

Review Article

From Research to Application: Supportive and Therapeutic Environments for People Living With Dementia

Margaret P. Calkins, PhD, EDAC*

The Mayer-Rothschild Foundation, Kirtland, Ohio.

*Address correspondence to: Margaret P. Calkins, PhD, EDAC, The Mayer-Rothschild Foundation, 8051 Euclid Chardon Road, Kirtland, OH 44094.
E-mail: MCalkins@TheMayer-RothschildFoundation.org

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Abstract

The evidence about the role the designed and built environment plays in supporting individuals living with dementia has been steadily mounting for almost 40 years. Beginning with the work of M. Powell Lawton at the Weiss Pavilion at the Philadelphia Geriatric Center, there are now dozens of researchers who are exploring how the environment can be either supportive and therapeutic, indeed even serving as a prosthetic for various changes in cognition, or be a barrier to independent functioning and high quality of life. Two recent literature reviews published on the impact of environmental factors and characteristics on individuals living with dementia clearly delineate evidence that the environment can have a therapeutic or a debilitating impact on individuals living with dementia. Rather than duplicate these excellent reviews, this article puts the knowledge gleaned from this research into the shifting context that is long-term care. This article begins with an exploration of the evolution of approaches to the design of spaces for individuals living with dementia from traditional or medical models, to special care units (SCUs), to person-centered care (PCC), which is the organizing theme of this supplemental issue. A novel, person-centered way of conceptualizing the domains of environmental systems is then presented and used as the framework for structuring recommendations and creating supportive and therapeutic environments for individuals living with dementia. Although there are distinct pathophysiological and behavioral manifestations of different forms of dementia, there is almost no evidence that suggests alternative environmental characteristics are better for one type of dementia over another. Thus, this article will refer to “individuals living with dementia” as opposed to Alzheimer’s disease or other specific forms of dementia. Further, this article only addresses residential environments: homes in the community, independent and assisted living residences and nursing homes. It does not address other settings, such as hospitals or hospice, or work and public community spaces, such as stores. It is recognized that individuals living with dementia do spend time in all these spaces, and fortunately, there is growing interest in creating more dementia-friendly communities, but they will not be addressed in this article. Most of the research that has been done has focused on shared residential settings, so that will be the primary focus on this article.

Keywords: Alzheimer’s disease, Assisted living facilities, Environment (i.e. ergonomics), Falls, Nursing homes, Person-centered care, Quality of life

History of Settings for Individuals Living With Dementia

The history of environments for individuals living with dementia can be traced through several distinct routes. As stated above, the earliest theoretical work in this arena was conducted by M. Powell Lawton, who with his colleague, Lucille Nahemow, developed the most widely cited theory in environmental gerontology: the Ecological Model of Competence Press (Lawton & Nahemow, 1973; Lawton, 1983). See Scales, Zimmerman, and Miller (2018) in this issue for a deeper description of this model. By the mid-1990s, several notable environment-gerontology designers and researchers had developed distinct but related versions of “therapeutic goals” that could be used to guide the development of environments—both physical and social/programmatic (see Table 1) (Calkins, 1988; Cohen & Weisman, 1991; Parker et al., 2004; Weisman, Lawton, Sloane, Calkins, & Norris-Baker, 1996; Zeisel, Silverstein, Levkoff, Lawton, & Holmes, 2003). The earliest was developed in 1986 by Lawton, and the most recent was published in 2004 (Parker et al., 2004). There is significant overlap in many of the concepts put forth by these different authors: Awareness & Orientation appear on all versions except one, and Support for Physical Functioning/Daily Activities is in every set. It is worth noting that several of these were not developed specifically for individuals living with dementia, but for older adults in general (Lawton, 1986; Parker et al., 2004)—yet the constructs remain consistent between those for older adults and those for individuals living with dementia. These therapeutic goals were used as the basis for creating supportive environments, conducting research, and developing new assessment tools, such as the Professional Environmental Assessment Protocol (Lawton et al., 2000; Parker et al., 2004; Zeisel et al., 2003).

An alternative way to examine the history of environments for individuals living with dementia is by examining the actual care settings. The focus in this section of the paper will be on shared residential settings, as they have been specifically designed for these individuals, as opposed to homes in the community which generally are not—though many of the principals are translatable. Lawton also oversaw the development of the first specialized care unit for people living with dementia. (A note about language: The term “unit” reflects older, more institutional language and will be used in this article when referring to areas, primarily in nursing homes, that were designed under that care model. Newer designs that seek to de-institutionalize and create households that reflect the homes people have come from will be referred to as either households or living areas.) The Weiss Pavilion at the Philadelphia Geriatric Center was the first purpose-built nursing home for individuals who are living with dementia (Lawton, Fulcomer, & Kleban et al., 1984). It was a radical departure from the 60-bed, double-loaded corridor design that was typical at the time, and featured an open plan with rooms for 40 residents (most in rooms shared by 2-persons) around the perimeter with central social spaces easily visible from virtually anywhere. All of the goals Lawton had

developed in 1986 were clearly used as a basis for this design: there was clear visibility to all important spaces to support orientation, the open plan allowed for superior negotiability, the ability to see other people and what was going on was designed to encourage social integration; and they worked to de-institutionalize the esthetics of the setting with plants and trellis work separating spaces (Lawton et al., 1984). Lawton estimated that this design increased the cost of construction by about 10%. But the evaluation of the Weiss institute demonstrated that “everyday behavior, including participation in enriched activities and social behavior, did not show a decline in parallel with the decline in basic functions” (Lawton, 1986, p. 131). This was the first solid evidence that the design of the built environment has an impact on the functioning (physical and social) of individuals living with dementia. Following this, a growing number of (primarily) nursing homes across the country started creating their own specialized environments for people with dementia, such that the term special care unit (SCU) was in wide use by the late-1980s. Unfortunately, many of these SCUs were nothing but a traditional unit with the doors locked to prevent what was termed “elopement.” Staffing might be not consistent, they may or may not have been given any extra dementia-focused training, and the programming might or might not have been tailored to the abilities and preferences of the residents living there. There were of course exceptions, but also real concerns over the benefits residents might (or might not) be getting for the extra costs associated with many of these units.

It was almost 10 years before there were other examples of specially designed dementia care settings, and the first and best-known examples were for assisted living. The Corinne Dolan Center at Heather Hill (Chardon, Ohio, opened in 1989) and Woodside Place (Oakmont, Pennsylvania, opened in 1991) were two early exemplary models, in part because both were subjected to rigorous evaluation research (Namazi et al., 1991; Hogle, Dimotta, Ledewitz, & Saxton, 1994). These two model care communities radically changed the standard of shared residential settings for individuals living with dementia: they were based on households of 10–12 residents (with two to three households per building), each household had a kitchen, dining room, and living room that reflected familiar spaces one might find at home (vs. the large multipurpose spaces common in more traditional long-term care settings), and each provided direct and largely uncontrolled access to substantial outdoor gardens and walking paths (Day & Calkins, 2002). Out of these designs and the accompanying research, a new approach to how to create care settings for individuals living with dementia was born. It was now possible to see concrete examples of how the therapeutic goals that had been developed were actually expressed in the design of the built environment. Through the 1990s and into the 2000s, increasing numbers of nursing homes and assisted living communities were built or converted existing units into household-based designs. And in the beginning, the vast majority of professionals (design and medical) continued to believe that these individuals who

Table 1. Therapeutic Goals for Settings Designed for Individuals Living With Dementia

	Lawton (1986)	Calkins (1988)	Cohen & Weisman (1991)	Weisman, Lawton, Sloane, Calkins, & Norris-Baker (1996)	Zeisel et al. (2003)	Parker et al. (2004)
Domains	Safety	Safety	Safety & Security	Safety & Security	Exit Control	Safety & Health
	Orientation	Wayfinding & Orientation	Wayfinding & Orientation	Awareness and Orientation	Walking Paths	
	Negotiability (increase functionality in ADLS)	Competence in Daily Activities	Support Functional Abilities	Support Functional Abilities	Autonomy Support	Support for Physical Frailties
	Aesthetics		Stimulation & Change	Regulation & Quality of Stimulation	Residential Character Sensory Comprehension	
			Autonomy & Control	Opportunities for Personal Control	Outdoor Freedom	Choice and Control
				Provision of Privacy		Privacy
	Social Integration	Privacy & Socialization	Social Contact & Privacy	Facilitation of Social Contact	Individual Space Common Space	
	Personalization	Personalization	Ties to the Healthy & Familiar	Continuity of Self		Personalization
			Adapt to Changing Needs			Normalcy & Authenticity
						Connection to Community & Awareness of Outside World
						Comfort
						Support for Cognitive Frailties

Adapted from Lawton et al., 2000.

are living with dementia had distinct and unique needs that other residents in long-term care did not have (Weisman, Kovach, & Cashin, 2004).

But that too began to change. Although care and environments might (with a stress on *might*) be better for those individuals living in these specially designed settings, these settings accommodated a small minority of all individuals living in long-term care, and many of them were subjected to highly institutional buildings (and care practices). Why do just a small number of people living with dementia deserve to live in a place that feels more like home? Shouldn't everyone? Aren't the therapeutic goals that were largely developed primarily for individuals who are living with dementia be equally applicable to any individual? Increasingly, the answer to these questions is being seen as "yes," and this reflects the growing person-centered care movement in long-term care (which is addressed in other articles in this issue).

Segregation Versus Integration

Although the development of segregated living areas solely for individuals living with dementia continues, there is also increasing discussion that segregation—whether as a separate living area within a larger care community or as a free-standing memory care building—contributes to the stigma that is currently attached to having diagnosis of dementia. A more person-centered approach is one that allows individuals who are living with dementia to live in rooms or apartments alongside individuals who do not currently have dementia (Powers, 2017a). Beyond the ethics of stigmatization, integration makes sense given the statistics that 40–42% of assisted living residents and 61% of nursing homes residents have moderate-to-severe cognitive impairment (Alzheimer's Association, 2017). It has been argued that all long-term care staff should be dementia-capable, and all environments should be supportive of the needs of individuals living with dementia. But it is often

the stigma, brought on by the fear of developing dementia that makes people not currently diagnosed want to separate themselves from individuals living with the symptoms of dementia (Lachs et al., 2016; Powers, 2014; Teresi, Holmes, & Monaco, 1993). Indeed, there is even research on the stigma of being a caregiver for individuals living with dementia (Walmsley & McCormack, 2016). This line of reasoning, however, is by no means absolute. There are also individuals living with dementia who may not want the changes they are experiencing to be seen and potentially judged by others; they may be more comfortable in a setting with people who are at a similar cognitive and functional level as they are (Gilster, S., Personal communication, 2017). There is mixed evidence about whether segregated living areas result in better outcomes. Marquardt, Buettner, and Moyzek (2014) in a recent literature review identified six studies with improved behavioral outcomes and five studies with no benefit on behavioral scores of segregated living areas. A recent Cochrane review (Lai, Yeung, Mok, & Chi, 2009) suggests there is a lack of evidence for better clinical outcomes, and other studies demonstrate an increased risk of elder-to-elder aggression or mistreatment (Lachs et al., 2016) and potentially higher antipsychotic use in segregated units (Cadigan, Grabowski, Givens, & Mitchell, 2012; Powers, 2017b). Kok, Berg, and Scherder's (2013) literature review of the topic suggests that longitudinally, residents in SCUs demonstrated greater neuropsychiatric diagnoses, displayed more deteriorations in behavior and resistance to care, as well as less decline in activities of daily living (ADLS), compared to individuals not residing in SCUs. Van Haitsms, Lawton, and Kleban (2000), in a well-designed and controlled study, found there were poorer outcomes for individuals who lived on the segregated living area than for a matched sample of residents who lived in integrated living areas. Thus, the evidence that exists about the benefits of segregation versus integration is somewhat contradictory. See also the discussion under safety versus autonomy, in the following, for a discussion of whether secured units are considered a form of restraint. It is recommended that both living options be available, to accommodate people who prefer not to be segregated or to have to necessarily relocate as their abilities change (which is common with segregated living areas), and people who prefer to live with others who are experiencing similar changes. Having both options available lets people choose—but *only if* the living areas are equally supportive. Regardless of location, it is the care community's deep adoption of person-centered care values and practices, including staff training, the approach to programming and activities and having a supportive environment, that will ultimately make the setting successful—a place where individuals living with dementia care be comfortable, feel at home, have their preferences honored, and be in meaningful relationships with those around them.

The Merger of SCU and PCC Values

Just as there were several versions of therapeutic goals listed in Table 1 for settings for individuals living with dementia (Calkins, 1988; Lawton, 1986; Cohen &

Weisman, 1991; Weisman, 1998; Zeisel et al., 2003), so too are there many conceptualizations of goals or Practice Recommendations, as they are being referred to them in this series of articles, supporting person-centered care values and practices (Harris, Poulsen, Vlangas, 2006; DHFS, 2006; Geboy & Meyer-Arnold, 2011; Koren, 2010; Pioneer Network, 2017; Weiner, Ronch, & Lunt 2013). Although there is significant conceptual overlap between the Practice Recommendations, each article in this issue has its own set of Practice Recommendations based on the different foci of that article. Previous versions of the Alzheimer's Association Best Practices documents have primarily followed a therapeutic goal framework, similar to those in Table 1. Although useful, this approach can lead to a noncohesive approach to design because there is no overarching conceptual framework that links all the therapeutic goals together. Person-centered care can, however, provide a more cohesive foundation that links the different recommendations together in a more meaningful way. The therapeutic goals are still inherent in these Practice Recommendations, but they are now subservient to higher level, person-centered goals. For example, awareness and orientation are important *because* they serve to increase individuals' comfort within a given setting. This article accepts the person-centered care values that are articulated in the first article of this issue (Fazio, S., Pace, D., Flinner, J., & Kallmyer, B. 2018), which include: know the person with dementia; recognize and accept the person's reality; identify and support ongoing opportunities for meaningful engagement; build and nurture authentic, caring relationships; create and maintain a supportive community for individuals, families, and staff; evaluate care practices regularly and make appropriate changes. Based on an extensive literature review of both research and gray literature conducted over a period of years (Calkins, Brush, & Abushousheh, 2015), a set of five overarching practice recommendations which reflect core person-centered values is proposed, each of which addresses a number of different specific design strategies for home and shared residential settings.

1. Create a sense of community within the care environment
2. Enhance comfort and dignity for everyone in the care community
3. Support courtesy, concern, and safety within the care community
4. Provide opportunities for choice for all persons in the care community
5. Offer opportunities for meaningful engagement to members of the care community

Create a Sense of Community With and Within the Care Environment

The first practice recommendation is more than just physical design-related but provides an overall framework for considering settings for individuals living with dementia. This fundamental principle suggests that designing

settings that provide continuing opportunities for individuals living with dementia to continue to be engaged with their community—with friends and church/synagogue/mosque, with shopping and restaurants, with working and volunteering—demonstrates that they deserve to continue to be considered an important part of the fabric of the community, not people to be shunned and set apart (Swaffer, 2016). This is the basis for the dementia-friendly communities movement, which is gaining traction in the United States. Unfortunately, one of the realities in the United States is that many shared residential settings for older adults are “set apart” from the community, either physically (located long distances from residential neighborhoods) or functionally (not offering any reason for people other than good friends and family to visit; Green & Calkins, 2003). Research clearly shows that the vast majority of people want to age in an age-integrated neighborhood, with children and younger people close by (Merrill Lynch, 2016). Our society still has a strong ageist bias that devalues older adults, which is compounded when considering someone who might also be living with dementia (Burgener & Berger, 2008). But a person-centered approach to care is fundamentally based on a conviction that each and every person can be equally valued and appreciated and have their personhood respected, regardless of age or ability (Geboy & Meyer-Arnold, 2011). And one way to do that is to bring people together in creative and meaningful ways.

Examples include care communities that are creating restaurants open to nonresidents/visitors, or include exhibit space that local artists use for their shows, both of which can bring many people into the care community who do not have any other connection there (AIA, 2016). Some offer meeting space for local groups, whereas others have an on-site day care that not only serves the children of staff but parents in the neighborhood, bringing them into contact with the care community on a regular basis. Every time someone who does not have a relative or friend who lives in the care community crosses the threshold, it is an opportunity to create community. Some of these ideas require dedicated space, but not all. In a traditional care community, individuals living with dementia would likely be excluded from any or all of these events and spaces. But a care community that deeply adopts person-centered care values and practices will find ways to include individuals who are living with dementia (Zeisel, 2009). From an environmental perspective, the design of these (and other) spaces needs to consider the amount of ambient stimulation in the room or area. Highly stimulating environments (visually or acoustically) tend to be overwhelming to individuals living with dementia (Hall & Buckwalter, 1987). Providing ways to control direct sunlight (which produces glare) and including surfaces with high noise reduction coefficient values can help tremendously. Since some individuals living with dementia experience stress or distress in unfamiliar environments (Lawton et al., 2000), providing

some smaller spaces that accommodate fewer people will better support their participation.

Enhance Comfort and Dignity for Everyone in the Care Community

The related concepts of comfort and dignity are at the core of person-centered care values but vary in one important way. Comfort is fundamentally how an individual feels, and dignity is more related to how they are treated. Both are something that some individuals living with dementia sometimes find difficult or lacking. In research, comfort is often stated as the avoidance of *discomfort*. Although there is certainly evidence of underdiagnosed pain in individuals living with dementia (Worcester, 2008), it is important to recognize that discomfort is not just physical; there is also mental discomfort, which Cohen-Mansfield suggests is expressed as agitation or behaviors labeled as challenging or aggressive (Cohen-Mansfield, Thein, Marx, Dakheel-Ali, & Jensen, 2015). A person-centered approach would argue that avoiding discomfort, while important and laudable, is not the same as being truly comfortable. Translating this to the design of the environment, Calkins (2013) suggests that an ideal shared residential setting is one where the resident feels “at home”—which signifies a deep level of comfort. However, because of changes in cognitive processing abilities and recent memory, even places (homes) that a person knows well and has lived in for years may seem unfamiliar or be perceived of as potentially threatening, and therefore be uncomfortable. People who relocate to a shared residential setting may not remember that the decision to move was based on their needing increasing levels of assistance, so they too are often uncomfortable. In the context of environmental design for shared residential settings, enhancing comfort and dignity translates into creating familiar environments such as households (vs units), providing appropriate personal space, and supporting orientation to time, place and activity, each of which is addressed in the following paragraphs.

Creating a *Household* is one core strategy for moving away from traditional institutional or medical model approaches to adopting the values of person-centered care such as supporting meaningful engagement that have purpose and are familiar. Although not exclusive to settings for individuals living with dementia, a household is often the main design part for memory care settings. Although there is no single widely accepted definition of a household, Abushousheh, Proffitt, and Kaup (2011) achieved consensus with a wide stakeholder group on the following definition:

A household is a small grouping (typically 10–20) of residents and their dedicated staff with the purpose of fostering self-directed relationship-based life. The household has pleasing homey spaces with a functional kitchen at its hub - nurturing daily life, responding to individual residents, and fostering community life. It

is intimately-sized with clear boundaries and a variety of spaces typical of home, including the flexibility of private and shared bedroom spaces as desired by the residents.

A household includes clinical best practices, the tasks and routines and pleasures of daily life, cutting edge technologies to encourage life choices and promote functionality, mobility, wellness and growth.

Household life is facilitated by an empowered self-led team of residents and staff. Deep knowing, reflective of true home, fosters a good life for everyone and is supported by the resources of the organization. The organization has been redesigned to position households and their leadership with the autonomy and accountability to respond to individual resident needs, as well as, the responsibility to create meaningful household life. In other words, the households, together as a team with the Administrator and Director of Nursing Services, become the vehicle for all operational decisions and administration, replacing the traditional department structure.

The environmental aspects of this definition include a relatively small number of residents (10–20), living together with house-based rooms (kitchen, living room, and dining room), and being distinct (meaning it has everything it needs to operate independently) from adjacent households or living areas. The importance of spaces that are familiar, such as a kitchen, is that they help individuals recognize the space and often what types of activities are appropriate for that space (Wrublowsaky, 2017). Large multipurpose spaces do not convey that type of information to people in the setting. There is a growing body of research that shows that designs that reflect these characteristics are associated with a broad range of positive outcomes such as less distress or agitation, greater social engagement, maintenance of functional abilities, and more individualized care (honoring residents' preferences), whereas larger traditional units are associated with greater agitation, faster cognitive decline, and more resident conflicts (Marquardt et al., 2014; Hutchinson et al., 1996; Suzuki, Kanamori, Yasuda, & Oshiro, 2008; Reimer, Slaughter, Donaldson, Currie, & Eliasziw, 2004). Funaki, Kaneko, and Okamura (2005) found that having an opportunity to engage in household-related activities resulted in a significant improvement in quality of life. There is also evidence that more home-like environments have positive impacts on staff morale, which might translate into secondary positive outcomes for residents (Parker et al., 2004).

Along with creating the scale and spaces of a home, it is important to create an enriched environment that provides positive distractions and things to do, such as tactile art or interesting views and access to the outdoors, with opportunities to explore the setting and find props that support different kinds of activities that might be engaging (Bourgeois, Brush, Elliot, & Kelly (2015). Research on

the positive impact of these types of environmental characteristics is sparse because they are often part of the whole household or enriched environment. However, the evidence that exists has shown that a more home-like environment is associated with deeper engagement in social interaction, activities of daily living, reduction in excess-walking episodes, and higher autonomy in food and hydration intake (see Chaudhury, Cooke, Cowie, & Razaghi, 2017 for an excellent summary). From a design perspective, the environment should maximize perceptual clarity and reduce perceptual noise (e.g. visual clutter or signage that is only for staff; Hall & Buckwalter, 1987; Orfield, 2015). In both shared residential and home environments, setting out clear props that indicate a room's use, such as keeping the dining room table at least partially set with a place mat and glass of water, can help with understanding the purpose of this space and encourage the individual living with dementia to participate in daily household activities such as setting or clearing the table.

Territoriality is an issue in shared bedrooms, which are common in shared residential settings. The most common bedroom design in nursing homes (and many assisted living communities) places the headboard of both beds on the same wall, with a piece of fabric (misnamed a "privacy curtain") between them. This means that the person in the bed by the window must always trespass through the space or territory of the person who stays in the bed closest to the hallway. For someone who may not understand why they are living with a "stranger," why that person keeps coming into their space, possibly going through their belongings (or what they think are their belongings), this situation, which relates to the person-centered value of accepting the person's reality, can cause significant discomfort. There is some evidence that there is greater resident-to-resident aggression when residents live in this type of shared room versus being in either a private room or what is referred to as an enhanced shared room (Figure 1), where each individual has their own clearly defined space, with a window, that has equal access to the door and bathroom (Calkins & Cassella, 2007). There is a clear need for more research on this type of room design, in terms of benefits to residents and staff (Chaudhury et al., 2017).

Awareness and Orientation skills become compromised in dementia, making it more difficult for individuals living with dementia to rely on memory to find their way from one location to another. Tying to the person-centered value of accepting the person's reality, a therapeutic environment is one that provides a variety of meaningful cues to support orientation. A "signage system" is not the same as an orientation system, which uses many more elements beyond signs (Brawley, 2006; Silvis, 2011). For people still living at home in the community, making sure that frequented destinations are visually accessible (easily visible) and distinctive is important. The front of the house or the door of the apartment might need to have a unique and personally meaningful/recognizable element added so it stands out

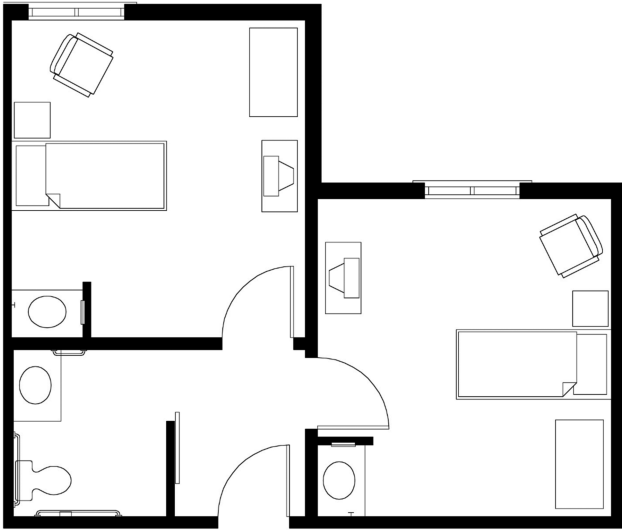


Figure 1. Enhanced shared-bedroom. Credit: Gaius Nelson, Nelson Tremain Partnership, P.A.

visually from its neighbors. An open floor plan not only makes it easier for the individual living with dementia to find a destination but also makes it easier for the care partners to see where the person is. This same principal of visual cues is also applied in shared residential settings where often bedroom or apartment entrances have a case or shelf for residents to display personal mementoes. There is some research that suggests that it is the meaningfulness of the items that is most critical in having these display areas be effective (Namazi, 1990; Namazi, Rosner, & Rechlin, 1991; Nolan, Mathews, Truesdell-Todd, & VanDorp, 2002; Gibson, MacLean, Borrie, & Geiger, 2004). Other researchers have found that buildings or living areas with simple plans that have few required changes in direction or open plans, support better orientation (Marquardt & Schmieg, 2009; Brush & Calkins, 2008). There is also strong evidence, albeit from only one study, that direct visibility of the desired destination may have a profound impact on successful destination finding: a study from the Corinne Dolan Center found an eightfold increase (from 37 to 285) in use of the toilet when it was directly visible (not behind a door or curtain and in high contrast with the surrounding walls and floor; Namazi & Johnson, 1991). Color, in and of itself, has not been shown to be an effective wayfinding cue (Cooper, Mohide, & Gilbert, 1989).

Orientation to activity is more naturally supported in a household design, because the combination of smaller scale and familiar spaces such as a kitchen and dining room are more easily understood by individuals living with dementia over more traditional medical model designs (Cohen & Weisman, 1991; Calkins, 2009; Elmståhl, Annerstedt, & Ahlund, 1997; Marquardt & Schmieg, 2009). While having props, such as place settings in the dining room, can help with orientation, a more person-centered approach would also include the residents setting the tables themselves (Bourgeois, Brush, Elliot, & Kelly, 2015). Orientation to

time is supported with views to the outside, as well as large face, high-contrast clocks.

Support Courtesy, Concern, and Safety in the Care Community

Another essential tenet of person-centered care is that of respect for others. Although in many ways the concepts of courtesy and concern would seem to be more person-based (how people treat one another), there are environmental correlates as well. Settings should be pleasant (noninstitutional) with visual and physical access to engaging but safe outdoor spaces, support privacy of confidential information and security of personal space, provide sufficient support for the individual living with dementia and, as needed, care partners, to maneuver and be successful while completing personal care activities, and provide systems that support a sense of security, while also ensuring that sometimes necessary safety features may also need to be in place.

The environment can be designed to *Support Functional Abilities* in individuals living with dementia, often in subtle, unobtrusive ways. For example, dressing is a complex activity that requires significant decision-making skills (what clothes to pick out, making sure all the necessary items are gathered, knowing in what order clothes should be donned, managing different closures systems [buttons, zippers, shoelaces, etc.]). Several studies have examined environmental strategies to support more independent dressing (Beck, Zgola & Shue, 2000; Calkins, 2012; Cohen-Mansfield et al., 2006; Sabata & Pynoos, 2005). Calkins (2012) demonstrated that limiting the number of choices, presenting clothes in the order in which they were to be put on and providing other prosthetic supports in an assistive wardrobe can increase independence in dressing substantially. Similarly, setting up personal care items around the sink with clearly labeled items and eliminating unnecessary and potentially distracting items, supports successful self-care (Brush, Calkins, Bruce, & Sanford, 2012). The bathroom should be highly visible, both during the day and at night, which supports both orientation and maximizing functional abilities. Making grab bars readily available and in the best location is also important. The standard ADA design with the toilet 18" from the wall and a grab bar along the back wall does not support how most older adults transfer (AIA, 2012). Recent research identifies that having the centerline of the toilet at least 24" from the wall and having two bi-lateral grab bars, placed 14" off center, 30" above the floor, is the most preferred configuration for both independent and assisted transferring (Lee, Sanford, Calkins, & Barrick, 2017). Ensuring that lighting is sufficient and even throughout a space will also serve to support functional independence. The Illuminating Engineering Society guidelines for *Lighting and the Visual Environment for Seniors and the Low Vision Population* has recently been revised (IES, 2016) and should be followed in settings for individuals living with dementia.

Balancing Safety with Autonomy in a person-centered manner is a delicate balance between supporting remaining independence and choices for the individual, while recognizing that sometimes systems need to be in place to mitigate risks for individuals living with dementia. This relates to two person-centered values of know the person (what's important to the individual) and accept the person's reality (in terms of their inability to judge the dangerousness of a given situation). Whether living at home or in a shared residential setting, at some point in the course of the disease the individual may lose the ability to recognize risks. Individuals getting lost is a major concern in all settings. A typical non-person-centered response to this is to simply lock the doors so people cannot go out. This is not considered the best solution, especially from a person-centered perspective. First, "locking people in" is what our society does to criminals, and individuals who are living with dementia are not criminals and should not be treated as such (Swaffer, 2016). Second, there are important physical and psychological benefits to spending time outside on a regular basis (Brawley, 2006; Zeisel & Tyson, 1999). Third, particularly in nursing homes but also for home and community-based service providers, creating a secure living area is now viewed as a restraint according to CMS' Rules of Participation (DHHS, 2016), and should only be applied when specifically needed for an individual, and only for as long as necessary. Having a diagnosis of dementia does not mean that the individual is necessarily at risk for walking away, and being "placed" on a unit or living area that is secure is only appropriate for individuals who have a known propensity for walking away, otherwise it is considered involuntary seclusion. One study (Parker et al., 2004) found that a "culture of safety and health requirements could be creating risk-averse environments which act against quality of life" (p .941). There is some evidence that when people are actively engaged in activities that they find interesting and appropriate to their cognitive and functional levels, they are less likely to spend time walking around (what we used to call wandering) or walking away (what was called elopement; Geboy & Meyer-Arnold, 2011; Futrell, Melillo, Remington, & Schoenfelder, 2010). First, individuals living with dementia need to be actively engaged in the decision about whether they want to move to a secured living area. They should not be "placed" by family or staff without being a part of that decision-making process. If they show or indicate that they do not want to live there but have a repeated pattern of walking away, there are two options. One is to try to find a different care community that has the programming and staffing that will help the individual be comfortable and not want to walk away, or, in what should be rare cases, a doctor's order for the individual to live on the secure living area may be necessary. This is an example where the safety of the individual and the preferences of the individual may not be able to be equally accommodated. It is a value decision of the whole care team (including the person living with dementia and

his or her chosen care partners) as to which set of values will be honored. Having frank discussions (and documenting the discussions) early in the course of the disease about what an individual might want in the future can make these later decisions easier to address (see Fortinsky & Maslow article in this issue for more information on this).

Every setting for individuals living with dementia should have direct and relatively unrestricted access to a secure outdoor area which provides individuals the opportunity to choose whether to be inside or outside. Consideration should be given as to when doors (to the outside or to other areas of the care community) need to be secured (inclement weather and perhaps at night) and when people can freely choose whether to remain in this living area or go to a different place in the care community. This requires effective communication with staff across the community, and possibly with neighbors and local shop owners for people still living in the community. Finally, there is an increasing variety of technology systems that can be tailored to the needs or preferences of individual residents: some will secure a door when an individual with the device approaches it, others are simply locational systems that can easily let staff see residents' locations. These should be used with caution as they can be considered a form of restraint, and devices that are large and stigmatizing should be avoided.

Falls are another common safety concern (though this is not unique to individuals living with dementia). In home environments, common risk factors include rugs and slippery flooring, changes in level (steps and thresholds), poor lighting and clutter. Recommendations include eliminating all rugs (even if they are secured to the floor, the height transition can be a problem for someone who has a shuffling gait); adding high-contrast slip-resistant material to flooring, especially where people are transferring their weight, such as around a tub, shower, or stairs; ensuring the lighting is sufficient and even throughout a space and using motion-sensor lighting to assist in navigating at night (especially from bed to bathroom); creating a clear path through the house with stable furniture that can be leaned on for support (Warner, 1998). The Fall Prevention Center at USC (no datea, no dateb) has a variety of resources on environmental strategies to reduce fall risk at home. Grab bars or handrails in hallways and bathrooms are much more common in shared residential settings, but they can also be implemented in the home environment. One home-based study found that a handrail along a wall covered with family photos allowed the individual living with dementia to have necessary support for balance while looking at the familiar images (Gitlin, Liebman, & Winter, 2003). There is some interesting research that shows that individuals with Alzheimer's disease have a reduced contrast perception ability (it has not been tested with other forms of dementia; Gilmore & Levy, 1991; Gilmore, Groth, & Thomas, 2005), meaning they need higher visual contrast to maximize function in any visual task. Thus, high contrast is important when considering safety and functionally supportive

features, such as thresholds and steps, between floors and walls, and at place settings in the dining room. Research found that increasing lighting and using brightly colored dishes increased independent caloric intake by as much as 500 Kcal over a 3-day calorie count (Brush, Meehan, & Calkins, 2002). However, high-contrast patterns should be avoided on flooring. The floor is a functional surface and should have minimal or low-contrast patterning: avoid the use of border and inset patterns and make sure there is contrast between the floor and the wall. There is also clear evidence that a significant proportion of falls occur at night when people are trying to get to the bathroom in the dark. Research by Figueiro (2008) has shown that amber-colored night lights do not disturb the circadian rhythm the way regular incandescent or fluorescent lighting does, which can cause people to have trouble falling back asleep. Figueiro recommends amber-colored LED lighting in the bathroom, either on motion sensors or on all night, or around the bathroom doorway to create a clear path from bed to toilet (see Figure 2). All of these modifications are appropriate for both home and shared residential settings.

There are times when it may be appropriate to limit access to unsafe items. What needs to be secured, and when and how, can be very individualized, and care should be taken not to assume that because someone has a diagnosis of dementia they are immediately incapable of using

any potentially hazardous item. Someone who has spent a lifetime cooking may be perfectly capable of using a sharp knife safely well into later stages, whereas another individual might try to use a knife or a saw to cut open a can of beans because they can no longer use a can opener. Common items that may eventually be secured and used only with supervision include cleaning chemicals, sharp utensils (kitchen, workshop, garden), potentially hazardous appliances such as a gas stove. When securing items, it is best to be as inconspicuous as possible: do not put an obvious lock on a cabinet, which not only can cause frustration but also reinforces to the individual living with dementia that this is yet another skill or capability they have lost. Instead, either remove the item, or make the security inconspicuous. Replace gas or electric stoves with an induction cooktop, which are much safer to use (reduced fire and burn hazard). Move harsh cleaning chemicals to a different secured cabinet, and put safe or green cleaning products in more accessible areas. In shared residential living areas, because there are likely individuals at different stages of dementia, unsafe items are more often made inaccessible. Caregivers should not assume that none of the residents could no longer use a sharp knife safely, but consider that this might be a supervised activity. Knives should be kept in a secured drawer in the kitchen, which allows staff to access them as appropriate, but keeps safe the residents who should not have independent access to them. Codes for nursing homes require that stove in a domestic kitchen serving 30 or fewer residents have a separate power switch that is on a timer, located in a cabinet (or similar) that only staff can access, and that there be smoke alarms and fire extinguishers readily available. These safety features are also appropriate for assisted living communities that have residential kitchens.

Provide Opportunities for Choice for All Persons in the Care Community

CMS, in its new Rules for Participation, makes it quite clear that nursing home residents' choices are to be honored to the greatest extent possible (DHHS, 2016). Although much of this focuses on resident preferences related to delivery of care, it also expressly refers to offering the resident choices from which to make meaningful decisions. Therefore, designing spaces and places that accommodate different levels of activity and types of stimulation, that are meaningfully varied in terms of size, scale, and décor, and that include both indoor and outdoor areas, gives people choices about where and how they want to spend their time. This construct is generally thought of more in relation to shared residential settings, in part because many traditional care settings offer virtually no choices for the residents: there may be only one common shared multipurpose room that serves for meals and activities, and staff encourage residents to spend their time there or sitting in front of the nursing station, so they are easily visible. While being able



Figure 2. Amber LED lights to outline the bathroom door. Credit: Dennis Guyon, Lighting Research Center, Rensselaer Polytechnic Institute.

to see where residents are and what they are doing is not necessarily bad, limiting residents' ability to have meaningful options of where to spend time is. Ideally, every setting should provide a full continuum from private to semi-private to semi-public to public spaces, and individuals can choose where, when, and how to spend their time (Cohen & Weisman, 1991; Zeisel, 2009).

Spaces need to be meaningfully different: having two or three rooms that each accommodates six to eight people and have essentially the same furniture and décor is NOT meaningfully different. There are times when people want a quiet conversation with one other person, and times when 12 to 15 people might gather for an event. Choice is also limited when all the furniture (especially chairs) are the same size: people come in different sizes, and thus find different styles and sizes of furniture comfortable. Not every space should be on the household: having locations in other areas of the building or complex can give people a greater sense of freedom, which is important. One care community in western Ohio is comprised of 6 to 8 different buildings, and the residents, who are all living with dementia, routinely go from one building to another, often without being accompanied by staff, though staff may communicate with each other that someone is on their way over. Sometimes, the residents walk to the convenience store that is just down the road. The people who work in the shop know the residents who visit and make sure they are headed in the right direction when they leave; sometimes calling the care community with a heads up that someone is on their way back. These individuals are living a normal life with respect to their rights and abilities, in an environment that supports their making meaningful choices. They like where they live and have no desire to leave it.

Although bedroom configurations were discussed previously, the issue of being able to have privacy was not addressed. People may desire privacy for a variety of reasons—maybe just a chance to be alone or a chance to have a private conversation with a family member or friend or staff. Sexual activity among elders in long-term care settings is often ignored (as an uncomfortable topic) and yet care communities are having to address this issue on a regular basis (Doll, 2012). The issue is more complex when the individuals are living with dementia (and the ethical issues surrounding this will not be addressed in this chapter), but from an environmental perspective, it is important for the care community to plan how they will accommodate this activity. If all the bedrooms are private, this is not an (environmental) issue. However, if there are shared rooms, then accommodations must be made. One community made an arrangement with a local hotel for conjugal visits between residents and their nonresident partner/spouse. Other communities may have a guest suite that is available for visitors that can also be used for this activity.

In supporting the person-centered value of supporting opportunities for meaningful engagement, the choice to spend time outside is also important, as is having different

options for how to engage with the outdoor space. Some people are more passive observers, whereas others want to explore, or garden, or take walks along a path, or sit and soak up the sun. This likely varies as much between individuals as it does by stage of dementia. Having both sun and shade is preferred; nontoxic plantings that might attract butterflies or hummingbirds, and container pots that can be moved around to create larger or smaller social spaces all create different options and choices for residents (Brawley, 2006; Tyson, 2002). A few small porcelain or cement animal figurines that are moved around the garden by staff can create an opportunity for exploration every day. Some residents may want to garden from a seated position at a raised bed, whereas others still want to dig more deeply into the soil and feel they are really working. Flexible seating has benefits, but be sure it does not compromise necessary safety features (e.g., enable people to climb over a fence). There is a growing body of research that suggests that spending time outdoors can reduce agitation and aggression (Murphy, Miyazaki, Detweiler, & Kim, 2010; Gonzalez & Kirkevold, 2014).

Offer Opportunities for Meaningful Engagement to Members of the Care Community

Just having choices about where to spend time does not necessarily guarantee that people will know what to do, how to engage in activities, or relate to others. A study by Bergland and Kirkevold (2008) on thriving in a nursing home suggests that relationships need to be positive and meaningful. Relationships—especially meaningful relationships—do not develop while sitting and watching television, they develop by doing things together, especially things that bring out memories, conversation, and sharing together (Kane, Lum, Cutler, Degenholtz, & Yu, 2007). Although few studies explore social relationships related to dining and kitchens, Chaudhury, Hung, Rust, and Wu (2016) found that having the elements of a domestic kitchen (refrigerator, microwave, coffee maker) facilitated not only resident independence but also social interaction. Anecdotally, this is one of the reasons why residential kitchens that allow residents and staff and family to work together, preparing the meals that are the sustenance of life, are becoming increasingly common. Design features that support active engagement include a lowered (30" high) section of counter that faces the kitchen or a table with chairs in the center of the kitchen. Eating a meal requires a lot of concentration (Brush, Meehan, & Calkins, 2002) and can be more difficult if the environment is noisy (people talking, dishes clinking, loud ice machines) or visually chaotic (staff bustling about quickly trying to get everyone served). Small scale dining rooms for 20 or fewer individuals can help keep the level of stimulation manageable (Hall & Buckwalter, 1987) and enable people to not only enjoy the meal but converse with others.

Every activity is an opportunity for meaningful engagement, even personal care activities. In a traditional unit, the daily activity program typically consists of one to two large group “events” a day, led by someone in the activities department, which residents are often only passively engaged in (Orsulic-Jeras, Judge, & Camp, 2000). In a care community that has deeply adopted person-centered care values, every day is seen as an opportunity to try something new and different. Some person-centered communities use a learning circle (Action Pact, 2001) where each person is offered a chance to express her or himself and talk about something of importance. This type of sharing requires a space large enough to accommodate everyone sitting in a circle and is best when there is no background noise. Some communities use this to determine what the residents want to do that day (choice and self-determination), but to be effective, there also needs to be lots of props available to do these activities. Easily accessible storage, some of which might be highly visible and some of which might be less visible, is essential: almost no care community ever says they have enough storage (Bourgeois, Brush, Elliot, & Kelly, 2015). Meaningful engagement is also facilitated when chairs are placed close enough and at right angles to facilitate successful conversation. It is much more difficult to talk with someone who is sitting beside you, facing the same way, than it is to talk with someone who is at right angles to you (Calkins, 1988). Several small conversational clusters of chairs, which look out over an interesting view (inside or outside), with easy props such as books, magazines or personal photo albums, can also support relationship development.

Similar practice recommendations apply to the home environment: having easy access to items that support engagement and sharing with others is important. In the study by Gitlin and colleagues mentioned previously, it was having a wall full of family photographs that was sufficiently interesting for reminiscing which made having the handrail along the wall important. Whenever guests came to visit, the individual living with dementia would bring them to the wall, stand there and talk about each photo.

Conclusion

The designed environment is clearly a resource that can support functional abilities, meaningful relationships, and high quality of life for individuals living with dementia, yet is often still considered only the backdrop in front of which “real life” actually takes place. We need to consider both how the environment is designed by architects, interior designers and landscape architects, as well as how it is activated by the people in the setting. Care partners and caregivers generally are not trained to think about the importance of turning on a light, or closing curtains to reduce glare, or eliminating unnecessary background noise, all of which either contribute to excess disabilities or support more independent functioning in individuals

living with dementia. Furthermore, although many studies still lack from small sample sizes, poor controls, and insufficient detail about the environmental characteristics being studied, the body of research on the specific impacts of different environmental features and characteristics continues to grow. More rigorous studies, especially ones with larger sample sizes, appropriate control groups, and multiple sites, are needed.

The growing focus on person-centered care values and practices will spur greater innovation, in large part based on an increasingly active role that individuals living with dementia are and will continue to take. There are increasing numbers of forums that individuals living with dementia are taking control of—organizations, blogs, books, and websites to name a few. But this has not yet translated into the design of the environment: we have not yet seen enough involvement of people with early-stage dementia being actively engaged in planning their living environments, either at home or in shared residential communities. Although no individual can honestly know what the future will hold and how they will perceive their world when they are deeper into their condition, getting their insights at an early stage is a critical, but currently missing, step. Finally, given the statistics on the percentages of people who are developing dementia as they age, *everyone* has the opportunity to give consideration to the thought of where and how they want to live, should they develop dementia. Write it down—one day you might need it. Each of the Practice Recommendations in this chapter provides a person-centered framework for creating supportive and therapeutic environments for individuals living with dementia.

Practice Recommendations for Fostering a Person-Centered Therapeutic and Supportive Environment

1. Create a sense of community within the care environment.

The care community includes the person receiving care, their family and other chosen care partners, and professional care providers. The environment should support building relationships with others as a result of sharing common attitudes, interests, and the goals of the individuals living with dementia, their caregivers, and other care providers.

2. Enhance comfort and dignity for everyone in the care community.

It is important that members of the care community are able to live and work in a state of physical and mental comfort free from pain or restraint. Environments are designed to maintain continuity of self and identity through familiar spaces that support orientation to place, time, and activity.

- Support courtesy, concern, and safety within the care community.

Members of the care community should show politeness and respect in their attitudes and behavior toward each other. Doing so includes creating a supportive environment that does not put unnecessary restrictions on individuals and helps them feel comfortable and secure, while also ensuring their safety. The environment compensates for physical and cognitive changes by maximizing remaining abilities and supporting caregiving activities.

- Provide opportunities for choice for all persons in the care community.

The culture of the care community supports a range of opportunities for all persons to make decisions concerning their personal and professional lives, as well as their health and welfare. The environment can provide opportunities for self-expression and self-determination, reinforcing the individual's continued right to make decisions for him/herself.

- Offer opportunities for meaningful engagement to members of the care community.

Relationships are built on knowing the person, which itself is based on doing things together. An environment that provides multiple, easily accessible opportunities to engage in activities with others supports deeper knowing and the development or maintenance of meaningful relationships.

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Conflict of Interest

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