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Planning for Dementia-Friendly Communities

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Many planners have thought and written about the numerous impacts of America's aging population. Rightly so, given that the country's population over the age of 65 is set to increase by 54 percent over the next two decades (Federal Interagency Forum on Aging Related Statistics 2017).

Much of this discussion has focused on the visible impacts of a "graying" community—from the need for more wheelchair-accessible homes to changing desires about retirement communities (Dunham-Jones and Williamson 2011; Stafford 2021). Yet one impact has not been discussed, despite its salience for community planning and the well-being of older adults. That aspect is the increase of people with dementia in American communities.

In the United States, about one in 10 older adults—roughly five million people—have some form of dementia (The Economist 2020). The aging of the population, however, means that this number will likely grow to about eight to 10 million people over the next 20 years (Federal Interagency Forum on Aging Related Statistics 2017).

People with dementia will be a growing population in almost every community, and will be increasingly present in public spaces and local neighborhoods (Przydatek 2014; Su 2013). Though they are often assumed to live in congregate facilities such as nursing homes, about 90 percent of people with dementia live in community settings, most often with family members (Sustasis Collaborative 2020; Turner and Morken 2016). Many experts predict that an even higher share will "age in place" as time goes on, as the disproportionate impact of COVID on nursing homes has made many families wary of placing loved ones in institutions (Abelson 2021). People with dementia and their care partners will instead seek services, environments, and opportunities in the communities where they already live. Indeed, many funding and support structures encourage people with dementia to live in their communities.

This process will happen in a built environment that does not always suit people with dementia. Dementia affects the way people interact with and in spaces, and many people with memory loss find typical ways of interacting with the built environment or other people difficult or impossible. The way that planners plan neighborhoods, facilities, and services can make it easier or harder for people with dementia to use, live in, or go to and from these places (Figure 1). As is the case with many other people with disabilities, people with dementia are disabled by the environments around them (Biglieri 2021a; Turner and Morken 2016; McGettrick and Williamson 2015).

Many planners simply have not thought about dementia—but they should. When the needs of people with dementia are considered, places become safer and easier to navigate. A dementia-friendly community allows people with dementia to have a safe, accessible, and dignified life in the community (Hanley 2021; Turner and Morken 2016). This can be empowering, especially in a society that is biased against people with



Figure 1. Benches, safe sidewalks, distinct buildings, and a welcoming streetscape all play a role in helping older adults with dementia (Jonathan Paul Katz)

dementia (Barbarito 2021; Patterson 2021; Su 2021). By making dementia-friendly spaces, planners can play a big role in achieving that goal.

This *PAS Memo* identifies strategies and best practices to incorporate dementia-friendly approaches in planning for transportation, housing, public space, urban fabric, and social services. To prepare planners for doing this work, it provides background information about how people with dementia experience the built environment, offers guidance on how to reach out to people with dementia and their care partners, and introduces various organizations and actors that work with people with dementia and their care partners that can connect with planners' work. Throughout, it suggests action steps and highlights examples from across North America to help planners create more dementia-friendly communities.

Dementia in the Community Context

"Dementia" is not one disease, but rather a family of progressive conditions (CDC 2019). As noted in the sidebar, dementia encompasses different conditions that cause memory loss, sensory and mobility changes, slower cognitive processing, and differences in communications and retaining new information (Akagi and Adachi 2015; Biglieri 2018; Cipriani and Borin 2015).

People with dementia are still part of their communities, and their experience with dementia is connected to their social contexts. The medical focus of dementia discourse, however, means that social aspects of dementia often go unaddressed (Biglieri 2021a; Goldman 2021; Stafford 2021; Su 2021).

Communities and neighborhoods provide a key sense of stability for people with dementia, as well as many tangible and intangible quality-of-life benefits (Biglieri 2018; Mitchell, Burton, and Raman 2004; Smith et al. 2019; Stafford 2021). But people with dementia face cognitive and physical barriers to access as they move among homes, public facilities, and open space in their daily lives and use different modes to do so (Diamond et al. 2021; Florida Department of Elder Affairs 2010; Hauger et al. 2019; NADTC 2018).

Memory, navigation, and communication pose special challenges for people with dementia in the built environment. Most people with dementia experience memory loss and may forget how to get to places, why they went to a place, or to which places they need to go, including their homes (Marquardt 2011; Passini et al. 1998). Furthermore, many people with dementia have trouble navigating areas. Environments can be confusing, especially if they change often (Brorsson et al. 2011; Mitchell, Burton, and Raman 2004). Complex directions and multiple travel options can also overwhelm people with dementia (Biglieri 2018; Su 2013; Akagi and Adachi 2015). They often miss cues that help people navigate the built environment—for example, signs that mark places to turn, traffic lights, or verbal or written directions on transit. Many of these difficulties are exacerbated by inadequate environments (Marquardt 2011; Biglieri 2021a; Stafford 2021; Su 2021).

Physical needs also matter. Many people with dementia take slower, longer steps that are less balanced than typical walking patterns. This gait can become more irregular in sensorily

Definitions

"Dementia" encompasses a series of progressive conditions that occur overwhelmingly in older adults. People with dementia experience intensifying memory loss, changes in cognition and sensory processing, loss of language, and loss of executive function. Common types of dementia include Alzheimer's disease, vascular dementia, and Parkinson's dementia. Alzheimer's disease comprises the majority of dementia diagnoses (Cipriani and Borin 2015; Mitchell, Burton, and Raman 2004).

"Care partner" is anyone who is the main provider of care for someone with dementia. Care partners can be spouses, adult children, other relatives, or close friends. Though the term "caregiver" is more common, many advocates with dementia, their families, and their friends prefer the term "care partner" (Shin 2018). This term encompasses the idea that people with dementia also participate in decisions about their care, and deserve the same dignity as those that give care (Goldman 2021; Kenney 2021).

overwhelming environments—places with crowds, significant noise or light, or high amounts of information. This means that people with dementia are at a high risk of falls that can cause serious injury or death, especially when many obstacles or slippery surfaces are present (Akagi and Adachi 2015; Volkmer et al. 2020; Shaw 2002). Too much sensory input can make it harder for people with dementia to navigate and can be very distressing (Marquardt 2011). In addition, many people with dementia have incontinence or urgent toileting needs (Greed 2003; Tales et al. 2017; Whetzel 2021).

The needs of people with dementia will also vary depending on their type of dementia. For example, someone with Down's syndrome-related dementia may have more trouble with communication than someone with more typical forms of Alzheimer's disease (Moran 2017). Many people with Parkinson's disease have a more affected gait than people with mild cognitive impairment (Volkmer et al. 2020). The most effective planning interventions for dementia account for these multiple experiences—and, as forms of universal design, often help other people with disabilities and various marginalized experiences as well (Dementia Friendly America 2021; Hendren 2020).

These physical, mental, individual, and social needs all occur—and must be planned for—together. A dementia-friendly community is one that supports the active participation of and agency for people with dementia in all community contexts (Turner and Morken 2016). In a dementia-friendly community, people with dementia can go about their day and interact with others while facing minimal barriers to access (Mitchell, Burton, and Raman 2004).

Planners can help create dementia-friendly communities by taking the following actions:

- Providing usable transportation options for people with dementia
- Supporting the construction of accessible housing, public spaces, and streetscapes
- Bolstering social infrastructure and social services that serve people with dementia and their loved ones
- Reaching out to people with dementia and their care partners in appropriate ways
- Ensuring that public meetings and communications are accessible to people with dementia

There are many strategies that planners can apply within their communities to improve quality of life for people living with dementia and their care partners.

Dementia-Friendly Planning in Specific Contexts

Planners can act in a wide range of sectors and contexts to improve the dementia-friendliness of a community. These include transportation, housing, public space, urban fabric, and social services and infrastructure. The following sections describe the common challenges faced by older adults with dementia within each of these contexts, along with policy, design, and programmatic recommendations for planners to help address barriers to access.

Transportation Interventions

People with dementia, their care partners, and professionals that work with them often cite transportation as the main challenge that they face.

Most people with dementia lose the ability to safely drive or use public transportation alone (Diamond et al. 2021; Hauger et al. 2019), so care partners often spend significant amounts of time providing transportation (Hanley 2021; Katz 2020b; Kenney 2021). Many people with dementia remain isolated at home, which can be a significant constraint in car-centric areas (DeGood 2011; Su 2013). Most program providers for people with dementia specifically consider transportation, because otherwise clients will not have the ability to attend (Barbarito 2021; Diamond et al. 2021; Riley 2021; Stafford 2021).

Staff training, volunteer driving programs, and paratransit service design have proven helpful in many places. Transit

agencies that have trained staff on dementia-friendly communications report that people with dementia feel more comfortable using their fixed-route and paratransit services (Diamond et al. 2021). Volunteer driver programs, often provided through neighborhood-level groups called “villages,” help thousands of older adults access their daily needs every year (Figure 2) (Florida Department of Elder Affairs 2010). These programs are particularly effective in highly car-dependent neighborhoods (AARP 2020a). Some small German towns even provide volunteer-operated fixed route services for older adults, called Bürgerbusse (Röhrig et al. 2018). Improving paratransit services and other mobility services to better meet people with dementia’s needs through changes to practice or assistance in enrollment is also often helpful (Diamond et al. 2021). These methods are best supported by funding, targeted programs, and programmatic outreach.

Actions that planners can take include the following:

Work with and expand programs that help people plan for driving cessation. When older adults, especially those with dementia, are no longer able to drive themselves, this can cause feelings of depression, infantilization, or constraint. This adjustment also requires significant learning and work for care partners (Diamond et al. 2021). Programs that help people plan for driving cessation have proven beneficial (NADTC 2018; Dorner, Rieder, and Stein 2011). Staff in these programs help people plan for moving around without a car, learn about local transportation resources, and emotionally prepare for this major life change (AARP 2020a; Weiss, Schneider-Schelte, and Jansen 2018).

Planners in local governments can advertise these programs widely and refer community members to their services. Planners in public transportation agencies can collaborate with driving cessation programs to help people with dementia and care partners navigate services in the context of the program.

Work with and support volunteer driver programs. Volunteer driver programs tend to operate independently of local governments (AARP 2020a; Florida Department of Elder Affairs 2010). Planners can provide financial and technical support to such organizations, and direct residents to their services (National Center for Mobility Management 2021). These programs



Figure 2. Volunteer drivers often form a key transport support for people with dementia (Vermont Agency of Transportation n.d.)

are often short-staffed, so planners can also help recruit drivers, many of whom are older adults themselves (Kenney 2021; Nelson 2021). Some transit agencies in Missouri, New Hampshire, New York, and Vermont work closely with volunteer driver programs and help coordinate their operation, which can help integrate volunteer driver programs more closely with other transportation options (Studebaker 2018; cf. Nelson 2021). If there is no volunteer driver program in your area, consider working with stakeholders to start one.

Work with and expand paratransit programs. Many older adults with dementia also have other mobility disabilities that make volunteer drivers' cars inaccessible (CDC 2019). Paratransit provides an essential connection for many older adults with dementia. Many social service providers successfully engage with paratransit services to provide transport to and from programs (Katz 2020b).

Planners should work with paratransit providers to expand services for older adults with dementia, which may include removing requirements for service such as an ability to independently get from the door to the vehicle (Diamond et al. 2021; Hauger et al. 2019). Expanding paratransit service boundaries will provide another transportation opportunity (Iseki 2021; Nelson 2021). Do note that drivers will need additional training to ensure that people with dementia can effectively and safely use their services (Diamond et al. 2021).

Pursue Section 5310 funding for transportation programs. This grant program from the Federal Transit Administration is provided to states and localities to support transportation for older adults and people with disabilities (Federal Transit Administration 2021). Funding can be used to support driving cessation programs, volunteer driver programs, paratransit equipment, mobility management programming, and other support for transportation for older adults with dementia. The National Aging and Disability Transportation Center provides support for Section 5310-funded and other projects, and it has supported dementia-targeted programming in the past (Diamond et al. 2021; Nelson 2021).

Expand mobility management programming. For many older adults with dementia, neither public transit nor paratransit are effective or appropriate ways to travel (Vanderbur and Silverstein 2006; NADTC 2018). Mobility managers help clients, including older adults, identify transportation resources and set up ways to access them (Dementia Friendly Massachusetts 2021).

Expanding mobility management programming will allow more older adults with dementia and their care partners to access resources like specialized transportation services, paratransit where appropriate, and volunteer driver programs. Service providers and human services agencies across the United States already have established programs to learn from, and the National Center for Mobility Management also offers technical assistance and resources (National Center for Mobility Management 2021).

Provide training for transportation staff. Bus drivers, ride schedulers, train operators, and others frequently interact with people with dementia. Problems often occur because these workers do not have adequate knowledge of how to communi-



Figure 3. This housing development in Columbia, Maryland, includes residences with and without step-free entrances, which are a key accessibility feature (Jonathan Paul Katz)

cate with and assist riders with dementia (Diamond et al. 2021).

Planners can share information on dementia-friendly training videos and work with local communities to help these essential workers better serve community members with dementia (Dementia Friendly America 2021).

Housing Interventions

Housing design in many North American communities is inappropriate for older adults, and advocates, architects, and planners have long noted the inadequacy of most housing for older adults with dementia (Fausset et al. 2011; Lewis 2020; Su 2013).

People with dementia whose sensory and navigation abilities are greatly reduced often burn themselves, fall, or experience other injuries in part due to problematic housing designs (Kenney 2021). Older adults usually have mobility, visual, and hearing limitations, which are exacerbated by the processing loss inherent to dementia (Lewis 2020). Though accessory dwelling units (ADUs) and denser housing benefit many older adults (AARP 2020b), people with dementia often still experience the same risks and barriers in these units (Przydatek 2014).

Supporting people with dementia and their care partners who wish to remain in the homes and communities to which they are attached will require increasing the amount of housing with life-long designs that reduce risk (Fausset et al. 2011). Planners can play a role in this effort through the planning and approval processes for development.

Actions that planners can take include the following:

Encourage life-long housing designs and architectural interventions that reduce risks. Barrier-free design encompasses features such as step-free entrances, kitchen counters at varying heights, and the ability to keep a residence on one floor (Figure 3) (Biglieri and Dean 2017; Hendren 2020). These designs can be enhanced by aids such as automatic timers on burners, clear boundaries between rooms and areas of the house, and easily visible controls (Social Care Institute for Excellence 2020).

Most of these interventions will be the responsibility of architects and developers, but planners can help make them a reality. Some states, such as Maryland, offer incentives and financial assistance for building homes that meet certain accessibility standards (Maryland Department of Aging 2016). Some counties and municipalities already mandate a certain number of accessible units for plan approval (Guzman, Viveiros, and Salomon 2017). Planners can work with developers to encourage construction of units with these features. Renovation and restoration programs, such as some local efforts in Maryland, can also mandate these efforts for some or all units (Lien et al. 2016; Howard County 2020).

Public Space Interventions

As described above, the physical and cognitive changes of dementia affect the ability to navigate the built environment. People with dementia may wander, meaning that they roam without full knowledge of awareness of their location, and they can easily become disoriented, especially in new places (Marquardt 2011). This disorientation and changes in gait can lead to falls, which, as noted earlier, can be deadly (Shaw 2002; Volkmer et al. 2020).

Planners can design public spaces such as parks, squares, and plazas with features that mitigate the problems people with dementia might face. Because needs differ significantly among individuals and across the progression of dementia, these areas may not be perfectly accessible for all, but designing for better orientation, safe and comfortable walking, and

easier navigation can significantly reduce the barriers for people with dementia in public spaces (Biglieri 2021a; Goldman 2021; Stafford 2021; Su 2021).

Actions that planners can take include the following:

Offer multiple forms of wayfinding. People with dementia have different capacities in following text, verbal, and visual cues. Some may need to follow a path or line to a single place, while others need repeated input from signs or other information (Su 2013). Therefore, wayfinding systems that provide multiple types of information and input tend to work best (Akagi and Adachi 2015; Marquardt 2011).

Architectural designs, art such as murals and statues, and cues such as paving color can also help to direct people. Signs should include words and images. Photo wayfinding, which incorporates photographs of landmarks or destinations in signage and other wayfinding devices, can be easier for many people with dementia to follow (Figure 4) (Biglieri 2021a; Seetharaman, Shepley, and Cheairs 2020).

Provide seating and easily distinguishable rest areas. Many older adults with dementia have mobility disabilities that reduce the amount of time they can walk, but they may not respond to their exhaustion unless they see a place to sit down or rest (Volkmer et al. 2020). Making seating available every 200 to 300 feet on a pedestrian route will make walking more pleasant and possible for many older adults with dementia (McAdam and Williams 2017).



Figure 4. Photo wayfinding from the Hagerstown Cultural Trail, Hagerstown, Maryland (City of Hagerstown/Icon Graphics)



Figure 5. Ample seating and distinguishable places help make public spaces, like this park in Cincinnati, more navigable for people with dementia (Jonathan Paul Katz)

Seating areas should be easily visible from paths and the surrounding environment (Figure 5)—“natural” benches or secluded seats are hard to perceive (Marquardt 2011). In addition, visible seating provides sensory input that many people with dementia find pleasurable or comforting (McAdam and Williams 2017). Many care partners note that their loved ones with dementia enjoy sitting in and watching vibrant public spaces (Katz 2020a).

Provide public restrooms. Generally speaking, public restroom infrastructure is lacking in the United States (Molotch 2010). People with dementia are especially affected, as they often suffer from incontinence and have other illnesses that affect elimination (Tales et al. 2017). Many people with dementia and care partners account for restroom availability whenever leaving the house and may plan travel based on toilet access (Lowe 2018; Whetzel 2021).

Planners can advocate for the construction of accessible public restrooms in public spaces and promote best-practice design guidelines (Hanson, Greed, and Bichard 2004). Restroom exits should be clearly marked, as they are often difficult for people with dementia to find (Tales et al. 2017). Single-user restrooms are especially helpful for people with dementia who need a care partner’s assistance in the bathroom (Greed 2003).

Ensure that sidewalks and crosswalks are easily distinguished and are not sensorily overwhelming. Because people with dementia have difficulty processing disjointed or slight changes in information, common crosswalk and sidewalk designs, such as zebra stripes and subtle paving variations, are difficult for them to follow (Brorsson et al. 2011). Crosswalks at intersections are also difficult for many people with dementia to cross, since they cannot manage the varied sensory inputs of crossing, acknowledging cars coming from multiple directions, and turns (Brenac and Fournier 2018; Brorsson et al. 2016; Su 2013). Sidewalks with high levels of light and sound input have similar issues (Lewis 2020).

Crosswalks and sidewalks should be marked with continuous paint or paving that is easily distinguishable and that visibly contrasts with surrounding roads and environments. Placing crossings mid-block requires less cognitive processing for people with dementia to cross, and they can also be a useful traffic calming measure (Lewis 2020). In parking lots, back-in parking will reduce risk, as reversing vehicles are particularly tricky for many people to perceive (Brenac and Fournier 2018).

Help people navigate around or through changes in the built environment, such as new features and construction sites. People with dementia may not be able to identify new routes through or around changes in their environment (Mitchell, Burton, and Raman 2004). People on the autism spectrum can also experience this challenge (Ezell, Korniyenko, and Stein 2018).

Mark paths around construction sites and street works in multiple ways with suitable wayfinding. Consider doing the same when new buildings or structures are developed or older structures are removed; these structures are often landmarks for local people with dementia, who may become disoriented as a result (Biglieri 2021a; Stafford 2021). One low-cost example is to include arrows on the sidewalk or path for navigation.

Urban Fabric Interventions

The challenges that affect people with dementia in public spaces also apply to neighborhoods and communities as a whole. Many struggle to navigate, especially in new developments or in large neighborhoods with complex street and architectural patterns (Biglieri and Dean 2017; Mitchell, Burton, and Raman 2004).

Going to places independently is important for well-being for many people with dementia, but difficulties in navigation and orientation often become most apparent when leaving a street, public space, or development (Mitchell, Burton, and Raman 2004). Research is still ongoing, but certain interventions have been shown to help. These include changes to street patterns, architectural texture, and the provision of recognizable landmarks (Akagi and Adachi 2015; Biglieri 2018, 2021b; Brorsson et al. 2011, 2016).

Actions that planners can take include the following:

Plan for shorter streets, and where possible, incorporate gentle winding or irregular grids. Long, straight streets, as well as regular grids, can be difficult for people with dementia to navigate or process (Mitchell, Burton, and Raman 2004). Research has found that shorter streets with irregular grids are more navigable (Biglieri 2021a). Shorter grids also reduce the confusion between different intersections. Adding a gentle wind or curve also helps some people navigate along the streets’ paths (Mitchell, Burton, and Raman 2004).

Incorporate clear lines of sight. Familiarity and consistency in the environment are key for independent navigation by people with dementia (Lewis 2020). Researchers find that being able to see familiar components clearly makes navigating clear and less stressful (Brorsson et al. 2016). Make sure that important destinations, signs, and other things are



Figure 6. This “Mural of Unusual Size” in Hagerstown, Maryland, is an example of public art that can ease navigation (Jonathan Paul Katz)

clearly visible from multiple angles and for people coming from multiple directions. These clear lines of sight also help people with dementia see the various landmarks they use to navigate (Lewis 2020).

Include and maintain architectural variety. Researchers have found that monotonous or highly regular architectural environments are difficult for people with dementia to navigate (Mitchell, Burton, and Raman 2004). People with dementia often use distinctive buildings or specific houses or structures as reference points, especially on routes they take regularly (Biglieri 2021a).

Ensure that regulations encourage variety in elements such as house color, building size, and setbacks. Changes may be needed in your community’s design regulations, homeownership association bylaws, or historic district rules (Avin 2021), as conformance to strict design constraints may lead to environments that are less navigable by people with dementia (Su 2021).

Use recognizable landmarks and public art. Murals, monuments, and distinctive buildings make it easier for people with dementia to navigate public spaces and to orient themselves in a place, especially areas that they go through regularly (Biglieri 2021a; Marquardt 2011; Mitchell, Burton, and Raman 2004; Su 2013). Researchers have found that people with dementia find these things more useful than many traditional wayfinding interventions (Przydatek 2014; Seetharaman, Shepley, and Chairs 2020).

Planners should encourage public arts initiatives that bring landmarks and other arts installations to areas, because these are a boon for residents with dementia. One example is the Mural of Unusual Size in Hagerstown (Figure 6), which has eased navigation for residents and visitors there (Syrkett 2017)—among them, likely, many people with dementia.

Social Services and Social Infrastructure Interventions

Social infrastructure is the set of institutions that provide opportunities for socialization, assistance, and cognitive and emotional stimulation. These include libraries, senior and



Figure 7. A senior center in Edison, New Jersey (Jonathan Paul Katz)

community centers, parks, schools, adult day cares, and cultural programs (Figure 7) (Klinenberg 2018).

Though this is beginning to change, most social infrastructure lacks dementia-targeted programs (Katz 2020b), which are essential for the well-being of people with dementia in the community. These facilities can provide activities, food, and transportation, as well as a break for care partners and access to other community resources (AARP 2016). Such services are particularly helpful for people with dementia as they adjust to new realities (Turner and Morken 2016), live through disasters and other large-scale events (Smith et al. 2016), or face new challenges as their conditions progress (Weiss, Schneider-Schelte, and Jansen 2018). The social interaction these spaces offer is directly linked to better physical and mental health (Dementia Friendly America 2021).

No design intervention can substitute for the essential role that social infrastructure plays. The shutdown of social infrastructure due to the coronavirus pandemic had particularly strong effects on clients with dementia who used these services (Barbarito 2021; Patterson 2021). A robust social infrastructure is essential to support healthy and happy living for people with dementia in the community. Planners have a role in supporting such programs.

Actions that planners can take include the following:

Expand senior center and library programming for older adults with dementia. Cognitively and culturally appropriate programming for people with dementia offers opportunities for engagement, care partner respite, and improvements to well-being. Many senior centers around the country already provide targeted programming; programs in Seattle and Vancouver have been particularly successful (Katz 2020b). Libraries, often more readily accessible in neighborhoods, are also frequent gathering places and can provide programming (AARP 2016; Klinenberg 2018).

Ensure that programming is welcoming and engaging and meets the cultural context of the community (Portland State

University 2020). Planners should consult with social workers and other practitioners who already provide programming to older adults with dementia.

Develop programming through parks and recreation departments. These departments often manage and offer the programming in senior and community centers across the country, so staff have significant experience working with older adults (AARP 2016). Exercise, nature-centered, and social programming offer chances for social and cognitive engagement, and these can be blended with other programming for intergenerational activities. Much of the current dementia-related programming focuses on fall prevention (Katz 2020b; Kenney 2021). While this effort is important, more variation in programming will create a more inviting environment (Goldman 2021).

The Town of Groton, Connecticut, has developed a range of programming for older adults with dementia through its parks and recreation department. Programming at the senior center includes opportunities for social and cultural engagement, exercise, and access to other town- and state-provided services. Service providers also trained members of the Groton Police Department to better work with residents with dementia, and family members can register loved ones for protection from incidents. This integrated approach has helped better the lives of Groton's older adults with dementia who live in the community (Patterson 2021; Riley 2021).

Work with local volunteer programs, social infrastructure, and nonprofit organizations to connect with older adults. Many volunteer programs and local nonprofit organizations already serve older adults with dementia and their care partners, as do many senior centers, libraries, and community centers (AARP 2016). These programs and networks communicate information about opportunities and initiatives to their members (Kenney 2021). Many jurisdictions already work with these programs to identify potential clients, as is the case in Groton (Patterson 2021; Riley 2021). Such organizations are particularly important when working with older adults with dementia who are members of minority communities, especially if they do not speak English well or at all (Portland State University 2020; Sütterlin, Hossman, and Klingholz 2011). These organizations can provide planners important cultural information, language assistance, and contextual knowledge about needs and desires. Montgomery County, Maryland, works with culturally specific community organizations such as churches and charities to better serve Hispanic and Asian-American older adults (Katz 2020b; Kenney 2021).

Train social infrastructure staff and first responders on dementia-friendly communication. Staff in these settings interact with people with dementia very frequently (American Red Cross 2020). Dementia-friendly training will allow staff to better meet clients' needs. The Dementia Friendly America toolkit recommended for planners and transportation staff is a good start (Dementia Friendly America 2021). However, many of the needs these staff may address require additional training. Some communities have found success in training first responders by engaging with their local Alzheimer's Associations (Patterson 2021; Riley 2021; Stafford 2021).

Incorporate dementia perspectives in emergency planning. People with dementia are at increased risk during emergencies and are also often unable to follow standard evacuation orders and directions (American Red Cross 2020). Proactively include dementia-friendly protocols when planning for disaster preparedness or other emergencies, including signage, planning for service procedures, and making preparedness plans. Many jurisdictions collaborate with local Alzheimer's associations and dementia advocates to prepare plans and protocols (Barbarito 2021).

Informing the Process: Communications

In creating dementia-friendly communities, planners must also look beyond programs and built environment design. Outreach to people with dementia and their care partners is the cornerstone of any dementia-friendly policy. Interventions and programs for people with dementia work best when people with dementia are consulted and included in the process (Hanley 2020).

Area agencies on aging, departments of human services or on aging, and nonprofit groups that focus on aging often have expertise in this area (Kenney 2021). The following recommendations will help inform planners' outreach, communications, and interactions.

Communicate with people with dementia and their care partners—not just the latter. Many service providers and people only speak to a person with dementia's care partner, because they assume the person with dementia will not be capable of communicating with them (Dementia Friendly America 2021; Turner and Morken 2016).

This practice is mistaken for three reasons. One is that the care partner may not be aware of specific aspects of how a person with dementia does things; that information is best elicited from people with dementia themselves (Pape-Raschen 2012). Secondly, most people with dementia are able to communicate with others, even if some assistance or adjustments are needed (Stafford 2021). Finally, this practice can be humiliating and traumatic for many people with dementia, which can impact the efficacy of any intervention, tool, or communicative practice (Barbarito 2021; Goldman 2021; Kenney 2021).

That said, do also communicate with care partners. Many common interventions, such as volunteer driving programs, are meant to benefit care partners too (NADTC 2018). Care partners may also notice things their loved one does or needs help with that the person with dementia may not notice themselves (Biglieri 2021a).

Area agencies on aging, senior centers, and human services departments often work with people with dementia. These groups can help you reach out to people with dementia and their care partners, as can any local organizations or facilities that specifically serve people with dementia, such as a memory cafe (Barbarito 2021; Kenney 2021; Stafford 2021; Memory Cafe Directory 2021).

Use dementia-friendly language and refer to people how they wish. Generally speaking, use "person with dementia" or "person living with dementia," or substitute the word

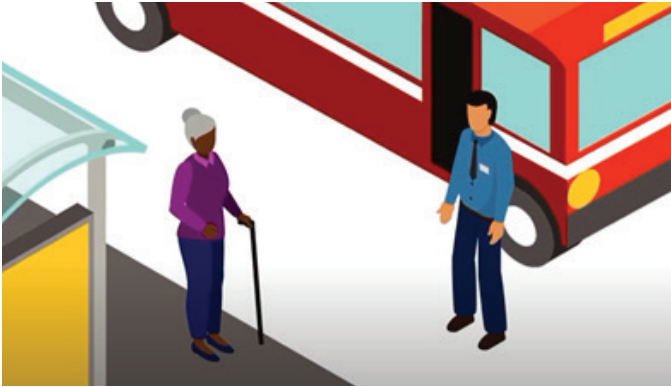


Figure 8. A screenshot from one of Dementia Friendly America's training videos (Dementia Friendly America 2021)

"dementia" for a diagnosis (Dementia Friendly America 2021). Using the word "suffering" to describe the condition or the term "demented" offends many people with dementia (Smith et al. 2019; Swaffer 2014). Always refer to people by their name, and only refer to someone else's dementia in public if that person with dementia has given their consent. Many people with dementia prefer to keep their diagnoses private, and disclosing diagnoses can be problematic from an operational or legal standpoint (Whetzel 2021).

Train yourself and your staff with Dementia Friendly America's materials. Dementia Friendly America (www.dfamerica.org) offers a free video course that trains users in good communication practices with people with dementia (Figure 8). These videos offer practical advice and examples, such as how to help someone with dementia at a public facility like a library (Dementia Friendly America 2021). Many governments and linked organizations already use these materials, and this is often the first part of many detailed trainings for first responders (Barbarito 2021; Hanley 2020, 2021; NADTC Staff 2017).

Disseminate communications that are dementia friendly. Dementia leads to changes in reading comprehension; most people with dementia have trouble with long, complicated writing (CDC 2019). Some people with dementia also have difficulty reading, or with digital communications (World Wide Web Consortium 2021).

For dementia-friendly documents, write in plain language, and avoid long paragraphs and small fonts. Use both images and text. Disseminate communications by multiple media to reach as many people as possible. Repeat important information a few times, which can help with comprehension (Biglieri 2021b; Mitchell, Burton, and Raman 2004; Smith et al. 2019). New guidance on cognitive accessibility from the World Wide Web Consortium, which provides standards for web content, covers best practices for dementia-friendly websites (World Wide Web Consortium 2021).

Ensure that public meetings are accessible for people with dementia. Make sure that spaces are accessible. This effort should include the following practices (Biglieri 2021b; Stafford 2021; Swaffer and Radnofsky 2016; Whetzel 2021):

- making sure that rooms and facilities have clearly marked entrances, exits, and bathroom facilities
- ensuring that trip hazards are removed wherever possible
- making sure that sound does not ricochet or echo, which can be overwhelming
- providing safe and accessible public toilets
- ensuring that lights are not too bright or too dim
- arranging information and seating such that things can be seen at once

Many people with dementia and their care partners also benefit from respite rooms or quiet spaces where they can recover from sensory overload, anxiety, or fatigue (Swaffer and Radnofsky 2016). Providing such a room can also benefit people on the autism spectrum (Ezell, Korniyenko, and Stein 2018). Conference guides for people with dementia are also helpful, such as Dementia Alliance International's conference guidelines (Swaffer and Radnofsky 2016).

Use visual recording and arts for greater engagement.

For many people with dementia, visual recording and looking at images can aid comprehension and spur cognitive engagement (Brorsson et al. 2011; Seetharaman, Shepley, and Cheairs 2020). Some conferences and events have employed visual recorders to help note what occurred and what is being imagined, which can also help with visualizing proposed interventions (Stafford 2021; Swaffer and Radnofsky 2016).

Many places have also engaged people with dementia as co-creators in art projects that communicate their needs, desires, and perspectives (Seetharaman, Shepley, and Cheairs 2020; Smith et al. 2019). Researchers and advocates with dementia in Greater Manchester, England, created zines to illustrate how people with dementia live in the community and various interactions they may have throughout the day (Figure 9, p. 10). These richly illustrated documents were distributed throughout advocates' neighborhoods. The zines helped residents learn what people with dementia in the community might need and helped dispel many stereotypes about how people with dementia live. The zines also showed various points at which local government and organizations might provide assistance for residents living with dementia—for example, by moving trash bins for residents (Smith et al. 2019; University of Salford 2020). Such projects not only help people with dementia feel empowered, but also communicate various intricacies that might otherwise be lost (Biglieri 2021a; Smith et al. 2019).

Action Steps for Planners

Many of the actions proposed in this article require building significant relationships, pursuing various funding, or developing programming. The sooner planners take action that will inform future dementia-friendly programming and interventions, the better community outcomes they can achieve for all.

To get started, planners can identify transportation, housing, social, and advocacy organizations that work with people with dementia and their care partners, and reach out to these organizations to establish relationships and to reach out to



Figure 9. Panels from a zine about people with dementia developed in Manchester, England (University of Salford)

people with dementia, as described above. The sidebar offers more information on partners for dementia-friendly community planning.

As noted throughout this article, it is important to engage directly with people with dementia and their care partners to learn about issues and challenges they are facing in the community. Plan for a meeting, survey, or other event to collect input and information from people with dementia and their care partners to gather information that will help inform dementia-friendly planning efforts.

The best practices highlighted in this *PAS Memo* can help planners identify areas in which their communities are already dementia-friendly, as well as places that may require improvement or new initiatives. Both the program and built environment practices described above here can be used as indices, whether by tracking the presence or absence of a practice or how well-supported or well-implemented that practice is. Planners should assess built environment and program aspects together because they work best in tandem. For example, a community center and surrounding complex that has a dementia-friendly design is helpful, but its benefits to people with dementia can be bolstered by the presence of dementia-friendly programs at the center and accessible transportation from and to the facility.

Finally, all planners can pursue dementia-friendly training from advocacy organizations such as Dementia Friendly America.

Conclusion

People with dementia are not the only people that benefit from dementia-friendly policies. Many of these interventions also benefit other people with disabilities and parallel recommendations for autism-friendly planning (Ezell, Korniyenko, and

Community Partners for Dementia-Friendly Planning

Various organizations frequently work with older adults with dementia in community contexts. In the United States, area councils on aging, human services departments in local governments (such as departments of aging or social services), and community-based social service organizations manage many of these efforts. This work includes the following activities:

- Providing basic nutrition, health, mental health, and safety services
- Helping people with dementia get around (Figure 10)
- Delivering programming for socializing, health maintenance, and care partner respite (Kenney 2021)
- Creating opportunities for social and emotional engagement (Patterson 2021)
- Advocacy around access and care for people with dementia (Sustasis Collaborative 2020)

These organizations all can offer valuable advice for reaching out to, the needs of, and considerations for people with dementia. In addition, these services can help planners identify specific problems people with dementia face in a specific community—for example, trouble with transportation or difficulty with navigating public space. Planners who work on transportation or housing for older adults often work with community organizations exactly in this way (Diamond et al. 2021). Planners can also coordinate new initiatives with these organization's initiatives—for example, a new paratransit service may align with a program's transportation efforts (NADTC 2018). This collaboration can bring better results for people with dementia and their care partners.



Figure 10. Government agencies that provide paratransit are among many organizations that serve people with dementia (Adam Moreira, CC BY-SA 3.0)

Stein 2018). Other accessibility practices also benefit people with dementia. These intersections are particularly important because many people with dementia have other disabilities. For example, wheelchair use is common among people with dementia, and people with Down's syndrome very frequently develop dementia later in life (Moran 2017).

Many of these changes, such as improved wayfinding or providing more seating areas and public restrooms, benefit the entire community. Such changes are often called "universal design" (Hendren 2020)—but specific attention to dementia is important. If interventions meant to be universal are not helpful for people with dementia, then the intervention is not dementia friendly. Specific attention to people with dementia and their needs usually produces the best and longest-lasting results.

Experience from other countries can help planners design dementia-friendly spaces. Many of the suggestions in this article come from successful programs in Germany, Austria, the United Kingdom, Canada, and Sweden (Biglieri and Dean 2017; Brorsson et al. 2011; Dorner, Rieder, and Stein 2011; Smith et al. 2019; Weiss, Schneider-Schelte, and Jansen 2018). Many communities in these countries are already experiencing a burgeoning aging population and higher numbers of people with dementia, both of which the United States can expect in the future (Turner and Morken 2016). Planners can and should research and reach out to comparable communities abroad for best practices and ideas on new programming.

Most importantly, though, planners must listen to people with dementia themselves. They are the people who benefit from these interventions, and they are the ones who experience dementia. Remember to listen—and be open to what you may learn. Encourage colleagues to reach out and listen to people with dementia, too. Building a dementia-friendly community is a team effort.

About the Author

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