatient medical settings, medical, legal, and social service professionals encounter people with dementia who are unaccompanied by family or friends. The individual may be unable or unwilling to provide accurate information on next of kin or emergency contact information. In these circumstances, the person is classified as “unrepresented” or “unbefriended.” Many of these people have someone who cares about them who would be willing to help make decisions and choices; the challenge is how to identify and connect with them to enlist their help. Health care and social services professionals have said that a thorough search often results in the identification of a person or people who know the individual well who are willing and able to help. The American Geriatrics Society position states that “the most appropriate surrogate for the incapacitated patient is one who has loving and intimate knowledge of the person’s wishes or value system” (American Geriatrics Society Ethics Committee, 2016). A person may not have next of kin but may have a close friend, partner, neighbor, or others who may know the person well and may be willing to step in.

Steps to take if a person appears confused or cannot provide reliable information

Below are steps you can take with the individual to identify their family, friends, or other supports. If someone is unwilling to allow help, attempt to respond to the person's identified needs to establish trust.

- Start by making the person comfortable and asking about family, friends, and neighbors.
- Look for a card or identification bracelet saying, "In case of emergency please contact." Past medical records may also have contact information. If there is no useable information, start with the assumption that the person has no support from family or friends until someone is identified.
- Take the time necessary to develop trust and listen to the person's stated concerns.
- Gradually ask about who they rely on for different tasks, who they trust or don't trust and why.
- If the person has a cell phone, ask permission to look for contacts or stored phone numbers. Look for an emergency contact number.
- When visiting the person's residence, get permission to look for personal address books, photographs of the person and others, holiday or special event cards, or old mail at the person's home. Check their answering machine or voicemail for messages from family or friends.
- If any legal, financial, or insurance documents are found, get permission to talk to the professionals who prepared the documents.
- Get permission to talk to health care providers, service providers, neighbors, and local faith

Hospitals' Obligation to Notify

Health care providers report that a relatively high percentage of people who are admitted to hospitals, unable to communicate and with no indication of who to contact, do in fact have family or friends somewhere. Federal interpretative guidance asks virtually all hospitals to make a reasonable effort to promptly notify known next of kin or representatives of a patient to inform them that a person has been admitted who is unable to communicate (42 C.F.R. §482.13). It also says that if the patient is unable to communicate, the hospital must make a reasonable effort to identify family or other representatives, including past health care providers, and promptly notify them. The notice needs to be made promptly; the guidance says that notice by first class mail is not prompt (CMS Manual System Pub 100-07, 12-2-2011). All facilities that have inpatient admissions and receive any funding from Medicare or Medicaid are covered by this rule. Two states, Nevada and New Jersey, have laws requiring hospitals to notify next of kin (Nev. Rev. Stat. 483.641 to -.663 [Eff. July 2, 2015] and N.J. Stat. Ann. §39:4-134.2 [Amended as of eff. April 1, 2016]).

The Veterans Health Administration's guidance may serve as a better model for other institutions and professionals. Health care providers must make a reasonable inquiry as to the availability of other possible surrogates. Each VA facility must have a procedure in place for identifying surrogates, including, if necessary, examining personal effects, health records, and other VA records such as benefits and pension records (VHA, 2017).

and community organizations. Ask about family, friends, or visitors.

- If the person rents, get permission to talk to their landlord or management office.
- Get permission to talk to current or previous employers. Employers may have records of family or references from the past that can lead to interested family and friends.

Important note: Lawyers will often say, “we can’t tell you about our client.” Although that is technically correct, they are able to be informed of concerns and may be able to—without breaching confidentiality—reach out on behalf of the client to contacts they may have in their files. A call from the lawyer to the beneficiary in the will may lead to a long-estranged family member or interested friend, for example.

Concerns about an individual’s privacy are an important consideration as providers work with other members of the community to identify a support system for an individual with dementia living alone. Most health care providers are subject to the Health Insurance Portability and Accountability Act of 1996 (HIPAA), which restricts the sharing of health care information about patients outside of their health team or insurance carriers, although an exception to the rule exists for suspected abuse or neglect. More specifically, every health care provider or health plan, regardless of size, who electronically transmits health information in connection with certain transactions is required to comply with HIPAA. These transactions include claims, benefit eligibility inquiries, referral authorization requests, or other transactions for which the U.S. Department of Health and Human Services (HHS) has established standards under HIPAA (HHS, Office of Civil Rights, 2003). Key community members, such as neighbors or mail carriers, who have relevant

information to share are not restricted by HIPAA. Other professionals, even lawyers and financial advisors, have ethical rules that allow, to one degree or another, the sharing of confidential information when an individual's safety or well-being is in danger because of possible dementia.

Evaluating Decision-Making Capacity

Decision-making capacity is the ability to make and communicate decisions about whatever situation the individual faces. Capacity is task- and time-specific. State guardianship and conservatorship laws provide definitions of capacity that allow state intervention to assist a person's decision-making. The definitions vary by state, but their basic themes are similar. Decision-making capacity can be said to require four abilities (Grisso & Appelbaum 1998):

- The ability to understand information relevant to the decision
- The ability to appreciate the significance of that information for one's own situation (e.g., with respect to one's illness and the probable consequences of one's treatment options)
- The ability to reason with relevant information as a way to engage in a process of weighing the options
- The ability to express a choice

Assessment of capacity is a complex process. If it is unclear whether the person has the ability to understand and make decisions, it is important to consult with a professional who has expertise in assessing capacity such as a physician, neuropsychologist, or geriatric psychiatrist.

How might assent or passive acceptance apply to individuals living alone with dementia? When is it good enough?

Assent or even acquiescence can be sufficient in certain circumstances such as with interventions intended to maintain the individual's independence when there is a legal presumption of capacity. Passive assent is essentially a failure to object. For example, if a mechanic says, "while you are here, let me change the air filter" and you don't object, you have in effect agreed. When a person lacks decisional capacity, passive acceptance cannot be presumed to indicate assent or consent. But still, the person's participation in making decisions should be maximized and the person's values, goals, and wishes should be elicited and complied with to the extent feasible (National Guardianship Association Standards, 2013).

In all states' laws, every adult is presumed to have legal capacity. And, from a purely legal point of view, the only thing that terminates the legal capacity of an adult is a court order. A key point to remember is that diagnosis of dementia does not end a person's legal capacity to make decisions or their legal rights. However, capacity will determine how much legal planning can be done for naming a surrogate decision-maker or providing guidance for future decisions. The validity of planning documents can be challenged in court based on a lack of capacity to understand the document at the time it was signed.

An assessment of capacity should be task-specific, such as the person's ability to knowingly add a name to a bank account or sign a valid power of attorney. With the progressive nature of dementia and the fluid nature of capacity, the assessment needs to be done at the time of the act. The individual may be more lucid in the early part of the day but mentally "sundown" by late afternoon or capacity may be affected by the timing of medications. Understanding these kinds of factors is important because they will vary for each person and could impact the outcome of any assessment.

A person living with dementia should be encouraged to engage in planning whenever possible and to name people to step in to help. When the dementia progresses, health care providers, lawyers, and bankers will be unwilling to accept consent from the person.

Screening for Elder Abuse, Neglect, and Financial Exploitation

When working with a person living with dementia living alone with no known support, it is important to continually screen for abuse, neglect, and financial exploitation. Changes in memory and decision-making can increase the vulnerability of people with dementia. Abuse can take many forms: physical, sexual, emotional, neglect, or financial exploitation. The warning signs of abuse include unusual injuries, emotional withdrawal, changes in financial circumstances or missing valuables, unmet care needs, bedsores, poor hygiene, poor nutrition, or unexplained weight loss (NCOA, 2017). Anyone who has access to the person is a potential source of abuse. Even though abuse is often perpetrated by family and friends, a person without support can be abused or exploited by strangers with the abuse less likely to be noticed.

Many people with dementia who live alone are at risk for self-neglect. Self-neglect is one of the most frequently reported concerns brought to Adult Protective Services. Cases of self-neglect can be among the most difficult to address. 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). 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

Understand Your Legal and Ethical Responsibilities as a Professional

Practice standards and ethics rules apply to a variety of professionals likely to encounter abuse, neglect, and financial exploitation of individuals living with dementia. Attorneys have the ethics rules of their state, most based on the American Bar Association (ABA) Model Rules of Professional Conduct (ABA, 2016c). Social workers have practice standards and the code of ethics through the National Association of Social Workers (NASW, 2018). Physicians have the American Medical Association Code of Medical ethics (AMA, 2016). Other professions also have legal and ethical guidance through their professional associations.

Specific training in detecting abuse, neglect, and financial exploitation should be completed by all professionals working with vulnerable populations. Health professionals, for example, play an important role in detecting and reporting abuse because they are usually the first contacts victims may have, and their ability to recognize the signs and symptoms of elder abuse is critical (Rinker, 2009). Some state laws require certain professionals to participate in training related to detecting abuse and financial exploitation. For example, Connecticut requires that all financial agents (e.g., employees of any bank, credit union, investment company, insurance company) complete training to detect potential fraud, exploitation, and financial abuse (Forum and Clearinghouse for Best Practices and Training Resources for Financial Institutions PA 15-236).

hidden problem with cases frequently going unreported. According to the National Center on Elder Abuse (NCEA; Teaster et al., 2006), self-neglect is the most frequent category of abuse investigated and substantiated by Adult Protective Services.

Self-neglect is defined as “self-care and/or living conditions that are potentially hazardous to the health, safety or well-being of adults.” Signs of self-neglect¹ include the following:

- Inadequate heating, plumbing or electrical service disconnected
- Pathways unclear due to large amounts of clutter
- Animal feces in home
- Residence is extremely dirty, filled with garbage, or very poorly maintained
- Not cashing monthly checks
- Needing medical care, but not seeking or refusing
- Lacking fresh food, possessing only spoiled food, or not eating
- Refusing to allow visitors into residence
- Giving away money inappropriately
- Dressing inappropriately for existing weather conditions

Source: <http://www.napsa-now.org/get-informed/other-safety-concerns-2/>

Financial exploitation is the illegal or improper use of a vulnerable adult’s funds, property, or assets (NCEA, 2014). Such exploitation can take many forms, and perpetrators can include family members, friends, legal guardians, paid caregivers, and strangers. Examples of

¹ Definitions of self-neglect vary from jurisdiction to jurisdiction. Please contact your local Adult Protective Services office for additional information.

forms of elder exploitation include theft of cash or other valuables, withdrawals from bank accounts or use of credit cards, transfer of deeds, misuse of power of attorney privileges, misappropriation of income or assets, and identity theft (GAO, 2012).

According to several studies, financial exploitation is one of the most commonly reported types of elder abuse in people with dementia living alone (Acierno et al., 2010; NCEA, 1998; Peterson et al., 2014).

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; are repeatedly targeted by cold callers and scams; or leave money, bills, and other financial information around the house. People with dementia are 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 friends for money (Alzheimer's Society, UK, 2011).

Working Effectively with Adult Protective Services

All states have abuse-reporting laws. In most states, any person may report suspected abuse. Most professionals are obligated to file a report if they have a reasonable basis to suspect abuse (Stiegel & Klem, 2007). Anyone working with vulnerable individuals should become familiar with the specific reporting requirements in their state. State laws determine to whom reports are made—generally to Adult Protective Services or the police—and dictate the minimum content of the report. Professionals should become familiar with the reporting requirements and the elements needed to file a report in their state.

At a minimum, the report to Adult Protective Services needs to say:

- who the person is;
- where the person is living or how the person can be located;
- what abuse, neglect, or financial exploitation is suspected;
- the basis for suspicion; and
- if known, who the perpetrator might be.

Get to know the local Adult Protective Services program and identify opportunities to work collaboratively. Some Adult Protective Services programs do more than investigate crimes. These programs may provide extensive social services and connect to friendly visitor programs, Meals on Wheels, care management, and other services depending on resources and staffing available.

Enhancing Safety

The remainder of this handbook focuses on providing supports and intervening to enhance the safety of a person living with dementia living alone without the support of family or friends. We present key safety issues, capacity, and ways to intervene including use of assistive technology.

When assessing the needs of a person living with dementia without the support of family and friends, professionals should account for the following factors (Gwyther & Ballard 2002):

- Safety: Assess the safety issues affected by the person's condition
- Risks: Assess the risks the person faces

Quotes from the Field

Community resources are often limited and difficult to access by older adults in general. However, when a client no longer has the skills to initiate activities, advocate for his or her needs, coordinate with various providers, or manage paperwork and phone calls, they can miss out on helpful services unless someone is available to assist them.

—ACL grantee

- Capacity: Understand what the person can and cannot do, including providing self-care and performing activities of daily living
- Aids: Determine technology that can be used to mitigate risks
- Services: Identify individuals, programs, and services that can be relied on for help

Key questions for consideration follow.

How does the person get around?

Some individuals with dementia continue to drive. Capacity to drive requires a complex set of sensory, cognitive, and motor skills (Anstey et al., 2005). For many adults driving is highly valued and represents independence. If a person's driving poses some risks, sometimes an agreement can be reached that extends the time a person can drive, such as agreeing to drive during less congested times, driving for limited distances and on familiar roads, and driving only in daylight during good weather and only when the person truly feels up to it. When a person stops driving it is important to provide other transportation options. Other transportation options need to be considered carefully and assistance may be needed for the person living with dementia to use them successfully and safely. In urban areas, mass transit may be an option for individuals with early stage dementia who are already familiar with using public transportation or who can be accompanied by a companion. Other options include rideshare providers like Lyft or Uber (may be accessed without a smartphone in some areas), village networks (grassroots organizations committed to helping their members age in the place of their choosing by coordinating access to support services (Village to Village Network, 2017), paratransit transportation providers, or other community-based transportation programs. Local Area Agencies on Aging

can provide referrals and determine eligibility for low- or no-cost transportation services. The Administration for Community Living's ElderCare Locator website can assist in identification of local service providers and their contact information.

Is the person able to manage housekeeping and home maintenance?

Unhealthy living conditions affect not only the individual and family members but also neighbors and can become a public health concern (NCEA, 2017). Compulsive hoarding or extreme clutter and debris in the home can contribute to an 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 pest control problems and poses safety risks such as fire and fall/trip hazards. Help with housekeeping, taking out the trash, and basic home repair can mitigate this risk. Regular home safety assessments are appropriate as dementia progresses to ensure that additional risks are addressed that may develop over time.

Is the person getting adequate nutrition and hydration?

A person living with dementia without family or friends may be at increased risk of not eating properly or becoming dehydrated without someone noticing. People living alone with dementia are at greater risk for malnutrition than those living with others (Nourhashemi et al., 2005). People who provide home-delivered meals, friendly visits, and home health visits should be alerted to monitor nutrition and look for signs of dehydration. A poor diet or dehydration can

worsen confusion and memory issues. For example, Southern Maine Agency on Aging trains community Meals on Wheels providers on warning signs and has volunteers who will “warm up” home-delivered meals for people assessed to be at risk of malnutrition (L. Weaver, personal communication, August 7, 2017).

Does the person have pets that they are caring for?

For many people who live alone, with or without dementia, pets become trusted companions. The value of pets in promoting a person’s mental health should not be overlooked. For some individuals living alone with dementia, caring for a pet may become impossible on their own. Meals on Wheels America (2017) offers funding through grants to local Meals on Wheels organizations to assist elderly and disabled homebound clients care for their pets. It may be possible to bring in outside volunteers to care for pets. For example, in Sacramento, California, KeepYourPet.com offers older adults and those with limited mobility opportunities for assistance to keep their pets with them, including a list of mobile veterinary clinics and pet-walking services. The Humane Society (2018) offers a state-by-state listing of veterinary assistance and other services that could be useful for people with dementia who would like to keep a pet at home. If it becomes unhealthy, for the person or the pet, to care for the pet in the home, it is important to recognize that removing a pet from the home is an area of tremendous stress for the person living alone with dementia. The person will need reassurance that the pet is going to a good home and may benefit from other options for animal companionship. Visiting pet programs that go into individual homes may be able to fill some of the void left by the removal of the pet. Therapy Dogs International has a Home Visit Program that brings

therapy dogs into personal homes (TDI, 2018). Local visiting pet programs may also offer home visiting services (DogPlay, 2012).

Can the person living with dementia get help and find their way to safety?

Alzheimer's and other dementias cause changes that can impact 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. Remaining safe at home requires the ability to recognize when help is needed or being able to dial a phone or go to a neighbor to ask for help.

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). 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). Alden et al. (2005) found that most people with dementia who had burn injuries 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.

Various types of assistive technology are available to reduce risk of injuries in the home such as gas

detectors, room air temperature monitors, devices that monitor water levels to prevent accidents and damage from flooding, and safe temperature settings on hot water heaters. Technology is available to alert a caregiver or emergency response system when the person living with dementia has fallen. A recent innovation includes wearable fall detectors that automatically call for help if the person does not signal that they are okay when a fall is detected (Tidyware, LLC, 2017). Phones with programmable one-touch dialers have made making phone calls much easier. Panic buttons or emergency call buttons are also possible options based on the person's ability to trigger the request for assistance. New technologies continue to emerge that may be helpful to people with dementia.

Emergency personnel at the time of a crisis should have access to concise, accurate information about the person's medical conditions, medications and dosage, and other important information. Home and community-based service providers should be trained to aid first responders including, but not limited to, fire personnel or police in locating individuals in emergency situations, effective communication strategies for people with dementia, and effective approaches when offers of assistance meet resistance (A. Burstein, personal interview, July 28, 2015).

Is the person likely to wander and get lost?

Every person living with dementia who is ambulatory is at risk of walking away and getting lost (Alzheimer's Association, 2016). 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. If a person is willing to agree, a variety of emerging technologies are available to help with concerns about wandering, including wearable GPS tracking systems or virtually any smart phone (Alzheimer's Association, 2017; Burm, 2017). However, GPS technologies require someone to monitor for safety risks and report to the appropriate authorities.

Another option is for the person to wear identification such as Medic-Alert®+Safe Return® through the Alzheimer's Association or [Road ID®](#), a simple ID tag originally created for runners and bicyclists who don't want to carry a wallet. Dementia-friendly communities rely on training of members of the community to help people with dementia find their way home (Dementia Friendly America, 2017). Dementia-capable community-based organizations can work with and train first responders and local businesses on how to engage with people with dementia. When the limits of these options are reached, a supervised living arrangement may be needed to protect the safety of a person who no longer understands the risk caused by wandering.

What about managing locks and home security?

Some people with dementia are at increased risk of being locked out of their homes, either because they forget their keys or because they are unable to follow the steps needed to unlock the door when they have the key. Leaving the home unlocked may present another set of risks related to diminished security in the home. Based on the person's ability, possible solutions include placing the key on a wristband for the person to wear, simplifying the lock, or leaving a key with a trusted neighbor, friend, or doorman. Technology such as smart locks or remote access may

Assistive Technology is Not for Everyone

Research shows that technologies such as GPS trackers, automated medication dispensers, falls monitors, and emergency call buttons are most effective if you start using them at the first sign of memory loss or disorientation (O'Keeffe et al., 2010). Various technologies for the home offer the promise of longer independence, but the progressive nature of many dementias may eventually reach the limits of technology.

Some important considerations:

- » GPS and other assistive technologies are dependent on transmission and reception capability to be effective, and buildings or other objects can impede signal transmission.
- » A person living with dementia may not like wearing or carrying a device and may remove it (O'Keeffe et al., 2010).
- » Someone needs to manage the device in the home to be sure that it is working properly.
- » The person living with dementia must have some comfort with using the technology.
- » The assistive technology product should match the person's abilities and preferences.
- » The provider should conduct ongoing assessments to identify any cognitive changes that may negatively impact the person's ability to continue to use the technology.

Although a location device may increase personal freedom and provide peace of mind to the person living 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 recommend that the person living with dementia be involved in decision-making regarding assistive technology and that this decision should be made in a formal structured meeting facilitated by a professional team (Landau & Werner, 2012).

be viable options for people to remain in their own homes. Some smart locks use Bluetooth technology that allows for an individual to open their door when they are within Bluetooth range. Other technology connects the smart lock to a network so someone can unlock the door for the individual remotely. For more information, go to

<https://www.cnet.com/news/smart-lock-buying-guide/>

What are some ways of minimizing risk for financial exploitation?

Care providers and family members can reduce risk of financial 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. Some financial institutions and utility companies will allow their customers to name a trusted third-party contact to be notified in the event of suspicious financial activity or nonpayment of bills. The [Consumer Financial Protection Bureau](#) (n.d.) has published a series of guides on managing someone else's money. These guides provide common signs of financial exploitation and scams and list resources for responding to exploitation.

A person living with dementia who is living alone may also be vulnerable to allowing strangers into the home who may exploit or abuse him or her. Professionals should assess the risk with each person. The greatest challenge for abuse and exploitation of people with dementia without family or close friends is that it is difficult to identify with whom the person has been in contact. Not everyone will allow strangers into the home, but if the person has a history of allowing

strangers into the home, extra care needs to be taken to protect his or her safety.

For additional information on assessing safety of a person with dementia living alone, access the following resources on the National Alzheimer's and Dementia Resource Center website:

- [Considerations for Those Who Live Alone with Dementia](#)
- [Can a Person with Alzheimer's Live Alone?](#)
- [Risk Assessment for People with Dementia Who Live Alone](#)
- [Fraud Protection for Elders Living Alone](#)

Managing Money

Managing money requires memory, cognition, judgment, and performance skills, such as counting money, paying bills, and keeping a check register. Dementia affects these skills. A person needs to remember what income should be coming in and what bills and obligations need to be paid. A person needs to decide where to keep money, to pay bills, and when and how to pay them. Judgment is needed to set priorities on what to spend money on, what investments to make, and what debt to incur.

The best option is always voluntary planning for financial management. The starting point is assessing the person's understanding of their finances; whether the person knows that they have income or assets; that they need to pay for food, shelter, or health care; and that they want to have someone help manage their finances. If so, they have the basic ability to engage in planning. If the person lacks this level of understanding, other alternatives for money management and possibly involuntary planning

Quotes from the Field

Lack of needed help with financial management can be a barrier to solving many other problems, and there are few solutions available outside of representative payee services or automatic debits (which the person often cannot set up themselves).

—ACL grantee

include a representative payee or limited guardianship/conservatorship.

Simplifying Finances

If the person has a basic understanding of their finances, it is possible to help them simplify and use direct deposit and automatic pay as much as possible. Simplified processes may enable the person to manage finances longer. The first step to simplification is working with the person to identify all income and confirming past bank records and tax records. For many people with dementia, Social Security is going to be a core source of income, which is delivered by direct deposit (SSA, 2017a). Other possible sources of income include pensions; distributions from IRA, 401(k) plans, or interest or dividend income on investments; and rental income from real estate.

For individuals with modest resources, encouraging the person to use one or two bank accounts will simplify finances. Individuals with investments should be helped by a financial professional. Efforts should be taken to minimize risk and ensure that money is available when needed. A financial professional such as a financial advisor or broker can provide guidance responsive to a person's specific needs. Brokerages, insurance companies, other financial institutions, and utility companies increasingly provide an option for account holders to name another individual to be notified in the case of any suspicious or unusual transactions. The extra set of eyes can trigger remedial action when problems begin to appear.

Paying the Bills

Most recurring expenses can be set up on automatic payment. To set up utility bills, insurance payments, and property taxes on automatic payment, contact the agency or if possible set it up online with the person's

permission. Other expenses such as groceries can be managed with the use of credit cards automatically paid from the person's account or debit cards. The goal is to minimize the amount of help that is needed to pay bills. Automatic payment will help to ensure that the essentials are paid on time.

Bank Accounts

The individual living with dementia may or may not be willing to add an authorized signer on bank accounts. An authorized signer is not the same as a joint account holder or owner. Joint accounts can create legal rights of inheritance and make the account subject to debts of the joint account holder. Being an authorized signer is more like being able to sign on a business account. Banks may also offer a bank power of attorney form to be used to create limited access by another person. Powers of attorney are discussed below. It is important to monitor accounts to ensure that income is received and withdrawals or debits are appropriate. Creating a checklist with expected due dates and amounts may be helpful. Online access to banking information allows banking to be monitored from a distance.

Professional Money Managers

If someone else is needed to manage the money, it is important to find someone trained and trustworthy to handle the money and account(s). Daily Money Managers (DMMs) are an option for middle- to lower-income individuals. DMMs manage finances, review mail, and help with routine financial management tasks. DMMs come from a variety of backgrounds and experience. DMMs are not licensed or regulated by any state (Khalfani-Cox, 2016). The American Association of Daily Money Managers (2017) offers a voluntary certification for DMMs. Certification requires a background screening and passing on knowledge test. Nevertheless, in looking for a DMM it is important to

check references, learn about the scope of the person's experience, understand what fees are associated with the service and how they are paid, and ensure that the DMM has liability insurance or bonding. If the individual has significant financial resources and the ability to hire a professional, it may make more sense to hire a finance professional such as an accountant or law firm. In looking for a finance professional, it is important to ensure that the individual is insured or bonded and to verify experience, reputation, certification, or licensing.

Representative Payee

If a person lacks the ability to manage Social Security benefits, the Social Security Administration (SSA) has the Representative Payee program, which is designed to help Social Security beneficiaries pay their bills. An individual or organization is appointed as a Representative Payee by SSA and receives a person's benefit payments and uses those funds to pay for the current and future needs of that person. The appointed Representative Payee is subject to regular SSA reporting to ensure that funds are being used in an appropriate manner. One advantage of the Representative Payee program is that it is a nonjudicial process and only affects benefits payable through SSA. Concerns about the actions of a representative payee should be reported to SSA. It is a less restrictive option than guardianship, with less paperwork and less third-party involvement in the life of the person (for more details, see sidebar on page 27).

Durable Power of Attorney

One of the most powerful tools in helping a person living with dementia is a durable power of attorney, which becomes or remains valid when a person is mentally incapacitated. To create a valid durable power of attorney, the person living with dementia

needs to have the ability to understand that the document names someone authorized to serve as his or her agent in managing his or her financial affairs and be willing to delegate that authority. It can be challenging to find someone willing and able to serve. The agent appointed in a durable power of attorney can be any adult of the person's choice. Generally, the agent serves as a volunteer, although compensation can be specified in the document if desired (ABA, 2016d). The laws for creating a valid durable power of attorney are state specific; some states have statutory standard forms (ABA, 2016d). Even if a statutory form is available, durable powers of attorney need to be carefully customized to the individual's needs and desires and risks. Given the complexity of the role, using the services of a lawyer is recommended.

Durable powers of attorney are also unfortunately a common vehicle for financial exploitation, so care must be taken to minimize risks. Of utmost importance is selection of a trustworthy agent under the power of attorney. Other safeguards are also important to consider, such as limitations on gifting, required financial reports including an inventory of assets to a third-party monitor, and a second signature/approver on large transactions.

Representative Payee

A representative payee is most useful when the individual's income consists solely of Social Security and money management is the only financial area needing support, because it can avoid the need for guardianship or conservatorship. But if there are other capacity issues that require the use of guardianship, the Social Security Act still requires that the guardian or someone else apply for and be approved by SSA as the person's representative payee to have legal authority over Social Security payments.

A person can also voluntarily ask SSA to appoint a payee for their benefits. Anyone who knows of a Social Security beneficiary who is unable to manage their benefits can start the process for appointment of a representative payee by filing a request with the local Social Security field office (SSA, 2017b). SSA sends a verification to a physician who has seen the beneficiary recently asking them to certify that because of illness or injury the person needs help managing Social Security benefits. SSA sends a notice to the person advising them that an application for appointment of a payee has been filed and gives the person an opportunity to object, either to the need for a payee or to the proposed payee (if known).

The payment is direct deposited into a separate account following instructions from Social Security and must be kept separate from other money. Most payees must file an annual accounting of the money, and in general, what categories it was spent on. The money must be spent for the benefit of the person, and any remaining funds must be held for the person. With a narrow exception for qualified nonprofit organizations, the payees are volunteers and are not allowed to receive a fee from the beneficiary for serving as payee.

The biggest challenge is finding someone to serve as payee. In some areas, governmental agencies, nursing home facilities, residential care, and faith or community-based organizations serve as volunteer payees. SSA does a basic screening on proposed payees and will disqualify someone who has a history of financial abuse or failure to act properly as a payee. Generally, Social Security payees are unpaid volunteers and SSA welcomes any qualified volunteer to help with this effort. As with any position of trust, instances of misuse of payments by representative payees do arise. Any concerns about the use of benefits should be reported to SSA.

Social Security Representative Payee only covers benefits payable through SSA. For about one-third of retirees, Social Security is their only income. For the other two-thirds, the security of other income needs to be addressed as well. Some government and private pension systems have payee programs, which vary significantly in how they operate. Some pension systems offer no options other than deposit to an account that the beneficiary has an ownership interest in, or a court order such as conservatorship.

The Department of Veterans Affairs (VA) payee system is similar to SSA. VA generally appoints a payee from lists maintained by VA. After an application is submitted, VA will assess the competence of the recipient and if necessary, appoint a representative payee, which VA calls a fiduciary (VA, 2017). Other federal and state agencies may have similar arrangements, and each agency may have different rules and procedures. Contact the agency that pays the check to learn about options.

For additional information, go to the following websites:

- » SSA [Representative Payment Program](#) for individuals receiving Social Security benefits. This site includes SSA's [Representative Payee Interdisciplinary Training](#), which includes modules to educate individuals and organizations about the roles and responsibilities of serving as a representative payee, elder abuse and financial exploitation, effective ways to monitor and safely conduct business with the banking community, and ways to recognize the changes in decisional capacity among vulnerable adults and seniors.
- » [Consumer Financial Protection Bureau guide for Social Security Representative Payees and VA Fiduciaries](#)
- » Justice in Aging provides an overview of the [Social Security Representative Payee Program](#) that includes several fact sheets for further guidance.
- » [VA Fiduciary Program](#) for individuals receiving VA benefits.
- » Office of Personnel Management [Representative Payee Program](#) for individuals receiving federal pensions and benefits.

Managing Health

A *Health Care Advance Directive* documents a person's wishes in case one becomes unable to make his or her own health care decisions. Formal Advance Directives include the *Health Care Power of Attorney* and the *Living Will*. Every state recognizes some form of advance directives by statute. However, there is sometimes confusion over terminology and distinctions made between types of Advance Directives.

A *Living Will* (or “medical directive” or “declaration” in some states) is a written instruction for the health care provider spelling out any treatments the individual wants or doesn't want in the event the individual is unable to express their needs and terminally ill or permanently unconscious.

A *Health Care Power of Attorney* (or health care “proxy,” or “medical power of attorney” depending on the state) is a document that legally appoints someone of your choice to be your authorized “agent” (or “attorney-in-fact” or “proxy”). You can give your agent as much or as little authority to make health care decisions as you wish. And (in most states) if you wish, you can include the same kind of instructions that you would put in a *Living Will*. Thus, a *Health Care Power of Attorney* can do everything a *Living Will* can do, plus more.

Capacity to appoint a health care agent is not precisely defined in law. Generally, such capacity requires an ability to understand what it means to have another individual make health care decisions for oneself and determining who would be an appropriate individual to make those decisions (ABA, 2017). Although all service providers can be trained to be more aware of certain red flags that relate to an individual's capacity

to make decisions and understand risks, only trained health professionals should directly assess capacity. Even if a person lacks the capacity to make health care decisions, which can be quite complex, the person may still be able to legally appoint a health care agent.

If a person who now lacks capacity to make health care decisions has no agent under a health care power of attorney and no guardian authorized to make health care decisions, most states will give the next of kin the right to make health care decisions for the person where capacity is lacking (ABA, 2017). Where next of kin are unavailable, about half the states authorize legal recognition of a close friend if qualifying criteria are met for that status. Only a few states provide alternative administrative procedures for health care decision-making for people who have no known family or friends and who lack capacity (ABA, 2017). In most states, the last default option is appointment of a guardian through the courts.

Basic Estate Planning and Funeral Arrangements

The general standard of capacity for estate planning requires a person to know generally what they own, whom they wish to benefit with gifts (usually family, if any), and to connect these two elements sufficiently to make and communicate a plan for disposition of their estate (National Paralegal College, n.d.). If the person living with dementia meets this standard, it can be helpful for them to engage in at least basic estate planning. All states have laws directing who inherits without a will or other estate plans, and all states have laws that focus on distributing assets to family. If the person lacks family, this can make settling the estate without a will or other estate planning very difficult. The [Legal Services Corporation](#) can provide

information on the local legal aid organizations that can assist people age 60 and older or with limited incomes with will or estate planning.

When a person without readily identifiable family or friends dies, funeral arrangements can be a struggle. If the person has the ability to make choices, they should be encouraged to engage in planning. In most areas, funerals can be planned in advance, with or without paying for them. After death, state law determines who can make funeral arrangements and what happens if the body remains unclaimed.

If the person applies for Medicaid to pay for medical care, home and community-based services and supports, or long-term care, it is important to prepay funeral arrangements in accordance with state guidelines. Under federal law all states allow an exemption for qualified funeral and burial funds for people on Medicaid.

Reviewing Decision-Making Options

When working with a person who is living alone with dementia and has no known informal support it is important to do as much as possible to ensure the person's health, well-being, and safety. Protective actions such as moving the person or obtaining guardianship of the person can have devastating impacts on the person's mental and physical well-being. Those changes signal a real loss of independence, choice, and dignity. The hope is that involuntary actions can be avoided or at least delayed.

The [PRACTICAL Tool](#), developed by the ABA Commission on Law and Aging with other partners, is specifically developed for attorneys but may also help

other professionals to review decision-making options and overcome obstacles to implement a plan for supported decision making (SDM) before considering filing for guardianship or conservatorship.

The steps in the PRACTICAL Tool follow:

- **P**resume that guardianship is not needed. Guardianship or conservatorship should be the last resort, only if all reasonable alternatives for providing them support fail.
- **R**eadon—Clearly identify the reasons for concern. This section of the tool contains a detailed checklist of needs the person living with dementia may or may not have. Understanding the true needs of the individual is essential to tailoring solutions that are least restrictive.
- **A**sk if the concern is caused by a temporary or reversible condition. Illness or injury where recovery is likely can create a temporary disability. Permanent action should be delayed, and time should be allowed for recovery and healing. For example, delirium, an acute fluctuating syndrome of altered attention, awareness, and cognition, is common and potentially life-threatening among people who are 65 years of age or older (Inouye, 2006; Kalish et al., 2014). Certain medications, sensory impairments, cognitive impairment, and various medical conditions are a few of the risk factors associated with delirium.
- **C**ommunity—The vast majority of care is provided by family, friends, and community-based services. These resources are essential in building the supports needed for SDM. SDM should include a full exploration of available

community-based resources to help each person.

- **T**eam—Ask an individual trusted by the person to provide help in making decisions. Many people already have in place an informal circle of family and friends who can fill the role of advisors/agents for SDM.
- **I**dentify the abilities and needs of the person. SDM assistance should be limited to areas the person needs help with.
- **C**hallenges presented by potential SDM advisors or agents—It is important to carefully review and address concerns about challenges presented by the advisors or agents selected to support the person in decision making.
- **A**ppoint advisors and empower them as legal agents to carry out the choices of the person. Giving the advisors legal authority such as naming the person as the agent in a power of attorney makes it possible for the SDM choices to be implemented when third parties question the capacity of the person with a disability to make choices or when the person with disabilities needs help carrying out those choices.
- **L**imit any guardianship or conservator appointments to only the issues absolutely needed. Limited appointments preserve the human and constitutional rights of the person living with dementia.

Supported Decision Making

SDM is a person-driven decision-making tool based on the premise that all people, as long as they can make and communicate a choice, have a fundamental right to do so; that it is normal for adults to seek advice and guidance in making decisions; and, finally, that the choices of the person should be honored. In SDM a

Quotes from the Field

It may not be possible for a person with dementia living alone to participate in developing a care plan in the usual way. Their goals and values may have to be elicited over time through more casual encounters, and then confirmed by direct questioning.

—ACL grantee

person selects and empowers supporters, advisors, and agents such as neighbors, volunteers, and social service providers who help the person understand questions, issues, and options; offer advice; and ask the person for a choice or preference. As dementia progresses, the spectrum of issues the person may need help with will expand. Capacity to perform most tasks is affected by multiple variables including, but not limited to, time of day; place of residence; neighborhood; and the person's emotional, cognitive, or physical health. Too often, diminished capacity is taken as a given without considering strategies that may alter the impact of these variables enough to enable individuals' continued engagement in decision-making with necessary supports.

Applying the principles of SDM when working with a person living with dementia helps the person maintain a level of dignity and control. It is important to select supporters, advisors, and agents who are willing to take the time and effort to explain—in terms understandable to the person—the issues and options, offer advice, and ask the person for input. Supporters, advisors, and agents need training in communicating with a person living with dementia and in the principles of SDM. Online training modules are available on the following:

- [Supported Decision-Making: Protecting Rights, Ensuring Choices](#)
- [Introduction to Guardianship and Alternatives Video Series](#)
- [Supported Decision-Making: EVERYONE has the Right to Make Choices](#)
- [Legal Planning Essentials for Persons with Dementia](#)

Whenever possible, when working with a person living with dementia who lives alone and has no known

support from family or friends, professionals need to work as quickly as possible to help the person develop a network of supporters, advisors, and agents who can help, even on a daily basis, as the dementia progresses. One useful strategy to identify the types of support needed is to break down the areas of support needs such as home maintenance, financial management, grocery shopping, food preparation, and transportation. Neighbors, volunteers, social service providers, or others are all potential members of the support team. A facilitator and coordinator are necessary to assemble a team that will be acceptable to the person living with dementia.

Professionals should use caution when reaching out to family members and friends as potential supports. Before reaching out to anyone, the provider should try to understand the history of why relationships are disconnected to avoid reintroducing someone who brought unhealthy or unsafe conditions to the life of the person living with dementia.

It is key for providers to understand how involved the family member or friend may be in an individual's life and what, if any, barriers exist for that family member or friend to provide additional care and assistance. Caregiver assessments are critical for determining ability and willingness of potential caregivers. The assessments require examination of the caregiver's history with the individual and whether he or she fully comprehends the individual living with dementia's level of need. Providers can help create a plan, ensure follow-through so that the person's needs are met, and provide ongoing monitoring for additional needs that may arise as the conditions change or if the family member or friend is unable to continue.

Guardianship: The Last Resort When All Else Fails

When all the steps in the PRACTICAL tool fail, guardianship or conservatorship may become necessary. Guardianship should always be a last resort when less restrictive options are exhausted.

Guardianship law is state specific; in some states a guardian is for personal decisions, and a conservator is for financial matters. The terms can be interchangeable, depending on state law; it is important to know what each term means in the state in which the individual resides.

In a guardianship, the court determines whether the person is in need of protection based on state law standards (ABA, 2016a). The court appoints a person to serve as guardian. The order appointing the guardian defines the scope of the responsibility and authority of the guardian. The process and terminology for this process varies from state to state (ABA, 2016b). The ABA has resources available on [Guardianship and Supported Decision Making](#). Additionally, local legal services programs and state bar associations often have materials explaining state guardianship laws and procedures.

If family or friends cannot be identified to serve as a guardian, look to local community-based resources and volunteers. In many states, state or local government agencies serve as the guardian or recruit volunteers to serve as guardians for people when no other person is available (ABA, 2014). Public guardians are not available in all states.

A recent study (Wood et al., 2017) found that guardianships sometimes outlive their necessity, so care should be taken to periodically reassess the need

for a guardianship. When no longer needed, the guardianship should be cancelled. In the situation where a person living with dementia outlives their guardian, the court will appoint a replacement guardian if the guardianship appointments did not contain a backup guardian.

Conclusion

Legal, medical, and social services professionals all struggle with how to help individuals with no known support network of family or friends (Flaherty, 2017). Serving these individuals requires a lot of time and resources but it is also essential for protecting the most vulnerable members of our society. Professionals need to be able to coordinate with each other because there is often more than one professional involved with providing care for the individual. It is important to use approaches that maximize individual choice and autonomy and to create a network of individuals who understand the person's goals and values.

Because of the progressive nature of dementia, the earlier we try to help people living with dementia who do not have an established support system, the less complicated it will be to provide assistance. Early identification of individuals at risk of not having a support system and early intervention is the best answer. The starting point is always understanding the person's decision-making capacity and needs. These need to be assessed on an ongoing basis. This is a high-risk population, and special and ongoing attention should be paid to abuse, financial exploitation, and neglect and reported if suspected. Guardianship or involuntary changes should be a last resort, when all else fails to protect a person from harm who is unable to protect themselves. Because resources, laws, and regulations vary by state and locality, it is important to

know what laws and regulations apply and what resources are available locally.

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