

Preparation

part **2**

CONCEPTUAL FRAMEWORK FOR ENVIRONMENTS FOR PEOPLE WITH DEMENTIA

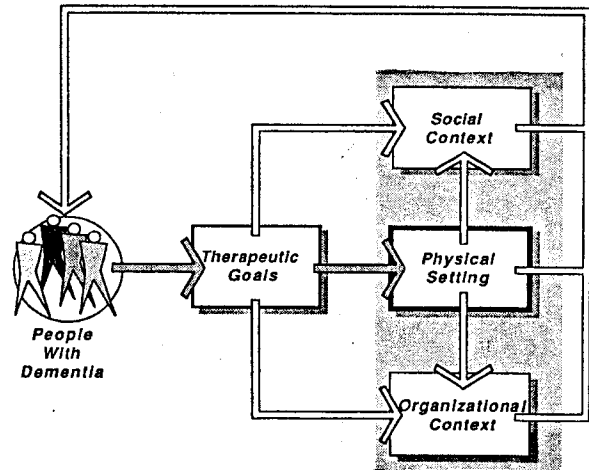


Figure 1. A conceptual framework for the organization of the person-environment system.

The environments inhabited by people with dementia and those who care for them constitute a complex system comprised of organizational, social, and architectural factors that interact in multiple ways. For purposes of analysis, programming, and design, environments for people with dementia can be conceptualized in terms of a five-part framework (Figure 1).

First and foremost are people with dementia, defined in terms of their physical, functional, and emotional needs, as determined by the characteristics or deficits that result from their disease. In keeping with overall project goals, the following section on People with Dementia presents a detailed exploration of behavioral/functional, cognitive, social, and emotional deficits associated with the disease. General strategies for design are also presented here, and further elaborated in Parts 3 and 4.

In response to the nature and needs of people with dementia, a variety of therapeutic goals such as "preservation of dignity" or "encouragement of independence" are commonly raised in the literature. Such goals, while clearly abstract in themselves, do provide guidance and

direction for subsequent decisions regarding organizational and social planning, as well as architectural design. Secondary goals, which may differ slightly in recognition of personal and setting variability, are subsumed under these global goals.

The final three components of this framework are the organizational, social, and physical environments within which people with dementia live. The organizational context is conceptualized in terms of the policies and program of a special care unit. The social context is represented by family and friends who serve as informal caregivers. Staff and other residents also form part of this group. The physical setting is defined in terms of its materials and finishes, furnishings and equipment, sensory and spatial properties.

The design of responsive settings for people with AD must recognize social, organizational, and physical considerations. Unless there is congruence among these three subsystems and their interactional effects, therapeutic goals cannot be realized.

THERAPEUTIC GOALS

- Ensure safety and security
- Support functional ability through meaningful activity
- Heighten awareness and orientation
- Provide appropriate environmental stimulation and challenge
- Develop a positive social milieu
- Maximize autonomy and control
- Adapt to changing needs
- Establish links to the healthy and familiar
- Protect the need for privacy

Figure 2. Therapeutic goals to guide the development of responsive environments for people with dementia.

Review of the literature on dementia and design (Rand et al., 1987) reveals a variety of therapeutic goals intended to provide direction in the creation of appropriate and supportive environments. While one clearly cannot make specific planning or design decision on the basis of these global statements, such goals serve to highlight desired relationships between people with dementia and the environments they occupy, and provide direction for policy, programming, and design decisions. The following set of goals has been distilled from the authors' review of the literature, and has proved useful in both the analysis and the design of environments for people with dementia.

These goals are, of course, an abstraction. In some instances, goals may overlap or even conflict with one another. Nevertheless, an understanding of such goals can sensitize the reader to many higher level imperatives to which all environments for people with dementia should respond. Furthermore, it is often through efforts to accommodate therapeutic goals that are inherently and necessarily in conflict that the richest and most creative strategies for problem solving emerge (Alexander, 1969).

1. Ensure Safety and Security.

Ensuring that users sustain no harm is the first imperative of any therapeutic environment. As emphasized by Calkins (1988), people with dementia are potentially vulnerable as a consequence not only of cognitive impairment, but also due to physical disabilities related to the process of aging, as well as to the dementing illness. Thus, it is essential to ensure the physical safety and psychological security of people with dementia. In addition to issues of life safety (e.g., fire retardant construction, adequate emergency exits), the physical environment may impact the safety and security of people with dementia in less obvious ways. The absence of adequate grab bars, an unsecured gas stove, or, at a larger scale, floor plan configurations that thwart staff supervision of residents, may all compromise security.

2. Support Functional Ability through Meaningful Activity.

Both Mace (1987) and Peppard (1986) emphasize the importance of maintaining those abilities not totally impaired by dementia. Support

of the highest level of functional ability can have important and positive implications for the sense of competence and self-esteem of people with dementia, especially when facilitated by the incorporation of activities from the past, such as household work, that is relevant and meaningful to residents.

This goal can be further realized through the provision of prosthetic devices that compensate for limited ability (e.g., handrails in corridors to facilitate walking) and spaces and equipment that support familiar activities of daily living (e.g., modest cooking or housekeeping).

3. Heighten Awareness and Orientation.

Program, policy, and design should all assist people with dementia in "knowing where they are" in spatial, temporal, and social terms. Disorientation brought on by confusing, illegible, and unpredictable environments can be decreased. The design of clear paths to desired destinations, differentiation or elimination of repetitive forms, and the incorporation of physical landmarks are among possible interventions.

4. Provide Appropriate Environmental Stimulation and Challenge.

People with dementia may be unable to process high levels of stimulation without experiencing overload and distress; conversely, many institutional settings represent a degree of sensory and social deprivation that is clearly not therapeutic. The physical environment can provide "unobtrusive" stimulation—such as views to the outdoors, color schemes, things to touch—that does not overwhelm residents.

5. Develop a Positive Social Milieu.

Environments that provide opportunities for social interaction and maintain a degree of challenge for residents may slow atrophy of skills, reduce deprivation, and enhance quality of life (Lawton et al., 1984). The physical environment can provide opportunities for involvement, ranging from places for passive viewing of activities to an arena for participatory activities (e.g., a domestic kitchenette).

6. Maximize Autonomy and Control.

People with dementia should, to the greatest extent possible, have the ability to make decisions and to take responsibility for their own lives and environments. "Personalization" of one's own space can foster a degree of individuality. Control over social and environmental stimuli can be supported by providing places for retreat and reflection, thereby allowing residents to moderate their desired level of sensory input.

7. Adapt to Changing Needs.

It is essential to respond to both changing needs of individual residents over the course of the disease, and to differences in the needs and abilities among the resident population. It is also necessary to respond to evolving therapeutic approaches. Facilities must determine the population (in terms of size, services needed, and stages of dementia) they are best equipped to serve. A flexible design can provide a better fit between varying levels of resident competence and the degree of environmental press to which they are exposed.

8. Establish Links to the Healthy and Familiar.

People with dementia are confronted with an ongoing series of changes in themselves and

their world. It is important, to the extent possible, to maintain their ties to that with which they are familiar and comfortable. Patterning the facility after familiar environments—the home and the past—can provide a "soft transition" to the institution (Mace & Rabins, 1981). Inclusion of things from the past and encouragement of homelike environments suggest many design applications.

9. Protect the Need for Privacy.

As a consequence of the need for surveillance and assistance with activities of daily living, relocation to an institutional setting often results in an accompanying loss of privacy for people with dementia. Although it is often both expensive and difficult to provide physical privacy, environments for people with dementia should allow residents to choose between solitude and participation in activities by providing a range spaces from public to private. Clearly defined boundaries between public and private areas minimize ambiguity between that which is shared and that which belongs to an individual. Demarcation of territorial boundaries in the bedrooms of institutionalized elderly is related to increased self-satisfaction and improved mental status among both organically impaired and unimpaired residents (Nelson & Paluck, 1980).

PEOPLE WITH DEMENTIA

Although many readers will be familiar with Alzheimer's disease and its characteristics, some may find the following brief review a useful introduction to this topic. This section includes a description of the nature and history of the disease, current research topics, typical symptoms, and their impact.

INTRODUCTION TO ALZHEIMER'S DISEASE

- *Dementia is a disease, and not a result of normal aging*
- *Alzheimer's disease usually develops in the mid-60s, but can occur earlier*
- *More than 2.4 million U.S. citizens suffer from severe Alzheimer's disease*
- *60-70% of all patients in nursing homes have Alzheimer's disease*

The most devastating illness associated with aging is Alzheimer's disease (AD). This progressive irreversible neurological disorder is seen in its most severe form in 5% of the population over 65 years of age, and in 20% of the population over 80. Alzheimer's is the most common of the dementing diseases of the elderly, accounting for 50-60% of all such cases. In developed nations, it ranks fourth as a cause of death (after cardiovascular disease, cancer, and cerebrovascular disease).

The severe disabilities resulting from AD, which usually renders its victims helpless, are a major reason for institutionalization, and have created

a major public health problem. The magnitude of this problem is projected to increase as the number of elderly people in the population increases.

In the United States, the number of individuals with severe AD will more than double in the next 30 years (Heston & White, 1983; Reisberg, 1983; Lindeman, 1984; Office of Technology Assessment, 1987).

SIGNS AND SYMPTOMS

- *Decline in functional, cognitive, emotional, and social abilities*
- *Reduced mastery and control over the environment*
- *Prognosis: people with Alzheimer's disease usually die seven to ten years after the onset of dementia, although this period may last up to 15 to 20 years*

The first sign of AD is forgetfulness, especially of recent events. Other cognitive functions are gradually compromised: judgement and the ability to orient one's self in space and to time are lost; new learning cannot take place; and expressive speech becomes difficult. Disabling personality changes and mood swings occur. This cognitive, emotional, and behavioral deterioration is not linear, and may differ greatly among individuals (however, see Figure 3 for an outline of a typical progression).

AD is relentless, irreversible, and devastating, as personal competence is eroded, and the afflicted person slips into a state of complete dependence. In the final stages of the disease, which is eventually terminal, neuromuscular changes interfere with mobility and physical abilities (Heston & White, 1983; Reisberg, 1983; Gilleard, 1984; Lindeman, 1984; Shamoian, 1984; Office of Technology Assessment, 1987). These changes are summarized in Figure 3.

ETIOLOGY

- *Diagnosis is difficult*
- *Cause is unknown*
- *AD develops regardless of gender, race, or social status*

The etiology (or cause) of Alzheimer's disease is unknown. Early signs and symptoms may be mistaken for normal aging, and, as the disease progresses, are difficult to distinguish from those of other dementias. Therefore, the goal of diagnosis is to rule out both other forms of irreversible dementias and reversible dementias, which may respond to treatment. For this reason, a battery of tests, usually including a medical history, physical examination, psychological and laboratory tests, and various kinds of brain scans, may be administered (Heston & White, 1983; Gubrium, 1986; Office of Technology Assessment, 1987). Drugs are sometimes used to ameliorate symptoms such as agitation and paranoia, but, currently, there is no effective treatment that can arrest the underlying pathology of AD.

IMPACT ON CAREGIVERS

Most people with dementia are cared for at home, at least in the earlier stages of the disease (Office of Technology Assessment, 1987). The unrelenting demands placed upon the caregiver,

usually the spouse or close family member, create what Mace and Rabins (1981) have characterized as the "36 hour day". Without respite, the caregiver often becomes the second victim of the disease.

Problems in caregiving are exacerbated with the progression of AD, and include: difficulties with activities of daily living (ADL) such as feeding oneself, getting dressed, etc.; getting lost or constant wandering; rummaging behavior; disorientation in time and space; agitation or occasional violent or catastrophic behavior; and withdrawal. The consequence of these problems is that eventually the person suffering from Alzheimer's disease cannot be left alone, and the caregiver ultimately becomes bound to the home almost completely. Complete care is required at all times (Kelly, 1984; Office of Technology Assessment, 1987).

Supportive therapies that help both the person with dementia and the family to adjust to the progressive decline, by improving coping and daily living skills, constitute the main assistance that can be offered. Activities and environmental modifications that help to minimize dysfunction and maximize remaining capabilities should also be implemented.

DEFICITS OF ALZHEIMER'S DISEASE AND THEIR RELATION TO ENVIRONMENTAL DESIGN SOLUTIONS

The major performance deficits of Alzheimer's disease can be divided into four categories: behavioral/functional, cognitive, emotional, and social. Behavioral/functional deficits include those changes associated with dementia that result in detrimental task performance (e.g., reduced ability to deal with demanding employment situations) and significant physical changes (e.g., incontinence). Cognitive deficits result in difficulty in mental functioning (e.g., remembering names, abstract thinking). Emotional deficits include changes in affective response (e.g., personality changes and catastrophic reactions). Social deficits include changes in behavior towards others (e.g., decreased performance in social situations and alienation.)

In Figure 3, these four types of performance deficits are plotted against the stages of the disease (as described in Reisberg, 1983) in which they are likely to occur. Stage 1 is the period in which symptoms are first likely to be noticed; there may be anxiety and some decrease in task performance and social aptitude, but there is not typically a diagnosis of Alzheimer's disease at this stage. Stage 2 witnesses increased deficits, including major changes in the ability to perform tasks, concentrate, remember recent events, and conduct reasonable or abstract thought. There is also a significant decrease in the display of emotion, and in the ability to function in social situations. Stage 3 is the final stage, in which the most severe consequences of dementia are likely to surface, including wandering, incontinence, severe loss

of memory and orientation, severe and significant changes in personality, and an inability to tolerate most social situations.

The second column of Figure 3 links the problems associated with behavioral/functional, cognitive, social, and emotional deficits to general environmental strategies for resolution or amelioration of these problems. For example, people in the second stage of dementia may find themselves getting lost easily (cognitive deficit). Strategies for resolving difficulties associated with this deficit may include: 1) increasing the ease of locating someone who is lost; 2) increasing the safety of the environment in traditionally "unsafe" areas, thereby circumventing any accidents that might occur if a wandering person entered these areas; 3) employing multi-sensory clues to encourage wayfinding, such as color coding and successful signage, and associating distinctive smells and sounds with specific areas; and 4) developing easy, memorable and consistent routes with recognizable landmarks for use by people with dementia.

BEHAVIORAL/FUNCTIONAL DOMAIN	
Deficits	General Strategies for Resolution
<p>Stage 1 Early a) No observable deficits in home or work situation</p> <p>Late b) Coworkers, spouse, close friends begin to note poor performance (e.g., getting lost, losing things)</p> <p>Stage 2 Early a) Difficulty with complex tasks in situations that require decision-making or that are highly stressful (e.g., handling finances, driving in traffic)</p> <p>Late b) Unable to perform complex tasks (e.g., grocery shopping, traveling)</p> <p>c) Nocturnal restlessness</p> <p>d) Reduced coordinational and motor skills (e.g., as manifested in household falls, inability to use some utensils, tools, or equipment)</p>	<p>a, b): Reduce distractions and simplify tasks as much as possible. Some tasks and equipment are fundamentally confusing to all (e.g., single-handle faucets), but most people are capable of adapting to these. Because people with dementia cannot make these adaptations, it is necessary to explore means of making complex tasks, activities, and equipment less complex.</p> <ul style="list-style-type: none"> • Define subtasks • Limit choices to a restricted, well-defined set of possibilities • Use visual and verbal instructions • Conduct only a single activity at a time • Define sequences of tasks, and break complex tasks into simple steps • Eliminate those tasks that cannot be broken down and are too complex to be completed by the person with dementia. <p>c): Modify physical settings or activities. Environmental strategies:</p> <ul style="list-style-type: none"> • Create a soothing and restful night time environment, as well as a day time environment that is not over- or understimulating • Separate sleeping environment from other spaces <p>Activity strategies:</p> <ul style="list-style-type: none"> • Introduce appropriate night time activities for restless individuals • Schedule day time activities to encourage sleep at night <p>d): Provide support and mitigate hazards.</p> <ul style="list-style-type: none"> • Employ prosthetic devices such as grab bars, stair rails, or furnishings stable enough to provide support • Mitigate hazards by avoiding potentially dangerous surfaces and equipment

Figure 3. Deficits of Alzheimer's disease and their relation to environmental design solutions.

BEHAVIORAL/FUNCTIONAL DOMAIN (continued)

Deficits	General Strategies for Resolution
<p>Stage 3 Early</p> <p>a) Cannot initiate or complete purposeful tasks (e.g., doing crafts, cooking, choosing clothing independently, making phone calls)</p> <p>b) Nocturnal confusion, wandering</p> <p>c) Reduced mobility, shuffling gait</p> <p>Late</p> <p>d) Incontinence</p> <p>e) Dependent for all care</p>	<p>a): Clarify and simplify purposeful tasks.</p> <ul style="list-style-type: none"> • Amplify important environmental messages • Dampen unnecessary environmental messages • Use consistent sequential ordering of steps in tasks and of necessary equipment/utensils <p>b): Minimize the causes of and/or accomodate wandering.</p> <ul style="list-style-type: none"> • Enhance the ease with which environmental messages can be understood • Accommodate wandering as an acceptable activity <p>c): Create more negotiable environments.</p> <ul style="list-style-type: none"> • Aviod surfaces that are difficult to traverse (e.g., highly polished materials or exceedingly thick carpeting) • Eliminate barriers to mobility, including great distances and changes in levels • Employ protheses and other means of support <p>d): Facilitate toileting by making toilets easier to locate and use Make clean and sanitary environments easier to maintain Make assistance with toileting less problematic</p>

COGNITIVE DOMAIN	
Deficits	General Strategies for Resolution
<p>Stage 1</p> <p>Early</p> <p>a) Difficulty remembering names of people, familiar place, objects</p> <p>Late</p> <p>b) Obvious word-finding deficit</p> <p>c) Loses objects of value</p> <p>Stage 2</p> <p>Early</p> <p>a) Poor concentration</p> <p>b) Impaired reason, judgement</p> <p>c) Gets lost</p> <p>Late</p> <p>d) Difficulty recalling recent events, personal history</p> <p>e) Financial incompetence</p> <p>f) Impaired abstract thought</p>	<p>a, b) Aid in remembering names and other words.</p> <ul style="list-style-type: none"> • Employ cues such as labels to aid remembering and recognition • Make names of people, places, objects and their functions more obvious <p>c) Make objects harder to lose.</p> <ul style="list-style-type: none"> • Assign or develop specific locations for objects • Make objects easier to spot/locate <p>Make objects of value harder to lose.</p> <ul style="list-style-type: none"> • Make objects of value inaccessible • Substitute items of lesser value for those likely to be lost. <p>a) Manipulate the environment to increase ease of concentration.</p> <ul style="list-style-type: none"> • Amplify important environmental messages • Dampen unnecessary environmental messages • Use consistent sequential ordering of steps in tasks • Limit the number and length of activities that require intense concentration <p>c) Reduce the problems associated with wayfinding in environment.</p> <ul style="list-style-type: none"> • Increase ease of locating a person who is lost • Increase the safety of traditionally "unsafe" areas and environments • Employ multi-sensory cues to encourage wayfinding • Develop easy and consistent routes <p>d) Use personalization of the environment to aid in recall of recent events and personal history.</p> <ul style="list-style-type: none"> • Incorporate familiar artifacts from residents' personal pasts (e.g., photos of family or of local landmarks) • Utilize "every day" items

COGNITIVE DOMAIN (continued)

Deficits	General Strategies for Resolution
<p>Stage 3 Early</p> <p>a) Severe memory loss, cannot recall major aspects of life, names of close family members</p> <p>Late</p> <p>b) Largely unaware of time, space, events</p> <p>c) Loss of speech</p> <p>d) Loss of intentionality</p>	<p>a) Use environment to support short and long term memory.</p> <ul style="list-style-type: none"> • Reduce dependence on memory for daily functioning • Introduce "memory-jogging" activities and artifacts • Incorporate "reality" orientation devices and activities • Reduce the number of critical, memory-dependent tasks <p>b) Use environment to increase awareness of time, space, and events.</p> <ul style="list-style-type: none"> • Make function of places readily apparent • Incorporate "reality" orientation devices and activities <p>c) Increase ability to communicate without speech.</p> <ul style="list-style-type: none"> • Keep key artifacts of daily living in visible and accessible locations <p>d) Increase ability to remember name, identity.</p> <ul style="list-style-type: none"> • Provide verbal labels and/or pictograms for important spaces and objects

SOCIAL DOMAIN	
Deficits	General Strategies for Resolution
<p>Stage 1</p> <p>Early</p> <p>a) No observable deficits</p> <p>Late</p> <p>b) Decreased performance in demanding social situations</p> <p>c) Communication difficulties</p> <p>Stage 2</p> <p>Early</p> <p>a) Inappropriate, embarrassing social situations</p> <p>Late</p> <p>b) Socially inept</p> <p>c) Social alienation</p>	<p>b) Manipulate environment to regulate and support social interaction.</p> <ul style="list-style-type: none"> • Provide a range of opportunities for social interaction—more to less demanding—and for solitude • Provide sociopetal spaces to support interaction when it is desired <p>c) Use environmental cues to facilitate communication.</p> <ul style="list-style-type: none"> • Provide nondistracting, appropriately stimulating environments to support communication (e.g., carpeting and other surfaces to reduce extraneous noise) • Encourage sustained relationships with a limited numbers of caregivers, who will communicate more easily with residents whom they know well • Limit the amount of unnecessary communication by providing autonomy and a supportive environment for people with dementia, limiting the number of services, etc. they must request directly <p>b) Provide sufficient opportunities for nondemanding social interaction and solitary activities.</p> <ul style="list-style-type: none"> • Provide spaces for a range of interactions, both more and less demanding • Structure social spaces and activities to allow for choice • Moderate the number and variety of people with whom the person with dementia must interact at a given time. Encourage regular contact with familiar people • Provide an appropriate degree of stimulation and a supportive environment <p>c) Employ sociopetal environments and policies and practices that encourage social interaction.</p> <ul style="list-style-type: none"> • Provide a variety of spaces for a range of interactions • Ensure opportunities for passive and active participation • Use "family"/household organization of units • Support meaningful and familiar roles for people with dementia • Encourage and support visiting by families and friends

SOCIAL DOMAIN (continued)

Deficits	General Strategies for Resolution
<p>Stage 3 Early</p> <p>a) Only simple, structured familiar social situations can be tolerated</p> <p>b) Reality orientation needed</p> <p>Late</p> <p>c) No social interaction possible</p>	<p>a) Provide a healthy, familiar, "normal" environment.</p> <ul style="list-style-type: none"> • Offer varying degrees of stimulation and a range of opportunities for interaction • Provide spaces and time for solitude • Maintain a structured schedule of activities, to take place in predictable locations • Provide opportunities for normal interaction in familiar roles and activities and with familiar others <p>b) Manipulate environmental variables to enhance orientation to reality.</p> <ul style="list-style-type: none"> • Provide a "normal," familiar residential environment, atmosphere, and activities • Increase visual and physical access to the outdoors (to maintain orientation to time, season, and location) • Encourage visiting as a source of information about "reality"

EMOTIONAL DOMAIN	
Deficits	General Strategies for Resolution
<p>Stage 1</p> <p>Early</p> <p>a) Anxiety and appropriate concern about symptoms</p> <p>Late</p> <p>b) Moderate anxiety about symptoms</p> <p>c) Irritable</p> <p>Stage 2</p> <p>Early</p> <p>a) Anxiety about symptoms</p> <p>Late</p> <p>b) Denial of symptoms</p> <p>c) Flat affect</p> <p>d) Withdrawal from challenging situations</p>	<p>c) Provide soothing and nonfrustrating environmental options.</p> <ul style="list-style-type: none"> • Offer access to soothing, calming, private spaces as relief from overstimulation, which may cause irritability • Moderate environment to decrease irritability due to environmental frustrations (e.g., trouble with activities of daily living, difficulty remembering functions of household objects) <p>c) Support activities and opportunities for the display of affect.</p> <ul style="list-style-type: none"> • Encourage sustenance of affective response by encouraging opportunities for exercising emotions (e.g., caring for pets, reminiscence, social interaction in sociopetal spaces, physical contact) <p>d) Encourage people with dementia to continue to perform at or near their maximum level of capability.</p> <ul style="list-style-type: none"> • Support autonomy in decision making and in activities of daily living whenever possible • Limit environmental frustrations • Provide meaningful and achievable choices and challenges • Provide a range of opportunities, more to less challenging, to meet individual needs over time • Encourage people with dementia to undertake challenges and reward their efforts

EMOTIONAL DOMAIN (continued)	
Deficits	General Strategies for Resolution
<p>Stage 3</p> <p>Early</p> <p>a) Denial and shame</p> <p>b) Catastrophic incidents: irritability, agitation, and violent episodes</p> <p>Late</p> <p>c) Personality changes: paranoia, hallucinations, delusions</p> <p>d) Obsessional behavior</p>	<p>b) Prevent, moderate, and isolate catastrophic incidents.</p> <ul style="list-style-type: none"> • Moderate the level of environmental stimulation, especially during times that catastrophic incidents are likely to occur (e.g., late afternoon) • Provide access to a soothing, private space for use during catastrophic incidents to lessen their duration, intensity, and likelihood of spreading to other residents <p>c) Ensure a healthy and familiar ("normal") environment to discourage hallucinations and delusions.</p> <p>Encourage retention of normal and healthy roles for people with dementia (e.g., friend, supporter, participant in leisure activities, group member.)</p> <p>d) Discourage and moderate harmful obsessional behavior.</p> <ul style="list-style-type: none"> • Recognize that not all "obsessional" behavior is harmful (e.g., wandering as a form of activity) • Provide distractions for obsessional behaviors (e.g., create a rummage box for residents who go through others' closets)

