

**HOUSING FOR INDIVIDUALS WITH DEMENTIA:
PROCEEDINGS FROM A WORKSHOP SPONSORED BY THE
CANADA MORTGAGE AND HOUSING CORPORATION**

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SUMMARY

In conjunction with the 18th Annual Conference of the Alzheimer Society of Canada, the Canada Mortgage and Housing Corporation (CMHC) sponsored a two-part workshop entitled "Housing for Individuals with Dementia." This document provides an account of the proceedings of the workshop.

Currently there is much activity related to housing for individuals with dementia in Canada. In part one of the workshop, participants heard about: 1) the use of technology to provide help at home for persons with Alzheimer Disease, 2) adapting municipal housing for people with dementia and 3) the CMHC project "Housing Options for Canadians with Dementia."

In the second part, participants were updated on three housing projects that were highlighted at the 1995 Annual Conference of the Alzheimer Society of Canada in Edmonton. These are projects being undertaken by the Alzheimer Society of Ottawa-Carleton, the Alzheimer Society of Manitoba and the Capital Care Group from Edmonton.

In addition to the six presentations, this document reports on issues raised by participants about housing development for individuals with dementia in Canada.

Résumé

Dans le cadre de la 18^e conférence annuelle de la Société Alzheimer du Canada, la Société canadienne d'hypothèques et de logement (SCHL) a parrainé un atelier en deux volets intitulé «Le logement des personnes démentes». Ce document présente un compte rendu de l'atelier.

À l'heure actuelle, la question du logement des personnes démentes suscite beaucoup d'activités au Canada. Les sujets suivants ont été traités dans le premier volet de l'atelier : 1) l'utilisation de la technologie pour fournir une aide à domicile aux personnes atteintes de la maladie d'Alzheimer; 2) l'adaptation des logements municipaux aux besoins des personnes démentes; 3) le projet de la SCHL «Choix de logements pour les personnes démentes au Canada».

Dans la seconde partie de l'atelier, on a fait le point sur trois projets d'habitation dont il avait été question à la conférence annuelle de 1995 de la Société Alzheimer du Canada, tenue à Edmonton. Ces projets ont été entrepris par la Société Alzheimer d'Ottawa-Carleton, la Société Alzheimer du Manitoba et le Capital Care Group d'Edmonton.

Outre les six exposés, ce document rend compte des questions soulevées par les participants à propos de la production de logements pour les personnes démentes au Canada.

**The Potential Role of Technology to Provide Help at Home
for Persons with Alzheimer's Disease**

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Assistive technology can provide help for people with Alzheimer's Disease (AD) and reduce the burden of caregiving. To succeed, designers of assistive technology and architects must understand the stages of progression of the disease and its impact on cognitive function and safe mobility. We have identified four principles that we use as a guide in the development process:

1. The aim of technology should be to provide the individual with as much responsibility, safe mobility and privacy as possible. We know that exercise is necessary to minimize physical decline. The same effect is seen with cognitive function. If the individual is not challenged, because too many tasks are taken over by technology, then isolation and confusion may increase and feelings of self-worth may diminish.
2. The right to take risks is acknowledged (and even encouraged).
Conversely, the emphasis with technology so often is on reducing risks. This emphasis not only reduces the quality of life, but also, in the long run can be counterproductive. For example, increasing the amount of walking may increase the risk of falls but enables socialization and stimulating

exploration. The temptation is to reduce independent mobility or to decrease the area within which the individual may be mobile. However, as the level of activity and lifespace declines, so does the level of fitness. This causes the risk of falling to actually increase.

3. Consistency is important. Changes to the environment can have very negative effects on elderly people with AD. For example, it is well known that spatial disorientation and the rate of falling are increased during the six-month period following a move to a new environment. There is a need to pay particular attention to achieving the optimum balance of environmental stability and stimulation. Too much stimulation can precipitate anxiety and escalate to agitation, whereas some level of stimulation is often necessary to induce activity, maintain cognitive ability and foster enjoyable reminiscence.
4. The health and function of the caregiver is at least as important as that of the individual with AD. Premature institutionalization is generally precipitated by a crisis for the caregiver including illness, a back or upper limb injury from lifting or collapse from general fatigue and too little sleep and "Time-Out." The need for technological adjuncts for caregiving to reduce the physical and psychological burden also extends into retirement and long-term care facilities where staffing ratios are becoming "skeleton."

Caring for someone with AD involves understanding precipitating factors of behaviour changes in order to manage and adjust them. As the disease progresses, problems associated with changing behaviours increase and become disruptive to family lifestyles. We will consider the potential for technology in terms of each of these behavioural issues and some physical issues.

Short Term Memory Loss.

The first sign of AD is loss of short term memory. Several current technologies target remembering to take medications at appropriate times. These are well-known and range from plastic boxes divided into sections labelled by times and day, to electronic systems that have various levels of sophistication. The simplest of the electronic systems are timers on medication container caps that are reset for the same time interval every time the cap is opened. The more complex are systems that dispense the drugs at the correct time and sound an alarm if the drugs are not taken within a given length of time. Some systems will cause missed doses to be locked away to prevent them from double-dosing.

These pill reminder systems illustrate some design problems. The most common device that we all use to assist memory is the writing of a note. The system collapses and errors are made when we forget to read the note at the right time or forget where we put the note. Similarly, the simple compartmentalized pill boxes do not work if the user forgets to open them at the right time or forgets the time of day. Electronic devices can be used to provide audible and visual cues at the right time but this also discloses the disability to others. Also, there is

a trade-off between portability and other properties such as the size and readability of keyboards and visual displays and the number of days and daily doses of medications that can be stored. We envisage these trade-offs will become less severe and the stigma associated with the technology will disappear as more electronic daily reminder systems are used routinely by the general population. Small, affordable message recording devices exist and are marketed to the general population to help in such tasks as shopping lists, travel directions or remembering where the car is parked. Wrist watches and executive electronic day planners are becoming more common. Most of these devices are too complex and too miniaturized for use by people with even mild AD. However, they will reduce stigma associated with needing a reminder device. It may be possible to incorporate some of the technology into packages that are designed for this population.

Current housing designs should include a large white board prominently positioned in the kitchen where the caregiver can write messages to reinforce remembering by and comfort of the family member with AD. It is best if only a single day's worth of appointments and directions is displayed. We would like to explore the potential for a design that allows messages for the next day to be prepared but remain hidden until the following morning. Perhaps future display systems will have associated audible reminders that the caregiver can set to draw increased attention to visual messages at specific times. One might even imagine being able to edit the message board remotely when the technology allows freehand writing and graphics to be reproduced and displayed economically.

It becomes difficult to remember where to find various items, especially in the numerous cupboards found in kitchens and bathrooms. One quick fix is to remove the doors but this is not a very attractive solution. Perhaps transparent doors with internal lighting might become standard features in future homes. Clothing cupboards may also be organized with appropriate lighting and in such a way that the clothes can be stored in the logical sequence with which they are worn. A lockable storage area is required for out-of-season clothes and kitchen items that are rarely used in order to simplify the environment and enable decision making. It may be helpful to use the analogy of a briefcase or purse with compartments to keep items organized. The home needs to be organized in the same way. People with AD like to have a special place for each activity and for storing each item.

Loss of memory has some important safety implications. One problem is scalds from hot water. This is easily remedied by limiting the maximum hot water supplied to faucets in the home and by using mixing valves. A less serious problem with water is over-filling and flooding the sink or bathtub. There is a need for adequate overflow drains or automatic shut-off valves. Fires resulting from smoking accidents are of great concern. Will new housing incorporate more intelligent proactive fire suppression systems such as sprinklers that are triggered by smoke alarms and are directed by infrared sensors? Can we make direct connections of alarm systems to emergency response services (ERS) and fire services more economical by providing a quick way of verifying the cause of the alarm and thereby reducing the number of false alarms? In addition to opening a

voice channel, will activation of an alarm turn on all the lights and cause images to be transmitted to the ERS?

The ability to use the telephone is important for safety and socialization. Ease of use is increased if the number of functional options is limited and if the device is familiar. Peter Zimmer has described his RISES approach to the design of telephones. His invention can be used to modify any familiar telephone by replacing the keypad with four push bars. The top three bars speed dial family or friends. There is no need to remember numbers--the person's name and a small photograph can be displayed on the push bar¹. The bottom bar is for emergencies and dials the ERS. The identity is automatically transmitted to the ERS in the usual manner and the individual's file is displayed for the operator. The person with AD may wear a pendant alert to access this ERS capability from anywhere in the home.

Orientation

Often the next step is a loss of orientation to time, then place and then people. Classically, orientation to time is addressed by having numerous clocks (with audible hourly signals) and other displays of the date. Certainly clocks are useful if they are providing the correct time and if all of the clocks agree on the same time. Picture clocks link time and daily functions. Providing a view of the outdoors that orients to time of day and season is also useful. Windows should be

¹ If family members will be away from their phone then leaving a personalized message on their answering machine - "Hi mom. I'll be with you at 10 o'clock this morning" will make the call reassuring rather than rejecting.

low enough to see the ground outside while sitting inside. One of the cleverest ways of reminding a person to perform a certain function at a certain time of day is to use the telephone. A desktop computer can be used to store pre-recorded messages and to phone the user at designated times. Answering the phone to receive a message is a familiar and non-stigmatizing activity.

Orientation to place can be assisted by retaining as many familiar cues as possible. Environments for people with AD should include familiar items of furniture and memorabilia. Of course, photographs of valued but functional 'things' are also very beneficial. Distinctive features such as alcoves, shelves, window shapes, lighting fixtures and wall coverings should be incorporated particularly at room entrances and corridor junctions to provide wayfinding cues.

Comprehension

Eventually, it becomes difficult to work things out as the AD person becomes more confused. Technologies that are helpful at this stage will share four characteristics: familiarity, simplicity, safety and affordability. Again, Peter Zimmer has illustrated some of these with his thermostat design. The design resembles the familiar "Honeywell" kind of circular thermostat. Elderly people are used to rotating these in a clockwise direction to make the environment warmer and in an anti-clockwise direction to make it cooler. The number of degrees is not important, the AD person only knows that he or she wants to be warmer or colder. The thermostat would be programmed for the most suitable day and night temperatures. Clockwise settings would cause the temperature to rise a few degrees above the preset value and vice-versa. After one or two hours

the thermostat would reset itself to the preset level. Unfortunately, this concept has not yet become a product.

The problem of leaving stove elements on is partly caused by poor memory and partly by difficulty in understanding the relationships between the controls and the stove elements. We will see more attention paid to aspects of ergonomic design that aid in comprehension as well memory. Front controls and guards prevent skin and clothing contact with burners. Some stove reminder devices have been developed but we have not seen them become widely available².

Every conference that relates in any way to technology and housing for the elderly always includes a significant emphasis on concepts concerning the intelligent house. The idea is, of course, to wire the house so that many functions are automated. These capabilities will only be of use to people with AD if the messages and actions are entirely concrete (easily understood relationships between actions, consequences and information feedback). A message on the television screen that relates to the need to answer the front door or to the washing machine finishing its cycle will just produce more confusion or be ignored. Powered closing of drapes and remote operation of entrance doorways are examples of features that are very useful to people with physical impairments but may be of little use to those with AD.

² Instead of the usual solution of removing the fuses, perhaps we should consider some means of activating a familiar voice message that might say "I'll be home at five mom - there is a snack for you in the fridge."

Frustration and Agitation

Progressive losses of memory, orientation and comprehension lead to frustration and agitation. There are many ways of easing the level of frustration. TVs, VCRs, radios and other entertainment devices can be selected for simplicity of operation. Buttons and controls that cause frustration because they are too complex should be covered in some way. CDs have helped greatly since they are much less complex to operate than record players and will play continuously without fault. Their value will increase when those of us who currently use them age and still find them familiar. In the meantime, Peter Zimmer again, had a great idea for his mother. He mounted a simple volume control on the front of a speaker that resembled a radio. A timer turned on a CD player that played favourite types of music continuously from a selection of CDs during the daytime and turned itself off at night. The only option was to adjust the volume but the result was always success since her favourite music was always played without delay.

Confabulation and confusion are common and often lead to very restless sleep. Awakenings in the middle of the night then lead to the caregiver's sleep also being disrupted. The ability to be able to pre-select music and non-threatening audio-taped stories may be very helpful. Televisions are not always a good idea for the bedroom because watching can delay or disrupt sleep. Good insulated blinds in the bedrooms to avoid early hour wakening in the summer should also be considered.

Agnosia and Apraxia

The diminished ability to recognize familiar objects and the inability to initiate sequential actions involved in daily activities may be facilitated through technology. For example, we imagine a voice-reminding system that might be developed that could be situated in various parts of the home where these activities occur, and could be triggered in various ways. For example, removal of the razor would trigger a friendly voice to say that this is the razor and to describe the actions that are necessary to shave. Standing up from the toilet might trigger messages, with appropriate time delays, to remind of the need to flush the toilet, do up clothing and wash hands. Leaving the fridge door open might trigger a gentle reminder to shut the door. Such verbal reminders may be acceptable since we might expect to understand and accept instructions given by a familiar voice who is out-of-sight in another room. There are interesting opportunities to explore multi-sensory approaches to helping people with apraxia. In addition, tasks, such as opening doors and windows, must be designed to be accomplished with one single motion. Combinations of actions such as turning and pushing should be avoided unless done deliberately to prevent access.

Wandering

Often agitation leads to wandering behaviour. There is nothing by itself harmful about wandering. In fact, wandering is a very understandable activity and at least provides some exercise. Wandering only becomes a problem when the behaviour becomes disruptive to other individuals or when the wanderer endangers him or herself by straying beyond familiar secure settings and becoming

lost.

There are many simple environmental modifications that are now quite well-known and are quite effective at controlling and limiting wandering. For example, the entrance door to the home should never be at the end of a blind corridor since the wanderer will always want to test the door when reaching the end of the corridor and sometimes will go on through. Doors can be disguised by painting them the same colour as the wall. Hanging a picture or a mirror on the back of a door is a particularly successful technique of disguising it. Straps or tape placed across inner doorways and over drawers and cupboards that are out-of-bounds can be quite helpful, as can be red on white octagonal street-like "STOP" signs with bold letters (in the familiar language). Audible alarms at entrances to unsupervised areas have been shown to curb entry by some people with AD. Brightly coloured, attractive and interesting areas will attract wanderers. Numerous products exist that provide an electronic alarm when a wanderer wearing some triggering device passes through a doorway. Unfortunately, if that doorway is the main entrance to the house, the alarm might be too late. It has also been difficult to prevent people with AD from turning off, removing or destroying the triggering devices.

Sometimes it is helpful to warn the caregiver that the wanderer is about to get out of bed since falls often occur under these circumstances. Future homes are quite likely to have intercoms so that caregivers can continually monitor the level of agitation of the AD person. Presently we find the commercially available baby intercoms to be very sensitive, very successful and very affordable. The

caregiver wears the portable battery-powered receiver clipped to a belt or plugs it into a nearby outlet. It is effective for the prevention of falls and to support time-out.

If the home of the future is going to monitor the location of its occupants in order to optimize energy delivered to different rooms and to provide greater security, then a technology that identifies which room is occupied by the person with AD could also be very helpful to the caregiver. If the house could provide continuous knowledge of the location of the resident to the caregiver then the system could be programmed to lock doors, provide reminders and provide aversive-conditioning stimuli to protect the wanderer. The objective would be to let the caregiver sleep or work with as little interruption as possible and to make decisions about the level of threat and the need for intervention before alerting the caregiver.

Falls

Falls are not a behavioural problem but they are one of the most serious consequences of disorientation, agitation and wandering behaviour, especially when combined with mobility impairments. Although it is desirable to provide as much responsibility to the individual as possible, an appropriate exception might be the automatic turning on of lights throughout the house in response to wandering. As we age, we all need very much more light (approximately three times the level of a 30-year old) but we also accommodate to changes in light levels much more slowly (approximately 1/10th of the speed). Consequently the

lights should fade in and out gently and should not flicker. Of course, glare must be avoided since this can lead to temporary blindness and further confusion.

Frequently fallers have trouble getting up from the floor to call for help. Emergency response systems have provided many users and caregivers with comfort and reassurance. The two-way audio systems seem to work very well now even throughout the house. Intercom technology or wiring in future houses may make them even more effective. The major problem is that the users often forget or refuse to wear or carry the pendants with them from place to place or forget to use them. Buses or subway trains are equipped with ribbon switches that can be pressed anywhere along their length in the event of an emergency. Incorporating this kind of technology in the baseboard of future homes may be helpful if it can be designed to avoid accidental triggering by pets, toys and furniture and if it can be made recognizable at least by people with moderate levels of AD without introducing too great a level of stigma.

Barbara Cooper has shown that when elderly people are given the opportunity to test handrails that are coloured safety yellow in comparison to rails that are an inconspicuous grey that they express a strong preference for the brighter colour not only because of its increased visibility but also because it appears to act as a reminder to use the device for added safety. Insisting on colouring all private household rails yellow may be unreasonable, however, encouraging the use of a brighter contrasting colour (preferably in the red to yellow range) may be practical. Our own research has shown that handrails should be approximately circular in cross-section and 38mm in diameter. All

walls should be equipped with handrails and there may be opportunities to provide useful tactile cues and visual cues by their shape, colour and texture. Carpet does reduce the likelihood of hip fracture from a fall but it tends to promote tripping and significantly increases the rolling resistance of wheeled mobility aids. Energy absorbing protective clothing is being tested as an injury preventing aid.

Immobility

The common combination of cognitive dysfunction and impaired mobility is devastating. Each condition confounds the other. The fear of falling, low morale, masked depression and the dependence on the caregiver discourage mobility. In turn, the lack of mobility further reduces health and increases the tendency to falling, upper respiratory conditions and the dependence on the caregiver. More limited mobility also leads to greater isolation and to increased levels of verbal or physical aggression because of the hemmed-up energy, anger and resentment that it causes. Ultimately, it leads to withdrawal, sensory deprivation and growing levels of confusion.

Confused elderly have a lot of difficulty managing walking aids. The sequence of operation of walkers that have either no wheels or just have two wheels is too complicated. They cannot remember to lift and advance them and then step forward to them. Four-wheeled walkers, on the other hand, require that the user knows how to operate the brakes and remembers when to use them. We envisage walkers with electronic systems that will automatically lock all four wheels whenever they are stationary for more than a brief period of time and will

automatically release the wheels when the user starts to advance. The rolling resistance of these walkers will also be able to be set to increase with increasing speed. Considerable research will have to be done on how to sense the intentions of the users in a transparent way.

There is no question in our minds that there is an important role to play for powered mobility for people with AD. This may be a disturbing thought to an audience, at the present time, who imagines users running down their caregiver, colliding with each other, descending staircases and disappearing out-of-sight over the horizon. Fortunately, all of these are technical issues that can be addressed sensibly with collision-avoidance systems and other electronic gadgetry. In fact, the general level of safety of the individual is likely to be increased. The ability to move freely without great energy expenditure around the environment in a safe manner may reduce levels of agitation and provide for a very much more interesting and satisfying quality of life. The driving characteristics will have to be programmed to match the capabilities of the user and to avoid over stimulation. The controlling actions will have to be natural. Moving around the environment should not require driving skills per se. These powered vehicles will have to be designed with particular attention to easing transfers, especially for regular toileting. One option that we will explore is incorporating transfer/lifting technology within powered chair design.

Incontinence

The major cause of incontinence in the elderly population in general is involuntary contraction of the dome of the bladder (detrusor) that cannot be

successfully inhibited. However, people with AD have an increased likelihood of appearing incontinent as a result of confusion and disorientation and mobility limitations that prevent them responding appropriately with timely toileting. A schedule of regular toileting substantially reduces or eliminates incontinence in many people with AD. The proper resolution of this problem involves a combination of technologies that make access to toileting easier and electronic systems that provide appropriate reminders. Some progress has been made toward practical bladder volume measurement transducers but accuracy and convenience are not yet appropriate for this population.

There has been much talk recently about a report that suggests that placing the toilet so that it is visible in the living or bedroom space of the elderly provides a continuous reminder of the need to use it. The study found that these visible toilets were flushed more frequently than the toilets that were in bathroom enclosures but did not actually demonstrate that there was a reduction in incontinence. It is highly probable that the presence of a toilet within sight would lead it to be flushed more frequently but other problems may be caused because of their reduction in privacy and dignity. The presence of odour and unsanitary environments must also be addressed realistically.

Concluding Thoughts

There has been little attention paid to the systematic application of technology to assist people with AD and their caregivers. Provincial moves to caring for elderly people in the community and family preferences for continuing to provide care in the home increase the urgency of developing creative

affordable solutions to ensure that the quality of life is acceptable for the person with AD and the caregiver. The old trick that 'expert' consultants play is to always include a recommendation in their reports for further study. Reluctantly, we will play the same game since it is obvious that the knowledge base is limited but the opportunities are there to help people with AD and their family/friend caregivers very significantly.

Adapting Municipal Housing for Dementia

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The Problem

The Canadian Study on Health and Aging estimates that there are approximately 250,000 Canadians 65 and over with some form of dementia; about 161,000 of them have Alzheimer Disease. It is estimated that half the Canadians with dementia live in the community.

The number of Canadians with Alzheimer Disease and related dementias is expected to increase to 450,000 by the year 2011. This increase, coupled with current trends in which older adults increasingly remain in the community, means that both the number and percentage of people with dementia living in the community will increase significantly.

Many of these community dwelling seniors with dementia will live in municipal housing which was not designed to accommodate them. In fact, some of these buildings already contain residents with dementia.

This is a situation of potential concern, since residents with dementia may pose a safety risk to themselves or other tenants. Many of these residents cannot look after their own needs, and require assistance with activities of daily living, including personal hygiene, preparing and eating meals and taking medications. As the disease progresses, they may need regular supervision to ensure they do not engage in activities which jeopardize their well-being or that of other tenants.

The increased likelihood that multi-unit seniors' buildings will contain residents with dementia led to this research, which was designed to address environmental adaptations, policies and procedures relating to the accommodation of people with dementia in multi-unit accommodation.

The study focused on existing housing, rather than new initiatives, because most residents of municipal seniors' housing live in "standard" buildings and this is where the potential problem is most acute.

Methodology

The study used a two-stage methodology. In the first stage, which is completed, mailed surveys were used to identify what is currently being done to accommodate tenants with dementia. The results also allowed us to identify municipal housing providers who are active and innovative in their response to having tenants with dementia living in their housing.

The second stage—to begin soon—will consist of detailed case studies with some of these more active providers. The goal is to develop a more complete understanding of their methods, informally evaluate their effectiveness and develop an understanding of the circumstances which led to their approach to the problem.

The survey sample consisted of 375 organizations, representing all provinces and territories. Replies were received from 250 respondents from eight of the twelve provinces and territories. The high completion rate of 66.7% appears to reflect in part the interest that municipal housing providers have in the study topic. Although not random, the sample did provide instructive information

about how municipal housing providers across Canada are responding to people with dementia living in their buildings.

Results

Survey results confirmed our belief that municipal housing is indeed home to residents with dementia. Just over half the respondents were aware of senior tenants with dementia in their buildings.

That their presence in these buildings is of concern was confirmed by a question about concerns respondents had about these residents. The most common response had to do with the safety of tenants with dementia and of other tenants. Several people mentioned aspects of tenants' disorientation—wandering, getting lost, going outside, entering other residents' apartments, locking themselves out or losing keys or belongings. Another major response category concerned how the affected tenant disturbs his/her neighbours.

The most common response to these types of problems was for the housing agency to contact the tenant's family. Alternatively, they contacted a social agency, a doctor, hospital or mental health professional, a community relations worker or on-site housing staff person to monitor the situation. Some housing providers were very active; for example, they met with the family, took fuses out of a stove or set up a buddy system right away. The least common response was to make arrangements to move the tenant to a long-term care setting.

We asked providers about six strategies they might use in order to deal with the presence of tenants with dementia. The most commonly used strategy was to work with other agencies; fully half the respondents had implemented this

measure. As well, about 25% had provided training and education for staff. The least common strategy was to increase staff.

However, among those who did not have tenants with dementia, only 6.8% had provided education and training for staff—and fully 50% had not considered it. Perhaps the most striking finding, however, is that there is little evidence that these respondents are thinking ahead about a problem which may arise in the future.

Other strategies for dealing with the presence of tenants with dementia, identified through open-ended questions, include increasing the amount of time staff spend on supervision and monitoring, and programmatic changes which allow tenants with dementia to remain in their apartments. Some respondents described physical changes to buildings that will increase tenants' safety and security, and others mentioned approaches which convey a value of community development and self-reliance.

A structured question revealed that respondents clearly recognized the importance of addressing the safety of all residents in planning how to respond to dementia in their buildings. It is notable, however, that housing providers place greater emphasis on the needs of other tenants (reducing stress for other tenants) than on the needs of the residents with dementia (“helping the person with dementia to live independently” and “increasing the length of time the tenant with dementia can remain in your housing”). In fact, the goal rated least important was increasing the length of time the tenant with dementia can remain in their current housing.

The final survey questions were open-ended. The first of these asked about the kinds of changes which would be most effective in helping accommodate tenants with dementia in the future.

Many respondents stated that more staffing would allow needed supervision and monitoring of residents, liaison with social and health services providers and on-site activities. Recognizing that “people with dementia need a caretaker first and foremost,” respondents called for “highly trained ... full-time ... in-house staff” who do not have to be “with the local housing authority.”

Also mentioned were modest physical changes to buildings, such as security systems, security locks on outside doors, resident-specific door alarms and modest changes to interior design and appliances, such as locked cabinets for medication and “stove minders” for ranges.

Additional suggestions included developing a type of enriched or supportive housing, including specialized suites, communal space, “on-site 24-hour response,” “added services” and a cafeteria-style dining area; education for staff and tenants; networking among housing, health and social service organizations; clustering tenants together in one space to make security and service delivery more efficient; and providing day programs.

Clearly these suggestions are not mutually exclusive. Many of the features suggested—such as on-site, 24-hour supervision and surveillance, clustering tenants, providing day programs—combine to make a picture of supportive housing. In fact, when these suggestions are combined into one concept, they far outweigh the call for more staff.

Cost was by far the most frequently mentioned barrier to change. Other barriers include lack of staff, lack of education and training for staff, resistance to and fear (among tenants, their families and housing staff) of turning seniors' housing into long-term care facilities, the inappropriate design of buildings, a lack of skilled workers in rural areas and human rights and legislative concerns (e.g., tenants' right to refuse assistance).

The most common suggestion or advice from housing providers to their colleagues who have tenants with dementia was to network and work proactively with health and social service providers and with families. Other advice was to provide supervision and monitoring for tenants with dementia; provide education about dementia to administration, front line staff and tenants; work with and be concerned about other tenants; create buddy systems in the buildings; transfer the tenant(s) with dementia to an appropriate long-term care setting; and finally, adapt their buildings.

Respondents were able to identify a wide range of community organizations to consult or collaborate with (e.g., home support services such as Home Care and CLSCs, Alzheimer organizations, provincial ministries and regional departments of health, long-term care facilities and psychiatric facilities). They said the best help these organizations could give would be to provide a regular and frequent on-site presence. They also mentioned activity and meal programs (both in and out of the buildings), help with activities of daily living, house cleaning and friendly visiting.

Organizations can also help by providing follow-up to crisis situations;

education and training for housing staff, tenants and tenants' family members; a 24-hour on-call service; and on-site nursing services. Respondents suggested that these organizations could help with assessment of residents and referral to other organizations or settings when necessary. Several looked to these organizations for guidance about when the person with dementia could no longer live in their building.

The final survey question asked about the most important things social housing providers need to know to deal with an increasing number of tenants with dementia living in their housing.

Housing providers strongly state that, first and foremost, they need to know about dementia—its signs, its stages, its consequences, the needs of people with this illness, how to manage tenants with dementia and at what stage these special tenants must be placed in a long-term care facility for their own and for other tenants' safety. They also need to know who to go to (and where) for help—they want names and telephone numbers. Finally, they need to know how to make their buildings safe and secure for their tenants with dementia and for the other tenants.

Some survey respondents stated clearly that their mandate does not include providing health care and supervision of tenants (although there was no survey question specifically asking about this). On the other hand, most responses indicated utter dedication to maintaining the highest possible quality of life for tenants with dementia, and a reluctance to move them to institutional settings, except as a last resort.

Discussion

The results of this study indicate that just over half the municipal housing providers in our sample are already providing accommodation to people with dementia. This trend is likely to continue, and it is likely that an increasing number of municipal housing agencies will be providing accommodation to tenants with dementia. We may also expect to find a growing percentage of senior tenants with dementia among the tenants of any individual provider.

Challenges relating to how to respond to this circumstance appear to fall into two major categories. The first has to do with specific practical responses to issues which emerge from the study data. The second has to do with some factors that must be considered when developing a longer term response to accommodating people with dementia in municipal housing.

Practical Responses to Specific Issues

The results of this study suggest that much needs to be done to enable municipal housing organizations to respond to the presence of tenants with dementia. Their own responses, particularly to the open-ended questions, suggest that providers have a wide variety of needs and problems, and the number and variety of responses makes the task of assisting them seem quite daunting.

However, a more careful consideration of the study results suggests that the responses to the study findings fall into four major categories. All of them are areas in which local and provincial Alzheimer organizations may make a contribution.

Educate housing providers about the nature of the problem.

Although just over half the survey respondents reported having one or more tenants with dementia, few appeared to have developed a systemic response to the problem. Among those who reported not having any residents with dementia, the most striking pattern is that there is little evidence that these respondents are thinking ahead about a problem which is likely to arise in the future. Housing providers need to be made aware of the projected prevalence of Alzheimer Disease and related dementias and of the increasing probability that their buildings will be home to a growing number of people with these disorders.

Encourage housing providers to develop a plan to respond to this situation.

Once housing providers are aware of the problem, they need to plan a response. Responding to individual cases will prolong the time the resident can remain in the housing, but a more comprehensive approach will help the provider develop a response which balances the needs and rights of the resident with dementia against those of other residents and their families, as well as housing staff and administration. A more comprehensive approach to planning will also allow housing providers to consider how to provide for the safety of all tenants within the constraints imposed by the existing structure, financial constraints and the organization's mandate. Such a plan could also provide guidance about when a person with dementia would need to move to a higher level of care. In turn, this would assist family caregivers in their own long-term planning for care of their relative.

Help housing providers get the information, education and training they require about dementia and dementia care.

When respondents were asked about what they need to know to deal with a growing number of tenants with dementia in their housing, they said that, first and foremost, they need to know about dementia—its signs, its stages, its consequences, the needs of people with this illness, how to manage tenants with dementia and at what stage these special tenants must be placed in a long-term care facility for their own and other tenants' safety. They also need to know who to go to (and where) for help—they want names and telephone numbers. Finally, they need to know how to make their buildings safe and secure for their tenants with dementia and for other tenants. Education and training are called for.

Ensure that staff of the agencies they work with have the information and skills to provide good dementia care.

Since the most common response to having tenants with dementia was to work with other agencies, it is important to ensure that agency staff are able to provide quality dementia care. At many of the agencies, staff will already be versed in this area, but there will be exceptions. Alzheimer organizations can assist with staff training or suggest other ways in which necessary staff training can be provided.

Strategic Considerations

As housing providers develop a response to the growing presence of tenants with Alzheimer Disease and related dementias, they will have to balance a number of complex factors. Some of these are discussed briefly below.

An issue of equity

A strategy for accommodating residents with dementia will need to address the question of whose needs are to be met and which perspectives will be incorporated into the response. It must respond in an equitable and balanced manner to the needs of residents with dementia and the non-impaired. Both these groups have the right to a safe and secure environment which facilitates, to the maximum level possible, their ability to function independently and to have a good quality of life.

The response should consider the right of all residents to age in place, to remain in their own homes (i.e., the units they are living in) for as long as possible. Although it is important to meet the needs of residents with dementia, this must be tempered by the recognition that municipal housing should not "become a nursing home." This concern about adapting buildings and services to the point that the housing becomes a long-term care facility was expressed by several respondents, and is a legitimate concern of housing providers, housing staff, other residents and their families.

In part, this concern has to do with the self-image of non-demented residents, who may feel concerned about their own future in the face of the cognitive deterioration of their neighbours. Research in long-term care settings indicates that cognitively well elderly have made it clear they do not want to spend their lives with people who are cognitively impaired.

The results of this study indicate that cognitively impaired residents of municipal housing may engage in activities which are disturbing to their

neighbours (e.g., making noise, knocking on their door, entering the neighbours' apartments). The potential for caregiver burnout exists if non-demented tenants are expected to provide care for those with dementia or otherwise assume responsibility for their well-being.

As well, it is important to ensure that municipal housing continues to attract new residents, who have both the right and the need to take advantage of this kind of living. If municipal housing is perceived to have become a community living facility for people with dementia, cognitively intact residents will no longer wish to move there.

Legislative and regulatory barriers

A number of respondents referred to the legislative and regulatory barriers to responding to the presence of tenants with dementia. The most frequently mentioned was the mandate of the housing provider and the question of whether its role was to provide shelter ("bricks and mortar") or whether its mandate also includes the provision of services. This issue, which often involves other levels of government, needs to be given consideration in planning a response.

Another factor which must be dealt with is an individual's right to refuse assistance. This difficult issue is not unique to the question of how to respond to tenants with dementia in municipal housing, but it also needs to be addressed in any strategy which is developed.

Funding sources

Responding to the presence of tenants with dementia will involve additional costs, and costs were the most frequently mentioned barrier to making

changes. This raises the question of who will pay for additional services, a particularly thorny issue in a time of increasing financial restraint.

Each housing provider will have to arrive at its own resolution of where the increased funding will come from. To the extent that this is viewed as a provincial, as opposed to a local, issue, discussions should take place between the Ministry of Health and the ministry responsible for housing in each province.

A number of arguments can be made that provincial Ministries of Health should provide funding towards programs which will help residents with dementia remain longer in municipal housing. The simplest of these arguments has to do with the relative budgets of the ministries responsible for housing and those responsible for health. In every province, the budget of the Ministry of Health far exceeds the budget of the ministry responsible for housing. Furthermore, if residents with dementia were forced to move from municipal housing to a long-term care setting, the cost of caring for them would increase significantly, a cost which would then be paid in full by the Ministry of Health. As well, where people with dementia live in municipal housing and receive home care, the money spent on specific programs for them could be found through a reallocation of some existing home care expenditures to fund these dementia-specific programs. Indeed, this might represent a more efficient use of existing resources, which would allow increased numbers of residents with dementia to benefit from the same number of dollars.

Conclusion

The aging of the population, combined with policies to promote aging in place, means that municipal housing will be home to a growing number of tenants with dementia. A survey of municipal housing providers has highlighted the need to develop systemic responses to this situation. A review of major themes in the data suggests some important roles for Alzheimer organizations in assisting housing providers to meet the needs of residents with dementia.

Long-term responses to the situation must achieve a balance between the needs of residents with dementia and those who are cognitively intact. The response must also recognize the presence of legislative and regulatory barriers to housing residents with dementia, as well as funding implications. Although these factors represent significant challenges to developing a long-term response, they should not be viewed as preventing a successful resolution to the question of how to accommodate residents with dementia in municipal housing.

Note: This study is currently underway and is being funded by Canada Mortgage and Housing Corporation (CMHC) through the External Research Program. The study is expected to be completed in the fall of 1996.

Housing Options for People with Dementia

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Background

The rapid growth of the senior population—people 65 old or older—in Canada could result in a substantial increase in the number of people who suffer from dementia and this, in turn, might have significant implications for many segments of the population. More and more caregivers, including families and friends of those suffering from dementia, health care providers and housing sponsors and managers are likely to be affected. However, innovative housing solutions may offer some help. From experience in countries where the proportion of the seniors' population is greater than that in Canada, such as the Scandinavian countries, it would appear that the availability of housing options designed to meet the needs of people with dementia, and their families, could play an important role in easing the consequences of dementia.

Dementia, one the most severe brain disorders affecting seniors, particularly those 75 years old or older, is becoming one of the most important challenges of our times. According to the 1991-1992 Canadian Study on Health and Aging, undertaken by Health Canada and the University of Ottawa, more and more seniors will be affected by this disorder in the years to come. Today, about 250,000 Canadians are suffering from dementia. By the year 2031, when the baby boom generation moves fully into the ranks of seniors, it is expected that this

could increase to 800,000. Given that about 50% of those who suffer from dementia also suffer from severe physical disabilities, it is very difficult for them to carry out their daily activities in conventional housing environments.

Recognizing the challenges posed by the growing numbers of seniors with dementia, the public, private and non-profit sectors have implemented a range of initiatives that are designed to address the needs of seniors, as well as those of their families. As a result, a variety of long-term care facilities and special care units for people with dementia are available across Canada. Progress has also been made in making available a wide range of respite programs which are designed to enable seniors to remain in their homes for as long as possible. However, from day-to-day feedback received from formal and informal caregivers, as well as from many individuals representing organizations, associations and agencies that provide services for seniors and their families, it seems evident that very few housing options exist in Canada which can fill the gap between institutional environments and conventional individual homes.

On the other hand, results from preliminary research in this area by the Research Division of Canada Mortgage and Housing Corporation (CMHC) indicate that a number of innovative housing options have been implemented successfully in a few communities in Canada and in other countries such as Australia, Sweden, Denmark and the United States. It is also evident that a number of publications are currently available in Canada and abroad which deal with the design of the physical environment for people with dementia. However, no publication exists which is designed to increase awareness about the kinds and

range of housing options that are, or could be made, available in Canada.

Therefore, CMHC, in collaboration with the Alzheimer Society of Canada, decided to undertake a research project that will lead towards the production of a guide document on innovative housing options for people who suffer from dementia.

Objectives and Scope of the Publication

The guide will identify, describe and illustrate a wide variety of examples of accommodation options that could help meet the needs of people with dementia and their families and caregivers. The emphasis will be on residential options rather than on institutional accommodation such as special care units, nursing homes and long-term care facilities. However, the guide will discuss the role that institutions play, or could play, in helping people with dementia live in the types of residential accommodation included in the guide. Residential options will include ways of adapting individual homes and multiple-dwelling buildings, as well as innovative types of housing that are specifically designed and built to meet the needs of people with dementia and their caregivers.

The Purpose of the Publication

While the main purpose of the guide is to increase public awareness of the range and types of accommodation options that are, or could be made, available in Canada, the guide will also identify and provide guidance on the basic considerations, strategies and approaches that would result in supportive and home-like solutions, in terms of:

- location

- types of development and buildings
- types of accommodation
- architectural design of the dwellings, buildings and sites
- privacy and opportunities for social and recreational activities
- support services, which could include on-site services as well as facilitating access to community-based services
- technologies that could help both people with dementia and their caregivers.

Participants at this workshop were presented with a range of examples of the types of projects that are being considered for the publication. They were also asked to identify other projects for consideration.

Completion of the research project that will lead towards the production of the publication is planned for the fall of 1996. CMHC is planning to make the publication available to the public in the third quarter of 1997.

Update: Dementia Care Facility

Alzheimer Society of Ottawa-Carleton

**Kathy McKinlay, B.A., Certif. Ed., M.B.A.
Director, Facility Project**

In June 1994, the Board of Directors of the Alzheimer Society of Ottawa-Carleton adopted a new strategic direction for the organization. It voted to investigate the feasibility of building an innovative residential-style facility that would demonstrate a new way of caring for people with dementia in the early to middle stages of the disease. This decision was taken at the end of a two-year strategic planning process that included a family needs study and extensive community consultation.

This presentation addresses the kind of facility the Society is planning to develop, the steps involved and some of the challenges.

What kind of facility?

After consulting with family members and community agencies to confirm the need for specialized housing for people with dementia in Ottawa-Carleton, the Society completed a research report to identify housing options available to meet the needs. It settled on a design that is a modification of a facility in Tasmania, Australia that is called the ADARDS Nursing Home. The facility will consist of four residential-style bungalows which will each house nine residents. During the day, the bungalows remain as four self-sufficient units. At night, the walls in the central area are opened up, converting the bungalows into a 36-bed nursing unit that is staffed by two people who supervise the residents in all four houses from

the central area. Each bungalow has a combination of private and semi-private rooms.

What is unique about the facility?

The facility:

- will be small, homelike. It is designed to be as much like a family home as possible with bedrooms, living, dining and laundry areas.
- will be home for people who all have dementia.
- will include special design features (e.g., wandering path, camouflaged exits, sound-proof areas, fecal drains, specially designed cupboards for people who rummage).
- will offer meaningful activities. The activity program will revolve around activities of daily living and residents will be involved in the management of the home as much as possible.
- will have innovating staffing. Generic workers will be assigned to residents on a consistent basis.
- will put a major focus on staff training.
- will maximize the use of outdoor space (e.g., enclosed yard for each house that has amenities such as gardens, toolsheds).
- will be a cost-efficient design.

How will the facility be managed?

The Alzheimer Society of Ottawa-Carleton will create a new non-profit corporation with its own board of directors to manage the facility.

What are the expected results?

The Society is excited about replicating the results from the ADARDS Nursing Home in Ottawa-Carleton. After five years, the ADARDS project is reporting:

- high quality care at reasonable cost
- fewer problem behaviours
- decreased drug use
- high staff morale, low staff turnover.

What steps have been taken?

The following action steps were taken between April 1995 and April 1996:

- site visits. Several facilities were visited including residential care facilities in Madison, Wisconsin.
- visit by Dr. Tooth, Clinical Director, ADARDS who gave presentations to the District Health Council and the Board of Directors of the Society.
- fundraising feasibility study (November 1995 to February 1996). It confirmed a high level of interest and support for the facility. The Society learned that fundraising would be a challenge in this economy and that they would have to be creative and use many different strategies to raise funds.
- marketing and financial feasibility study (completed March 1996). This study was undertaken to confirm that there was a population who needed the care and who were prepared to pay for it at the cost structure that was developed. This was an important step because costs will not be subsidized.

- task forces. The following four task forces were initiated: Financial and Planning Task Force, Architect Selection Committee, Partnership Task Force and a committee to develop admission and discharge policies. They hope to incorporate input from all four committees into a detailed business plan which will be presented to the board in late spring or early summer 1996.
- feasibility study for a Dementia Studies Certificate Program. In a related project, the Alzheimer Society of Ottawa-Carleton has funded a study to investigate the feasibility of developing a post-diploma program in dementia studies at Algonquin College in Ottawa. If sufficient need for this program is demonstrated, it will be the first of its kind in Canada. The care workers at the new facility would be required to take this program. It would also be made available to other professional and family caregivers in the region.

What are the challenges?

Two challenges are highlighted--funding and partnering.

Funding

No operating subsidies have been secured to date. The Society will continue to make every effort to ensure that the facility will eventually be subsidized. Until such time as funding is secured, the facility will operate on a private pay basis, with fees in the range of \$110 to \$135 per day. This includes all expenses such as medication and incontinence products, if required. It may be possible to offer a small number of subsidized beds through donations from private sources.

The Society recognizes that it may be criticized for developing a facility that caters to a high income group. Its goal is to serve the greatest number of people from all economic groups. However, the Society considers it important to proceed with a demonstration project that can be copied in whole or in part by other long-term care providers across Canada, and result in operating subsidies being available in the future. The Society hopes to influence government decision makers by demonstrating a more effective approach to caring for people with Alzheimer Disease and related dementias.

Partnering

A number of long-term care facilities and hospitals have expressed interest in partnering for this project. The terms for such a partnership are still open for discussion. Benefits of partnering include the following:

- the facility could be built on or adjacent to the partner's land which would be provided free or below market value.
- shared services which would decrease costs.
- possibility of resident exchanges. People with dementia in long-term care facilities or hospitals with low and medium care needs may be exchanged with those from the home as their needs increase.

Some concerns about partnering include:

- the decision-making process may be slower and more bureaucratic.
- a possibility of moving toward the status quo if the new facility is paired with a larger organization with its own well established care practices.

- being seen to be aligned with one organization, may result in being viewed as endorsing their care practices, practices over which they would have no control.

Update: Alternative Housing

Alzheimer Society of Manitoba

Joan Ernst Drosdoski, R.N., B.S.N., M.S.
Program Director

Last year, the Alzheimer Society of Manitoba reported on a theoretical project on alternative housing. Since then, the Society has undertaken a feasibility study to determine the costs of building and operating two types of homes—a single unit residence (group home) to house 10 people and a multi-unit residence to house 36 people. This study, which took approximately 13 weeks, has just been completed. This presentation reviews some of the steps and related factors involved with the study.

Choosing the Architect

One of the first steps in the study was to put the project to open tender for architects in Manitoba. Among the challenges in choosing an architect were the following:

- in general, architects in Manitoba were not experienced in designing facilities for people with dementia.
- those responsible for interviewing the architects expressed a lack of confidence in their ability to do so and recommend using architectural and construction consultants not involved in the tender process to review the initial proposals.
- consideration needs to be given to the choice of architectural firm itself. Will you be considered a significant client with a large firm? Does a smaller firm have adequate resources to create something innovative?

Developing the Steering Committee

A Steering Committee was developed to work with the architectural team. The committee consisted of four board members, three staff members, two consumers, a volunteer with a special interest in this area and the architectural team (one architect and one interior designer).

Consumer input was very important. The two consumers brought a Personal Care Home (PCH) perspective to the committee because their family members had resided for some time in PCHs. If doing the study again, the investigators would choose consumer representation differently. They would choose one person caring for a younger family member with Alzheimer Disease at home, one with a family member currently in a PCH and one who had been through the entire process and who had worked through his or her grief over the loss of the family member.

At the start of the project, four members of the Steering Committee attended the conference in San Diego organized by the Institute of Aging and Environment from the School of Architecture and Urban Planning at the University of Wisconsin.

Licensing

In Manitoba, the facility would be licensed as residential care under Family Services rather than under Health. Residential care is a group home type of model. There are numerous residential care homes already in existence. They are private pay and offer a lower level of care than a PCH. Although some of these facilities have residents with dementia, they are not designed or equipped to

provide this type of care.

Targeted Clientele

The targeted clientele of the facility are those people who cannot stay at home with home care, those going to PCHs and those in residential care facilities not designed for people with dementia. This would include those whose required care is classified at Level I and II and perhaps some people at Level III.

Costs

Projected operating costs per day of the 36-bed unit are lower than what is currently being paid in PCHs in Manitoba. The estimated daily operating cost is approximately \$66. The projected daily operating cost for a 10-bed unit is \$75 which, in Manitoba, is similar to the low end of nursing home costs because of the staffing component which could not be reduced.

Estimated building costs for the 36-bed unit are \$2.7 million. Per square foot, this is cheaper than building a nursing home in Manitoba. However, per square foot per resident, costs are higher because of the provision of considerably more space in designs for walking, wandering, communal living and personal hygiene in bedrooms. To build a 10-bed unit is probably no cheaper than building a PCH.

It is possible that the cost estimates for the building could be reduced somewhat through such measures as sharing equipment between homes and consolidating parking or deleting features such as greenhouses and fireplaces.

Fact Sheet

The Alzheimer Society of Manitoba has prepared a Fact Sheet (provided at the conclusion of this section) to indicate what makes this model different from a PCH. It outlines the philosophy of care, unique design features and the non-medical approach to staffing and providing care.

Summary

To be implemented, this model will have to be cheaper than PCHs. Manitoba Health has indicated verbally that they will help subsidize another approximately 100 to 150 alternative places in the next years. However, what this involves has not been clearly defined.

The Board of the Alzheimer Society of Manitoba has not decided if the Society itself will proceed with the project, if they will partner with other groups or if they will encourage someone else to do it.

Update: McConnell Place North, Edmonton

The Capital Care Group

Helene Rust, B.P.T., M.S.A.
Director, Clinical and Support Services

McConnell Place North opened in July, 1995 and is the first facility of its kind in Canada. It provides specialized care for persons with Alzheimer Disease in a home-like residential setting. It is part of the Capital Care Group, a publicly funded continuing care organization.

The project to develop this facility was a total team effort. It began with the front line staff and family members who identified the need to have special places for people with Alzheimer Disease. At the same time, the senior management of the Capital Care Group recognized the need to diversify and specialize and chose to emphasize the needs of special populations. They toured several facilities and received information from the United States and from Dr. Tooth in Australia, did research and undertook feasibility studies.

The project came in under budget (\$2.5 million) and on time. The facility is almost 25,000 square feet and was constructed at a cost of \$75 per square foot or \$69,000 per bed. It is located in North East Edmonton, adjacent to a long-term care facility from which nursing, pharmacy and medical services can be delivered to the home.

A donation of \$1.5 million has just been received from an individual with Alzheimer Disease. It will be put toward the building of a second centre which is scheduled to begin in March 1997.

McConnell Place North is innovative in areas of: design, resident care, funding, outreach services, education, evaluation and research.

Design

The facility is modeled on Woodside Place in Oakmount, Pennsylvania. The design was modified to suit a northern climate and to reflect Canadian culture. As home to 36 people, it consists of three 12-bed houses linked by a common and administrative area. Each house has 10 private bedrooms, one double room, private bathrooms with showers, a full kitchen and a dining/living room, quiet areas, a recreational area and an area for personal laundry. As well, each house, with its own colour theme, has a secure outdoor courtyard, a great room, TV room and family and dining room. Rooms have quilts handmade in Alberta and art on the walls that depicts prairie themes that residents can identify with. There is a separate dining room for private family functions. In total there are over 1,100 feet of walkways in the complex.

Resident Care

The facility was designed for those in moderate stages of Alzheimer Disease who can participate with direction and assistance in everyday activities but who may require support with behaviours such as wandering and anxiety. Staff assist residents in carrying out those activities they can still manage, such as making their bed and doing their laundry. Residents are usually referred through Home Care or a physician. Some have transferred from other centres. All have been assessed through Alberta's single point of entry system.

Care is based on the social model, is focused on small groups, everyday living and flexible routines. The staff are multi-skilled workers referred to as resident companions. There is not one person assigned to do recreation, another to do laundry, food service, etc. Staff are chosen because they want to be there and are selected according to their personal traits. A two and a half week training program is provided by the facility and is taught by in-house teachers and experts from the University of Alberta Centre for Gerontology and others in the field.

There is a Licensed Practical Nurse on-site 24 hours a day and a Registered Nurse manager in the building during the day.

Funding

The facility was funded through a partnership of local and provincial governments, a public health facility and a volunteer society. Capital funds (\$2.5 million) for construction were raised by The Capital Care Foundation. Probably as much as 25% of this came from staff donations. Alberta Health, following a series of negotiations with the Capital Care Group, approved reallocation of operating funds from the closing of long-term care beds in other facilities. The City of Edmonton provided 2.4 acres of land. The Alzheimer Society of Edmonton also gave support which allowed for a lot of public relations work to be done. Building the facility increased public awareness in Edmonton and provincially about Alzheimer Disease, the potential of what can be provided for those with the disease and what needs to be accomplished.

Outreach Services

An Alzheimer Support Centre is managed from the administrative area of the home. It provides a HELP line and ongoing support for families of residents and community caregivers. Information sessions and discussion groups are held at the Centre.

Education

Tours of the facility are arranged on a limited basis (pre-arranged, one afternoon a week, no more than three people at a time) so as to cause minimal disruption for the residents. The Outreach Coordinator gives lectures to community groups and educational institutions. The centre is also a site for student placements.

Evaluation

The Centre is being evaluated as a New Models in Continuing Care Demonstration Project through a New Horizons Grant funded by Health Canada EPICC (Evaluating Programs of Innovative Continuing Care) Evaluation. As well, the University of Alberta and the Capital Care Group are carrying out a 2-year evaluation. The University of Wisconsin (Milwaukee) Institute on Aging and Environment will also be conducting an evaluation.

Research

The Centre has very recently set up a partnership with the University of Alberta, Centre for Gerontology to do research.

Summary

At the present time, there are 36 residents in McConnell Place North. Two residents have been discharged over the nine-month period and one is waiting placement in a long-term care facility. There are 21 people on the waiting list.

Issues

The following issues were raised by participants at the workshop in response to the six presentations. No priority has been assigned to the issues.

1. Providing separate facilities for those with dementia in municipal housing.

The idea of the separation of people with dementia from those without dementia is extending from institutional settings to retirement homes and now to municipal housing. Myra Schiff expressed her belief that separate units in institutional settings provide advantages to those with dementia by reducing the stress of being expected to perform at a certain level. The same advantages may apply for residents with dementia in retirement homes and municipal housing.

There are a number of potential solutions for municipal housing that will be researched through case studies. These include special programming for people with dementia (meal programs and day programs) and moving people into one section of the home. The aim would be to have programs available when people need them and not, for example, during a three-hour block of time in the morning.

2. Developing housing for those in early and middle stages of dementia as a replacement for home care.

Presenters indicated that there was no intention to replace care provided at home. Rather, care in the residential-style units is planned 1) for those who

cannot be cared for at home for whatever reason, 2) for those being cared for in nursing homes who do not require that level of care or 3) for those being cared for in homes that are not designed or equipped for people in the early and middle stages of Alzheimer Disease.

3. Funding demonstration projects that involve care that is not subsidized and therefore beyond the financial means of most people.

Kathy McKinlay indicated that it is important to determine that this model of care works. When this is shown, it is hoped that either all or parts of the project will be taken on by others and that in the future, subsidies will be available.

4. Demonstrating that care in residential-style facilities is cheaper and more appropriate than care in existing long-term care facilities.

It may be possible to argue that a residential-style facility is providing more appropriate care at similar or lesser costs than in existing long-term care facilities. Most of the costs will be for staffing. In Ottawa-Carleton, staff ratios during the daylight hours will be two staff for nine residents. The costs of providing this ratio is within the range of a public facility's daily operating expenses.

1. Raising public funds for a project aimed for those with high incomes.

Kathy McKinlay indicated that whatever fundraising is done for the Ottawa-Carleton project, the Society will be open with the public about where the

money is going. They are exploring a variety of ways to raise money such as contributions from service clubs, foundations and corporations, mortgage financing and resident investments (families invest a certain amount of money when the resident moves in and get it back when the resident leaves). At this time the Society is hoping not to hold a public fundraising drive.

5. Providing tax deductions for people living in unsubsidized housing.

The possibility of tax deductions is being investigated by the Financial and Planning Task Force of the Ottawa-Carleton project.

6. Making the transition to other settings when the need for care increases.

It is important to keep people in the same environment for as long as possible. On the other hand, this environment may no longer enhance the residents' quality of life once they reach a certain stage of the disease. There are many other people who could benefit from a setting where they can move around and benefit from activities.

One speaker indicated that the initial plan of care in their home would include a discussion of where the resident will go when he or she is no longer able to remain in or benefit from a residential-style setting. Another speaker suggested that it may be possible for people to stay until the end stage of the disease if the family or community agency can provide the extra care required to make remaining in the home feasible. If this is not possible, the staff would

work with the family and a placement service to make the transition to a new setting as smooth as possible. To date, a perfect solution to this problem has not been found.

7. Losing volunteers when residents move to new facilities.

The potential exists for volunteers to be lost from the system when residents are required to leave a home and move to a facility providing a higher level of care. However, in the Alberta experience this has not been the case.

Volunteers moved with the residents from the home to new settings and in some situations came to the home with new residents.

8. The role of the local Alzheimer society in the provision of residential-style housing.

A variety of roles were proposed. A new non-profit corporation will be created by the Alzheimer Society of Ottawa-Carleton to operate the facility. The Society sees a benefit to being at some distance from the operation of the facility. The nature of the relationship between the Alzheimer Society and the new non-profit corporation has not been determined.

Numerous options are being investigated by the Alzheimer Society of Manitoba. A home may contract with the Society for education and training. A facility may include meeting space for Alzheimer support groups in its design plans. Board members from the Alzheimer Society may sit on the

facility board. The Society may manage the facility.

In Edmonton, the Alzheimer Society was involved on some of the Steering Committees (design and program) and was considered a partner in the venture. The public relations and support derived from the Society's name were important.