History of Creating Settings for People with Dementia

Creating specialized care settings for people with dementia or cognitive impairments is a recent development. Yet, Alzheimer’s and other forms of dementia are not new diseases, although they have received increasing recognition and differentiation within the medical and care fields, as well as in the popular press. In the first half of the 20th century, most people with dementia would have been cared for in state mental hospitals or asylums. By 1946, roughly 45% of all admissions to state and county mental hospitals had a diagnosis of organic brain syndrome. As the community mental health system developed from 1955 to 1980, state mental hospitals lost 75% of their population. Many of the elderly with cognitive diagnoses moved into nursing homes. The table below, from Losing a Million Minds, shows the respective decline in population of mental hospitals and the concurrent rise in census of nursing homes. It is worth noting that this shift in location of care was not based on what was best for the person with dementia, as described by the U.S. Congress, Office of Technology Assessment in 1987: 1

Historically, changes in the primary locus of institutional care for persons with dementia—from almshouse to State mental hospitals, and from there to nursing homes and board and care facilities—have occurred primarily in response to financial incentives. Placing these persons in State mental hospitals instead of almshouse transferred the cost of their care from local to State government. Similarly, placing them in nursing homes and board and care facilities instead of State mental hospitals transferred part of the costs to the Federal Government through Medicaid and SSI. There is no evidence that these changes occurred in response to the care needs of individuals with dementia, or that their care needs and the effect on them of changes in the locus of care were even considered. (p. 213)
Residents of Mental Hospitals and Homes for the Aged Who Were 65 or Older: 1950, 1960, 1970, and 1980

Rate per 100,000 persons 65 or older

<table>
<thead>
<tr>
<th>Type of institution</th>
<th>1950</th>
<th>1960</th>
<th>1970</th>
<th>1980</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mental hospitals</td>
<td>1,150</td>
<td>1,074</td>
<td>563</td>
<td>200</td>
</tr>
<tr>
<td>Homes for aged/dependent</td>
<td>1,769</td>
<td>2,342</td>
<td>3,966</td>
<td>4,835</td>
</tr>
</tbody>
</table>


The first specialized nursing home setting for people with dementia was developed in the mid-1970s at the Philadelphia Geriatric Center under the direction of Dr. Powell Lawton. The Weiss Pavilion represented a radical departure from the traditional nursing home in that it was designed for only 40 residents and the bedrooms were arranged around a large, open pavilion. This provided both increased visual access to desired destinations, which was intended to improve wayfinding, and sufficient density of people to still support spontaneous interactions. Dr. Lawton was concerned that a unit that was too small in number would provide insufficient opportunities for unplanned social encounters. A post-occupancy evaluation of the building found increased engagement in planned/staff-led activities, decreased pathological behaviors, increased visual gazes (i.e., looking around more), an increase in the number of physical areas of the unit accessed, and an increase in the number of visitors. There was no increase in social behavior or decrease in sleeping or null behavior. Lawton, Fulcomer, and Kleban concluded that while basic competency declined (i.e., measured by test of cognitive ability), the more pliable behavioral variables did not decline and showed improvement in five instances.(2)

As promising as this research was, there were few other efforts to create settings specifically for individuals with dementia until the late 1980s. Friendship House in West Bend, WI opened in 1976 and was another early nursing home
designed for people with dementia, although it received little attention. The Alois Alzheimer Center, reconfigured from an elementary school, opened in 1987. Shortly after, two assisted living communities opened: (1) the Alzheimer’s Care Center of Gardner Maine in 1988 and (2) the Corinne Dolan Alzheimer Center in Chardon Ohio in 1989. Only the Corinne Dolan Center and Woodside Place, which opened in 1991, attempted to systematically evaluate the impact of the physical environment on residents with dementia and their caregivers. Both these projects received significant attention. At the same time, researchers and designers were beginning to explore the therapeutic potential environment for this population. Design for Dementia: Planning Environments for the Elderly and the Confused, the first comprehensive design guide for these settings was published in 1988, followed by the more comprehensive Holding Onto Home.(3)(9)

Partly due to the publications mentioned above, and to attention some of these early adopters of “specialized” care for residents with dementia garnered, providers increasingly moved to segregating residents with dementia from non-cognitively impaired residents. However, the potential benefits of segregation were not always clear. Often, it was to please other residents and families who did not want to be in close proximity to residents with dementia. Another, possibly less altruistic reason, was that separation meant providers could market the “specialized” unit differently, often charging more. In fact, the concern that families were being charged more, but not receiving any specialized care in return was the impetus for the government to examine the whole special care unit movement. Losing a Million Minds: Confronting the Tragedy of Alzheimer’s Disease and Other Dementias provided the first in-depth analysis of the full range of issues and policies related to dementia in the US.(4)(11)

The question of segregation versus integration remains salient today. Many providers feel that the benefits of having individuals with similar cognitive levels reside together, which allows staff to specialize in offering a daily activity routine that is suited to their cognitive level, outweighs the negative outcomes associated with relocation. Indeed, some providers have several levels of care, even within the same licensure (e.g., multiple levels of assisted living units catering to people at
different stages of the disease). Other providers follow a different epistemology and feel that once an individual has moved into a long-term care setting, the value in being able to stay in that apartment or bedroom, regardless of care need, is paramount to creating a feeling of comfort and security. If the goal is to feel at home, then the resident (possibly with his/her family) should be the only one to make a decision about relocating. It is hard to feel secure when the provider has the authority to basically force someone to move whether they want to or not. Such providers argue that a supportive and appropriate activity program does not have to take place adjacent to resident rooms or apartments. There are a number of well-known, successful day programs where residents from different parts of a building come together and interact in activities that they find meaningful and successful for their stage of dementia.

**Therapeutic Goals**

The issue of control over relocation decisions is but one example of the debate surrounding the ways in which the physical, designed environment impacts individuals with dementia and their caregivers. DementiaDesignInfo is fundamentally based on a structure that uses a set of therapeutic goals or user needs that have been derived over the past 20 years by some of the most well-known environment-behavior researchers\(^5\). Each user goal is described briefly below.

**Support Activities of Daily Living**

Most individuals with dementia in shared residential settings have a number of conditions that cause physical limitations, in addition to cognitive deficits. Design should help to compensate for both types of changes. The occupational therapy concept of task breakdown can be applied to the environment, for example, by designing a closet that allows one set of clothes to be displayed in the order in which they are donned. Clothes must also be positioned at a height that is easy to reach,
regardless of whether people are standing or sitting in a wheelchair. Similarly, designing the dining room and meal service so that people can be served only one course at a time can support independence at meals. Many individuals with dementia have a contrast perception deficit, which makes it difficult to see objects that are similar in color to their background (e.g., a white plate on a white table or tablecloth, chair seats that are similar in color or hue to the floor, a white toilet in a white or beige bathroom, or distinguishing clothes in a poorly lit closet).

**Aesthetics**

Many nursing homes, particularly older buildings from the era when cleanliness and organization were considered paramount, often lack any type of positive décor or aesthetics. Identical long corridors do not create welcoming and inviting places, particularly if they have little to no artwork and highly reflective floors, large common dining rooms that also serve as the main activity space, and numerous bedrooms painted the same color with identical bedspreads and curtains. Much can be done by following basic interior design principles: introducing better (i.e., indirect and non-glare) lighting; installing carpeting to reduce glare and noise; using a broad color palette with some patterns; providing greater variety in the size, style and design of furniture, especially chairs; adding more diverse artwork that does not consist solely of framed prints behind glass (which often produces glare); and incorporating knickknacks, pillows, throws, and other items to create a richer and more enlivened space. If the care community is on a tight budget, encourage residents to bring personal possessions with them to be placed in common areas of the building (see the Personalization section).

**Affective Experience**

Affective experience refers to the extent to which the environment might cause or add to agitation levels of an individual with dementia, or help individuals be calm and comfortable in a given space. This is related to aesthetics, but goes beyond just how a space looks to how different elements may impact the psychological and emotional states of the residents. For example, large rooms with high ceilings, poor acoustics, and potentially multiple groups of people moving around are likely to be
over-stimulating and cause anxiety and distress, regardless of how attractive the room is. Glare that reflects off shiny floors, and appears to move as a person moves through a space, can cause pain and/or fear of falling because the surface often looks wet. In contrast, rooms that are meant to accommodate 6 to 8 people with comfortable seating that faces each other to support effective communication, as well as interesting art or views outside to initiate conversation, will likely encourage more positive emotional states among residents.

**Increase Personalization**

Relocating into a supportive residential setting, be it a retirement community, assisted living, nursing home, or other option, can be traumatic and almost always means giving up many of the things that one has chosen to live with. Furniture may be too large, not fit the “image” the care community wants to convey to visitors, or may occasionally be in such bad repair that it is hazardous, despite one’s emotional attachment to it. Although few people will be able to move with all their furniture and possessions, they have the right to have some of their familiar possessions with them in their new setting. Care communities need to move away from the mindset of “allowing” people to bring a few possessions to a philosophy that embraces and finds ways to accommodate as much as the person wants to bring as a basic right. These residents are not convicts who have had certain rights removed because they violated our society’s laws. These are individuals deserving of our respect, who have contributed greatly to our society. In some care communities, residents who want to bring furniture that does not fit in their rooms (e.g., a large china cabinet or a piano) are welcome to place these items in shared areas. Consider how much richer and more enlivened these shared spaces could be when furnished with everyone’s possessions. Families may need to take an active role in helping the elder make reasonable decisions about what is most important to bring to the new residence. Possessions that reflect what this individual has accomplished in their earlier years—places he’s gone, things she’s done, awards, photos of family, art that has been created or acquired—are particularly important, as these can help other people in the residence understand the values of this elder. This is particularly important for
people with dementia who may find it increasingly difficult to communicate their values and accomplishments verbally.

Environmentally, this means spaces should be designed or accessorized to accommodate and encourage more personal belongings. The design of the bedroom or apartment should accommodate different arrangements. This is difficult in older buildings where bedrooms were designed to accommodate the hospital-style side-by-side furniture arrangement. Therefore, even more effort should be placed on alternative ways to help people accommodate what they want to bring in with them. Most people will use shelves if they are provided. Display cabinets at bedroom entrances may provide cuing for some residents, but if artfully filled with memorabilia that says something about the individual, they can serve to educate others about what is important and valued by each individual. Wall or corner cabinets in the dining room filled with residents’ china or other collectables are other ways to support people in maintaining their possessions.

**Autonomy**

One of the essential components of virtually all new philosophies is to maximize opportunities for expressing choice of people who live in care communities. The old institutional and medical models were predicated on a philosophy that “staff knows best” and should therefore be responsible for making most of the decisions. In the new era, it is the person who knows what is best. After all, isn’t that what most of us think about our own lives? Most people think of this issue in the context of staff interactions and policies, but the physical environment can play a role as well.

When every room is the same, especially the shared spaces, there is little meaning or purpose to choosing one space over another. Institutional settings are often characterized by a sameness—the same chair in every room (or even worse, multiples of the same chair within a single room), wall treatment in all rooms that is identical or so similar (only the border changes) that it is difficult to discern any differences, or the same style of window treatment in every space. This is often true within what was traditionally called a unit, between different units, and in spaces shared by the whole community. The chapel is often the only exception. However,
some care communities have made a conscious effort to differentiate spaces so that residents have meaningful choices in determining where they want to spend time. For example, the Alzheimer Center at Gardner Maine has a living room that evokes the image of Maine winters, with plaid sofas gathered around a fireplace. The sunroom, on the other hand, celebrates summer with a wall of windows looking out to the gardens and brightly colored, floral wallpaper, which was selected by one of the first residents to move in.

Designers should strive to create spaces that vary in meaningful ways: size, ceiling height, décor and style of furniture, and access to the outside and to different activity props. Create a darker, cozy, enveloping kind of space, something like the old “men’s club room.” Consider a café or a bar that is a fun space in which to hang out. Include a greenhouse/sunroom, a light and airy space where one welcomes the sun pouring in the windows. Provide opportunities for residents to freely choose to go outside to a courtyard as the sun beckons them.

**Privacy**

Increasingly, providers undergoing new construction are seeing the benefits of all, or mostly, private rooms. It eliminates roommate issues, which can be very staff intensive and often create dissatisfaction among families. There are also a number of newer floor plans where two people share a bedroom entrance and bathroom, but essentially have their own space and window. However, these rooms typically still use the ubiquitous “privacy curtain,” which only provides visual, not auditory or olfactory privacy, and provides no sense of control over one’s territory. It can be difficult to provide privacy in small, shared, side-by-side bedrooms. In some designs, it may be possible to add a narrow wall, maybe half height, with shelves for personalization on each side between the two beds. If possible, try to rearrange bedroom so both beds are not on the same headwall.
Stimulation

Another characteristics of traditional institutional settings is that they are often beset with repeated, random, and, to the residents, meaningless noises. As a source of stimulation, noise has high mobility, meaning it impinges on people whether they want to receive it or not. To a large extent, people cannot choose what they hear in the same way they can control what they see. People with dementia may be particularly sensitive to alarms and other loud noises that can be disturbing and cause higher stress, which is then reflected in behaviors that may be disruptive to others. Beyond eliminating negative noise, also focus on enhancing positive sources of stimulation. A community in rural Michigan plays a tape of local songbirds every morning, which is a familiar way to help the residents wake up naturally.

There are two basic strategies for sound attenuation. The first is to minimize the sources of the noise. Take the following test. Go to the center of one of the residential areas, close your eyes, and just listen for a few minutes. Repeat this several times over the course of a day. What are the sounds that can be eliminated or modified? Eliminate noisy alarms to the greatest extent allowed. Look into whether your call system can be modified to work with staff pagers, which are silent and can often provide better information on response time. How loud are staff when talking to each other? Do they need a refresher course on minimizing unnecessary noise?

The second strategy is to add sound-absorbing materials to the environment. Hard floors, such as vinyl, linoleum, or wood, cause sound to reverberate longer, particularly when people walk in hard soled shoes. There are many excellent carpets available that are stain and odor resistant. Choose a pattern that is not too busy, avoid high light-to-dark contrasts, and remember that a small flecked or heather pattern will not show specks of daily dirt as quickly as a solid color. Heavier draperies on windows will also help to absorb sounds.
Safety and Security

The cognitive impairments associated with dementia, as well as more general age-related physical deficits, can threaten the safety and security of people with Alzheimer's disease and those who provide care for them. The cognitively impaired individual may not be able to understand the potential hazards in any given situation, and thus needs to be closely monitored by staff, ideally in an unobtrusive manner. In addition, the physical environment can serve to minimize potential problems through the inclusion of a variety of safety precautions. One common design approach is to make it relatively easy for staff to visually monitor residents throughout the household (see white paper on Care Setting Size and Configuration). This does not mean there should be no enclosed spaces where people can go for a private conversation, but rather that staff work spaces be positioned for visual access into different areas of the household. Equally important, residents need to be able to find a staff member easily.

Safety is often thought about only in terms of restricting access, such as out of the household, to the outside, or to unsafe equipment. While some restrictions are necessary, it is unnecessary or inappropriate to simply uniformly restrict access to anything even if it is potentially dangerous. For instance, having a kitchen for residents to participate in meal-related activities is an important program element. Clearly, the stove and any other hazardous equipment need to have security precautions, such as separate power switches that are staff-controlled, but residents might still have access to the kitchen so they can independently get a cup of coffee or a snack. Although unauthorized exiting is a valid concern, it is best addressed by providing a secure outdoor space that residents can freely access so they do not feel locked in.

Orientation

Dementia may engender confusion with respect to time and place, which is often exacerbated by the information-deprived nature of many institutional settings, as well as the tendency of some residents to walk or wander. Thus, programs,
policies, and design should all contribute to awareness of time, place, and social situation; residents should not be confronted with a confusing, illegible, and unpredictable environment.

Residents' level of awareness and orientation should not be viewed solely in terms of simple recitation of facts (e.g., today's date). As Coons and Spencer argue, orientation to "reality" must be seen "as a natural outgrowth of the person's involvement in a complex and purposeful environment\textsuperscript{(10)}. Thus, awareness and orientation may be enhanced by time, scheduling, and physical markers, such as the regular scheduling of events or by denotation of future events by physical artifacts (e.g., tablecloths forecast that there will be a meal served). Likewise, meeting orientation needs should not be confused with simple management of "wandering" as a problem behavior; wandering may be a natural response and outlet of energy for some individuals and should be appropriately accommodated and/or reduced through the provision of interesting and meaningful activities and interactions. Design should include features that impact the ability of residents to determine: (1) present location and social situation and (2) relationship (spatial or temporal) to other desired activities and locations. The larger the neighborhood or household, the more difficult it is to provide equal visual access to all areas, hence larger units are likely to place greater cognitive demands on people with dementia and awareness and orientation are less easily achieved.

Socialization

The focus is not on whether or not social contact and interaction are desirable, but rather on the extent to which they are facilitated or discouraged by the environment. Physical proximity between people is a precondition for social interaction, with interaction also contingent upon the acuity level of residents. For more impaired individuals, contact may be all that one can reasonably expect. More generally, it should be recognized that levels of contact and interaction for people with dementia may not be very high and that interaction does not necessarily imply verbalization.
Thus, major indicators of environmental support for contact include existence of multiple common spaces, enlargement (i.e., beyond the limits of the 8-foot corridor) of floor space around areas of high activity, spaces where walking patterns cross, and spaces where there is interesting activity to watch as well as the presence of chairs and their appropriate placement (e.g., at right angles or facing each other to support visual connections during conversation). Functional uses of space, interesting activity, and associated props often generate onlookers, and sometimes interaction will occur.

Conclusion

This is only a short list of possible environmental interventions that should be considered when making a setting supportive of residents with dementia. There are a number of excellent resources that provide more comprehensive information on this topic, in addition to the four listed below.


A decade ago there was a general sense that people with dementia needed “special” settings. What we have come to understand is that much of what we tout as good for people with dementia is also good for people without cognitive impairments —they fundamentally relate to our shared qualities and values of personhood. These recommendations are also better for staff and visitors. All of the recommendations above should be applied to all long-term care settings, with only minor modifications.
References


