HOUSING OPTIONS FOR PEOPLE WITH DEMENTIA

CMHC SCHL

HOME TO CANADIANS
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Housing Options for People with Dementia

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Introduction

The aging of the baby boomer population has caused many Canadians to look more closely at aging-related issues. Aging is a normal part of life and, for some, the retirement years are filled with travel and hobbies; however, illness can affect the lives of others.

One disease that can affect older people is dementia. This is a term used for a group of symptoms that affect mental abilities, including: the ability to remember, reason, make decisions, judge and communicate. There are various forms of dementia: the effects of some can be reversed; those of others, currently, cannot.

For those people with a progressive type of dementia, specialized care in specialized environments is required to enhance their abilities and quality of life.

Much has been learned about dementia care, and progress is being made to integrate that knowledge into programs and services that meet the needs of this population.

Purpose of the guide

All of us – whether we are individuals caring for a family member, professionals responsible for designing, building or managing group housing or providers of support services for people with dementia – need to understand dementia if we are to succeed in making the lives of people with dementia more comfortable, dignified and satisfying. Also, we need to know the resources that are available to us in caring for them. This guide sets out to increase public awareness of new housing options for people with dementia and to encourage the development of more community-based solutions. More specifically:

- it describes a range of **housing options** designed to meet the particular needs of people with dementia;
- it outlines a range of **support services** that can help caregivers to fulfil their responsibilities;
- it discusses a number of housing **management principles** that can help in the care of people with dementia; and
- it discusses **environmental design** considerations for housing people with dementia.

One of the important concepts presented in this guide is that of "residentiality." Very simply, this concerns the importance of creating a home-like setting for those suffering from dementia. The guide discusses two primary options for those suffering from dementia – to remain at home (whether that is a detached suburban bungalow, a condominium apartment or a dwelling unit in a retirement community), or to move into housing specifically designed for people with dementia. For those who can no longer remain at home, the guide presents a number of housing options where persons with dementia can maintain a comfortable sense of living normally.

Methodology

The research program included two searches, one in North America and the other worldwide, by mail, phone and fax, the purpose being to uncover innovative and interesting housing projects to care for those with dementia in a community setting.

In collaboration with the Alzheimer Society of Canada and with local chapters of the Alzheimer Society in Victoria, Vancouver, Edmonton, Calgary, Toronto, Montréal and Halifax, the project team conducted a total of 10 focus group interviews with developers, researchers, planners, designers and caregivers – both family and professional. Participants urged that the guide should clearly define the concept of housing options for people with dementia, with particular emphasis on the little understood concept of "residentiality." They also expressed frustration with the regulatory and funding barriers that currently inhibit the development of alternative community-based housing. They stressed the need for policy-makers to encourage more support for caregivers at home and for the development of alternative accommodation.

Participants in all 10 groups were asked to list terms that signified residentiality as it relates to specialized accommodation and services. Those terms were combined and analysed to help define "residentiality" as it is used in this guide. (See page 5.)

People with dementia also contributed to the process, through discussion and presentations. One of these groups was made up of five women in the early stages of dementia who belong to a Day Health program; five couples, with all five men suffering the early stages of Alzheimer's disease, formed another. All five couples were in their 70s and still living together in the family home. These two groups addressed the same topics as did the other ten; however, their discussions focused more on personal experience and long-term memories. They talked about home – in childhood and present-day – and how they cope with dementia and the need to coordinate many, varied service-providers in their lives.

The varied contributions of all these people, but especially those who were themselves suffering from Alzheimer's disease, underline the fact that not everyone is the same. The situation of every aging person or every person suffering the effects of dementia is unique in its needs, opportunities and challenges. Fortunately for people with dementia and their families, society and the various organizations and agencies that address the problems of dementia are beginning to recognize and to reflect that diversity in a wide range of services and housing options.

Chapter 1: Background

Dementia

The condition: Characteristics and causes

Dementia impairs cognitive capacity – the ability to think, remember, understand, reason, judge and communicate. The loss of these abilities affects an individual's capacity to function and perform daily activities, such as handling finances, cooking and driving.

There are several types of dementia, the most common type being Alzheimer Disease. A recent study shows that two-thirds of those affected by dementia in Canada have Alzheimer Disease, which is a progressive degenerative disease of the brain that damages brain cells. It gradually renders independent people totally dependent.

Other causes of dementia include:

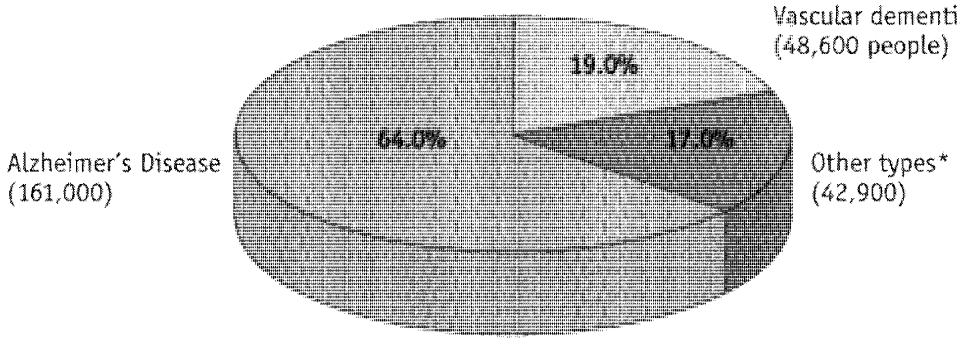
- Vascular dementia or multi-infarct dementia – caused by a stroke or loss of circulation to the brain. If this condition is controlled, further damage may be prevented. Some people with vascular dementia can regain function as undamaged areas of the brain learn to compensate for the damaged ones.
- Creuztfeldt-Jakob, caused by a rare virus.
- Parkinson's disease.
- AIDS.
- Huntington's.
- Korsakoff's, result of heavy, long-term use of alcohol.
- Dementia pugilistica, caused by head injuries.

Depending on the causes, dementia can affect the brain in different ways and impair cognitive abilities in differing patterns. Only a thorough medical assessment can diagnose dementia and determine the exact cause.

Demographics: The social context

Dementia is closely associated with old age. It follows that, as the number of elderly people increases in Canada, the number of people with dementia is also growing. Presently, more than a quarter million Canadians over 65 are affected by dementia; that number is expected to increase to over 750,000 by the year 2031.

TABLE 1: CAUSES OF DEMENTIA AMONG SENIORS IN CANADA



The estimated total number of seniors (people 65+) with dementia in Canada in 1991 was 252,600.
* Other types include: Parkinson's disease, Pick's disease, Huntington's disease, Creutzfeldt-Jakob, post-head injury, and other unclassified dementia.
Source: The Canadian Study on Health and Aging (1991-92)

TABLE 2: ESTIMATED NUMBER OF SENIORS WITH DEMENTIA IN CANADA, 1991-2031

Year	Number of People
1991	252,600
2001	364,000
2011	475,000
2021	592,000
2031	778,000

Source: The Canadian Study on Health and Aging (1991-92)

TABLE 3: PERCENTAGE OF CANADIANS WITH DEMENTIA BY AGE GROUP

Age Group	Percentage
65 to 74	2.4
75 to 84	11.1
85 or older	34.5
65 or older	8.8

Source: The Canadian Study on Health and Aging (1991-92)

The Canadian Study of Health and Aging (1991) surveyed some 10,000 people in 36 Canadian cities and surrounding areas with a view to establishing the relationship of health to age for people both in the community and in institutions. The study confirmed that the prevalence of dementia increases with age and that a full 8 per cent of those over 65 have dementia. Because women tend to live longer, almost 68 per cent of those with dementia are female.

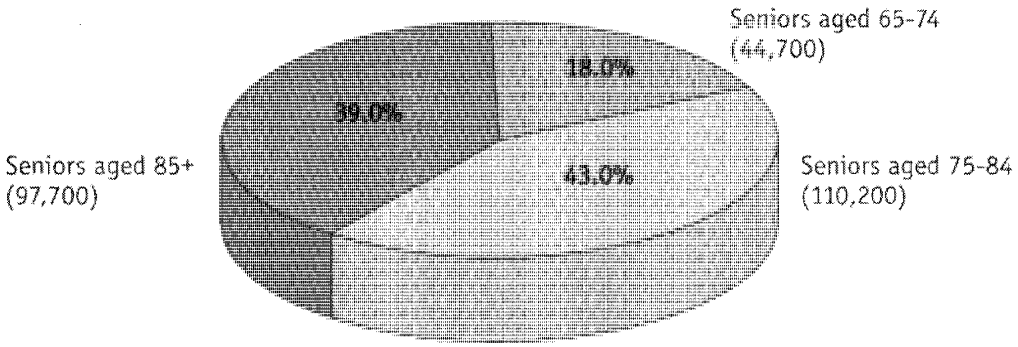
In 1991, of all seniors who suffered from dementia, 18 per cent were from 65 to 74 years old; 43 per cent were 75 to 84 years old, and 39 per cent were 85 or older.

In 1991, nearly 50 per cent of Canadians over 65 with dementia were living in the community; the remaining 50 per cent were living in institutional settings, such as nursing homes, hospitals or other institutions. Until recently, there were few residential alternatives.

The stages of dementia

Dementia, as stated, has many causes and, for each type, the condition follows a different course and manifests a different set of symptoms. The following stages refer only to the progression of the Alzheimer's Disease.

TABLE 4: CANADIAN SENIORS WITH DEMENTIA BY AGE GROUP



The estimated total number of seniors (people 65+) with dementia in Canada in 1991 was 252,600.
Source: The Canadian Study on Health and Aging (1991-92)

Early Stage

People in the early stages of Alzheimer's Disease have difficulty remembering recent events and processing new information. Their ability to concentrate is affected, and they begin to have difficulty following directions. Problems with communication start with difficulty in finding the right word. Their moods seem to shift, happy one minute, sad the next. Frequently, depression is a problem. They may appear withdrawn and anxious. These difficulties are often noticed when people have trouble with normal activities, such as handling the finances or cooking a recipe.

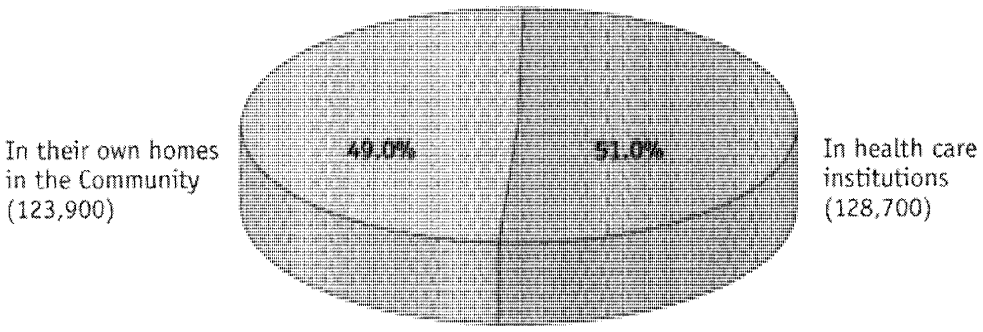
Middle Stage

In the middle stage, memory loss increases, and people begin forgetting the past. Family and friends become difficult to recognize. Mood swings increase and the person may become confused, anxious or suspicious. The ability to concentrate declines further. Individuals may begin to exhibit behaviours such as repetition, wandering and aggression. Sleep patterns begin to be interrupted. Appetites often fluctuate. People begin to experience problems with visual spatial abilities. Communication difficulties increase. More and more assistance is required to perform day-to-day activities.

Late Stage

The losses that occur in the early and middle stages of the disease increase. Memory and the ability to communicate are greatly impaired. People gradually become unable to recognize even the closest of family members. They appear withdrawn and require more sleep. Gradually, the ability to walk and talk is lost. Communication may be limited to crying or groaning; however, individuals may respond to music or touch. Bowel and bladder control are also lost. Swallowing food may become a problem, and weight loss often occurs even with a good diet. Individuals in the late stage eventually become totally dependent on those around them.

TABLE 5: SENIORS WITH DEMENTIA IN CANADA:
WHERE WERE THEY LIVING IN 1991?



The estimated total number of Canadian seniors (people 65+) with dementia in 1991 was 252,600.
Source: The Canadian Study on Health and Aging Working Group. "Patterns of Caring for People with Dementia in Canada." *Canadian Journal on Aging*, 13, (1994): 470-487.

Changes along the way

In the *Handbook for Care*, the Alzheimer Society of Canada points out that Alzheimer's Disease eventually affects every part of life, including how a person thinks, feels or acts. Everyone is affected somewhat differently. However, some changes can almost certainly be expected as the condition progresses.

Changes in mental abilities

Dementia affects a person's ability to understand, think and communicate. At first, the changes are small and subtle. People become gradually unable to learn new things and make decisions. They forget how to do simple tasks that they have done for years. They have trouble remembering names, where they are or what they were about to do. They have difficulty following a conversation or making themselves understood. For a long time, they may clearly remember past events. Eventually, even the past will be forgotten. However, even in very advanced stages of dementia, they will still be able to hear, respond to emotions and be aware of touch.

Changes in emotions and mood

People with dementia are relatively inexpressive and passive, and they tend to become withdrawn. At the same time, they become unable to control their emotions. Their moods may change rapidly and with increasing unpredictability. They may become suddenly and inexplicably sad, angry, inappropriately hilarious or frantically worried over apparently trivial matters. At other times, they may become inordinately suspicious of people close to them. In fact, it may seem as though their whole personality has changed. Eventually, they will seem to react very little, if at all, to people and their surroundings.

Changes in behaviour

Changes in mental ability and mood result in changed behaviour. However, the kind and degree of change is different for each person and certainly will be influenced by physical condition. New behaviours may include pacing or wandering, repetitive actions, hiding things, constant searching, undressing, disturbed sleep, physical outbursts, restlessness, swearing, arguing and inappropriate sexual advances. These changes in behaviour are not intentional. They are caused by a progressive condition beyond the control of the person with dementia.

Changes in physical abilities

Changes in the brains of people with dementia also result in decreased physical ability. Beginning with alterations in the way people move and loss of coordination, these effects become gradually more severe. Eventually, people with dementia may have difficulty feeding, dressing or bathing themselves. Bladder and bowel control will be lost. They will become less and less able to move about and, eventually, they will be unable to look after themselves at all.

The social and physical environment

People with dementia need a social and physical environment that offers clear cues as to appropriate behaviour and that will support the safe expression of their needs. Such "dementia-friendly" and supportive environments will allow people with dementia to function with relative normality for as long as possible.

Everyone is different

The types of behavioural change and the speed at which the condition progresses is different for each person. There is no way to know how long people will be able to dress themselves or when, if ever, they will need to go into a long-term care facility. The

condition may progress very rapidly in some people, while others may be able to live almost normally for many years. However, as the condition progresses in older people, access to appropriate health and social services becomes critical, and this access should be integrated into any appropriately designed environment.

Residentiality

Residential dementia care refers to housing and services that enhance the individual's quality of life by maintaining them in familiar and comfortable surroundings. Residentiality ensures each person the independence to choose their own level of safety and risk in a way that leads to dignity and empowerment. Residentiality is made possible by the caring and support of both family and community.

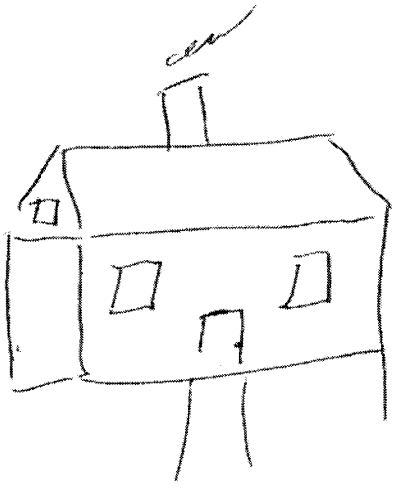
Traditionally, elderly people with dementia were cared for at home. Where this was impossible, they moved into institutional health care. Today, there is a much broader range of choices linked to modern support services, technologies and housing alternatives designed to help people with dementia and their caregivers to live satisfying lives. New, community-based housing alternatives are called "residential" options, because they are home-like in their design and operation. Community-based solutions include the homes where those with dementia lived before the condition became well established, the homes of their family members and, increasingly, a variety of home-like housing options specifically designed to meet the needs of people with dementia and their caregivers.

People with dementia and their families face one important choice – to remain at home or to move into some form of specialized housing. For those who make the decision to move, the focus groups involved in this study were unanimous in identifying residential care, as opposed to institutional care, as most appropriate for people with dementia throughout the course of the condition. People who require periodic medical attention can generally receive this at home or in an individual or group residence. People who must go into a health care facility from time to time can usually return to residential care after treatment.

The feeling of home

Five people with dementia formed one of the focus groups. When asked, "What is home to you?" they responded in a variety of ways. Some associated it with a quality – home was clean or roomy. Others remembered the home of their childhood, recalling buildings of a certain size and colour, or associated a feeling of comfort with a favourite room or a familiar smell or sound. One participant drew a childlike picture of a house. Still others thought of home in terms of people – a mother, children or a husband.

Figure 1: A drawing of "home" by a person with Alzheimer's Disease.



WHAT IS HOME?
FROM PEOPLE WITH DEMENTIA

• A calm atmosphere. • My son and daughter. • Being by myself; my husband is no longer. • Clean. • People who run it are very nice people. • A four-bedroom brick house. • Roomy. • One of the first to have a radio in town, a wooden radio with a bump. • I rode a horse to school and back. • A two-storey house. • The house was green. No, it wasn't. • Lots of fruit trees; apple, pear and cherry. • A pond in the bottom of the field. • There was a butcher shop in the front, and we killed the animals in the back. • I like the kitchen best; it's homier. • My mother played the piano in the living room. • If someone bothered me, I said: "I have to go home. • I had a brown-coloured house. • The smell of home-made bread. • We had an attic in our house; I liked to look out the attic window and wave hello. • In our attic we had clothes my mother brought from Scotland in 1903. • I went to sewing class; made all the kids' clothes and then my own. • I sewed up all the flies in my husband's underpants as a joke – he got the point eventually. • Our sewing machine was upstairs in a long hall. • My sewing machine was on the upper floor near a bay window; we got a lot of light there. • My machine was a "Seamstress" with a treadle. • After I got married I moved to a house with a living room, dining room, two bedrooms and a basement. • Once I had children I moved again. • In our kitchen we had a big stove, two cupboards next to the door and a table for six people. • A garden was OK then, but it's too much hard work now. • I live in a bungalow. • It's hard to get around in a large building.

The survey also included 100 people – caregivers, relatives of those with dementia and professionals from a variety of fields – who participated in ten focus groups. They were asked, "What words would you use to describe the qualities of a new residential model for those with dementia?" Their answers spanned a range from practical – focusing on such factors as affordability, safety and manageability – all the way to social and spiritual factors. Some of the more important terms were repeated frequently, even within a single group, and these have been italicized in the following chart. Overall, the responses of focus group participants paint a picture of a place that is safe and supportive but that, at the same time, offers an optimum level of privacy, flexibility and independence. The ideal residence is a place filled with natural light, plants and music. It is a place where fun and communal activities are balanced with ample room for individuality.

WHAT IS THE IDEAL RESIDENTIAL MODEL?
FROM CAREGIVERS AND EXPERTS

• Access to groceries. • Achievable. • Affective. • Affordable. • *Autonomy.* • Bathrooms for each resident. • Builds on strengths. • *Caring.* • A chance to remember. • Children. • *Choices.* • Church on Sunday. • Clergy of any religion. • *Client is the expert.* • Clothes. • *Comfortable.* • Common sense. • *Community.* • Cooking. • Cozy. • Creative. • *Dignified.* • Diverse. • Empathy. • *Empowerment.* • Encouraging. • Enjoyment. • *Familiar.* • *Family.* • *Flexible.* • *Free movement.* • Friendly. • Fun. • Gardens. • Holistic. • *Home.* • *Home cooking.* • Humour. • *Independence.* • *Individual.* • Innovative. • Intimate. • *Living.* • Low stress. • Manageable. • Meaningful. • Music. • Natural. • Needs of people. • Normalized. • Nurturing. • Ordinary. • Out of doors. • Participation. • Partnerships. • Patience. • *Personal space.* • Pets. • Plants. • Potluck suppers. • Personhood. • Privacy. • *Privacy for sex.* • *Quality of life.* • Quick response to need. • Reflect a person's culture. • Relationships. • Relaxed. • *Respectful.* • *Risk-taking.* • Run just like a house. • *Safe.* • Seasons. • Self-directed. • Simple living. • *Smaller.* • *Social.* • Spacious. • Spiritual. • Stimulating. • *Supportive.* • Sympathy. • Time. • Touch. • Understanding. • Unobtrusive. • User friendly. • *Values.* • *Warm.* • Welcoming. • Wellness.

A close analysis of the above terms suggested that there are five essential elements to the concept of residentiality, as follows:

Housing

A physical setting is residential when it is comfortable, small, manageable, home-like, homey, familiar and welcoming.

Quality of life

The goal is to provide as high a quality of life as possible for each resident, accepting each person's limitations and recognizing their abilities. Adequate health care is essential to support a good quality of life.

The individual

Residentiality strives first to satisfy the needs and desires of the individual, and to accommodate his or her habits and personality; the requirements of facility management are secondary.

Dignity and empowerment

By respecting the dignity of people with dementia and by offering them as much independence, choice, freedom and privacy as possible, caregivers can empower residents. Though people with dementia may have lost certain skills, they will feel confident to use what remains to do things for themselves and to escape a feeling of total dependence.

Family and community

The residential setting is oriented to family, with family members playing an important role in caring for people with dementia. Moreover, residential facilities are community-based in that they provide a community service, receive services from the community and are connected to the community through long-term care institutions, stores, pharmacies and service organizations that help people with dementia and their families to live well.

Chapter 2: Caring for People with Dementia

Seeking the "dementia-friendly" environment

People with dementia and their families may eventually face a decision – to continue living at home or to move into some kind of specialized accommodation. "Home" in this sense can mean many things – a single-family house, a multi-unit rental apartment building or seniors condominium with certain support services already in place. Specialized accommodation may also vary in kind, size and management type, but it should always include design and operational features intended to create a "dementia-friendly" environment. In either case, whether the person with dementia remains at home or moves, it is vital to their sense of well-being to ensure that their housing delivers a high degree of residentiality.

It is not easy to care for a person with dementia. In everyday life, we all live with explicit and implicit constraints. These tell us when it is appropriate to cross the street, when it is time to eat and when to turn lights or machinery off and on. There are innumerable rules that define acceptable behaviour, and we learn these at an early age. People with dementia begin to forget those rules. The "shoulds" and "should nots" that used to be second nature are gradually forgotten. People with dementia, as they gradually become unable to make sense of the world around them and have difficulty making themselves understood, exhibit behaviours that others may find challenging.

These are the kind of behaviours that lead to a decision to move. However, even if a person with dementia moves into specialized accommodation, it is vital not to uproot them entirely from past associations and activities. "Residentiality" means letting people with dementia live safely in a protected community while, at the same time, remaining connected to the larger community from which they acquire essential services (from local doctors, a nearby pharmacist, the taxi company, a neighbourhood hairdresser and so on). The community approach means that a group of people with somewhat differing needs can be cared for and live together in an interdependent community that paradoxically allows everyone to remain as independent as possible for as long as possible, even as the condition of dementia progresses.

People with dementia need affection, attention and help to live full lives and to draw to the fullest extent on their remaining faculties. Housing that is safe, dignified and familiar can support this way of life. Empathetic and appropriately trained caregivers working with family members can focus their attention on and respond to the needs of individual residents, while drawing on the larger community for essential support services. In the small community designed specifically to meet the needs of people with dementia, there is no right or wrong – only what works best for the residents, their family, friends and the caregivers who work with them.

Caring for people at home: The implications

The everyday residential approach – which means helping people with dementia to continue to live at home – can put considerable strain on caregivers. In a single-family house, the primary caregiver is likely to be a family member – possibly a spouse or offspring. In a multi-unit apartment building, however, the housing manager may also be involved. In both cases, support services will be needed to help care for the person with dementia. Also, certain changes should be made in the environment to make the home safe and manageable for the person with dementia. (See also Chapter 5: Designing Housing for People with Dementia.)

Implications for people with dementia

For those who remain at home, in an environment that is full of familiar and comfortable things, "residentiality" is not an issue. The lighting, the wallpaper, the furniture - every detail of the house speaks of home and comfort. It is vital, in adapting the environment to the needs of the person with dementia, not to lose this sense of homeliness. For example, it is not helpful to import "institutional" equipment, such as hospital beds and furniture, brackets to hold televisions on the wall, institutional-type eating trays and so on. While such equipment might be recommended by some professional caregivers to make caring for the person with dementia easier, a price will be paid in terms of comfort and happiness. The extra effort of working with ordinary household fittings and fixtures is likely to pay off with interest in terms of its therapeutic effect.

People with dementia feel at home because they are surrounded by familiar objects that comfort them. Sleeping in their own beds, with pictures and photographs around them, they retain much longer a sense of their own individuality. Their dignity is enhanced by the freedom to act and, within limits, to make choices about when to bathe, when to lie down, where to walk. Even such a degree of independence makes them feel better about themselves and their quality of life.

That does not mean that living at home is without its problems. People with dementia respond to environmental cues that remain with them from before the onset of dementia. Kitchens or dining rooms are associated with eating. An easy chair means sitting down and relaxing. A bed means lying down. A front door that opens means going somewhere. However, people with dementia can respond inappropriately to such cues, thereby putting themselves at risk. Forgetting that they have just eaten, they may open the refrigerator in search of food. Turning on a stove to boil water, they may forget to turn it off. Opening the front door, they may forget where they intended to go or, even worse, how to get home again. Certain activities which the individual has performed safely for years – such as cutting the lawn – may become dangerous. There are also inherent dangers of living at home. The carpet that provides so much comfort and coziness may trip a person whose coordination is failing. Electrical outlets pose another risk, if an individual no longer understands their purpose.

Caregivers have to be vigilant to prevent fires, falls and accidents. It is the caregivers' role to protect people with dementia from their environment and from inappropriate and risky actions. However, in attempting to protect them, caregivers need to focus not on an individual's limitations, but on bolstering their remaining capacities and fostering independence. This can be done by planting clues in the environment to engender appropriate action. For example:

- keep the bathroom door open and the lid of the toilet up;

- mark dangerous changes in floor level so that they are clearly visible;
- put safety devices on the stove;
- post signs on clothing drawers, etc.

Implications for caregivers

Deciding to keep a person with dementia at home means a significant commitment of time, effort and patience on the part of the caregiver. A caregiver at home can never relax. Even in the middle of the night, the person with dementia may get up and wander. Moreover, people with dementia lack the capacity to plan activities for themselves; that means that the caregiver must plan for two people instead of one. Caregivers are responsible not only for protecting people with dementia from mishap; they also must constantly think and create activities to keep them busy and happy. Such planning and supervision is both a responsibility and a burden.

Caregivers, especially family members or friends, who take on the responsibility of caring for people with dementia often make one major mistake: they forget to take care of themselves. They forget that they are human and need time out. They forget that only by staying strong can they provide the needed care. Caregivers are typically very busy – helping the person with dementia to the bathroom or at least reminding them to go, making meals, making the bed, cleaning up, running errands and so on. Many caregivers find that they have no time to themselves and that they are delivering a level of service that is impossible to sustain over the long term. All too often, they burn out.

Finding appropriate help is thus an important part of the decision to remain at home. At this point, caregivers at home become both providers and managers. On the one hand, they are caring for the person with dementia; they are also, in effect, beginning to manage staff resources. Management begins with the identification of resources – in this case, by drawing up a list of people that caregivers can call on, including relatives, friends, paid employees and government services. Then, they must arrange schedules and, if necessary, transportation, payment and so on for the person being called on. They must also work to make sure that the person with dementia accepts the substitute caregivers.

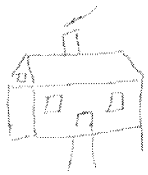
As manager, the caregiver arranges with others outside the home to provide services that he or she cannot. Such services might include help with dressing or preparing for bed, grooming, bathing, meal preparation, going out for a walk or to the doctor's, reading to the person with dementia, playing checkers or cribbage and, most importantly, watching day and night to ensure safety.

Implications for housing managers

Not every "home" is a detached dwelling or traditional family house. Indeed, many elderly people have moved into apartment buildings or retirement communities long before the onset of dementia. If residents in these communities who are experiencing progressive impairment are to continue living at home, the housing manager – whether or not the housing was specifically designed for elderly residents – may have to respond creatively to their special needs. To do that successfully means understanding the needs and risks of dementia, reformulating the responsibilities of management and drawing on professional resources in the surrounding community.

In multi-unit apartment buildings

It is not uncommon for certain apartment buildings to have a relatively high proportion of elderly residents. Often, older people have decided fairly early in the course of their retirement to move from a



single-family house, with all its onerous responsibilities, to an apartment building where life will be easier over the long term. Sometimes, when numerous older people have simultaneously moved into a single building, this can result in a "naturally occurring retirement community" (NORC). Existing and new apartment buildings can easily be designed or modified to meet the needs of these older residents. Such buildings are often staffed by a housing manager, superintendent or concierge whose function is to keep the building running efficiently. Sometimes, they also provide a limited number of support services to the residents.

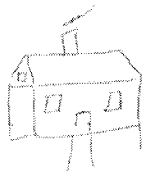
As residents in these apartment buildings age, a proportion is likely to develop dementia. As the condition progresses, they may forget where they are, leave the taps running, leave their apartment doors open or wander off. Others may get up in the middle of the night and knock on a neighbour's door. Housing managers may only become aware that a resident is having difficulty when he or she gets lost in the building, forgets to pay bills on time or is disruptive is some way. When housing managers decide to allow such residents to continue living in their apartments, their traditional job may change to that of care manager.

What does this mean? Simply that a housing manager's job description may need to be changed and expanded to meet the needs of people with dementia, day and night. In particular, the manager must arrange for someone – if not themselves – to be available, for example, to handle crises in the middle of the night. Although home care agencies can provide this service, managers who take responsibility for housing people with dementia must face the fact that they are on-site to deal with emergencies, and that – when it comes to people with dementia – the night is no longer their own.

Often a family with a relative in an apartment building may assume that housing managers are fully responsible for their relative. This is not true. Though housing managers have a role to play, they cannot – and should not – accept full responsibility for people with dementia. As soon as they recognize the onset of the condition, managers should contact the family of residents to meet them to discuss their relative's situation and to get them involved in caring for their relatives. The manager may also direct the family members to dementia support groups, such as the local Alzheimer Society, which can in turn refer them to readily available sources of information, such as books and videos.

The staff of an apartment building normally provides certain services to residents (for example, guaranteeing their safety). However, if people with dementia are to continue living in the building, managers may have to hire additional staff to address their particular safety needs and to provide necessary services. Again, this may be accomplished through home care service agencies.

Simple changes in the building rules may help residents with dementia continue to live there comfortably. For example, allowing residents to put distinctive decorations on their doors may help them to orient themselves and find their way back to their own apartment. The housing manager, when dementia is diagnosed, may find an appropriate moment to inform the rest of the tenants so that they are less alarmed and more understanding of the affected person's behaviour. In fact, neighbours – if adequately briefed – are quite likely to be helpful to the tenant with early dementia. The manager may also play a role in alerting family that perhaps there is a problem.



Dementia, however, is not a static condition. Thus, the housing/care manager must constantly monitor changes in the number of residents with dementia and the nature and severity of the condition. When they observe that the condition has progressed to a point where they can no longer provide adequate support, they must inform the resident's family and consult them on possible relocation to safer accommodation with more appropriately trained staff.

In seniors housing without on-site services

Most management issues that relate to family apartment buildings also pertain to seniors housing. A great deal of seniors housing was originally designed for relatively active, "young old" people, and it is managed accordingly. Over time, however, as the average age of residents increases, housing managers are faced with more and more disabilities, including dementia, among the residents.

Increasingly, managers of private and subsidized seniors housing are planning in advance and establishing links with social service and home health care agencies against a future time when aging residents may require enhanced support. These agencies can eventually establish a regular presence in the building, managing their own service delivery to maximize affordability and access.

Moreover, to support delivery of housekeeping and support services, the housing manager might decide to make a small, on-site office available to the home care agency. The agency would then be in a position, by serving the entire community from on-site premises, to react much more quickly and efficiently than could any off-site agency serving individual residents. For example, working out of the building office, the home care worker could spend half an hour helping Mrs. Smith to get dressed, shop for groceries for her and two of her neighbours and, on returning, stop to remind Mr. Jones to take his medicine. With a continual presence in the building, home care workers can become aware of problems early, assess them in a timely way and arrange for service before the problem ever turns into an emergency.

The housing manager may also wish to coordinate access to a meals program and, in some cases, even choose to invest in the design and building of a common dining room and activity areas for the use of aging residents.

An option to working with other, independent agencies is to hire a full- or part-time service coordinator to work in the seniors residence, with the cost being covered by the rents (in a private building) or grants (in a subsidized building). Research has shown that even a small amount of attention from an in-house coordinator can allow impaired residents to go on living in relative independence. Furthermore, the coordinator can work to foster a spirit of cooperation in the building and to generate resident-to-resident support and understanding. The end result will be more people with dementia remaining longer in the retirement buildings they chose as homes for their old age, even if these buildings were not originally designed to serve those with dementia.

In seniors housing with on-site services

Many seniors residences – for example, congregate housing, sheltered housing, assisted living and Continuing Care Retirement Communities (CCRCs) – were designed to deliver not only shelter, but also a range of on-site services needed by older people. In effect, managers of such housing may find themselves in three businesses: they provide shelter, hotel-type services (for example, housekeeping and meals) and personal care services.

Services in such housing are mostly geared to residents who, though frail, are mentally competent. It follows that the range of on-site services that is traditionally offered in seniors residences does not usually encompass those that are needed by people with dementia – for example, medication reminders, escort to meals and help with shopping and handling money. Also, residents with dementia, even if they do not need daily help to dress, might benefit from assistance in bathing and managing their wardrobe. Most seniors residences house quite a few people with early- to mid-stage dementia, and the residence must provide this kind of support.

The awareness and attention of staff is key to helping residents with dementia to remain in the seniors residence for as long as possible. Training is the single most important factor for housing managers to address in preparing employees to understand the needs of people with dementia and to respond with appropriate and timely service. With the right kind of education and support, staff can learn to circumvent disruptive behaviour and can creatively assist residents to live comfortably and well for an extended period of time.

Turning point: The decision to move

As pointed out at the beginning of this chapter, home modifications combined with support services can help people with dementia to remain at home for a long time. However, the reality is that gradually the individual will need more supervision and care, 24 hours a day, seven days a week. For most, there comes a time when, having exhausted support services as an option or finding that the management of support services is impossibly complex and time-consuming, the family and caregiver come to realize they are at the point where they need to review other options than keeping the person at home.

Weighing the issues of quality of care against the positive effects of remaining at home leads to an important choice for caregivers and family of the person with dementia: Should they keep their relative at home or is it time to explore another housing option? Once again, it is important to stress that not everyone is the same, not every family is the same. There is no single solution, therefore, no easy answer.

Making the right decision for the person with dementia means taking into consideration all the resources of the caregiver and family, as well as the stage which the condition has reached. It also means scanning the market to evaluate housing alternatives, some of them very recently developed, that are now available to serve this extremely diverse group of consumers. Making the right decision also requires a careful review of the overall management and care philosophy of each potential housing option that may be available to families as they search for the best possible accommodation for the person with dementia. (See Chapter 4: Managing Housing for People with Dementia.)

The identification of alternative accommodation is possibly one of the most difficult and emotionally draining tasks that face the caregiver or family of a person with dementia. The decision-making process needs the assistance of as many friends, support groups, health care professionals and family members as possible.

Photo 1: An example of a group home – Maison Carpe Diem, Trois Rivières, Que.

Moving into new housing

No matter what kind of "home" people with dementia inhabited before their ability to function was undermined by confusion and forgetfulness – a house, apartment, townhouse or retirement community – they may well find themselves eventually needing services or support that is no longer available to them at home. In that case, they and their families may decide that a move is in order. In the past, when the decision to move was regretfully taken, there was a certain tendency to think of exclusively institutional care; fortunately, today's housing market is evolving and responding to the growing demand for residential solutions to the housing dilemma of people with dementia. The result is a range of appropriate housing options that balance to one degree or another the need for support and protection against the wish for a degree of independence and normality. In all likelihood, that range of options will continue to grow, keeping pace with the growing numbers of people who are expected to experience dementia in the first few decades of the 21st century.

The range of options

The range of residential housing options for people with dementia include a variety of multiple-unit settings in which small groups of people live together. There are currently three generic types of options.

Group homes

These homes can be either new or renovated, and they tend to be organized as large, single-family homes that house eight to ten people. In Canada, several large houses have been converted for the exclusive use of people with dementia. Similar residences exist in Scandinavia, the United States and elsewhere. While some group homes have been modified with the introduction of elevators or stair lifts, many have not, and residents must climb stairs with help. Group homes usually have a living room, dining room and kitchen, much like a regular house, and bedrooms for residents. Sometimes, residents sleep two to a room, and sometimes they have their own bedrooms. Bedrooms may, or may not, contain en-suite bathrooms.

There are appropriately trained staff on duty in the group home during the day and a staff person on call during the night. The staff treat residents like family members and try to create a family atmosphere. Generally, meals are cooked in a communal kitchen and served family-style. Activities such as music, dancing, reminiscences and walking are also carried out in small groups, sometimes jointly with everyone who lives in the house.

Assisted-living

This is the newest term for a very old concept, often known as "lodges," "personal care homes" and "boarding homes." Assisted-living can simply be defined as a home setting in which support services are provided. Assisted-living residences are

generally larger than group homes, accommodating from 30 up to as many as 120 people. They were originally developed for frail elderly people and look very much like oversized houses or small apartment buildings.

As a result of recent increases in the number of people with dementia, assisted-living residences are now being planned exclusively for this population. These are seen as an alternative model of continuing care that combines accommodation and support services, including health care, in a home-like environment. They can take several different forms, including:

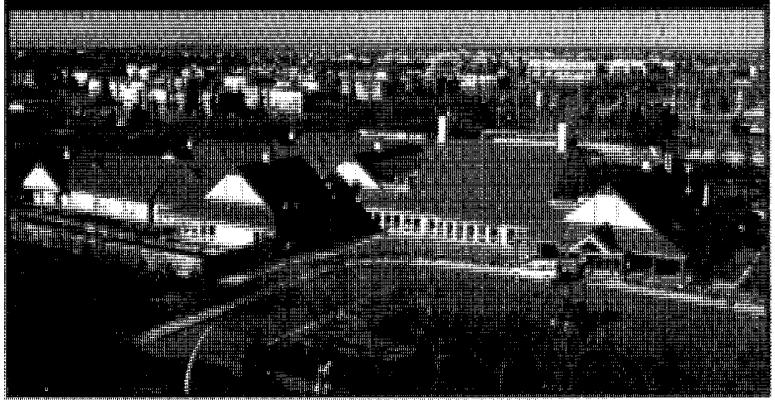
- free-standing residences where residents have their own rooms but share common living, dining and kitchen facilities;
- free-standing residences containing two to six separate apartments, each with its own living/dining room, kitchen, bedrooms and possibly a garden; and
- residences forming part of larger assisted-living residences for older people but operated independently and often having their own entrances, their own secure gardens and their own staff.

Supportive housing

This type of option tends to be seen not only as the high end of the continuum of residential accommodation and community support services for seniors but also as an alternative to unnecessary institutional health care. It combines a variety of accommodation, a range of on-site personal support and homemaking services (often with professional care services) and 24-hour personal supervision by trained staff.

The model of supportive housing is increasingly being used to house people with dementia, particularly those in the early- to mid-stages of the disease.

Photo 2: An example of assisted living – McConnell Place West, Edmonton, Alta.



Supportive housing for people with dementia may have been built new or it may have been converted, and it can take different forms of delivery, including:

- Small groups of self-contained dwelling units, usually six to ten in number, sharing common living/dining and kitchen facilities. These can be found in stand-alone buildings or as part of a seniors housing development.

Photo 3: An example of supportive housing – Rimmer House on the eighth floor of this seniors building, Winnipeg, Man.

- Small groups of bachelor apartments, or suites, usually eight to 12 in number, sharing common living/dining and kitchen facilities. These are usually found on a dedicated floor in a multi-storey seniors apartment building or as a wing or part of a floor.

Often there is a small staff office, activity rooms and other space appropriate to people with dementia. Residents live in their own fully equipped suites, or bachelor apartments, or self-contained units. Where there are kitchens, the stoves may be fitted with safety devices. Either the staff is hired directly by the building management or they are brought in under contract to support service providers.

Examples of housing options

With every year that passes, knowledge of the needs and problems of people with dementia grows, as does the number of successful experiments in the physical design and management of specialized housing. (Some of the thinking that underlies such experiments, and the criteria that they respond to, are described in Chapters 4 and 5, along with a description of actual housing examples in Chapter 6.)

Planning a continuum of care

A move or change in environment can be very disruptive to someone with dementia, so it is preferable to allow the individual to age in place. Therefore, as dementia can be a progressive disease, it is important to plan for care that can adapt to changing needs over time. A number of important criteria must be taken into account when planning a continuum of care for someone with dementia.[1] As well as a plan of care and a complete medical work-up, service providers should evaluate the social support mechanisms available to the person with dementia and help families assess the best residential alternatives, based on the nature and extent of family and social support available. Service providers are also advised to ensure that programming activities are available and creatively provided in all possible living environments. Families should also visit the housing they have chosen for their relatives at least twice, and they should discuss their decision with service providers before placing their family members.

[1] Based on Delores M. Moyer GNP, "Dementia Care: The Nurse Practitioner's Role," *Advance for Nurse Practitioners*, November 1995.

Chapter 3: Support Services for People with Dementia

The role of the caregiver is an onerous one, whether the caregiver is an elderly spouse of the person with dementia, another family member, a friend or someone else. As people with dementia often require around-the-clock help, the task of caring for them can be demanding, stressful and sometimes difficult, both physically and emotionally. When caregivers assume this responsibility, support and assistance is vital to ensure the highest possible quality of life for everyone concerned.

Principles of good service

The factors that affect caregivers looking after people with dementia at home are basically the same as those that affect caregivers looking after people in specialized housing.

Not every person with dementia is the same; and not every solution is suitable for all individuals or families. It follows that caregivers and families in search of support have to shop thoughtfully among the available services and housing options to find one that provides the optimal balance of comfort and support for their particular situation. However, there are certain principles of "good service" that are common to all situations. When shopping for assistance, therefore, families and other informal caregivers should examine the credentials of formal service providers to see that their programs are based on the following core principles:

- focus on individual dignity;
- adaptability and flexibility in service delivery;
- dedication to life-enriching activities;
- preservation and promotion of family contact; and
- integration into the larger community.

These principles can also help formal service providers to develop their own approaches to serving people with dementia and their families.

The service provider should also rely on the following management tools, which are essential to fulfilment of the core service principles:

- a clear statement of purpose;
- training and education that supports a suitably selected and qualified staff;
- ongoing program assessment mechanisms;
- personalized care planning that provides optimum flexibility;
- suitable programming and organized activities; and
- fiscal responsibility.

(See Chapter 4 for a more detailed discussion of these principles and tools.)

Types of services and support

Families are an essential part of the support system for people with dementia. They are often the primary caregivers during the early and middle stages of the disease. At some point during the course of the disease, however, their efforts must be complemented by a range of community-based support services, such as respite and relief services and help with daily living activities, or by formal care providers in specialized housing for people with dementia. Examples of the range of community-based support services and resources that are, or can be, available to families and other caregivers can be grouped in the following categories:

- information and training;
- support and counselling;
- respite and relief; and
- practical help.

A few actual examples of existing support services are given below.

Information and training

Understanding the condition and learning care strategies and techniques can give family caregivers the know-how they need to care for an individual with dementia. There are many books, videos and brochures, as well as educational workshops available in communities across the country. Local Alzheimer Societies are a good place to start.

The Alzheimer Society of Canada produces resources for those affected, their families and health care professionals to help them better understand the disease and how to give good care. For example, the *Guidelines for Care* outline what is good Alzheimer care. The guidelines, which are relevant to people with Alzheimer's disease regardless of type of residential setting, emphasize goals and values instead of rules and directions. *Guidebook for Care*, also published by the Alzheimer Society of Canada, helps caregivers achieve the goals outlined in *Guidelines for Care*. Both publications focus on aspects of care that are in addition to the needs of other older adults.

One of the most comprehensive training programs in Canada is offered at the Dr. L.U. McClusky Centre in Pembroke, Ont. The centre, which was designed by a team of staff from the Marionhill Home for the Aged, is run by the Order of Grey Sisters of the Immaculate Conception. The centre is linked to the existing home for the aged and offers a wide range of in-home, residential and educational programs that cater to the needs of family caregivers and persons with dementia.

Programs include a six-week assessment of the resident and a support and training program for family members to assist them in developing detailed strategies for those with dementia. All programs include family members and informal caregivers in the client's programming. While the centre is operated by the Marionhill Home for the Aged and funded by the Province of Ontario, user fees are levied based on provincial guidelines.

Support and counselling

The realities of dementia can be overwhelming for both the individuals affected and for their families. For those affected, the challenge is dealing with the loss of abilities; for their families, it is dealing with the responsibilities of caregiving. Support can help, whether it is found in a support group, where participants share their experiences and help each other, or one on one, through working with a skilled counsellor. Sharing emotions and feelings can provide reassurance, support and comfort.

Respite and relief

Caring for a person with dementia is a twenty-four-hour, seven-day-a-week job. Research shows that those caring for persons with dementia are at great risk of physical and emotional illness. Taking a break from the day-to-day responsibilities of caregiving is important to maintain the caregiver's health and to ensure that they are able to provide the care needed. There are various ways that the dementia caregiver can get relief: specifically, adult day programs, night-time care or overnight respite and in-home or vacation respite.

Day programs and services

These programs help families that are able to care for a relative with dementia at night but have difficulty during the day because of other commitments. Such programs enable family members to bring their relatives in the morning and pick them up at night. Not every Adult Day Program offers the same services. Some day programs offer social activities such as ball games, seated aerobics and meals. They may also include programs that help with general medical care, including physical and occupational therapy.

One successful day health respite program is offered by the Bethany Group in Alberta. The program, known as the Cross Roads Day Program in Camrose, Alta., offers help to people who live in the community and who need support and assistance to maintain their independent living situation. Program participants continue to live in their own residence and come in during the day for a variety of health and social programs. Services offered to participants include:

- nursing care and supervision;
- occupational therapy and physiotherapy;
- nutritional services to the client and family;
- education and support;
- recreation and leisure activities; and
- referral and coordination.

The day program is offered two days a week. A unique feature of this program is that it integrates its program with other community services for those with dementia: a full transportation link between the daycare centre and the home, an overnight diagnostic service combined with respite and medical assessment and in-home care review planning for the family. A nominal fee is charged to participants of the day program, with the balance of service costs being borne by the Alberta Ministry of Health.

Night-time care and overnight respite

These are similar to adult day programs with only a shift in time. Night-time and overnight programs provide families caring for those with dementia an opportunity for respite or a short holiday while the person with dementia is safely taken care of outside of the home.

One of the most comprehensive ranges of respite services is offered to families seeking short-term respite from the burden of care by the Harry and Jeanette Weinberg Hale Kako'o Respite Centre in Honolulu (see Chapter 6). The centre can house up to 12 overnight residents and, in addition, it serves up to 24 day clients. The respite care program provides a home-like setting where residents participate in some cooking activities, table setting and cleaning up, as well as some daytime recreation. Short-stay residents and their families are encouraged to participate in a range of support programs with staff and other family members.

The respite services are located in a single-family-like home in a neighbourhood in the community. The centre looks like any other house on the street, and the space is organized in such a way that, even though there are no defined corridors, there is a coherent wandering path. There is also continuity of service for day and night care which provides residents with a familiar place at any time of day. Security is unobtrusive, and there is visual access to most of the public parts of the building to ensure safety and security for all the residents.

In-home respite services

These provide an interesting variation on respite care. The Time Away Program, in Kingston, Ont., is operated by Kingston CARE, under the auspices of the Victorian Order of Nurses. The program offers in-home respite care that enables the family or family member to go away while the person with dementia is cared for in their own home. It was developed with assistance from the Alzheimer Society of Kingston.

Every effort is made to provide continuity in terms of respite workers to each family. The program is offered throughout the geographic area around Kingston. The cost of respite depends on the length of in-home stay and the family income. The program is partially funded by the Ontario Ministry of Health.

Vacation respite

This is beneficial to families who either want to take a vacation with a relative who has dementia, or to give the person with dementia a chance to have a vacation without the family. The setting for vacation respite may be a large vacation home with separate programs for family members and residents, or it may be a campground for a group of residents with dementia with special programs planned just for them.

Photo 4: Example of a holiday home for people with dementia and their caregivers – the St. John Holiday Home, Edinburgh, Scotland

An interesting vacation respite program is offered by the Order of St. John and the Alzheimer Society of Scotland, two charitable organizations that have acquired a large house near the sea and offer family caregivers and the person with dementia an opportunity to enjoy a holiday together. The large detached house is set in an attractive walled garden near a village. The home can accommodate up to nine guests in a range of single and shared rooms. There is a formal dining and living room and a glass conservatory overlooking the garden. The fully equipped kitchen offers self-catered holidays that reduce cost to guests and allow guests to plan their own schedules during the stay.

The entire home has been modified for the safety and security of those with dementia. Resident staff offer a range of practical help during the day, from assistance with daily living tasks to staying with the family member if the caregiver wants to go out alone in the day or evening. Staff and volunteers can be booked to be available with each reservation. Staff are trained so that the specific needs of guests are accommodated as much as possible.

Guests are asked to identify in advance the assistance that may be needed during their stay, and staff-to-guest ratio varies with client needs. Accommodation can be rented on a daily or weekly basis. A requirement for participation is that the person with dementia must still be ambulatory. Daily rates vary depending on staff and volunteer requirements.

Practical help

People with dementia and their caregivers may also need some practical help. Because of the loss of their abilities, people with dementia may need help with the activities of daily living – for example, bathing, dressing and grooming. If they are living on their own, they may need help with tasks like laundry, meal preparation, cleaning, etc. For caregivers, practical help with such tasks can provide relief in an already full day.

Among a variety of programs available throughout Canada, the SAINTS program (Students Assistance in North Toronto for Seniors) provides a range of services to seniors and their family caregivers in the North York area. The students assist the seniors with tasks they are unable to do for themselves. Office staff select high school students living close to the senior or family caregiver and attempt to match a request for service within 48 hours. The program is viewed as beneficial both to the high school students and to the seniors in the community. Services are provided to all seniors, however frail, who live in the community. Students work for a one-hour minimum at nominal wages and provide such services as shopping, light housekeeping, walking, gardening, house painting, letter writing and snow shovelling. SAINTS is funded primarily by the Ontario Ministry of Health, Long-Term Care Division, and the City of North York. Unique aspects of the program include the use of students who have been screened prior to placement, the provision of family support when needed, the inter-generational nature of the support service and the variety of support for simple tasks such as letter writing or companionship for walking.

Similar to SAINTS, the Senior Peoples' Resources in North Toronto (SPRINT) is a locally based non-profit society that offers a range of services, intended to provide respite and support to family members and those who care for frail or cognitively impaired seniors and disabled people in their own homes. Services offered in the local community include visiting and escorting, home respite, telephone assurance, case-management coordination, meals on wheels, home help and transportation. All SPRINT workers receive training and ongoing supervision. Specific instruction is also provided in the care of the physically frail and cognitively impaired. SPRINT is a non-profit organization partially funded by the Ontario government, the municipal government, private donations and the United Way. Although there is a charge for service, financial assistance is offered for families with limited income.

St. Leonard's is a modern 117-unit housing development in the centre of Edinburgh. This many-faceted complex was designed to meet the needs of a varied clientele, including home-owners, renters, student renters and people with special needs. In particular, 20 flats have been designated for people – including some with dementia – who can benefit from supportive housing as an alternative to a nursing home or residential care . Specifically, this housing is aimed at those who are deemed suitable for Care At Home Level I or II. All houses in the development are built to "Barrier-Free Design" principles and Scottish Homes' standards, so there is no physical separation between special needs and mainstream housing. The approach provides for a high degree of independence; however, it also

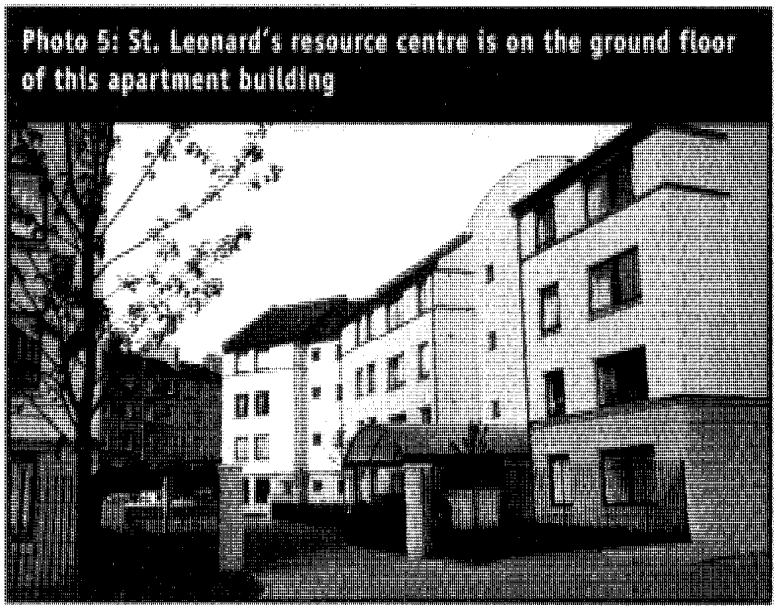


Photo 5: St. Leonard's resource centre is on the ground floor of this apartment building

provides reassurance and help when it is needed through, for example, a communications system for everyday use and emergencies.

The Edinvar Community Care Services provides visiting support to 20 frail, elderly people – including those with dementia – in their own homes within the St. Leonard's development. The service is essentially a resource centre located on the ground floor of one of the apartment buildings. Individually tailored support services are set out in Support Agreements and are delivered either individually or to groups, depending on the wishes of the client. Services include assistance with personal care (bathing or prompting with medication), practical tasks (cooking, laundry and shopping), helping residents to use community services (attending a club or day centre), or supporting personal and interest development (befriending or reducing isolation). Visitors also help people to deal with emotional issues.

Another vital daily life activity involves moving about and walking safely. The Alzheimer Wandering Registry, coordinated by the Alzheimer Society of Canada, is an important support to residents and families in that it provides a safety net for those who wander away from home. Registering the individual with the Alzheimer Wandering Registry can provide peace of mind. The nation-wide Alzheimer Wandering Registry was developed by the Alzheimer Society of Canada in collaboration with the Royal Canadian Mounted Police. The program is designed to help individuals with dementia return home safely following an episode of wandering. When an individual is registered, vital information about him or her is stored confidentially on a police database. Should an individual be found wandering or reported missing, the information can be accessed by police anywhere in Canada. Registration is voluntary. For a one-time fee, the Alzheimer Society provides an identification bracelet, a Caregiver Handbook and ID cards. For more information on the Alzheimer Wandering Registry in your area, call your local Alzheimer Society or 1 800 616-8816.

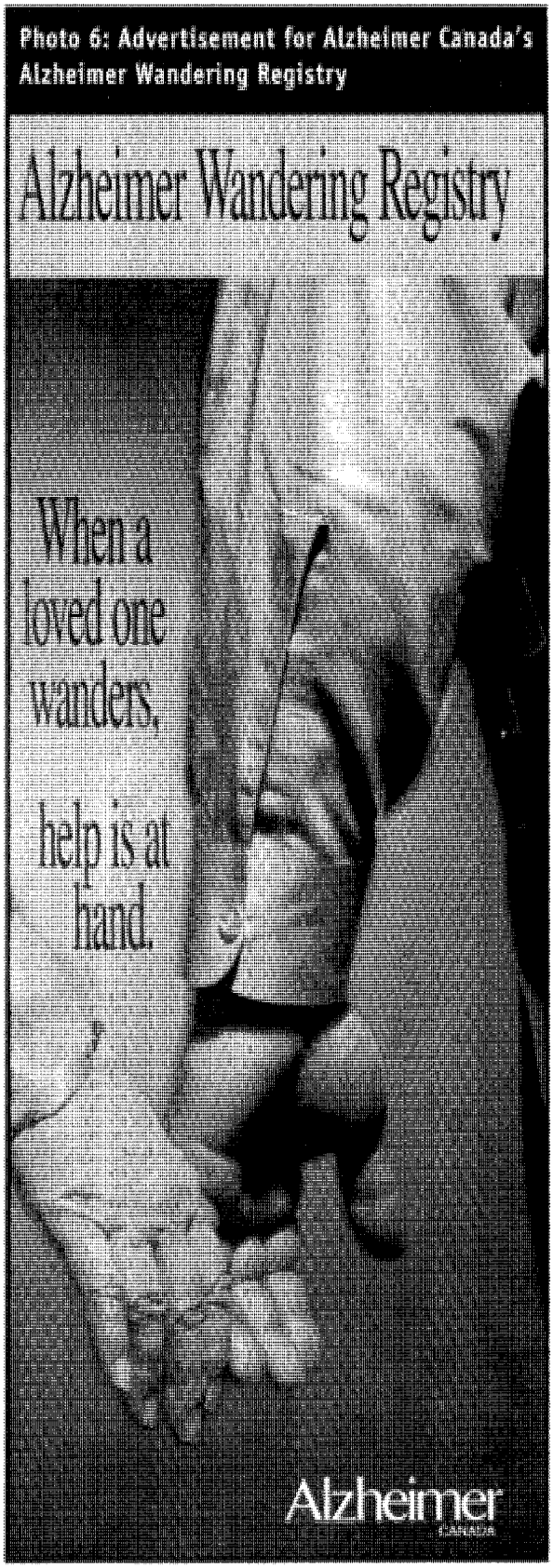


Photo 6: Advertisement for Alzheimer Canada's Alzheimer Wandering Registry

Chapter 4: Managing Housing for People with Dementia

Management principles

When planning new or renovating existing housing for people with dementia, it is essential to consider the unique responsibilities of managing such housing. Managing housing for people with dementia means understanding the condition, understanding the needs of people with dementia and their families and coordinating tasks of caregivers. Some important management principles include the following.

Focus on individual dignity

Each person's reactions to having the condition is different, requiring assessment and care planning that is responsive to his or her own personality. Caregivers should not standardize care.

Have a clear statement of purpose

Managers should develop a clear and cohesive statement of purpose that is reflected in all the practices of the residence. This leads to a sense of cohesiveness and comfort among residents.

Be adaptable and flexible

In order to respond adequately to residents' needs, management must empower caregivers to work together in teams to support one another throughout the day and night and to carry out a broad range of tasks.

Select and train suitable staff A good caregiver for people with dementia has patience, self-assurance and empathy. Special training on dementia is essential to help caregivers understand the disease and techniques that are necessary to providing good care.

Provide life-enriching activities

Activity programs must be well structured and varied to reflect residents' past lifestyles. Caregivers must treat each activity of daily living as the opportunity for a structured and fulfilling individual or group experience.

Maintain family contact

Family members need to participate in the caregiving team so that they can bring their familiarity with the person into care and activity planning. The entire family must be supported and helped in its response to the disease.

Remain integrated into the larger community

Visits from family members and friends link people to their previous community life. By remaining connected to the community – to stores, service providers, parks and people –people with dementia remain in contact with their memories and the feelings that sustain them.

Be fiscally responsible

The organization is expected to have adequate resources to support the programs necessary to provide the quality of care residents and families expect. Everyone expects the organization to remain solvent, to cover costs and make a profit or to make money for reinvestment.

Residents, staff, families and activities

The key to making the above principles operational is in correctly screening and assessing residents, selecting and training staff, teamwork, organizing daily life activities and involving families and other caregivers.

Defining clientele

Factors that are often considered in deciding what market to serve include:

- mission of the housing provider organization;
- needs in the market area being served;
- availability of support services;
- provincial and town regulations;
- building type and its ability to meet fire codes;
- government reimbursement programs; and
- residents' health conditions and need for help.

Assessing residents

Residents should be regularly assessed – at least every six months and more often if necessary – for health and ability to function. Current assessment focuses on the following key aspects:

- health and functional condition;
- need for help and support; and
- safety and security.

Selecting staff

Staff should have the following key characteristics:

- flexibility to respond to different reactions of individuals to their condition;
- reasonably good self-esteem and sense of humour;
- responsibility;
- common sense;
- team spirit;
- appropriate training; and
- experience.

Training staff

Dementia-specific training is important for all staff. Areas of training should include:

- normal aging;
- explanation of dementia;
- communication with people with dementia;
- program philosophy and mission;
- family issues;
- creating and maintaining a supportive environment;
- therapeutic techniques and strategies for daily living;
- understanding challenging behaviours;
- stress management; and
- team-building.

Team approach

Experienced service providers have found that a team approach allows staff closest to the residents to work together to meet their needs. Many providers use inter-disciplinary teams, so that staff with different backgrounds and training work together to coordinate services and provide a holistic approach to the needs of each individual resident. Some providers favour a primary care model, in which each staff person takes primary responsibility for about five or six residents.

Organizing daily life activities

Residents with dementia lose "executive brain function" early in the course of the condition. Executive function enables people to organize their time, to comprehend complex instructions and generally to foresee several steps ahead in time. "Activities" therefore, means "daily life" as the organizing principle for residents' days and nights. Daily life implies

a rhythm and flow from morning to evening, including intense group activities and quiet personal ones.

Among such activities are singing familiar songs, dancing, completing familiar phrases with omitted words, carpentry, planting, bowling – perhaps with a lightweight plastic balls and pins, organizing wedding photos and baking.

Involving family members and other informal caregivers

Families and other informal caregivers must be helped to:

- understand the disease;
- understand behaviours and their implications;
- get information about available options, services, costs and government programs;
- receive counselling in dealing with their feelings about the relative's condition; and
- receive training in how to care for or be helpful to their relative.

Families should be both members of the care team and clients of the organization. They can be actively involved in caregiving and can help in the following ways:

- as advocates for the residents' needs;
- attending care plan meetings;
- providing information about the resident's history and preferences;
- providing direct services as appropriate, such as grooming;
- helping resident with tasks such as shopping and maintaining a wardrobe;
- providing additional recreational and enrichment opportunities for the resident; and
- serving as volunteers in the residential program.

In summary, the keys to successfully caring for people with dementia include:

- screening and assessing residents correctly;
- training caregivers;
- working as a team;
- organizing daily life activities to flow seamlessly throughout the day and evening; and
- involving family members and other informal caregivers.

Chapter 5: Designing Housing for People with Dementia

As the Canadian population ages, the number of people with dementia will triple. Until recently, people with dementia were fairly evenly divided between care in institutions (51 per cent) and home-based, community care (mainly delivered by women, either spouses or daughters of the affected person). However, both of these traditional solutions are under considerable pressure at the moment; it is pressure that is bound to increase. On the one hand, governments are trying to cut costs to the public purse by minimizing unnecessary institutionalization. On the other hand, caregivers in the community – mostly women – are finding it increasingly difficult to care for their elderly parents at the same time that they raise children and work in full-time jobs.

These changing circumstances mean that governments, housing providers and designers, caregivers and members of the community must all search actively for new housing solutions. In particular, designers have a role to play in identifying cost-effective and appropriate designs for housing for people with dementia. In conceiving new forms of specialized housing for people with dementia, designers must take a number of considerations into account – for example, the location of the proposed project, the characteristics of the physical environment, the availability of support services, the proposed management structure and the kind of programming that is envisaged.

Once again, it is vital to stress that not everyone with dementia has the same needs or problems. It is fundamentally important, therefore, to build the maximum amount of flexibility into housing solutions for people with dementia. Only then can their differing needs and preferences be addressed. In particular, designers have to be aware of the need to create barrier-free housing that can be easily adapted to the differing needs of residents.

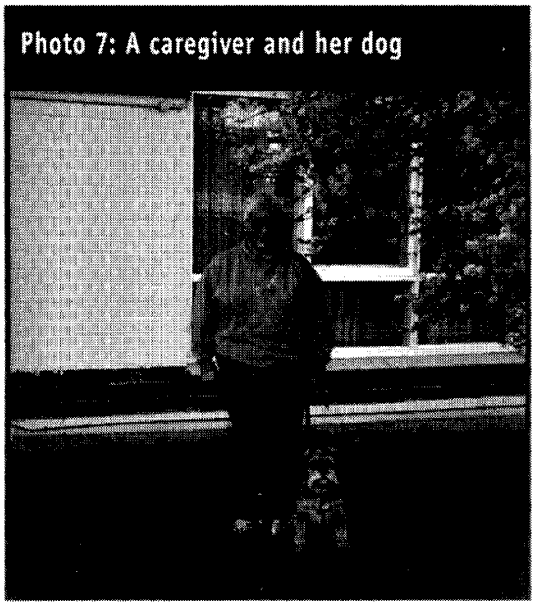


Photo 7: A caregiver and her dog

Making a home dementia-friendly

Despite the varying needs of those who suffer from dementia, they do face a number of common problems: forgetfulness, confusion and a tendency to wander. These problems need to be addressed through the creation of a supportive and therapeutic environment. Such an environment must be carefully planned so that it is comfortable, secure and safe, and also so that it promotes as much independence as possible. A well planned environment – and this includes physical design - can improve staff performance in group settings and promote a good family

feeling among residents. Of course, residential design is not the entire solution, nor can a safe and supportive environment alone resolve the problems of dementia. Continuous programs and activities are also necessary if those with dementia are to achieve any real quality of life. Nevertheless, design is key in that it links the three main dimensions of housing: environment, programming and quality of life.

Designing new or adapting old

Though there is no substitute for constant and careful attention on the part of the caregiver, there are a number of housing design features, some of them very simple, that can help to manage the problems of dementia and to promote the independence of the individual. Some features need to be considered by designers and incorporated by builders into new housing; others are simple things that can be easily added to existing houses or apartments to make life easier for people with dementia and caregivers alike. In sensitive combination, the architectural features and management considerations listed below can result in a suitable, pleasing and functional residential setting for people with dementia. Consider them as a checklist when designing new or adapting old housing for people with dementia. When considering any modifications or adaptations to existing buildings, however, bear in mind that because the needs and circumstances of people with dementia vary so widely and can change so rapidly, caregivers must decide for themselves what measures are appropriate and what expense is warranted. Before introducing changes, caregivers must also consult relevant local authorities. They must ensure that the proposed modifications will not cause hazardous or unsafe conditions and that they comply with applicable building codes and standards and fire and safety regulations.

DESIGNING FOR DEMENTIA

Key problems

- A tendency to walk and wander.
- A tendency to rummage.
- Confusion, forgetfulness.
- Difficulty with the activities of daily living (for example, bathing, eating).
- Safety, including slips and falls.

Key design principles

- Exits that are safe in an unobtrusive way.
- Hallways in which to walk and wander.
- Private rooms and small sitting areas where residents can be by themselves.
- A residential place that feels like a home.
- Supports that enable residents to maintain their independence.
- Understandable sounds, smells, colours and views.
- Shared spaces that are multiple and have diverse character.
- Adjacent outdoor space that is secure and planned.

Providing safety

Caregivers naturally think about the safety of residents. Will they slip and fall? Will they hurt themselves on a piece of furniture? Generally speaking, anything that promotes safety, also contributes to the autonomy of persons with dementia. The safer the environment, the more likely caregivers are to let people walk by themselves and make independent choices and the more independent and happier those people will be. Generally speaking, therefore, the best way to support an individual's independence is to create a safe environment, including the provision of handrails, non-slip flooring, solid furniture, appropriate locks on doors and windows, and so on. It is important to note that, as people with dementia age, they will become physically frailer and more in need of protection.

However, caregivers must also be aware of the danger of over-protection. Individuals vary enormously in the kind and pace of changes as they progress into dementia. The risk of physical injury is sometimes less than the psychological injury inflicted by prematurely depriving a person of the freedom to enjoy what remains of his or her capabilities. It follows that the key to appropriate protection is constant assessment to measure and respond to changes as they occur.

SAFETY TIPS

The following principles of general safety apply to any residence, and they should be strictly observed. However, there are also some considerations that apply specifically to residences for people with dementia. Remember that a certain amount of stimulation is necessary for people with dementia; however, you must balance the need for variety and interest in the environment against the desirability of removing elements that disturb, confuse and endanger.

General safety

- Near a centrally located telephone, post emergency numbers for doctor, police, fire, ambulance and readily available neighbours and family members. Write them in letters large enough so that they can be read without glasses if necessary.
- Double-tape area rugs and repair ragged carpeting to prevent a fall.
- Move appliances, if necessary, so that electrical cords do not cross walkways. Otherwise, tape cords down.
- Make sure there is easy access to fire extinguishers.
- Install smoke detectors in all necessary locations and replace batteries regularly.
- Do not overload electrical sockets.
- Repair frayed electrical wires.
- Arrange furniture so that it does not touch radiators and accidentally start a fire.
- Install radiator covers, insulate hot water pipes and remove auxiliary heating sources.
- Lower hot water temperature to below 49°C (120°F) to prevent scalding.
- Install power outlet covers to protect people from electric shocks.
- If there is a swimming pool, fence it in.

The challenge in creating a safe environment is making the trade-off between security on the one hand and residentiality on the other. The possible compromises are myriad and can only be made on a case-by-case basis. The principle to keep in mind is that even relatively safe homes contain more risks than does a traditional institutional setting; however, those dangers can almost certainly be offset by therapeutic factors. An underlying concept in the residential environment, both with regard to the physical setting and the care-giving program, is that risks are shared between caregivers, family members and people with dementia.

Dementia-related safety considerations

As abilities change so should the environment. People with dementia may lose their sense of balance. Also, they may tend to shuffle when they walk or to lean forward and look down. All this contributes to the likelihood of slipping and falling. When people age – and most people with dementia are older – the likelihood of breaking a bone is very high if they fall. Not all the following measures will be necessary in all homes, but anyone caring for a person with dementia should ask themselves the following questions and take action where appropriate.

Is the person easily confused and upset?

The amount of stimulation in the environment can play a role. Generally speaking, small, familiar objects are comforting to people with dementia. However, if the clutter of ornaments or decorations becomes upsetting and confusing, clear some or all of them away. In particular, examine paths of travel and make sure that they are clear of unnecessary clutter. Also, look at lighting and levels of sound, as both can contribute to an individual's state of confusion or anxiety. The key is finding a balance between too much and too little stimulation.

Is the person unsteady or off-balance?

Make sure that chairs where a person might lean for support are sturdy enough to bear the weight without tipping. Alternatively, when necessary, it might be helpful to provide a cane or walker, aids that increase independence without risking injury. Frail or unsteady persons may also benefit from handrails in hallways, skid strips on the stairs or, in extreme cases, from a stair/elevator chair or ramps (at the front and back of the house) to get up and down stairs. If the person has a tendency to bump into things, consider padding sharp corners or even removing low furniture (such as coffee tables and stools). Very unstable people may need a wheelchair or someone to accompany them when walking. Unsteadiness is especially problematic in the bathroom. If you are worried about an individual's balance, consider putting non-skid mats in bathtubs to help prevent slipping and install grab bars. If a bathtub has become too difficult for safe bathing, think about using shower chairs or a tub seat.

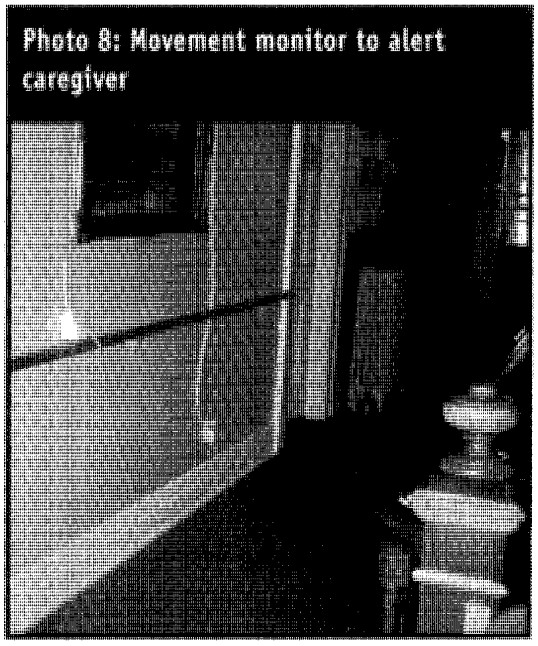


Photo 8: Movement monitor to alert caregiver

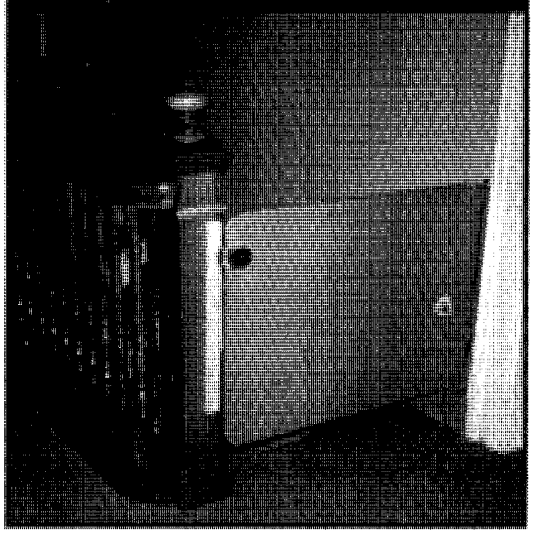
Does the person wander?

Remember that wandering has a therapeutic purpose and you should find safe ways and places to allow it. However, if some parts of the house are particularly dangerous (for example, attics and the cellar), consider installing locks. If necessary, exit doors should probably be locked to prevent the person from leaving the house unaccompanied. Avoid automatic locks as they tend to lock people out inadvertently, though perhaps you could hide a key outside to prevent that.

Does the person wander at night?

If so, it might be helpful to install night lights in hallways and bathrooms. If the person's condition is such that it is really unsafe for them to be up alone, you could install a movement monitor to alert the caregiver that the person with dementia is up and about or if they want to leave the house. Also, consider installing a gate to prevent anyone from falling downstairs.

Photo 9: Gate to prevent people from falling downstairs



Is the person liable to turn on the stove and forget it?

Think carefully before you decide to install kitchens in private apartments; alternatively, make sure the power to the stove can be easily disconnected or else immobilize it by removing dials.

Does the person rummage through drawers and closets?

If you fear that matches may be misused, think about storing them in locked or hard-to-reach places to prevent people from accidentally starting a fire. Similarly, consider storing medications in locked or hard-to-reach cabinets.

Is the person having trouble handling sharp objects?

If you're worried about accidental cuts, store household kitchen appliances, sharp kitchen tools and household cleansers in locked or hard-to-reach places. If cuts from shaving are becoming a problem, consider a change to electric razor, though this may not be worth while if it means upsetting someone who has used a straight or safety razor all his life.

Does the person smoke?

Provide large deep ashtrays for people with dementia who continue to smoke: this can prevent cigarettes from falling and starting a fire. If possible, limit smoking to non-carpeted areas with non-upholstered chairs.

Is there more than one caregiver in place?

Cellular phones and beepers may be useful to keep caregivers in touch.

Exits

People with dementia often feel a strong need to walk, even if they have no idea where they are going: this is called "wandering." It is important to recognize that people with dementia wander for legitimate reasons, even if it is only keeping busy or getting exercise. They may even have a sense of purpose – though they may not know what it is. Perhaps they are seeking something or responding to some need that they cannot express or even understand. Understanding a certain behaviour is helpful in developing strategies to prevent those that put the person at risk.

People with dementia suffer from short-term memory loss. They have trouble remembering things they have heard or seen in the recent past. For example, they might forget a phone message they have just taken or lose the way back along a path they have just walked. Those who wander away from home on their own are extremely likely to lose themselves, which is a distressing experience for everyone involved – for the confused individual, who will tend to become agitated, for caregivers and for members of an alarmed public. On the other hand, turning the house into a fortress can also cause agitation.

Having said that, in the interests of safety, people with dementia who are at risk of getting lost should only leave home when accompanied. People with dementia, because they fail to recognize the meaning of an object, may try to leave the premises in inappropriate ways. For example, on the ground floor of a building and looking out a window, they may decide to use that window instead of the door to get out. Unless the exits of the home are firmly secured, caregivers must keep a close eye on people with dementia.

Ways to prevent egress

Limit window openings

If absolutely necessary, you can limit to 20 centimetres the distance that windows will open (if within fire code requirements). Do this by installing window locks as well as strong blocks to opening windows. Alternatively, install – or have the manufacturer install – a plastic strip along the side of the window to prevent a sliding window from opening beyond 20 centimetres, while still allowing it to be easily pulled out in case of fire.

Make doors difficult to open by people with dementia

Increase the complexity of unlocking and opening exit doors by installing two latches that must be pushed simultaneously (except on fire exits) or a lock with a combination that must be remembered.

Disguise exit doors and windows

In many "normal" homes, exit doors (front and back) stand out as special. They may have windows or sidelights, special hardware and often window treatments that tell people, "This is the way out." For people with dementia, these messages prompt them to try to leave and, if they are prevented, they may well become agitated. Make windows and doors look less like exits. Disguise exits to look like connecting doors to private rooms or the common area.

Emphasize non-exit doors

To distract residents with dementia from exit doors, make the "safe" doors – those that lead into safe areas – more attractive: add windows, hang curtain, post signage, install eye-catching decoration and paint the non-exit doors brightly to attract attention. Then, leave the doors open so that people with dementia can see and hear activities on the other side of the door and easily satisfy their curiosity.

Make a garden door attractive

The door into a securely fenced garden can be used to attract residents and decrease attempted elopements. Such a door can be made to look and feel like a front door by including windows, sidelights, a weather lock and all the trimmings of a front door. In some cases, people with dementia will begin to refer to such doors as the "front door" and will ask for it to be opened so they can walk outside. If this door has the appearance of a "front door" from the garden, it naturally directs people back indoors.

Avoid hardware that is bright and attractive

For reasons that are not clear, residents with dementia do not forget what door hardware means: it says loud and clear, "twist or push here, and you get through the door." Even waist-high fire exit push bars – the ones we all grew accustomed to at school – are clear invitations to exit. Remove such hardware (when fire regulations permit) and install a new kind of hardware that serves the same purpose but is unobtrusively hidden in the door frame. Another alternative is a small box on the top of the door frame that holds the door closed with a strong magnet. In both cases, when a fire alarm sounds, the door automatically opens for safety.

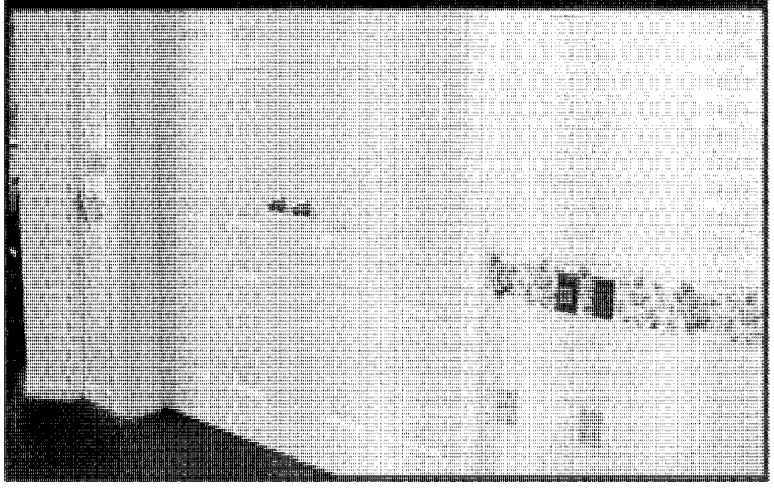
Install push-pad door locks

Install coded push-pad door locks that allow only those who know and can remember the combination to leave. In case of fire, the locks should release and open the doors automatically. Locate the locking device at a slight distance from the door and, if possible, disguise it or conceal it in the wall.

Install electronic buzzers on exit doors

Install a buzzer that sounds to alert the caregiver whenever an exit door opens. Also, install a door buzzer outside so that, if a person with dementia has wandered, he or she can be heard trying to get in.

Photo 10: Push-pad door locks located in the flower border allow for unobtrusive control



Supportive housing components

The goal is to create housing that makes it easier for people with dementia to live satisfying lives and to be as independent as they can be for as long as possible. In effect, that means constantly balancing the costs of too little freedom and stimulation against the disturbance and anxiety of too much. It also means constant evaluation of the environment to ensure that it matches – and

Photo 11: A key pad is hidden by decoration

continues to match – the changing condition of the person with dementia. There are five principle components to supportive housing. They are:

- safe wandering paths;
- distinct functional areas;
- familiarity;
- cues; and
- simplicity.

Safe wandering paths

People with dementia have a strong desire to walk and, though they often wander without a clear sense of destination, the activity tends to be beneficial, both physically and mentally. Therefore, alternative places for free and safe wandering should be provided.

Create a system of corridors

Designers should work out a thoughtful connection of corridors that passes through common areas and connects up again to the same corridors in a way that avoids "dead ends."

Photo 13: Orienting objects along walking path

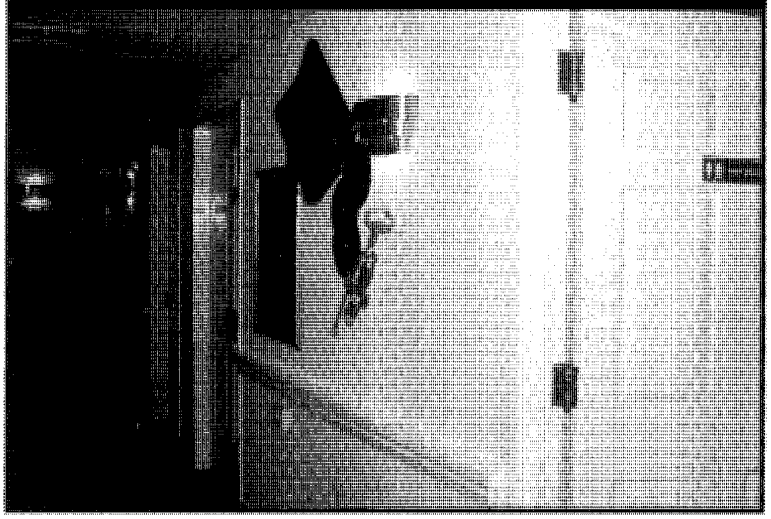
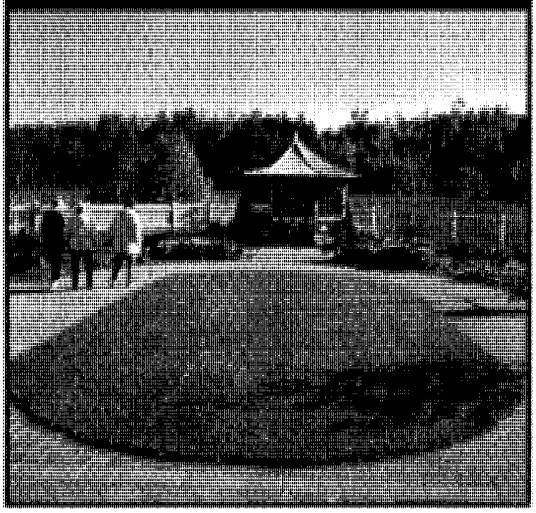


Photo 12: A healing garden: Sedgewood Commons, Falmouth, Maine



Create a sense of "place"

People with dementia walking down a hallway or corridor may have little idea of where they are or where they are going. Although they have a sense they are "someplace" and are going "somewhere," they do not retain a cognitive map of the environment. Wall art and objects arranged along the walking paths will give them a sense of place and well being. Orienting objects, including paintings, windows, planters, lights and signs arranged in an orderly way, can be extremely soothing, especially if a number of similar or related objects are displayed in groups to create a series of moods as a resident passes from one clearly identifiable "place" to another.

Clear paths between bedroom, bathroom, common areas and kitchen

In all kinds of living units – including single rooms, apartments or houses – keep the pathways between different areas of the dwelling clear of obstruction and as straight and obvious as possible. Otherwise, even the simplest living environment can confuse a person with dementia, causing them to get lost and upset or to fall and be injured.

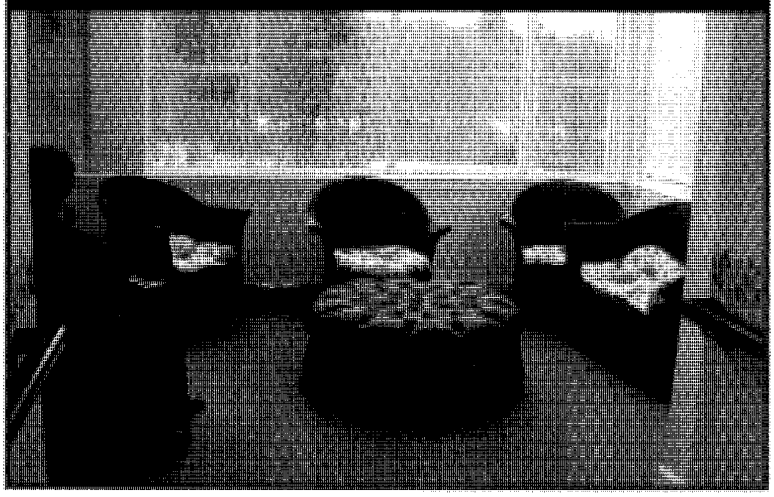
Create visible destinations

People with dementia have difficulty remembering where they are; they have even more difficulty remembering where they are going. A caregiver may say to someone with dementia, "Mary, why don't you go to the kitchen at the end of the hall?" While Mary may start down the hall in the right direction, she is likely to forget where she is going long before she gets there – unless the kitchen is in sight for the whole time as she walks. Locate common spaces visibly at the end of walking paths to help people with dementia orient themselves in relation to obvious destinations.

Create turn-around places

When people with dementia arrive at the "dead end" of a corridor or walking path, they will often just stand there, facing the same direction and motionless. Unless they happen to turn around, they have no idea what is behind them and no sense of requiring or seeking another destination. The idea is to encourage the person to turn. Place something – a three-dimension statue, wall art or a bench – at the end of every walking path that will encourage turning. Alternatively, put a window on the side wall so that people will naturally turn sideways and notice what is behind them. Also, communal spaces, such as living rooms and kitchens, can be located at the end of hallways, as they are used in a way that will lead residents to notice the path leading back out of the common area and towards another destination.

Photo 14: Visible destinations at end of hallway



WANDERING: COMMUNICATING THE PROBLEM

Even without extensive design input, there are some simple actions and modifications that caregivers can make to protect the person with dementia.

- Notify neighbours of the person's condition, describing potential problems and the actions you are taking to support the person's safety and independence.
- Register with the Alzheimer's Society, which will provide the person with an attractive or inconspicuous identification bracelet, displaying name, address and phone number, along with a comment about forgetfulness, so that strangers can help the wanderer get home.
- Place identification information – name, address, phone number and phone numbers of family members – in the person's wallet and pockets, along with a note about the person's forgetfulness.
- Keep readily available several copies of a current photo so that, if the person with dementia gets lost, you can help find him or her by showing the photographs.

Distinct functional areas

People with dementia living in group residences spend almost all of their time in the residence and together. When planning communal areas in a home or group housing, therefore, it is important to include as many as possible of the "common rooms" that are typical of a traditional home, such as eat-in kitchen, living room and den. These spark deep memories of house and home and help to cue people with dementia to appropriate behaviours. These rooms also satisfy a need for diversity, thus reducing boredom and agitation, so it is essential to have at least two, if not three, different communal spaces in the residence. These include a dining area, a living area and possibly an activity room or television lounge. Making communal areas different from one another through size, lighting, finishes and furnishings makes it easier for people with dementia to distinguish the rooms from each other and to remember the moods and emotions that are associated with each.

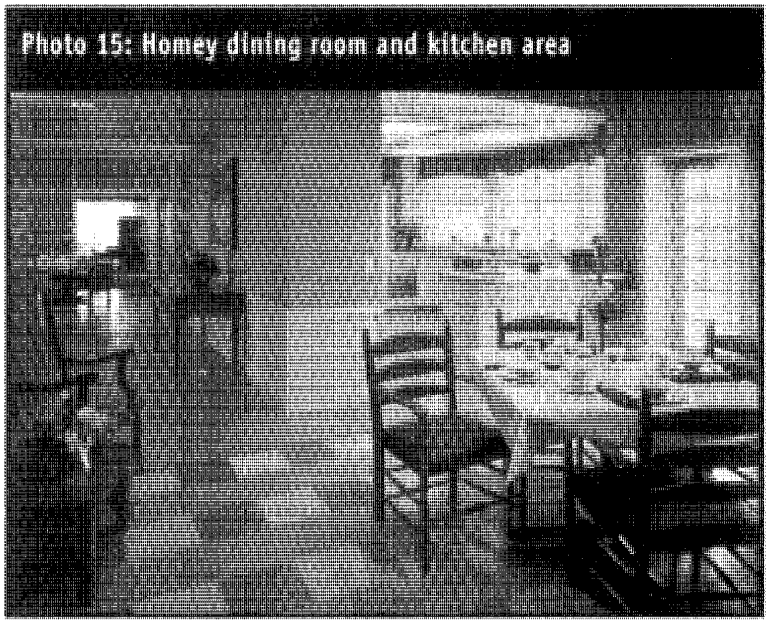


Photo 15: Homey dining room and kitchen area

The therapeutic value of household chores

Other communal spaces in group residences – for example, the laundry room or kitchen or other rooms – are generally places where people meet informally to chat and work. Healthy activities include washing the dishes or car or sweeping. The laundry room in particular, with its distinctive smells and tactile experiences, has pleasant associations for many people. At the same time, pouring in the soap, turning on the machine and eventually folding clean laundry are simple skills that reassure people with dementia that they are still in control of their lives.

Photo 16: A homey living room setting

Photo 17: People meet in the kitchen to work and chat

Familiarity

Everyone needs a place to retreat to periodically and escape the pressure of social interaction. For those with dementia, the need to get away is heightened by their difficulty in dealing with the constant stimulation of group life. A sure way to make an environment comprehensible to people with dementia – and thereby head off difficult behaviour, anxiety, agitation and anger – is to make the residence home-like. That means providing a degree of privacy and individuality in a setting filled with familiar objects and furniture. It also means introducing a range of decorations, lighting, textures and finishes that all suggest "home." Carpeting where appropriate, wood floors or tile floors that look like wood, glare-free and non-skid tiles in kitchen areas and decorative wallpaper can all help someone with dementia to feel comfortably at home and to remember appropriate behaviour for various rooms.

Quiet areas for retreat

Provide several quiet and private areas in communal spaces – an alcove with a corner chair or one facing a window – where people can be alone. Visiting family members can also use such withdrawn spaces to sit quietly and privately with their relative.

Caregiver respite room

Looking after those with dementia demands constant attention and patience. Caregivers also need a quiet place where they can retreat and rest from time to time. Provide some solitary space, inaccessible to those with dementia, where caregivers can relax without interruption.

Encourage personal, easy to use furnishings

Encourage people with dementia, even those who have moved away from their own houses, to bring some of their own furniture with them. As people become increasingly confused, it is even more important to surround them with things from their past. The familiarity and comfort of their own furniture keeps them in touch with reality, helps them remain calm and gives them a sense of continuity and dignity. The environment can help people with dementia to remain independent by supporting their strengths. One simple way to support independence is to select furniture that is easy to get out of: chairs with arms, and couches and easy chairs that are firm enough that even frail residents can push themselves up.

Photo 18: A private bedroom with personal furniture and mementoes

Photo 19: Bedroom with personal furnishings

Lay out rooms for "furnishability"

Rooms and apartments for people with dementia need to be small to be manageable, but they should also be shaped and configured in a way that promotes furnishabililty and a sense of living in a whole home. No matter how small and simple, the space must be adequate to accommodate at least a bed, dresser and a sitting area. This can be accomplished in a single room (L-shaped or rectangular) just as well as it can in a small apartment. In designing such spaces, create at least two long walls (one for a bed, another for a small couch). Also, leave at least 30 cm (12 in.) wall space beside a window and allow for stub walls to create corners for furniture.

Photo 20: Wide window sills provide shelves for personalization

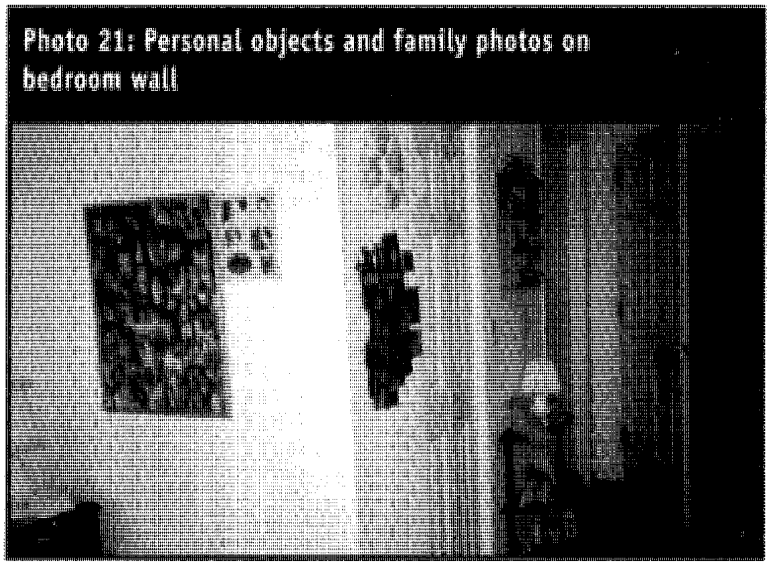


Photo 21: Personal objects and family photos on bedroom wall

Provide suitable flooring

Residential floors are covered, depending on the room, by materials such as carpet or wood (in bedrooms, living rooms and hallways) and decorated vinyl tile (in the kitchen and bathrooms). Use a mixture of flooring in different areas to define them according to function. If a carpet is laid, it should be stain-resistant and of appropriate quality and texture. To facilitate cleaning, stain-resistant vinyl tile can be used to simulate wood but be careful not to create too much glare.

Provide residential window treatments

Curtains and blinds will generate a residential atmosphere. However, attach them securely to the walls and valences so that when an unsteady or angry resident pulls on them, they do not fall down easily and, if they do fall down, they can be easily replaced. Curtains can sometimes cause problems, but should not necessarily be avoided. Horizontal blinds that can be raised completely out of the way are a practical alternative.

Allow for personal objects on walls

Photos of grandchildren, familiar paintings, mementoes, a wall clock – all these give the person with dementia a feeling of being in familiar, safe and comforting surroundings. That feeling of safety helps in turn to promote calm and a sense of well being. Make sure that such items can hang without damaging the walls. If using gypsum walls, consider instituting a repair program to deal with damage when people move. Alternatively, think about installing wall mouldings from which to hang framed objects, strips of durable material that can support nailed objects or a wall-mounted shelf for mementoes.

Cabinet, shelf and countertop finishes

Countertops and built-in cabinets all contribute to a feeling of home. In choosing textures and colours, favour those that set the right kind of mood rather than worrying only about ease of maintenance. Also, even if one type of countertop is more economical, use several different types if they are needed to differentiate the way different areas "feel."

Cues

Make rooms accessible and recognizable

People with dementia need to be able to retreat easily to their own rooms or apartments. Even if living units are small or shared, they should be located so that they are readily accessible from common areas at any time during the day. Find a "cue" for each person that indicates their room – a picture, a poster or memento that will help them to distinguish one room from another.

Install chair rails in halls

One readily visible sign of institutional living is the ubiquitous "handrail," a strip of shaped wood or metal attached with brackets to the walls on both sides of every corridor. To create a residential atmosphere in communal spaces and hallways, install a chair rail instead, one that is strong enough to hold the weight of a person leaning on it and wide enough for the whole palm of the hand. Such a chair rail combines support for the unsteady with the residential character that reduces anxiety among people with dementia.

Use residential furniture

In communal areas, a number of seemingly conflicting needs must be met. Furniture must suggest residentiality and feel familiar to residents at the same time that it is sturdy enough to stay upright; it must withstand liquids in case of incontinence; and it must be movable in case a caregiver is obliged to rearrange the furniture.

Simplicity

Choose residential wall covering

Decorate with wallpapers and paint rooms in a way that suggests a residential feeling, but choose plain colours and simple patterns that are not over stimulating or confusing. Paintings and objects on walls also help to provide cozy and familiar residential imagery.

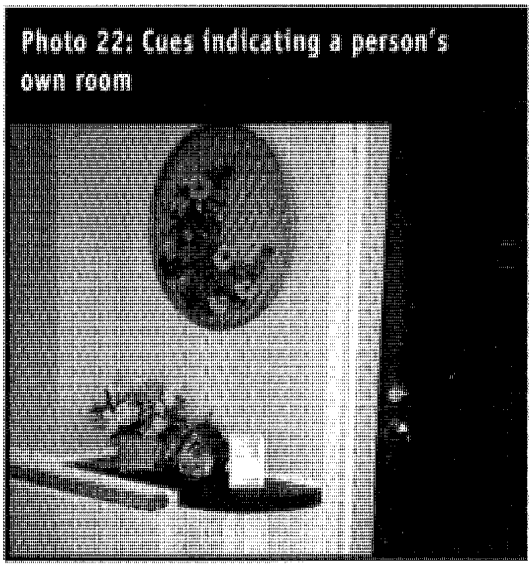


Photo 22: Cues indicating a person's own room

Photo 23: A communal area with residential furniture

CUEING: CLUES TO APPROPRIATE BEHAVIOUR

People with dementia, as they wander, have trouble recognizing where they are or appreciating any hazards. Also, they may tend to forget what is appropriate in the use of places and objects. By providing them with environmental cues, people with dementia can be helped to use spaces and objects safely and appropriately, as follows:

- Tape or paint stair edges to help a person with depth perception problems to avoid falling.
- Use signs and pictures to identify objects – for example, the toilet, bed or garden – and suggest appropriate behaviour.
- Use reflector tape on floor and walls as way finding devices.
- Reduce visual confusion by eliminating shiny and glaring surfaces.
- Put decals on glass windows and doors to protect people from walking into glass.
- To prevent confusion and falls, clear walking paths and the centre of every room of dangerous obstructions, including low furniture.
- Do not move furniture unless absolutely necessary, as the familiar arrangement steadies and comforts people with dementia.
- Improve the lighting in stairways, hallways and bathrooms so that people with dementia know where they are and can act appropriately.
- Post a daily schedule of what people will be doing each day, including getting up and dressed, eating lunch and cleaning up, taking a walk and going to bed. People in the early stages of dementia can thus orient themselves to a daily rhythm; the caregiver can also use the schedule to orient others.
- Post a calendar on a frequently seen wall, remembering to cross off each day that passes. Record appointments and list activities so that a disoriented person can use these visual cues to regain a sense of the passing of time and the events that punctuate their lives.
- Set up clocks in a number of rooms to help people with dementia to orient themselves easily and frequently to the time of day.
- Use automatic dial telephones to simplify making a telephone call.

Photo 24: Toilet symbol identifies bathroom

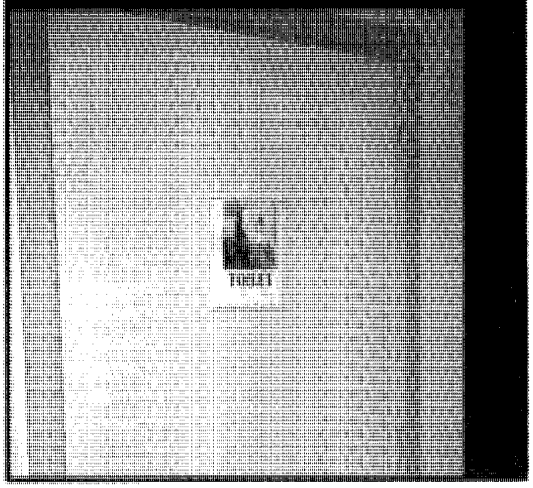


Photo 26: Posting a daily schedule of activities helps people orient themselves

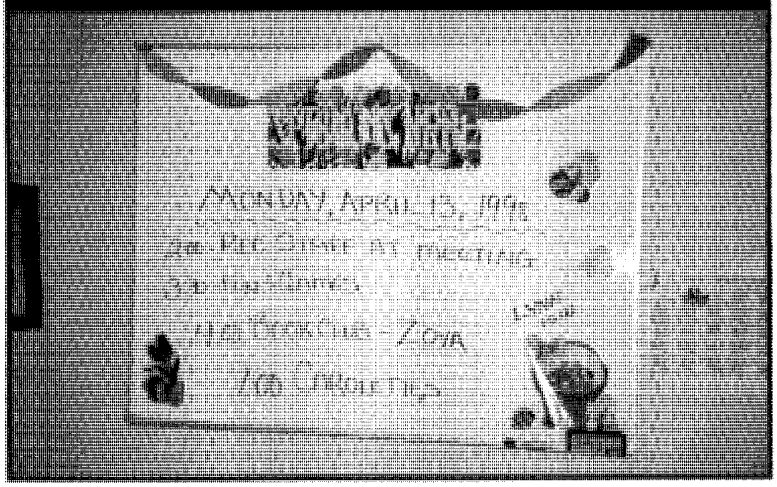
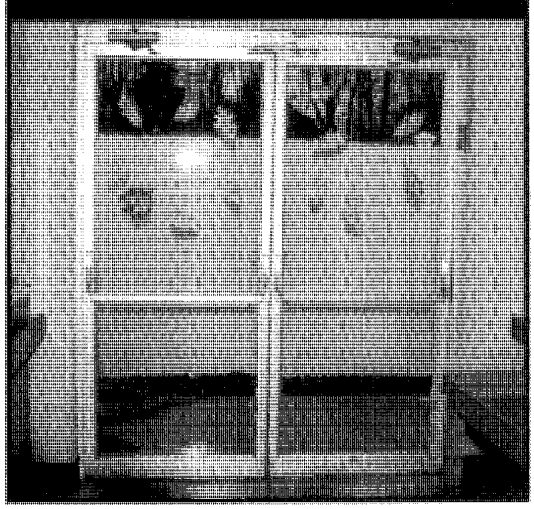


Photo 25: Leaf decals on glass doors to prevent accidents



Incontinence

Incontinence is common among people with dementia, and it is a major source of agitation and dismay. Having several toilets adjacent to communal spaces, such as the kitchen and living rooms, in addition to those in residents' rooms or apartments, can help to prevent accidents. Staff should remind residents on a regular basis to use a toilet.

Rummaging

The residential quality of communal areas does not depend on furniture alone. In every real home, people are surrounded by a range of homey objects, including books, lamps, records and so on. Select a range of miscellaneous objects for communal rooms, choosing them for their old-fashioned, homey feeling and their generic familiarity to residents. Some caregivers complain that this sort of material merely encourages "rummaging" – a behaviour characteristic of people with dementia – and, indeed, disoriented people do tend to remove and hoard objects from tables or bookshelves. So what? If a person's agitation is reduced by regular rummaging, the caregiver is paying a small price in having to retrieve objects from private rooms or to check the garbage before it is thrown away. A caregiver should not try to ease his or her job by emptying the common rooms of all those homey objects that help to orient and relax the person with dementia. Create a drawer specially for rummaging.

RUMMAGING: MADE SAFE AND EASY

Just as people with dementia may not have a goal in mind when walking, they often look for lost things without having a sense of what they are looking for or, indeed, that they are looking. This activity is called "rummaging." Protect the safety of a person who is rummaging and prevent damage or loss in the following ways:

- Limit the number of places where a person might rummage, so that objects can be easily returned to their places at the end of the day.
- Keep the person's belongings in the same place all the time so that they are not driven to rummage and, also, so it is easy to return displaced items.
- Install locks on closet doors to prevent unwanted rummaging.
- Store valuable or dangerous items in locked or inaccessible areas.
- Do not make it too hard for people with dementia to go rummaging. Make some dresser drawers unobtrusively difficult and others easy to open.

Reducing confusion

Creating a supportive environment

Confusion is the central problem facing people with dementia. It follows that a central responsibility of the caregiver is to reduce the opportunity for confusion and the panic and anxiety that follows in its wake. Fortunately, there are a number of quite simple techniques that will make the environment more intuitively comprehensible to a confused and forgetful person.

Maintain two closets, one for long-term and one for daily storage

People with dementia find it more and more difficult to make choices, but the caregiver can help to set them up for success, for example, in getting dressed. As people with dementia lose the ability to recognize familiar objects – pants, a bra, underwear and so on – choices are confusing. When faced with a lot of clothes in a closet, the person with dementia might put their pants on first, then their underwear and finally two sweaters, one over the other. The answer is to minimize choice by ordering clothes and providing cues. Having at least one simply organized closet will help people with dementia to avoid confusion, thus making them feel more competent. Keep the long-term storage closet locked and use the other, unlocked, for clothing in daily use.

Colour contrast on doors, in dining room and in bathroom sink and toilet bowl

People with dementia often mistake one object for another. In a bathroom, for example, a sink, toilet and white garbage pail can be mixed up one with the other. To "cue" appropriate behaviour, and thus support the person's feeling of dignity and self-worth, find ways to make these objects distinct from one another. Mark the toilet with a bright colour, either on the wall behind the toilet or by installing a coloured toilet seat. For men, there is also a device available that points a light like a target into the toilet bowl. Also, to support independence of action, provide toilet seats that are high enough for aging people to get up from easily. While people with dementia may need to be reminded to use the toilet, they should be able to get up by themselves without help from a caregiver.

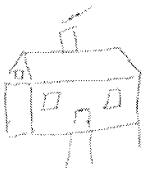


Photo 27: Toilet high enough to raise up from

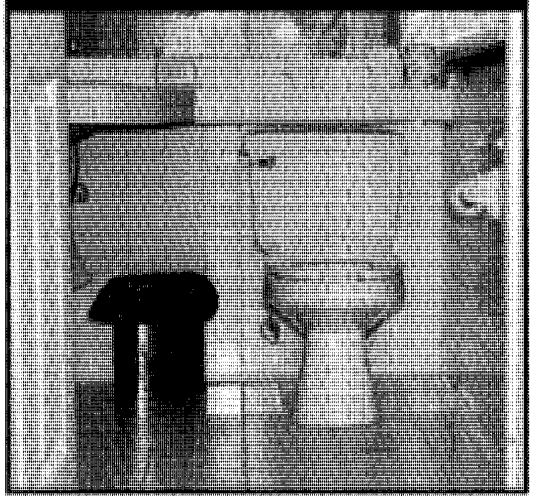
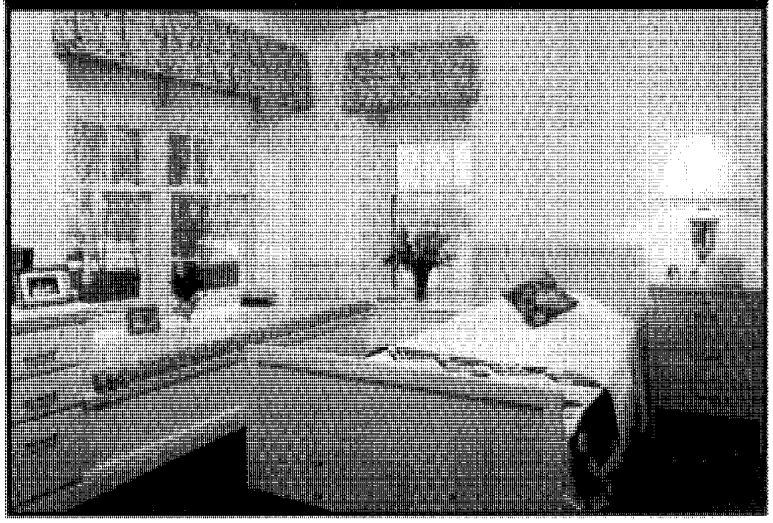


Photo 28: Small manageable bedroom



Create rooms small enough to be manageable

There is an overlap between support for independence and catering to the mental faculties of people with dementia. For example, a room or dwelling unit that is small enough to be understood in its entirety by a person with dementia will also support that person's independence. They will tend to be most comfortable and in control in a small-size room that they can tidy themselves and that does not overwhelm them by an excess amount of "stuff."

Create a mix of single-person and two-person units

A sense of territory is central to maintaining a sense of calm and security. People with dementia differ in history and preferences. Some have lived alone for many years; others have never lived alone. However, even if they have lived long years in a community, many people with dementia maintain a sense of territory and a need for a place of their own. To respond to the full range of needs, include a mix of single- and two-person units in the housing design; but, even with two-person units, strive to create a separate territory for each resident.

Smart house technology

Control panels and other programmable computer-driven devices are now readily available. They can turn on lights, make coffee, alert caregivers to movement in the home and otherwise make the building "smart." Such "smart house" devices can reduce the chance of fire and accident. Unfortunately, they can also be confusing to a person with dementia.

Creating a therapeutic environment

People with dementia are often confused, but not by everything around them. When the sounds or sights they experience are familiar, they can cope with them and even enjoy them. A common mistake in some existing residences is to make everything sedate and bland. The setting should create enough activity to keep the residents interested and to make sure the activities are understandable to them. Colours are fine, and traditional patterns for wallpaper are better than abstract modern patterns. A television is fine; however, films shown on video can be more satisfying.

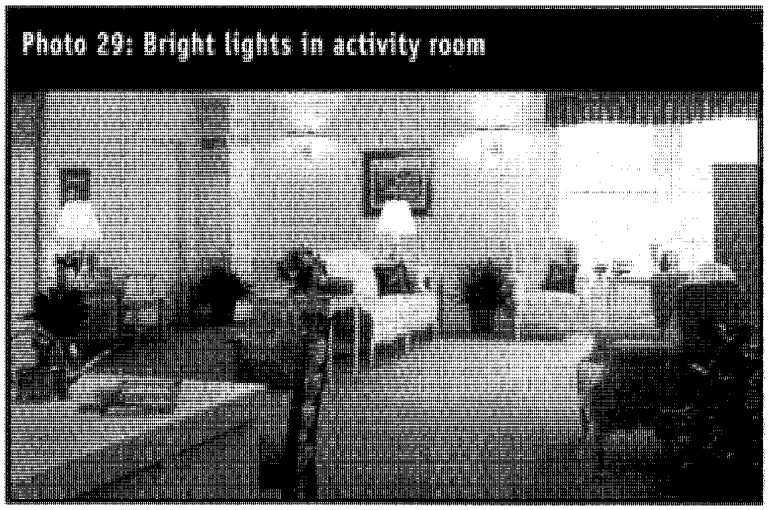


Photo 29: Bright lights in activity room

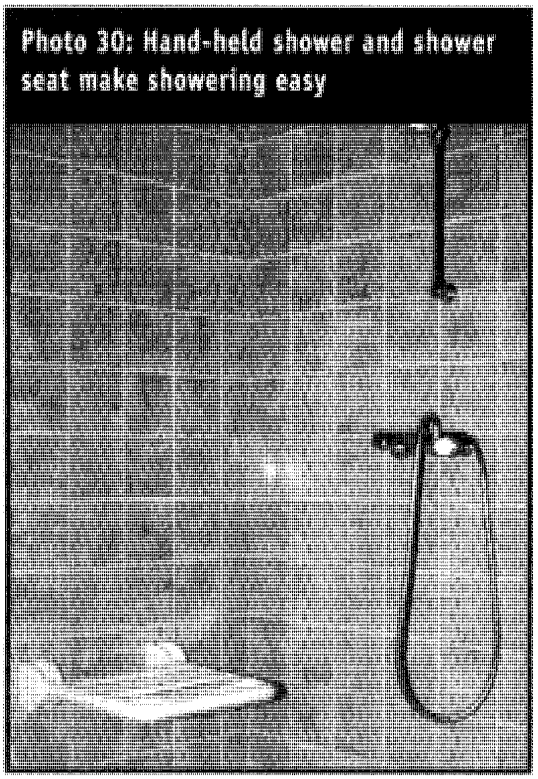


Photo 30: Hand-held shower and shower seat make showering easy

Install sound baffling

As people age, it becomes increasingly difficult for them to distinguish particular voices and other sounds in an otherwise noisy environment. Residents with dementia and with a hearing problem face an even more daunting task in such situations because they may not fully understand the meaning of words. Use "sound baffling" material in heavily used communal areas: in particular, carpet living room floors and the dining room walls below the chair rail to baffle sound. Sound-absorbing ceiling tiles are not particularly residential, but they are effective.

Simplify choices

Multiple choices – an entire menu in a restaurant, for example – is much more confusing than a simple choice: coffee or tea? Because people with dementia have lost much of the brain's "executive function" – the ability to keep in mind and organize a series of linked tasks – the simpler the choices that face them, the better they will be able to function. In design, this means providing, among other things, not more than two choices of direction in a hallway. In a room with two occupants, it could mean locating closets and closet doors separately, rather than side by side, even though side by side may be more convenient to build. There are many such design decisions to be made.

Install night lights

Another way to help people understand their environment is to include built-in night lights in the bedroom, the hallway and especially on the way to the toilet.

Install bright lights

A loss of visual acuity among older people accompanies an increasing inability to distinguish and recognize objects among people with dementia. Good lighting – but not glare – can help, especially in communal areas. Install bright lights that "wash" the area, thereby reducing excessive contrast between dark areas and bright ones (one of the definitions of glare). Alternatively, position recessed lights overhead and add task lighting where the person with dementia might want to sit, read or just relax.

Install dimmer switches

At the same time that bright lights help people with dementia to see and understand their environment more clearly, dimmer switches allow caregivers to modulate and control the brightness when appropriate and therapeutic. This is especially useful in the evening, when a sense of falling darkness is needed to prepare the person with dementia for bed.

Avoid visual clutter

Just as unorganized noise can be confusing to disoriented people, so can visual clutter: objects and furniture randomly placed in the environment; messy tables; pictures hung randomly on the wall. Avoid visual clutter so that people with dementia, through a clear understanding of their environment, can remain calmer and more in control of their own lives.

CLEANLINESS: PROMOTING INDEPENDENCE

People who have difficulty recognizing objects or who have difficulty with motor skills or incontinence may need extra help to stay clean and neat. However, individuals have different needs and preferences, and good care means catering to these. For example, bathing can be a challenge, as getting into a tub requires more help than getting into a shower; however, a bath can also be a source of familiarity and comfort. On the one hand, a person who has problems with depth perception may be frightened by a bathtub full of water; another may never have taken a shower. Thus, while showers may be generally easier to deal with, make sure that some bathtubs are available for those that prefer them. Some small-scale home modifications, such as installing a hand-held shower, can help people with dementia to look after their own personal hygiene.

- If possible, add an additional bathroom on a floor that has none to enable an incontinent person to use a toilet easily in any part of the house.
- Install a hand-held shower to help people with dementia and their caregivers to take and give showers with ease.
- Protect upholstered furniture with plastic coverings to prevent damage from incontinence and to enable patients to sit anywhere without worry; alternatively, investigate the availability of furniture specially designed and manufactured for use by the incontinent.
- Make a commode available so that caregivers can help incontinent people easily in any part of the house.
- Use vinyl tablecloths so that spills at mealtime can be easily cleaned up.
- Help people who have difficulty recognizing or using utensils to eat independently by preparing food that can be eaten with the fingers. Provide straws for liquids.
- Use sturdy plastic plates that cannot be easily pushed off the table by an uncoordinated person and that will not break if they fall to the floor.
- Promote independence by providing grooming materials, such as curved hairbrushes and special toothbrushes, that have been specially designed for people with small motor skill deficiencies.

Outdoor spaces

It is hardly surprising that people with dementia who live in groups day in and day out would occasionally like to walk outside on their own. Moreover, regular contact with weather and the seasons is therapeutic. A safe and secure garden or yard attached to the residence can provide safe and pleasant access to the outdoors, especially if the area is available to residents most of the time and if they can use it freely. If an outdoor garden is impossible – for example, if people live on the upper floor of an apartment building – caregivers need to find an alternative. One possibility is a nearby area, on grade or a roof patio, that residents can visit regularly when accompanied by staff on carefully planned expeditions. Most of the design issues that have already been discussed for interiors – such as shared areas, pathways and privacy – also apply to the design of outdoors areas. Security is also an important issue. If the garden area is made absolutely secure, care-givers will not have to limit its use, and people with dementia will be able to use it freely.

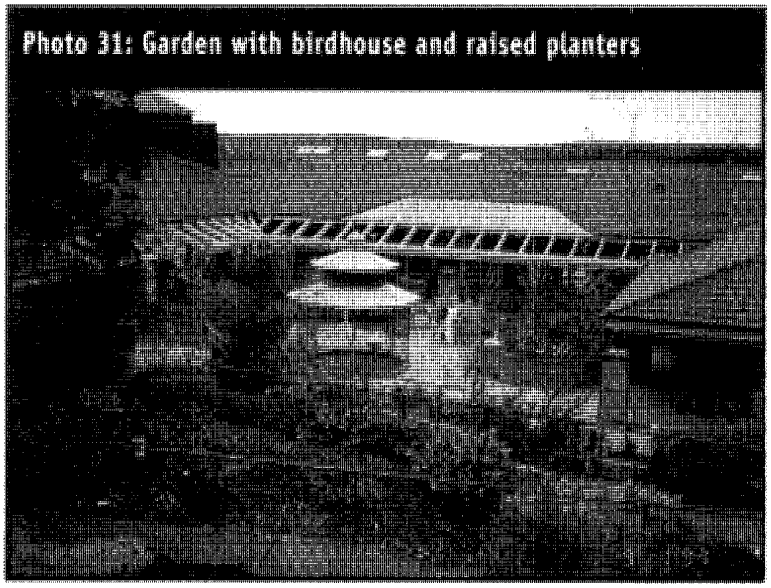


Photo 31: Garden with birdhouse and raised planters

Make the area visible from indoors

The outdoor area should be visible from indoors so that caregivers can keep an eye on people with dementia.

Install a high fence

Surround the garden with a high fence. The fence should be high enough – a 2.1m (8 ft.) fence is appropriate – to prevent residents from climbing over.

Lock gates, if any

If fire regulations permit, enclose the garden without a gate. Alternatively, make certain that the gate is lockable either from the outside, or with an electronic device.

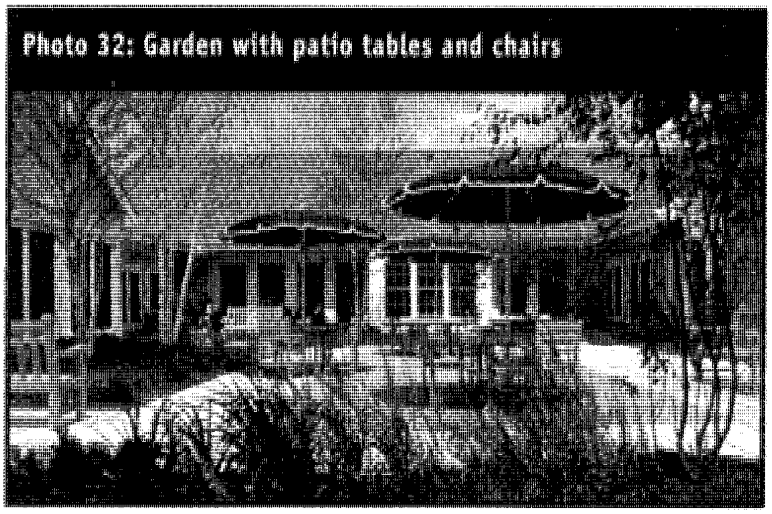


Photo 32: Garden with patio tables and chairs

Photo 33: A garden fence high enough to prevent elopement

Eliminate footholds

When constructing a fence, make certain there are no easy footholds that might permit a physically fit person with dementia to climb over.

Provide for private retreats

Just as residents with dementia need periodically to get away from the people they live with indoors, they need an opportunity to be private out of doors. For example, place a park bench under a tree in the corner of the open space.

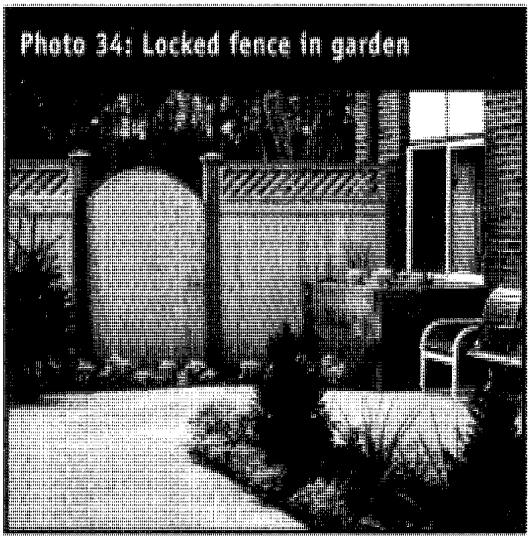


Photo 34: Locked fence in garden

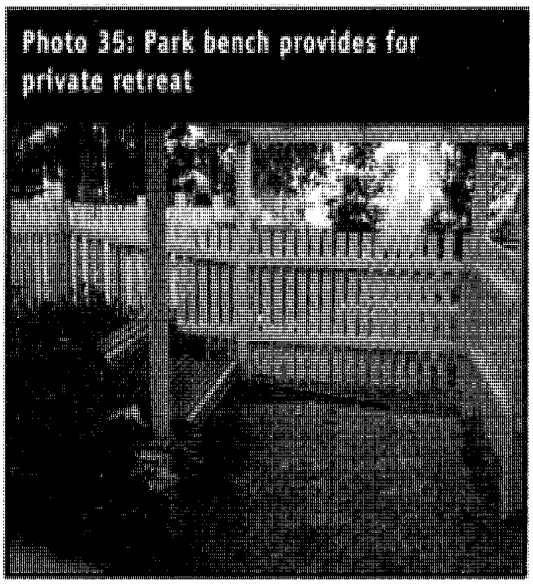


Photo 35: Park bench provides for private retreat

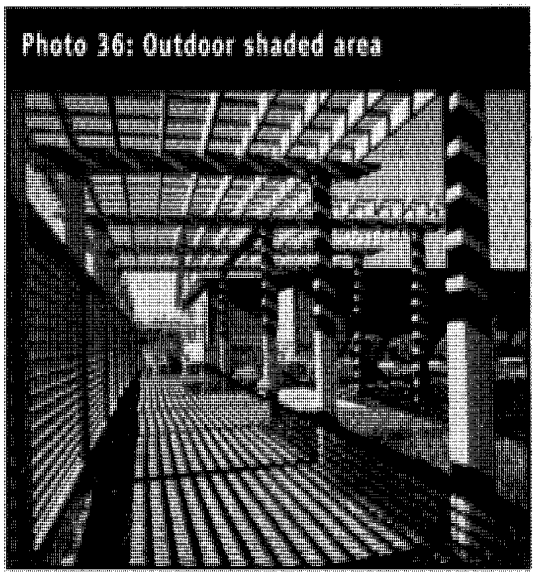


Photo 36: Outdoor shaded area

Make some shady areas

Especially in summer, people using a garden may prefer shade to sunlight. Use trees, umbrellas, trellises or well oriented fences to create some shady corners.

Design porches, front yards and back yards

People with dementia have deep memories of the physical elements in a garden that remind them of home. Include porches, front yards and back yards that will enable people to understand and enjoy being outside.

Plan a garden

Planting vegetables and flowers in a garden stir deep memories and keep people with dementia in touch with the weather and seasons. Whenever possible, include a garden that residents can use frequently.

Build raised planters and easy-to-use benches

Raised planters, 0.6m (24 in.) high, enable elderly people to plant seeds and harvest vegetables without losing their balance or tiring their limbs. Benches that are easy to get up from will also increase their comfort.

Basketball, golf and clothesline

People with dementia may also remember having enjoyed activities like putting a golf ball into a hole, or hanging clothes on a clothes line. Choose a few of the most culturally relevant of such activities – for example, washing a car or raking a lawn – and introduce them to enhance the therapeutic value of an outside area.

Photo 39: Basketball hoop

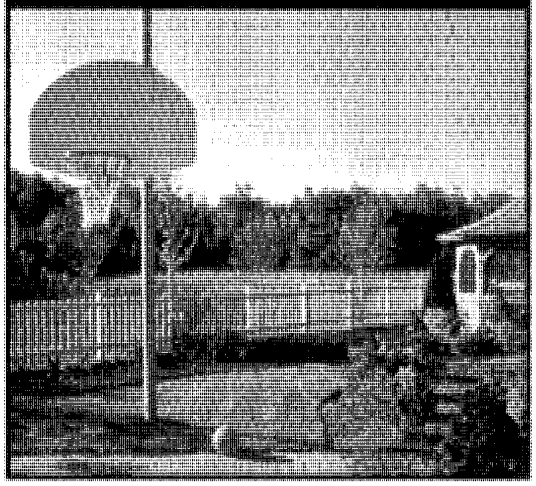


Photo 37: Raised planters in park-like garden

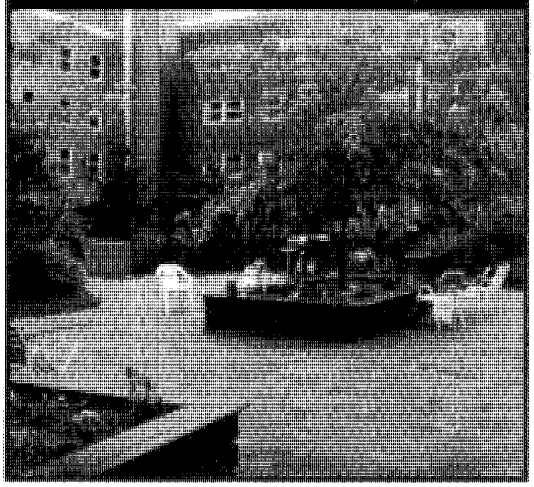


Photo 40: Convenient walkway

Photo 38: A raised planter allows people to garden while seated

Design walking paths

Walking paths enable residents to exercise and to feel in control of their lives. However, residents with dementia may be confused and upset by a lack of clarity in a system of paths: use plantings and elements such as a birdbath or arbour to define where outdoor paths begin and end. Clarity of this sort reduces the ambiguity and confusion that may agitate people with dementia. Also, to maintain comprehensibility, make the pathway clearly

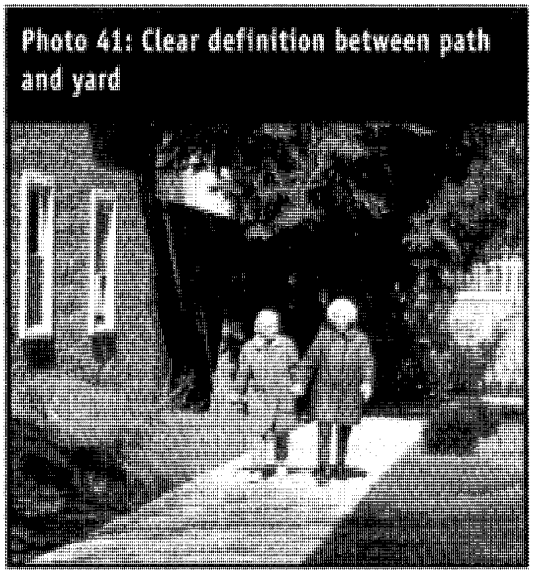


Photo 41: Clear definition between path and yard

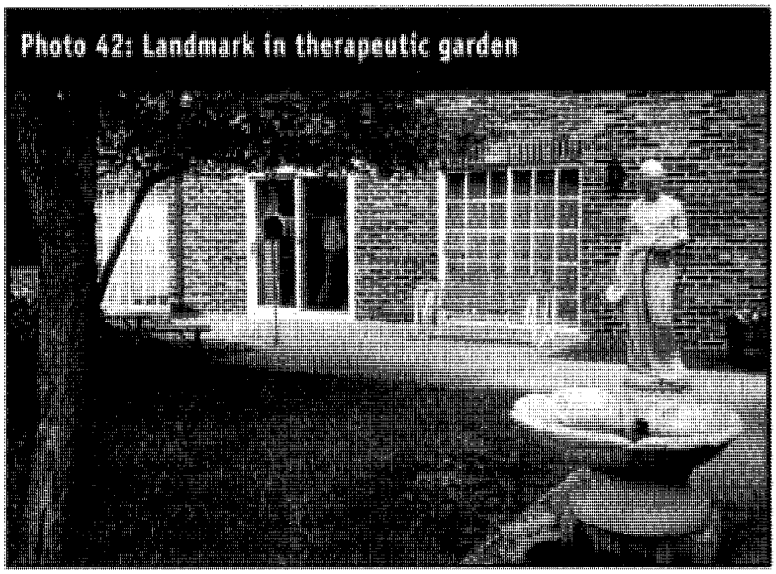


Photo 42: Landmark in therapeutic garden

distinguishable from the yard or planted area. The better these pathways are defined, the more independent and comfortable people will feel in wandering along them.

Design shortcuts

Because people with dementia are confused by complicated choices does not mean that the challenge of choice should be avoided altogether. One possibility is to include a shortcut from the main path to a given destination, perhaps the door leading back into the residence. If the shortcut is placed at a 90° angle to the main path, rather than as a 60° fork, the choice for people for dementia will be clear and unambiguous.

Introduce smells and colour

Give people with dementia a renewed sense of contact with nature by introducing plants that are colourful (such as roses) and fragrant.

Landmarks

Landmarks – an arbour, a flowering tree or some other plant or ornament – can make the environment more understandable.

Mark the way home

One of the biggest problems facing a person with dementia, when outdoors, is how to get back in, especially if there is more than one entrance. Reduce the complexity of the choice by visually creating a single entry to the residence. This can be done with colour or by adding an entry foyer or any architectural element that communicates: "This way back home."

Chapter 6: New Housing Options

The previous chapter outlined a full catalogue of design features that have been conceived to maximize the capabilities, independence and quality of life of people with dementia. This may be seen, in effect, as a wish list because rarely in the real world can every good idea be incorporated into a single project. Individuals setting out to adapt their houses or apartments to the needs of those with dementia, though they can achieve a great deal, are very often limited by existing conditions or tight budgets. Theoretically, the designers of new housing could integrate as many features of dementia-friendly housing into their plans as they want. However, they too face limitations. In actual projects, budget or physical location or program philosophy may dictate certain approaches, and the designer too must make trade-offs among the various design features, deciding which to focus on, which to play down and which to ignore altogether.

This chapter shows how some decision-makers have incorporated dementia-friendly principles into actual housing projects. Though in each case the designer has preferred some criteria over others, all of these cases respond in their own way to the needs of people with dementia, and each demonstrates the practical implications of planning options for this population. The housing options presented here range from a specially adapted apartment through a variety of groups homes and residences to an all-encompassing care centre for people with dementia in a large retirement community. They include various scales and reflect the various complexities of group residential living. A few plans have been annotated to highlight the specific ways in which they respond to the needs of people with dementia.

The housing examples in this chapter are not presented as "best practice." Rather, they suggest the range of housing options that is beginning to be available for people with dementia. These designs are meant to interest, inspire and encourage those who are struggling with the need to find or create appropriate housing for an important and growing part of our aging population.

Therapeutic apartment, Toulouse, France

This one-bedroom apartment was adapted to help an elderly couple, one member of whom has dementia, to remain in their own home and community. The adaptations include technological devices (such as dimmer switches and coded door locks) and physical modifications (such as visual connection between rooms and protective devices added to windows).

This project was implemented on a pilot basis to achieve four precise therapeutic objectives:

- to prevent accidents;
- to lessen the effects of dementia;
- to accommodate physical handicaps; and
- to create a climate of well being and encourage contact with the surroundings.

Photo 43: The top floor apartment on an existing building has been adapted

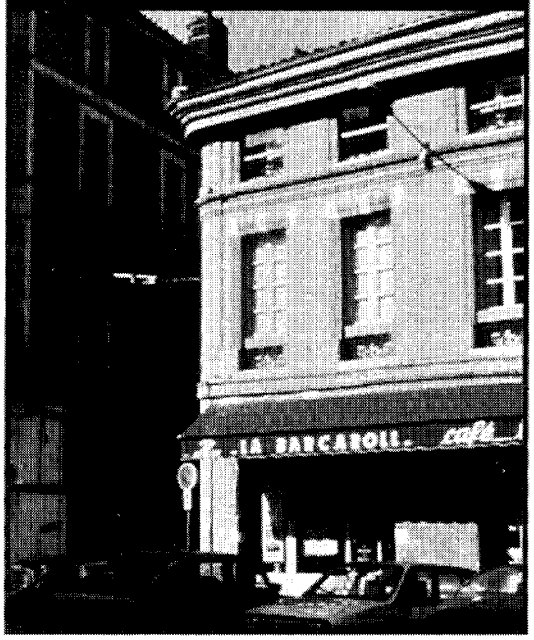


Photo 44: Lighting intensity can be controlled to compensate for loss of vision

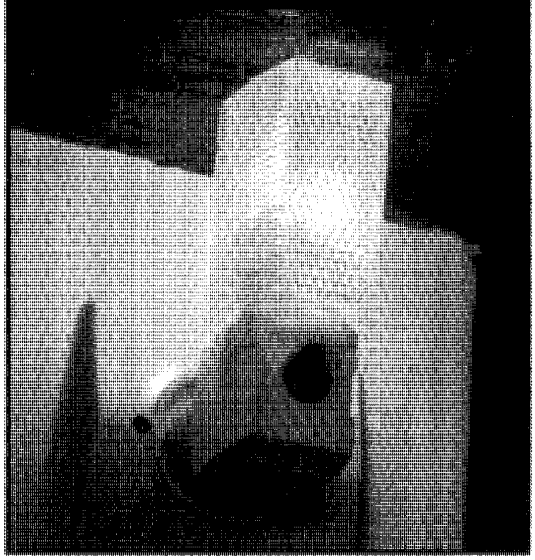
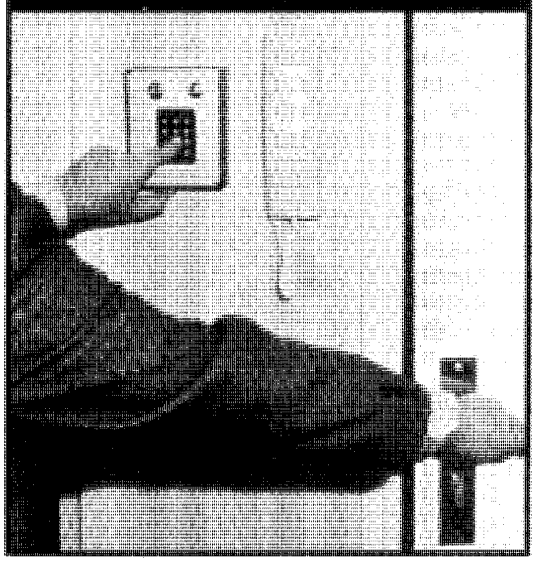


Photo 45: A code combination lock prevents the resident with dementia from wandering



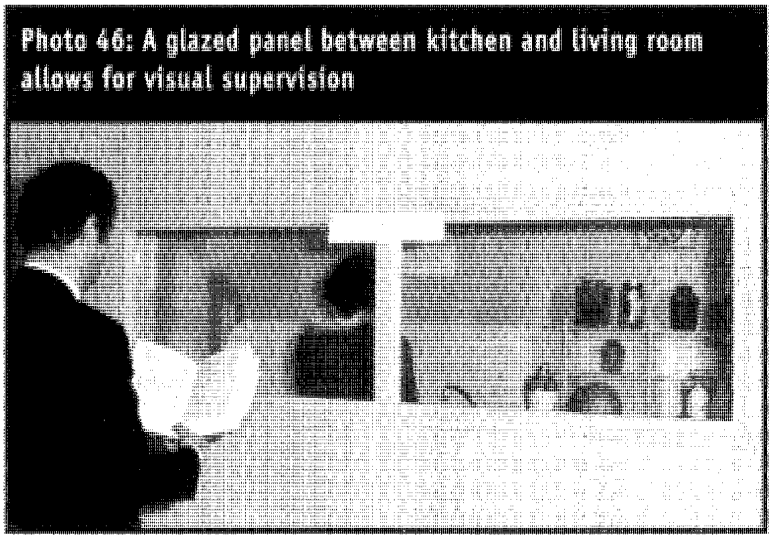


Photo 46: A glazed panel between kitchen and living room allows for visual supervision

The front door of the apartment has a code combination lock to prevent the resident with dementia from wandering off unaccompanied. Hazardous fixtures were eliminated, replaced or protected. Each window is covered with a safety glass shield to protect the resident with dementia from falling out an open window. A thermostatic faucet was installed to prevent scalding. Furniture is stable without angles or sharp edges. Thresholds have been removed, carpets nailed to the floor and slippery surfaces replaced to prevent slips and falls. Time and space landmarks were installed in the apartment: conspicuous clocks and calendars, signs on doors, bright colours behind grab bars and handles, consistent furniture arrangements and night lights. Clocks that chime and music that is pre-programmed are auditory cues to the passing of time and for regularly scheduled activities. Familiar objects and photographs around the apartment help the resident to feel at ease. The design of the apartment is also intended to eliminate physical barriers. The toilet location between and near both bedroom and living room is intended to help an incontinent resident find the bathroom easily. There is a hermetically sealed garbage can concealed in a bathroom cupboard. To encourage healthy eating, the kitchen has highly visible and easy-to-reach elements, and there is a glazed panel between living room and kitchen to allow for supervision. Light intensities can be adjusted throughout the apartment to compensate for loss of vision. There is a sofa bed in the

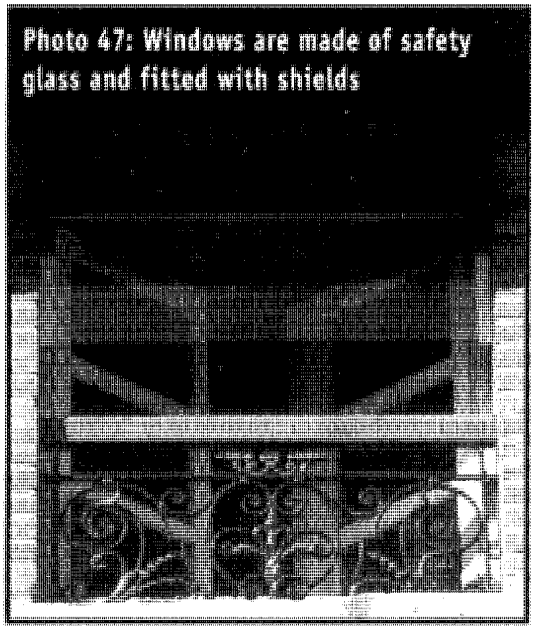


Photo 47: Windows are made of safety glass and fitted with shields

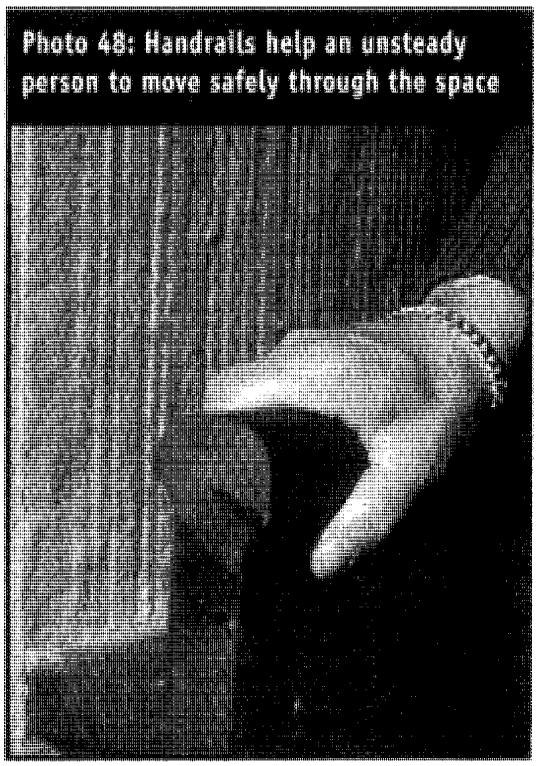
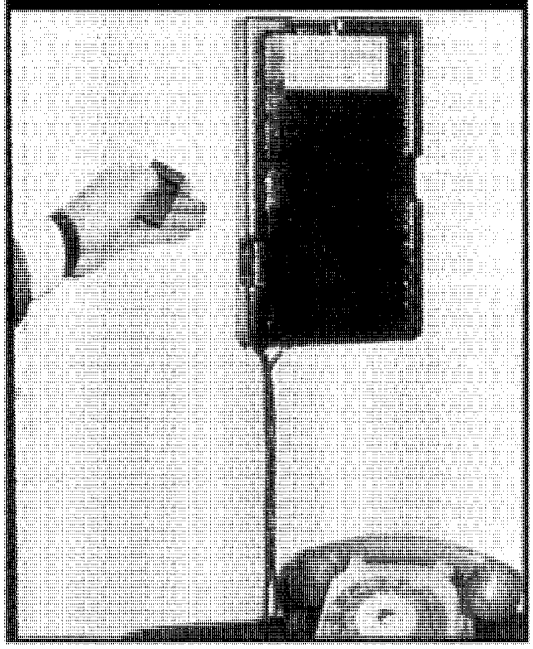


Photo 48: Handrails help an unsteady person to move safely through the space

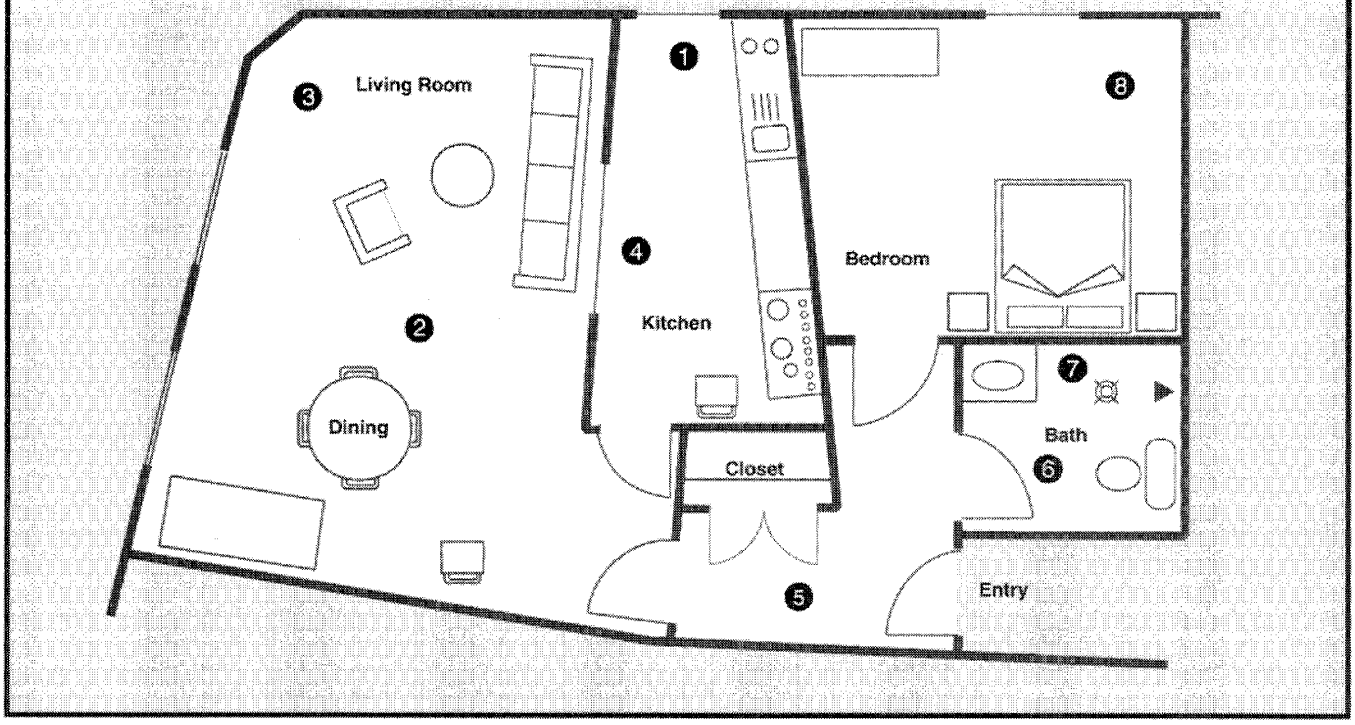
Photo 49: A telephone alarm system offers prompt assistance in case of emergency



living room for the spouse to sleep on if the person with dementia is restless; sound proof walls are intended to prevent neighbours from being disturbed; and security is enhanced by a telephone alarm system.

Conceptualized by Patrick Vellas of the Faculty of Architecture and Aging, University of Social Science, Toulouse. Funded by IPSEN Foundation for Therapeutic Research and Le Patrimoine Building Society.

THERAPEUTIC APARTMENT



1. Window at the end of the kitchen may be a dead-end that entraps the person with dementia.
2. Different spaces in a small living area combine to give a feeling of home.
3. Ample wall space in living room allows for furnishing with familiar pieces and objects.
4. Interior window allows for monitoring from, and orientation between, the living room and kitchen.
5. Indirect path from the bedroom to the living room and kitchen may confuse the person with dementia.
6. Toilet immediately visible through the open of the bathroom cues the person with dementia when passing to use the toilet.
7. The open shower in the bathroom, next to the toilet, allows for thorough washing with easy assistance, especially if the person with dementia suffers from incontinence.
8. Long walls in the bedroom allow for ease of furnishing and decoration with personal objects so that the bedroom will look homey.

Aldergrove bungalow, Edmonton, Alta.

Aldergrove is a four-bedroom bungalow in which care is provided to four women diagnosed with dementia. Residents and their families pay for 8 per cent of the services, pay all rent, food and utilities, are involved with service planning and attend regular family meetings.

This project aims to provide a safe, familiar residential environment for people with dementia, to support their remaining functional and social competencies, to minimize the number and severity of unsafe behavioural incidents and to meet the personal support needs of residents in a cost-effective manner.

The project began as an emergency response to one woman's housing and support needs and subsequently expanded. The house was purchased and renovations completed to create a fourth bedroom and to replace carpet in the hallway with hard flooring. Once funding for the necessary support services was obtained, the families of the four residents met to determine what was needed to set up the house. Families brought in furnishings and belongings, such as dishes, cutlery, drapes and cooking utensils, to personalize the home.

The bungalow is situated in a quiet cul de sac and backs on to a field. It has four bedrooms and large common areas that accommodate residents walking. The openness of the living room, kitchen, dining area and sitting rooms to the central hallway gives residents a view of housekeeping and meal preparation, thus cueing daily activities. With the unobtrusive guidance of staff, residents participate as much as they can or wish in activities they have done all their lives. Both front and back doors are fitted with alarms to prevent elopement, and doors are visible from sitting areas so that residents can observe the comings and goings to their home. Each resident has her own bedroom, which can be closed off for privacy; one bedroom has its own bathroom, one has a two-piece bathroom and the remaining two share a bathroom. Personal linens are colour-coded for staff convenience and to provide cues for residents. The home is decorated with personal belongings, such as a family coat of arms, one women's needlepoint, another's porcelain doll collection and pictures depicting past occupations and interests. For safety, access to the basement has been closed off, as has the fireplace. The back yard is fenced.

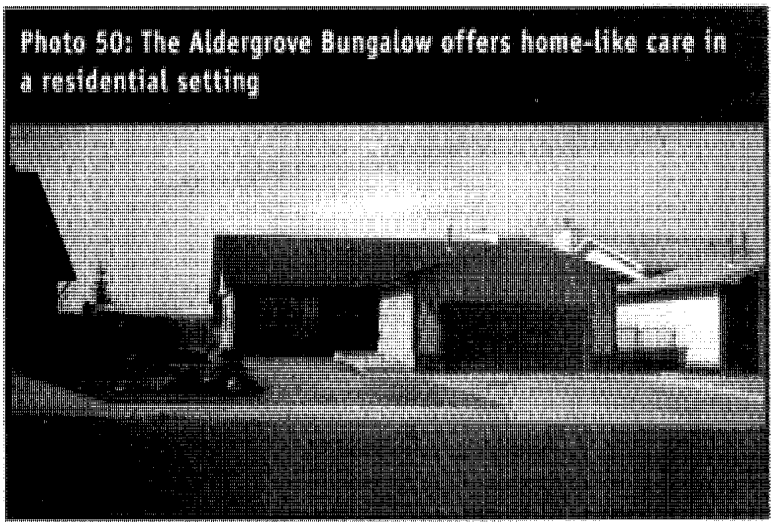


Photo 50: The Aldergrove Bungalow offers home-like care in a residential setting

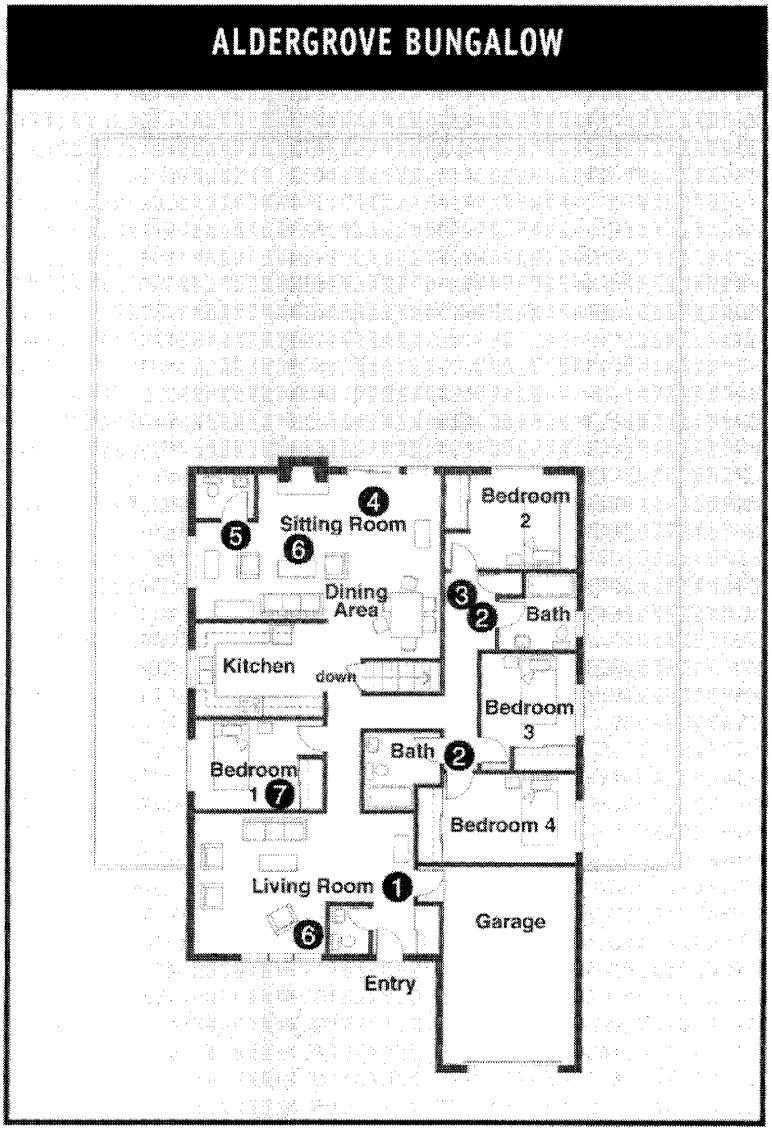
Among the interesting findings from an evaluation carried out at Aldergrove were:

- The initial "settling in" period, although difficult for residents, was better understood and accepted by families who were involved in caregiving decisions.
- A daughter, when her mother recognized Aldergrove as "home," realized that the move had been the right one.
- Because of the size of the home, staff believed that they were in the residents' home rather than residents being on the staff's turf; they spoke of acting like guests and treating residents like adult ladies, with respect and not like children or patients.

Because of difficulty in integrating one of the original residents into the life of the house, the organizers decided that "client matching" was an important part of the process. Important areas to consider for client matching in such a small house include: community living skills, functional status in activities of daily living, transportation needs, walking and stair climbing abilities, general mobility, speech, diet, eating, activity tolerance, environmental concerns and willingness of families to remain involved with the residents.

Capital Region Health Home Care Program and the Good Samaritan Society.

ALDERGROVE BUNGALOW



1. Location of front door at the end of the walking path may frustrate people with dementia and cause them to attempt elopement.
2. Location of shared bathrooms near bedrooms enable people with dementia to find them easily.
3. Dead-end hallway in the bedroom area can disorient people with dementia.
4. French doors leading to a securely fenced back yard offer people with dementia an enticing view of the outdoors and draw them out to enjoy it.
5. Location of a shared bathroom within sight of the sitting room meets the needs of people with dementia who suffer from incontinence.
6. Living room and sitting room located at either end of the walking path give people with dementia a destination and a turning point.
7. A person with dementia in this isolated bedroom may find it difficult to find a bathroom at night.

Mountain Road, N.B.

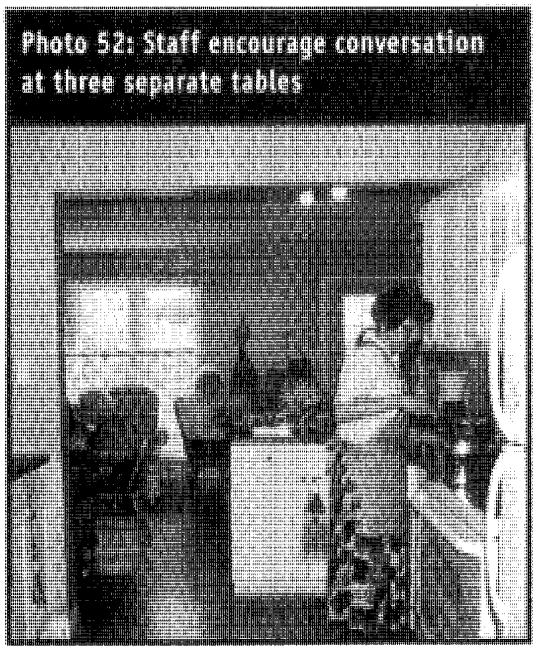
Opened in February 1996, this privately owned residence (246 m^2) for 10 people stands on a large treed lot (27.5 x 46 metres). The project was created out of an existing home, completely renovated inside and outside, with an addition. The home was designed specifically to meet the needs of people in the early or middle stages of dementia, with the emphasis on safety, comfort and the need for personal space.

Hallways create a circular pattern. Walls have extra insulation to minimize noise. To ensure that residents can distinguish colours, rooms are brightly painted (most bedrooms in a different colour). All exit doors are fitted with a coded security system. In the dining room, to minimize confusion for residents, there are three separate tables with a staff member at each table to encourage conversation and to support those who need assistance eating. One full bath and a half-bath are located in a central area to minimize confusion for residents: these facilities have proven adequate for 10 residents, all of whom are bathed by staff. Most of the residents are also on a toileting schedule. The double bedroom off the kitchen is beneficial because night staff can keep a close eye on residents there, and those who require the most attention are placed in this room. The house has a secured, landscaped backyard with a wandering path, benches and large flowerbeds.

The house features a resident-staff ratio of 3:1 during the day, as well as the Program Director and owner (who is a registered nurse whose attention is divided between 20 residents in the company's two homes and who is available 24 hours a day by cell phone). The resident/staff ratio is 10:1 at night. Staff is selected according to the following criteria: ability to learn, to work as part of a team and to serve this particular clientele. Staff has varied education and differing employment histories to support a psycho-social model of care.

Photo 51: An existing house was renovated and enlarged to house people with dementia

Photo 52: Staff encourage conversation at three separate tables



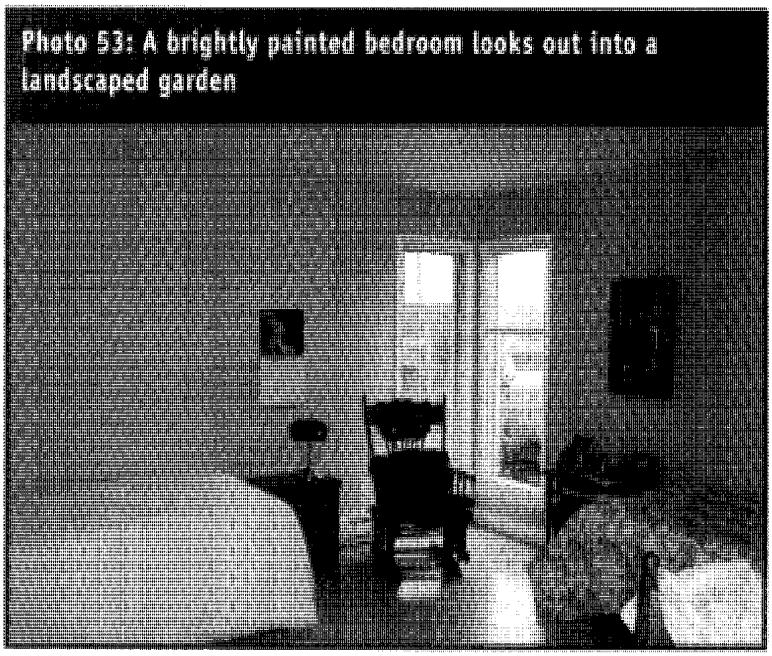


Photo 53: A brightly painted bedroom looks out into a landscaped garden

In July 1997, the company opened a second home (260 m²) for 10 residents at 2166 Mountain Road, a block away from the first home. This home is for residents in the late stages of dementia and for those in the middle stage who are confined to wheelchairs. This secured property (61 x 46 metres) is professionally landscaped with a walk-out patio and garden. Like its predecessor, this was a renovation/addition project, and it includes 10 private rooms, no carpeting, wheel-in showers and a sprinkler system.

Protem Health Services Inc., Moncton, New Brunswick, Canada

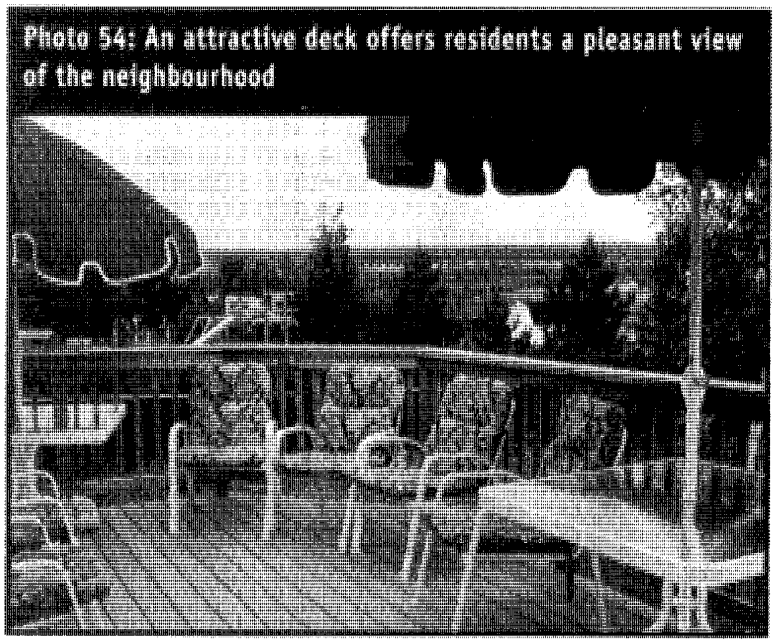
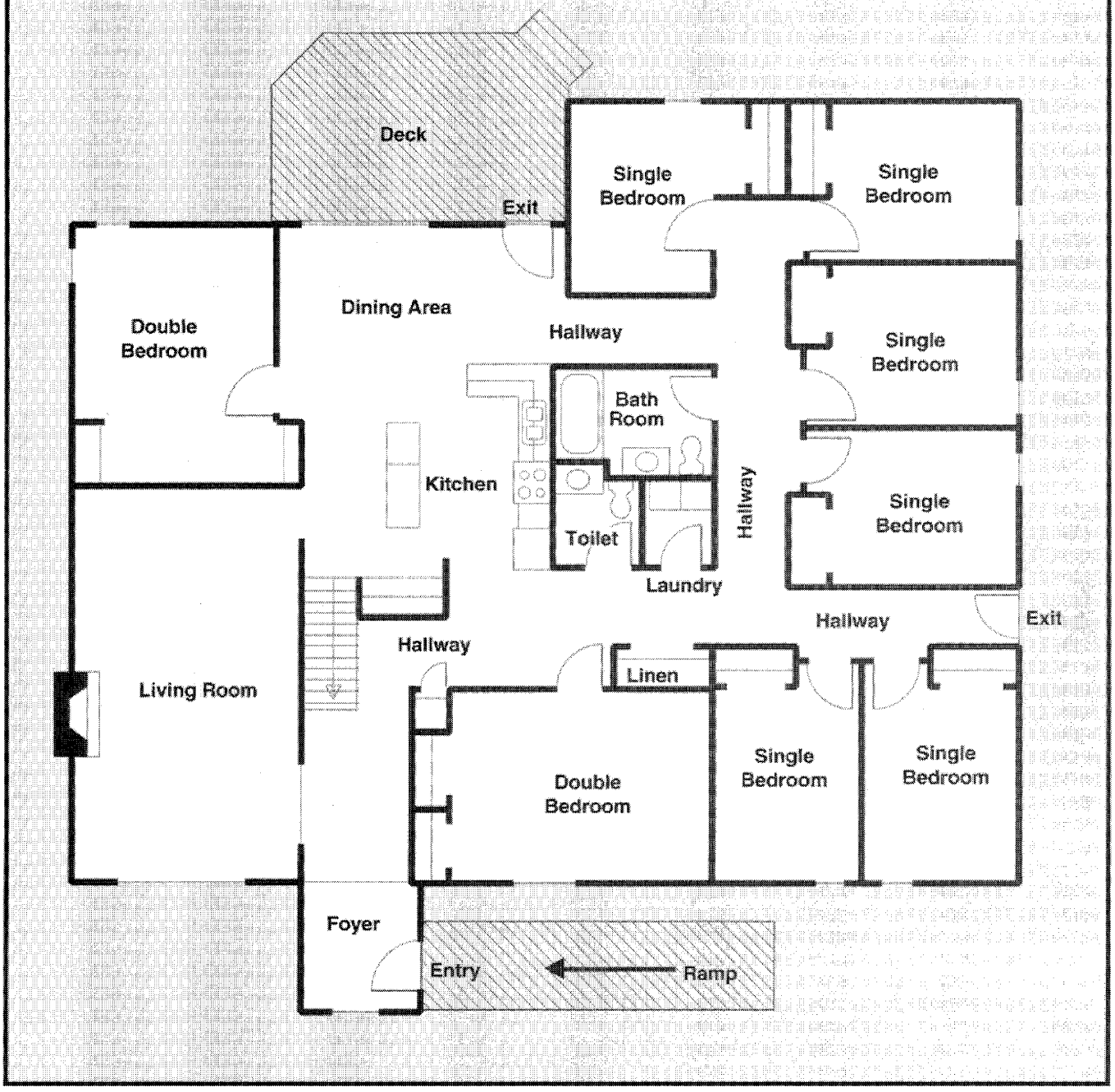


Photo 54: An attractive deck offers residents a pleasant view of the neighbourhood

MOUNTAIN ROAD



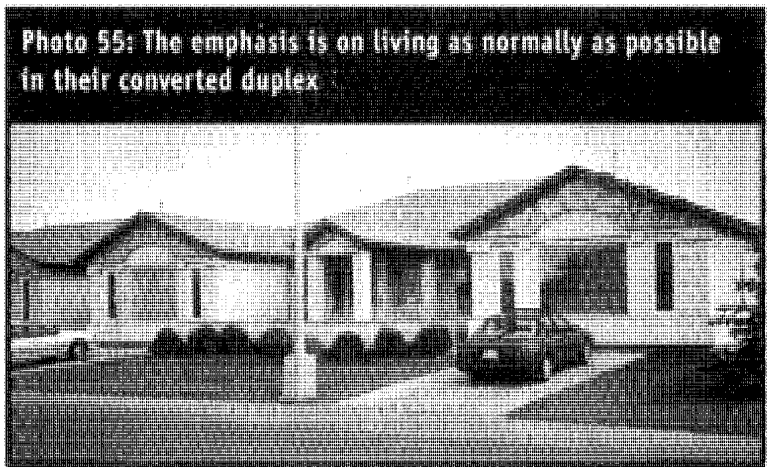


Photo 55: The emphasis is on living as normally as possible in their converted duplex

Photo 56: Residents share a meal in a family-like setting

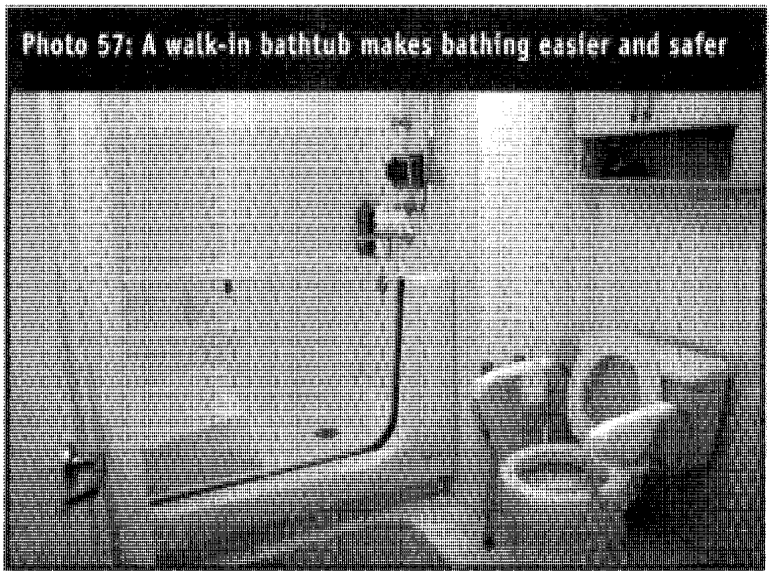


Photo 57: A walk-in bathtub makes bathing easier and safer

Wedman Village Homes, Edmonton, Alta.

This residential model consists of two 8-bedroom duplexes (16 beds) for the care of elderly persons with dementia who can no longer benefit from other community-based services such as home care or day care programs.

The care component of the program focuses more on a social than a medical model of care, with emphasis being placed on personal autonomy and competencies. Residents must be able to communicate their basic needs and move around with minimum assistance in order to participate in daily home-like activities, with staff acting as role models. The goals are to create a familiar, home-like environment; to combine privacy with around-the-clock staffing and to involve residents in familiar household routines.

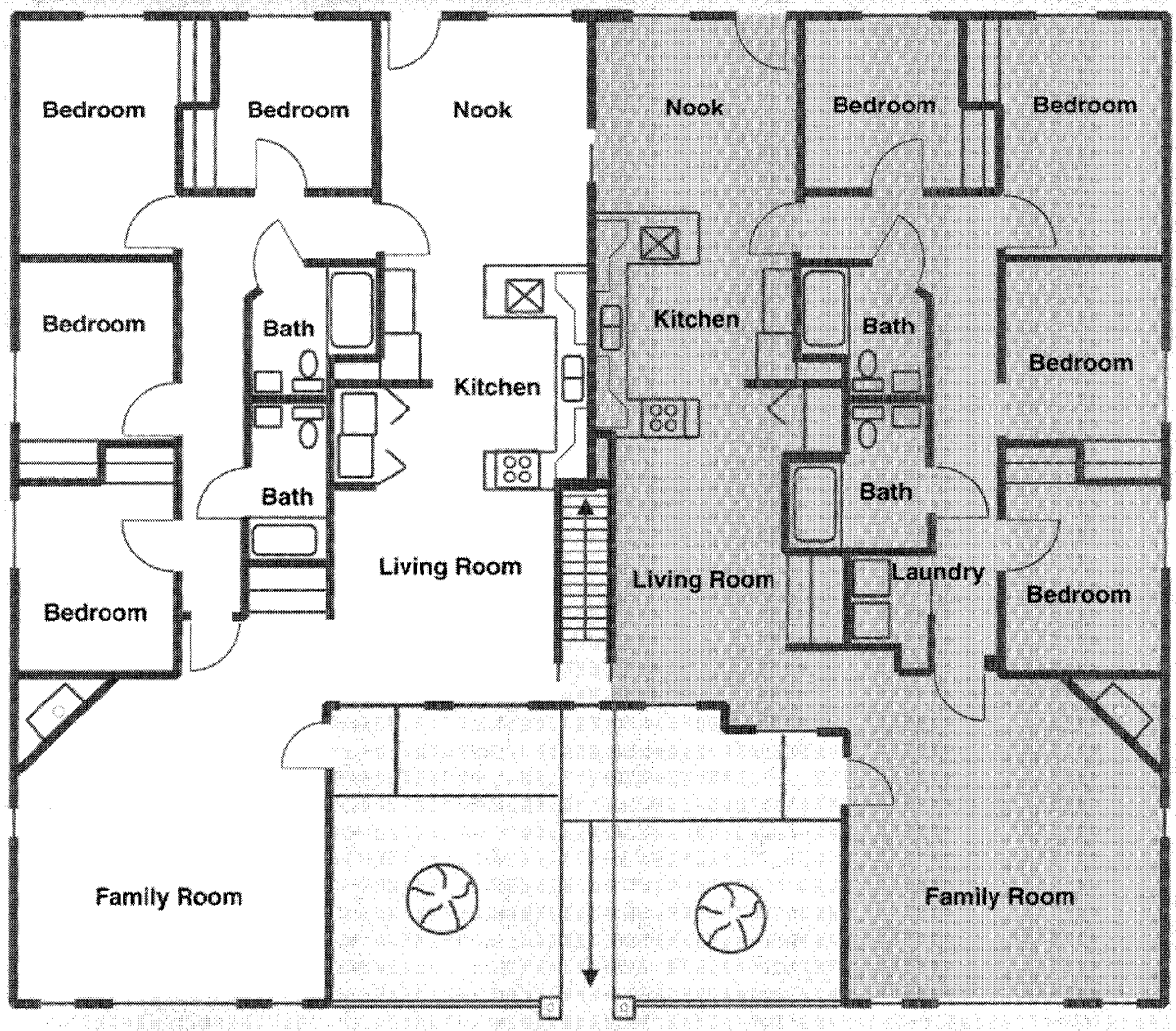
Photo 58: A shower stall provides choice

Residential Care Aides, specially trained in the philosophy of assisted living and in caring for persons with dementia, staff the homes 24 hours a day. The ratio of caregivers to residents is 1:4 during the day and evening shifts, and 1:8 at night. A program manager is on site to assist caregivers and to participate in social activities.

Residents have access to a full range of health care providers. A registered nurse is on site or on call 24 hours a day, seven days a week. Doctors, a pharmacist, rehabilitation staff (delivering physiotherapy, occupational therapy and recreation therapy), a dietician, social workers and pastoral care staff serve residents when needed.

The Good Samaritan Society, a Lutheran Social Service Organization.

WEDMAN VILLAGE HOMES



Östad Group Home, Tanum, Sweden

This group home for six people with dementia is located in a purpose-built one-storey house in the centre of a small town. "Clustered homes," as they are called in Sweden, aim to create permanent homes specially designed to accommodate people with dementia. Such housing is integrated into an ordinary residential environment, where residents can be close to relatives and remain in touch with established social networks. Close personal interaction among residents and caregivers in a small community and in a calm and uncomplicated environment is intended to offset the difficulty that people with more severe dementia have in recognizing others in the community.

Located in either multi-storey apartment buildings or in self-contained single-storey buildings, such as the group home described here, the homes focus on common areas such as a kitchen, dining room, TV/hobby/work and living areas. The layout of both private apartments and common areas is meant to be simple and easy to follow, without corridors or many doors. Östad's six apartments are located three on each side of a common area, all on one level. Each apartment is 45 m^2 in area and includes a bedroom, shower room and sitting room with kitchen appliances along one wall. Common areas in the group – a kitchen/dining room opening into the sitting area – link the two sets of apartments. Also, enclosed rooms open on to this common space and serve as a staff room, office and day room. A patio is located adjacent to the kitchen/dining room.

An evaluation was carried out of seven group homes in Sweden with a similar design, with some findings as follows:

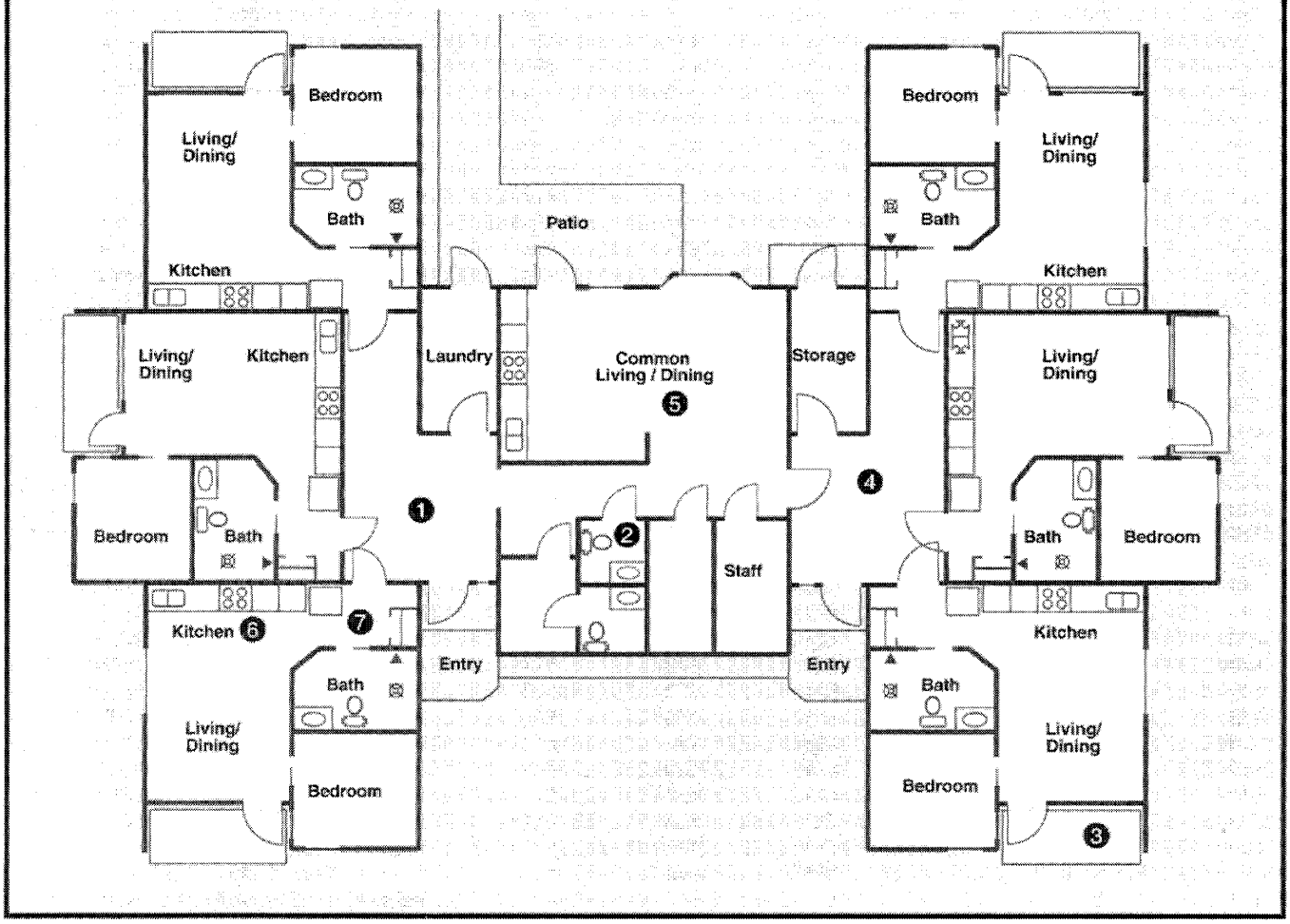
- Code locks on doors seem to serve residents well, preventing elopement but enabling trips out accompanied by staff.
- In such homes, it is essential to plan common areas that are large enough to house residents in wheelchairs and with walkers. If not, residents in wheelchairs are either confined or staff has a great deal more work to do.
- Similarly, small bedrooms are less useful. When residents need more care in the later stages of the condition, if bedrooms are small, beds are eventually moved into the living room, and the bedroom is used as a guest room for family members.
- The common kitchen is the most important element in the group home, though residents also have kitchens in their own apartments. Some staff feel that these private kitchens should be small; others feel that kitchens help create a home atmosphere. A solution is to provide kitchens as planned, but not fully equipped.

Other positive elements for residents and staff were: convenient laundry rooms, outdoor spaces directly connected to the common rooms, direct and visible connection of the apartments and common rooms, and large shower rooms with sliding doors.

Municipality of Tanum, Sweden.

Photo 59: A "clustered" home where people with dementia remain in contact with society

ÖSTAD GROUP HOME



1. Excessive space at entry door may confuse people with dementia and cause them to attempt elopement.
2. Location of toilets in common, as well as private, areas meets the needs of people withk dementia who suffer from incontinence.
3. Porches off living rooms can be unsafe, unless they lead to or are adjacent to secure areas.
4. Excessive corridor space is difficult for caregivers to oversee.
5. Large common living and dining room allows for group activities and serves as a comprehensible centre of the house.
6. Kitchens with operating stoves can be unsafe for people with dementia, unless the residents have low level of dementia or live with their spouses.
7. Location of bathrooms in the apartments makes them easy for people with dementia to find from hallways but difficult to find at night.

The Kelly House, Topeka, Kan., U.S.A.

The Kelly House, a home for eight residents, aims to preserve the dignity and quality of life of an individual while maintaining a balance between body, mind and spirit in a home-like environment. It operates under Contemporary Housing Alternatives of Topeka, Inc., a not-for-profit corporation formed in 1990 by a caregiver's family whose mother had been diagnosed with Alzheimer's disease.

The idea was to develop and operate small residential settings and to create an "Aging in Place" concept that will allow services to adapt in a "single living environment" as residents become increasingly dependent. Project initiators also wanted to demonstrate how quality of care can be enhanced in a smaller, more responsive

Photo 60: Eight people with dementia live in a residential setting at the Kelly House

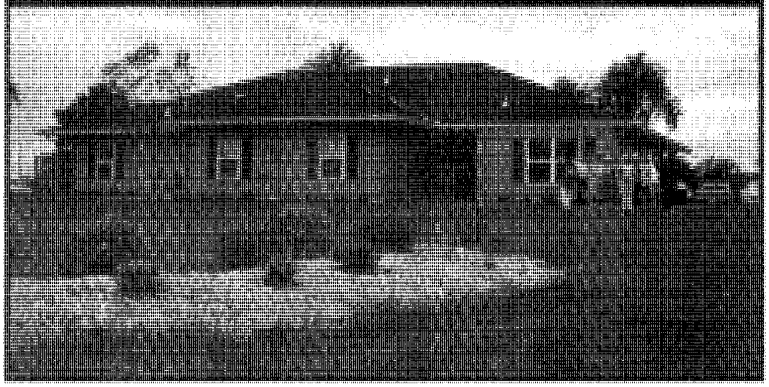


Photo 62: A resident enjoys the comfort and companionship of a pet

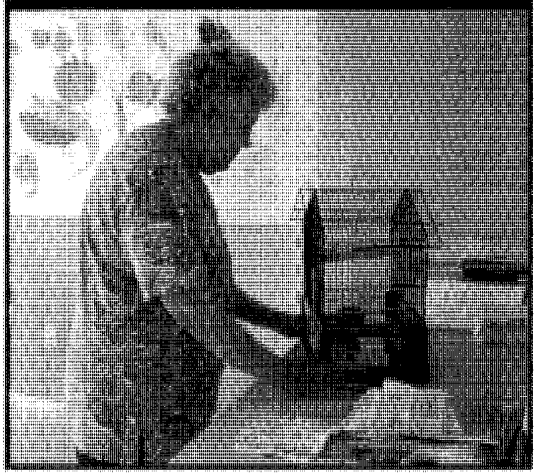


Photo 61: A walking path gives residents a place to wander safely

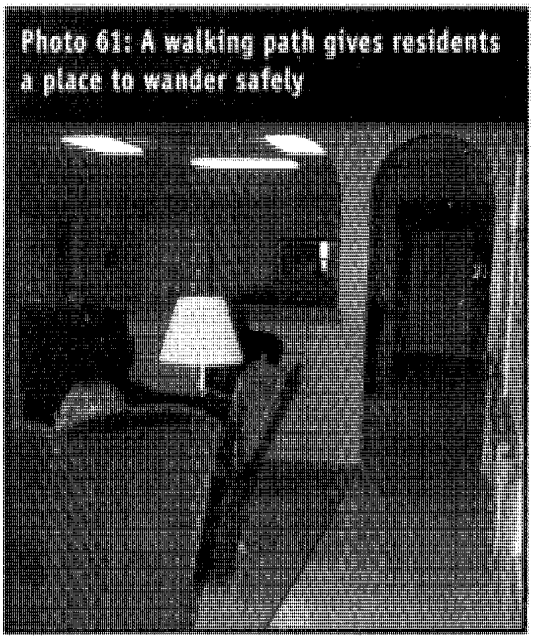
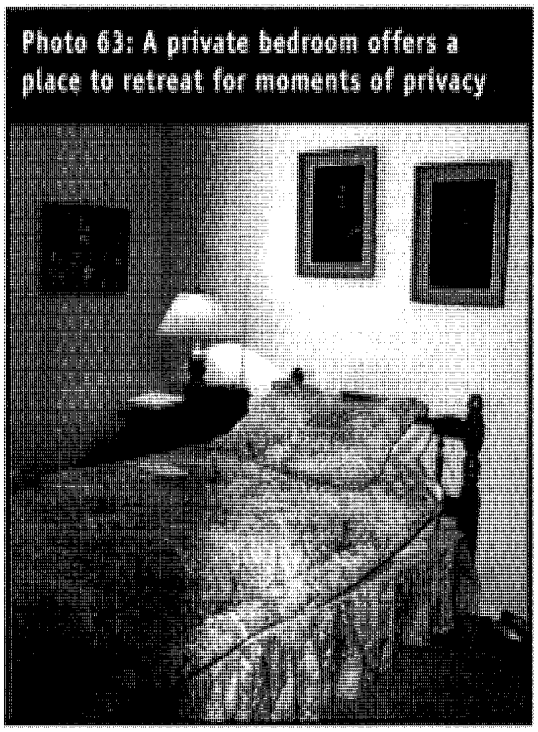


Photo 63: A private bedroom offers a place to retreat for moments of privacy



environment and that the highest level of functioning can be restored and prolonged with appropriate programming, staff training and environmental design. Finally, they intended to create a research environment that enables medical and scientific disciplines to study the disease and combat its causes and effects.

Eight bedrooms surround a large multi-purpose room with distinct areas for recreation, kitchen, dining/card playing and a living room. A laundry room is included, as are a common toilet room and a common bath/shower room. Each bedroom has its own toilet and sink, while one bedroom has its own shower and another its own bathtub.

The Kelly Houses operate under Contemporary Housing Alternatives of Topeka, Inc., a not-for-profit corporation.

Photo 65: A shower stall with grab bars combines safety with independence

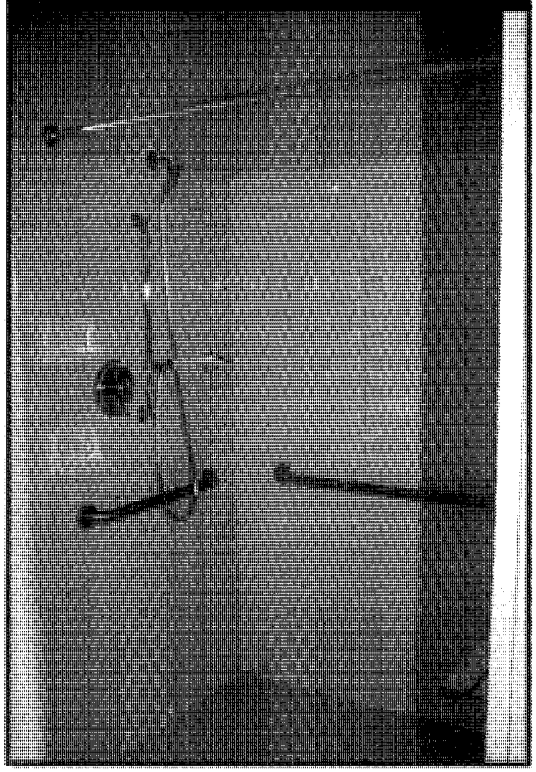


Photo 64: Each bedroom has a convenient toilet and sink

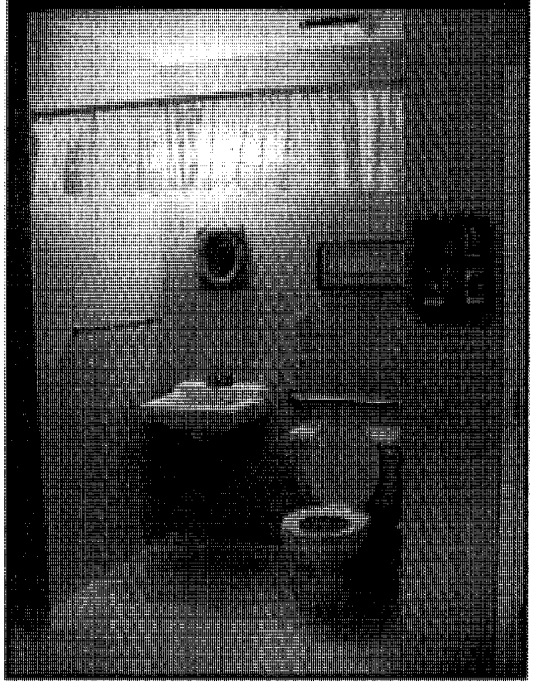
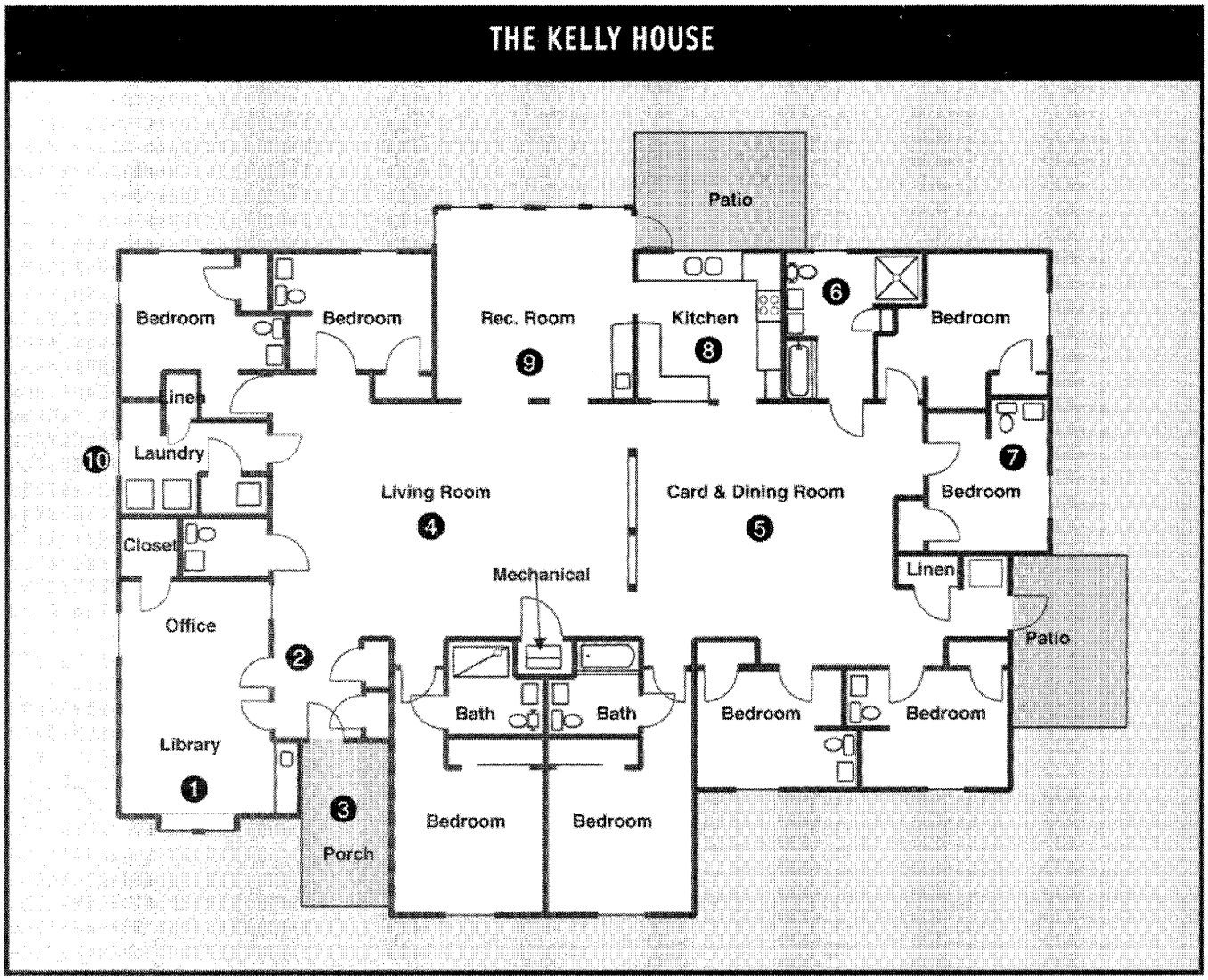


Photo 66: An enclosed garden keeps residents in touch with the outside environment

THE KELLY HOUSE



1. Location of the library away from other common areas offers staff a quiet place where they can go to unwind.
2. Location of office near the front door allows staff to monitor residents' activities and prevent elopement.
3. The house's front door area is small, discrete and moderately unobtrusive.
4. Small amount of wall space in living room hampers furnishing of the space.
5. Bedroom doors enter directly into the card and dining room with little transition. Size and number of doorways into the room hamper furnishing of the space.
6. Shower stalls and bathtubs in common bathrooms provide residents with alternatives.
7. Bedrooms with toilet facilities are available to meet the differing needs of residents.
8. Layout of the kitchen is homelike and offers an interesting walking path.
9. Separate recreation room acts as a retreat for residents and enables small groups to focus on individual activities.

ElderKare, Beloit, Wis., U.S.A.

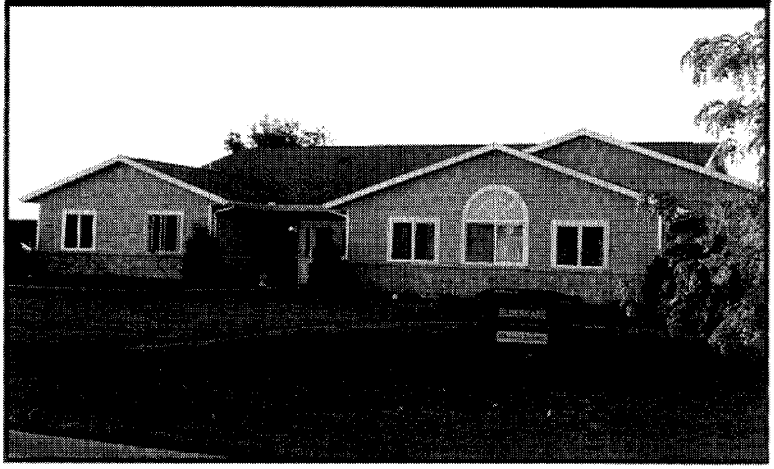
The ElderKare is one of a nation-wide group of housing options designed for people with dementia. It houses 12 residents and, like all homes developed by Elder Care Concepts, now known as Encore Senior Living, is located in a quiet, attractive neighbourhood. Such homes offer an alternative to traditional nursing homes.

The philosophy of the privately owned Encore Senior Living is summarized by the following statement: "While Alzheimer's disease is not curable nor even treatable in the traditional medical sense, it is a disease that people can live with, continuing to enjoy many parts of their lives, when offered a home where care providers understand the disease, strive to provide an environment that supports the person's unique needs and have a 'resident first' attitude."

The design of the small, free-standing model is intended to ameliorate the symptoms of dementia. The floor plan, for example, allows residents to pace without disturbing others. Large windows provide contact with the outside and a sense of freedom for residents. A fireplace is calming and soothing. Each resident has his or her own bedroom, offering a sense of personal space, but the bedrooms are not large, so that residents are discouraged from spending a great deal of time alone, as a tendency to isolation is part of the disease. Residents are encouraged to provide their own furniture and pictures, to create a familiar environment. Enclosed courtyards are provided to promote outdoor activity.

Family members, when they surrender the primary responsibility for caregiving to professional staff at Encore Senior Living, are comforted to know that their relative has access to recreational and therapeutic activities as well as medical care and social support. The home also offers programs to help families understand the disease and to show them how to continue meaningful relationships with their loved ones.

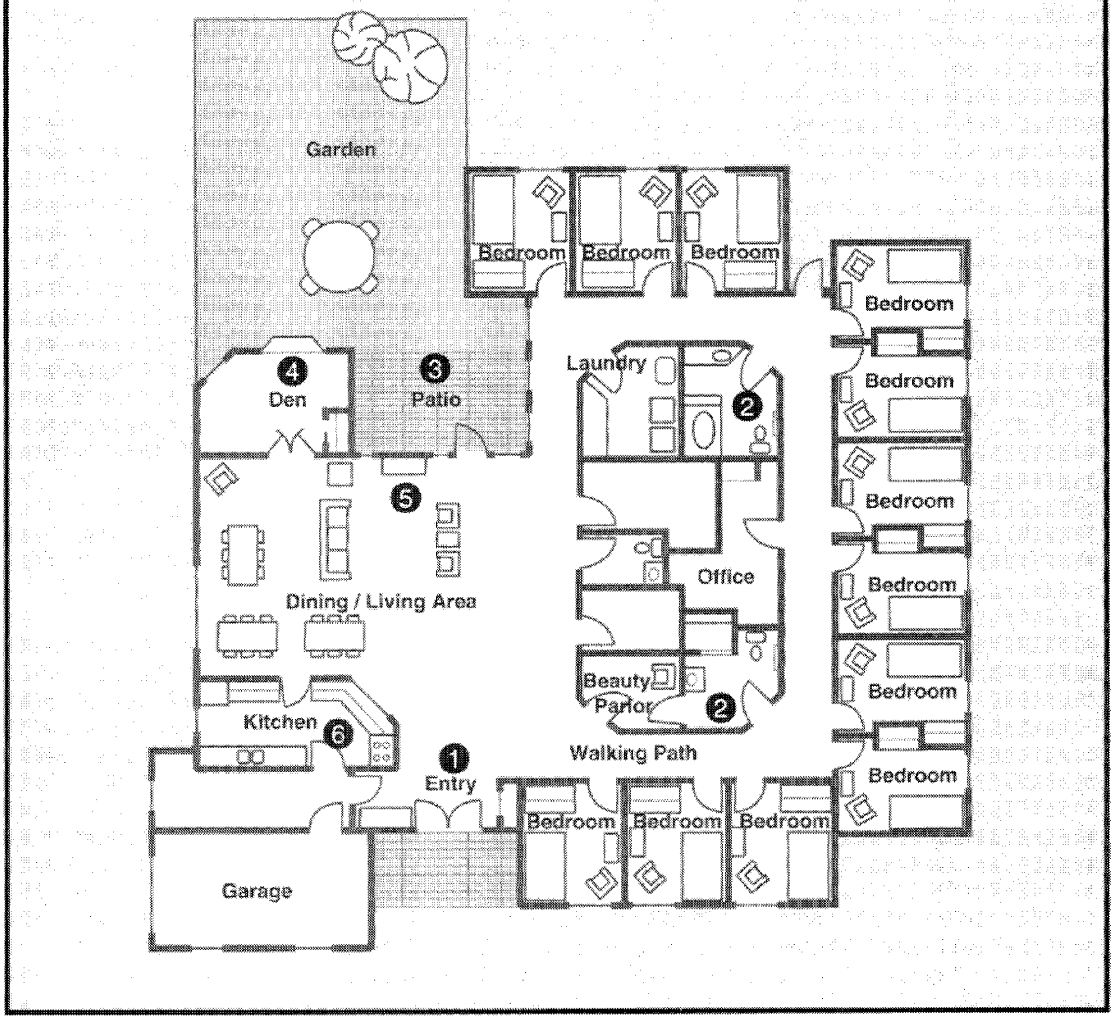
Photo 67: The ElderKare offers an alternative to traditional nursing care



Though Elder Care Concepts succeeded in developing an excellent care model, it proved to be an expensive model that has needed some refinement. Management, seeking to improve on the original concept and to develop more cost-effective ways of delivering optimum care, resolved to merge the company with Encore Senior Living. One of the results of that merger was the availability of three models of care – one to accommodate 12 people (as described here) and one to accommodate 16 (see Madison Village on page 69). Both of these are designed for northern climates and have limited access to the outdoors; the third model, known as the southern model, is designed specially for warm climates and has year-round access to an outdoor walking path.

Designed by Elder Care Concepts. Managed by Encore Senior Living, Madison, Wisconsin, U.S.A.

ELDERKARE



1. Large, prominent front door at the end of the living room and next to the kitchen may encourage elopement.
2. One common bathroom with shower and another with bathtub offer alternatives to meet the varying needs of residents.
3. Shaded patio at the garden door allows residents to sit outdoors in comfort, even in hot weather. It also says clearly to residents: "This way back in."
4. Separate den with a window overlooking the garden can be used as a retreat for agitated residents and their caregivers.
5. Prominent hearth visible from entry door contributes to the residential character of the house.
6. Separate kitchen can be safer for residents. A large window opening from the combined dining/living area into the kitchen contributes to the residential character of the house.

Madison Village, Madison, Wis., U.S.A.

Madison Village is an assisted living home in a residential neighbourhood. The residence combines a home-like environment specifically designed for people with dementia with high-quality care that costs considerably less than the industry average. Each of three houses on the property is divided into two wings, with each wing accommodating eight persons – an optimal number that allows for a "family" scale of care without the confusion of a large group or the isolation of a small one.

Whether using the 12-person model (see page 67), the larger Madison Village model or the southern model (with year-round access to an outdoor walking path), the recipe for "failure-free" living is a combination of design and programs. Each unit is designed to function as a "home" – small in scale and filled with orienting cues. The one-storey homes are characterized by clean, contemporary lines with therapeutic colour schemes and natural, elegant finishes. Large windows overlook landscaped gardens and fill the house with comforting sunlight. Art has been selected to evoke happy memories of ordinary life, and residents are encouraged to personalize their rooms with their own furniture and decorations for a feeling of continuity and comfort. An open kitchen allows the activities and aromas of cooking to circulate throughout the house, while private rooms offers residents a place to retreat in privacy. Common areas include a charming living room with a fireplace, which is in constant use, and a den that is ideal for one-on-one activities or as a venue for private family gatherings.

Photo 68: Attractive contemporary design creates a welcoming sense of "home"

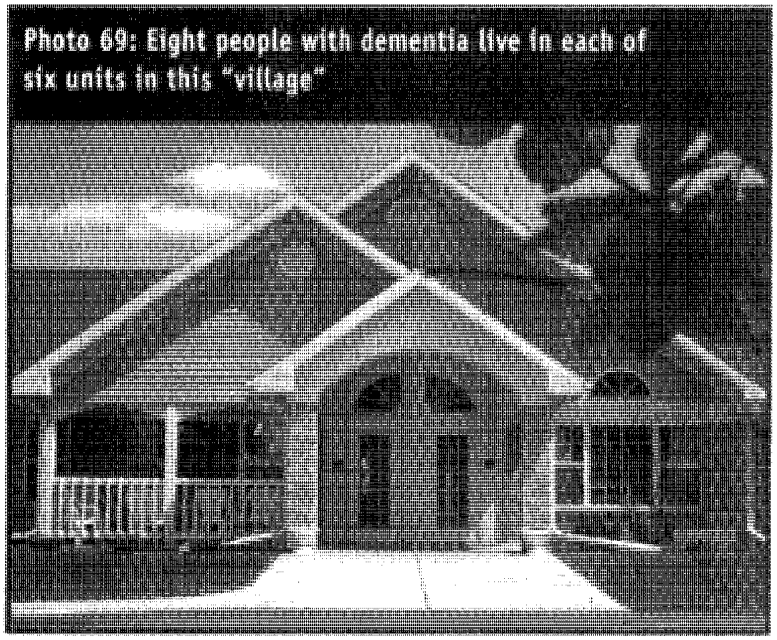


Photo 69: Eight people with dementia live in each of six units in this "village"

A staff ratio of 4:1 or 5:1 allows for ample personal attention and means that employees – each of whom receives 56 hours of specialized training – can develop strong, positive relations with each resident. Staff organize up to nine daily activities and programs, often delivered one-on-one.

Weekly visits to restaurants, parks, museums and shopping centres provide stimulation and variety.

Visual cues abound throughout the house, including "memory boxes" outside each resident's room (with old family photos and memorabilia). Bedrooms are decorated each with different colours and wallpapers so that residents can easily find and recognize their own space. A circular corridor runs through the house with no sharp angles or dead ends to confuse the person with dementia, so that residents can wander and work off nervous energy. Bathrooms are easily recognized, have sit-down showers and highly visible water closets and are easy to use.

Designed by Elder Care Concepts. Managed by Encore Senior Living, Madison, Wisconsin, U.S.A.

Photo 71: The den offers a quiet place to meet family or friends

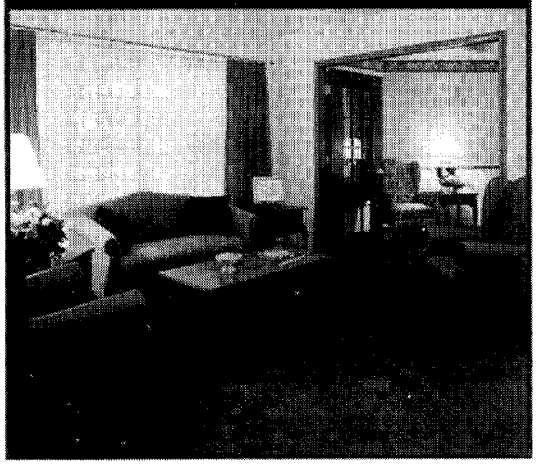


Photo 72: A cozy bedroom, which residents are encouraged to personalize

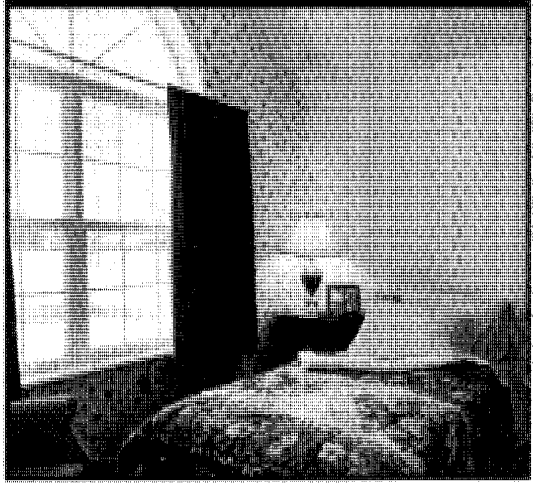
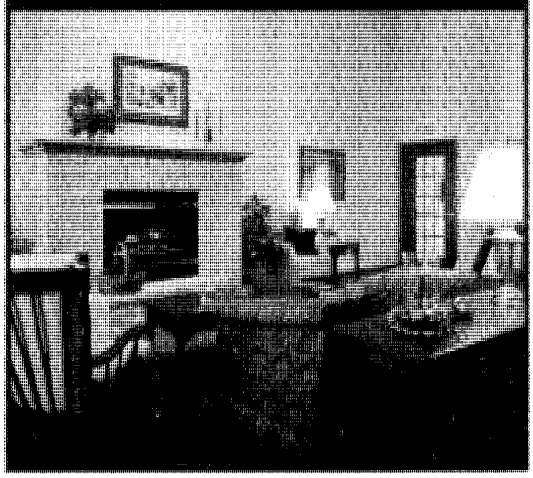
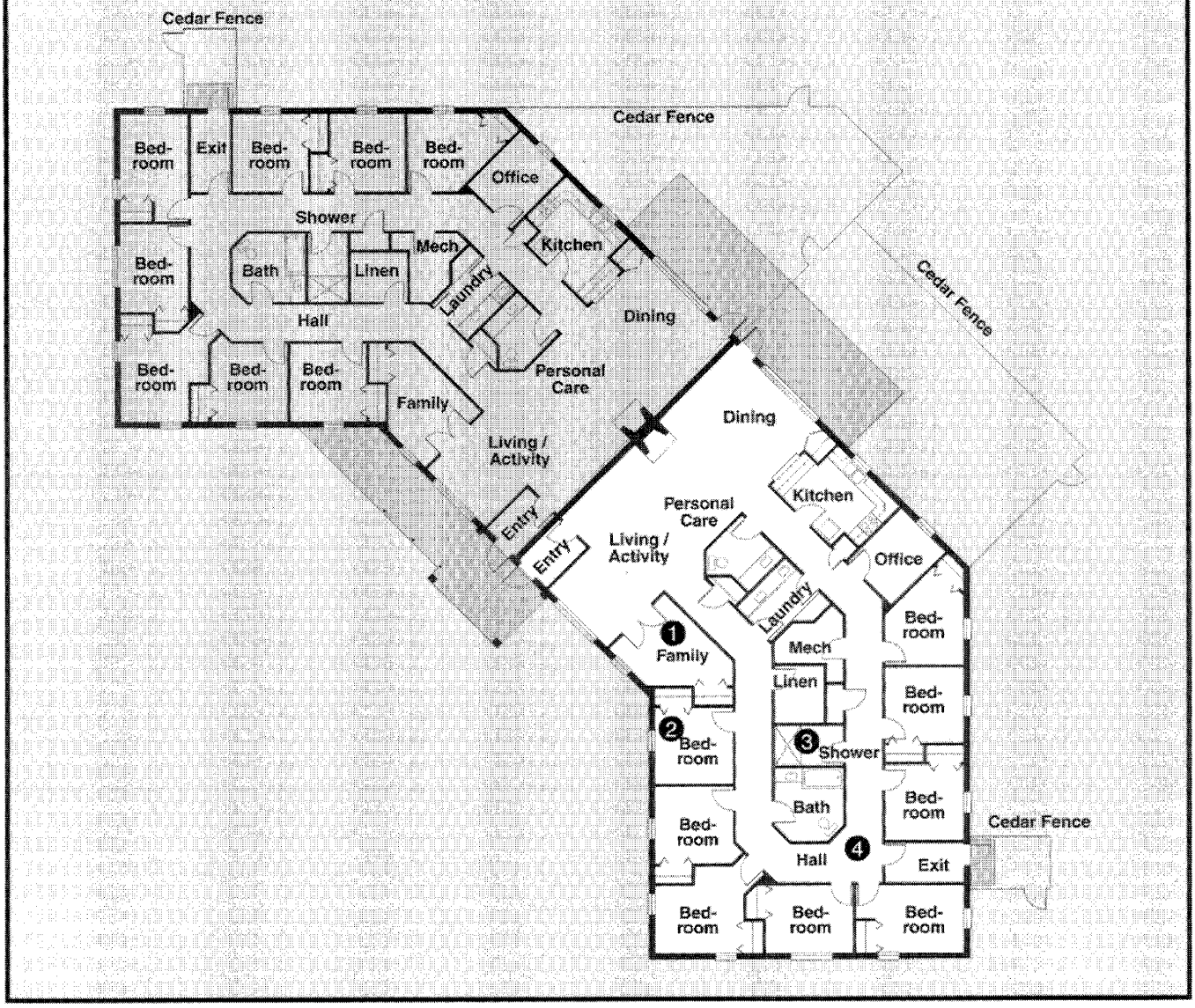


Photo 70: Chairs cluster around a well used fireplace in the living room

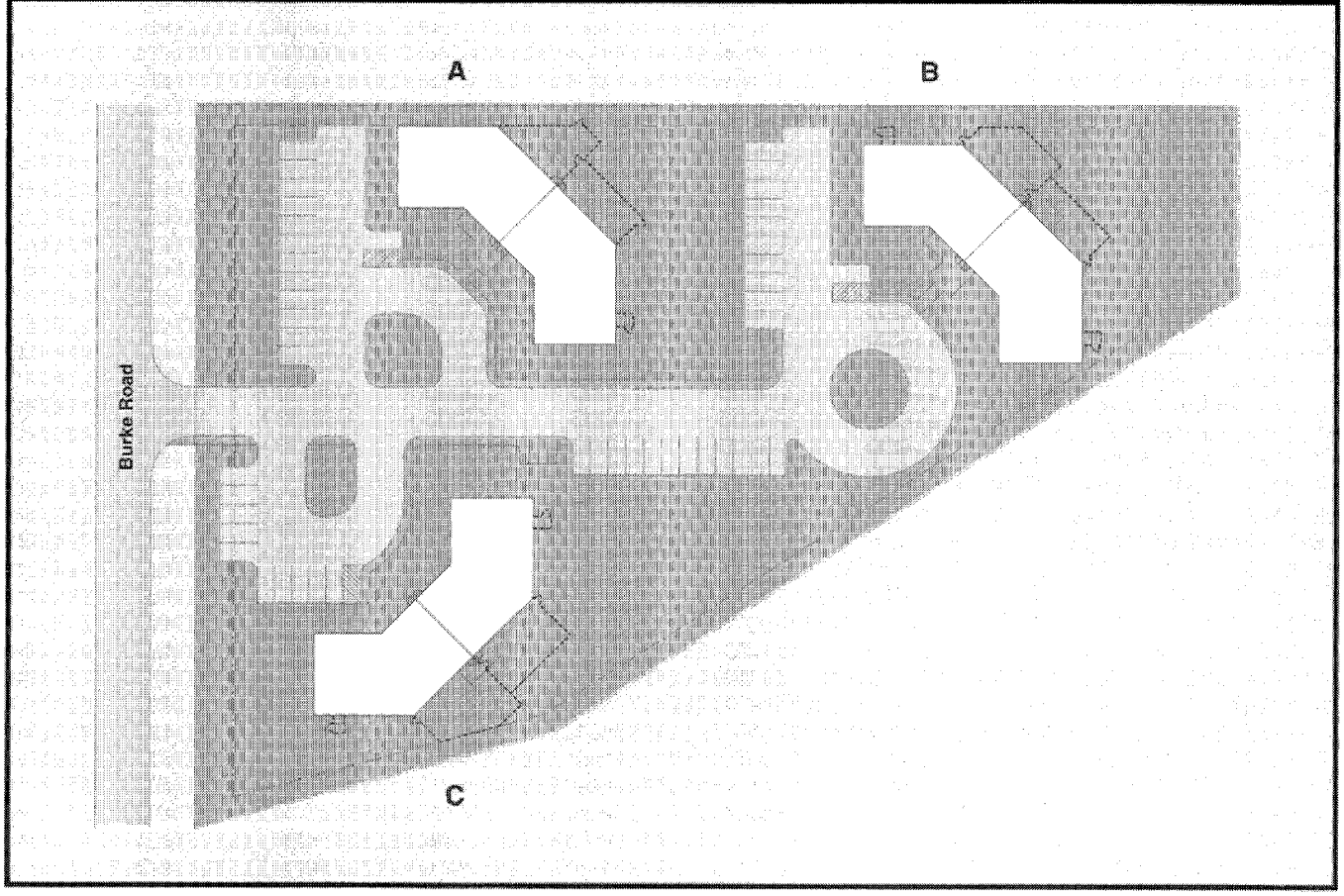


MADISON VILLAGE



1. The family room allows for one-on-one activities with residents and staff or for private family gatherings.
2. Private rooms allow residents to retreat, relax and rest whenever they wish.
3. Sit-down shower promotes the comfort and safety of residents.
4. A walking path with no right angles or dead-ends offers residents an endless route to explore.

MADISON VILLAGE
SITE PLAN



Le Cantou familial de Rueil-Malmaison, France

In many small towns throughout France, small houses have been constructed to house cognitively impaired seniors. The Cantous, principally designed for persons with dementia, have resulted from partnerships between the operators of nursing homes, homes for the aged and municipalities. The Foundation of France, created in 1969 as an initiative of Charles de Gaulle and André Malraux, has sponsored and promoted the concept throughout the country and has evaluated existing projects.

The word "Cantou" comes from the "langue d'oc" and means "little corner." In rural areas, the term refers to the corner of the hearth, furnished with a bench where, under the large mantel of the fireplace, elders would keep themselves warm. At the Cantous, the emphasis is on quality of life and the active prevention of decline rather than on technical life support and medical treatments. The key concepts are independence, activity, participation and sharing. Projects are very local in character so that people are not dragged away from their communities as they age, and a strong effort is made not to uproot individuals, to keep them near their families and communities and to allow them to age in place.

This Cantou, situated in a private house with garden, houses 12 residents. It was originally conceived by 12 families needing to find good communal housing for aging parents. Notwithstanding the protection that is generally required by persons with dementia, the Cantou sets out to promote the highest possible degree of independence and social integration in a family-like setting. To that end, the centre of the house is designed as a large common area, where household activities – such as meal preparation – take place and a spirit of community develops. A "maîtresse de maison" organizes activities and assigns tasks that will foster the abilities of residents and stimulate them to be as active as possible.

Photo 73: Student assistants live rent-free on the second storey at Le Cantou

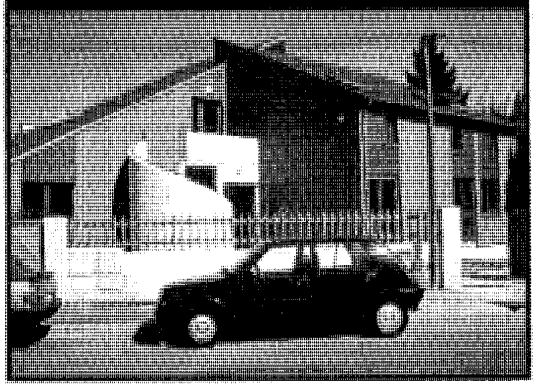


Photo 74: Helping with a meal makes a resident feel part of the community

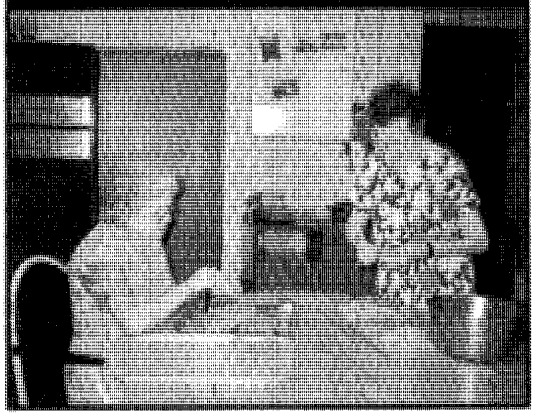
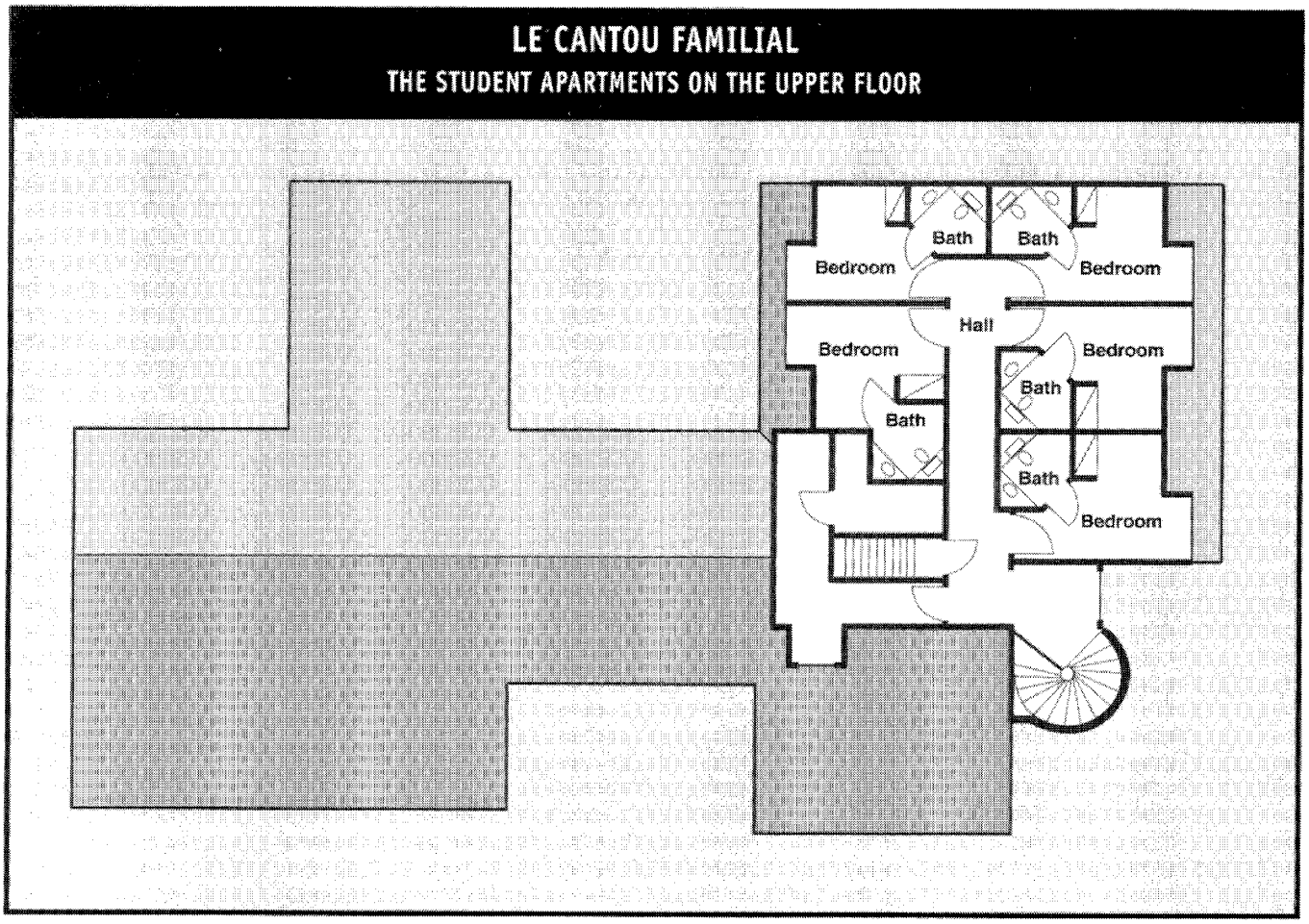


Photo 75: Twelve residents sit down to dinner with staff and a student helper

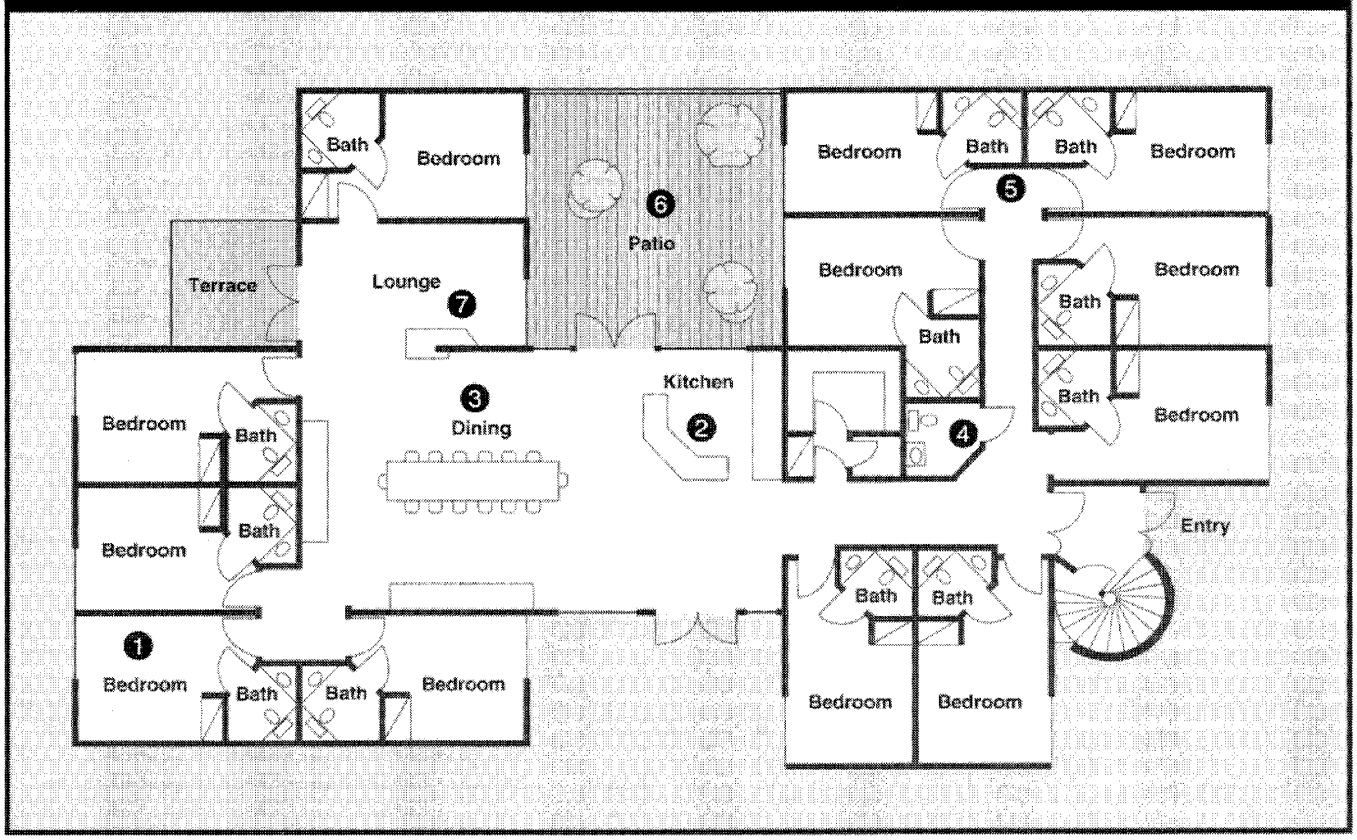
The Cantou stands on a lot approximately 200 m² and comprises: a large day room – the centre of community life – with living room and kitchen areas within it; 12 private bedrooms with private bathrooms; a garden; and six bachelor apartments on the upper floor designed for student residents who each supervise the residence on five nights a month in return for free accommodation.

In terms of staff, the Cantou has two full-time, multi-skilled "maîtresses," six student supervisors and a maid who works three hours a day at the residence. In addition, the management counts heavily on family support and involves them at numerous levels in operating the residence.

Association des Cantou, Rueil-Malmaison. Monsieur Georges Caussanel, président.



LE CANTOU FAMILIAL
GROUND FLOOR PLAN



1. Private bedrooms with full bathrooms and closets create a family atmosphere, as well as giving residents privacy.
2. Kitchen counter defines the cooking area and makes it easy to serve residents who need help.
3. Central common area can be used for dining or other large group activities.
4. Common bathroom meets the needs of people with dementia who suffer from incontinence.
5. Dead-end corridor may trap residents who wander.
6. Enclosed and secure patio with a door from common area brings residents into contact with the outdoors.
7. Separate lounge with terrace and view of the patio provides for small group activities.

Maison Carpe Diem, Trois-Rivières, Que.

"Carpe diem" means "seize the day," or "take advantage of the present," and that is the underlying philosophy of the Maison Carpe Diem, a nine-bedroom residence specially dedicated to persons suffering from Alzheimer's disease. Here, the emphasis is on the remaining potential and not on the deficits of residents, and developing a positive relationship with the resident is the most important element in the care. Despite the intellectual loss associated with Alzheimer's disease, the individual remains in close emotional contact with his or her surroundings and needs constant stimulation, security and encouragement. The individual with Alzheimer's needs to feel useful and accepted in order to live positively and with the maximum degree of independence. Maison Carpe Diem aims to go with the individual and with his or her family through the course of the disease in a spirit of respect and dignity rather than control and power. In particular, the individual is involved for as long as possible in decisions

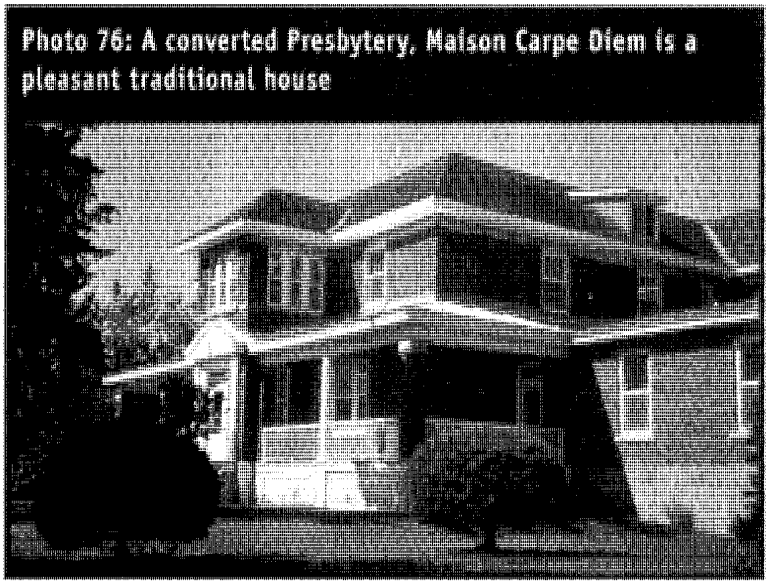


Photo 76: A converted Presbytery, Maison Carpe Diem is a pleasant traditional house

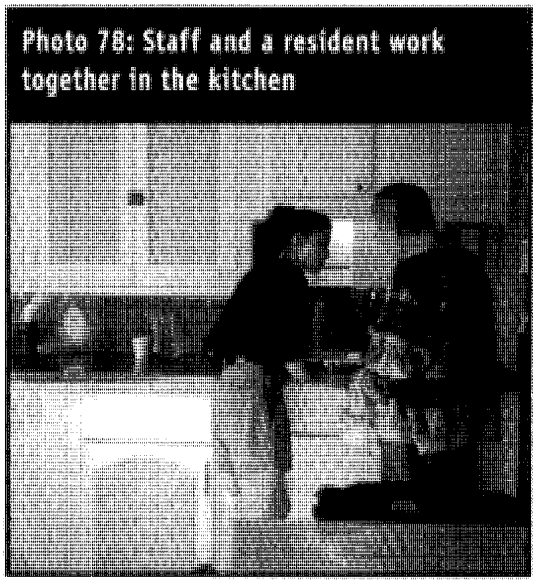


Photo 78: Staff and a resident work together in the kitchen

Photo 77: Some residents keep pets, who perform a therapeutic role

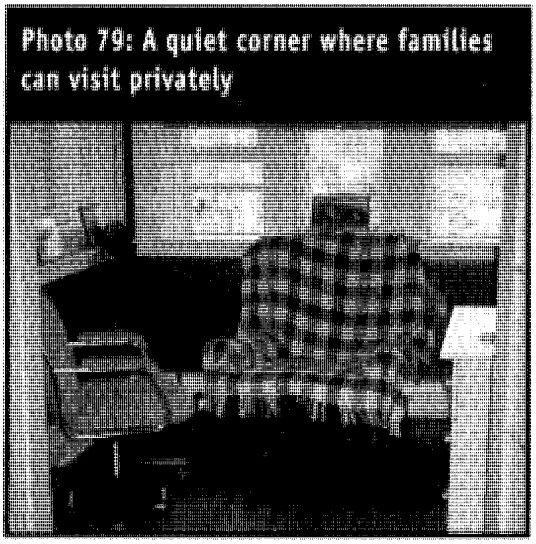


Photo 79: A quiet corner where families can visit privately

relating to care and activities, and a flexible daily schedule of activities responds to a need for personal choices.

People with Alzheimer's in the community are helped, through a program of at-home care, to remain in their own residences for as long as possible. A limited number of those who need more care live at the Maison Carpe Diem, where the emphasis is on creating a strongly residential and home-like setting. The functional capabilities of residents are regularly evaluated, and activities are designed to maintain those capabilities for as long as possible. Residents are encouraged to participate in stimulating activities related mostly to daily life and to their own care. Residents are also encouraged to remain in contact with people of all ages from outside the residence, especially members of their own family, who are involved as much as they want and are able to be, in the life of the resident. Families are consulted and involved on management directions for the residence and in the care of their relative. In order to limit the confusion of residents, stability and consistency of service are the keynotes of the program delivered at Maison Carpe Diem.

Maison Carpe Diem is a large, nine-bedroom house set on a residential street. The house, which used to be a Presbytery, adjoins a church next door. It has an attractive, traditional appearance outside and a warm and personal decor inside. The pleasant two-storey residence, surrounded by trees and hedges, is designed for safety and simplicity, so that residents can go everywhere, inside and out, freely and without supervision. As well as a living room and dining room, there is a large eat-in kitchen and a large, fenced garden where residents can enjoy the outdoors. In the fenced garden, there are chairs and awnings where residents can enjoy the fresh air and greenery.

Managed by The Alzheimer Society of the Mauricie.

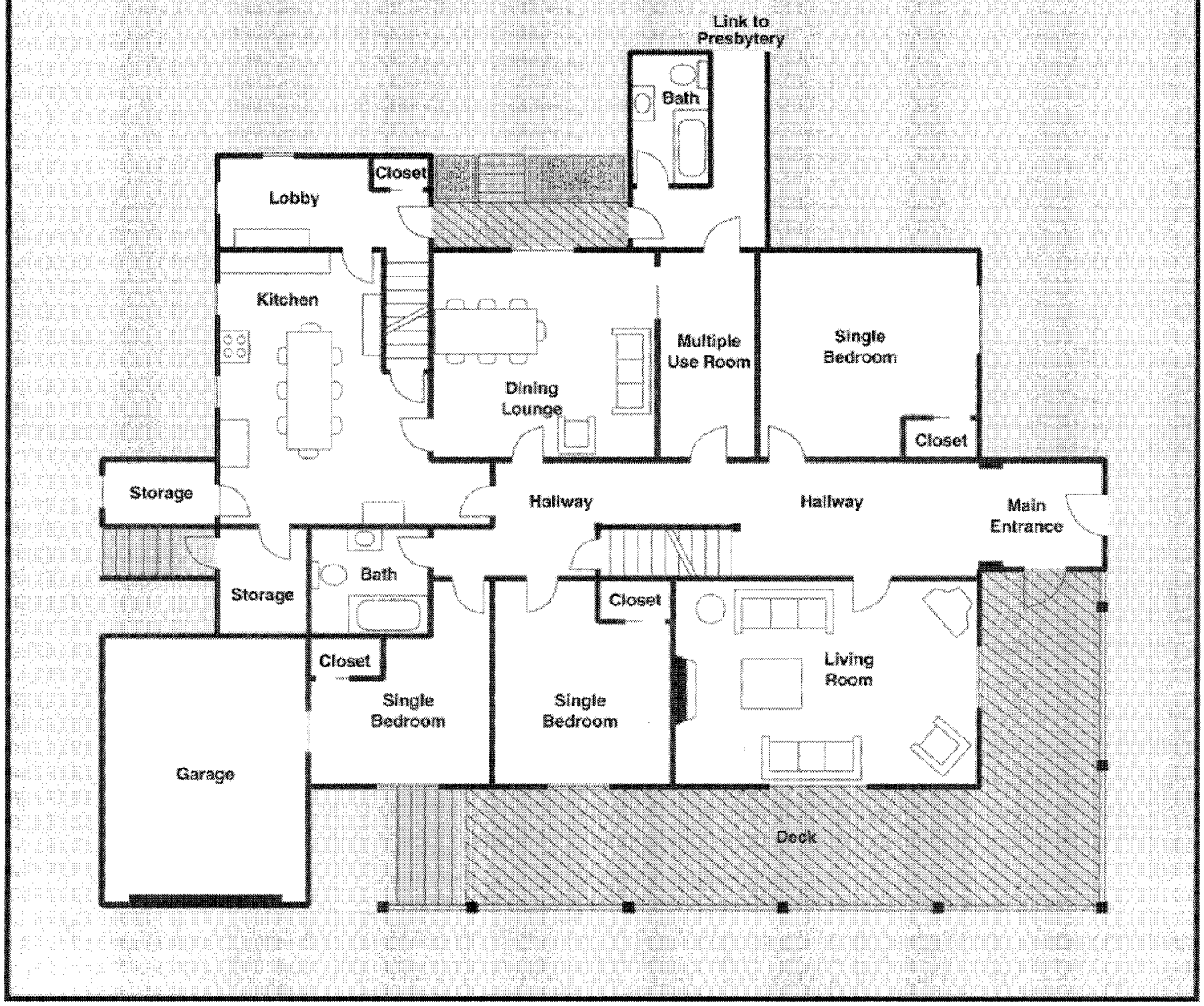
Photo 80: The fireplace is a warm and homely centrepiece in the living room

Photo 81: Chairs are shaded by awnings in the safely enclosed healing garden

Photo 82: Transportation is provided to help residents visit in the community

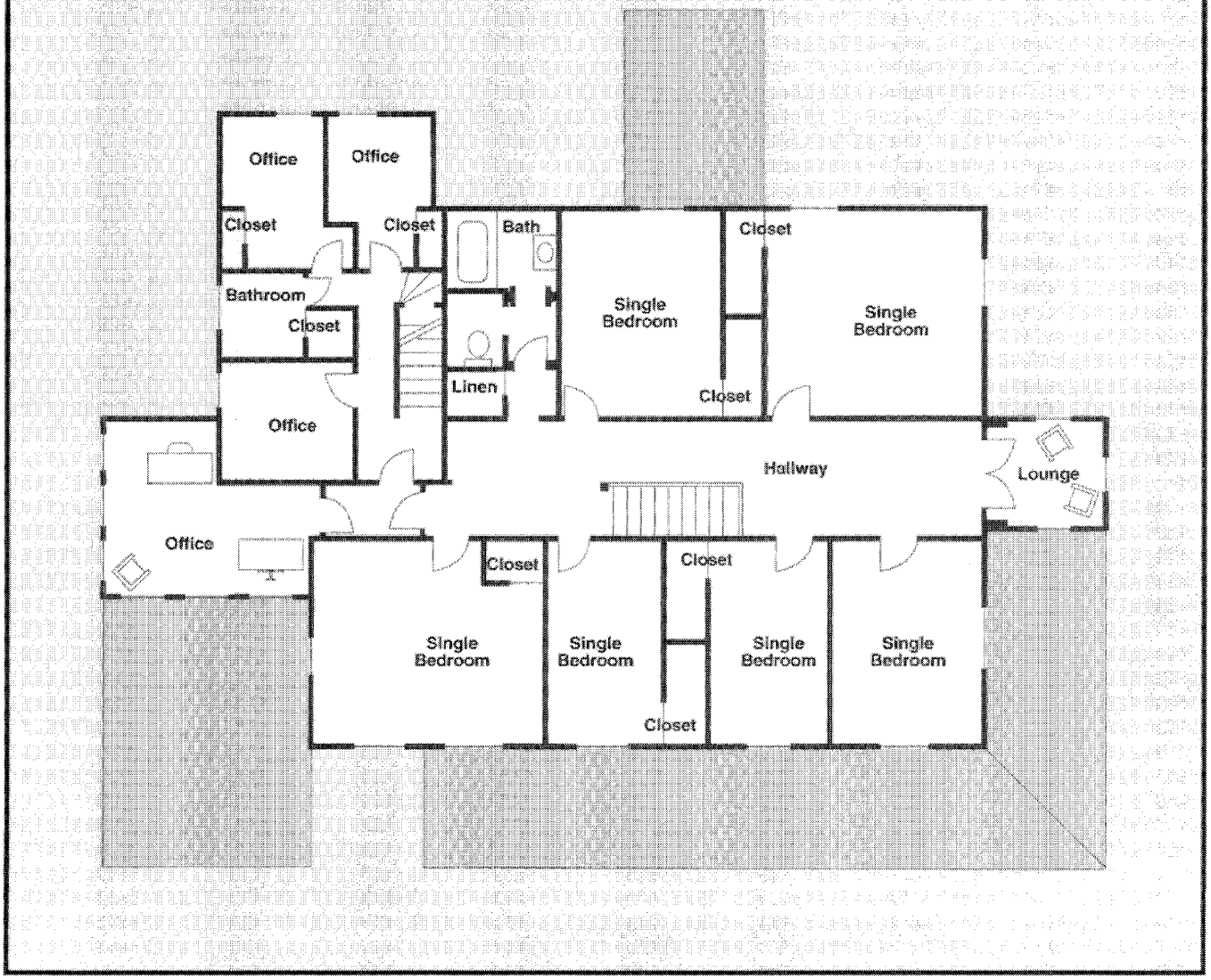
MAISON CARPE DIEM

GROUND FLOOR PLAN



MAISON CARPE DIEM

SECOND FLOOR PLAN



Leigh Place, Sydney, Australia

Leigh Place is a supportive housing project consisting of six large brick houses offering hostel-type accommodation for 62 residents in total. One of the houses – House Five – offers a residential setting for 10 residents with dementia.

Leigh Place focuses on people rather than the disease. In particular, it aims to communicate with and to promote the self-esteem of residents by adapting the environment to the person, not the person to the environment. It is intended to provide a home-like environment and to enhance the dignity of the resident in a non-regimented context, to build on resident's skills and to be flexible in the design and delivery of services.

Photo 83: One of six houses at Leigh Place is dedicated to people with dementia

Photo 84: The living room is a large common area decorated in the style of the 1930s

Photo 85: Residents can bring their own furniture to bedrooms and even common areas

Every resident has a personal care plan that is subject to ongoing assessment. At every stage, family involvement is encouraged. There are two staff members on duty at all times, and they take responsibility for all daily living activities, personal care and meal preparation. Residents are encouraged to help prepare meals when appropriate. At night, one staff member sleeps on the premises and is on call. To integrate the life of residents into the community, Leigh Place has an open visitors policy, and it interacts with many community agencies, for example, with local schools that provide work experienced students on a regular basis. The house dog is a graduate of the Pets as Therapy Program.

A Consultative Committee made up of health professionals and representatives from the Department of Health meets every six weeks, and the Management Board meets with that committee twice a year. In

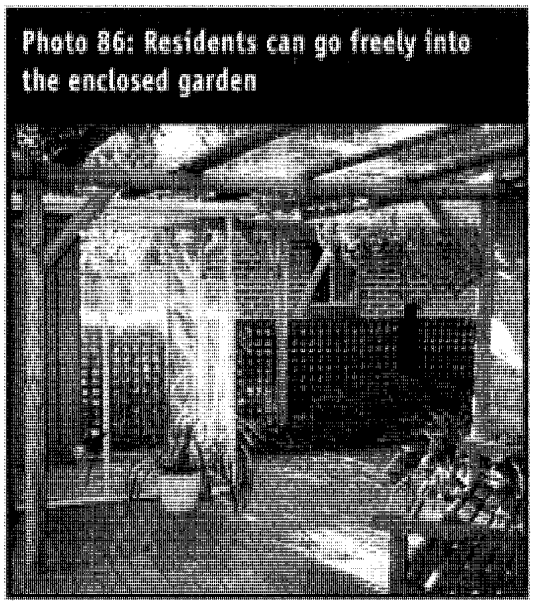


Photo 86: Residents can go freely into the enclosed garden

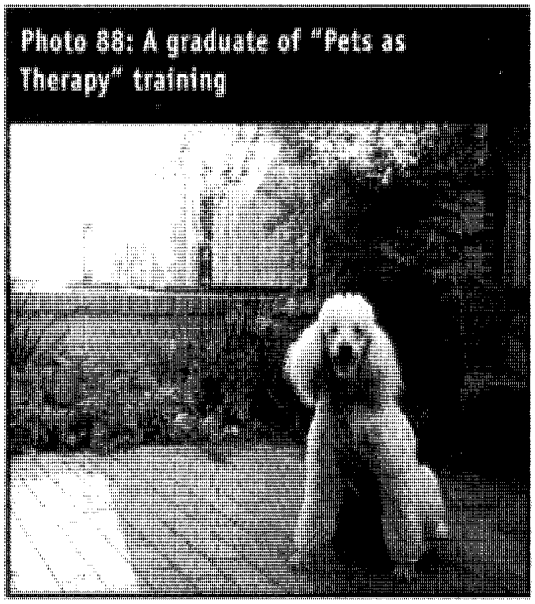


Photo 88: A graduate of "Pets as Therapy" training

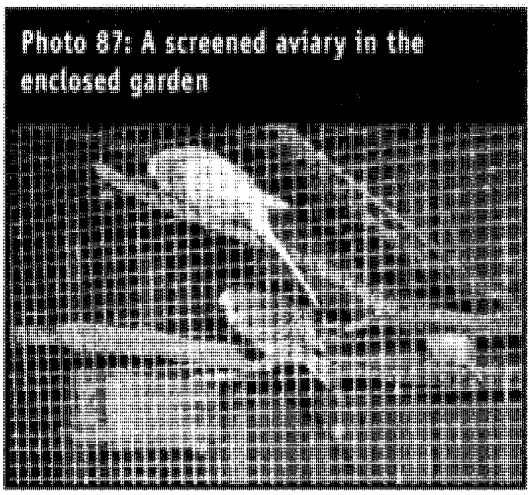


Photo 87: A screened aviary in the enclosed garden

terms of day-to-day management, there is a strong emphasis on ongoing staff training, and weekly meetings of the staff give them an opportunity to address their difficulties and find solutions.

Leigh Place is located on a quiet cul de sac in a residential neighbourhood close to a shopping centre and local corner shops. House Five is a brick house that fits in with other housing in the neighbourhood. Inside, it is designed with private rooms arranged around an interior courtyard and a large central living and dining area. The open concept and interior courtyard give a sense of spaciousness, privacy, light and comfort. The house is furnished to create a home-like atmosphere, with many design elements, such as picture rails and pastel colours schemes, drawn from the 1930s (an era that represents a secure past for most residents). Lounge chairs have washable covers and waterproof cushion linings and wooden arms to allow residents to lever themselves up easily. In-slab heating provides warmth in winter while minimizing risks to residents. A community room is available for group functions. Individual rooms are personalized with the resident's own furnishings and decoration, and some personal items are also placed in common areas. The house is set in an enclosed garden, and its many large windows keep residents in touch with the outside, with weather and with the seasons. An unobtrusive lattice fence fits in with the landscaping of other houses along the street, though there is a suggestion that this will be replaced with pool-type fencing for greater security. The pool-type gate has a childproof lock and is too high for residents to climb. The interior courtyard allows for unobtrusive supervision of residents when they go outside, as they are allowed to do whenever they want. There are waist-high

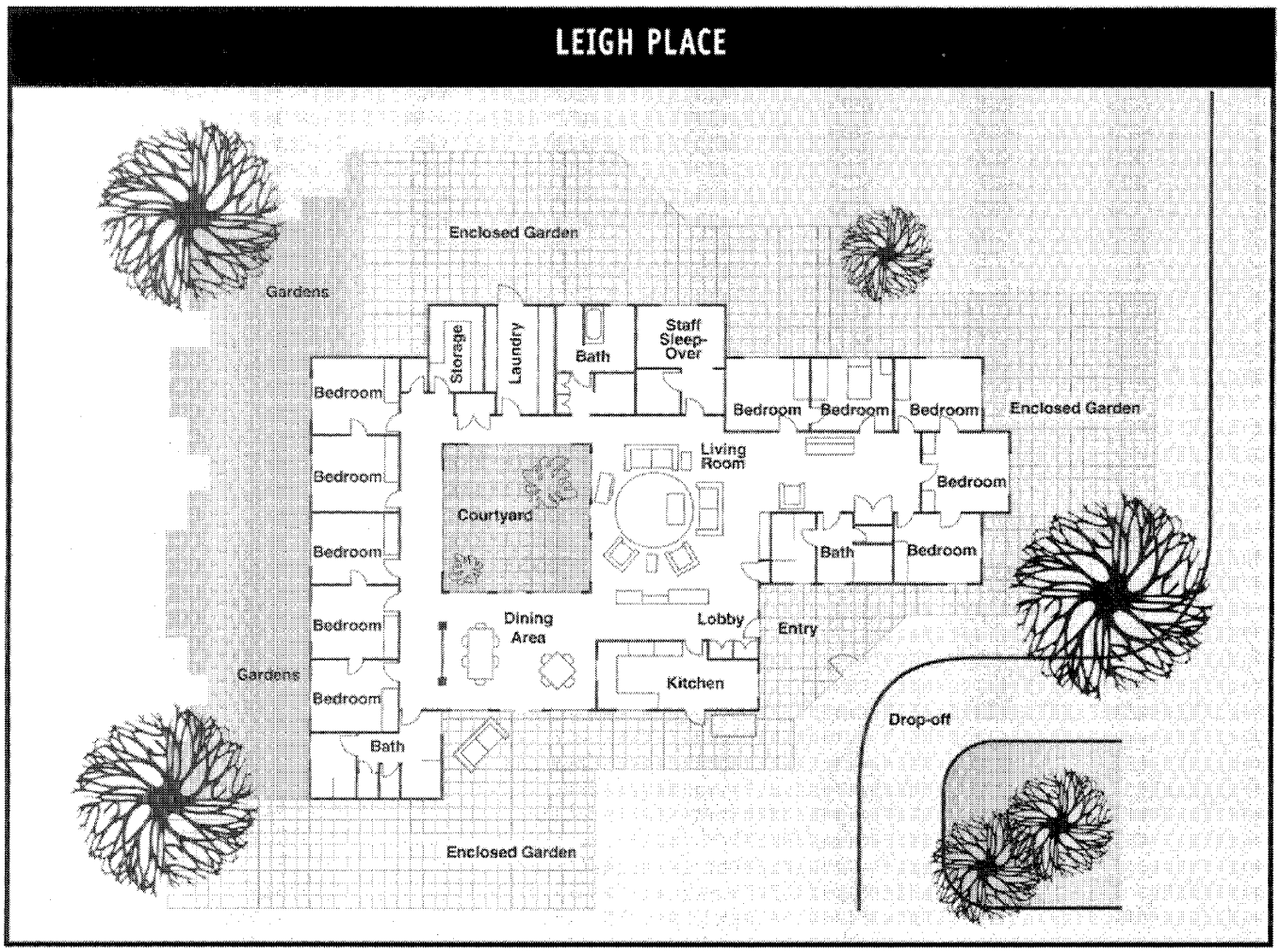
garden beds outside the house where residents can indulge their interest in gardening.

The Hostel and Care Program, working with the Department of Housing, Southern Sydney Region, reviewed the project in 1996 "to identify good features of housing and care for older people from the perspectives of residents, staff and management." The review praised Leigh Place for its homelike philosophy of care, the non-institutional design and layout of the premises and the friendly atmosphere.

The staff who work at Leigh Place attribute its success to things like the privacy of individual units, the small scale and homelike quality of the residence in terms of organization and decoration, the openness and spaciousness of the many-windowed rooms and the possibility of safe and casual access to a conveniently organized courtyard. At the same time, staff would like to see each unit and the garden area fitted out with bathrooms. They also recommend an increase of outdoor space (especially in front of the house and through an extension of paved walkways), the replacement of fencing with a more secure type and the introduction of office space. Staff were also concerned with the quality and durability of carpeting and upholstery.

Designed, constructed and managed jointly by the Department of Housing of New South Wales and the Canterbury Municipal Council, with additional capital and recurring funding from the Department of Human Services and Health.

LEIGH PLACE



Leisure Way Community Group Home, Medicine Hat, Alta.

This therapeutically designed community group home houses six people who are in the middle stages of dementia. The project emphasizes preserving the individual's skills and ability to perform daily living activities.

The Leisure Way Community Group Home is a unique alternative to institutional care for those seniors living in a rural area in southern Alberta who can no longer manage independent living in their own homes. By providing comprehensive support and consulting services in such a setting, the group home helps residents to remain longer in the community, thus addressing quality-of-life issues in a cost-effective manner.

Leisure Way, which offers 24-hour, individualized care for seniors, focuses on the promotion of dignity and independence. A multidisciplinary professional staff cares for residents. In addition, they instruct family members, supporting them and encouraging them to remain in contact with the person with dementia.

The Leisure Way Community Group Home is the first privately owned home of its type in southern Alberta that is licensed to provide community-based continuing care. The owners and operators of the group home are a recreational therapist and a former nurse. The house is divided into two parts, the first comprising a group home for people with dementia and the second serving as a private residence for the caregivers.

Residents have private rooms and share a common living room, a dining room and kitchen. They also are encouraged to take part in a range of daily therapeutic activities and to take advantage of the private transportation service provided by the home to go shopping or attend medical appointments. Residents can enjoy nutritious meals, housekeeping and laundry services. Outside the home, the garden is safely fenced to encourage residents to enjoy the countryside freely.

Photo 89: A group home shelters six people with dementia in rural Alberta

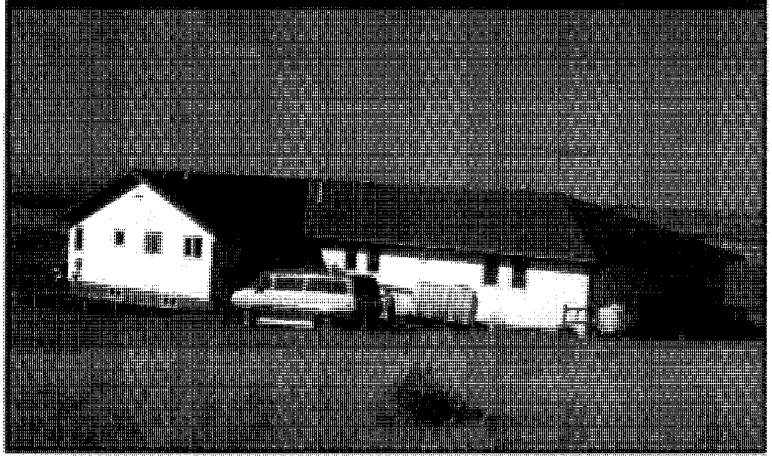
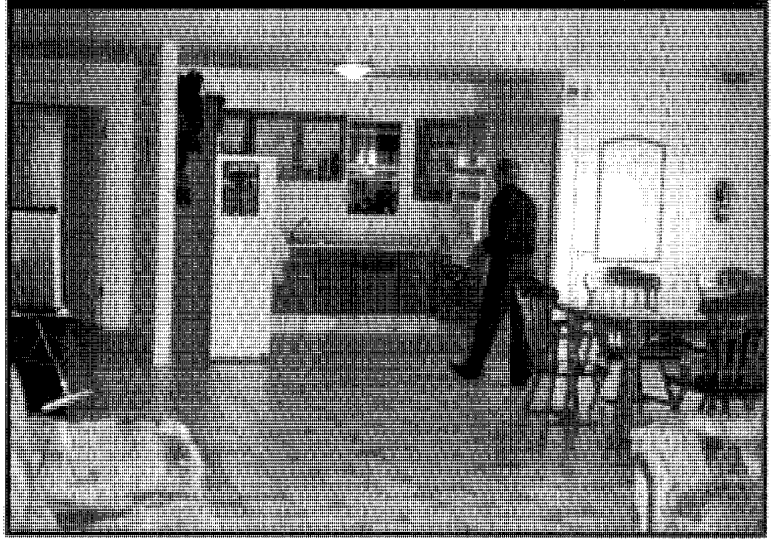
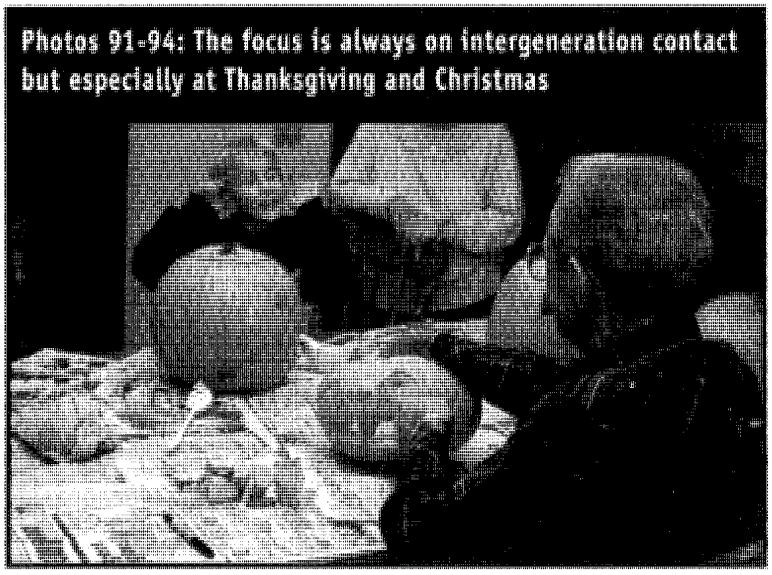


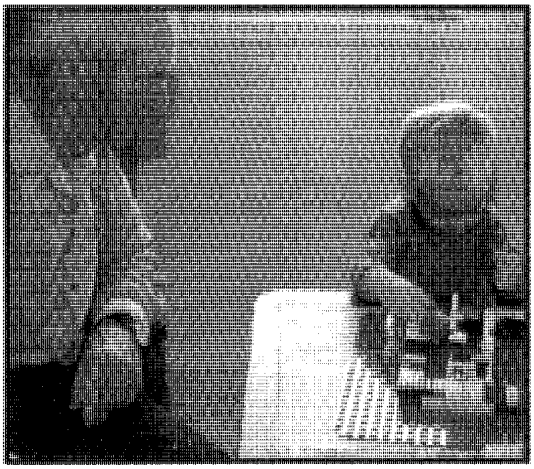
Photo 90: Residents share a common living and dining room and adjoining kitchen



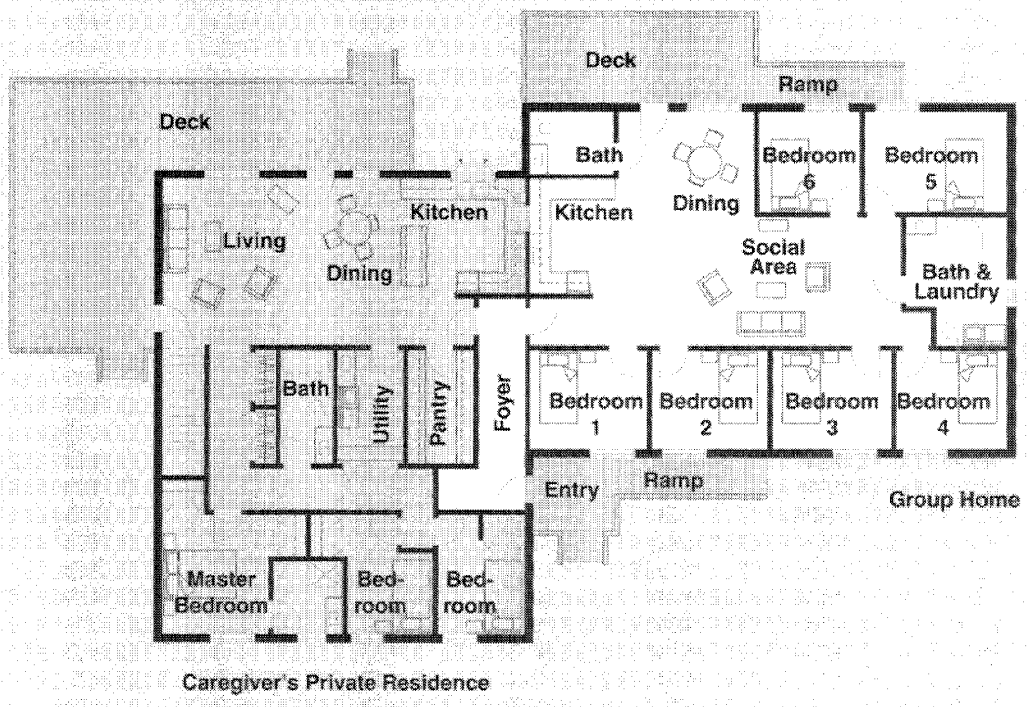
Leisure Way Community Group Home Inc. and Pallisar Health Authority



Photos 91-94: The focus is always on intergeneration contact but especially at Thanksgiving and Christmas



LEISURE WAY COMMUNITY GROUP HOME



Ärdal, Norway

This 600-square metre home, similar in appearance to other houses in the neighbourhood, has been in operation since September 1996. It houses eight people with early to mid dementia. The design of this home resulted from the close collaboration of architect Erling B. Haugen and researcher Thorhild Holthe from the Norwegian Centre for Research in Dementia.

The primary impetus of this project was to develop a home rather than an institution for those with dementia. This involved planning a building that would allow the residents to be able to live and work in a group. Residents have a private bedroom and bathroom, and are encouraged to provide their own furnishings. Bedrooms measure 32 m^2 and are situated so that residents, when leaving their rooms, are able to see at least one of the common areas: this helps residents to orient themselves. The centre of the building is designed to allow residents to "wander" freely without being stopped or confused by walls and to find chairs along the way where they can rest. From this walkway, residents can enter the dining and living room areas, as well as their bedrooms. As people with dementia find fire exit systems difficult to use, a sprinkler was installed to protect them in case of fire.

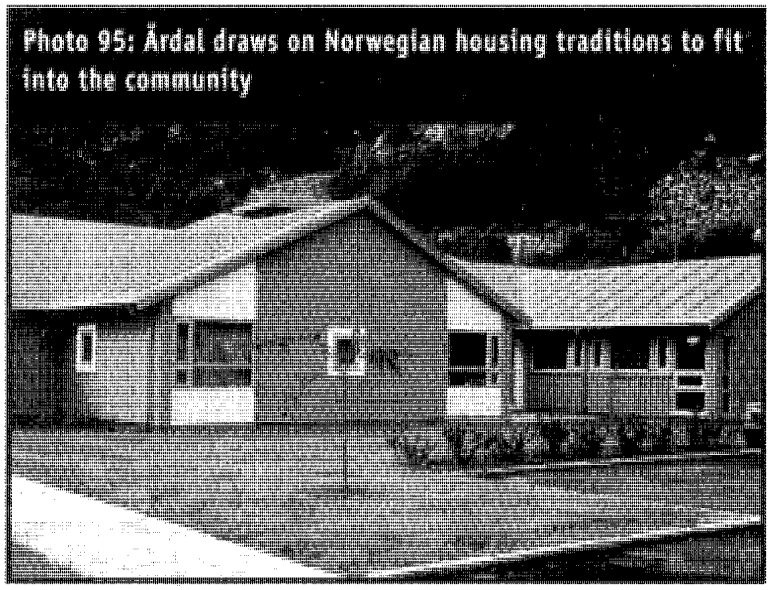


Photo 95: Ärdal draws on Norwegian housing traditions to fit into the community

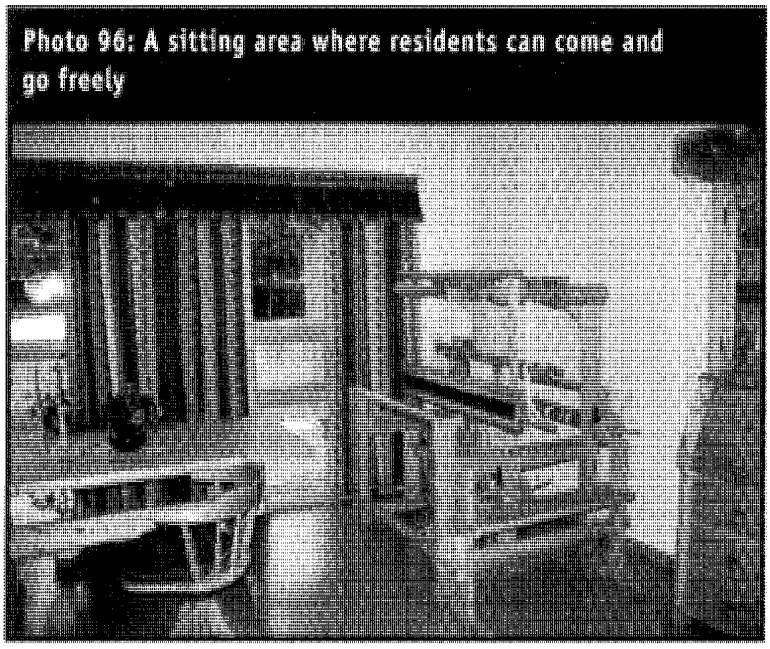


Photo 96: A sitting area where residents can come and go freely

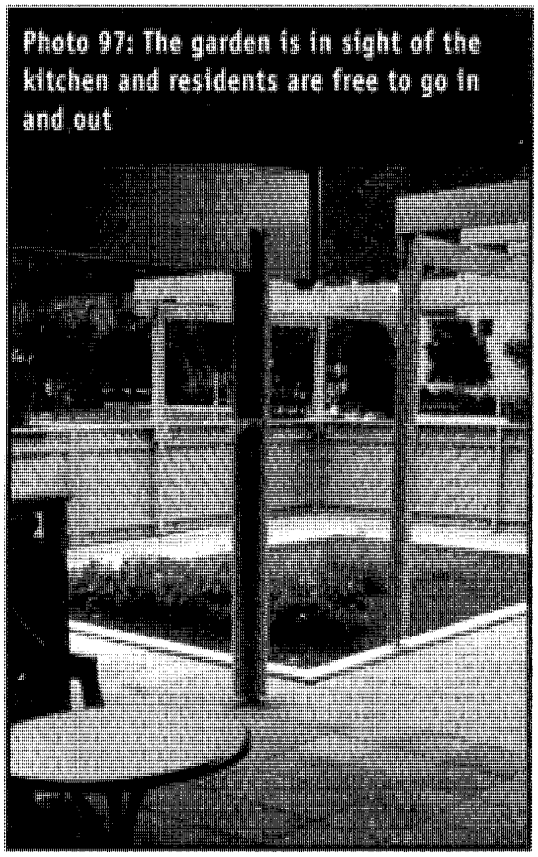


Photo 97: The garden is in sight of the kitchen and residents are free to go in and out

The staff area is independent of the home and therefore allows staff to come and go without distracting the residents.

All activities focus on the creation of a friendly, home-like environment where staff support home-like activities. The residents are free to walk at their leisure through the home and outside.

Ärdal City Council and the Norwegian Centre for Research in Dementia, Sem, Norway.

Photo 98: Residents are encouraged to help out in the kitchen

Photo 99: Homey materials and colours create a warm feeling

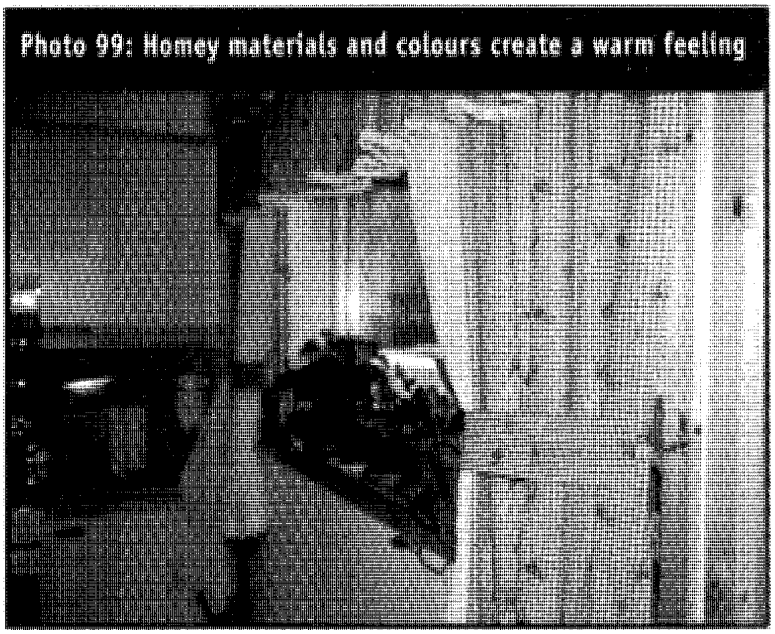
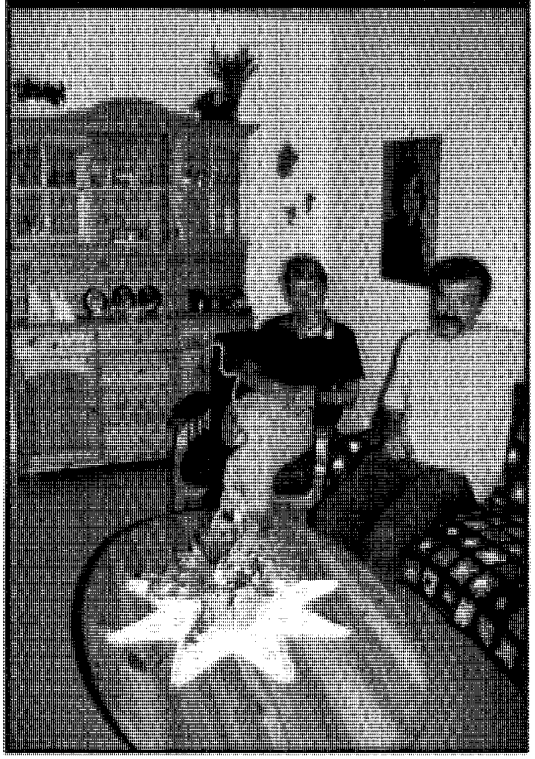
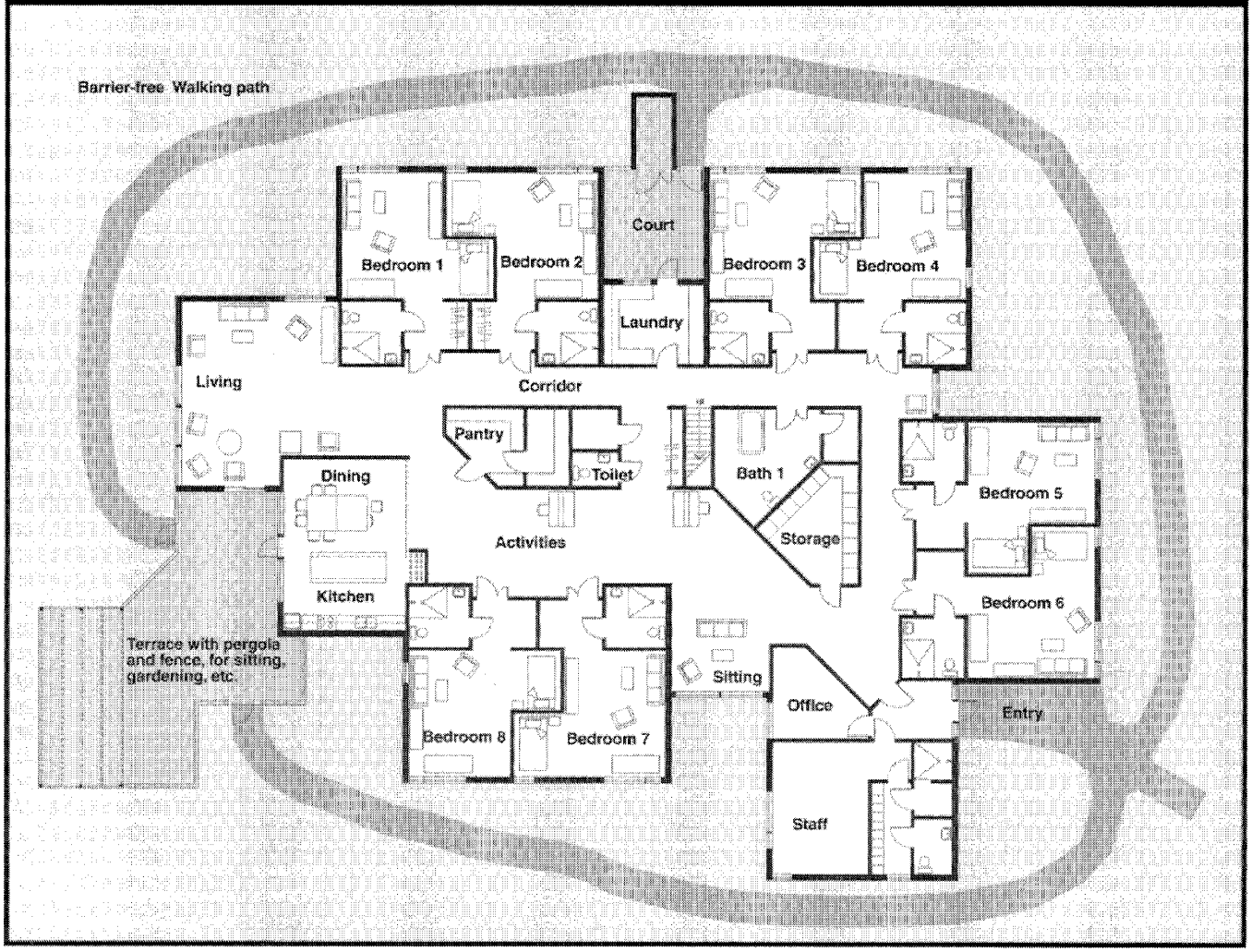


Photo 100: Families are encouraged to visit and make themselves at home



ÄRDAL


Barrier-free Walking path
Court
Bedroom 1
Bedroom 2
Bedroom 3
Bedroom 4
Laundry
Living
Corridor
Pantry
Toilet
Bath 1
Bedroom 5
Dining
Activities
Storage
Kitchen
Bedroom 6
Terrace with pergola and fence, for sitting, gardening, etc.
Sitting
Office
Entry
Bedroom 8
Bedroom 7
Staff

Kerttula-Home, Tampere, Finland

This is one of a group of 10 small homes developed for people with dementia by the Sopimusvuori Foundation. All 10 homes operate out of detached houses, purposely designed to resemble other houses in the small residential neighbourhoods where they are located. The Kerttula home was built in a residential area about seven kilometres from the City of Tampere. Like other homes in the group, this one operates as an independent family-like unit. Staff and residents work together to create a therapeutic, safe and secure environment where every person is treated with respect.

Diverse group, hobby and recreational activities – in the home and outside it – are a part of everyday life at Kerttula and at the other homes in the group, as are regular get-togethers and socials. Relatives are invited to these events. Indeed, the active involvement of relatives in the life of the home is critical to the success of the program and the well-being of the residents. In fact, there are no specific visiting hours, and it is possible for relatives to stay overnight if they wish to do so. Staff and residents share the housework, cook and eat together and jointly make all decisions about everyday life. The residents are encouraged to interact and help each other according to their abilities.

The houses in this group are designed to be as simple as possible. They have few corridors. Bedrooms open directly into sitting rooms, and the common areas are open and easy to find. Windows have been specially placed to allow the residents to see out when sitting; this creates a strong visual link to the outside world. The houses are also designed to be home-like, with furniture that is typically old, solid and comfortable. Shared bedrooms are furnished with the residents' own furniture and linens and, in keeping with Finnish tradition, there are saunas in each house.

Photo 101: This group home was specially designed to resemble others in the community

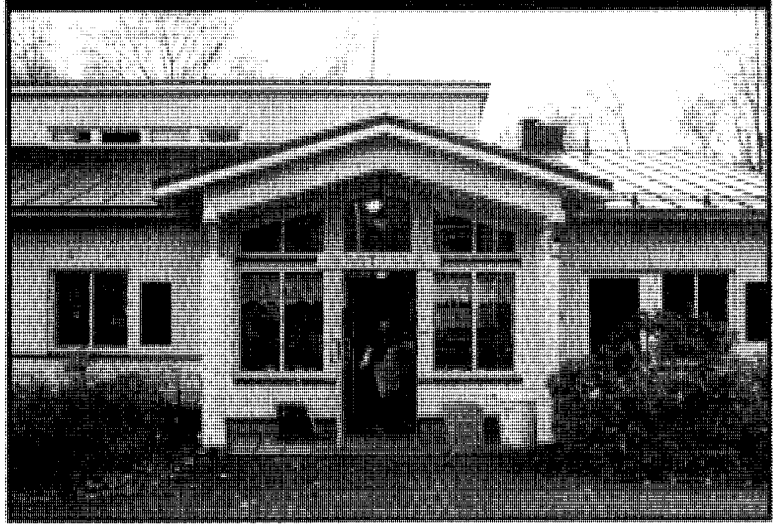


Photo 102: The living room is furnished to resemble that in any Finnish home

Sopimusvuori Association and Foundation.

Photo 103: Staff and residents work together to prepare meals in a bright, modern kitchen

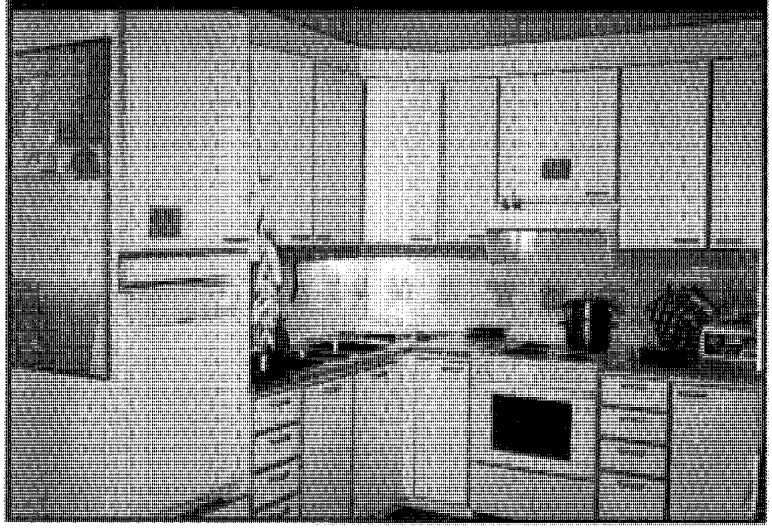


Photo 104: Residents – and their families – are encouraged to interact

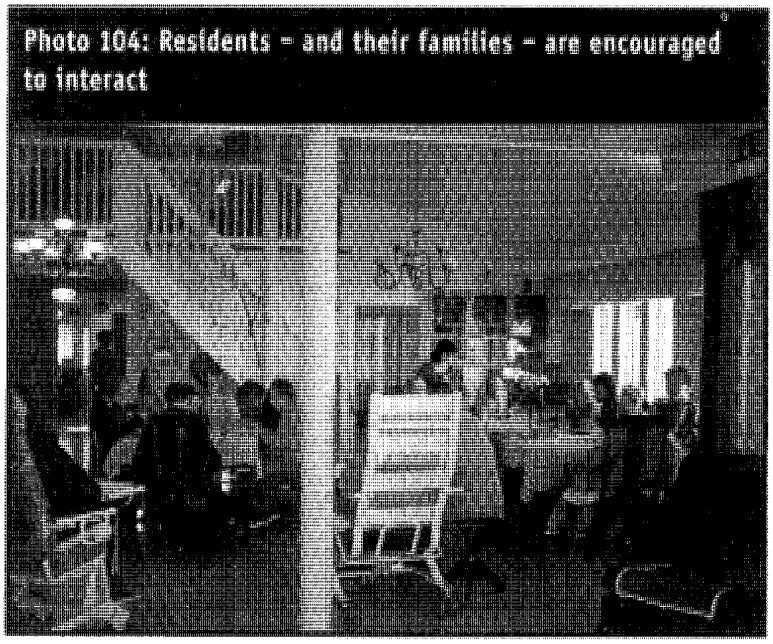


Photo 105: Residents furnish private bedrooms with their own furniture and linens

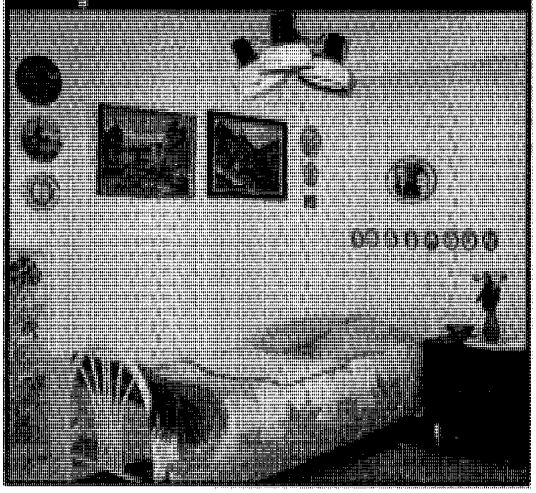
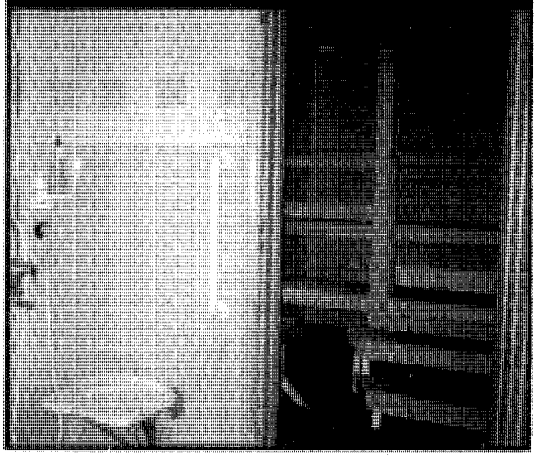
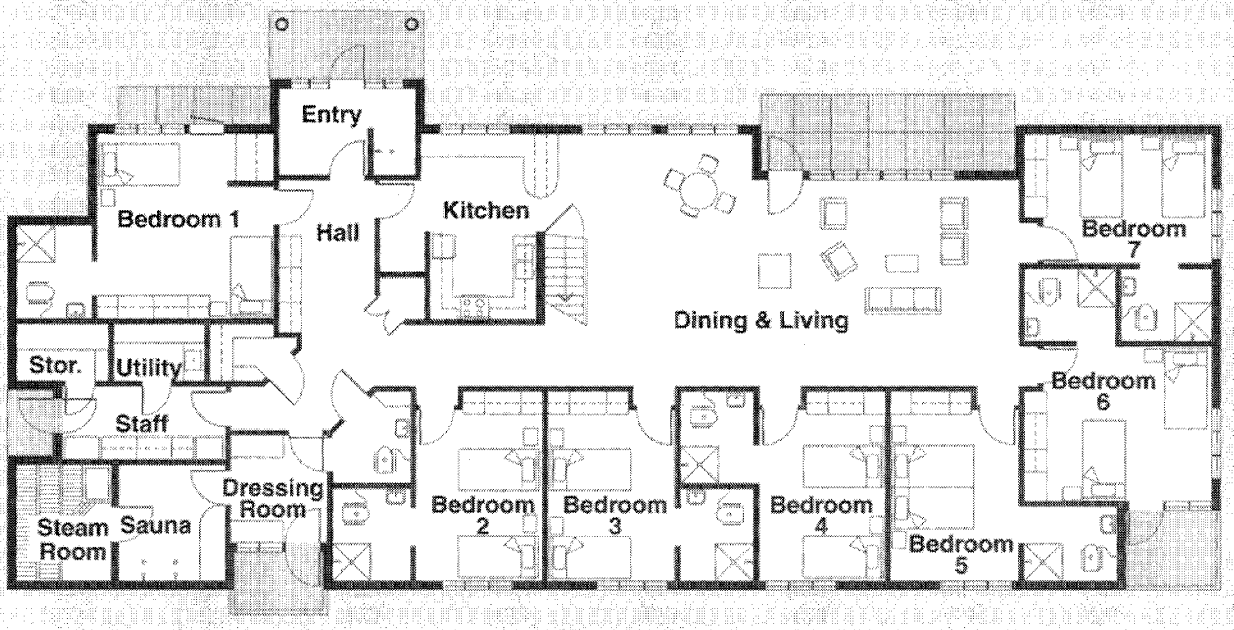


Photo 106: A traditional Finnish sauna



KERTTULA-HOME



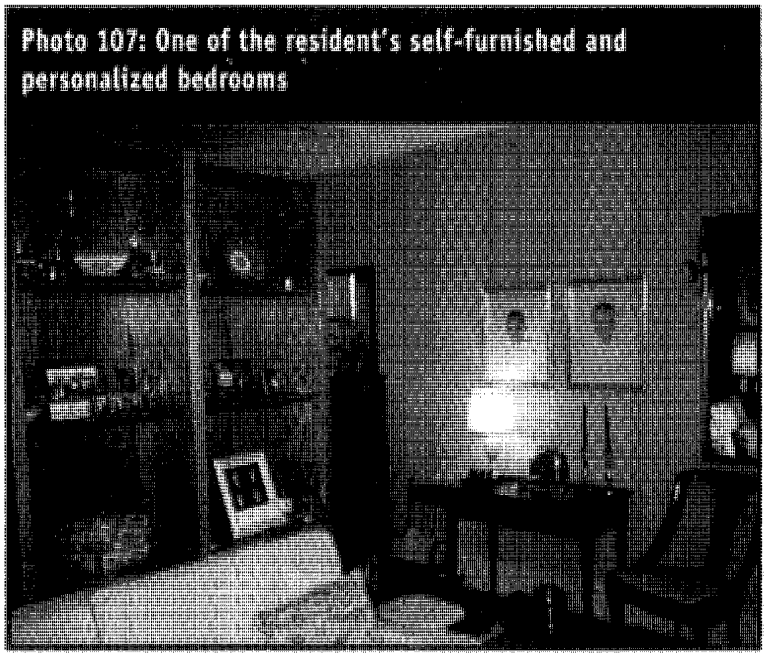


Photo 107: One of the resident's self-furnished and personalized bedrooms

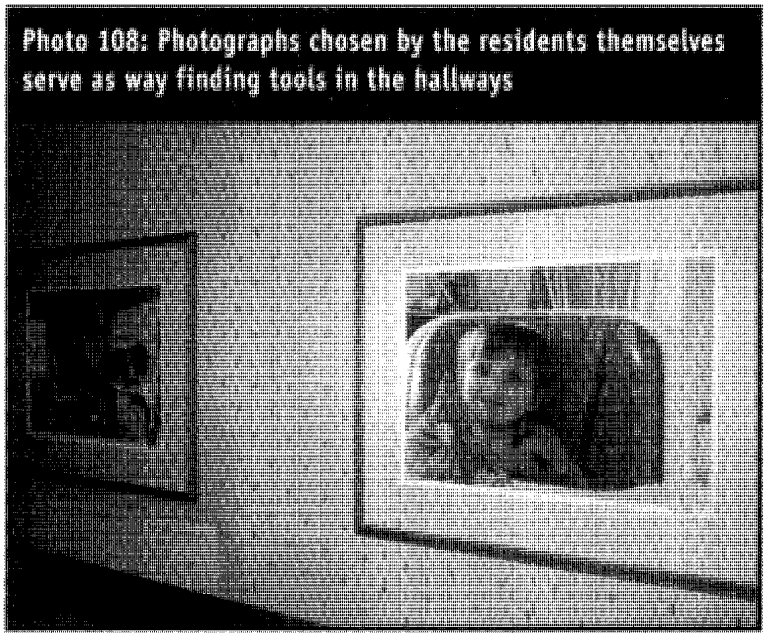


Photo 108: Photographs chosen by the residents themselves serve as way finding tools in the hallways

Hearthstone at the Esplanade, Manhattan, N.Y., U.S.A.

A single floor in a 12-storey assisted living apartment building was converted into a residence for 30 people with dementia.

The design of this residence came from the work of Hearthstone Alzheimer Care, a private management company in New England that treats dementia through the development of dementia-specific assisted living accommodation. The company establishes strategic partnerships with assisted living operators, nursing care providers and developers in order to create new or convert existing space for assisted living residences able to offer a continuum of residential care. Staff are multi-tasked workers who help residents with all activities and aspects of daily life. Staff ratios vary between one to four and one to five during the day.

Hearthstone's statement of purpose is "to create residential environments where people with Alzheimer's and related disorders can flourish," with emphasis on the term "flourish." The organization focuses on residents' quality of life, as well as basic health and therapy concerns. In order to achieve these goals, Hearthstone has established its own Life Quality Model for providing residential care.

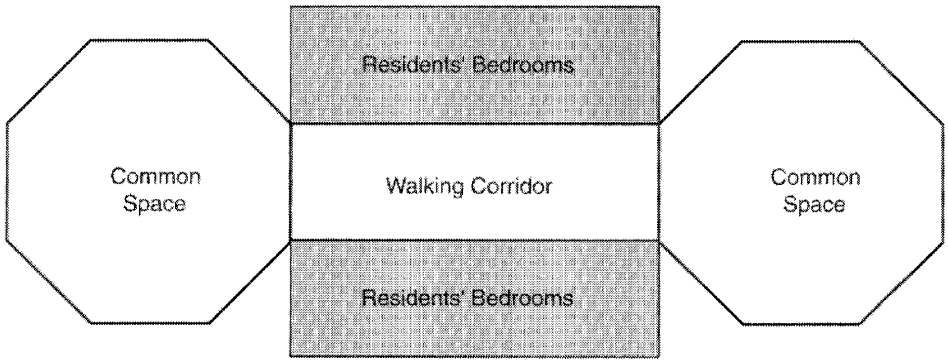
No one with dementia is refused admission for any behavioural problem. The only reason for non-admission or release is a resident's need for intermittent and unplanned nursing care throughout the day and night, in which case they would be better served in a nursing home.

Keyed elevator doors and chime-alarmed stair doors assure families and staff that the residents are safe within a specially planned supportive environment. Straight easy-to-follow corridors, which are decorated with residents' personal items and specially

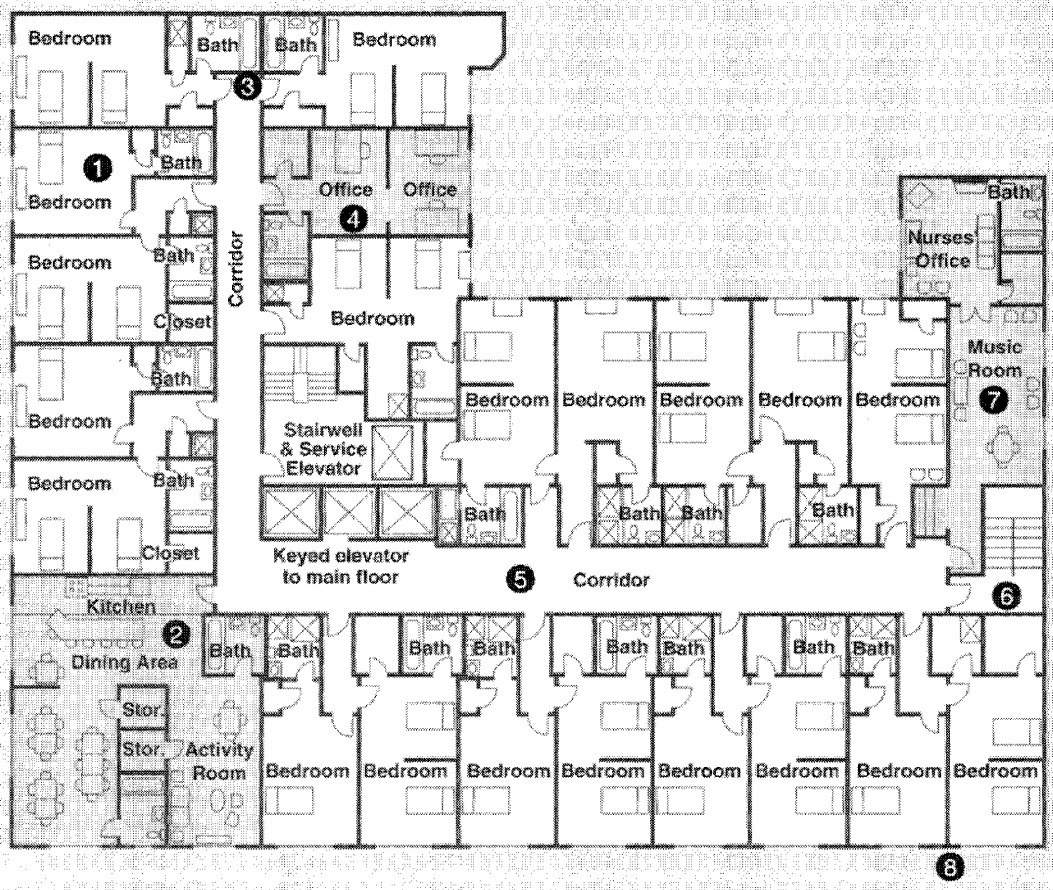
selected photographs, allow residents to walk freely. One apartment has been converted into a common kitchen/dining/activity room and another into a music room, so that residents have a sense of place and a place to enjoy the activities that are appropriate to these spaces. These common spaces and the staff office have been located at the end of corridors to prevent dead ends. This is known as the "barbell/dogbone" concept (see Figure 2 below). Single and two-bed units (with a wall separating the two sleeping areas) provide privacy and independence. Accompanied by staff, residents can walk to Riverside Drive park, one block away, to come in contact with the weather, seasons and times of day. Home-like furniture, window curtains and kitchen appliances provide residents with a calming environment. Hand rails for support and window safety stops support the safety and independence of residents. Managed sounds (music), smells (food), touch (plants) enable residents to feel at home in an understandable environment.

Owned and operated by Hearthstone Alzheimer Care.

Figure 2: The Hearthstone "barbell/dogbone" concept



HEARTHSTONE AT THE ESPLANADE



1. Every bathroom has a shower, sink and toilet.
2. Common area, made up of kitchen, dining and activity room, is well situated at the junction of two corridors.
3. Dead-end corridor may cause residents to wander into the bedrooms of other residents.
4. Office close to the corridor dead-end allows staff to monitor residents and prevent them from wandering into bedrooms.
5. Straight corridors, decorated with residents' personal items and photographs, give people with dementia a comfortable place to walk freely.
6. Exit stair doorway at the end of the corridor may attract residents.
7. Music room at one end of the corridor attempts to avoid a dead-end.
8. A combination of private and shared bedrooms offers therapeutic alternatives.

ArlingtonHaus, Winnipeg, Man.

The third and fourth floors of an 11-storey seniors apartment building were converted into supportive housing for persons with early to middle stages of dementia. Each floor consists of common areas – a kitchen, dining room, living room and a walking path – as well as eight studio and two one-bedroom apartments. These are arranged along a central corridor that has a loop at each end: the loops are designed to prevent dead end corridors and to provide a continuous and safe walking path for residents.

Photo 109: One floor of an existing seniors residence, converted with common kitchen

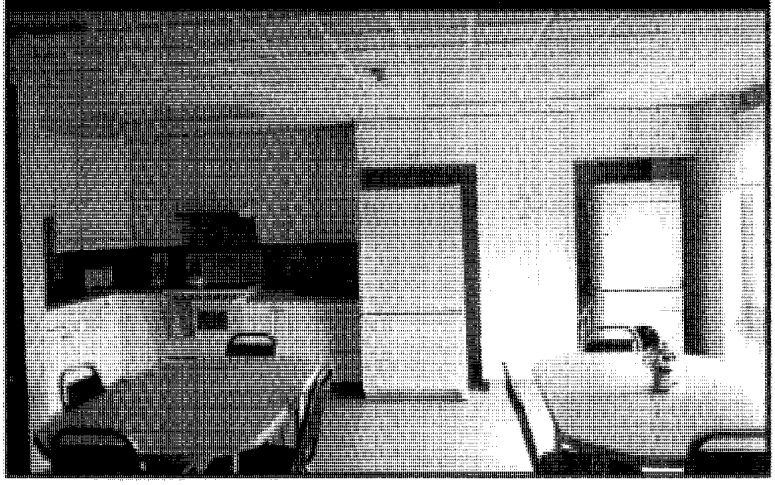


Photo 110: Small private apartments have kitchens without stoves

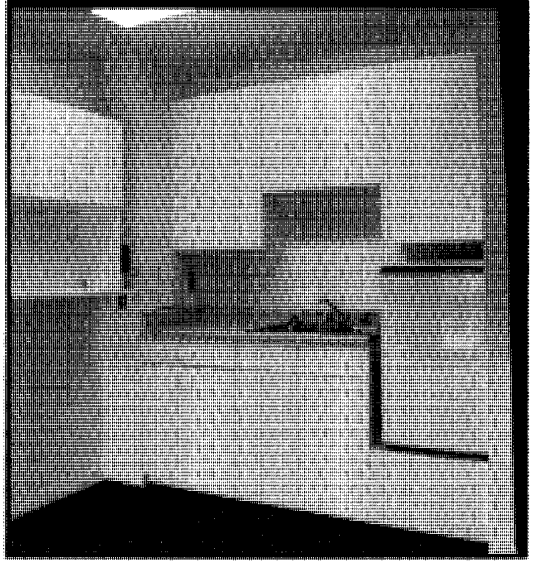
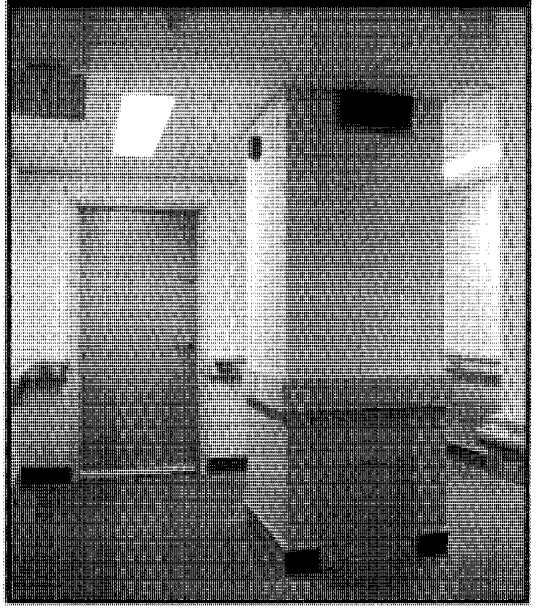


Photo 111: The central corridor loops around to provide a continuous walking path



The renovated floors offer a fully supportive housing environment. Staff are on duty for 24 hours a day, and they work to encourage and support daily-living activities. They offer familiar lifestyle recreational opportunities with an emphasis on active living. They also do the housekeeping and laundry and cook three nutritious meals a day and escort residents to medical and other appointments and provide access to counselling for residents and their families.

Manitoba Housing, Manitoba Health, and Bethania Mennonite Personal Care Home.

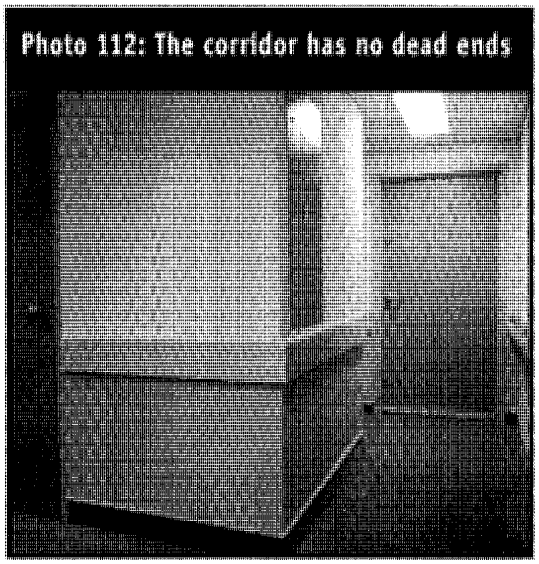
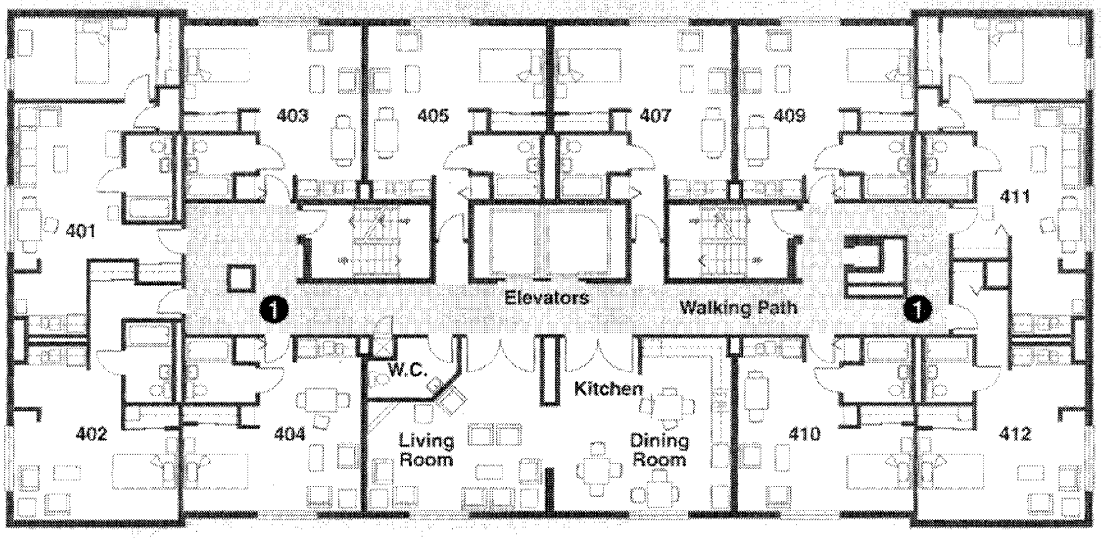


Photo 112: The corridor has no dead ends

ARLINGTONHAUS



1. Loops at corridor ends prevent people with dementia from encountering dead-ends. Loops allow residents to walk freely and safely along a continuous path.

Rimmer House at Lions Manor, Winnipeg, Man.

Rimmer House, a Supportive Housing Unit located on the eighth floor of a high-rise seniors residence, offers specialized housing to people with early to middle stages of Alzheimer's Disease or related dementia.

Rimmer House provides a home-like environment, with specialized health care attendants providing 24-hour supervision. Other services include housekeeping and laundry (with linens provided), personal care assistance, medication reminders, meals, therapeutic programs and activities, home care nursing visits as required and consultation services. Residents have access to a barber and hairdresser in the building and to a bank and church services.

The floor plan is rectangular in design, with residents' apartments located around the perimeter, and each apartment opens out into a continuous walkway (allowing residents to wander freely without confusion). The common area – essentially one large open area, used for relaxation and recreation and as a library – adjoins a common kitchen and dining room. At one end of the floor is an office, a medication room and a tub room; at the other end, there are two private suites that share a bathroom. All other rooms are private. The bathtubs in all suites have been covered over for safety, and closets were built above them. The flooring in each apartment is high-grade vinyl, while easily maintained, simulated wood flooring was used in the dining and kitchen areas. Good quality carpeting covers the floors in the hallway and living room. Hallway lighting was brightened to eliminate shadows.

Lions Club of Winnipeg Housing Centres and Manitoba Health.

Photo 113: One floor of a seniors residence has been adapted for people with dementia

Photo 114: A clock in the living room helps to anchor people in time

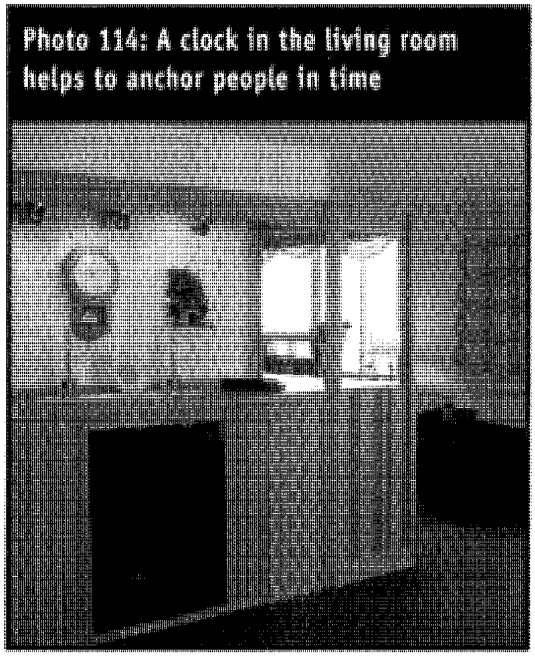


Photo 115: A fish tank and bird cage bring brightness and life to the living room

Photo 117: A common kitchen with adjoining dining room

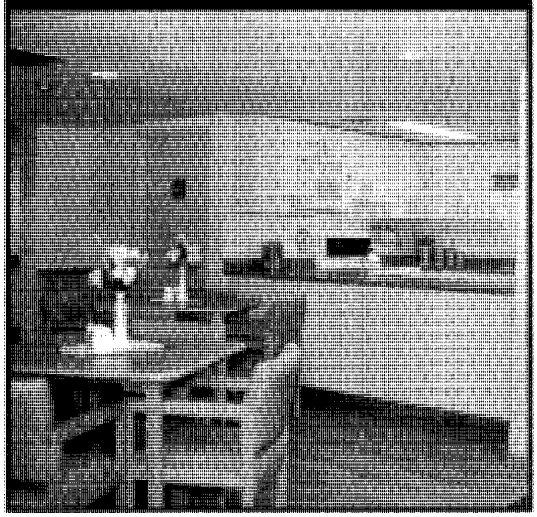
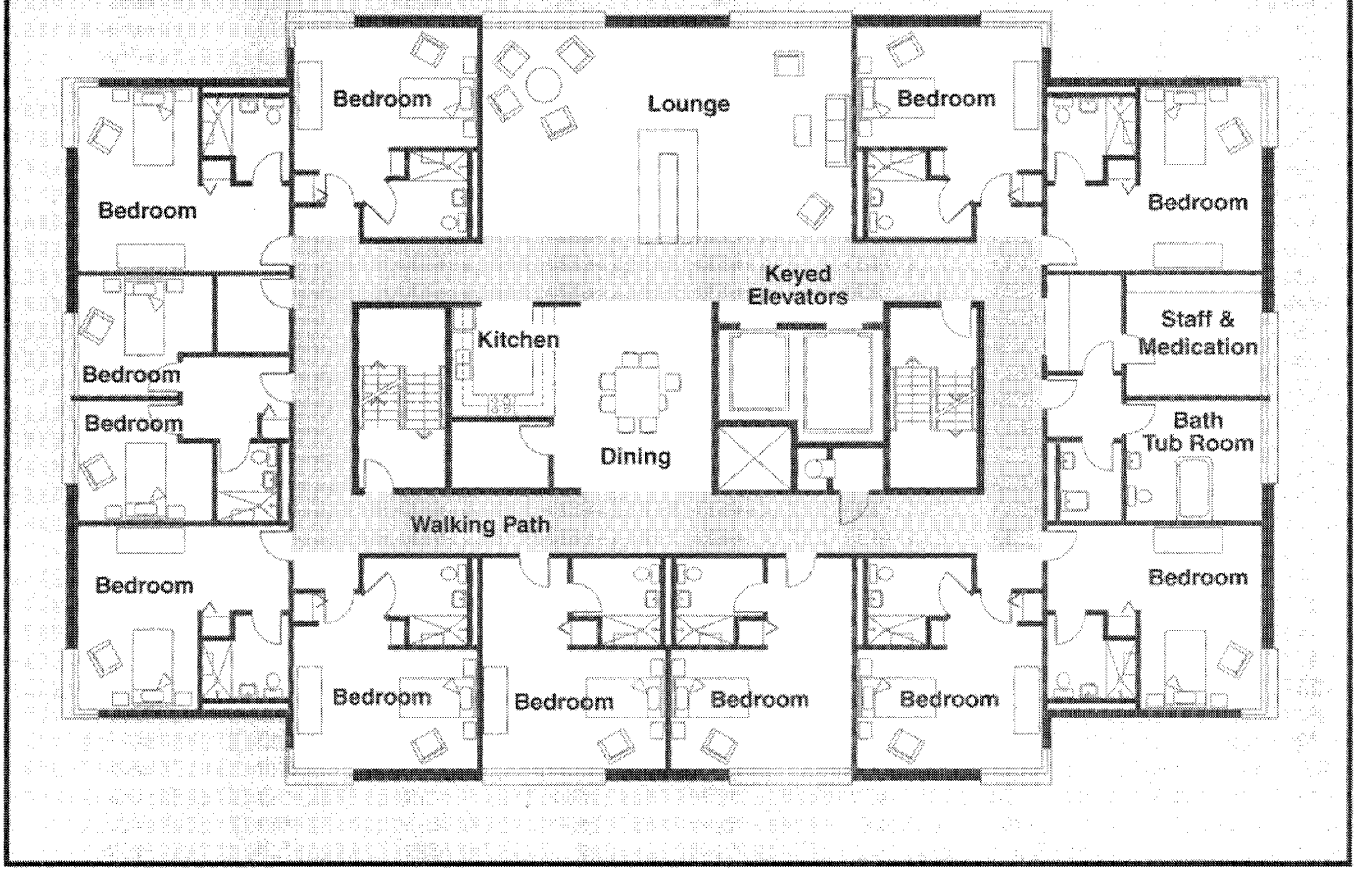


Photo 116: A large common area brings residents together for relaxation and recreation

Photo 118: Private bathtubs have been sealed and a specialized tub room constructed

RIMMER HOUSE AT LIONS MANOR



McConnell Place West, Edmonton, Alta.

McConnell Place West is the second assisted living centre constructed by the Capital Care Group in Edmonton, Alta. It opened on February 12, 1998. Like McConnell Place North, built in 1995 across the city, it is designed to be home-like, with the objective of keeping residents with mid-stage Alzheimer's disease functioning for as long as possible at an optimal level, in an environment that will cause few emotional outbursts and little agitation. Both centres are modelled on Woodside Place in Oakmont, Pennsylvania. The centre uses Alberta's Single Point of Entry System to admit persons who qualify for care in a long-term care or continuing care facility. There are 36 residents, 12 of whom are accommodated in each of the three houses that comprise each centre.

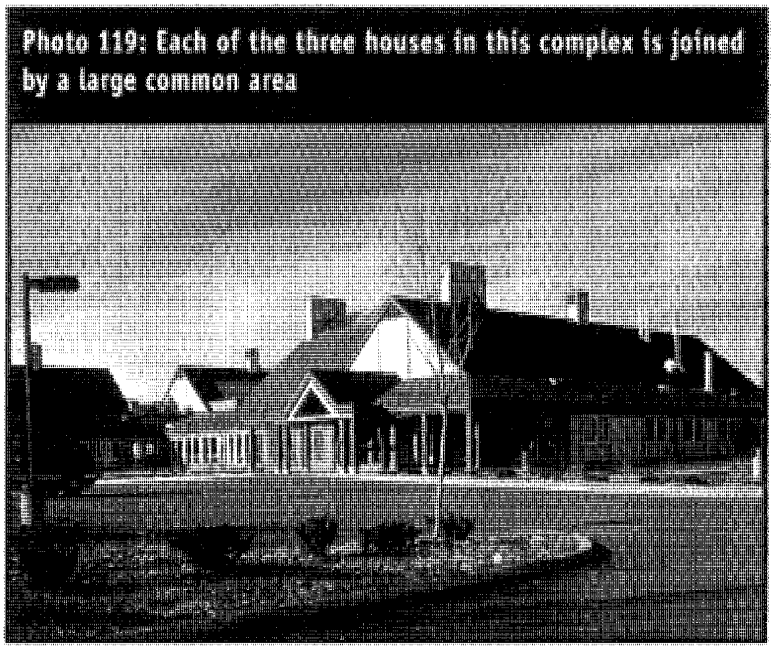


Photo 119: Each of the three houses in this complex is joined by a large common area

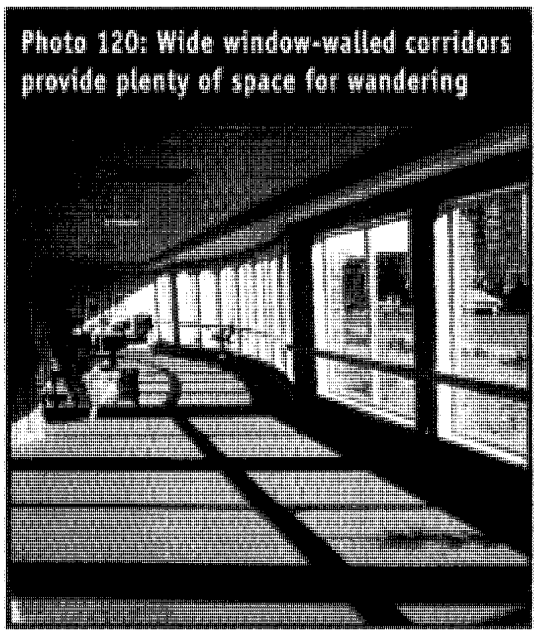


Photo 120: Wide window-walled corridors provide plenty of space for wandering

McConnell Place West sits on 1.4 hectares of land and has 2,681 m^2 of floor space. It is very similar to McConnell Place North, which sits on one hectare and has 2,578 m^2 of floor space. McConnell Place North was 820 m^2 larger than Woodside Place, the architectural model that has inspired the design of at least seven other Alzheimer centres. The footprint in the only two Canadian examples of this design look, in both cases, like a capital letter E, with the three houses joined by large common spaces. These spaces are dominated by a large room with adjacent sitting areas centred on a fireplace. Other public spaces include a beauty salon and a family dining room with an attached kitchen that can be booked for family parties. The Capital Care Group's researcher, Dr. Doris Milke, conducted a post-occupancy evaluation in 1996 to determine how the design features of McConnell Place North influenced the operations of the home and affected the residents, staff and family of residents. One of the findings that most influenced the interior design of McConnell Place West

was that some of the special activity rooms at McConnell Place North were not well used. Fewer have been developed at McConnell Place West, but the footprint of the centre was not reduced in size; instead, the space was used to augment the kitchen, living and dining rooms in each house. These areas were found to be the hub of most activities.

Photo 121: Some meals are brought in, others are prepared in this kitchen

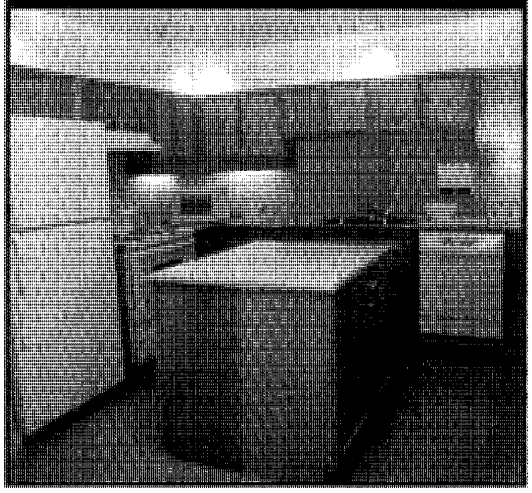


Photo 122: Each dining room has several tables where residents and staff eat together

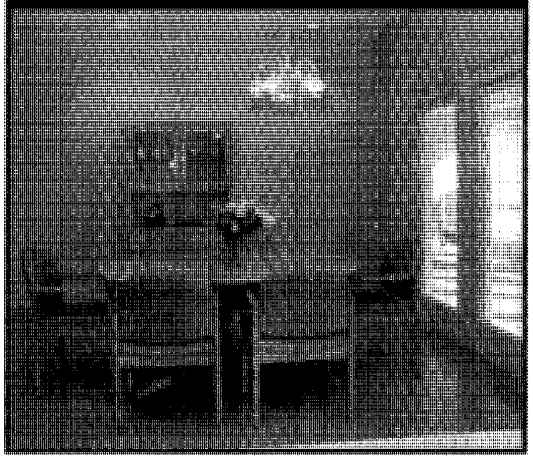
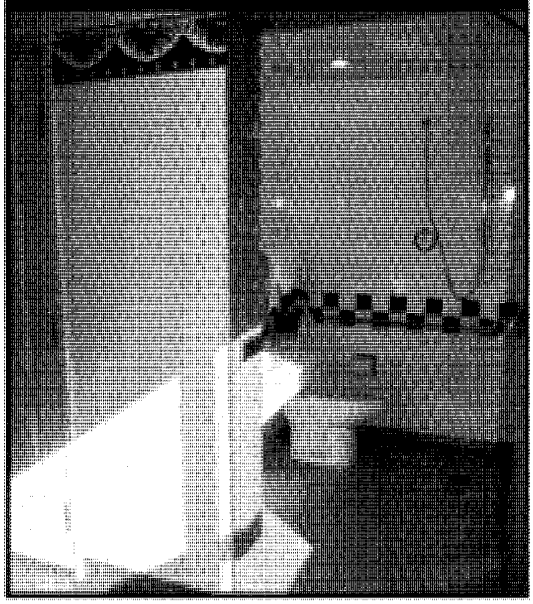


Photo 123: Each private bedroom has an attached three-piece bathroom



Each of the three houses in each centre has a dining room, kitchen with an adjacent half-bath, laundry room and a small medication room. Each dining-living room has a number of small tables to seat residents and their care providers, who join residents for meals (a meal program adopted from Swedish Alzheimer group homes). Each house's kitchen is used both to prepare meals (all breakfasts and three lunches per week), as well as to serve imported meals (all dinners and four lunches per week).

Each house has 10 private bedrooms, each with an attached three-piece bathroom with sink, toilet and shower. The latter, which has a fecal drain, was inspired by showers at Dr. John Tooth's ADARDS site in Tasmania, Australia). The private bedroom and bathroom have a net floor space of 15.6 m^2. The one double bedroom, also with an attached three-piece bathroom, has 44.3 m^2 of net floor space. A tub room

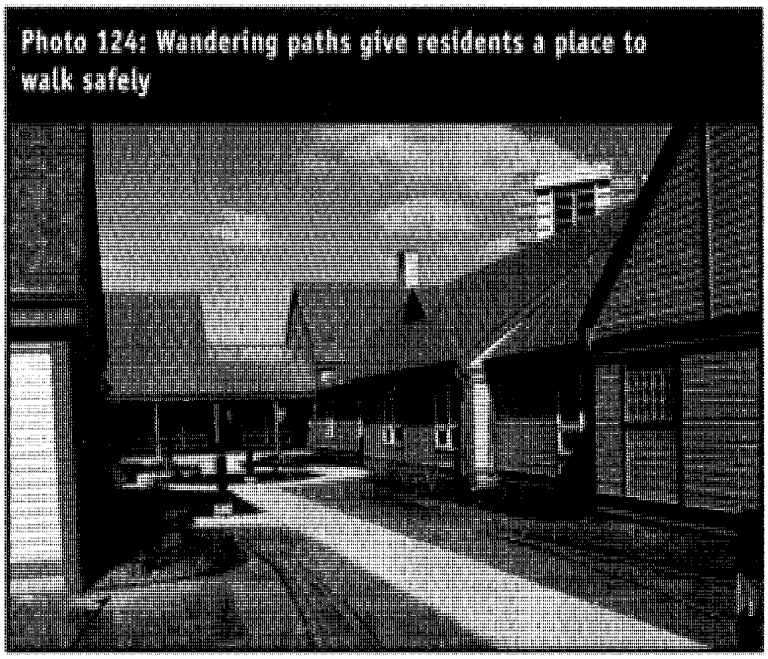


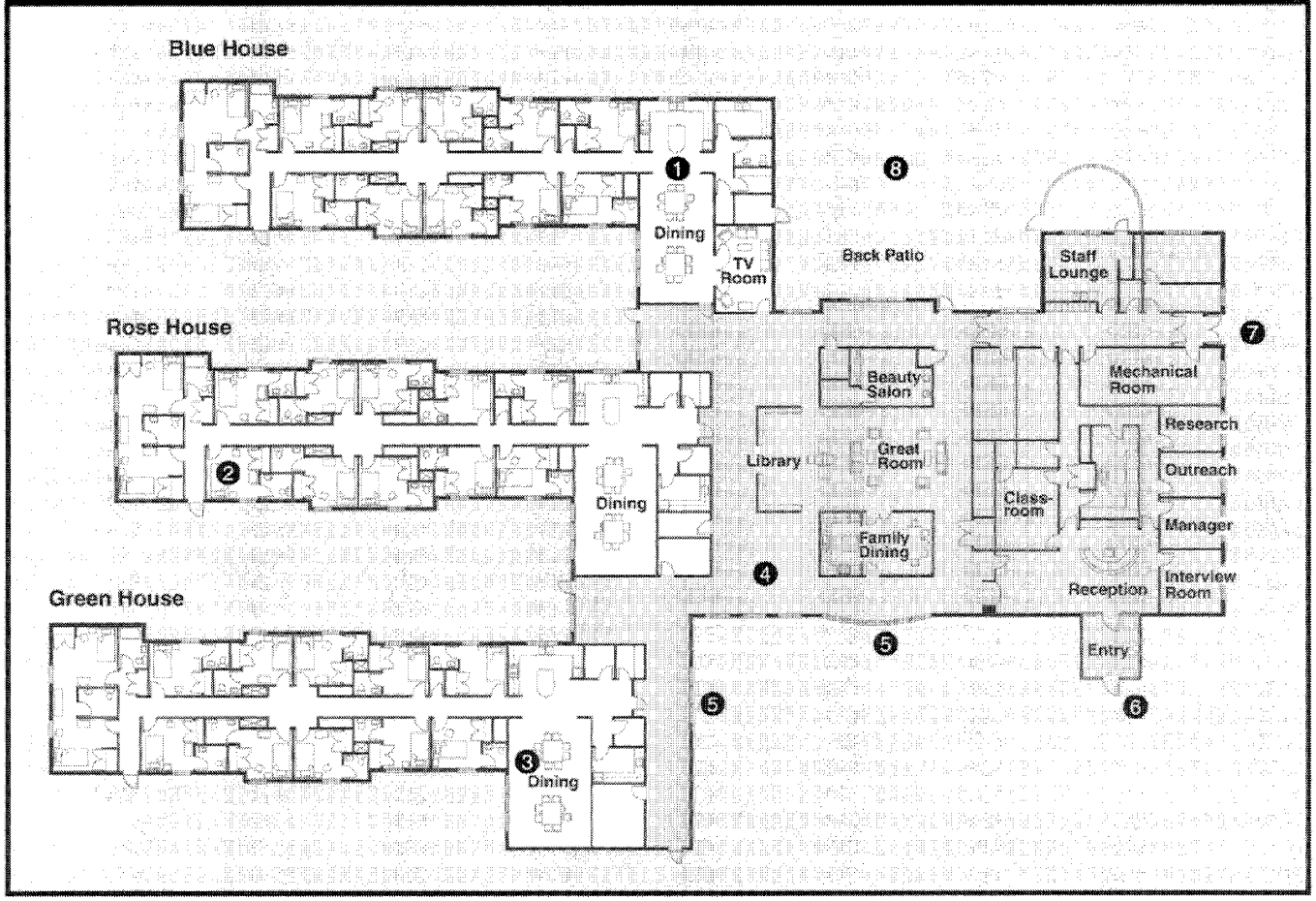
Photo 124: Wandering paths give residents a place to walk safely

with a standard residential bathtub is situated near the end of the bedroom hallway farthest from the living and dining room (Woodside Place had a single, central room with a specialized tub). The location of the tub room in each house means that it can sometimes act as an extra toilet for the residents of the double bedroom at the end of the bedroom hallway. The design of the double bedrooms at McConnell Place West was changed slightly to enhance the privacy of residents (McConnell Place North opened with two married couples in double bedrooms but has had all unrelated persons since then).

McConnell Place West has a slightly wider hallway in the bedroom area than McConnell Place North, and design features make it seem much wider. The bedroom hallways in each house at both centres are L-shaped with no dead ends. They lead to a side door and an outdoor courtyard that has a number of areas of interest. For example, at McConnell Place North there is a 1979 car in which residents may sit, as well as a large gazebo. Approximately 335 linear metres of concrete sidewalk encourage residents to walk outdoors. Sidewalks lead back into the houses or into the indoor public spaces that link the three houses. Ten exit doors provide twenty varied wandering routes. The window-walled hallways in the common spaces extend the wandering paths. They are so wide they easily accommodate groups of armchairs and small tables. Casual observation suggests that the design of McConnell Place West makes good use of public spaces, and residents use these more than at McConnell Place North.

Built by The Capital Care Group in Edmonton, Alta.

McCONNELL PLACE WEST



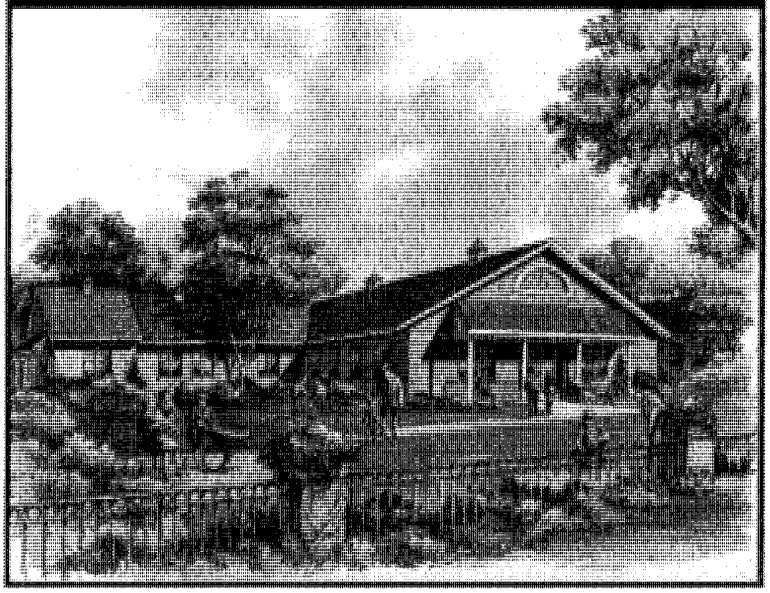
1. Kitchens in each house make it easy for residents to get a snack and to introduce some flexibility to their eating patterns. The kitchens are visible and accessible and allow residents to maintain some of their independence without sacrificing safety.
2. Thirty private rooms decorated with personal possessions enhance the self image of residents. Three additional rooms are doubles to meet differing needs.
3. Dining rooms designed for small groups allow residents to enjoy a non-stressful, residential kind of experience, at the same time permitting staff to monitor health and nutrition.
4. Events and activities take place along the corridors and give purpose and interest to wandering.
5. Outside views help residents to orient themselves to the changing cycles of day and night and of the seasons.
6. The residential image of the building exterior speaks to staff and visitors about the social model care that is practised here.
7. Discrete staff entrance prevents residents from noticing or being upset by staff changes.
8. Secure courtyard allows residents to walk outside whenever they want in good weather.

Dementia Care Residence, Ottawa, Ont.

The Regional Municipality of Ottawa-Carleton, in collaboration with the Alzheimer Society of Ottawa-Carleton, is planning to build a residence for 48 people with dementia. This residence will demonstrate how high-quality care can be provided in a small home-like setting. The residence, which will be an integral part of the Peter D. Clark Long-Term Care Centre Project, will consist of four bungalows linked to a central area.

Each bungalow will have 10 private bedrooms and one semi-private bedroom, each with its own ensuite bathroom. Common spaces will include a living room, dining room, den, kitchen and bathroom. Special features such as camouflaged exits, an indoor wandering path, rummaging cupboards and signs and cues to assist in orientation will be incorporated into each bungalow.

Photo 125: Garden view of typical bungalow (fence height is not to scale)



The benefits of separate bungalows for small groups of people with dementia have been well documented. This environment will provide the certainty and comfort of the familiar, controlled stimulation, security without frustration, a relatively high level of freedom, access to the outdoors, appropriate support and an opportunity to continue to engage in the normal activities of a home.

During the day, the bungalows will operate independently from the central area and from each other. At night, doors from the bungalows to the central area – which are disguised and closed during the day – will be opened to allow staff to supervise residents from a central staff station. The central area will also provide additional activity spaces for residents, administrative offices, a family dining room where residents can enjoy meals with their families, staff spaces and services areas.

The provision of gardens and yards will enhance and reinforce the home-like character of the bungalows. Besides providing pleasant places for walking and sitting, they will also include points of interest such as an old car for polishing or going for "drives."

Anticipated date of completion for this project is spring 2000.

The Regional Municipality of Ottawa-Carleton, in collaboration with the Alzheimer Society of Ottawa-Carleton.

Foxwood Springs Alzheimer's Care Center, Raymore, Mo., U.S.A.

Foxwood Springs Living Centre – a retirement community offering a full continuum of care – is composed of garden homes, apartments, a residential care centre, a nursing centre and an Alzheimer's Care Centre that delivers three levels of care, including: an eight-person Group Home for early-stage Alzheimer's residents; the Atrium, a 30-resident home for those in the middle stages of the disease; and the Atrium Extension, a 12-bed special care unit for those in the late stages of Alzheimer's disease. The guiding philosophy at the Foxwood Springs Alzheimer's Care Center can be summarized as "light, laughter, colour, optimism, activity, energy, fun and life."

The Group Home houses eight residents who are in the early stages of Alzheimer's disease, and it offers them a home-like environment. It incorporates a family atmosphere along with the comfort and freedom of a large, well appointed home to allow residents as much independence as possible. The Group Home includes common areas (a living room with a beamed ceiling, dining room, a large family-style kitchen with laundry facilities and an activity room). As well, each resident has a private room containing his or her personal belongings, furniture, pictures and mementoes. Daily activities for residents include cooking, shopping, going for walks, attending exercise groups, assisting with laundry and housekeeping and visiting friends and family. Staff members wear street clothing, and provide 24-hour supervision, seven days a week, as well as all meals, housekeeping and laundry.

Photo 126: Entrance to Foxwood Springs, which serves people at all stages of dementia

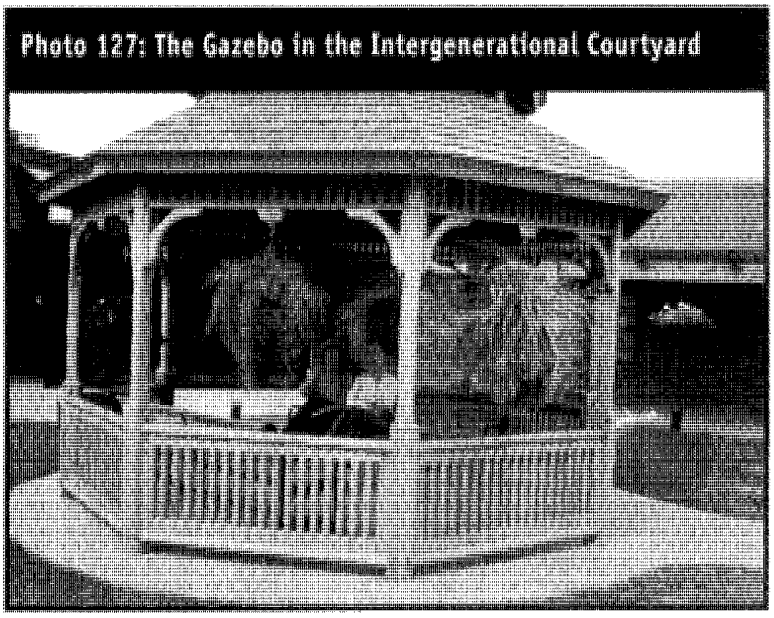


Photo 127: The Gazebo in the Intergenerational Courtyard

The Atrium consists of 15 large, comfortable semi-private rooms, where residents benefit from a plan of care designed to identify and build upon their individual capabilities and interests. The 30 people who live here are in the middle stages of Alzheimer's disease. To enhance the familiarity of their surroundings,

residents bring their own belongings to their rooms. The lofty architecture of the Atrium, along with open spaces, overlapped lighting and soothing decor, reduce the busy elements that confuse or distract those with Alzheimer's disease.

The Atrium Extension, a 12-bed wing located just down the hall from the Atrium, serves people in the late stages of Alzheimer's disease. The goal here is to bring a measure of joy to life, not only by providing for the physical needs of residents, but also by keeping them as active as possible.

Photo 128: Residents in the early stages of dementia help out in the Group Home

Photo 130: The large spaces and uncluttered look of the Group Home reduce confusion

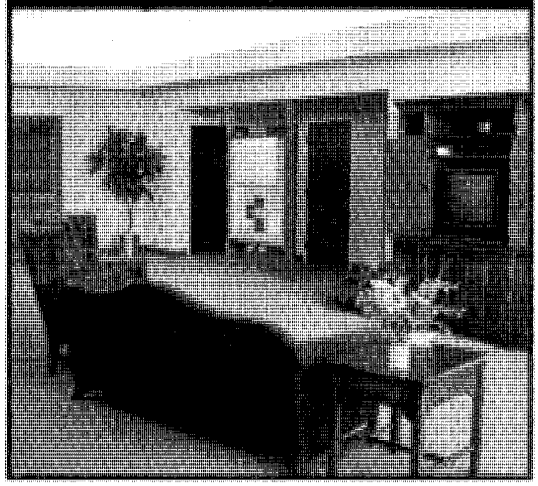


Photo 129: Bedrooms in the Group Home are furnished with personal belongings

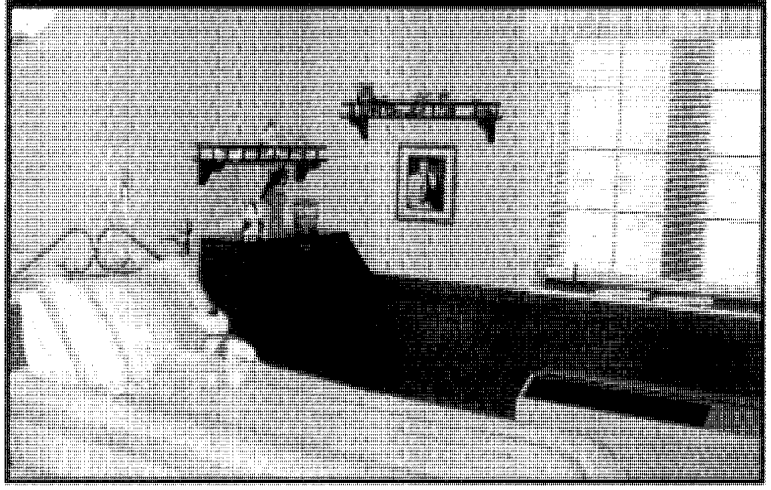
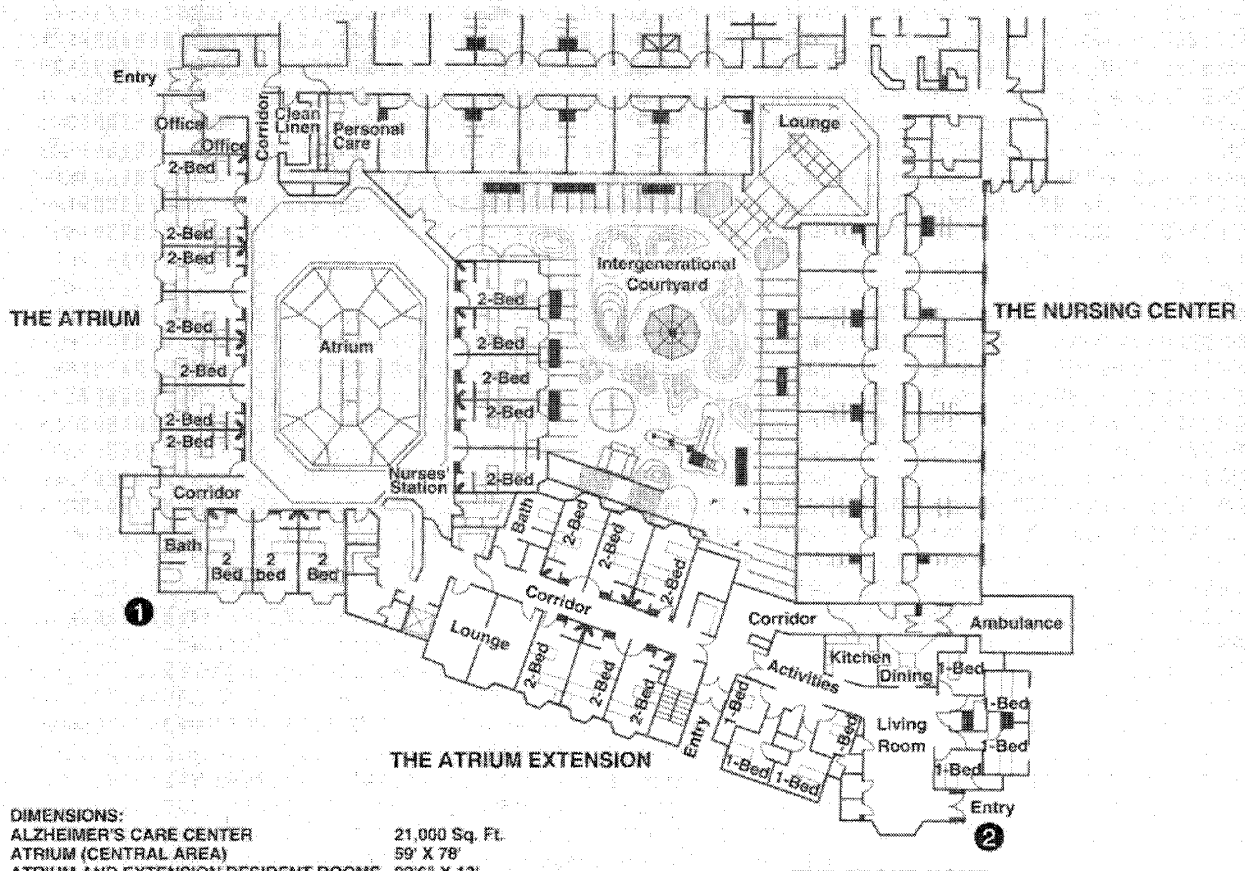


Photo 131: The dining room is a place where residents can interact

Children from the on-site Landis Child Development Centre visit residents in the Group Home and the Atrium. They come for story time and cookies or for a walk in the courtyard.

Managed by Foxwood Springs Alzheimer's Care Center, a unit of the National Benevolent Association of the Christian Church.

FOXWOOD SPRINGS ALZHEIMER'S CARE CENTER



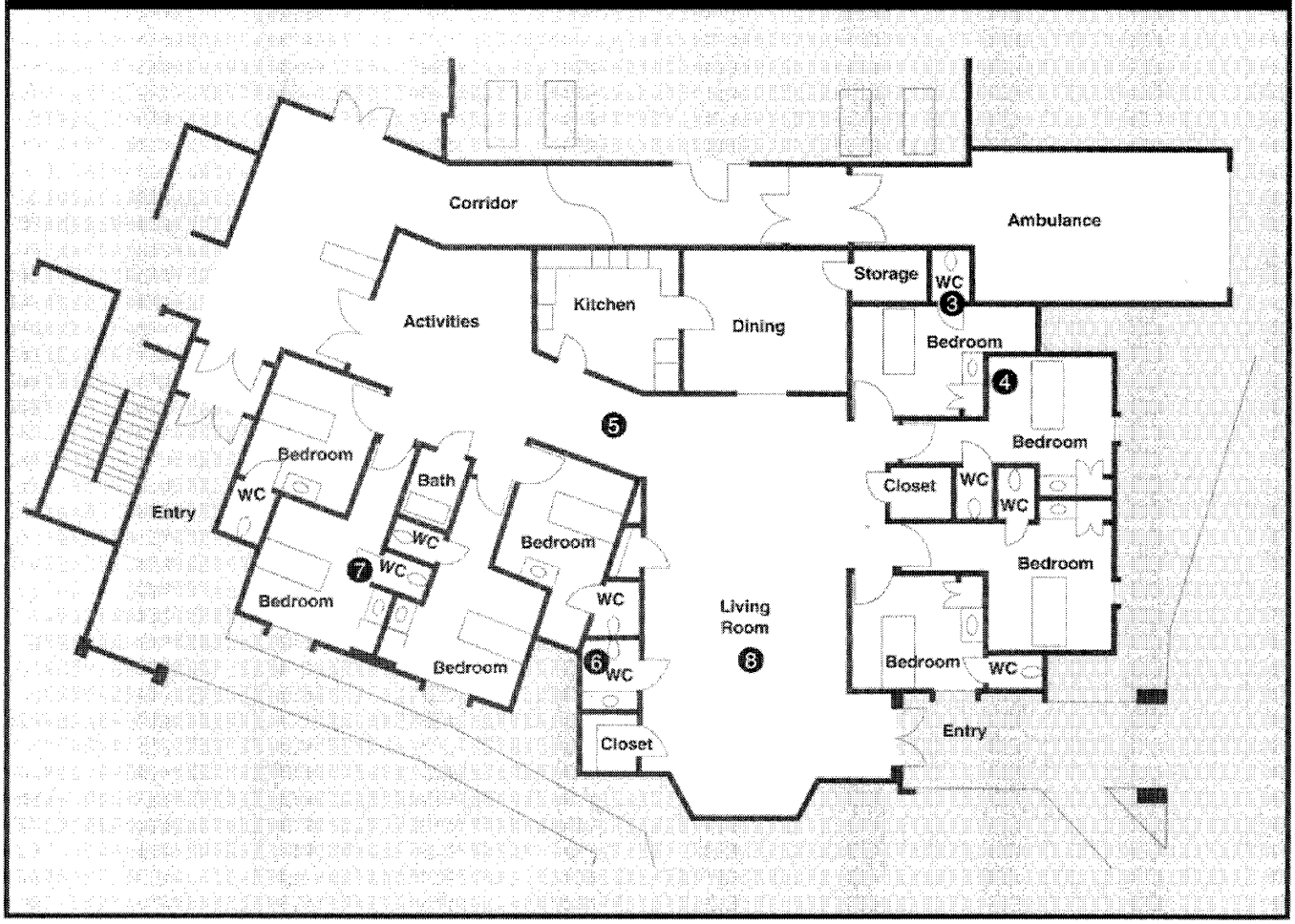
DIMENSIONS:	
ALZHEIMER'S CARE CENTER	21,000 Sq. Ft.
ATRIUM (CENTRAL AREA)	59' X 78'
ATRIUM AND EXTENSION RESIDENT ROOMS	22'6" X 13'
GROUP HOME (CENTRAL AREA)	1,400 Sq. Ft.
GROUP HOME RESIDENT ROOMS	14' X 12'

1. Corner location gives the care centre a distinctive look.

2. Separate entry to the group home gives residents a sense of individuality and dignity.

FOXWOOD SPRINGS ALZHEIMER'S CARE CENTER

THE GROUP HOME



3. Small toilet rooms may hinder caregivers from helping residents.

4. Each bedroom has its own easy-to-find, easy-to-use toilet room to meet the needs of residents with dementia who may suffer from incontinence.

5. Four distinct common spaces (activity room, kitchen, living room and dining room) provide residents with alternative spaces, each with a different atmosphere.

6. Toilet off the living room helps caregivers to look after the needs of people with dementia who suffer from incontinence.

7. Residents in most bedrooms, while lying in bed, have a clear view of the toilet: this reminds waking and napping residents to use the facilities.

8. Lack of wall space in the living room hampers furnishing. The use of free-standing furniture in this type of spaces can block resident pathways.

Harry and Jeanette Weinberg Hale Kako'o Respite Center, Honolulu, Hawaii, U.S.A.

Hale Kako'o – a six-bedroom respite home for adults with dementia – was developed through a private-public partnership. The Local Department of Housing and Community Development built the home on city land. The site, about two-thirds of an acre, was leased to the Alzheimer's Association, Honolulu Chapter, and the Weinberg Foundation provided funding for furniture, equipment, repair and building maintenance.

The goal of Hale Kako'o is very clear: "Our mission is to provide services that enable families to continue to care for their loved ones at home in the hopes that such support will delay or avoid the need for institutionalization." They address this goal by providing day respite in a home-like environment. The Center provides three things – a secure and user-friendly atmosphere, first-class care and understanding, and programming that helps caregivers and the patients to achieve a better quality of life. The focus is on helping residents to maximize their remaining abilities.

The Center is open from 8 a.m. to 5 p.m., Monday to Friday, and delivers a variety of programming in three areas – the living and dining area (upstairs), the activity rooms – including an indoor gymnasium (downstairs), and the outside yard with a walking path to allow for safe exercise.

The Hale Kako'o Center is a new, two-storey home located on a small, secluded site with beautiful views of Diamond Head and Pearl Harbour. Designed to be a home and not an institution, the Center offers a safe, secure and attractive environment combined with state-of-the-art services for people with dementia. The beauty of the fenced garden with walking paths is in keeping with the fine setting and is matched by the peaceful interior environment.

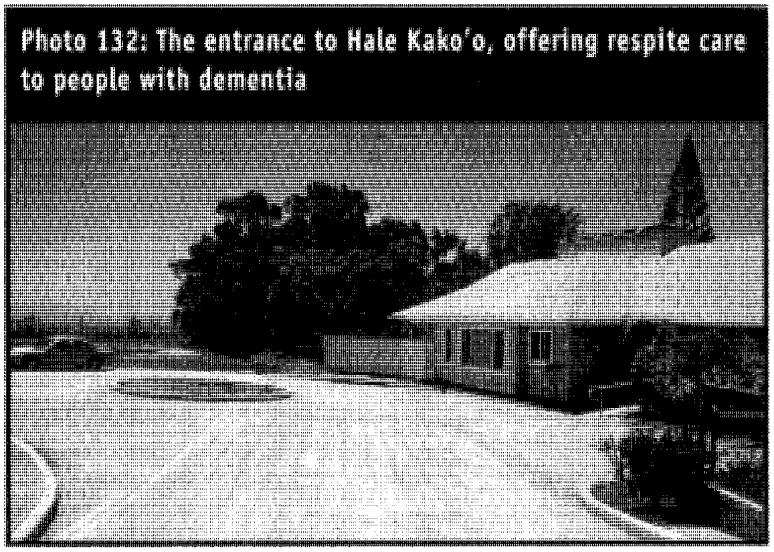


Photo 132: The entrance to Hale Kako'o, offering respite care to people with dementia

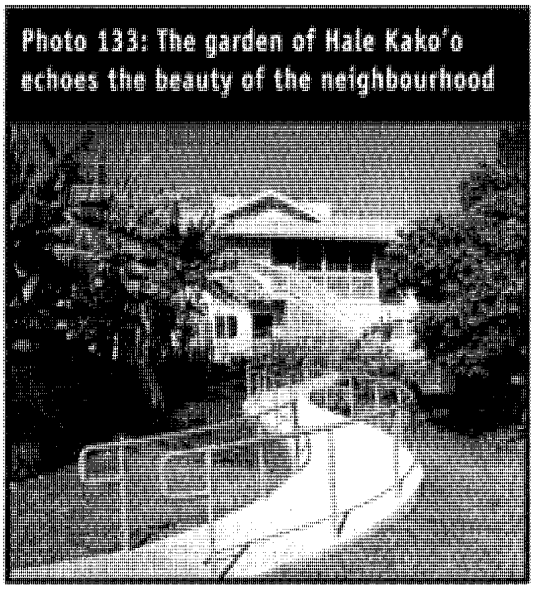


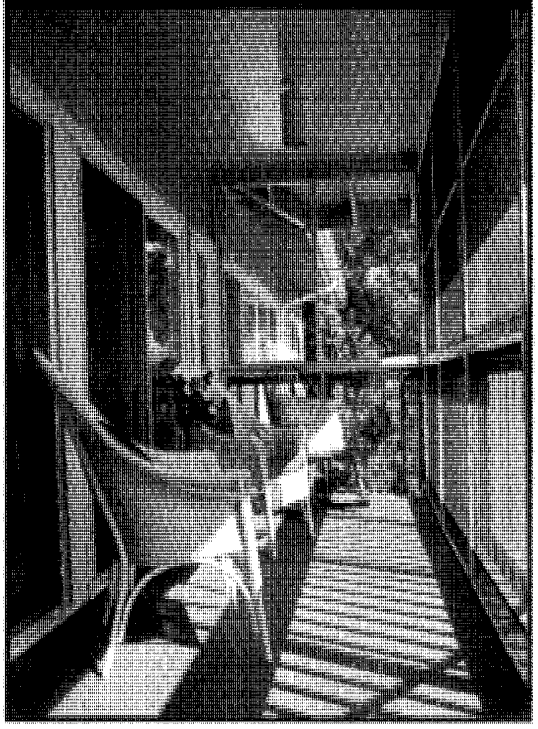
Photo 133: The garden of Hale Kako'o echoes the beauty of the neighbourhood

The six-bedroom house was designed to accommodate between 6 and 12 people overnight and is currently licensed to take up to 24 adults for day care. The Weinberg Foundation has funded the purchase of art and comfortable furniture and a great attention was paid to detailing and to creating a harmonious colour scheme. This includes special colour codes that help patients recognize their assigned rooms.

The Honolulu Chapter of the Alzheimer's Association, the Honolulu Department of Housing and Community Development and the Weinberg Foundation.

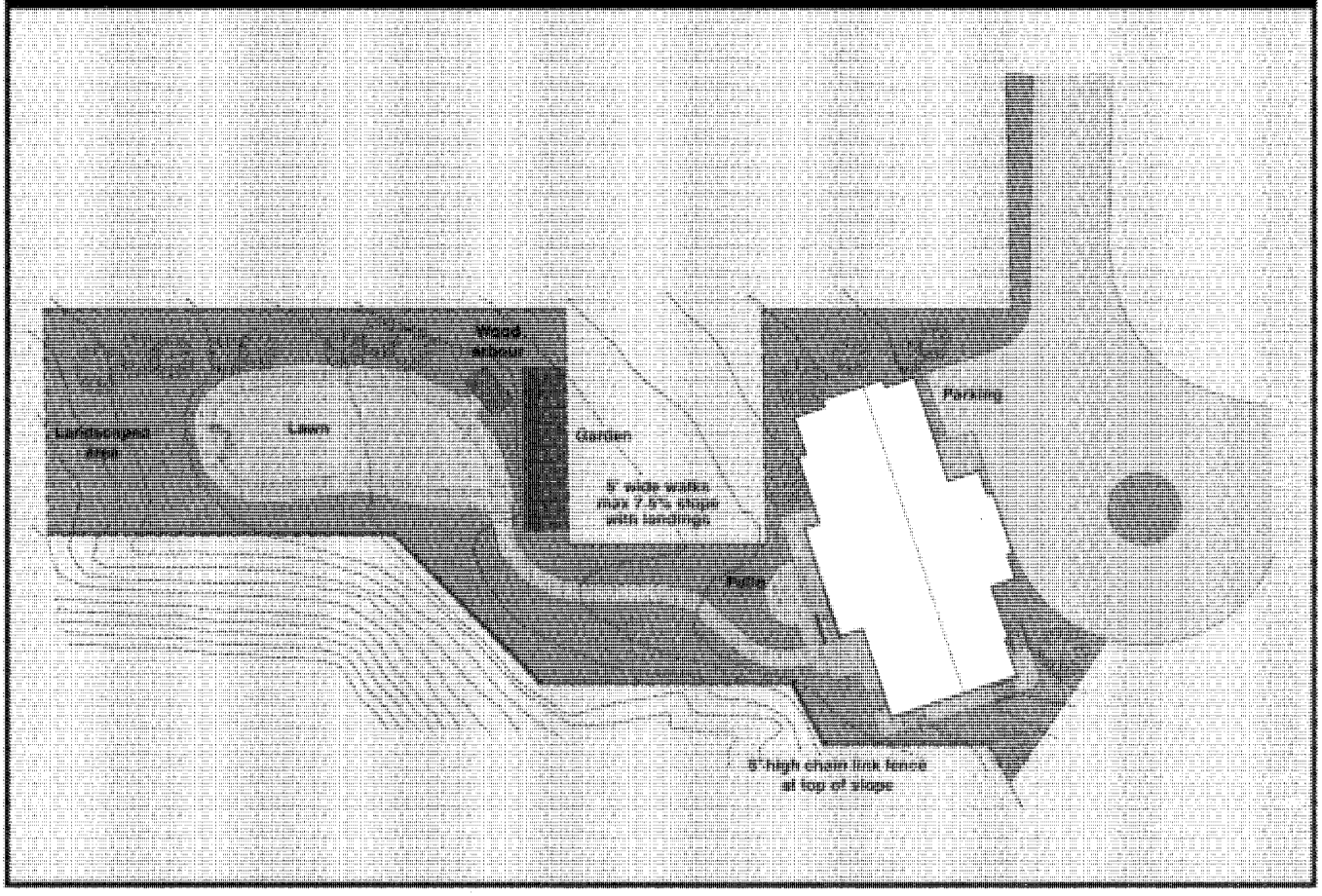
Photo 134: Harmony and fine detailing define the interior at Hale Kako'o

Photo 135: A balcony overlooks a wandering path



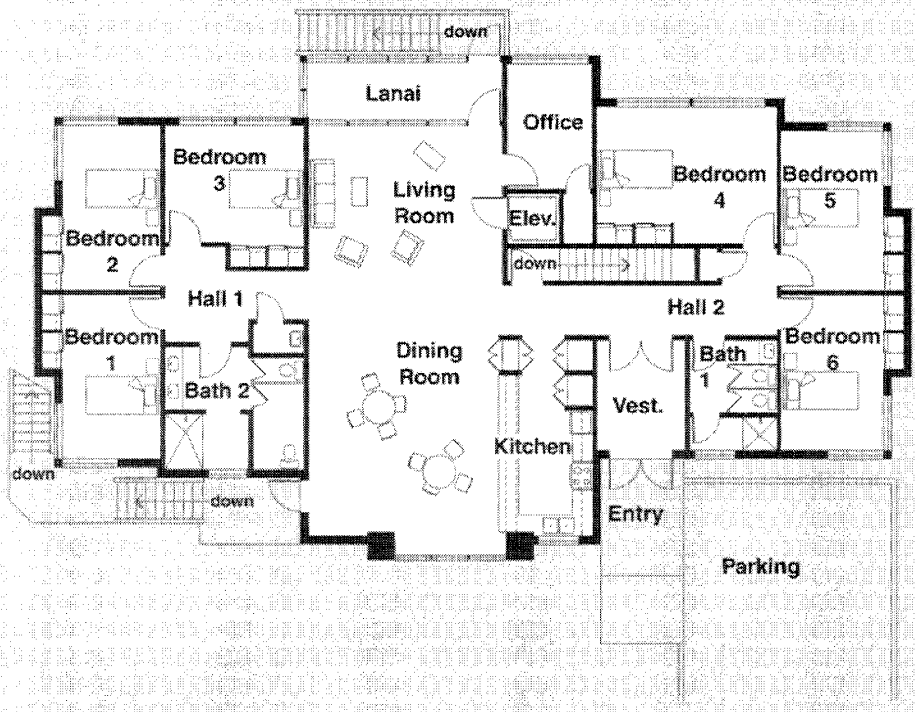
HARRY AND JEANETTE WEINBERG HALE KAKO'O RESPITE CENTER

SITE PLAN

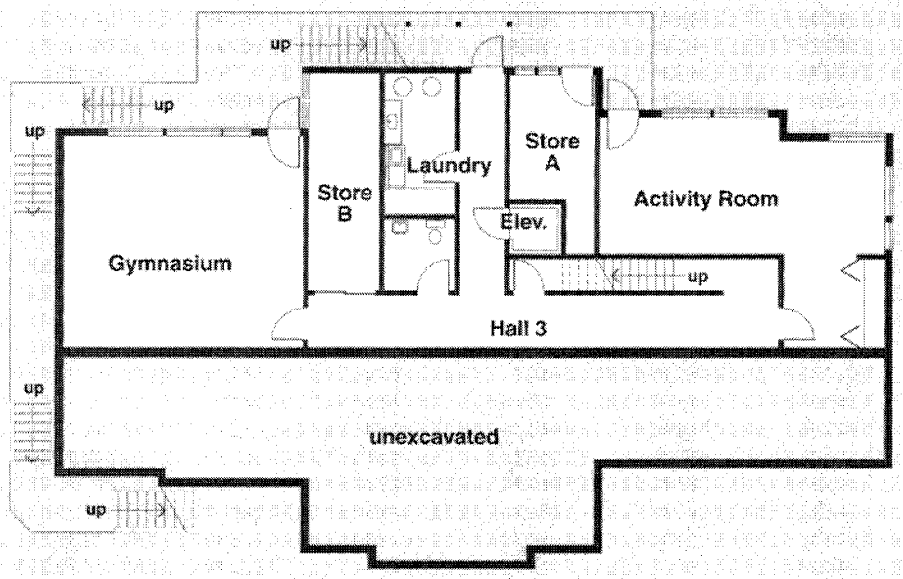


HARRY AND JEANETTE WEINBERG HALE KAKO'O RESPITE CENTER

MAIN FLOOR PLAN



LOWER FLOOR PLAN



New Moon Garden, Cedarview Lodge, North Vancouver, B.C.

Research suggests that people of all ages benefit from contact with the natural world. The research of landscape architect Patrick Mooney goes further in suggesting that people with Alzheimer's Disease or other forms of dementia also benefit in real and measurable ways from access to a garden. It follows that landscape architects can have a special role to play in the development of housing for people with dementia. In light of these findings and taking into account the results of a post-occupancy evaluation of the newly constructed Cedarview Lodge, Mooney designed a Special Care Garden that is suitable for people at various stages of the disease.

The garden was laid out according to what is called an "environment/behaviour" model – that is with exit control, wandering paths and nooks that allow for private retreat. The garden was constructed on a residential scale and allows for maximum outdoor freedom and independence. In order to minimize confusion, Mooney attempted to reduce glare on pathways and at entrances and installed continuous footpath lights and handrails to guide residents as they walk a continuous loop pathway connecting directly to the corridor system within the lodge. Seasonal colours in the garden were kept low-key so that they soothe but do not over-stimulate garden-users, at the same time that the familiar scents calm and reassure them. Trellis and trees were also situated to act as landmarks. With an eye toward safety, the designer enclosed the garden with a security fence, densely screened so as not to attract the attention of residents to the boundaries of the garden or to what lay beyond it; and he used non-toxic plants to prevent accidental poisoning. Small, shaded seating areas give the illusion of privacy.

Photo 136: New Moon Garden, with lighted handrail, coloured paving and thick planting to screen the outer world

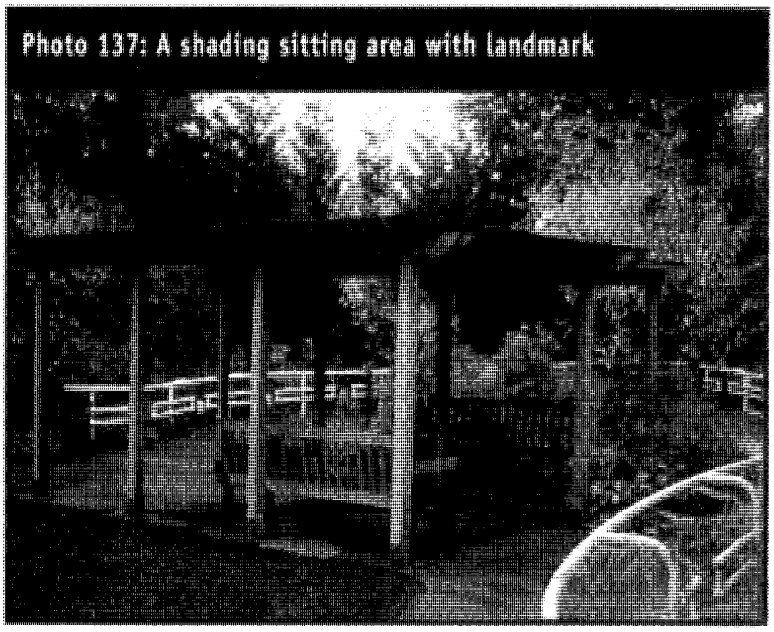


Photo 137: A shading sitting area with landmark

When the garden was finished, researchers monitored its effect on resident behaviour for a period of one year. It was found that "incidents" – and, in particular, aggressive behaviour – had decreased by 3.5 and 19 per cent respectively, compared to increases of 319 and 681 per cent respectively in residences without gardens. Observers noted that residents were much more likely to walk in the garden, responding to a clearly defined walking path, than in the exterior use area (16 per cent more likely as a first activity and 32 per cent as a dominant activity). All residents at New Moon oriented themselves well in the garden, were at ease and "navigated" the area without frustration. By comparison, in an "undesigned" garden, researchers have recorded a 25 per cent incidence of frustration among users due to poorly designed furniture and exposure to inclement weather or unpleasant conditions of sun or wind. Generally speaking, the garden had a clearly beneficial and calming effect on the behaviour of people with dementia, reducing frustration and aggressive behaviour and, by extension, improving their quality of life.

The evaluation concluded that the garden should have even more clearly defined boundaries, which the residents cannot see; it should be sheltered from sun, wind and glare; furniture should be heavy and stable, as chairs that overturn are distressing to people with dementia; and, finally, the garden should be linked both visually and physically, through interior walking corridors, to the interior of the building.

Cedarview Lodge, North Vancouver, B.C.

Photo 138: One of several places to rest on the continuous walking path

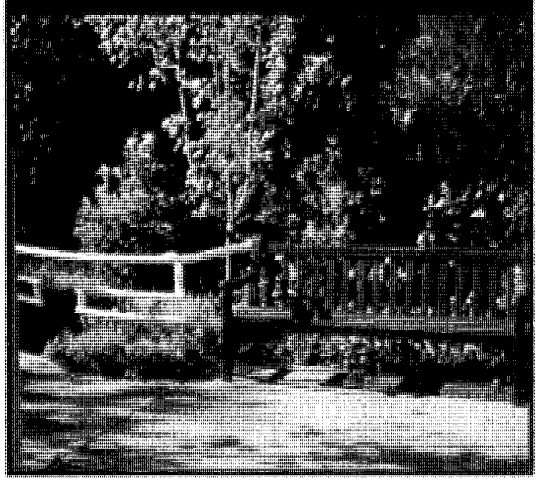
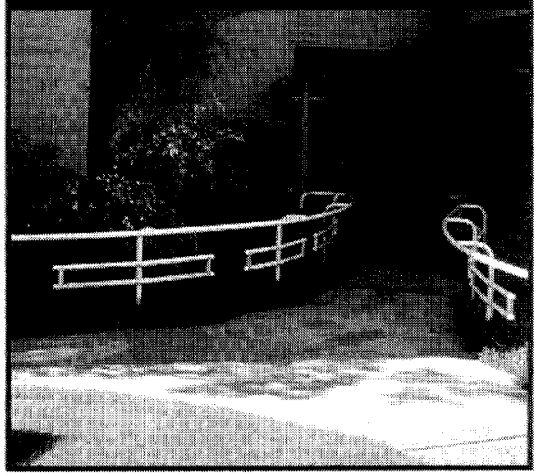
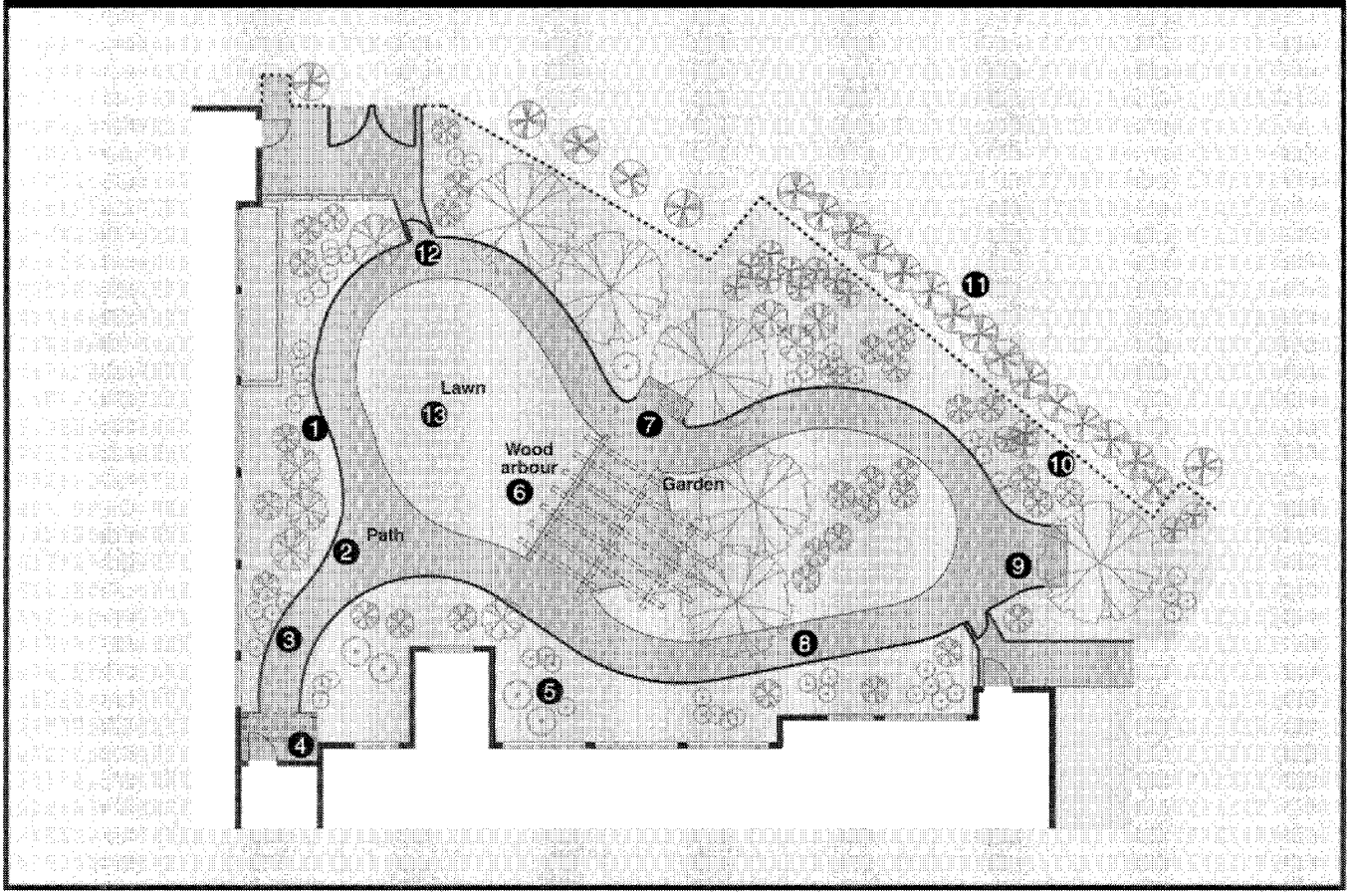


Photo 139: The walking path in the garden connects to interior corridors



NEW MOON GARDEN, CEDARVIEW LODGE

SITE PLAN



1. Pathway lighting at foot level illuminates walkway.
2. Handrail all the way around the garden keeps residents' feet away from the edge of the pathway.
3. Textured, non-glare concrete path for easy footing.
4. Boston ivy on trellis provides gradual transition in intensity of light from indoors to outdoors and vice versa.
5. All plants are non toxic, as residents may eat things growing in the garden.
6. Arbour is a central feature or landmark helping people with dementia to orient themselves in the garden.
7. Scented plants, such as thyme, heather and lavender grow near the benches and waft nostalgic and soothing scents to the residents.
8. A figure-8 walking pathway keeps residents from getting stuck in corners.
9. Seats provided at several different locations to avoid stressful crowding.
10. Chain link fence for the security and protection of residents.
11. Evergreens screen the fence and beyond so that residents are not attracted to the edge of the garden.
12. Gate with a continuous top rail, like the handrail, so that residents do not perceive it as an exit.
13. Lawn provides a soft area for outdoor activities.

Conclusion

The examples of alternative housing presented in this chapter are ample proof that designers, researchers and members of the medical profession are working successfully, as are those in the support services and housing industries, to understand the difficulties associated with dementia in order to evolve real, practical and humane housing solutions for the growing population of affected persons.

Though the examples described may not be available in a given area, they are a hopeful sign that, in the near future, the range and quantity of housing available to people with dementia will be much greater than at any time in the past. Those who have the responsibility of finding or operating good, safe housing for people with dementia should find these designs both encouraging and stimulating. At the same time, those who are working in their own community to develop solutions may use them to feed the interest and fuel the creativity of local government officials, health administrators, developers and designers.

Credits

1, 76-82: Courtesy of the Alzheimer Society of the Mauricie, Trois Rivières, Que.

2: Courtesy of the Capital Care Group, Edmonton, Alta.

3: Courtesy of the Lions Club of Winnipeg Housing Centres, Winnipeg, Man.

4: Courtesy of Katrina McKinlay, administrator, St John Holiday Home. Edinburgh, Scotland

5: Courtesy of Edinvar Housing Association Limited, Edinburgh, Scotland

6: Courtesy of the Alzheimer Society of Canada

7: Courtesy of Maria Page, Adelaide, New South Wales, Australia

8: Courtesy of the Alzheimer Society of the Mauricie, Trois Rivières, Que.

9: Courtesy of the Alzheimer Society of the Mauricie, Trois Rivières, Que.

10: Photo by John Zeisel, Hearthstone Alzheimer Care, Montréal and Boston. Design, Marc Maxwell AIA

11, 25, 27, 34, 37, 41, 42, 107 and 108: John Zeisel, Hearthstone Alzheimer Care, Montréal and Boston

12: Photo by Jim Daniels; Design, Robert Hoover, A.S.L.A.

13-14: Photos by John Zeisel, Hearthstone Alzheimer Care, Montréal and Boston. Design, Marc Maxwell, AIA

15-16: Photos by Curtis Martin; Design, Perkins and Eastman, Architects PC, U.S.A.

17: Courtesy of Phil Gaudet, The Good Samaritan Society, Edmonton, Alta.

18: Photo by Anton Grassl. Design by Marc Maxwell A.I.A. and Martha Tyson A.S.L.A.

19-21: Photos by John Zeisel, Hearthstone Alzheimer Care, Montréal and Boston. Design by Marc Maxwell, A.I.A.

22: Courtesy of Phil Gaudet, Good Samaritan Society, Edmonton, Alta.

23: Courtesy of the Capital Care Group, Edmonton, Alta.

24: Courtesy of Julie Cherney, St. Lawrence Court, Adelaide, Australia

26: Courtesy of the North Renfrew Long Term Care Services Inc., Deep River, Ont.

28, 29, 32: Photos by Curtis Martin. Design by Perkins and Eastman Architects P.C., U.S.A.

30: Courtesy of Danielle Counet and Jean-Marc Desnoe, Délégation départmentale de l'Agence Nationale pour l'Amélioration de l'Habitat (ANAH), La Mayenne, France

31: Courtesy of Wesley Gardens, New South Wales, Australia

33: Photos by John Zeisel, Hearthstone Alzheimer Care, Montréal and Boston. Garden design by Martha Tyson, A.S.L.A.

35: Courtesy of Peakhurst Retirement Village, Sydney, Australia

36: Photo by Jim Daniels. Design by Robert Hoover, A.S.L.A.

38: Courtesy of the North Renfrew Long Term Care Services, Deep River, Ont.

39-40: Photos by Jim Daniels. Design by Robert Hoover, A.S.L.A.

43-49: Courtesy of Patrick M. Vellas, architect, Auzeville, France

50: Courtesy of the Good Samaritan Society, Edmonton, Alta.

51-54: Courtesy of Protem Health Services Inc., Moncton, N.B.

55-58: Courtesy of Phil Gaudet, the Good Samaritan Society, Edmonton, Alta.

59: Courtesy of Elizabeth Edsjö, Bostadslaget Arkitekter A.B. Stockholm, Sweden

60-66: Courtesy of Contemporary Housing Alternatives of Topeka, Inc.

67-72: Courtesy of Delores M. Moyer, Encore Senior Living, Madison, Wis., U.S.A.

73-75: Courtesy of Georges Caussanel, president, Association des Cantou, Rueil-Malmaison

83-88: Courtesy of Ruth Toohey, Manager, Leigh Place, and the Hostel and Care Program, a division of Home Care Service of New South Wales, Australia

89-94: Courtesy of Leisure Way Community Group Home Inc., Medicine Hat, Alta.

95-100: Original text and photos by Ragnhild M. Eidem Krüger, editor of the magazine, DEMENS. Design by Erling B. Haugen, architect, Arkitekt Kontoret a/s Årdalstangen, Norway

101-106: Courtesy of Päivi Karjalainen, Sopimusvouri Foundation, Tampere, Finland

109-112: Courtesy of Rudy Friesen, Friesen Tokar Architects, Winnipeg, Man.

113-118: Courtesy of Mary Janzen, the Rimmer House at Lions Manor, Winnipeg, Man.

119-124: Photos by Bill Cadzo, courtesy of McConnell Place West, Edmonton, Alta.

125: Courtesy of the Alzheimer Society of Ottawa-Carleton

126-131: Courtesy of JoEllen Worth and Birdie Robertson, Foxwood Spring Institute, Raymore, Mo., U.S.A.

132-135: Courtesy of Janet Bender, Executive Director, Alzheimer's Association, Honolulu Chapter, Inc., Hawaii, U.S.A.

136-139: Photos by Patrick Mooney, landscape architect, Vancouver, BC. Garden design by Patricia Wadmore, Leonore Nicell and James Jarvis. Research, Patrick Mooney and Leonore Nicell

Appendix I: Selected Bibliography

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Appendix II: Frequently Used Terms

Adult Day Programs/Social Day Programs, also called Day Care, are centres that provide social activities, supervision and usually lunch for older people who are frail or have disabilities. Typically unregulated or less regulated than full Adult Health Centres, these programs usually do not provide health-related services and are not usually eligible for government subsidies.

Adult Day Health Centres provide organized activities, meals, health monitoring and limited nursing services to elders. Some Adult Day Health Centres specialize in programs for people with dementia, while others are more generic. Adult Day Health programs typically receive government subsidies, and they are regulated as health care providers.

Aging in Place is a term that assumes that, as older people age, they will become more frail over time and that they will need more services. The expression is used to describe settings that allow a person increasing access to services as they need them. Special care dementia residences with an "age in place" philosophy will allow individuals to remain even as they reach the late stages of the condition, become bed-bound and increasingly dependent on nursing services.

Alzheimer's disease is the most common cause of cognitive impairment ("memory loss") or diminished ability to perform social and occupational tasks normally. Alzheimer's disease causes progressive loss in complex thinking and memory functions. As the disease progresses, a person's ability to respond to the world around them and to control emotions is also impaired. Behavioural difficulties such as incontinence, wandering and agitation are typical consequences of the disease. Damage to the brain becomes so significant that the person finally becomes physically incapacitated.

Assisted Living Residence is a term more commonly used in the United States than in Canada. Such residences are similar to Congregate Care Residences (see below), providing private or semi-private accommodation with shared daily activities with other residents. Depending on the residence, common dining, recreational activities and housekeeping services are offered, though each resident enjoys private accommodation. Some Assisted Living Residences also offer medical and nursing services to residents.

Boarding Homes offer a rental accommodation that enables people to come and go as they please but provides basic services, such as regular housekeeping and a certain number of daily meals. Boarding homes allow people to live in a family-like setting with others in the home but on a smaller scale than either Assisted Living, Congregate Care or Long-Term Care Facilities.

Congregate Care Residences offer similar benefits to Assisted Living Residences, often with a broader range of recreational and social services. For example, a Congregate Care Residence may offer private or semi-private accommodation, housekeeping, transportation to shopping areas, movies, speakers and other recreational entertainment. In some Congregate Care Residences, residents organize advisory councils to work with staff on policies and home management. Congregate Care Residences can range in size from 20 to 200 units.

Continuing Care Retirement Community (CCRC) is a campus that includes independent housing offering many of the services that older people may need, such as meals, transportation, organized social activities, housekeeping and home health services, as well as assisted living and nursing home facilities. Often the older person has a contractual arrangement that prepays or otherwise reserves the right to use the full range of services provided by the CCRC.

Continuum of Care refers to the range of services that older people who are frail or have disabilities might need over time. In general, the term is used to refer to the loosely organized system of service providers and care settings designed to provide services to this population. In particular, it includes in-home services, day care, residential and nursing homes, as well as acute medical care. Implicit in this term is the assumption of progressive need for more general and medical services over time, as well as a sense that services are arranged in a coherent system.

Dementia, or "cognitive impairment," involves loss of mental skills, such as memory and mental analysis. It has many causes. Depending on the type of dementia, damage to different parts of the brain causes loss of mental and physical functions to such a degree that a person can become lost and afraid in a once familiar world. Often caused by strokes in old age, there is a broad range of dementias associated with specific disabilities.

Family Caregiver generally refers to someone who is caring for a family member at home. Often, the family caregiver may be a spouse or close relative, such as a son or daughter, of the person being cared for. The family caregiver may reside in the same household with the person who requires care or may visit frequently to provide support and assistance.

Foster Care is a system whereby a family takes in dependent children or elders and, with government support and stipend, provides the same care and supervision that they would provide for a family member in their home.

Home Adaptation is the term used for changes people make to their homes to accommodate physical disabilities. Common home adaptations made by families caring for someone with Alzheimer's disease are the adding of hand rails in bathrooms and the securing of exit doors to prevent wandering.

Long-Term Care is the term used to describe the personal care and health-related services used by people with chronic conditions and disabilities. While the phrase is often used, such services are not, in fact, organized in any systematic way.

Long-Term Care Facility is a setting in which nursing and other ongoing health-related services are provided. This term is usually synonymous with "nursing home."

Nursing Homes generally provide long-term or extended care services with 24-hour nursing for those who are frail or suffer from a chronic disease such as dementia. Nursing homes are suitable for persons who do not need supervision or treatment by registered nurses under the direction of a physician.

Professional Caregivers provide much the same services as the family caregiver but are hired by families where family members are incapable or unable to stay at home to care for a family member themselves. Professional caregivers can be retained on a part- or full-time basis and can offer a broad range of services, from housekeeping to dispensing of medicines, if qualified.

Residential Dementia Care refers to settings and services that focus on the quality of life of each individual. Such care

provides each person with independence and an ability to choose his or her own level of safety and risk. It is an approach that leads to dignity and empowerment. Residential care in familiar and comfortable surroundings is made possible through the caring and support of family and community.

Rehabilitation Centre or Hospital sometimes refers to a nursing home, especially those that specialize in short-stay rehabilitation nursing. However, true rehabilitation hospitals specialize in short stays for those recovering from trauma or acute disease, people who can benefit from rehabilitation therapies.

Respite is a term used to describe time off for family caregivers. Respite services include informal help from friends and family, community programs offering in-home companions, homemakers and home health aides, as well Day Care and Adult Day Health Centres and short stays in residential and nursing facilities. Respite care, therefore, refers to temporary assistance and/or accommodation given to the person with dementia so that the caregiver can take respite from the daily burden of care.

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