HOUSING ALZHEIMER'S DISEASE AT HOME

by

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ABSTRACT

This study investigated the practical, physical modifications made to private dwellings by caregivers and others in order to accommodate the characteristic behaviours of Alzheimer's Disease (AD) and the needs of caregivers. Information was gathered by means of a literature search, telephone interviews, a national survey questionnaire, and twenty-five personal interviews with caregivers of AD persons. Questions focused on: safety and security precautions; strategies for enhancing orientation and accommodating wandering; means of preventing or reducing agitation; and meeting caregiver needs. Pertinent findings are presented in a concise chapter in the form of suggestions to caregivers. Unintended findings and suggestions based on them are reported in appendices.

PREFACE

Six years' experience working directly with elderly institutionalized adults - many of whom had Alzheimer's Disease or a related disorder - followed by several years involved in research on the housing of elderly Canadians, led me to an interest in the question of housing Alzheimer's Disease at home.

Knowing that most of the caregiving to elderly people is given by the family, and that our institutions accommodate only a small proportion of the older population, including the population with Alzheimer's Disease (AD), I decided to investigate "what goes on behind closed doors"; that is, how families and their helpers accommodate the characteristic behaviours of AD and the needs of caregivers, in private dwellings.

As with my research on elderly widows living alone in their own houses, my focus is on the fit between existing, private housing and the characteristics of the users, rather than on ideal private or institutional housing for persons with AD.

There is a gap between two extant bodies of literature on the topic of housing people with Alzheimer's Disease. One concentrates on the psycho-social experiences and needs of private caregivers: the stress, emotional drain and exhaustion that they experience, their need for respite. Another small but growing body of work concentrates on "designing for dementia" - but the design principles and guidelines apply exclusively to institutional settings.

Therefore, there is clearly a need for some useful information on the <u>physical, practical aspects of housing Alzheimer's Disease at home</u>. Who needs this information? Three groups of people in particular: current and future caregivers of people with Alzheimer's Disease, so that they may take advantage of other people's creativity and solutions; architects and designers of retrofitted or purpose-built housing for cognitively impaired people, so that these professionals can learn about the spatial, safety and other needs of a special user group; and finally, policy makers, so that they may become more aware of what actually goes on in non-institutional environments, where the majority of people with Alzheimer's Disease are housed.

A number of people helped carry out this research project and produce this report. I am indebted to: Dorry Gould, Madelaine Honeyman and the many other executive members of the Alzheimer Society, in chapters across Canada, without whose support the research could not have been carried out;

Edward Leman of Chreod Associates, who helped in developing the proposal; Fanis Gremmanos of CMHC, who was a continual source of affirmation; Denise McConney, Catherine Adam and Lise Shapiro whose assistance was essential to getting the job done; Linda Coulter, whose comments helped in formulating the suggestions to policy makers; and Richard Limmert, whose sensitivity as an architect and experience in designing for Alzheimer's Disease were invaluable to both the research approach and the formation of suggestions to architects.

The greatest thanks, however, go to the current and former caregivers of people with Alzheimer's Disease, who were interviewed by me in their homes. Their courage and resignation, energy and exhaustion, devotion and guilt, helplessness and creativity, desperation and determination will never be forgotten. I dedicate this document to them.

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EXECUTIVE SUMMARY

This research on housing Alzheimer's Disease at home focuses on the practical, physical changes that have been made by caregivers and others to private dwellings in order to accommodate both the characteristics of Alzheimer's Disease (AD) and the needs of caregivers.

Research methods included a literature review, telephone interviews with key informants, a national survey by means of a mail-out questionnaire, and twenty-five personal interviews with private caregivers of people with Alzheimer's Disease, in every region in Canada.

Several themes emerge from research findings.

First, with regard to safety and security: the need for constant surveillance or supervision of the person with Alzheimer's Disease is revealed; and a number of basic safety precautions are common, such as the installation of extra locks on exit doors, the removal of dangerous objects or substances, the regulation of appliances with the potential to cause burns or fire, and the addition of a number of assistive devices in bathrooms.

To enhance orientation: the addition of night lights en route to or in the bathroom, or keeping on lights all day and night is typical; the removal, conscious closing or marking of doors, and the posting of signs, symbols or notes to aid orientation is not uncommon; and alternatively, keeping the environment as familiar and unchanged as possible to avoid an escalation of disorientation, is frequently reported. The number and degree of modifications to the home vary with the individuals involved and the stage of the disease. .

To accommodate the symptomatic pacing and wandering of the AD person: having furniture pushed back against walls and coffee tables and other small tables removed to clear a path is standard practice, as is recruiting neighbours, police and others to "keep an eye out" for the wanderer in the neighbourhood.

To prevent or reduce agitation: keeping curtains drawn (to eliminate reflections, which can be frightening when unrecognized) and removing or covering mirrors (for the same reason) is done in the later stages of the disease; simplifying household routines, keeping the television off, and carrying out favourite activities are all reported to be successful measures for preventing or reducing patients' agitation.

Regarding caregivers' needs: the need for "a room of one's own" is declared repeatedly, as is the need for respite, the opportunity to get away from the Alzheimer household more often than once or twice a week, for longer than a couple of hours.

The essential, practical information about housing Alzheimer's Disease at home is presented in chapters 1 and 2 of the report. Appendices contain unintended findings, suggestions to policy makers and architects, a description of research methodology and a bibliography.

1. INTRODUCTION

1.1 Alzheimer's Disease

Alzheimer's Disease (AD) is a progressive, degenerative disease that attacks the brain and results in impaired memory, thinking and behaviour. It is recognized as the most common cause of dementia and affects an estimated 300,000 Canadians.

Symptoms of AD include cognitive, behavioural and physical changes. Not all persons with Alzheimer's Disease have the same symptoms. They vary by individual and with the stage of the disease.

The main cognitive changes characteristic of Alzheimer's Disease include: gradual memory loss, especially recent memory; impairment of judgement; marred visual perception, especially depth perception; a decline in the ability to learn and react and to carry out routine tasks; loss of language skills and abstract reasoning; disorientation.

The typical behaviourial changes are: agitated, persistent, purposeless behaviour such as wandering and rummaging; changes in sleep patterns (typically getting up in the night); quickness to anger, often directed at the primary caregiver; demonstrated fear of darkness and fear of being alone; and a marked deterioration in personal grooming habits.

Although many persons with AD remain physically very fit well into the advanced stages of the disease, others experience physical changes, such as: loss of muscle strength and the resulting need for a walker or wheelchair;

the tendency to stumble (related to loss in depth perception for one thing) and to suffer unexplained "very heavy" falls.

AD victims eventually become incontinent and totally incapable of caring for themselves.

It is estimated that less than one percent of people under age 65 are affected by AD, while it affects 25% of persons aged 85 or over. With Canada's old-old population increasing at a faster rate than any other age group, it is apparent that there is - and will continue to be - an increase in the absolute number and proportion of older Canadians suffering from Alzheimer's Disease who will require appropriate housing and care.

1.2 Housing Alzheimer's Disease

Most Alzheimer patients live at home with their caregivers. The primary caregiver is usually a spouse; the secondary caregiver another family member or a hired part-time helper. The practice of housing people with Alzheimer's Disease at home - at least until the very final stages of the disease - will continue in Canada for both economic and humane reasons. First, we will not be able to afford to build special facilities for all of them; and second, it is already well known that the familiar, domestic environment is best suited for management of people with Alzheimer's Disease, causing far less agitation and loss in self-esteem than institutional settings.

Despite current practices and realistic future scenarios based on the intention of caring for AD victims for as long as possible at home, there is almost no literature concerned with physical aspects of housing Alzheimer's Disease in private dwellings. Instead, there exist two bodies of knowledge flanking this concern: one concentrates on the psycho-social needs and experiences of caregivers at home; the other is made up of design approaches and guidelines for institutional settings.

For these reasons, a study was designed and carried out which investigated the modifications made by caregivers and others to private dwellings where people with Alzheimer's Disease are housed. The purpose of the research was to gather information about "what goes on behind closed doors", in order to begin to fill the gap in our knowledge about housing AD. The larger objective was to produce a document which would be informative and useful to three groups of people: caregivers, both current and future, so that they may take advantage of other caregivers' creativity; architects, who may find these research findings useful, given the paucity of information available to them on designing for dementia; and policy makers, whose understanding of living with AD may be enriched by reading this report.

1.3 Scope of Research

The scope of research is national. Information was gathered from executive members of the Alzheimer Society and caregivers in every region in Canada. This was done in order to sample as many contexts and situations as possible, and to increase the chances that the results would be meaningful to people in all parts of the country. (Data gathering methods are described in Appendix D.)

The parameters of the research topic were quite specific. That is, the practical, physical modifications made by caregivers and others to domestic environments in order to accommodate the characteristics of Alzheimer's Disease and the needs of caregivers were investigated.

1.4 Outline of Report

Despite the fact that research questions (on both the survey questionnaire and in personal interviews) belaboured the theme of "practical, physical modifications", answers tended to include a great deal of information about the psycho-social stresses of being a family caregiver of a person with Alzheimer's Disease. In fact, the anguish of the caregiving role spilled over into almost all the responses.

In order to produce a report that is useful, practical and on topic - but at the same time, to retain the valuable, descriptive information provided by caregivers about their psycho-social stresses and needs - the intended research findings (those concerned with practical, physical changes to the domestic environment) were extracted to form the key chapter of this report, and the other findings were sub-divided into appendices.

The following chapter (2) is the essence of the report. Addressed to caregivers, it is a brief summary of the relevant research findings from all sources, and an organized list of suggestions about practical, physical modifications that can be made to the home to accommodate the typical behaviour of a person with AD and to meet some of the needs of caregivers. Two general suggestions with regard to housing policy, based on research findings, conclude the chapter.

Appendix A contains some of the findings that were not considered "on topic", since they describe living with Alzheimer's Disease, in particular the psycho-social impacts of the disease on caregivers and other family members. This material is not excluded from the report because it was felt, first, that caregivers' rich descriptions and poignant statements about living with Alzheimer's Disease should not be lost; and second, that an intimate portrait of the situation of caregivers would be useful to many readers.

Appendix B comprises suggestions for consideration by health and social policy makers, based on outstanding research findings (many of which are revealed in Appendix A) and on caregivers' comments or pleas directed to policy makers. The suggestions are not included along with those to caregivers, since they are not concerned with practical, physical changes to the domestic environment, but instead focus on caregivers' needs for health and social support services.

Appendix C is addressed to architects. A few architects are likely to be retained to make structural changes to private residences to accommodate AD, and many more are going to be called upon to design or retrofit institutional settings. For these reasons, and given the paucity of information available about designing for dementia, all the relevant information gathered in this study and considered to be useful to architects, is presented in Appendix C.

Appendix D contains a description of the methods used in carrying out this research project. It was assumed that the average reader would not be interested in a description of research methods, apart from a very brief account of information sources. Therefore, a chapter on research methods was not included in the body of the report. Other researchers, however, may find some of the details of the research process and sample characteristics useful.

Appendices E, F and G show the research instruments used - that is, the telephone interview guide, the survey questionnaire and the personal interview guide. Appendix H offers ideas for further research, and Appendix J is the bibliography. (There is no Appendix I.)

2. SUMMARY OF FINDINGS AND SUGGESTIONS FOR CAREGIVERS

2.1 Sources of Information

The following suggestions for housing Alzheimer's Disease at home are based on four sources of information, representing four different research methods. First, a literature search was carried out, including academic articles, how-to books, newsletters, and newspapers. Then, thirteen telephone interviews were conducted with knowledgeable people in the field; in particular, executive of the Alzheimer Society. Based on the information found from these two sources, a survey questionnaire for caregivers was designed and sent out to 1,000 members of the Alzheimer Society across Canada. It was assumed that a significant proportion of those members would be or would have been caregivers of people with AD. Finally, twenty-five personal interviews were conducted with former and current caregivers, in their own homes. (A detailed account of the research methods is presented in Appendix D.)

All the relevant findings from this four-tiered research project have been amassed, organized into discreet sections, and presented in this chapter - first, as a brief summary, and second, as suggestions to caregivers, since caregivers are the group most likely to use this knowledge. The suggestions are almost exclusively concerned with practical, physical changes to the home, although a few could be described as "practical lifestyle suggestions".

2.2 Brief Summary of Research Findings

Several themes stand out from the research findings. First, the need for constant surveillance or supervision of the person with Alzheimer's Disease, as a basic safety precaution before and after all else, is reported. In addition to this vigilance, a number of basic safety precautions are taken in many AD households, such as: the installation of extra locks on exit doors; the removal of dangerous objects or substances; the regulation of appliances with the potential to cause burns or fire (for example, by removing fuses from stove, lowering hot water temperature and putting a lock on the thermostat); the addition of a number of assistive devices in bathrooms (grab bars, bath seats and non-slip mats especially).

To enhance orientation, caregivers make a number of practical changes to their dwellings, the most common being the addition of night lights en route to or in the bathroom, or keeping on lights all day and night. Other strategies to help orientation are the removal, conscious closing or marking of doors, and the posting of signs, symbols or notes (with apparently limited effectiveness). At the same time, however, it is pointed out that too many changes might increase disorientation. Clearly, the number and degree of modifications to the home would vary with the individuals involved and the stage of the disease.

The physical environment is adapted to the wandering or pacing of the AD person, by having furniture pushed back against walls and coffee tables and other small tables removed to clear a path. The social environment is also adapted to take wandering and getting lost into account: neighbours, police and others are often recruited to "keep an eye out" for the wanderer in the neighbourhood.

The commonest physical changes made in Alzheimer households to prevent or reduce agitation are keeping curtains drawn (to eliminate frightening reflections) and removing or covering mirrors (for the same reason). Other strategies seem to be in terms of lifestyle rather than in terms of physical strategies. An attempt is made to simplify household routines. Televisions are kept off or turned off when causing upset to the AD persons. Demonstrations of reassurance and affection, and carrying out favourite activities, such as going for a drive, are reported as the most successful ways of preventing or reducing the agitation that is characteristic of AD.

Caregivers express the same needs over and over again. The need for "a room of one's own" - a place to lock oneself away and rest or read or cry with frustration and exhaustion - is one of these needs. (Caregivers' other needs and their own descriptions of some of the dilemmas of living with Alzheimer's Disease are presented in Appendix A. Suggestions to health and social policy makers based on these comments and on observations of caregivers are presented in Appendix B.)

2.3 Suggestions to Caregivers

The following hints are directed to caregivers of persons with Alzheimer's Disease (AD) who live in private dwellings. Based on research findings, they are presented in simplified, point form so that these pages may stand on their own as a useful reference. The suggestions are made to houses and apartments in order to accommodate both the characteristics of AD and the needs of caregivers. They are clustered into four groups, according to the intent of the alterations, that is: to increase safety and security; to adapt to wandering and disorientation; to prevent or reduce agitation; and to meet caregivers' needs.

2.3.1 Safety and Security

Many of the safety and security features and precautions suggested here are similar to "baby-proofing" a dwelling, but the difference is that the person with increasingly impaired judgement and memory is adult-sized, has years of entrenched habits and is deteriorating rather than growing and learning. To a considerable extent, then, modifications will have to take the individual characteristics of the AD person, as well as the progress of the disease, into account.

To protect the safety of the person with AD within the home, and to ensure that she/he does not wander away and get lost or come to harm, the following precautions are suggested.

Locks:

* place locks on doors and windows where they can not be seen or understood, in unusual places, such as at the top of doors, above the normal line of vision
* slide a bolt from the closet door into the floor if the AD person rummages incessantly in the closet
* keep one closet in the house locked, where everything precious can be locked away
* add a thermostat lock if the AD person is continually adjusting the temperature in accordance with their body temperature swings

- install second locks on exit doors (e.g., add a chain lock to a dead bolt, to make the whole process of unlocking too complicated for the AD person to carry out) or lock the exit doors with a key from the inside and pocket the key
- lock ground floor windows, in open position when appropriate
- add a fence to the back yard and a lock to its gate

Furniture/Furnishings:

- make swinging chairs stationary and remove rocking chairs
- move furniture away from the middle of rooms for patients using walkers
- use chairs with arms and if purchasing new pieces of furniture, make sure they have rounded corners

Bathroom:

- keep pills kept out of reach, locked in a cupboard away from bathroom (e.g. pantry) or locked in medicine cabinet
- slip-proof the bottom of tub or use a rubber mat
- install a grab bar by both toilet and tub (or clamp a grip handle to side of tub)
- purchase a plasticised seat and shower hose for bathing seated person
- keep shampoo and other liquids out of bathroom in case they are swallowed
- stick some contrasting coloured tape around the edge of the tub to help define its edges and depth
- install washable, rubber backed bathroom carpeting to reduce chances of slipping on wet bathroom floor

- rent a raised toilet seat
- install non-skid flooring and tiles that contrast with tub, if building or renovating a bathroom with AD in mind
- remove lock from bathroom door, so that AD person can not get locked in
- use contrasting colours in the bathroom so that fixtures will stand out
- purchase a deep soap container so that the soap will not fall into the tub or on the floor
- reinforce towel bars if they are used for balancing (a grab bar is better)
- always leave a night light on in the bathroom

Kitchen:

- when not in the kitchen, remove and hide the stove switch knobs, or take the fuses out of the stove or unscrew them, or turn off the gas underneath the stove, or switch off the circuit breaker for the stove
- hide away sharp knives, kettle and other small appliances in cupboards (this does not have to be elaborate - simply put the items out of sight)
- leave counter tops bare (if items and food tend to be stuffed into pockets and lost or rot)
- get a kettle that whistles when the water is boiling

Kitchen and Bathroom:

- install plastic safety latches in all kitchen and bathroom cupboards (if dangerous items and substances are not removed)
- remove and hide sink stoppers to avoid overflow accidents

Stairs:

- try a simple bar across the top of a stairway, at shoulder height, swinging into a bracket, or a wrought iron swinging gate (which looks less like a "baby gate") or an accordion gate or even wedge a piece of plywood, at the top of stairs, particularly stairs to basement
- install solid handrails on both sides of stairways, especially in steep stairwell to basement or to back door

General Safety and Security:

- remove the bed frame, so that a fall out of bed will not be so damaging
- remove sharp cornered furniture and sharp objects
- keep outside lights off at night to discourage AD person from going out of house (as darkness deters many AD persons)
- try distracting the AD person from escaping through windows or doors by camouflaging them with decorations, e.g., a hanging glass decoration in window
- put plastic plugs in all the outlets
- if the AD person smokes, put a little water in all the ashtrays
- put away power tools, scissors and any other items that the AD person can no longer use safely, such as liquor, fans, keys, lamps with cords, sport guns, lighters and matches, glassware from china cabinet and small electrical appliances (such as hair dryers)
- remove the rug from under the table where you eat (it may be too difficult for the AD person to push a chair back over, and may cause a bad fall; it is also easier to clean up a bare floor)
- remove items that are precious and breakable, such as ornaments and delicate antiques

- to avoid burns, lower the hot water temperature to avoid scalding, cover hot water pipes, and put pieces of furniture in front of radiators
- give away poisonous house plants which may be eaten
- do not wax floors - the slippery finish is more treacherous and the shininess may be agitating
- mark sliding glass doors with decals to prevent AD person from walking into them and porch steps with bright coloured paint contrasting with the rise (to help define the edges of steps and prevent trips)
- if possible, make part of the house so safe that the patient can be up and pacing while the caregiver is asleep in another room
- leave a squeaky door or floor squeaky so as to alert caregiver to wandering
- install rubber treads on inside and outside uncarpeted stairs to improve traction
- add a safety railing on outside steps or along verandah
- install bells or an electronic alarm system on exit doors
- remove locks from other inside doors if any besides the bathroom
- close up fireplace

2.3.2 Wandering and Orientation

Following are examples of changes that may be made to homes by caregivers and others in order to help with the wandering, pacing and disorientation that are characteristic of AD. (Because the disorientation of persons with Alzheimer's Disease is associated with changes in their visual perception, the modifications made to environments to add light and cues are included here under "orientation".)

Wandering and Pacing:

- buy a second hand walking machine
- move furniture back from centre of rooms, remove all small pieces of furniture, and keep hall ways clear of paraphernalia, to allow for pacing and circular wandering
- keep a solid armchair in kitchen or centre of quiet activity, so AD person can sit there and be part of an activity (this may discourage wandering)
- moving a bed or hide-a-bed to the main floor (if in a two storey house) so that the AD person can rest when weary without going upstairs

Orientation:

- for apartment dwellers - mark the door of the AD person's apartment in a very distinct way
- put a sign or symbol or the patient's name on her/his bedroom door and provide other way-finding cues, such as pictures and meaningful objects, for as long as these strategies work
- keep clothes closet doors open all the time so that AD person will remember what is in them (providing ceaseless rummaging and hiding of items is not a difficult behaviour of the patient)
- lock away clothes in a separate bedroom and dole them out one outfit at a time (if the patient is a rummage-and-hide person)
- allow AD person to carry out old habits, providing these habits do not put the patient or caregiver at risk
- leave lights on if the sufferer clearly feels surrounded and frightened by darkness; adjust lighting to reduce shadows
- remove carpeting if patient becomes confused about where to urinate (usually males)
- colour the water in the toilet bowl to assist aim

2.3.3 Agitation

Most of the strategies used by caregivers for dealing with the agitation that is characteristic of Alzheimer's Disease are not modifications to the dwelling, but instead are activities or personal responses. However, there are two main changes that can be made to the domestic environment to prevent or decrease the agitation of persons with AD.

- keep the television off, move it to a private caregiver's room, or watch only non-violent programs with AD person
- cover all the mirrors in the house and keep the curtains drawn at night, to prevent reflections which (when unrecognized) can be very frightening to a person with dementia

2.3.4 Caregivers' Needs

Following are some ways that caregivers may meet their needs for assistance and respite.

Assistance:

- get all the help that you can, from family, neighbours, shopkeepers, and hired helpers of every description
- use handicapped stickers on your car so as to be able to park close to shops when out with your patient
- if you are a spouse-caregiver, go out with another couple so someone of the same sex can take the AD person to the washroom
- get a VON to do baths rather than risk a back injury

- notify your neighbours and the police of your patient's condition and ask them to alert you if the AD person is seen wandering

Respite:

- use a basement den, a locked extra bedroom, a study, an attic as a "hideaway" or "refuge" when the patient is asleep or under the supervision of a helper
- keep "adult" things in this refuge, such as television, radio, fine decorations, letters
- get away from home whenever possible

Naturally, not all of these suggestions for precautions or modifications will be appropriate or affordable in all situations of housing Alzheimer's Disease at home. If even a few are carried out, however, the result may be that the vigilance of surveillance can be reduced, thus reducing the stress and exhaustion so typically experienced by caregivers.

2.4 Conclusions and Recommendations

There are few recommendations that can be made with regard to housing policy, based on this research. Results reveal that the main caregiving strategy is surveillance, and the most frequently repeated need is for increased training and support services for family caregivers. These needs, of concern to health and social policy makers, are addressed in Appendix B.

There are, however, two suggestions that can be inferred from the findings, which do relate to housing policy.

First - the caregivers' declared need to have "a refuge" within the home, a space that is aurally and visually private, is in keeping with the increasingly accepted notion of including space that could easily be converted to a self-contained apartment, in the design of single family dwellings. Such an apartment could serve several different functions over the various life stages of a family. One of these functions could be private space for a family or hired caregiver. (At a later stage, if there is only one elderly person left in the private dwelling, the space could be rented out to a senior homesharer or student, for example, as a source of income and security for the elderly person.)

It is suggested, therefore, that separate suites, or space that could easily be made self-contained, become a more common feature in housing design.

The second recommendation based on this research has to do with bathrooms. It is recommended that all bathrooms be built with: 1) enough room for two people to manoeuvre in them; 2) reinforced walls that could support grab bars mounted in any number of places; and 3) non-skid flooring. These three basic features would not only make it easier for caregivers of AD persons, but would also help assistants to disabled people, handicapped people themselves, mothers of young children and small children themselves, to function safely in the bathroom.

APPENDIX A

LIVING WITH ALZHEIMER'S DISEASE IN THE WORDS OF CAREGIVERS

A. LIVING WITH ALZHEIMER'S DISEASE: IN THE WORDS OF CAREGIVERS

A.1 Introduction

The core of this report is made up of a rather dry description of Alzheimer's Disease and a great number of hints to caregivers about practical modifications they can make to their dwellings in order to accommodate AD and a few of their own needs. What is missing is any kind of description of the impacts of Alzheimer's Disease on the relationships and daily lives of the family caregivers whose testimony this report is based on, or a clear picture of their actual situations.

Although such qualitative information is not required in a report that is essentially meant to be a "housing document", it is presented here for two reasons: first, so that readers can have a glimpse of how life is actually lived by caregivers of AD victims "behind closed doors", and therefore an enriched understanding; and second, because both the caregivers interviewed in person for this study and the respondents to the survey questionnaire clearly felt so strongly about their psychological stress, their social isolation, their frustration and their broken lives, that they let these concerns spill over into all the answers and advice they gave. As a researcher I feel compelled to report their situations and words.

A.2 The Impact of Alzheimer's Disease on Others

Caregivers' quotes reveal that Alzheimer's Disease does not just afflict the individuals diagnosed. It can devastate marriages and other relationships; it can ravage other personalities; it can cause incomprehensible stress to caregivers and other family members; living with it can take years or forever to get over.

The caregivers described the anguish of watching a loved one with AD and the impact of the disease on their relationships.

> I was out of energy, out of patience...and I was afraid I was out of love, because I was starting to scream at him....and he hit me one time. Every day he is slowly dying and part of me is dying with him, and our marriage is dying with him...... I am not widowed, not married....what am I?

> I was a caregiver (for my mother) for a period of 12 years (until five years ago). My father was at home during this period but could not adjust to Mother's illness and relied more and more on me himself....As the unmarried daughter I did this from love but it disrupted my life a great deal. All this happened before AD was talked about and there was no information or help available. Result - breakdown. Physical and emotional.

> How many sleepless nights I had, I can't tell you. I looked like the wrath of God. Eventually my kids said to me, `C'mon Dad, we're losing Mother, we don't want to lose you too!'

> He destroyed my personality...I didn't realize what an impact it had on me.

> When we - my daughter and I - went back out to the parking lot after leaving her in that place, we sat in the car and just bawled.

> I had my husband home for two years, all on my own. I had him under a doctor ..who did not help me one bit; only when I had to put him in a nursing home. I found out after I went through all this I should have had help. It was a terrible trauma to me.

> My mother is like a baby that we care for...our life has been shattered by this disease and it continues to shape our habits, but we wish to continue this experience to the end...our mother became ill when she was 72 years old, she is now 81 years old. She continues to be our mother in spite of her soul being gone.

> I don't think I would survive if I had to go through it again today. One has to have lived it in order to understand. I am still not able to remember the whole experience unemotionally, although it has been 8 years since he passed away.

> As I am printing this I have started to cry. God help other caregivers who have to go through all the stages of this horrendous disease.

A.3 The Daily Realities of Living with AD

Caregivers also described and revealed the everyday realities of coping with Alzheimer's Disease at home.

> I have written this for my father whose vision is severely impaired. When Mum was diagnosed as having AD, Dad was retired and was the primary caregiver. I worked full-time due to my husband's unemployment and was only part-time caregiver. With the coming of social services through VON nurses and part-time home care, Dad's load eased. But the stress was relentless in spite of the help. Mum's condition faced Dad every hour of every day.

My spouse was diagnosed as an AD victim in 1975. She was mobile until 1980 when she became bedridden because of injury to one of her feet. We lived in a two storey house. Because of her tendency to fall from time to time during her mobile phase of AD, I had to install additional banisters on stairways so that both hands could be used going up or down stairs. When the bedridden phase began and until 1983 when my spouse died, she had to be carried up and down stairs to her wheelchair or the chesterfield. She spent the day downstairs (wheelchair - chesterfield) and the night in our normal master bedroom.

She just wouldn't cook, wouldn't do anything, couldn't even thread a needle and she used to make all her own clothes. She might start to cook and then give up, saying `I don't know'. I had to do everything. I had never done laundry in my life.

I looked after my husband for ten years alone. Had a homemaker twice weekly for two years. Apartment became too small when he lost use of legs and had to use wheelchair. Too exhausted to continue care and found a place for him in a very good nursing home.

We are a farm family with two homes in one yard. We all had to watch him. He at one time put anti-freeze in all the gas tanks. We hid all the matches.

We cannot take holidays or socialize in any way, so our money goes into everything that makes things easier for my patient.....he is slowly moving into the fourth and last stage. I have the worst to come.

(At the onset of my husband's illness) I had a small child and had to work to support us. Except for the last year, when I got a homemaker for three days a week, I paid for care so my husband would not be alone.

(At the onset of my mother's illness) I had my husband who was terminally ill and I was caring for him at home and was going back and forth to (my mother in another town) trying to do for her. Then she was taken bad and was put in hospital.

> From there she went to a nursing home. At that time (12 years ago) no-one understood what was going on, including medical and home care people and even the nursing staff in the nursing home were ignorant.

> Cared for at home until getting up at night, wandering, putting on lights, incontinence. So application made to nursing home. After many months he was moved. I am very grateful. At my age (82) this is the best solution for me. My only problem is the transportation to see my husband once or twice a week.

A.4 Risks for Caregivers

Most of the emphasis in this report is on reducing the risk of the AD person coming to harm. What about the caregivers? The majority of respondents for this study were older adults, some of them quite elderly, who are carrying out an onerous job with very little assistance. In so doing, they are at great risk. They are at physical risk of injury, for instance, every time they bathe a very often unco-operative adult in a deep-sided bathtub or shower.

> I was always so frightened. He is a big man - about six foot two and over two hundred pounds - and I am five foot two! We would have a shower together because that was the only way I could lure him to wash himself, he was so petrified of stepping into that deep bathtub alone - but I would be afraid in the shower that he would slip and fall on me...and I have a bad heart. (Wife-caregiver, age 66)

> What I do to get her out of the tub is, first of all, I wipe up all the water from the floor with plenty of towels so it isn't too slippery; then I get her out of the tub in stages - let me tell you that isn't easy with a wet body that doesn't co-operate - and then I prop my body, sort of wedge it, between the counter and the tub, so that we won't slip and take a tumble, and then I pull her

> up leaning against me. There isn't room to do it any other way. Mind you, we did have a fall one time, and got pretty bruised too! (Husband-caregiver, age 75)

Older caregivers are also at great psychological risk. Lack of sleep and lack of respite make them candidates for breakdown. With the circle of friends they can call on for help diminishing, (as friends become increasingly frail) and their social lives becoming reduced to a few hours a week when a home care worker relieves them, they can find themselves socially isolated, at a time when they are in the greatest need of social support and emotional outlet.

> The tension is terrible! I tell you, if she hadn't gone in (to a nursing home) when she did, I think I'd have gone off a tall building. (Husband-caregiver, age 76)

Add to this the fact that most older people have at least one chronic health problem, which is likely exacerbated by the physical and psychological strains of caregiving, and it is clear that older caregivers are at risk of dying before the people they are caring for.

> I only had four weeks to get over my cancer operation, while he was is a respite bed in a nursing home, and then I had to come home and look after him...I was still so weak, and he was much worse than when he had gone into the nursing home, it really seemed to make him much worse.... so we were in a sorry state. (Wife-caregiver, age 82)

Caregivers, then, are not just a group of people who need assistance at home and respite to get out of the Alzheimer household - they are for the most part older people who are at very real risk of injury or even pre-mature death due to their caregiving roles.

A.5 About Safety and Security Measures

Adaptations to domestic environments for safety and security are typically minor in terms of scale and expense. The addition of locks, installation of hand rails and grab bars, the removal of dangerous objects and furniture, all appear to be unsensational modifications to people's homes to accommodate Alzheimer's Disease.

However, the average expenditure of respondents in this study was $81.00 for the purchase of locks, and another $114.00 for installation. This is an enormous amount of money for a pensioner. And the commonest reason given for not having electronic alarm systems installed was that they are too expensive.

As for the addition of a fence or hand rail or grab bar - any or all of these might seem impossible to caregivers for at least three reasons: lack of money; lack of time and energy to purchase the materials even when cost is not an obstacle; and the fact that carrying out any task beyond the activities of daily living is often an impossibility for caregivers.

> We almost went crazy when we tried to do renovations around here. He was into everything, picking up the hammers, getting into the paint, upset by the strangers - of course, he thought I (son) was a stranger sometimes! I wish we had finished the place down to the last detail before we brought him to live with us. We sure made a mistake on that one.

> Well, I was told there should be a grab bar in the bathroom. And I even managed to buy one. But the landlord will not co-operate and put it in. And I'm no carpenter. So there it sits.

It should not be interpreted that the lack of major or expensive modifications for safety and security found in this study (and therefore included in suggestions to caregivers) means a lack of need. Instead, it is more likely a reflection of lack of money and time, as well as the difficulty of the living situation for caregivers.

A.6 Accommodating Disorientation and Wandering

Although not all persons with Alzheimer's Disease are wanderers, certainly many are. In order to accommodate wandering or pacing, items such as furniture or scatter mats are removed from rooms. To assist with orientation, notes, symbols and signs are used, as well as other measures such as taking down closet doors and locking others, keeping lights on 24 hours a day and putting certain things out of sight (such as clothing) so that they will not be distracting.

But what do these modifications do to the atmosphere of the home? With the dwelling becoming increasingly altered, it is possible that it may become less homelike for both the caregiver and the patient. Here the balancing act comes into play. The dwelling should remain as familiar as possible for the patient, so as not to cause upset and disorientation, while at the same time being adapted more and more to the AD person's cognitive impairment and eventual physical decline.

But the home is still home to the caregiver, who by virtue of the caregiving role, spends almost every hour there. Caregivers claim that they "also have a need to have some aspects of 'home' intact for their emotional well-being". The solution seems to be that one room in the dwelling is set aside for exclusive use by the caregiver and is kept locked. In that room, activities which can not take place while looking after the AD person - such as sewing, reading, watching television and writing letters - can be carried out.

> I wait until I know she's asleep at night and then I go in there and put my feet up for a while. Then after a bit of a rest I have the energy to read.
>
> I save all my mail until the girl (home support worker) comes and then I retire to my little refuge and respond to letters and pay bills and so on - the sort of thing I can't possibly do when I'm alone here with E.

A.7 More About Agitation

As in the case of wandering, not all people afflicted with Alzheimer's Disease become highly agitated, but still, it is a well recognized symptomatic behaviour of the disease. This agitation can take many forms. In some cases, it is the inability to sit still, the need for constant movement. In others, it is caused by hallucinations and suspicions which can terrify AD victims and result in their lashing out, very often at the primary caregiver.

> She accused me of carrying on with other women. I never did, in fifty years of married life. She became suspicious and even swore at me, which she had never done before.

> One time he (father) got out at night, all the way down the road, so I followed him in the car, and when I tried to get him in the car, did he fight! He smashed the wind shield!
>
> She was always a peaceful lady, before she got this disease. Then she would swear at me, and jab me in the stomach or the ribs with her elbow. It was awful, especially when I was just after surgery (in the stomach).

Agitation does not always mean just fidgeting or pacing. It can mean abuse and violence. The need for protection of caregivers, therefore, should not be overlooked.

A.8 Caregivers' Needs

Besides revealing practical modifications that have been made by caregivers and others to private dwellings in order to accommodate AD, interviews with caregivers and questionnaire results revealed four basic needs of caregivers: help with both caregiving and housekeeping; private space in the home; education, training and knowledge about caring for people with Alzheimer's Disease; and financial assistance to make up for the expenses incurred in modifying the domestic environment.

It was reported that the commonest strategy of ensuring the safety and security of the AD person is "constant surveillance"; the most fundamental orientation for the AD person is to have the primary caregiver within sight or earshot at all times; and the most successful antidotes to agitation are personal attention, affection, and quiet rituals together with the primary caregiver. It is clear, therefore, that the caregiving role is draining, and leaves almost no time for other activities, whether social, domestic, or private. For this reason, help is required so that caregivers do not become completely cut off from their social networks, so that basic cleaning and other maintenance tasks get done, and so that caregivers have time to be private. Help for the caregiver at home was the most repeatedly expressed need.

Private space is an essential need of most people, but understandably is an even greater need of people who are under strain almost 24 hours of every day. In addition, there is a need for "sacrosanct" space in the Alzheimer household, a room where the contents will not be rummaged in, or taken and lost. As the dwelling becomes more modified to adapt to the patient's decline, the need for this "adult space" understandably increases. Thus, attention should be paid to the provision of private space in the household for the caregiver(s).

The need for education and training was also clearly stated by a number of the caregivers interviewed: not only the education and training of themselves, but of health care professionals. For themselves, the need for training in lifting, bathing, and coping with the agitation characteristic of AD, was declared numerous times. One caregiver stated quite clearly what she thought was required:

> A course to train AD caregivers, and home care workers, so they understand not to talk behind the person, to look them in the eye, to request things nicely, with short instructions, to talk about things they - the patients -have known and liked.

Home care workers were alternately praised and criticised. Most caregivers sympathized with them, saying "poor girls, it's so hard for them". Doctors and nurses, however, were more often than not criticized by caregivers. Their knowledge of Alzheimer's Disease itself, their skill in caring for patients with AD, and their awareness of the consequences of full-time caregiving, were all seen to be deficient. This lack of faith in health care professionals only added to the caregivers' burden.

> Sadly, my husband is now in chronic care. The ignorance on the part of the nurses about Alzheimer's and how to handle patients with this disease is appalling.
>
> I would suggest that the family doctor take more of an interest in the care of the AD victim. He should suggest help and have concern for the one in the family that is anxious, tired and overworked.
>
> Care is absent or inadequate in nursing homes. Patients cannot speak up for themselves and their suffering is magnified by inadequate care. It is not due to budget cutbacks but due to lack of professionalism...
>
> My wife was frightened that I would put her in a booby hatch; that made her try to run away. And I, too, was frightened to put her in a nursing home...just so frightened.

Finally, the fourth need that was repeatedly expressed by caregivers was the need for financial assistance. As mentioned earlier, the cost of purchasing and installing locks, grab bars, fences and alarm systems may be out of reach for many pensioners, and most domestic caregivers of people with AD are older people. Children—caregivers who renovate their homes, or even move to another dwelling in order to be able to accommodate a parent suffering from AD, incur tremendous expense in an effort to keep their parents at home. For example, one young couple was determined to care for a parent with AD at home. Renovations alone cost them $10,000.

> He needed to be downstairs, because he was having trouble walking. So we made the front room into a bedroom, two big closets into a bathroom, and another little room into a sitting room for him. All three rooms connected. We had to lock them from the outside at night because he was always trying to escape....... It was really, really hard...but we kept him with us here... he was here until the morning of the day he died.... We were at the point of total exhaustion.

Another caregiver (husband) perceived that his wife felt surrounded by darkness all the time, and this frightened her. His response was to spend $5,000 brightening up the kitchen: a sliding glass door was installed to allow more light into the room and provide a view of her beloved garden; the ceiling lighting was increased six-fold (and diffused); paler wood cupboards, lighter wall colour and pale linoleum were installed; and both refrigerator and stove were replaced with appliances of lighter colour. The response was that his patient spent almost all her peaceful waking hours in a chair by the sliding door, in this renovated kitchen.

Several caregivers pointed out that they were saving the health care system a large amount of money by keeping their afflicted relative at home.

In order to better understand what goes on "behind closed doors" in Alzheimer households, the research findings have been reported with a different slant, relying heavily on the words of caregivers. This has been done in an effort to give some flesh to the report, and to create a clearer context for the suggestions offered to policy makers and architects in the appendices to follow.

APPENDIX B

SUGGESTIONS TO HEALTH AND SOCIAL POLICY MAKERS

B. SUGGESTIONS TO HEALTH AND SOCIAL POLICY MAKERS

B.1 Limits of These Suggestions

Four general policy goals are presented for consideration by policy makers who are involved in health and social services. They are based on the findings from this research, primarily upon the poignant appeals of caregivers.

B.2 Increase and Improve Assistance to Caregivers

It is evident from the information provided by caregivers that they are in urgent need of assistance in their overwhelming task. Some support, of course, is already being provided, by means of home care, respite, day care, counselling and other programs, delivered by a bewildering array of agencies, institutions and associations across Canada. Despite the best efforts of human service organizations and the unquestionable devotion of some workers, however, the help provided to caregivers is still inadequate. Support to caregivers needs to be increased and improved in several ways. Following are some of the ways suggested by caregivers themselves.

B.2.1 <u>Expand Programs</u>

Where resources permit, it would help caregivers if existing programs could be expanded to include:

* assistance to caregivers in their own homes in the evenings and on weekends. This is especially required since it is during the evening and night time that AD

patients are typically more agitated than during the day. This "sundowning syndrome" is what makes caregiving so exhausting, because it means extra tension at the end of a day coupled with lack of sleep for the caregiver. Weekend assistance is also a frequently expressed need, because there are no day programs available either, where the AD person can go for a few hours, giving the caregiver a brief break to attend to domestic chores or visit a friend. So caregivers feel virtually abandoned on weekends. Two caregivers expressed this need very modestly:

> "I would like to see a programme where people are trained to come into a home and relieve the caregivers in the evening, possibly one evening a week. To me, this would be a wonderful change.....I'm sure many other caregivers would like to be able to have an evening .. out."

> "It is very important for the morale of the caregivers to maintain their outside activities and interests."

- more respite beds, and for longer periods, for AD patients in order to allow caregivers regular breaks and/or the chance to recover fully from illness or surgery of their own. Since so many full-time caregivers are older people themselves, with an increased likelihood of a chronic health problem, it is all the more urgent to allow them more time to rest and/or recover fully from set-backs of their own. One caregiver said simply:

> "After three years of caregiving for my Alzheimer husband, I believe there should be more adequate facilities (sic), from the very beginning for respite care, thus lengthening the life of the caregiver and preventing early placement to an institution on a full-time basis. I would suggest a week (off for the caregiver) every two months."

B.2.2 Increase the Range of Deductible Expenses

Those deductible expenses which already exist are: costs of a full-time attendant; travelling expenses for treatment in a place more than 80 km. from home; and prescription drugs. The financial burden of caregivers would be lessened if deductible expenses were expanded to include:

* expenses incurred directly as a result of housing Alzheimer's Disease at home, such as the purchase and installation of locks, fences, grab bars, extra lights, altered flooring; the cost of rented equipment; the cost of transportation to day care and other support programs which do not always have a transportation component; the costs of part-time help not only with caregiving but with housework; and the costs of other items, such as adult diapers (which can amount to over $80.00 per month). In the case of those people who make structural changes to their homes to accommodate a parent with AD or a hired caregiver who needs private space, part of these expenses should be reimbursable, since the changes are allowing private caregiving to take place, which saves the formal health care system significant amounts of money.

B.3 Increase and Improve Training and Education

The need for more and better education and training was stated by a number of the caregivers interviewed: not only the education and training of themselves, but of health care professionals. Based on caregivers' suggestions, it is apparent that there is a need for:

* more training for informal caregivers, especially in lifting, bathing, and coping with the agitation characteristic of AD.

* better training for home care workers, including training in approach and conversation with the AD person, and in reassuring the primary caregiver of

their competence, so that caregivers feel confident enough to leave their charges with the part-time caregiver. Inadequacies in the training of home care workers were also implied by caregivers who reported that a "different face showed up every time", reflecting high turnover in this field. Several caregivers stated that continuity of "surrogate caregiver" is important and that their patient often resented a new person.

* more positive rewards for home care workers, who are neither highly paid nor highly regarded for their work, despite its crucial importance to the survival of caregivers. Salaries which reflect the importance and stress factor of their work, and public recognition of some sort - perhaps in the form of scholarships and awards - may serve to make this work more attractive and fulfilling, resulting in more continuity of home care workers available to caregivers.

* mandatory study of Alzheimer's Disease and practical experience in working with AD patients, including those in the home, for both medical and nursing students. This study revealed that, in many cases, doctors' and nurses' knowledge of Alzheimer's Disease itself, their skill in caring for patients with AD, and their awareness of the consequences of full-time caregiving, were regarded by care givers and key informants as deficient. For those health care professionals who are already in practice, refresher courses could include a component on "understanding and working with AD".

By extrapolation, it is also suggested that there is a need for:

* the study of dementia, its characteristic behaviour and its effects on other family members, in other professional schools, such as architecture, social work and law. Given our demographic realities, it is likely that almost every architect, social worker and lawyer of the future will at some time require knowledge of and sensitivity to dementing illnesses.

B.4 Simplify the System

The physical and mental health needs, social needs and housing needs of seniors so often overlap and compound each other, that it is difficult even for professionals in the field to know whom or what agency to contact for help. For caregivers who are already stressed, especially those who are elderly and may not be as accustomed to bureaucratic procedures and language as their children, the jumble of services and dispersion of agencies providing these services can be overwhelming. Even a 48 year old successful businessman and devoted caregiver-son interviewed for this study was thwarted by the difficulty of access.

> "When you've never required social services or help of that nature...as an outsider, trying to break into the system is almost impossible. I do have to work for a living, I can't spend my day on the 'phone...some information is contradictory, three `phone calls and three different answers...when you're trying to do this between meetings, it's hard to decipher the information. There is no eagerness to come out and help you, the system isn't streamlined, it isn't geared for quick response. I know that help is available somewhere, and if you're dedicated to finding out, you'll find out in a couple of days of `phone calls - but you have other things in your life - a job, kids...."

One way of solving this dilemma might be to have a single entry point for all services for elderly in place in each province, with a toll free telephone number. This service and number could be advertised not only to all pensioners (by means of an insert in pension cheques) but to all health service agencies and personnel so that they may make referrals.

B.5 Looking at the Longer Term

Although the recent increases in government and private funding of research into Alzheimer's Disease are recognized and appreciated, professionals in the field know that there are still gaps in our knowledge. For this reason, policy makers and others in the field should consider:

* research into all aspects of Alzheimer's Disease, including the programs and training that are being designed and implemented to respond to the needs of both patients and caregivers;

* evaluations of every program designed to meet the needs of persons with Alzheimer's Disease and related disorders, and their caregivers - such as respite, home care, counselling and day care programs - in order to determine which components of the programs are successful, necessary, not cost-effective, and so on. In fact, an evaluation component could be a requirement of project funding.

* not limiting ourselves to the advice of so-called "experts"; instead, taking advantage of the vast experience and wisdom of those people who are perhaps our most valuable resource, the caregivers of people with Alzheimer's Disease.

* looking at the longer term in drafting policy guidelines, making them flexible enough to allow for a broad range of responsive services - services that can adjust to meet the heterogeneity of the older population, the differing manifestations of Alzheimer's Disease and the varied competence of caregivers.

* investigating in as much depth as possible just how the people who will be affected by social and health policy around AD actually live their lives. If this is done, the result can be sensitive, sensible policies which are reflected in sensitive, sensible programs.

APPENDIX C

SUGGESTIONS TO ARCHITECTS

C. SUGGESTIONS TO ARCHITECTS

C.1 Background

Although the majority of caregivers are unable to afford the services of an architect to modify their homes, some children of AD persons do add to or alter their houses in order to accommodate a parent, at considerable expense. This is done in an effort to keep their parents out of institutions for as long as possible. The spaces that are added usually have a longer term function. For example, in two known cases, a mother's suite was intended to be a family room after she entered a nursing home or died. In another, the rooms of a main floor apartment built especially for a father with AD were used after he died as winter bedrooms, so that the upstairs of the large house could be shut off, to save on heating costs.

With the increased emphasis on family and community responsibility for care of the elderly, and the level of affluence of Baby Boomers being what it is, it is not unreasonable to expect more demand on architects to come up with "double-duty" designs such as those described above. Given the importance of a home-like environment to persons with Alzheimer's Disease, too, it is possible that existing "homey" housing stock may be considered for retrofitting, to provide housing for Alzheimer patients in the future, rather than purpose-built, institutional settings. Again, the services of architects might be required for such conversions.

Despite the potential for residential modifications, however, the main response to housing Alzheimer's Disease still seems to be the building of purpose-built facilities, or the addition of special wings onto existing institutions, in order to house people in their last stages of dementing illnesses. With the old-old population of Canada increasing faster than in any other age group, it seems inevitable that there will be an increasing need for these "final stages facilities". Therefore, more and more architects will find themselves searching for information on the changing and varied needs of people with Alzheimer's Disease.

For that reason, some relevant findings of this research project have been translated into suggestions to architects, in the hope that this information will be a useful contribution to the design process. The hints may also be of interest to contractors and designers who are seeking guidance in designing, retrofitting and detailing the built environment to accommodate Alzheimer's Disease and related dementias. Some of the suggestions here repeat those presented in chapter 2, where they were addressed to caregivers. This has been done on purpose so that this appendix may stand on its own as a useful resource.

C.2 Design Principles

First, the architect must realize that people with AD have a variety of physical, cognitive and behaviourial characteristics, which vary by individual. That is, although there are certainly symptoms which are "typical" of persons with AD, not all sufferers exhibit the same symptoms. Allowances must be made, then, in designing or retrofitting private dwelling spaces, for individual traits.

A second fundamental principle is that in designing an environment which is supportive to the patient and reduces the stress of the caregiver, the architect must not lose sight of the importance of creating a home-like environment. In fact, the creation or preservation of a "sense of home" is a chief consideration, since it is fundamental to the well-being of both the patient and the caregiver.

C.3 Design Approach

Architects are strongly encouraged to start their assignment with a working knowledge of the disease. Research is necessary. Research may consist of: assembling available literature from societies, libraries and government departments and agencies; talking to gerontologists, geriatricians, nurses and caregivers (get names from the nearest Alzheimer Society); consulting with other architects who have done similar projects; or hiring a student to gather pertinent documentation.

Here are some fundamental facts that should be taken into account in carrying out the design of either private or congregate dwelling space for persons with Alzheimer's Disease (or related dementias):

* Simplicity but not austerity should prevail.

* The safety of the person with Alzheimer's Disease should be safeguarded.

* The focus of care shifts with the progress of the disease, from behavioural management to full-time nursing care.

* The caregiver(s) have a real need for stress reduction and for a private space, a refuge away from the patient(s).

C.4 General Design Suggestions

The following design suggestions are presented as responses to the most typical symptoms of the disease. A few of these suggestions will be too grand or expensive to apply to private residential settings, but with creativity, most can be adapted to domestic settings.

C.4.1 Wandering and Pacing

- create an outdoor walled garden - fencing may be screened by plants - secure with lighting and a lockable gate
- provide a "safe area" in the house, an accessible corridor or large open area in a room, with comfortable, safe seating (no sharp corners)
- permit caregivers an overview of entrances and exits
- minimize the use of doors, provide wider openings, remove doors where privacy or security are not required
- avoid dead ends in room layout
- consider protective measures - gates at tops of stairs or lockable doors, locks on exterior doors and patio doors (located at bottom or top rail)
- provide night lighting for night activity
- reinforce handrails on stairs or ramps
- provide alarm systems to alert the caregivers that the AD person is "on the move" or leaving the home

C.4.2 Rummaging

* provide locks or sliding bolts for closets and rooms where rummaging is not acceptable

* keep everyday items in view; some caregivers may remove doors on dressing and linen closets

* install plastic safety latches on all kitchen and bathroom cabinets

C.4.3 Confusion

* provide a comfortable, soothing environment; avoid the use of dazzling colour contrasts and complicated room layouts

* if a new room is being designed for the person with AD, consider designing it similar to that person's old room; keep the patient's familiar objects and furniture, and arrange them in a similar way, in the new room

* consider larger windows or access to the garden from a main floor bedroom, for more daylight and for visual interest

* control noise levels (as too much noise can trigger agitation) by using insulation and sound absorbing materials

* remove or do not install reflective surfaces, such as mirrors, which can cause agitation

* install automatic shut-offs for electrical fixtures and equipment

C.4.4 Handicaps and Poor Health

- outfit the premises with safety equipment and aids, as necessary and affordable, and make the environment receptive to future modifications, as the needs of AD persons change over time, sometimes quite rapidly (e.g., reinforced walls in bathrooms to support grab bars, even if they are not needed at the moment)
- accommodate the use of a wheelchair - guidelines exist elsewhere for such accommodation
- consider easy-care floor finishes, since incontinence and regressed eating habits may present problems for floor cleaning
- do not use loose floor coverings anywhere in the dwelling due to reduced co-ordination of the patient
- compensate for age-related physical changes, by providing handrails, ramps rather than stairs, rest stops, etc.
- consider a lift for the stairs in a two storey dwelling (obviously a high cost item, and beyond the reach of most people)
- install handrails on stairs, in corridors and bathrooms, and outdoors where the AD person is active, such as on a deck or front steps
- use large, easy to operate hardware
- use signs or symbols to identify rooms

Because the bathroom is considered by many caregivers to be the most treacherous room for persons with AD, suggestions for the design of this room are presented separately here.

C.4.5 Bathroom

- generally, apply guidelines for design of facilities for the elderly and the handicapped (physically, sight, and hearing impaired), especially safety and space requirements
- non-skid flooring is recommended for bathrooms
- the bathroom should be large enough for two people, one of whom may be in a wheelchair, to be involved in bathing, showering, toileting, drying and dressing
- if space permits, provide a large shower, with seat and hand sprayer (because AD persons, due to impaired depth perception, are typically afraid of bathtubs)
- eliminate sharp corners and fragile items
- do not install a lock on the entry door or toilet closet
- put a symbol on the bathroom door to help orient the AD person
- avoid anything that will distract, confuse or alarm - the caregiver will be able to supply information on what these items might be
- provide alarms in both the bathroom and the AD person's bedroom for summoning help

C.5 Attending to the Needs of Caregivers

Suggestions concerned with designing for dementia tend to focus almost exclusively on the safety and well-being of the patient. Caregivers needs must not be forgotten. Their main need is for respite, for separate, private, adult space where they can rest, calm down, and "re-charge their batteries". Therefore, it is suggested that there be provided, where possible:

* a separate space for caregiver(s), where they may rest, in visual and auditory privacy, away from the Alzheimer's patient(s). In the case of a private dwelling, if an addition or renovation is being done to house a parent with AD, this should ideally be located on a separate storey or in a different zone of the house from the caregiver's bedroom.

In summary, it is suggested that architects who are retained to design or renovate either private or institutional dwellings for people with Alzheimer's Disease should review at least some articles available on designing for dementia (listed separately in the bibliography) as well as the content of this report, so as to be able to engage in informed consultation with the client(s), before putting pencil to paper. If this is done, the resulting environment should be one which is supportive and safe, for both patient and caregiver.

APPENDIX D

DESCRIPTION OF RESEARCH METHODS

D. DESCRIPTION OF RESEARCH METHODS

D.1 Four Research Methods Used

The research methodology included four stages: a literature search; telephone interviews with key informants; a national mail-out survey; and in-situ personal interviews with a sample of caregivers. These various data gathering methods - described in detail on the following pages - were chosen in an effort to carry out a study of both breadth and depth.

D.2 Literature Search

The literature reviewed fell into the following categories: i) general information, in book, newspaper article and pamphlet form, on managing Alzheimer's Disease (AD) at home; ii) more narrowly focused articles in medical, nursing, aging, social work and mental health journals; iii) articles and videos on designing for dementia, with a focus on institutional settings; iv) chapters, segments, or most typically, paragraphs in more general books, and short inserts in Alzheimer Society and Alzheimer's Disease and Related Disorders Association (ADRDA) newsletters, on the topic of modifications to domestic environments to accommodate the characteristics of AD and the needs of caregivers; and v) bibliographies on Alzheimer's Disease. Many sources yielded no more than a sentence or a paragraph germane to this study.

D.3 Telephone Interviews with Key Informants

Ten executive members of the Alzheimer Society from across Canada, as well as three people deeply involved in work with AD in the Ottawa area, such as the founder of the Day Away Program, were interviewed by telephone for an average of 20 minutes each. Of the 13 informants, 11 claimed to be very familiar with Alzheimer households, and 6 had personal experience as caregivers.

The content of the telephone interview guide was based on findings from the beginnings of the literature search. (A copy of the telephone interview guide is presented in Appendix E.)

Responses served as a source of information for more written reference material, and as a base for questions to be used in the survey questionnaire.

D.4 National Survey Questionnaire

A survey questionnaire was developed, based on findings from both the literature search and the interviews with key informants. It was reviewed by an Alzheimer specialist and an architect for content, by three sociologists for format, and pre-tested on caregivers of persons with Alzheimer's Disease and members of the local Alzheimer Society.

One thousand survey questionnaires were mailed to a stratified random sample of the national membership of the Alzheimer Society of Canada from the society's national office in Toronto, in July, 1988. The choice of the membership of the Alzheimer Society as a target group was based on the general knowledge that a significant number of the members are, or have been, caregivers of persons with Alzheimer's Disease.

The sample was stratified by province, so that members in every province would receive the questionnaire, and by language, so that the proportions of members who preferred to receive correspondence in French versus English were approximately represented. Two hundred (200) French and eight hundred (800) English questionnaires were sent.

The purpose of the survey questionnaire was three-fold. First, it was a means of learning about how many caregivers had made modifications to their dwellings and how much these changes cost them (information needed by policy makers especially). Second, it was an attempt to gather new knowledge on physical strategies for coping with Alzheimer's Disease (knowledge useful to caregivers and architects). And third, it was intended that the questionnaire, which was largely in multiple-choice format, would be a source of information and new ideas to those people who received them, whether they found the time to fill them out or not. (Samples of the mail-out questionnaire are presented in Appendix F of this report.)

D.4.1 Response to the Survey Questionnaire

The total number of questionnaires returned was 162 out of 1,000 mailed out, yielding a response rate of 16%. Given that the questionnaires were sent to a target group (caregivers) who are likely to be more exhausted and stressed than most other people in our population, and given they were sent out during one of the hottest summers in our recent history, this response rate was considered quite respectable.

Of the 162 returned questionnaires, 24 were not useable, leaving 138 useable, completed questionnaires: 104 English and 34 French. Findings were recorded in terms of positive responses to questions, since there were "yes", "no" or "na" (for not applicable) categories. Both the absolute number and proportion of total number of the respondents who answered positively to each question were recorded. When the question "why not" was asked of respondents, the most typical responses was recorded. In addition, examples given by respondents in "other" categories were recorded, as were repeated or particularly striking comments to open-ended questions.

Numerous comments written on the returned questionnaires, such as "I hadn't thought of that", "I may have to do these things in time", and "Not yet", revealed that the questionnaire did serve as a source of information and ideas to respondents (which was intended) and not only as a research instrument.

D.4.2 Characteristics of Respondents

The people who responded to the national survey questionnaire were mostly caregivers of people with Alzheimer's Disease. Almost three quarters (74%) identified themselves as current or former full-time caregivers; 15% were part-time caregivers; and the rest tended to be a sons, daughters or sisters of AD persons. A little over two-thirds (68%) of the respondents were female and 32% were male.

The age of the respondents was fairly evenly distributed over the age ranges: 26% were under 49 years old; 20% were between 50 and 64; 31% were between 65 and 74; and 23% were over 75 years of age. (Those who identified themselves as under 49 years of age were generally sons or daughters of AD persons, this information being volunteered in another part of the questionnaire. It should be noted that the ages given did not necessarily represent the age of people while they were actively caregiving, however, because many of the respondents who answered the questionnaire did so after their relatives had been institutionalized or had died.)

The outstanding majority - 79% -of respondents reported that they lived in houses; only 4% lived in seniors' apartments; 14% lived in apartments and 3% lived in other kinds of dwellings, such as a mobile home or a retirement home.

Responses have been integrated into the suggestions addressed to caregivers, architects and policy makers in this report. Unintended findings - such as highly emotional and descriptive responses written at the end of the questionnaires, have been separated out and included in Appendix A - Living With Alzheimer's Disease: In the Words of Caregivers.

D.5 Personal Interviews with Caregivers

Twenty-five personal interviews were conducted with family caregivers of people with Alzheimer's Disease across Canada.

These interviews were arranged in advance by telephone and mail with the assistance of various chapters of the Alzheimer Society. The sample was by no means random, in that those people who agree to be interviewed for any research project by definition represent a biased sample. There was an effort made to interview a cross-section of caregivers in each locale: that is, spouses, children and siblings; former and current caregivers.

Although it would have been ideal to interview a representative sample of caregivers, in terms of age, gender, region etc., this would have been very difficult to do, for at least two reasons. First, a database does not exist on which to base a truly representative sample in terms of demographic characteristics. Second, caregivers of people with AD very often reach a stage of virtual social isolation and are understandably very stressed. These two factors auger against their being willing to be interviewed at all. For these reasons, one must be quite flexible about the interview sample and be grateful to those people who agree to share their experiences.

Photographs of the interviewees were not taken, since picture-taking would have seemed like an invasion of intimacy. Tapes were made of all but one of the interviews. (One gentleman refused to be recorded; he had recently placed his wife in a nursing home and was still suffering acutely. I did not insist.) These interview tapes were transcribed and the content analyzed in terms of: caregiver characteristics; strategies for dealing with safety/security, orientation, agitation, and caregiver needs; and caregivers' comments and recommendations.

D.5.1 Characteristics of Caregivers Interviewed

Although the caregivers interviewed in person for this study varied in age, income and educational level, and ability to cope, they had several characteristics in common: they appeared to be highly organized individuals; their devotion to the family member they were (or had been) caring for was profound; the stress and exhaustion they experienced was palpable, even in those people whose relatives had been placed in a special facility or had died years before; and they clearly needed to tell the world about their years of anxiety and grief.

The interviews lasted between an hour and two hours each. The interviewees lived in five regions in Canada, distributed as follows: British Columbia 6, Alberta 2, Manitoba 4, Ontario 6, Quebec 3, Prince Edward Island 4.

In the sample there were 17 spouses (9 wives, 8 husbands); 4 daughters; 1 son; 3 couples (two daughter-and-son-in-law couples and one son-and-daughter-in-law couple); and no siblings. Of the 25 interviews, 17 were with former caregivers and 8 were with current caregivers. Although it would have been ideal to interview all the caregivers in the same domestic environment where they had taken care of their AD patients, this was not always possible, due to relocation and, in two cases, separate dwellings from the AD person. As a result, 18 of the 25 interviews actually took place in the caregiving environment.

Eleven of the 18 "in-situ" interviews were in bungalows, 6 were in two-storey houses (three of these were farmhouses) and one was in a second storey walk-up apartment in a large old house.

Most of the caregivers interviewed were older people, both at the time of interview, and in the case of former caregivers, at the time of caregiving. The spouses who were current caregivers ranged in age from 60 to 82 years and those who were former caregivers had been in their sixties and seventies when looking after their spouses. The children who were current caregivers were in their fifties, sixties and seventies, whereas those who were former caregivers had ranged in age from mid-thirties to mid-sixties when looking after a parent with AD.

D.6 Summary of Research Methodology

The first three data gathering methods - literature review, telephone interviews with key informants and closed survey questions - were considered necessary to gain insight into <u>existing knowledge and practices</u> with regard to the practical, physical modifications to domestic environments, made by caregivers and others, in order to accommodate both the characteristics of Alzheimer's Disease and the needs of caregivers. The open-ended questions on the survey questionnaire, which were many, and even more importantly, the personal interviews, were required to <u>add to our knowledge</u> of housing Alzheimer's Disease at home.

APPENDIX E

TELEPHONE INTERVIEW GUIDE

HOUSING ALZHEIMER'S DISEASE AT HOME

TELEPHONE INTERVIEW GUIDE

QUESTIONS

1) **Are you very familiar with a household where someone with Alzheimer's Disease lives? Or several?** (If yes, carry on. If no, ask if they would be willing to try to answer some of the questions anyway.)

2) **What sorts of locks have you seen used in an Alzheimer household?** (Prompts: added? removed?)

3) **Have you noticed that furniture has been moved or removed to accommodate the characteristics of AD? How?**

4) **Has any re-decorating been done, like getting rid of boldly patterned curtains, or colour-coding rooms, for instance, in the households you are familiar with?**

5) **Have you seen any separate, private rooms or areas where the caregiver(s) can get away from the AD person to rest?**

6) **Has anything been done to reduce agitation, such as removing mirrors and shiny objects, in the households you have been in?**

7) **Have you seen signs or symbols used in Alzheimer households, to help orient the person with AD? (For example, a picture on the bedroom door depicting bed and rest.)**

8) **Are there any other physical changes that you can think of, that you have observed or learned about, that you think are successful? Any suggestions?**

Thank you very much for your information and your time. It is very valuable to our research.

APPENDIX F

SURVEY QUESTIONNAIRE

Alzheimer
SOCIETY OF CANADA
SOCIÉTÉ DU CANADA

National Office: 1320 Yonge St., Suite 302, Toronto, Ontario M4T 1X2 Tel: (416) 925-3552

Dear Member,

Enclosed you will find a questionnaire concerned with the practical, physical changes that have been made in houses and apartments in order to accommodate the special needs of people with Alzheimer's Disease (AD) and their caregivers.

This questionnaire represents part of a national study being conducted by one of our members, a gerontologist. The study is sponsored by an external research grant from the Canada Mortgage and Housing Corporation (CMHC) and is endorsed by the Alzheimer Society.

We have distributed this questionnaire from the National Office of the Alzheimer Society in Toronto and will be collecting the responses here in order to ensure your anonymity. We do not distribute membership lists to any person or organization.

It is very important that this information be collected, because it is needed by so many people: caregivers, housing designers, and policy makers, to name just three groups of people.

The findings from this study will be written in a report, Housing Alzheimer's Disease at Home, which should be available through CMHC in 1989.

Would you please help with this research by completing the enclosed questionnaire? If you are not the main caregiver of someone who has AD or if you are not very familiar with a household where someone with AD lives, would you please give this questionnaire, as soon as possible, to someone you know who is? It takes only a few minutes to complete and all responses are absolutely confidential.

Thank you very much for your help!

Sincerely,

Kevin Keefe

Kevin Keefe
President, Alzheimer Society of Canada

Patron: Her Excellency,
The Right Honourable Jeanne Sauvé, P.C., C.C., C.M.M., C.D.
Governor General of Canada

Charitable Registration #0547752-11-13

Housing Alzheimer's Disease at Home: A National Survey

This questionnaire is concerned with the changes that may have been made by caregivers or others to private homes where people with Alzheimer's Disease (AD) are living.

Information is needed on the practical, physical changes that have been made to houses or apartments, in order to accommodate both the characteristics of Alzheimer's Disease and the needs of caregivers.

The questions are based on ideas and information found in Alzheimer Society newsletters and other books and articles. They may be a very useful source of information and ideas for you.

Your answers will help others who are concerned with accommodating Alzheimer's Disease at home. **Responses are completely confidential.**

The questionnaire takes only a few minutes to complete. Simply check the boxes beside the appropriate answer(s), and fill in the blanks where requested. If there is not enough room for you to answer, feel free to add a separate sheet of paper.

Please be kind enough to complete this questionnaire as soon as possible.

Thank you!

Information about You
The following questions are about you, the respondent.

1) You are currently or were a:

1. full-time family caregiver ☐
2. part-time family caregiver ☐
3. hired caregiver ☐
4. social worker ☐
5. other (please specify)

____

____

2) You are:

1. female ☐
2. male ☐

3) Your age is:

1. under 49 ☐
2. between 50 and 64 ☐
3. between 65 and 74 ☐
4. over 75 ☐

4) You live in:

1. a house ☐
2. seniors' apartment ☐
3. an apartment ☐
4. other (please specify)

____

____

Please check ☑ yes or ☑ no or ☑ na (for not applicable or not sure) beside the appropriate answer(s) and fill in the blanks where requested.

Security/Safety

The following questions are about special items that have been added to or removed from the dwelling to increase the **safety and security** of the AD person. Please check as many responses as apply. ☑

1 a) Have extra locks been installed on doors, such as: (If no, please skip to 2.)

1. front door ☐ yes ☐ no ☐ na
2. door to basement ☐ yes ☐ no ☐ na
3. door to balcony/deck ☐ yes ☐ no ☐ na
4. garage door ☐ yes ☐ no ☐ na
5. closets ☐ yes ☐ no ☐ na
6. cabinets/cupboards ☐ yes ☐ no ☐ na
7. other (please describe) ☐ yes ☐ no ☐ na

1b) If yes, where?

1. near the top of doors ☐ yes ☐ no ☐ na
2. near the bottom of doors ☐ yes ☐ no ☐ na
3. near the handle of doors ☐ yes ☐ no ☐ na
4. other (please describe)

1c) If yes, the lock you would recommend is:

1. dead bolt ☐ yes ☐ no ☐ na
2. slide lock ☐ yes ☐ no ☐ na
3. padlock ☐ yes ☐ no ☐ na
4. chain lock ☐ yes ☐ no ☐ na
5. a combination of two locks ☐ yes ☐ no ☐ na
6. other (please describe)

1d) If yes, about how much did the purchase of these locks cost?

$ ________

1e) If the locks were installed professionally, about how much did installation cost?

$ ________

2) If no extra locks have been installed, what are the reasons why?

3) Has the lock been removed from:

1. bathroom door ☐ yes ☐ no ☐ na
2. other (please specify)

4a) Were any electronic systems installed especially to accommodate AD, such as: (If no, please skip to 4c.)

1. intercom system to AD person's bedroom ☐ yes ☐ no ☐ na
2. weight sensor on bed ☐ yes ☐ no ☐ na
3. door alarm system ☐ yes ☐ no ☐ na
4. other (please describe)

4b) If yes, please specify how much each one cost.

________ $ ________

________ $ ________

4c) If no special electronic system has been installed, what are the reasons why?

5) Have any items been removed from rooms for **safety** reasons, such as: (If no, please skip to 6.)

1. poisonous plants ☐ yes ☐ no ☐ na
2. sharp objects ☐ yes ☐ no ☐ na
3. small ornaments ☐ yes ☐ no ☐ na
4. other (please describe)

6) Have any special features been added to the bathroom, such as:

1. grab bar by tub ☐ yes ☐ no ☐ na
2. grab bar by toilet ☐ yes ☐ no ☐ na
3. long hose for shower ☐ yes ☐ no ☐ na
4. walk-in shower ☐ yes ☐ no ☐ na
5. colour strips around tub to indicate depth ☐ yes ☐ no ☐ na
6. other (please describe)

7) Have any items been removed from the bathroom? If yes, please describe and explain why.

8) Have any **special safety precautions** been taken in the kitchen, such as:

1. master switch for stove burners ☐ yes ☐ no ☐ na
2. removal of fuses from stove/oven ☐ yes ☐ no ☐ na
3. shut-off valve ☐ yes ☐ no ☐ na
4. other (please describe)

9) Have any other **safety or security precautions** been taken inside or outside of the dwelling, such as:

1. thermostat lock ☐ yes ☐ no ☐ na
2. safety gates ☐ yes ☐ no ☐ na
3. lowering hot water temperature ☐ yes ☐ no ☐ na
4. fence around yard ☐ yes ☐ no ☐ na
5. other (please describe)

10) Approximately how much money do you think has been spent on the **safety and security features** mentioned in questions 6, 8 and 9 above?

$ ____________

11) Have you tried any **safety/security measures** that have **not** been effective? If so, please describe them and explain why you think they did not work.

Orientation and Agitation

The following questions are concerned with changes that have been made to the dwelling in order to accommodate the **disorientation, wandering** and **agitation** that characterize AD. Please check as many answers as apply. ☑

1) Have you put up signs or cues to help orient the Alzheimer person inside the house, such as:

1. reflecting tape around bathroom door for night time orientation ☐ yes ☐ no ☐ na
2. nightlights in hallway and bathroom ☐ yes ☐ no ☐ na
3. signs, pictures or symbols on doors to identify rooms or apartment ☐ yes ☐ no ☐ na
4. other (please describe)

2) If any other physical changes have been made to **orient** the person with AD, please describe.

3) Have you moved any furniture because of **wandering,** for example:

1. removing coffee table or end tables ☐ yes ☐ no ☐ na
2. pushing furniture back against walls ☐ yes ☐ no ☐ na
3. other (please describe)

4) If any other physical changes have been made to accommodate **wandering,** please describe.

5) Has the decor been changed in any of the following ways to lessen **agitation**?

1. keeping curtains drawn to remove reflection ☐ yes ☐ no ☐ na
2. removing mirrors ☐ yes ☐ no ☐ na
3. replacing geometrically or boldly patterned wallpaper, fabric, carpeting or floor covering ☐ yes ☐ no ☐ na
4. repainting walls in soothing colours ☐ yes ☐ no ☐ na
5. other (please describe)

6) If any other physical changes have been made to lessen the **agitation** of the Alzheimer's person, please describe.

7) Have you tried any changes to help with **orientation** or to reduce **agitation** that have **not** been effective? If so, please describe them and explain why you think they did not work.

Caregiver Needs

The questions in this section are about the needs of the caregiver(s); specifically, the need for a "refuge" away from the AD person.

1) Is there a special room or area in the dwelling where the caregiver(s) can get away from the Alzheimer's person to rest? If no, please skip to question 2. If yes, please describe.

2) Do you think it is important to have a "refuge" in the home for the caregiver(s)? Please explain your answer.

3) If any other changes have been made to the dwelling especially to meet the needs of either a live-in or visiting caregiver, please describe.

Your Comments

Please use the space below to describe the practical, physical changes you or others have made, which have **not** been touched upon in this questionnaire, and which you think would be helpful to other caregivers. Or, if you have any ideas or suggestions that you have not tried or seen, please present them here.

Thank you very much for your cooperation. The contribution of your knowledge and experience is extremely valuable. If you have questions which need to be answered before you can complete this questionnaire, or if you would like to receive this questionnaire in French, please write or call:

The Alzheimer Society of Canada, 1320 Yonge Street, Suite 302, Toronto, Ontario, M4T 1X2
(416) 925-3552

Please return the completed questionnaire in the enclosed prepaid envelope as soon as possible.

THANK YOU!

Alzheimer
SOCIETY OF CANADA
SOCIÉTÉ DU CANADA

National Office: 1320 Yonge St., Suite 302, Toronto, Ontario M4T 1X2 Tel: (416) 925-3552

Madame,
Mademoiselle,
Monsieur,

Vous trouverez ci-joint un questionnaire qui porte sur les modifications pratiques, physiques apportées à des maisons ou des appartements pour tenir compte tant des caractéristiques des victimes de la maladie d'Alzheimer (MA) que des besoins des responsables des soins.

Ce questionnaire fait partie d'une enquête nationale qu'effectue l'un de nos membres, gérontologue. Une subvention à la recherche externe de la Société canadienne d'hypothèques et de logement (SCHL) permet cette enquête qu'appuie la Société Alzheimer du Canada.

Nous distribuons ce questionnaire à partir du bureau national de la Société, à Toronto. Nous y recueillerons également les réponses, afin d'assurer l'anonymat des répondants. Nous ne distribuons la liste de nos membres à personne.

Il est très important de recueillir ces renseignements, parce que plusieurs personnes en ont besoin : les responsables des soins, les concepteurs de maisons et ceux qui élaborent les politiques, pour n'identifier que trois groupes.

Les résultats de cette enquête seront consignés dans un rapport, L'hébergement des victimes de la maladie d'Alzheimer à la maison, qui sera disponible, en 1989, par l'entremise de la SCHL.

Auriez-vous l'amabilité de nous aider, en répondant à ce questionnaire? Si vous n'êtes pas le principal responsable des soins d'une victime de la MA, ou si vous ne connaissez pas vraiment la famille où vit une victime de la MA, veuillez, je vous prie, transmettre ce questionnaire, le plus tôt possible, à une personne qui, à votre connaissance, vit cette situation. Il suffit de quelques minutes pour répondre au questionnaire; toutes les réponses demeureront totalement confidentielles.

Veuillez agréer, Madame, Mademoiselle, Monsieur, mes remerciements les plus sincères et l'expression de mes sentiments distingués.

Le président,
Société Alzheimer du Canada,

Kevin Keefe

(Kevin Keefe)

Patron: Her Excellency,
The Right Honourable Jeanne Sauvé, P.C., C.C., C.M.M., C.D.
Governor General of Canada

Charitable Registration #0547752-11-13

L'Hébergement des victimes de la maladie d'Alzheimer à la maison: Une enquête nationale

Ce questionnaire porte sur les modifications que les responsables des soins ou d'autres personnes ont pu apporter à des maisons privées où vivent des victimes de la maladie d'Alzheimer (MA).

Nous avons besoin de renseignements sur les modifications pratiques, physiques apportées à des maisons ou des appartements pour tenir compte tant des caractéristiques des victimes de la MA que des besoins des responsables des soins.

Les questions découlent d'idées et de renseignements tirés des bulletins de la Société Alzheimer du Canada ainsi que d'autres livres et articles. Ces documents peuvent constituer pour vous une source très utile d'idées et de renseignements.

Vos réponses aideront d'autres personnes que l'hébergement des victimes de la maladie à la maison préoccupe. **Elles demeureront totalement confidentielles.**

Il suffit de quelques minutes pour répondre à ce questionnaire. Vous n'avez qu'à cocher les cases appropriées et à remplir les blancs. Si l'espace est insuffisant, n'hésitez pas à ajouter une feuille.

Veuillez avoir l'amabilité de répondre le plus tôt possible.

Merci!

Renseignements personnels
Ces questions s'adressent au répondant.

1) Vous êtes présentement ou avez été:

1. responsable familial des soins à plein temps. ☐
2. responsable familial des soins à temps partiel. ☐
3. responsable des soins embauché. ☐
4. travailleur social. ☐
5. autre (veuillez préciser)

____

____

2) Vous êtes:

1. une femme. ☐
2. un homme. ☐

3) Vous avez:

1. moins de 49 ans. ☐
2. entre 50 et 64 ans. ☐
3. entre 65 et 74 ans. ☐
4. plus de 75 ans. ☐

4) Vous habitez:

1. une maison. ☐
2. un centre d'accueil pour personnes âgées ☐
3. un appartement. ☐
4. autre (veuillez préciser)

____

____

À chaque question, veuillez cocher la case appropriée ☑ oui, ☑ non, ☑ na (ne s'applique pas, incertain), ou remplir les blancs.

Protection et sécurité

Les questions suivantes portent sur les articles que vous avez retirés du logement ou que vous y avez ajoutés pour accroître la **protection et la sécurité** de la victime de la maladie d'Alzheimer. Cocher tous les points pertinents. ☑

1 a) Avez-vous installé des serrures additionnelles aux portes, par exemple, (Dans la négative, veuillez passer à la question 2).

1. à la porte d'entrée? ☐ oui ☐ non ☐ na
2. à la porte qui mène au sous-sol? ☐ oui ☐ non ☐ na
3. à la porte qui mène au balcon/ à la terrasse? ☐ oui ☐ non ☐ na
4. à la porte du garage? ☐ oui ☐ non ☐ na
5. aux portes des garde-robes? ☐ oui ☐ non ☐ na
6. aux portes des armoires? ☐ oui ☐ non ☐ na
7. aux autres portes? (veuillez préciser)

____

____

1b) Dans l'affirmative, à quel endroit?

1. près du haut de la porte. ☐ oui ☐ non ☐ na
2. près du bas de la porte. ☐ oui ☐ non ☐ na
3. près de la poignée. ☐ oui ☐ non ☐ na
4. ailleurs (veuillez préciser)

____

____

1c) Dans l'affirmative, quelle serrure recommanderiez-vous?

1. une serrure à pêne dormant? ☐ oui ☐ non ☐ na
2. une serrure coulissante? ☐ oui ☐ non ☐ na
3. un cadenas? ☐ oui ☐ non ☐ na
4. une serrure doublée d'une chaîne? ☐ oui ☐ non ☐ na
5. un jeu de deux serrures? ☐ oui ☐ non ☐ na
6. un autre dispositif? (veuillez préciser)

____

____

1d) Dans l'affirmative, combien leur achat vous a-t-il coûté approximativement?

______________ $

1e) Si vous avez confié l'installation à un professionnel, combien vous a-t-elle coûté?

______________ $

2) Si vous n'avez installé aucune nouvelle serrure, quelles en sont les raisons?

____

____

____

____

____

3) Avez-vous retiré:

1. la serrure de la salle de bain? ☐ oui ☐ non ☐ na
2. d'autres serrures? (veuillez préciser)

____

____

4a) **Avez-vous installé des systèmes électroniques spécialement pour la victime de la MA, par exemple, (dans la négative, veuillez passer à la question 4c).**

1. **un système d'intercommunication dans la chambre à coucher de cette personne?** ☐ oui ☐ non ☐ na
2. **un déctecteur de poids pour le lit?** ☐ oui ☐ non ☐ na
3. **un système d'alarme à la porte?** ☐ oui ☐ non ☐ na
4. **d'autres dispositifs? (veuillez préciser).**

____

____

4b) **Dans l'affirmative, veuillez préciser le coût de chacun.**

______________________ ______________ $

______________________ ______________ $

4c) Si vous n'avez installé aucun système électronique spécial, quelles en sont les raisons?

____

____

5) Par mesure de **sécurité**, avez-vous retiré des articles des diverses pièces, par exemple, (dans la négative, veuillez passer à la question 6).

1. des plantes vénéneuses? ☐ oui ☐ non ☐ na
2. des objets tranchants? ☐ oui ☐ non ☐ na
3. de petits ornements ☐ oui ☐ non ☐ na
4. d'autres articles? (veuillez préciser)

____

____

6) **Avez-vous ajouté des dispositifs spéciaux dans la salle de bain, par exemple,**

1. **une barre d'appui près de la baignoire?** ☐ oui ☐ non ☐ na
2. **une barre d'appui près de la cuvette de toilettes?** ☐ oui ☐ non ☐ na
3. **un long boyau pour la douche?** ☐ oui ☐ non ☐ na
4. **une douche horizontale?** ☐ oui ☐ non ☐ na
5. **des bandelettes de couleur pour indiquer la profondeur de l'eau dans la baignoire?** ☐ oui ☐ non ☐ na
6. **d'autres dispositifs? (veuillez préciser)**

____

____

7) **Avez-vous retiré des articles de la salle de bain? Dans l'affirmative, veuillez les décrire et expliquer.**

____

____

____

____

8) Avez-vous pris des **mesures spéciales de sécurité** dans la cuisine, par exemple,

1. l'installation d'un interrupteur général pour les éléments de la cuisinière? ☐ oui ☐ non ☐ na
2. l'élimination des fusibles pour la cuisinière/le four? ☐ oui ☐ non ☐ na
3. l'installation d'une soupape d'arrêt pour l'eau? ☐ oui ☐ non ☐ na
4. d'autres mesures? (veuillez les décrire)

____

____

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____

9) Avez-vous pris d'autres **mesures de protection ou de sécurité** à l'interieur ou à l'extérieur du logement, par exemple,

1. l'installation d'une serrure sur le thermostat? ☐ oui ☐ non ☐ na
2. l'installation de barrières de sécurité? ☐ oui ☐ non ☐ na
3. la réduction de la température de l'eau chaude? ☐ oui ☐ non ☐ na
4. l'installation d'une clôture autour de la cour? ☐ oui ☐ non ☐ na
5. d'autres mesures? (veuillez les décrire)

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10) Combien pensez-vous avoir dépensé, approximativement, pour les **mesures de protection** et **de sécurité** identifiées aux questions 6, 8 et 9?

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11) Avez-vous essayé certaines **mesures de protection ou de sécurité** qui n'ont pas fonctionné? Dans l'affirmative, veuillez les décrire et expliquer pourquoi, à votre avis, elles n'ont pas fonctionné.

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Orientation et agitation

Les questions suivantes portent sur les modifications apportées au logement pour tenir compte de la **désorientation, de l'errance** et de **l'agitation** qui caractérisent la victime de la MA. Pour chaque question, veuillez cocher la case appropriée? ☑

1) Avez-vous placé des affiches ou des notes pour aider cette personne à s'orienter dans la maison, par exemple,

1. un ruban phosphorescent autour de la porte de la salle de bain pour la nuit? ☐ oui ☐ non ☐ na
2. des veilleuses dans les couloirs et la salle de bain? ☐ oui ☐ non ☐ na
3. des affiches, des images ou des symboles sur les portes pour identifier les pièces ou l'appartement? ☐ oui ☐ non ☐ na
4. d'autres affiches? (veuillez les décrire)

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2) Si vous avez apporté d'autres modifications physiques aux lieux pour **orienter** la victime de la MA, veuillez les décrire.

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3) Avez-vous déplacé des meubles à cause de **l'errance**? Par exemple, avez-vous

1. retiré la table à café ou les tables de bout? ☐ oui ☐ non ☐ na
2. poussé les meubles contre les murs? ☐ oui ☐ non ☐ na
3. pris d'autres dispositions? (veuillez préciser)

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4) Si vous avez apporté d'autres modifications physiques à cause de **l'errance** de la victime, veuillez les décrire.

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5) Avez-vous modifié l'intérieur de l'une ou l'autre des façons suivantes pour réduire **l'agitation**? Avez-vous

1. tiré les rideaux pour éviter les reflets? ☐ oui ☐ non ☐ na
2. retiré les miroirs? ☐ oui ☐ non ☐ na
3. remplacé les papiers peints, les tissus, les moquettes ou les couvre-planchers ornés de formes géometriques ou prononcées? ☐ oui ☐ non ☐ na
4. repeinturé les murs en des teintes plus douces? ☐ oui ☐ non ☐ na
5. apporté d'autres changements? (veuillez préciser)

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6) Si vous avez apporté d'autres modifications physiques pour réduire **l'agitation** de la victime de la MA, veuillez les décrire.

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7) Avez-vous essayé certaines mesures pour faciliter **l'orientation** ou reduire **l'agitation** qui n'ont pas fonctionné? Dans l'affirmative, veuillez les décrire et expliquer pourquoi, à votre avis, elles n'ont pas fonctionné.

Besoins du responsable des soins

Les questions suivantes portent sur les besoins du responsable des soins, plus précisément sur le besoin de disposer d'un «refuge» loin de la victime de la MA.

1) Y a-t-il, dans la maison, une pièce ou un coin où le responsable des soins peut se reposer en se soustrayant à la victime de la MA? Dans la négative, veuillez passer à la question 2. Dans l'affirmative, veuillez décrire.

2) Croyez-vous importante l'existence d'un «refuge» pour le responsable des soins à la maison? Veuillez expliquer votre réponse.

3) Si on a apporté d'autres modifications au logement, spécialement pour répondre aux besoins du responsable des soins qui y loge ou s'y rend, veuillez les décrire.

Commentaires

Veuillez utiliser les lignes suivantes pour décrire les modifications pratiques, physiques que vous, ou d'autres personnes, avez apportées et dont ce questionnaire **ne traite pas**, et qui, à votre avis, seraient utiles à d'autres responsables des soins. Si vous avez des idées ou des suggestions portant sur des modifications que vous n'avez ni essayées ni rencontrées, veuillez nous les soumettre.

Merci beaucoup de votre coopération. Le partage de vos connaissances et de votre expérience est extrêmement précieux. Si vous désirez des réponses à certaines questions avant de remplir ce questionnaire, ou si vous désirez en recevoir un en anglais, veuillez nous écrire ou nous téléphoner.

La Société Alzheimer du Canada,
1320, rue Yonge, Pièce 302, Toronto (Ontario) M4T 1X2 (416) 925-3552

Prière de nous faire parvenir vos réponses dans l'enveloppe pré-affranchie ci-jointe, le plus tôt possible.

MERCI!

APPENDIX G

GUIDE FOR INTERVIEWS WITH CAREGIVERS

G. GUIDE FOR INTERVIEWS WITH CAREGIVERS

The interviews with caregivers were based on the same basic questions as those posed in the survey questionnaire, in approximately the same order, to facilitate transcription. Interviews were taped. It was not always possible, of course, to follow the questions in the planned order, because the people interviewed sometimes had determined in advance what it was they wanted to relate and in what order.

In general, however, I asked about: the caregivers' relationship to the Alzheimer's person; the length of time they had been caregiving; the first indication they had that their relative was afflicted with a dementing illness; the safety and security precautions they had taken over time; and the strategies they had employed to aid orientation and reduce agitation. At the close of the interview, caregivers were asked "What advice or special information would you like to give to other caregivers? to architects? to policy makers?"

APPENDIX H

IDEAS FOR FURTHER RESEARCH

H. IDEAS FOR FURTHER RESEARCH

During the conduct of this research, ideas for two related studies were spawned. The first idea was the result of detailed discussions with a practising architect about one of his contracts, which was to design an addition to a single family home, to accommodate an elderly parent with Alzheimer's Disease. His frustrated struggle to find relevant information made me curious about one aspect of "doing architecture", that is, the processes used by architects to inform themselves about the special needs of their clients; and this led to questions about whether or not research techniques (focusing on people, not materials) are in fact part of the core curriculum in university schools of architecture. The results of a study which focuses on the learning and doing of architecture, as it relates to researching the needs and characteristics of special user groups, might be inspiring and useful for both practising and teaching architects.

Another related idea sprang from the information that I was continually getting from caregivers about "marvellous new" facilities, or additions to existing institutions, especially designed for people with Alzheimer's Disease and related disorders. I wondered "Who's designing these places? Where and how are they getting their information? Do any of the architects use public input in their design decisions, that is, do they get information from caregivers, nurses, neighbours, cleaning people, and patients themselves? Have any of the architects, or the architectural planners they may employ, used participant observation, spending a day or night in a nursing home or extended care ward of a hospital, to get an idea of what it's really like? What would happen if a few did? How are they going to test whether or not their designs work?" And so on. I think we risk producing a great number of not-quite-successful institutions for the very frail and cognitively impaired if too many buildings are built too soon, without thoughtful and sensitive research being carried out, both before design and after occupancy.

APPENDIX J

BIBLIOGRAPHY

J. BIBLIOGRAPHY

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