
Providing Services to Individuals with Dementia Who Live Alone

A GUIDE OF PRACTICAL STRATEGIES

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Introduction

Like other older adults who live alone, many people with Alzheimer's disease and related dementias (ADRD) want to remain independent and prefer living alone.^{1,2} National and regional data indicate that a significant number of people with dementia live alone; according to a recent analysis of data from the National Health and Aging Trends Study (NHATS), more than 30% of people with dementia lived alone in 2011.³ However, ADRD will eventually lead to changes in an individual's ability to plan, organize, and follow through with daily activities and personal care needs. If there is no one else living in the home who can observe changes in the individual's cognitive and functional abilities, the progressive decline associated with ADRD may go unnoticed until an emergency occurs.⁴

Early intervention in an individual's life requires recognizing signs of dementia and getting the person the supports they need. It is challenging to identify people with dementia who live alone and provide them with services, and research from several countries indicates that this population underuses needed services.^{5,6,7} Challenges associated with providing essential services for people with dementia who live alone include the limited availability of services designed to support this population, the diversity of this population's needs, and the coordination of the multiple agencies that are necessary to meet their needs.

It is important to note that people with dementia who live alone may have varying degrees of support. Such support scenarios include the following:⁸

- An individual lives alone with frequent support, visits, and monitoring from relatives and friends living nearby who are looking out for the individual's best interest.
- An individual lives alone with some support or check-in calls from long-distance relatives and friends who are looking out for the individual's best interest.
- An individual lives alone with no support and has no one dedicated to looking out for the individual's best interest.

Determining the scenario that is most relevant to the individual will enable providers to determine the individual's level of risk, and develop care plans and provide services that are most relevant to the individual.

How to use this guide

The purpose of this guide is to provide practical strategies that can be used to address certain prominent challenges that service providers face when working with individuals with dementia who live alone. It builds on the 2015 report by the National Alzheimer's and Dementia Resource Center⁹ (NADRC) that discusses *what* is known about the prevalence of people with dementia who live alone in the community and the opportunities for identifying and providing services to this population. This follow-up guide provides specific strategies for *how* home- and community-based service professionals can work with this population. The guide is organized by the following six major sections that address different practical challenges of working with individuals with dementia who live alone:

- Identifying individuals with dementia who live alone.
- Building trust.
- Supporting safety and autonomy.
- Involving family and friends.
- Coordinating paid providers and formal support services.
- Assisting with transition to a new setting.

In each of these six major sections of the guide, subsections address specific challenges and concerns with providing services to individuals with dementia who live alone. First, an overview of the specific challenge or concern is provided. Next, a few key questions related to the challenge or concern are addressed. Additionally, case examples are offered that provide practical illustrations of the challenge or concern and practical advice and lessons learned from various state or regional agencies or organizations that work with individuals who have dementia and live alone. Legal considerations for providers serving people with dementia living alone are also included in each section. Each section concludes with practical resources for use by community-based service providers.

This guide is developed by the NADRC, which provides technical assistance to Administration for Community Living/Administration on Aging (ACL/AoA) grantees, including Alzheimer's Disease Initiative-Specialized Supportive Services (ADI-SSS) grantees and Alzheimer's Disease Supportive Services Program (ADSSP) grantees. The ADI-SSS grants are designed to fill gaps in dementia-capable long-term services and supports for persons living with or those at high risk of developing ADRD and their caregivers. The ADSSP grants support efforts to expand the availability of community-level supportive services for persons with ADRD and their caregivers, deliver supportive services, and facilitate informal support using proven models and innovative practice. The primary aim of this guide is to provide specific strategies for ADI-SSS and ADSSP grantees that are addressing the development and delivery of supportive services to persons with dementia who live alone in the community.

The information and strategies provided in this guide primarily come from a series of interviews we conducted with subject matter experts who have experience with community programs or services for people with dementia who live alone. These expert interviews informed the strategies addressed in this guide. We relied on the experiences and knowledge of the experts rather than solely on empirical evidence developed from controlled studies in an effort to ensure that these strategies have been tried and tested in real-life situations.

A total of eight people were interviewed, including representatives from adult protective services (APS), emergency first responders (i.e., law enforcement), geriatricians, geriatric care managers, legal professional staff from the American Bar Association (ABA), state officials from departments on aging, and researchers participating in the ADI-SSS grant programs.

Endnotes

- 1 De Witt, L., Ploeg, J., & Black, M. (2009). Living on the threshold: The spatial experience of living alone with dementia. *Dementia*, 8(2), 263–291.
- 2 Harris, P. B. (2006). The experience of living alone with early stage Alzheimer's disease: What are the person's concerns? *Alzheimer's Care Quarterly*, 7(2), 84–94.
- 3 Amjad, H., Roth, D. L., Samus, Q. M., Yasar, S., & Wolff, J. L. (2016). Potentially unsafe activities and living conditions of older adults with dementia. *Journal of the American Geriatrics Society*, 64(6), 1223–1232.
- 4 Soniat, B. A. (2004). Dementia patients who live alone: Research and clinical challenges. *Journal of the American Geriatrics Society*, 52(9), 1576–1577.
- 5 Edwards, D. F., & Morris, J. C. (2007). Alone and confused: Community-residing older African Americans with dementia. *Dementia*, 6(4), 489–506.
- 6 Lehmann, S. W., Black, B., Shore, A., Kasper, J., & Rabins, P. V. (2010). Living alone with dementia: Lack of awareness adds to functional and cognitive vulnerabilities. *International Psychogeriatrics*, 22(5), 778–784.
- 7 Wattmo, C., Londos, E., & Minthon, L. (2014). Solitary living in Alzheimer's disease over 3 years: Association between cognitive and functional impairment and community-based services. *Clinical Interventions in Aging*, 9, 1951–1962. doi:10.2147/CIA.S71709
- 8 Alzheimer's Association. 2009. *Dementia care practice recommendations for professionals working in the home setting*. pp 53–54. Available at https://www.alz.org/national/documents/phase_4_home_care_recs.pdf
- 9 Gould, E., Maslow, K., Lepore, M., Bercaw, L., Leopold, J., Lyda-McDonald, B., Ignaczak, M., & Wiener, J. (2015). *Identifying and meeting the needs of individuals with dementia who live alone*. Report prepared for Administration on Community Living. RTI International. Available at http://www.aoa.acl.gov/AoA_Programs/HPW/Alz_Grants/docs/2015_PWD-Living-Alone.pdf

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Identifying People with Dementia Who Live Alone

Strategies from the experts for identifying people with dementia who live alone

This section discusses several strategies that providers can use when trying to identify people with dementia who live alone. The strategies are based on input from the experts who were interviewed with experience in identifying people with dementia who live alone, including geriatricians, APS workers, emergency first responders, and geriatric care managers.

Process for identification

Individuals with dementia who live alone may have symptoms that vary along a spectrum of cognitive impairment. Rather than immediately developing clear signs of dementia, individuals are more likely to have mild cognitive problems that progress to identifiable symptoms of early-stage dementia. Identifying individuals living alone with dementia as early as possible enables providers to help them access appropriate resources and protection.

It is important to note that there are many conditions that may cause impaired cognition but are treatable, such as undiagnosed depression, infections that cause delirium, nutritional deficiencies, low blood sugar, medication misuse, or alcohol abuse. Increased awareness of these conditions that may influence cognition is needed along with immediate referral to a medical provider.^{10,11}

Providers attempting to identify individuals with dementia who live alone should be prepared to conduct a comprehensive assessment of an individual's functional status and health status (i.e., assess whether an individual needs assistance with activities of daily living [ADLs], such as eating, bathing, and dressing; or instrumental activities of daily living [IADLs], such as housework, money management, and medication management) and an assessment of an individual's community support system (e.g., who may be included in an individual's social network).

In some cases, identification of individuals living alone with dementia may start with setting up a system of "watchful waiting" for individuals considered to be at risk. Watchful waiting is used with other conditions

Background information

Identifying individuals with dementia who live alone is a primary challenge to meeting their needs. This population may be isolated from the community and have limited interactions with many of the typical resources (e.g., family members and friends, primary care providers) used to identify individuals who have developed dementia-related symptoms.

The ability to identify whether an individual has developed dementia and the progression of the disease is the first critical step in being able to provide the necessary supports and services to help the individual adequately manage his or her personal care needs and daily activities while ensuring the individual's safety.

Comments from researcher participating in an ADI-SSS grant to identify people with dementia who live alone:

“Now that word is out [about available services], referrals are starting to come from other community service agencies and providers. First responders, hospitals, other eyes in the community. We are finding that once we are able to talk about this population in the community, we are identifying a lot through word of mouth. The other entities that have been helpful—bankers, hairdressers—are learning how to build dementia-capable [systems] in terms of identifying warning signs and where to refer these individuals. That has been our strategy so far.”

as well. Providers may not need to take major action yet, but they can be aware of an individual’s situation and establish a system for reasonable monitoring. This system may include both the providers themselves and other community members.

Working with community

Relying on people with dementia to self-identify as having dementia and living alone is unlikely to result in successful identification; therefore, generating third-party referrals is critical. One strategy to generate third-party referrals is to work with key community partners who have frequent contact with individuals at their homes, such as Meals on Wheels or the postal service, to establish an initial system of identification. Referrals from other community members, such as bankers or building managers, either through focused outreach or word of mouth, can expand the capacity for identifying individuals with dementia who live alone. Dementia Friendly America, a nationwide movement to more effectively serve and support people with dementia and their family caregivers, has online tools available for various sectors of the community, such as local businesses, financial institutions, and faith communities that provide specific guidance on preparation, education, and response to the needs of these individuals.¹²

Key community members who can be educated and used as third-party referral sources to identify individuals with dementia who live alone include the following:

- apartment building managers, especially for those individuals living in more urban areas with numerous apartments;
- clergy and members of faith communities;
- hairdressers and barbers;
- postal workers;
- bank employees; and
- first responders, such as police or fire departments.

Often these referrals are not specifically made to identify individuals with dementia who live alone, but rather are made to identify a person who is older, frail, and has difficulty functioning in some way. Among these referrals, individuals with dementia who live alone can be identified.

Although community support service providers are critical to identifying individuals with possible dementia who live alone, the diagnosis and confirmation from a medical provider is often needed. In some cases, community support service providers may not be in the position to identify where an individual may be on the spectrum of cognitive impairment.

Legal considerations

Concerns about an individual's privacy should be considered as providers work with other members of the community to identify and maintain a system of watchful waiting for individuals with dementia who live 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.¹³ Patients can also consent to and direct the sharing of information with third parties, so this may be a possibility for certain individuals who are capable and willing to provide consent.

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. In cases in which abuse, neglect, or exploitation is suspected, APS reporting laws—discussed in Section 2—apply. It is crucial that providers learn about relevant state and federal laws, are fully cognizant of their own discipline's privacy and confidentiality rules, and are aware of the rules that must be followed by other providers with whom they interact. Working collaboratively through multidisciplinary teams and developing memoranda of understanding or memoranda of agreement can lead to better practice and policy.

Practical resources

- Cognitive Assessment Resources (Alzheimer's Association): This webpage provides guidance, instructional videos, and tools for conducting a brief cognitive assessment. Tools available for download include the Screening for Cognitive Impairment of Older Adults (Mini-Cog), the General Practitioner Assessment of Cognition (GP-Cog), the Memory Impairment Screen, the Ascertain Dementia 8-item Informant Questionnaire (AD8), and the Short Informant Questionnaire on Cognitive Decline in the Elderly. <http://www.alz.org/health-care-professionals/cognitive-tests-patient-assessment.asp>
- Dementia Friendly America is a national initiative that focuses on educating community members to become more dementia friendly and to be able to better support individuals with dementia and their caregivers and families. <http://www.dfamerica.org/>

First Responder on Why Educating Community Can Be Critical to Identifying Individuals Living Alone with Dementia

"One of the worst cases was when we found a monster sized mailbox that was completely full and the postman was just stacking the mail on the street. We didn't get a call [about the situation] until there was an odor on the street. I'm not sure what the postman was thinking because that was indicative that a person was either away from home or couldn't get out of their home."

- The St. Louis University Mental Status (SLUMS) examination is a 30-point screening questionnaire that initially tests for orientation, memory, attention, and executive functions. The tool can be used by both medical and community support service providers, and is free to use. http://medschool.slu.edu/agingsuccessfully/pdfsurveys/slumsexam_05.pdf
- Tools for Screening, Identification, Referral and Care Planning for People with Alzheimer's Disease and their Caregivers: This 2015 NADRC report describes screening instruments that can be administered by people without clinical training; needs assessment and referral tools; and tools used for care planning, screening, and referral by several grantees of ADSSP. <https://nadrc.acl.gov/node/27>

Endnotes

- 10 National Institute of Neurological Disorders and Stroke. 2015, Dementia: Hope Through Research. Available at: http://www.ninds.nih.gov/disorders/dementias/detail_dementia.htm#19213_8.
- 11 Callahan, C. M., Sachs, G. A., LaMantia, M. A., Unroe, K. T., Arling, G., & Boustani, M. A. (2014). Redesigning systems of care for older adults with Alzheimer's disease. *Health Affairs*, 33(4), 626–632.
- 12 Dementia Friendly America is a national initiative that focuses on educating community members to become more dementia friendly and be able to better support individuals with dementia and their caregivers and families. For more information, visit <http://www.dfamerica.org/>.
- 13 U.S. Department of Health and Human Services, Office of Civil Rights. (2003). *Guidance on significant aspects of the Privacy Rule*. Available at <http://www.hhs.gov/hipaa/for-professionals/privacy/guidance/personal-representatives/index.html>.

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Building Trust

Strategies from the experts for building trust

This section discusses several strategies that providers can use when trying to build trust and rapport with people with dementia who live alone. The strategies are based on input from several experts who have the experience and knowledge of trying to work with and provide services to this population, including geriatricians, APS workers, researchers, and geriatric care managers.

Building trust

Building trust with an individual with dementia who lives alone takes time and may require multiple contacts and meetings before a provider can start to ask questions about an individual's needs or conduct a needs assessment. A provider should not let the completion of a formal assessment get in the way of establishing trust with the individual.

In some cases, an individual living alone may have caregivers or friends and family who can provide a certain level of support. Providers should directly communicate with the individual and not just the individual's caregivers. If there are family members or friends present during a provider's visit, the individual may defer to the caregiver. It is important for providers to demonstrate that they care about what the individual has to say, and to recognize the possibility of abuse, neglect, or exploitation and how to look for signs of those problems. If, during the conversation with the individual, it is clear he or she is not understanding everything that the provider is saying, the provider should then inform the primary caregiver or other supportive people whom the individual trusts.

Accessing the home to assess level of risk

Assessing level of risk which may involve gaining access to the home of an individual with dementia who lives alone may require substantial time and effort. Rather than initially stating the reason why a provider would like to access the home (e.g., concerned for safety, APS referral), the provider can begin by building rapport with the individual from the moment he or she answers the door. A provider can start with general questions about the individual and their interests and preferences. Conversations about basic, tangible services such as home-delivered meals or assistance with transportation may also be an effective starting method to accessing the home. Trying to gain entry based on the individual's perception of his

Background information

Building trust and developing effective communication with a person with dementia who lives alone is essential to determining the individual's needs and areas in which community-based providers can provide assistance. Individuals with dementia who live alone can often have a strong sense of independence, and building trust may take time. Providers who have taken the time to build trust and establish a relationship with the individual will be most effective in delivering person-centered care.

Comments from researcher participating in an ADI-SSS grant about building trust with people with dementia who live alone:

“Using Meals on Wheels as an entry point is very helpful... The relationship is established around those assessors of ‘would you like a meal?’”

or her most immediate needs can be a helpful strategy. Providers can structure their approach with the individual around his or her values and preferences.

For those individuals who are reluctant about allowing a “stranger” in the home, a provider can stress that some of the basic services like food and transportation can help the individual maintain independence and remain at home. This strategy was recommended by subject matter experts because maintaining independence and remaining at home are common goals that people want to achieve.

If a provider is working with a third-party referral, the provider can engage them and ask what they think are the best methods for gaining access to the home. People who are known to the person with dementia may be able to introduce the provider and the individual. Relying on family members, other known providers, or caregivers to vouch for the provider can be an effective way to reassure the individual that the provider is trustworthy. When engaging family members or other caregivers, providers also should watch for indicators of elder abuse.

Providers should be clear in communicating with the individual about what they hope to accomplish during the visit. Minimizing overstimulation by slowing down movements and talking slowly can also help a provider better communicate with an individual with dementia.

Legal considerations

Providers who are trying to gain access to an individual’s home should keep in mind the individual’s right to voluntarily consent to services. Providers need to consider the balance between the rights of the individual to exercise autonomy versus the provider’s obligation to protect those who can no longer make decisions for themselves.

Also, in some cases, state or local law may limit the amount of time allotted to develop trust with the individual. For example, in some states, APS may have specific standards on how quickly they need to open and close cases, which can affect the time they can work to develop a relationship with the individual. Unless the APS caseworker is able to determine obvious neglect immediately, he or she may need several visits to establish trust and determine the needs of the individual with dementia who lives alone. However, in many states, APS is constrained from returning to an individual’s home unless there is another APS report filed on the individual’s behalf. In some cases, APS may be able to work with other service providers who have established relationships with the individual to generate a report for APS.

Practical resources

- Considerations for Those with Dementia Who Live Alone, Alzheimer's Association, 2009.¹⁴ Provides some guidelines for working with people who have dementia who live alone. https://nadrc.acl.gov/sites/default/files/uploads/docs/Considerations_For_Those_Who_Live_Alone.pdf
- Can a Person with Alzheimer's Live Alone? Duke Family Support Program, 2002.¹⁵ This toolkit provides questions for professionals and others to guide decisions about the safety of someone with dementia who lives alone. https://nadrc.acl.gov/sites/default/files/uploads/docs/Can_Person_With_Alzheimers_Live_Alone.pdf

Endnotes

- 14 Alzheimer's Association. (2009). *Dementia care practice recommendations for professionals working in the home setting*. pp 53–54. Available at https://www.alz.org/national/documents/phase_4_home_care_recs.pdf
- 15 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.

3

Supporting Safety and Autonomy

Background information

Persons with mild-to-moderate dementia are able to participate in decisions and express preferences in areas such as their own health care, daily care and activities, and place of residence.^{16,17,18,19} Whether an individual is capable of decision making depends on whether he or she can communicate relatively consistently, understand basic information about choices, evaluate the implications of different choices, and rationally comprehend the risks and benefits associated with different options.^{20,21}

Because these capacities fluctuate over time and different decisions require different levels of capacity, a diagnosis of dementia—or even a particular score on a cognitive test—should not be the only criterion for determining decision-making capacity.²² More importantly, people with dementia need to be supported in expressing their wishes in as many aspects of daily life as possible. When treatment goals and desires are supported by both caregivers and care recipients, caregivers gain a better understanding of the person’s wishes and therefore feel better prepared and less burdened with decision making.²³

A person’s ability to make decisions is not “all or nothing,” and exists on a wide continuum.^{24,25} It is always important to support an individual in choices he or she is still able to make. “Supported decision making” is defined as a process by which people with disabilities are encouraged to understand choices and make decisions for themselves, without a surrogate, and with the help of a support network.²⁶ Even when there is a surrogate decision maker, such as an agent under an advance directive or power of attorney, there may be choices in which the individual can take the lead with help. In other situations, the surrogate should seek to “step into the person’s shoes,” using the individual’s values and preferences if possible.

Strategies from the experts for supporting safety and autonomy

This section discusses several strategies that providers can use when trying to support an individual with dementia who lives alone to ensure his or her safety while trying to maintain the individual's autonomy. The strategies are based on input from several experts who have the experience and knowledge of trying to support safety and autonomy in a balanced way, including geriatricians, APS workers, geriatric care managers, and legal advisors from the ABA.

Commitment to every extent possible to maintaining an individual's autonomy is a principal concern when service providers work with individuals who have dementia and live alone. Service providers must support the individual's autonomy while addressing concerns about safety. To do both effectively, it is important for service providers to understand—and thus evaluate—the individual's capacity to make everyday decisions, weigh the associated risks involved, and carry out those decisions. 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.

Evaluating the risk an individual may face while also evaluating the individual's capacity to understand that risk enables providers to keep a person-centered focus on the individual and their specific circumstances.²⁷ Each case requires a different evaluation of capacity. For example, the capacity to execute an advance directive is different from the capacity to make specific medical decisions or decisions about where to live. If a provider can determine that an individual has the capacity to understand personal risk, then it may not be appropriate for the provider to interfere. Or, if the risk is considered very small, then a high level of capacity from the individual is not needed. However, an individual who is in a high-risk situation (e.g., living alone with dementia in a house with stairs, and has a history of falls), but has a low capacity to understand the risk (e.g., does not recognize fall risk), is of most concern. In such cases, a provider may need to intervene by determining whether there is any caregiver or other supports to help the individual meet his or her needs (addressed in Section 4) or to coordinate paid providers and formal support services (addressed in Section 5).

Risk assessment is often more complicated than generally thought. As a starting point, asking the following questions can be helpful:²⁸

- Is the risk something new to the individual or has the individual been living with the risk for a long time?
- Is the risk real? Are there concrete instances of injury?
- How grave is the risk?

Comments from a researcher participating in an ADI-SSS grant about the types of capacity assessments used for people with dementia who live alone:

"We use the live alone assessment from the University of Iowa, which includes four categories...With this, if someone scores in the emergent category, it can help the assessor figure out a course of action to take. Most of the time, assessing that safety might be gray."

Medical provider comments about weighing the balance between an individual's autonomy and safety:

"I have a patient with moderate to advanced Alzheimer's disease. She lives by herself with her daughter 30 miles away and she's not thriving. She's lived in her home for 60 years. So living in her home is very meaningful for her—she is very emotionally attached. One reason she functions pretty well is that she is in a very familiar environment. I know there's a big safety risk, so we've looked at certain things—like she has a gas stove, so we have recently cut the gas off. But she has microwave to heat things up. We try to make her home environment reasonably safe. And I had the conversation with her daughter, 'There might be some horrible crisis that could happen; are you okay with that?' By virtue of your mother's philosophy and needs, the answer is yes."

- Is the risk imminent or remote?
- Is there risk of harm to others? (Harm to others may increase the concern.)
- How objective is the assessment of risk? (The identification of risk may be from a family member whose assessment is mixed with other concerns.)
- Is the risk chosen or accidental?

Providers and community supports can deliver the assistance needed for people to maintain their autonomy by understanding their situations and learning over time how to evaluate the risks and whether and how they need to be addressed. Individuals can and should be allowed opportunities to make mistakes. Maintaining an individual's autonomy means that providers must consider the individual's personal values and preferences balanced with their safety and the safety of others. As discussed in subsequent chapters, providers can identify and expand the individual's network of support, mobilize formal home- and community-based services, and if necessary, help the person transition to another supportive setting of care.

Working with Adult Protective Services

According to the experts interviewed for this guide who are familiar with APS, providers will need to determine an individual's social supports and access to caregivers when an individual's capacity is determined low and his or her risk has been determined high. If the provider cannot identify any social supports or notices evidence of abuse, neglect, or exploitation, the provider may need to refer the individual to APS.

The criteria for a case to be eligible for APS intervention varies by state; as such, providers should be aware of their APS state law and policies. Each state defines eligibility for APS and which forms of elder abuse can be investigated by APS. In some cases, self-neglect may not be included as a qualifying reason for APS intervention. As of 2016, Arizona, Delaware, Georgia, Indiana, Montana, Oregon, Rhode Island, and Vermont do not include self-neglect as a category in state APS statutes.

After APS receives a report of suspected abuse, neglect, or exploitation, staff will determine whether the alleged victim is eligible for APS and whether an investigation is warranted. If appropriate, an APS representative will visit the individual's residence and conduct a risk assessment. Each state has its own APS agency, which relies on their own assessment tools. The assessments generally look for any number of indicators of abuse, neglect, or exploitation. Providers who have made the referral report may or may not be involved further with APS investigations. In some states, the APS representative cannot share the results of their investigation with the individual who made the report to APS.

Although anyone may report suspected abuse, neglect, or exploitation to APS, in all but one state (New York, as of 2016), the law requires certain individuals to report suspected abuse, neglect, or exploitation to APS and also possibly to other agencies such as law enforcement. Some state laws require everyone to report; others limit mandatory reporters to key groups of professionals and other providers who commonly interact with elders or vulnerable adults. Common categories of mandatory reporters include providers of in-home care, home-delivered meals workers, or other support providers who contract with the local agency on aging, such as case managers. For individuals who receive Medicaid home- and community-based services, APS may rely on the waiver case managers who must also assess individuals for eligibility purposes.

If APS determines that an individual is experiencing or has experienced abuse, neglect, or exploitation, APS can provide services to that individual or arrange for services from other providers.

Other laws may require that reports about individuals with dementia who live alone be made to agencies other than APS, such as law enforcement. Providers need to be aware of different reporting requirements that may apply.

Legal considerations

Assessing capacity for individuals with dementia who live alone can be difficult. Ensuring that the persons conducting the assessments are properly trained to determine capacity and risk of an individual is critical. Legal issues may result from relying solely on instinct and experience when determining if a person can accept or reject services.

In scenarios in which providers or family members are concerned about the capacity of individuals with dementia to make informed decisions and give consent, steps may need to be taken to identify and implement alternative decision-making options. Guardianship should be viewed as a last-resort option. Many state statutes prioritize less-restrictive legal options than establishing a guardian, such as appointing an individual to make financial decisions, including appropriate use of joint accounts, durable powers of attorney, trusts, and representative payment for public benefits; and appointing an individual for personal and health decisions, advance directives, living wills, and use of state default consent laws.²⁹ Most states have default consent laws that permit a prioritized list of family members or others close to the individual to make all or some medical decisions on behalf of the individual without court intervention. The list usually starts with one's spouse, followed by adult child, sibling, and in about half the states extends to close friends with a demonstrated knowledge of and concern for the individual.

Providers are encouraged first to focus on supported decision-making processes as key alternatives to the guardianship model. In some cases,

Case manager on the process for determining need for guardianship petition:

“We consult our own team, and then there’s an advisory panel that includes an interdisciplinary, interagency panel of case managers, APS, and legal aid for the elderly. So after we discuss in our care teams, we will take the case to the panel. The panel helps determine if there’s anything else we can try. If there’s nothing else, then legal resources will petition for guardianship.”

determining the right combination of community or family supports may help to increase the understanding and decision-making abilities of individuals with dementia who live alone. Providers could start with the challenge at hand and ask, “What would it take to enable this person to make necessary decisions in a supportive environment?”³⁰ If an individual does not have a decision-making support system in place, the provider will need to assess the individual’s strengths and limitations in the specific areas in which decisions are needed. On a practical level, there are sometimes family, friends, neighbors, and others (e.g. the mail carrier) who could all provide some support if there is someone to organize and coordinate their efforts.

Guardianship

If the court determines an individual is not able to make such choices without judicial oversight, guardianship allows the courts to appoint one person or entity to make financial, personal, legal, and health care choices. Guardianship procedures and terminology vary by state law and practice. Often—but not in every state—the term “guardian” refers to someone appointed to make health care and personal decisions, and “conservator” refers to someone appointed to make financial decisions.

Generally, the guardianship process begins with a petition by “any person,” followed by notice to the individual and to family members, possible appointment of counsel and a court visitor or investigator, identification of a clinical assessment, and a hearing on the evidence about the person’s abilities to care for self and property.³¹ With sufficient evidence, the court may make an order appointing a guardian, and may opt for full guardianship or a limited order in which only some decision-making rights are transferred. The court will continue to monitor the guardian, who must report to the court annually.

If a guardian is appointed, states often require that the order be limited to only those areas in which the individual needs decision-making assistance. Many state guardianship laws encourage limited guardianship, participation of the individual in decision making, and consideration of the person’s values and preferences in decision making.

The aim of guardianship is to protect a vulnerable individual, but, in doing so, it removes fundamental rights, reducing choice and self-determination. These fundamental rights include the right to make health care decisions, vote, marry, enter into contracts, manage property, determine where to live—and sometimes even with whom an individual can visit. Important things to consider about guardianship for people with dementia who live alone are:

- Guardianship should be a last resort, and should be used only if there is need for a legal decision in which the individual is unable to make the decision and no less-restrictive options will work.

- Guardianship can be limited in scope and duration. A person with dementia may be able to make some decisions but not others. Guardianship should remove rights only in those areas in which a person is not able to act. Most state laws provide for limited guardianship, but it may be used rarely in practice.
- The guardian should maximize autonomy and self-determination.³² The guardian should support the person in making choices, if possible.
- Guardians are subject to the oversight of the court. If a guardian is suspected of abusing, neglecting, or exploiting a person with dementia, it must be reported to APS and to the court. The court may send out an investigator, may hold a hearing, and could sanction or remove the guardian and appoint someone else.
- If there is no less-restrictive option and no family or friends to serve, examine whether your state has a public guardianship program. Determine the eligibility criteria and whether slots are available for the individual. Although many states have such programs, they are often underfunded and understaffed.³³

Practical resources

- People with Dementia Living Alone Risk Assessment, University of Iowa, 2004.³⁴ Developed for home care nurses and other community-based providers to assess level of risk when visiting a person with dementia who lives alone. https://nadrc.acl.gov/sites/default/files/uploads/docs/PWD_Living_Alone_Risk_Assessment.pdf
- Fraud Protection for Elders Living or Staying Alone, Duke Family Support Program, 2002.³⁵ https://nadrc.acl.gov/sites/default/files/uploads/docs/PWD_Living_Alone_Fraud_Protection.pdf
- Living with Dementia: Health Care Planning, Living with Dementia: Financial Planning and Making Decisions, NADRC, 2016. A newly published series of advance planning guides on financial planning, making decisions, and health care planning are developed for use by persons with dementia and family members to assist with planning for future needs. These guides are available at: www.nadrc.acl.gov
- The ABA provides information about state laws and resources regarding guardianship and supported decision-making. http://www.americanbar.org/groups/law_aging/resources/guardianship_law_practice.html. Also see the Center for Elders and the Courts. <http://www.eldersandcourts.org/>
- The PRACTICAL Tool aims to help lawyers identify and implement decision-making options for persons with disabilities that are less restrictive than guardianship, and may be useful for other professions as well. http://www.americanbar.org/content/dam/aba/administrative/law_aging/PRACTICALGuide.authcheckdam.pdf

State official/APS on petitioning for a conservatorship of finances:

"We worked with a woman in her 80s with dementia who was living in [the] community for years. She was friends with a neighbor, and...as the person's dementia got worse, she moved into the home of her neighbor who could help provide all of the personal care supports. However, the neighbor's child, who was helping the person with dementia's finances, was stealing money and misusing her funds...so what we did was request strictly conservatorship; it was truly only finances. We limited the decision to that because it was the best thing for this particular woman."

Endnotes

- 16 Feinberg, L. F., & Whitlatch, J. (2002). Decision-making for persons with cognitive impairment and their family caregivers. *American Journal of Alzheimer's Disease and Other Dementias*, 17(4), 237–244.
- 17 Menne, H. L., Tucke, S. S., Whitlatch, C. J., & Feinberg, L. F. (2008). Decision-making involvement scale for individuals with dementia and family caregivers. *American Journal of Alzheimer's Disease and Other Dementias*, 23(1), 23–29. doi:10.1177/1533317507308312
- 18 Mozley, C. G., Huxley, P., Sutcliffe, C., Bagley, H., Burns, A., Challis, D., & Cordingley, L. (1999). 'Not knowing where I am doesn't mean I don't know what I like': Cognitive impairment and quality of life responses in elderly people. *International Journal of Geriatric Psychiatry*, 14(9), 776–783.
- 19 Tyrrell, J., Genin, N., & Myslinski, M. (2006). Freedom of choice and decision-making in health and social care: Views of older patients with early-stage dementia and their carers. *Dementia*, 5(4), 479–502.
- 20 Karel, M. J., Gurrera, R. J., Hicken, B., & Moye, J. (2010). Reasoning in the capacity to make medical decisions: The consideration of values. *Journal of Clinical Ethics*, 21(1), 58–71.
- 21 Woods, B., & Pratt, R. (2005). Awareness in dementia: Ethical and legal issues in relation to people with dementia. *Aging and Mental Health*, 9(5), 423–429. doi: 10.1080/13607860500143125
- 22 Ibid.
- 23 Whitlatch, C. J., Judge, K., Zarit, S. H., & Femia, E. (2006). Dyadic intervention for family caregivers and care receivers in early-stage dementia. *The Gerontologist*, 46(5), 688–694.
- 24 Holm, S. (2001). Autonomy, authenticity, or best interest: Everyday decision-making and persons with dementia. *Medicine, Health Care and Philosophy*, 4(2), 153–159.
- 25 Samsi, K., & Manthorpe, J. (2013). Everyday decision-making in dementia: Findings from a longitudinal interview study of people with dementia and family carers. *International Psychogeriatrics/IPA*, 25(6), 949–961.
- 26 Blanck, P. & Martinis, J. (2015). The right to make choices. The National Resource Center for Supported Decision-Making, 3. *Inclusion* 24, 24–25.
- 27 Soniat, B., & Micklos, M. (2010). *Empowering social workers for practice with vulnerable older adults*. NASW Press. Available at <https://www.naswpress.org/publications/aging/vulnerable-adults.html>
- 28 Silberfeld, M., & Fish, A. (1994). *When the mind fails: A guide to dealing with incompetency*. University of Toronto Press.
- 29 American Bar Association. (2016). *PRACTICAL tool for lawyers: Steps in supporting decision-making*. Available at http://www.americanbar.org/content/dam/aba/administrative/law_aging/PRACTICALGuide.authcheckdam.pdf.
- 30 Ibid
- 31 Quinn, M. J. (2005). *Guardianships of adults: Achieving justice, autonomy, and safety*. New York: Springer Publishing Company.
- 32 National Guardianship Association. (2013). *Standards of practice*. Available at http://www.guardianship.org/documents/Standards_of_Practice.pdf
- 33 Teaster, P. et al. (2007). *Public guardianship after 25 years: In the best interest of incapacitated people?* University of Kentucky and ABA Commission on Law and Aging.
- 34 Hall, G., Bossen, A., & Specht, J. (2004). *Live alone assessment*. Iowa City, Iowa: The University of Iowa College of Nursing.
- 35 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.

4

Involving Family and Friends

Strategies from the experts for involving family and friends

This section discusses several strategies that providers can use when trying to identify family members and friends as potential caregivers for people with dementia who live alone. The strategies are based on input from several experts who have the experience and knowledge of trying to work with families and friends for this population, including geriatricians, APS workers, geriatric care managers, and legal advisors from the ABA.

Identifying family and friends who can help

In many cases, individuals with dementia who live alone may have social supports and people in the community who can potentially assist them. Providers can try to identify these social supports and make sure that they are connected to these individuals. Identifying potential caregivers requires getting a sense of who is included in the individual's social network and is trustworthy. After establishing trust with the individual with dementia, the provider can try to ask for names and contact information of an individual's family members or friends.

Providers should use caution when reaching out to family members and friends as potential caregivers for individuals with dementia who live alone. Providers may be quick to identify an adult child of the individual; however, the provider first should try to determine the quality of the relationship between the two family members. A provider could be reintroducing a family member into a relationship in which there was an abusive past. Providers can look to individuals outside of the individual's immediate family—sometimes referred to as “fictive kin”—to try and get a sense of who those people are and the quality of their relationships with the individual who lives alone.

It is also important for providers to be sensitive to issues of culture and diversity when interacting with an individual's family members and friends. Providers should consider the family's culture and general perceptions of aging, caring for family members, and memory impairment. Providers should understand that a family's culture impacts their choices regarding certain services provided to an individual with dementia who lives alone. Also, the faith community for many cultures can be used as a critical

Background information

Many people with dementia who live alone 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 disease and many 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.

State official/APS on identifying family and friends who can help:

“One of the ways we determine who is available is by asking the person about how they meet their needs—such as asking them questions about cooking food, paying bills, washing clothes, cleaning up. We ask what they do, and if someone says they can’t do much, or we can see they don’t have the capacity [to meet their daily needs], then we will ask who is helping with those things. We lead with a good idea of who is doing what. We may need to engage neighbors, and ask whether someone comes by. We may then find out from the neighbor they have some kind of home care service, but the person couldn’t articulate [that] to us.”

support system.³⁶

If providers are having a difficult time identifying any social supports, a provider may ask the individual if they can look through his or her cell phone or ask if the individual has a list of phone numbers written down. A history of cell phone calls or list of contact numbers may provide critical information to help a provider identify potential caregivers. Frequent contacts of specific people may indicate with whom the individual with dementia often connects.

A provider should request permission and a signed release from the individual before making contact with family members or friends. In some cases, the individual may refuse permission, and the provider should attempt to determine why contact is being refused. In cases of contact refusal, capacity and risk should be assessed to determine the individual’s capacity to understand the level of risk. In cases where the risk level is high and the capacity to understand the risk is low, a provider may be more likely to reach out to the individual’s social network without the individual’s permission. As mentioned in Section 3, assessing capacity requires adequate training, and providers should take care to rely on qualified professionals to conduct the assessments.

Assessing ability and willingness to help

Engaging others takes time and may require multiple contacts from a provider. It is key for providers to listen carefully to get a sense of how involved the family member or friend may be already in an individual’s life and what, if any, barriers exist for that family member or friend to provide care and assistance. In some cases, the provider may need to focus on reengaging a family member. Family caregiver support programs can help connect caregivers to certain community resources that will help them build the necessary skills to provide assistance to individuals with dementia. The level of involvement of a caregiver with an individual with dementia who lives alone can range from providing direct personal care to helping with transportation.

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 is aware of the level of needs of the individual who lives alone. Providers can help the caregivers create a plan to ensure the adult’s needs are met, and stay involved long enough to ensure the caregiver follows through with the care plan. Creating a caring group or network around the individual with dementia who lives alone may be the most beneficial option. Involving more than one caregiver with assisting an individual may help prevent any one caregiver from overstepping his or her duties.

Helping family and friends understand the level of support needed

In some cases, a family member may have a difficult time accepting that the person's level of functioning has deteriorated. Providers may need to work with potential caregivers over time to ensure that the caregivers understand the level of risk for the individual with dementia who lives alone. Family caregiver support programs, which are generally funded through the Older Americans Act, can provide education, training, and counseling services to family or friend caregivers.

Community support providers can also rely on other professionals to help explain to potential caregivers the types of risk an individual with dementia who lives alone may have or assistance the individual may need. For example, one case manager noted that she often tries to incorporate occupational therapists (OTs) in the assessment process. An OT will focus primarily on function, an individual's ability to manage daily activities, and the type of assistance needed. Family members may be more receptive to specific suggestions that include defined tasks and the time commitment needed to assist with those tasks.

Legal considerations

As providers try to identify and coordinate with informal caregivers, they should be careful to consider if they are sharing personal health information. Please see Legal Considerations under Section 1 for more information and useful guidance for providers to consider around privacy concerns for the individual with dementia who lives alone.

Practical resources

- Social Network Scale³⁷ is a self-report measure of social engagement including family and friends. http://www.brandeis.edu/roybal/docs/LSNS_website_PDF.pdf
- Preparedness for Caregiving Tool³⁸ is a caregiver self-rated instrument that consists of eight items that asks caregivers how well prepared they believe they are for various aspects of caregiving, such as providing physical care, providing emotional support, setting up in-home support services, and managing stress. <https://consultgeri.org/try-this/general-assessment/issue-28.pdf>
- Brief Cope Scale³⁹ consists of 28 items that assess an individual's ability to cope with stress. The individual is asked to rate each item in the following areas: active coping, self-distraction, denial, substance use, use of emotional support, use of instrumental support, planning, humor, acceptance, self-blame, religion, venting, positive reframing, and behavioral disengagement. The tool is also available in Spanish, French, German, Greek, and Korean. <http://www.psy.miami.edu/faculty/ccarver/sclBrCOPE.html>

Endnotes

- 36 Alzheimer's Association. *Providing culturally sensitive dementia care*. Chicago, IL: Alzheimer's Association. Available at http://www.alz.org/resources/diversity/downloads/about_culturallysensitivedementiacare.pdf
- 37 Lubben, J. (1988). Assessing social networks among elderly populations. *Family & Community Health: The Journal of Health Promotion & Maintenance*, 11(1), 42–52.
- 38 Archbold, P. G., Stewart, B. J., Greenlick, M. R., & Harvath, T. A. (1992). The clinical assessment of mutuality and preparedness in family caregivers to frail older people. In S. G. Funk, E. M. Tornquist, M. T. Champagne, & L. A. Copp (Eds.), *Key aspects of eldercare* (pp. 328–339). New York: Springer Publishing Company.
- 39 Carver, C. S. (1997). You want to measure coping but your protocol's too long: Consider the Brief COPE. *International Journal of Behavioral Medicine*, 4(1), 92–100.

5

Coordinating Paid Providers and Formal Support Services

Strategies from the experts for mobilizing formal supports

This section discusses several strategies that providers can use when trying to mobilize and coordinate formal supports for people with dementia who live alone. The strategies are based on input from several experts who have the experience and knowledge of working with other community-based providers to support this population, including APS workers, geriatric care managers, researchers from the ADI-SSS grants, and legal advisors from the ABA.

Providers should start by conducting a functional assessment for individuals with dementia who live alone to determine their support needs, taking into account whether they have any current social supports, including family members or friends. Providers should ask the individual about personal preferences and perception of needs. Offering assistance in transportation or home-delivered meals may be the easiest services to gain acceptance from the individual. Once the provider builds trust with the individual, additional services such as home care, case management services, and financial management assistance services may be offered.

Providers should also account for the individual's financial situation to determine if any financial assistance is needed to cover the support services. Each state Medicaid program offers home- and community-based services through their state plan or waiver programs. Providers may need to coordinate with the state Medicaid agency to determine eligibility for the individual and which services the state Medicaid program will cover. State and local organizations may also provide additional funding for support services for individuals living in the community who need more assistance.

Having a coordinated community response in which the variety of providers who may work with an individual with dementia can communicate and exchange information is the most effective method of ensuring an individual is receiving the supports and assistance that he or she needs. However, providers should keep in mind the limitations within the health care and support services system as they try to provide

Background information from literature

Coordination and communication among community support service providers and physicians is an important strategy to fill gaps in understanding the needs of individuals with dementia who live alone.⁴⁰ To ensure that person-centered services are provided to individuals with dementia who live alone, good communication must be a priority among the individual, his or her health care proxy decision maker, family caregivers, and the entire care team. To be effective, providers must understand strategies for communicating with people who have dementia. They must also consider what, how, and when information should be delivered to family and other team members.⁴¹

care to individuals with dementia who live alone. Many community-based providers are siloed in their approaches to providing services and supports to individuals and do not have a consistent and direct way to exchange information or communicate with other providers who are working with the same individual. For example, a physician may not be able to easily communicate with the personal care or home-delivered meals provider who may have different perspectives on an individual's personal capacity, risks, and support needs. As described elsewhere, HIPAA privacy rules also limit communication. However, the individual's informed, written consent to the sharing of information can lessen these barriers.

The use of technology, such as electronic messaging or shared electronic medical records at the provider level, has the potential to facilitate communication and coordination across providers. Providers who have access to such technology, including medical providers and those in social services, can be in touch with each other more efficiently to coordinate the care and services provided to an individual.

At the individual level, assistive technology can also be used to ensure individuals are receiving adequate supports to remain in the community. Providers should note that assistive technology may work for some individuals and not for others, depending on an individual's level of comfort using technology and his or her cognitive abilities. For example, there are machines that can assist an individual living alone with medication management. It is important to note that the assistive technology can support individuals with dementia who live alone, but is not necessarily an appropriate replacement or substitute for home- and community-based services. For more on this topic, refer to Legal Considerations in this section.

Financial management is often one of the first areas to decline as individuals develop cognitive issues. For individuals receiving Social Security benefits, the Social Security Administration (SSA) may establish a representative payee to manage benefits and work with the individual to ensure that bills are paid and his or her finances are protected. SSA will try to identify the appropriate person connected to the beneficiary and appoint that person as the representative payee, if possible.

Setting up a financial management system requires a provider to build a good rapport with the individual. A provider should clearly explain to the individual how a financial management system will work. It is also important to emphasize how much money the individual will continue to have control over. For example, a provider could communicate with the individual that he or she will get \$200 a month to spend on whatever he or she wants.

Legal considerations

When an individual with dementia who lives alone does not accept services, providers should consider the individual's capacity to understand the risk that results from not accepting such services. If the individual is in a high-risk situation, the provider can create a referral for a capacity assessment to be completed by a trained health professional. Providers may face the difficult dilemma of balancing individual autonomy and safety.

Providers who would like to use assistive technology, such as GPS monitoring devices, should check the state laws and regulations about privacy and consent of the individual. The provider should attempt to determine whether the individual understands what he or she is agreeing to with regard to using a monitoring device, and gives consent. The first legal requisite to accomplish when trying to incorporate such devices is to determine the extent to which the individual can consent.

Providers attempting to coordinate and communicate with other providers when furnishing care and supports to individuals with dementia should consider privacy regulations. Please see Legal Considerations under Section 1 for more information and useful guidance for providers to consider around privacy concerns for individuals with dementia who live alone.

Practical resources

- The Eldercare Locator, a public service of the Administration on Aging, is a nationwide service that connects older Americans and their caregivers with information on senior services by identifying trustworthy local support resources. <http://www.eldercare.gov/eldercare.NET/Public/index.aspx>
- Functional Activities Questionnaire, 1982.⁴² Informant rates the person's abilities to manage daily activities. Administration and scoring instructions are included on the instrument. <http://www.healthcare.uiowa.edu/familymedicine/fpinfo/Docs/functional-activities-assessment-tool.pdf>
- Instrumental Activities of Daily Living Scale, 1971.⁴³ The examiner should complete the scale based on information about the patient from the patient, informants (such as the patient's family member or other caregiver), and recent records. Administration and scoring instructions are included on the instrument. <http://www.healthcare.uiowa.edu/IGEC/tools/function/lawtonBrody.pdf>

- Several federal Representative Payment Program websites provide further information for individuals receiving a range of federal benefits:
 - SSA Representative Payment Program for individuals receiving Social Security benefits: <https://www.ssa.gov/payee/>. SSA's Representative Payee Interdisciplinary Training: 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. https://www.ssa.gov/payee/rp_training2.html. Justice in Aging also provides an overview of the Social Security Representative Payee Program that includes several fact sheets for further guidance. <http://www.justiceinaging.org/our-work/economic-security/rep-payee-program/>
 - Veterans Administration (VA) Fiduciary Program for individuals receiving VA benefits. <http://www.benefits.va.gov/fiduciary/fiduciary.asp>
 - Office of Personnel Management Representative Payee Program for individuals receiving federal pensions and benefits. <https://www.opm.gov/retirement-services/my-annuity-and-benefits/representative-payees/>

Endnotes

- 40 Newhouse, B., Newhouse, E., & Niebuhr, L. (2002). "I'm fine": Meeting the challenges of living alone with dementia. *Home Health Care Consultant*, 9, 11–16.
- 41 Gould, E., Tilly, J., & Reed, P. (2009). *Dementia care practice recommendations for professionals working in a home setting*. Chicago, IL: Alzheimer's Association Campaign for Quality Care. Available at http://www.alz.org/national/documents/Phase_4_Home_Care_Recs.pdf
- 42 Pfeffer, R., et al. (1982). Measurement of functional activities in older adults in the community. *Journal of Gerontology*, 37(3), 323–329. doi:10.1093/geronj/37.3.323
- 43 Lawton, P. (1971). The functional assessment of elderly people. *Journal of the American Geriatric Society*, 19(6), 465–481.

6

Assisting With Transition to a New Setting

Strategies from the experts for transitioning to a new setting

This section discusses several strategies that providers can use when trying to assist individuals with dementia who live alone transition to a new setting. The strategies are based on input from several experts who have experience with transitioning people with dementia who live alone to new settings, including geriatricians, APS workers, geriatric care managers, and legal advisors from the ABA. Several strategies were identified that can help providers confidently determine when it is appropriate to transition an individual with dementia who lives alone to another setting, and can help make such a transition smooth for the individual.

Deciding if transitioning to another setting is necessary

Determining whether an individual with dementia who lives alone needs more assistance than what can be provided with available supports is a critical step in care transitions that requires consideration of many factors. Providers recommending care transitions must consider the risks involved with the individual staying in his or her home, the risks of moving to a new setting, the capacity of the individual to understand these risks and willingness to transition to a new setting, as well as the availability of new and appropriate settings for the individual. Section 3 of this guide provides information on how to assess safety and respect autonomy, which are key to this step.

Evaluating the risk of the individual living alone and his or her capabilities, social network, and access to services at home is important before recommending a change in residence. As one of our experts reported, certain individuals with dementia who live at home alone can be kept at home, even until the end of life, if they get enough care through programs, such as a Medicaid home- and community-based waiver program, and if hospice is engaged at the end of life. The expert emphasized that if it is important to the individual to stay at home, efforts should be made to keep him or her there, but the expert also recognized it is not always possible for the individual to stay at home. Ultimately, the experts who were interviewed encouraged attempting to involve family and friends, and to find services in the community that can meet

Background information

Transitioning an individual with dementia who lives alone to another setting—such as a long-term care residence or a relative's home—is sometimes necessary. People with dementia who live alone are at high risk for unmet care needs,⁴⁴ commonly underuse needed long-term services and supports,^{45,46} and have a high risk of nursing home placement.⁴⁷

Transitions to a new setting can be challenging, especially when the individual wants to stay in his or her home, when appropriate settings are not available locally, or when making the transition is expected to be upsetting or disorienting for the individual.

Senior service organization representative:

“We are able, for certain clients, to keep them at home, even until the end of life, even people with dementia living alone, if they are getting enough care through the Medicaid waiver program—the Elderly, Blind and Disabled waiver. We’ve made that work and brought in hospice at the end. If that’s important to the client we try to keep them at home. It’s not always possible.”

Adult Protective Services/ state official:

“If we can’t find things in the community to meet the individual’s needs, that is what would make us shift toward some kind of different living arrangement. We initially look for friends or family, then a personal care home or assisted living, then nursing home care. With dementia, the person may also have wandering behaviors, and not all personal care homes are equipped [to manage wandering], so rather the person may need a nursing home. We always look at that level of unmet need and consider if we can get that need met at home or where they want to be.”

the individual’s needs and keep him or her safe remaining at home, if the individual wants to stay there.

The decision to transition to another setting can be either voluntary or involuntary. If a relocation becomes necessary, a provider should support the individual’s decision making as much as possible. In some cases, the transition is involuntary. For involuntary moves, providers must prove in court that an individual no longer has the capacity to make decisions. The individual must meet the standard a court uses to determine whether guardianship is necessary. See Section 3 for further information on guardianship.

Deciding where to transition

When the decision is made that an individual with dementia who lives alone will transition to a new setting, it is critical to assess the needs of the individual, the abilities of the new caregiver(s), and the characteristics of the new environment. Assessing both practical/logistical needs and emotional needs is important. If gaps are identified between what the individual needs and what the new caregiver and environment can provide, it may be necessary to involve additional social services.

One expert explained that they initially look for friends or family who might have a home where the individual may be able to live. Potential caregivers should be adequately assessed for their ability and willingness to have the individual move into their home. If there is no appropriate option among family and friends, a provider may look for a personal care home or assisted living community. As a final option, a provider may consider nursing home care. However, it also is important to consider the individual’s specific needs and symptoms. For example, if the individual has a tendency to wander away from home, the ability of the new residence to securely keep the individual from unsafe wandering will need to be considered.

Regardless of the type of setting where the individual may move, having the individual visit the setting before relocating is encouraged, as this can help the individual feel safer and more comfortable when the move does occur.

How to transition

When assisting an individual with dementia’s transition from living at home alone to living in a new environment, providers should work with the person as much as possible to understand his or her needs. Engaging the individual’s informal social network can also be helpful. (Section 4 of this guide provides information on engaging informal social networks.) Engaging someone whom the individual trusts to be actively involved during the transition process can support him or her to feel more comfortable about relocating from the home to a new setting, and can help

ensure that the new environment meets the individual's needs. Working with an individual's trusted family members or friends can also help determine alternative living arrangements when the person is no longer able to express a preference.

During the first few months after such a transition, the individual is oftentimes upset or agitated in the new environment. It is helpful to actively communicate with the care providers in the new setting to set realistic expectations and to acknowledge that the transition can be difficult. Providing access to mental health counseling also can help in processing into a new living environment.

After the relocation occurs, maintaining consistent contact with the person at least long enough to make sure all the needed services are in place to his or her satisfaction is important. Typically, the first 2 to 3 months are the most stressful time for the individual after a transition. Maintaining contact throughout the transition time to ensure he or she has comfortably settled into the new setting is encouraged.

Legal considerations

As noted above, there are risks to living alone with dementia, and sometimes relocation is necessary. To avoid legal complications when determining if an individual needs to be relocated to another setting, service providers are encouraged to use evidence-based or evidence-informed tools—rather than relying on their “gut instincts”—to assess an individual's capacity to safely live at home alone. (See Section 3 for assessing capacity discussion and tools.) For example, the Assessment of Capacity for Everyday Decision making (ACED) tool is one option.⁴⁸ Providers should only work with trained clinicians to use many capacity assessment tools. It is helpful for providers to have an understanding of which trained clinicians are appropriate for which tools, and who may be available for such services in the community.

Service providers also are encouraged to engage the individual's family and friends when attempting to determine if relocation is necessary, as these individuals may understand the individual's preferences for living environment, may be able to offer assistance, or even may invite the individual to live with them. Service providers also are encouraged to engage other experts and knowledgeable individuals in determining if an individual who lives alone needs to relocate because having supportive opinions from others can help allay legal concerns.

Physician expert:

“During the transitional time, you need a trusted person to help with transition. If you have a patient moving into [a] dementia care assisted living facility, it's important to have frequent contact [with the patient]. In the first few months after the move—when you may see a lot of upset and agitation—set realistic expectations with staff and family to the extent that you can. Providers should acknowledge that it will be tough, and they can set up mental health counseling, even for people with early-stage dementia.”

Practical resources

- The NADRC's Care Transitions Resource Guide provides an overview of peer-reviewed literature and other resources related to various aspects of care transitions for people with dementia. <https://nadrc.acl.gov/sites/default/files/uploads/docs/Care%20Transitions%20Resource%20Guide%202015.docx>
- The Care Transitions Notebook: Caring for Some with Memory Loss or Alzheimer's After a Hospitalization from the Alzheimer's Greater Los Angeles can help caregivers better understand Alzheimer's disease and related dementias and how to care for someone after a hospitalization. <http://www.alzgl.org/professionals/hospital-home-transitions/>

Endnotes

- 44 Wattmo, C., Londos, E., & Minthon, L. (2014). Solitary living in Alzheimer's disease over 3 years: Association between cognitive and functional impairment and community-based services. *Clinical Interventions in Aging*, 9, 1951–1962. doi:10.2147/CIA.S71709
- 45 Edwards, D. F., & Morris, J. C., (2007). Alone and confused: Community-residing older African Americans with dementia. *Dementia*, 6(4), 489–506.
- 46 Lehmann, S. W., Black, B., Shore, A., Kasper, J., & Rabins, P. V. (2010). Living alone with dementia: Lack of awareness adds to functional and cognitive vulnerabilities. *International Psychogeriatrics*, 22(5), 778–784.
- 47 Soto, M., Andrieu, S., Gares, V., Cesari, M., Gillette-Guyonnet, S., Cantet, C., Vellas, B., & Nourhashemi, F. (2015). Living alone with Alzheimer's disease and the risk of adverse outcomes. *Journal of the American Geriatrics Society*, 63(4), 651–658.
- 48 Lai, J. M., Gill, T. M., Cooney, L. M., Bradley, E. H., Hawkins, K. A., & Karlawish, J. H. (2008). Everyday decision-making ability in older persons with cognitive impairment. *American Journal of Geriatric Psychiatry*, 16(8), 693–696.

Project Methodology

We used a two-pronged approach to develop this guide. We first conducted a literature review comprising peer-reviewed journals, grey literature—non-peer-reviewed literature such as government or advocacy organization reports—and practical tip sheets to determine the state of the science and current practices implemented with individuals who have dementia and live alone. The available information about people with Alzheimer's disease and other dementias who live alone is limited. There are many published studies about people with Alzheimer's disease and other dementias, and some published studies about older people who live alone, but very few studies have addressed the intersection of these groups.

We also conducted a series of interviews with subject matter experts who have experience with community programs or services for people with dementia who live alone. These expert interviews informed the strategies addressed in this guide. We relied on the experiences and knowledge of the subject matter experts rather than just empirical evidence developed from controlled studies in an effort to ensure that these strategies have been tried and tested in real-life situations.

A total of eight people were interviewed, including representatives from APS, emergency first responders (i.e., law enforcement), geriatricians, geriatric care managers, legal staff of the ABA Commission on Law and Aging, state officials from departments on aging, and researchers participating in the Alzheimer's Disease Initiative grant programs.

Two project members conducted each interview, with one individual leading the discussion while the other focused on taking comprehensive notes. The interviews were structured around a core set of questions that covered six major challenges and concerns of working with individuals with dementia who live alone. Interviews lasted approximately 1 hour each. With the permission of the interview participants, all interviews were audio-recorded. Team members took detailed notes during each interview, which were verified from the audio recordings. The interview notes were then summarized and incorporated into the strategies detailed in the guide.

This study has certain limitations that deserve noting. The literature review entailed a targeted examination of materials specifically focused on individuals with Alzheimer's and other dementias who live alone, but is not a comprehensive examination of all literature related to each individual topic under consideration. Additionally, we conducted a limited

number of interviews with experts who have experience with community programs or services for people with dementia who live alone; however, other important perspectives are not included, such as those of other experts, those of individuals with dementia who live alone, and their family members or other informal caregivers. Although limited in scope, our research sheds light on many important strategies for serving individuals with dementia who live alone.

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