

# RESEARCH REPORT

External Research Program



Adapting Your Home to Living with  
Dementia  
Volume I



## CMHC—HOME TO CANADIANS

Canada Mortgage and Housing Corporation (CMHC) has been Canada's national housing agency for more than 60 years.

Together with other housing stakeholders, we help ensure that Canada maintains one of the best housing systems in the world. We are committed to helping Canadians access a wide choice of quality, affordable homes, while making vibrant, healthy communities and cities a reality across the country.

For more information, visit our website at [www.cmhc.ca](http://www.cmhc.ca)

You can also reach us by phone at 1-800-668-2642  
or by fax at 1-800-245-9274.

Outside Canada call 613-748-2003 or fax to 613-748-2016.

Canada Mortgage and Housing Corporation supports the Government of Canada policy on access to information for people with disabilities. If you wish to obtain this publication in alternative formats, call 1-800-668-2642.

ADAPTING YOUR HOME  
TO LIVING WITH DEMENTIA

VOLUME 1  
FINAL RESEARCH REPORT

July 2008

Submitted to  
Luis Rodriguez  
Canada Mortgage and Housing Corporation  
Ottawa, Canada

By  
Nancy Rushford M.A., MSc. (OT)  
Alzheimer Society of Niagara Region, Canada

This study was partially funded by the Canada Mortgage and Housing Corporation (CMHC) under the terms of the External Research Program. The views expressed are the personal views of the authors and do not represent the official views of CMHC.

## **PURPOSE**

The purpose of this research was to collaborate with individuals in the early stages of dementia, their family caregivers, and the Alzheimer Society of the Niagara Region to develop an educational resource about *environmental adaptation* that would guide individuals and families through the process of adapting their home environments to living with dementia. This includes making simple physical changes to the home to enhance safety & security, or adaptations to specific activities and tasks to maximize independence and participation. The involvement and input of individuals with dementia and their caregivers was fundamental to the research process. Their experiences, including their adaptive coping strategies, lay the foundation for the development of the resource titled **Adapting your home to living with dementia: A Resource Book for Living at Home with Dementia and Guide to Home Adaptations.**

## ACKNOWLEDGEMENTS

**'Adapting Your Home to Living with Dementia: A Resource Book for Living at Home and Guide to Making Home Adaptations'** was carried out with the assistance of a grant from the Canada Mortgage and Housing Corporation (CMHC) under the External Research Program. It was developed in collaboration with the Alzheimer Society Niagara Region [ASNR] and a group of extraordinary individuals living with dementia and their caregivers. A special thanks to the staff at ASNR for their knowledge and expertise, and to the participants who volunteered to share their time, experiences and wisdom. Furthermore, six publications served as key references in the development of the resource. Combined with the information and insights gained from this study, with permission, some of the material from these resources has been included in the publication.

Canadian Association of Occupational Therapists. (1998). *Living at Home with Alzheimer's Disease and related Dementias, A manual of resources, references and information*. Ottawa, ON: CAOT Publications ACE.<sup>1</sup>

Canada Mortgage and Housing Corporation. (1989). *Maintaining Senior's Independence: A Guide to Home adaptations*. Canada Mortgage and Housing Corporation.

Canada Mortgage and Housing Corporation. (2003) *Maintaining Senior's Independence through home adaptations: A self assessment guide*. Canada Mortgage and Housing Corporation.

Canada Mortgage and Housing Corporation. (2002) *At Home with Alzheimer's Disease: Useful adaptations to the home environment*. Canada Mortgage and Housing Corporation.

Canada Mortgage and Housing Corporation. (2008). Using the stairs. Available online at [http://www.cmhc.schl.gc.ca/en/co/maho/adse/masein/masein\\_002](http://www.cmhc.schl.gc.ca/en/co/maho/adse/masein/masein_002)

Chiu T., Oliver, R., Marshall, L., & Letts, L. (2001). Safety Assessment of Function and the Environment for Rehabilitation (SAFER) Tool Manual. Toronto, Ont.: COTA Comprehensive Rehabilitation and Mental Health Services.<sup>2</sup>

---

<sup>1</sup> For further information and/or to order this resource contact the Canadian Association of Occupational Therapists at [www.caot.ca](http://www.caot.ca)

<sup>2</sup> For further information and/or to order this tool, visit [www.cotahealth.ca](http://www.cotahealth.ca) or call 416-785-9230, extension 1174.

## **OPERATIONAL DEFINITIONS**

### **DEMENTIA**

Dementia primarily affects cognition (thinking abilities) such as memory, problem solving and language. Dementia is not a disease in itself but a group of *symptoms* that arise as a result of damage to the brain from diseases such as Alzheimer's Disease, Vascular Disease, Picks Disease, Lewy Body Disease, Parkinson's Disease and Frontal-Temporal Dementia. For the benefit of clarity and continuity the term 'dementia' will represent any of these diseases throughout the text.

### **HOME ADAPTATION**

Home adaptation is used synonymously with the terms 'environmental adaptation and 'environmental modification' in this document. This includes making simple physical changes to the home to enhance safety & security, or adaptations to specific activities, tasks, or behavioural approaches to maximize independence and participation in everyday activities.

## **ABSTRACT**

Understanding the care giving relationship and particularly how people with dementia and their caregivers naturally attempt to adjust and cope is an important starting point in interventions involving environmental adaptation. The primary aim of this research was to collaborate with individuals with dementia, their family caregivers, and the Alzheimer Society of the Niagara Region to develop an educational resource on environmental adaptation for individuals living with dementia and their families that appropriately represented their needs and experiences. This research followed a practical action research approach (FMECD, 2003; Somekh, 2006) involving focus groups and interviews with family caregivers and persons in the early stage of dementia. This involved an exploration of the lived experience of dementia and care giving, including difficulties and functional implications, as well as coping strategies. Participants of the study engaged in the process of incorporating their knowledge and experiences, issues and coping strategies into the resource and informing its development until completion. Data generated from the inquiry into the experience of dementia was analyzed inductively through a constant comparison method (Burnard, 1991).

Findings from the study revealed that the experience of dementia involves a process of adaptation experienced as a dynamic tension between the person with dementia and his or her caregiver. This tension manifested as 'holding on vs. letting go' (caregivers) and 'autonomy vs. self doubt' (persons with dementia). Empathy, gratitude and humor were the primary coping mechanisms by which both groups managed this tension. The primary output of this research was an educational resource and guide for home adaptation (Volume 2) based on actual experiences of dementia and care giving. These experiences were combined with the expertise of family support counselors at the ASNR and available literature on the topic.

Incorporating the knowledge and experiences of people living with dementia and family caregivers into a practical and easily accessible resource will potentially serve the following key functions: 1) Bridge the gap between research and practice 2) Empower families to access and use formal supports according to their needs 3) Support and encourages individuals and families to strengthen their skills and strategies used to cope with dementia.

## EXECUTIVE SUMMARY

### INTRODUCTION

A supportive environment is crucial for individuals living at home with dementia. Environmental ‘adaptation’ or ‘modification’ is an intervention approach used to enhance a person’s safety and security and maximize their independence and participation. It involves strategies such as modifying physical objects, simplifying task performance, introducing assistive devices or making home alterations (Gitlin & Corcoran 1996). Although many issues for creating a supportive environment are similar to the safety and accessibility concerns of people with physical disabilities, cognitive and behavioural symptoms also need to be considered for persons with dementia, as well as the appropriate selection, introduction and timing of physical adaptations (CAOT, 1998). Furthermore, the family’s ability to understand how to adapt the environment is also critical, as it is often the family that provides most of the supportive care for a person living with dementia in the community [Messecar, 2000; Cumming et al., 2001]. This research was carried out by Nancy Rushford with financial assistance under the External Research Program of CMHC. It involved collaboration with the Alzheimer Society of the Niagara Region, Canada [ASNR], and a group of extraordinary individuals living with dementia and their caregivers. Participants lived in the Niagara Region of Ontario.

### OBJECTIVE

The purpose of this research was to collaborate with individuals with dementia, their family caregivers, and the Alzheimer Society of the Niagara Region to develop an educational resource on *environmental adaptation*. This research followed a practical action research approach (FMECD, 2003; Somekh, 2006) including focus groups and semi-structured interviews with family caregivers and persons in the early stage of dementia. This included an exploration of the lived experience (Silverman, 2006) of dementia and care giving including difficulties and functional implications, as well as coping strategies. Action research integrates research and action (Somekh, 2006). It provided an opportunity for people living with dementia and their family caregivers to collaborate with the researcher to develop a meaningful resource that builds upon their experiences and responds to their changing needs. The primary outcome of this research is the resource titled “**Adapting your Home to Living with Dementia: A Resource Book and Guide to Home adaptation.**” It provides practical information and strategies for individuals and families to help them cope with the challenges associated with dementia.

The primary research questions for this project were:

1. What are the experiences of individuals with dementia living at home and family caregivers providing home based care?
2. What specific difficulties do they experience in the home and community and how do they cope with these difficulties?



## **METHODOLOGY**

A practical action research approach (Somekh, 2006; FMEDC, 2003) was implemented involving focus groups and semi-structured interviews with family caregivers and persons in the early stage of dementia. This involved an exploration of the lived experience of dementia and care giving, including difficulties and functional implications, as well as coping strategies. Participants of the study engaged in the process of incorporating their knowledge and experiences, issues and coping strategies into the resource and informing its development until completion.

Fourteen participants were selected by purposive sampling and recruited through ASNR including seven caregivers and seven persons with dementia. Informed consent was obtained from all participants.

### **Data Collection**

Data collection involved a seven step process. Two focus groups were facilitated; one with family caregivers and one with persons with dementia. The objective of these focus groups was to better understand and describe the experience of dementia and its impact on everyday life and activities. The data was analyzed inductively and the first draft of the educational resource '*Adapting Your Home to Living with Dementia*' was developed. The initial draft comprised of difficulties commonly experienced by persons with dementia and their families at various stages of the dementia. These difficulties were categorized according to type of activity and area of the home. Through 1:1 interviews in the home, participants were asked to elaborate on difficulties they experienced, and identify the strategies they used to manage these challenges. Categories arising from the focus group data were further elaborated upon and themes were verified. The data obtained through these 1:1 interviews was then incorporated into the second draft of the resource.

Seven staff members of the ASNR including family support counselors, the clinical services director and the educational director, were also given a copy of the initial draft. They were asked to elaborate on the issues presented in terms of their observations of the difficulties experienced by persons with dementia and their families providing care. They identified additional issues unrepresented in the draft and corresponding adaptive strategies/home modifications. The common themes, issues, and adaptive strategies that emerged from the experiences of the participants and ASNR staff were then compiled with available literature on the topic. This information was integrated into the third draft of the resource book which was subsequently distributed to the participants and ASNR staff for review and feedback. Revisions were made according to the feedback.

### ***Pilot phase***

The draft was piloted with representatives from the target audience including 3 caregivers, 3 persons with dementia (1 who lived alone) and 3 family support counselors from the ASNR. All reviewers were unfamiliar with the resource. Based on their suggestions more revisions were made to the draft. It was then reviewed again by 2 members of the same group in addition to two others who had not seen previous drafts (a caregiver and an ASNR family support counselor). The final version was then completed and submitted to the CMHC.

### ***Data analysis and processing***

The method of analysis used to interpret the data followed a system based on a constant comparative method (Burnard, 1991).

## **FINDINGS**

Findings from the study revealed that the experience of dementia involves a process of adaptation experienced as a dynamic tension between the person with dementia and his or her caregiver. This tension manifested as 'holding on vs. letting go' (caregivers) and 'autonomy vs. self doubt' (persons with dementia). Empathy, gratitude and humor were the primary coping mechanisms by which both groups managed this tension.

## **DISCUSSION**

Persons with dementia and their caregivers were both engaged in a process of adapting to the changes to the quality and nature of their activities, relationships, and roles as a consequence of dementia. This had implications on their sense of identity and was experienced as a dynamic tension between them. In the context of the care giving relationship, this tension manifested for caregivers as 'holding on or letting go' of their loved one in terms of encouraging independence in day to day activities or being protective. Individuals with dementia struggled in relationship with their caregiver, often a spouse or adult child, with exerting their autonomy or experiencing self doubt in relation to the performance of everyday activities.

Caregivers were primarily concerned with safety and security, particularly how to minimize risks and protect their loved one from experiencing failure. They felt at times like a parent rather than a spouse or a daughter. Persons with dementia expressed concerns about wanting to maintain their independence, yet needing and being grateful for help, and related their experience to that of a child. Shifting perspective and *seeing beyond oneself* at a particular moment in time (or looking at the 'big picture') was used as a key coping strategy for both groups. Empathy and gratitude were the primary mechanisms through which both groups shifted perspective. Persons with dementia commonly used humour as another coping strategy. These findings offer insights into the coping strategies of people with dementia and family caregivers in the context of the care

giving relationship. They are consistent with research into the subjective experience of dementia and coping strategies used by people in the early stages of Alzheimer's disease (Clare, 2002; 2003; Ward-Griffin & Oudshoorn, 2006).

## CONCLUSION

Dementia places major demands on individuals living with the disease and their family members providing care. Understanding the care giving relationship and particularly how people with dementia and family caregivers naturally attempt to adjust and cope is an important starting point in interventions involving environmental adaptation. *Adapting the Home to living with Dementia* involves more than simply making physical changes to the home, introducing assistive devices, simplifying tasks or adapting one's approach. It is a process that occurs within the context of relationships. In fact, research shows that adherence to recommendations for environmental adaptation is a complex process including factors such as purpose and meaning attributed to aspects of the home environment, caregiver skills and ownership of ideas, personal resources, and formal and informal supports. Consequently, health care professionals need to promote a collaborative approach to environmental adaptation that fosters joint decision making, provides clients with information, options and choices and ensures that the caregiver and care receiver's needs and preferences are respected (Messecar, 2000; Clemson et al., 1999). Providing families with a variety of options to suit their individual circumstances and strategies to overcome resistance to intervention are key factors to enhancing their capacity to adapt their homes to living with dementia.

**'Adapting your Home to Living with Dementia'** integrates the findings from this research into practice in that it incorporates a guide to home adaptation into the 'bigger picture' of the experience of dementia and the care giving relationship.

## IMPLICATIONS

Incorporating the knowledge and experiences of people living with dementia and family caregivers into a practical and easily accessible resource will potentially serve the following key functions: 1) Bridge the gap between research and practice; 2) Empower families to access and use formal supports according to their needs; and 3) Support and encourages individuals and families to strengthen their skills and strategies used to cope with dementia.

## Adapting Your Home to Living with Dementia

### A Resource Book for Living at Home and Guide to Making Home Adaptations

#### INTRODUCTION

Dementia impairs cognitive capacity—the ability to think, remember, understand, reason, judge and communicate. The loss of these abilities affects an individual's capacity to function and perform daily activities, such as handling finances, cooking and driving. There are several types of dementia, the most common being Alzheimer Disease.<sup>1</sup>

There are an estimated 364,000 Canadians over the age of 65 who have some form of dementia,<sup>2</sup> 50% of whom live in the community, 29% of whom live alone.<sup>3</sup> Each person experiencing dementia faces challenges that potentially compromise their safety and quality of life at home. A supportive environment is crucial for individuals with dementia since the disease affects not only physical capabilities but the ability to adapt behaviour to the environment.

Environmental adaptation or modification is an intervention approach used to enhance people's safety and security and maximize their ability to participate in society. It involves strategies such as modifying physical objects, simplifying task performance, introducing assistive devices or making home alterations. Although many issues for creating a supportive environment are similar to the safety and accessibility concerns of people with physical disabilities, cognitive and behavioural symptoms also need to be considered for persons with dementia, as well as the appropriate selection, introduction and timing of physical adaptations. Furthermore, the family's ability to understand how to adapt the environment is also critical, as it is often the family that provides most of the supportive care for a person living with dementia in the community.

This study was carried out by Nancy Rushford, MA, MSc (OT) with financial assistance under the External Research Program of Canada Mortgage and Housing Corporation (CMHC). It involved close collaboration with the Alzheimer Society of the Niagara Region<sup>4</sup> (ASNR) in Ontario and a group of extraordinary individuals living with dementia and their caregivers.

#### OBJECTIVES AND RESEARCH QUESTIONS

The objective of this study was to develop an educational resource on environmental adaptation for people with dementia living at home and their caregivers.

The study was inspired by families who sought support from ASNR to deal with the many challenges associated with dementia. Individually, these families had unique stories to tell. Collectively, they had a common experience and a wealth of knowledge and expertise that they had developed while coping with the disease. It was anticipated that a useful and practical educational resource—that could guide other individuals with dementia and their caregivers—could best be created by combining the knowledge and expertise of these families, the expertise of family support counselors at ASNR and information available in the existing literature. The involvement and input of individuals with dementia and their caregivers was fundamental to the research process.

---

1 *Housing Options for People with Dementia*, 1999, Canada Mortgage and Housing Corporation.

2 Alzheimer Society Canada, 2007.

3 Alzheimer Society Canada. Canadian Study of Health and Aging Working Group: Patterns of caring for people with dementia in Canada. *Can J Aging* 1994; Vol. 13 no. 4: 470-487. English and French. Retrieved August 2008 from <http://www.alzheimer.ca/english/disease/stats-caregiving.htm>.

4 The Alzheimer Society is a non-profit agency operating nationally, provincially and locally in Canada. The Alzheimer Society of the Niagara Region serves as a source of education, support, and advocacy for persons with dementia, their family members, health providers and the general public.

There were three primary research questions for the study.

1. What are the experiences of individuals with dementia living at home and family caregivers providing home based care for them?
2. What specific difficulties do they experience in the home and community and how do they cope with these difficulties?
3. What steps and strategies—from the environmental adaptation viewpoint—can be taken to alleviate these difficulties?

## METHODOLOGY

A practical action research approach was used to conduct the study, including focus groups and semi-structured interviews with seven family caregivers and seven persons in the early stage of dementia. It involved an exploration of the lived experience of dementia and caregiving, including difficulties and functional implications, as well as coping strategies. These study participants were engaged in the process of incorporating their knowledge and experiences, issues and coping strategies into the resource on environmental adaptation and informing its development until completion.

Study participants were selected by purposive sampling and recruited through the ASNR. Informed consent was obtained from all participants.

The research was conducted at the ASNR and in the study participants' homes, which were also located in the Niagara Region.

The study was conducted in seven phases.

### Phase One – initial focus groups and first draft of the educational resource

Phase One consisted of two focus groups—one with caregivers; the other with people with dementia. The objective was to explore the lived experiences from the perspectives of family caregivers and individuals diagnosed with dementia. A semi-structured questionnaire was developed, pilot-tested and finalized for each group; and a facilitator with extensive experience in dementia and psycho-social support used it as a guide to conduct the focus groups. Each focus group was audiotaped and transcribed, and a research assistant recorded field notes and observations. The primary investigator analyzed the data and produced the first draft of the educational resource *Adapting Your Home to Living with Dementia*. This first draft identified difficulties commonly experienced by persons with dementia and their families at various stages of dementia and categorized them by themes and types of activities carried out in the home and community.

### Phase Two—second focus groups and input from staff members of the ASNR

Two additional focus groups—one with caregivers; the other with people with dementia—were conducted with the same people who participated in the first focus groups. The objective was to verify emerging themes and elaborate on the list of difficulties with everyday activities and coping strategies that had been identified in the first focus groups. The second focus groups were also audiotaped and transcribed and a research assistant collected field notes.

The procedure for collecting data differed slightly for each group. The caregiver group was introduced to the first draft of the educational resource together as a group and participants were asked to reflect further on their experiences as a group.

In contrast, the persons with dementia group was not only asked to verify and elaborate on emerging themes as a group, but also individual participants were introduced to the first draft of the educational resource through one-on-one interviews in their homes. The interviewer recorded their responses to the draft in writing. Collecting data through one-on-one interviews in the home provided a more comfortable and appropriate environment where individuals with dementia could concentrate and more easily express themselves. It also provided a meaningful context to elicit responses to questions related to their activities around the home.

Furthermore, seven staff members of the ASNR, including family support counsellors, the clinical services director and the educational specialist, were given a copy of the first draft of the educational resource. They were asked to elaborate on the issues presented in terms of difficulties experienced with activities around the home and community as it related to their experience with people with dementia and their caregivers. They identified common difficulties they had observed that were not represented in the draft and added their suggestions and recommendations for adaptive strategies/home modifications.

### Phase Three—second draft of the educational resource

In Phase Three, the principal investigator analyzed the data from the focus groups and interviews conducted in Phase Two. She then carried out a literature review on environmental adaptations for dementia and the experience of dementia from the perspective of caregivers and individuals living with the disease and compiled emerging common themes, issues, challenges and coping strategies with relevant literature on the topic and the input from the ASNR staff. Using this information, she prepared the second draft of the educational resource.

### Phase Four—feedback on second draft of the educational resource

In Phase Four, a form was developed to obtain feedback from study participants on the content, relevance, style and layout of the second draft of the educational resource. A copy of this form and the draft of the educational resource were distributed to all participants, including ASNR. A week later the research assistant met with each study participant (persons with dementia and their caregivers) in their homes to discuss the draft and complete the form. ASNR staff completed the form independently.

### Phase Five—pilot test of the third draft of the educational resource

In Phase Five, the principal investigator reviewed feedback received on the second draft of the educational resource and revised the resource accordingly. The resulting third draft of the educational resource was then pilot-tested with people who were not familiar with it. These included three ASNR family support counsellors, three caregivers and three persons with dementia. The research assistant met with participants in the pilot phase on a one-on-one basis in their homes. They were introduced to the resource and given a copy of it to review along with a feedback form to complete. Two weeks later the research assistant returned to obtain feedback. Where assistance was needed the research assistant helped the participant complete the form.

### Phase Six—pilot test of the fourth draft of the educational resource

The fourth draft of the educational resource was further pilot-tested with one caregiver and one ASNR family support counsellor who had never seen the educational resource before. Further revisions were made to the resource to reflect their feedback.

### Phase Seven—final version of the educational resource

In Phase Seven, the final version of the educational resource *Adapting Your Home to Living with Dementia: A Resource Book for Living at Home and Guide to Making Home Adaptations* was completed.

## FINDINGS

This study revealed that living with dementia involves a process of adaptation experienced as a dynamic tension between the person with dementia and his or her caregiver, typically a spouse or an adult child. This tension manifested as “holding on vs. letting go” (caregivers) and “autonomy vs. self doubt” (persons with dementia). Caregivers were primarily concerned with safety and security, and particularly with how to minimize risks and protect their loved ones from experiencing failure.

People with dementia expressed concerns about wanting to maintain their independence yet needing and being grateful for help. Empathy, gratitude and humour were the primary coping mechanisms by which both groups managed this tension.

## CONCLUSIONS

Dementia places major demands on individuals living with the disease and their family members providing care for them. Understanding the caregiving relationship and particularly how people with dementia and family caregivers naturally attempt to adjust and cope is an important starting point in interventions involving environmental adaptation. Adapting the home to living with dementia involves more than simply making physical changes to the home, introducing assistive devices, simplifying tasks or adapting one’s approach. It is a process that occurs within the context of relationships. In fact, research shows that adherence to recommendations for environmental adaptation is a complex process including factors such as purpose and meaning attributed to aspects of the home environment, caregiver skills and ownership of ideas, personal resources, and formal and informal supports. Consequently, health care professionals need to promote a collaborative approach to environmental adaptation that fosters joint decision-making, provides clients with information, options and choices and ensures that both the caregiver’s and care receiver’s needs and preferences are respected. Providing families with a variety of options to suit their individual circumstances and strategies to overcome resistance to intervention are key factors to enhancing their capacity to adapt their homes to living with dementia.

The report that resulted from this research, *Adapting your Home to Living with Dementia* integrates the findings from the research into practice in that it incorporates a guide to home adaptation into the bigger picture of the experience of dementia and the care-giving relationship.

Incorporating the knowledge and experiences of people living with dementia and family caregivers into a practical and easily accessible educational resource will potentially serve the following key functions:

1. Bridge the gap between research and practice;
2. Empower families to access and use formal supports according to their needs; and
3. Support and encourage individuals and families to strengthen their skills and strategies used to cope with dementia.

## Research Highlight

### Adapting Your Home to Living with Dementia

*Adapting Your Home to Living with Dementia* is organized in two volumes. Volume One contains the research report; Volume Two the “Resource Book” and “Guide to Home Adaptations.”

The “Resource Book” provides general information about dementia, its symptoms and common problems that impact every day activities of people with dementia and their caregivers. It also contains strategies that can help people with dementia to continue to live safely in their home for as long as possible. In the book, individuals with dementia and their caregivers share their thoughts, feelings and experiences about living and coping with dementia.

The “Guide to Home Adaptations” provides suggestions and strategies to deal with difficulties associated with dementia and caregiving at home. These suggestions and strategies address cognitive and physical issues and are designed to make it easier for people with dementia to perform daily living activities in the home and the community. The guide is organized in the following three sections.

- A. “General Household Activities”
- B. “Activities of Daily Living”
- C. “General Community Activities”

Each of these sections is further organized into topics that reflect the types of difficulties that people with dementia and their caregivers typically experience. Tips and strategies to help manage these difficulties are also provided and, at the end of each section, there is a “Self Assessment Form” and a “To Do List” designed to help users make a list of, and prioritize, the most appropriate home adaptations.

*Adapting Your Home to Living with Dementia* is intended primarily for people with dementia living at home and their caregivers, but it can also be useful to community-based health professionals and local Alzheimer Societies as a tool to help individuals with dementia and their families. *Adapting Your Home to Living with Dementia* has been designed to complement other available resources.

**CMHC Project Manager:** Luis Rodriguez, Policy and Research

**Research Report:** *Adapting Your Home to Living with Dementia: A Resource Book for Living at Home and Guide to Making Home Adaptations*

**Principal Investigator:** Nancy Rushford M.A., MSc. (Occupational Therapist)

**Research Team Members:** Staff at the Alzheimer Society of the Niagara Region (ASNR) and a group of extraordinary individuals with dementia and their caregivers living in the Niagara Region.

This project was funded (or partially funded) by Canada Mortgage and Housing Corporation (CMHC) under the terms of the External Research Program (ERP), an annual research grant competition. The views expressed are the personal views of the author(s) and do not represent the official views of CMHC. For more information on the ERP, please visit the CMHC website at [www.cmhc.ca](http://www.cmhc.ca) or contact the Project Officer, Responsive Programs by e-mail at [erp@cmhc-schl.gc.ca](mailto:erp@cmhc-schl.gc.ca), or by regular mail: Project Officer, Responsive Programs, External Research Program, Policy and Research Division, Canada Mortgage and Housing Corporation, 700 Montreal Road, Ottawa ON K1A 0P7.

To find more **Research Highlights** plus a wide variety of information products, visit our website at

**[www.cmhc.ca](http://www.cmhc.ca)**

or contact:

Canada Mortgage and Housing Corporation  
700 Montreal Road  
Ottawa, Ontario  
K1A 0P7

Phone: 1-800-668-2642

Fax: 1-800-245-9274

©2008, Canada Mortgage and Housing Corporation  
Printed in Canada  
Produced by CMHC

08-10-08

Although this information product reflects housing experts' current knowledge, it is provided for general information purposes only. Any reliance or action taken based on the information, materials and techniques described are the responsibility of the user. Readers are advised to consult appropriate professional resources to determine what is safe and suitable in their particular case. Canada Mortgage and Housing Corporation assumes no responsibility for any consequence arising from use of the information, materials and techniques described.



## L'adaptation de votre logement en fonction des besoins d'une personne atteinte de démence

Un manuel de référence pour vivre chez soi et un guide pour l'adaptation des logements

### INTRODUCTION

La démence réduit la capacité cognitive, c'est à dire la capacité de réfléchir, de se souvenir, de comprendre, de raisonner, de juger et de communiquer. La perte de ces aptitudes influe sur la capacité d'une personne de fonctionner et de mener à bien des activités quotidiennes, comme s'occuper de ses finances, cuisiner et conduire. Il y a plusieurs types de démence, la plus courante étant la maladie d'Alzheimer<sup>1</sup>.

On estime que 364 000 Canadiens de plus de 65 ans ont une forme quelconque de démence<sup>2</sup>. Parmi ces personnes, 50 % vivent dans la communauté et 29 % vivent seules<sup>3</sup>. Chaque personne atteinte de démence connaît des problèmes qui pourraient compromettre sa sécurité et sa qualité de vie à la maison. Un milieu de soutien est essentiel pour les personnes atteintes de démence, puisque la maladie nuit non seulement à leurs habiletés physiques, mais aussi à leur capacité d'adapter leur comportement à l'environnement.

L'adaptation ou la modification du milieu est une méthode d'intervention qu'on utilise pour améliorer la sécurité des personnes et augmenter au maximum leur capacité de participer à la société. Elle comprend diverses stratégies, comme modifier les objets matériels, simplifier l'exécution des tâches, introduire des dispositifs d'aide ou modifier le logement. Bien que de nombreuses questions qui entrent dans la création d'un milieu de soutien soient semblables aux

préoccupations en matière de sécurité et d'accessibilité à prendre en compte pour les personnes ayant des déficiences physiques, il faut aussi tenir compte des symptômes cognitifs et comportementaux lorsqu'on a affaire à des personnes atteintes de démence, et en plus, il faut choisir les adaptations matérielles appropriées et les introduire au bon moment. De plus, il est essentiel que la famille comprenne comment adapter le milieu, puisque c'est souvent elle qui assure la plus grande partie des soins à une personne atteinte de démence vivant dans la collectivité.

La présente étude a été réalisée par Nancy Rushford (M.A., M.Sc. [ergothérapie]) grâce à une aide financière du Programme de subventions de recherche de la Société canadienne d'hypothèques et de logement (SCHL). Elle a été menée en collaboration étroite avec la Société Alzheimer de la région de Niagara<sup>4</sup> (SARN) en Ontario, au Canada, et un groupe extraordinaire d'individus atteints de démence et leurs soignants.

### OBJECTIFS ET QUESTIONS DE RECHERCHE

La présente étude avait pour objectif de mettre au point une ressource éducative sur l'adaptation du milieu pour les personnes atteintes de démence vivant chez elles, et leurs soignants.

1 Société canadienne d'hypothèques et de logement. Les choix de logements pour les personnes atteintes de démence, 1999.

2 Société Alzheimer du Canada, 2007.

3 Société Alzheimer du Canada, Groupe de travail de l'Étude sur la santé et le vieillissement au Canada. « Méthodes de soins pour les personnes atteintes de démence au Canada », *Journal canadien sur le vieillissement*, vol.13, n°4 (1994), p. 470-487. Français et anglais. Consulté en septembre 2008 à l'adresse : <http://www.alzheimer.ca/french/disease/stats-caregiving.htm>

4 La Société Alzheimer est un organisme sans but lucratif qui fonctionne à l'échelle nationale, provinciale et locale, au Canada. La Société Alzheimer de la région de Niagara sert de source d'information, de soutien et d'action sociale pour les personnes atteintes de démence, les membres de leurs familles, les fournisseurs de soins et le grand public.



Ce sont les familles qui demandaient l'aide de la SARN pour faire face aux nombreux défis liés à la démence qui ont donné à la chercheuse l'idée de mener cette étude. Chacune de ces familles avait une histoire unique à raconter. Ensemble, elles avaient une expérience commune et une mine de connaissances et de savoir-faire qu'elles avaient acquises en apprenant à composer avec la maladie. La chercheuse a pensé que la meilleure façon de créer une ressource éducative utile et pratique qui pourrait guider d'autres individus atteints de démence et leurs soignants serait de combiner les connaissances et le savoir-faire de ces familles, les compétences des conseillers en soutien des familles du SARN et l'information présente dans la documentation existante. La participation et l'apport des individus atteints de démence et de leurs soignants ont été un élément fondamental du processus de recherche.

L'étude visait à répondre à trois principales questions :

1. Quelles sont les expériences des personnes atteintes de démence vivant chez elles et des soignants membres de la famille qui leur assurent des soins à la maison?
2. Quelles difficultés particulières rencontrent-ils à la maison et dans la collectivité et comment viennent-ils à bout de ces difficultés?
3. Quelles mesures et stratégies en vue d'adapter le milieu peuvent être prises ou adoptées pour atténuer ces difficultés?

## MÉTHODOLOGIE

Pour réaliser l'étude, l'équipe de recherche a utilisé une approche de recherche-action pratique faisant appel à des groupes de consultation et à des entrevues semi-structurées avec sept soignants membres de la famille et sept personnes à un stade précoce de démence. L'approche visait à explorer l'expérience vécue de la démence et de la prestation de soins, y compris les difficultés et conséquences fonctionnelles, ainsi que les stratégies d'adaptation utilisées. Ces participants à l'étude ont pris part au processus d'intégration de leurs connaissances et de leurs expériences, enjeux et stratégies d'adaptation dans la ressource sur l'adaptation du milieu et ils ont contribué à son développement jusqu'à son achèvement.

Les participants à l'étude ont été choisis par échantillonnage au jugé et ont été recrutés par l'entremise de la SARN. L'équipe de recherche a obtenu le consentement éclairé de tous les participants.

La recherche a été menée dans les locaux de la SARN et dans les logements des participants à l'étude, qui étaient aussi situés dans la région de Niagara.

L'étude s'est déroulée en sept phases.

### **Phase un – première réunion des groupes de consultation et première ébauche de la ressource éducative**

Pendant la première phase, deux groupes de discussion ont été constitués. Le premier regroupait des soignants et l'autre, des personnes atteintes de démence. L'objectif était d'explorer les expériences vécues du point de vue des soignants membres de la famille et des personnes chez qui la démence avait été diagnostiquée. L'équipe de recherche a établi un questionnaire semi-structuré pour chaque groupe, l'a mis à l'essai et en a ensuite révisé la version définitive, et un facilitateur ayant beaucoup d'expérience dans le domaine de la démence et du soutien psychosocial l'a utilisé comme guide pour diriger les discussions des groupes. L'équipe a enregistré les discussions de chaque groupe sur bande sonore et en a fait la transcription, et une adjointe à la recherche a consigné ses observations. La chercheuse principale a analysé les données et produit la première ébauche de la ressource éducative intitulée *L'adaptation de votre logement en fonction des besoins d'une personne atteinte de démence*. La première ébauche exposait les difficultés que connaissent couramment les personnes atteintes de démence et leurs familles aux divers stades de la démence et les classait par thèmes et par types d'activités exercées à la maison et dans la collectivité.

### **Phase deux – deuxième réunion des groupes de consultation et suggestions des membres du personnel de la SARN**

L'équipe de recherche a convoqué une deuxième fois les deux groupes de consultation, composés des mêmes personnes, dans le but de vérifier la justesse des thèmes ressortant de la recherche et d'obtenir plus de détails sur les difficultés liées aux activités quotidiennes et les stratégies d'adaptation qui avaient été relevées pendant la première réunion des groupes. Les discussions des groupes pendant la deuxième réunion ont aussi été enregistrées sur bande sonore et transcrites, et une adjointe à la recherche a pris des notes.

La méthode utilisée pour recueillir les données pour chaque groupe a été légèrement différente. L'équipe de recherche a présenté la première ébauche de la ressource éducative à l'ensemble du « groupe des soignants » et a demandé aux participants de poursuivre en groupe leur réflexion sur leurs expériences.

Dans le cas du groupe des « personnes atteintes de démence », l'équipe a demandé aux membres de vérifier en groupe les thèmes qui étaient ressortis de la recherche et de fournir plus de renseignement. Elle a aussi présenté la première ébauche de la recherche éducative à chaque participant individuellement au cours d'une entrevue menée dans son logement. L'intervieweuse consignait par écrit leurs réactions à l'ébauche. En menant des entrevues individuelles à la maison pour recueillir les données, l'équipe pouvait rencontrer les personnes atteintes de démence dans un milieu plus confortable et approprié où elles pouvaient se concentrer et s'exprimer plus facilement. De plus, elle disposait d'un contexte concret lui permettant d'obtenir des réponses aux questions ayant trait à leurs activités à la maison.

En plus, l'équipe de recherche a remis une copie de la première ébauche de la ressource éducative à sept membres du personnel de la SARN, dont des conseillers en soutien de famille, le directeur des services cliniques et le spécialiste en éducation, et elle leur a demandé d'ajouter des détails sur les questions présentées, notamment les difficultés éprouvées dans les activités à la maison et dans la collectivité, d'après leur expérience avec des personnes atteintes de démence et leur soignants. Les participants à ce groupe ont mentionné des difficultés courantes qu'ils avaient observées et qui n'avaient pas été incluses dans la première ébauche de la ressource éducative. Ils ont aussi ajouté des suggestions pour surmonter ces difficultés.

### **Phase trois – deuxième ébauche de la ressource éducative**

Pendant la troisième phase, la chercheuse principale a analysé les données obtenues au moyen des groupes de consultation et des entrevues qui avaient eu lieu pendant la deuxième phase. Elle a ensuite fait une analyse de la documentation sur les adaptations du milieu pour les personnes atteintes de démence et sur l'expérience de la démence du point de vue des soignants et des individus vivant avec la maladie. Puis, elle a établi les thèmes, questions, défis et stratégies d'adaptation communs qui ressortaient des documents pertinents sur le sujet et des suggestions du personnel de la SARN et s'en est servi pour préparer la deuxième ébauche de la ressource éducative.

### **Phase quatre – rétroaction sur la deuxième ébauche de la ressource éducative**

Pendant la quatrième phase, l'équipe a préparé une formule pour obtenir la rétroaction des participants à l'étude sur le contenu, la pertinence, le style et la structure de la deuxième ébauche de la ressource éducative. Elle a distribué une copie de cette formule et l'ébauche de la ressource éducative à tous les participants, y compris au personnel de la SARN. Une semaine plus tard, l'adjointe à la recherche a rencontré chaque participant à l'étude (les personnes atteintes de démence et leurs soignants) dans leur logement pour discuter de l'ébauche et remplir la formule. Les membres du personnel de la SARN ont rempli la formule de façon autonome.

### **Phase cinq – essai pilote de la troisième ébauche de la ressource éducative**

Pendant la cinquième phase, la chercheuse principale a examiné la rétroaction obtenue concernant la deuxième ébauche de la ressource éducative et en a tenu compte pour réviser le document. L'équipe a ensuite fait l'essai pilote de la troisième ébauche ainsi obtenue auprès de personnes qui n'avaient pas vu les versions précédentes, dont trois conseillers en soutien de famille de la SARN, trois soignants et trois personnes atteintes de démence. L'adjointe à la recherche s'est rendue chez les participants à la phase de l'essai pilote pour s'entretenir individuellement avec eux dans leur logement. Elle leur a présenté la ressource et leur en a remis une copie pour qu'ils puissent l'examiner, ainsi qu'une formule de rétroaction à remplir. Deux semaines plus tard, l'adjointe à la recherche est retournée chez les participants pour obtenir leur rétroaction. Lorsque cela était nécessaire, elle aidait le participant à remplir la formule.

### **Phase six – essai pilote de la quatrième ébauche de la ressource éducative**

L'équipe a fait un essai pilote de la quatrième ébauche de la ressource éducative en faisant appel à un soignant et à un conseiller en soutien de la famille de la SARN qui n'avaient pas vu les versions précédentes. D'autres révisions ont été apportées à la ressource pour tenir compte de leur rétroaction.

### **Phase sept – version définitive de la ressource éducative**

Pendant la septième phase, la chercheuse a terminé la version définitive de la ressource intitulée *L'adaptation de votre logement en fonction des besoins d'une personne atteinte de démence : un manuel de référence pour vivre chez soi et un guide pour l'adaptation des logements*.

## RÉSULTATS

L'étude a révélé que vivre avec la démence nécessite un processus d'adaptation qui est perçu comme une tension dynamique entre la personne atteinte de démence et son soignant, habituellement un conjoint ou un enfant adulte. Cette tension se manifeste par le désir contradictoire de « se raccrocher ou laisser aller » (chez les soignants) et le tiraillement entre « vouloir être autonome et douter de soi » (chez les personnes atteintes de démence). Les soignants s'inquiétaient surtout pour la sécurité de leurs proches et se demandaient notamment ce qu'ils pouvaient faire pour réduire les risques au minimum et les protéger contre l'expérience de l'échec. Les personnes atteintes de démence ont exprimé leurs inquiétudes liées au désir de conserver leur autonomie, tout en sachant qu'elles avaient besoin d'aide et en étant reconnaissantes pour celle qu'elles recevaient. L'empathie, la gratitude et l'humour étaient les principaux mécanismes d'adaptation qu'utilisaient les deux groupes pour gérer cette tension.

## CONCLUSIONS

La démence est lourde à porter tant pour les personnes qui en sont atteintes que pour les membres de leurs familles qui en prennent soin. Comprendre la relation entre le malade et le soignant, et notamment comment les personnes atteintes de démence et les soignants membres de leur famille tentent naturellement de s'adapter et de composer avec la maladie, est un important point de départ de toute intervention visant à adapter le milieu. Adapter le logement en fonction des besoins d'une personne atteinte de démence ne consiste pas simplement à apporter des changements matériels à l'habitation, à introduire des dispositifs d'aide, à simplifier les tâches ou à adapter l'approche qu'on utilise. C'est un processus qui se produit dans le contexte de relations entre personnes. En fait, la recherche démontre que la mise en œuvre des recommandations visant l'adaptation du milieu est un processus complexe englobant divers facteurs, comme le but et la signification attribués aux divers aspects du milieu de vie, les compétences des soignants et leur acceptation des idées, les ressources personnelles et les mesures de soutien officielles et officieuses. Par conséquent, les professionnels des soins de santé doivent encourager une approche de l'adaptation du milieu axée sur la collaboration, qui favorise la prise de décisions conjointe, donne aux clients de l'information, des options et des choix et assure le respect des besoins et des préférences du soignant ainsi que de la personne qui reçoit les soins. Donner aux familles une variété d'options adaptées à leur propre situation et de stratégies pour surmonter la résistance aux interventions est un facteur clé pour améliorer leur capacité d'adapter leur logement à la vie avec une personne atteinte de démence.

Le rapport découlant de cette recherche intègre les résultats de la recherche dans la pratique, en ce sens qu'il présente un guide de l'adaptation des logements dans le contexte plus vaste de l'expérience de la démence et de la relation entre le soignant et le soigné.

L'intégration des connaissances et expériences des personnes atteintes de démence et des soignants membres de leur famille dans une ressource éducative pratique et d'accès facile devrait remplir les fonctions clés suivantes :

1. Faire le pont entre la recherche et la pratique;
2. Donner aux familles les moyens d'accéder aux mesures de soutien officielles et de les utiliser selon leurs besoins; et
3. Aider et encourager les personnes et les familles à renforcer leurs compétences et les stratégies qu'elles utilisent pour composer avec la démence.

Cette étude s'est soldée par la production du rapport intitulé *L'adaptation de votre logement en fonction des besoins d'une personne atteinte de démence*, qui comprend deux volumes. Le premier contient un rapport de recherche, et le deuxième est un manuel de référence et un guide pour l'adaptation des logements.

Le manuel de référence présente de l'information générale sur la démence, ses symptômes et les problèmes courants qui ont un impact sur les activités quotidiennes des personnes atteintes de démence, et de leurs soignants. Il propose aussi des stratégies qui peuvent aider les personnes atteintes de démence à continuer d'habiter chez elles en toute sécurité le plus longtemps possible. Dans le manuel, des personnes atteintes de démence et leurs soignants partagent leurs réflexions, leurs sentiments et leurs expériences concernant la vie avec la démence et l'adaptation à la maladie.

Le guide de l'adaptation des logements présente des suggestions et des stratégies pour venir à bout des difficultés liées à la démence et au soin des personnes atteintes dans leur domicile. Ces suggestions et stratégies portent sur les problèmes cognitifs et physiques et visent à faire en sorte qu'il soit plus facile pour les personnes atteintes de démence d'exécuter les activités de la vie quotidienne chez elles et dans la collectivité. Le guide est divisé en trois sections :

- A) Travaux ménagers généraux
- B) Activités de la vie quotidienne
- C) Activités communautaires générales

Chacune de ces sections est subdivisée en sujets qui reflètent les types de difficultés que connaissent habituellement les personnes atteintes de démence et leurs soignants. On y trouve aussi des conseils et des stratégies pour aider à gérer ces difficultés et, à la fin de chaque section, il y a une formule d'auto-évaluation et une liste de choses à faire, destinées à aider les utilisateurs du guide à dresser une liste des adaptations les plus appropriées de leur logement et d'en établir l'ordre de priorité.

La publication *L'adaptation de votre logement en fonction des besoins d'une personne atteinte de démence* vise principalement les personnes atteintes de démence vivant chez elles et leurs soignants, mais elle peut aussi être utile aux professionnels communautaires de la santé et aux sociétés Alzheimer locales en tant qu'outil pour aider les personnes atteintes de démence et leurs familles. Elle a été conçue pour compléter les autres ressources offertes.

**Directeur de projet à la SCHL :** Luis Rodriguez, Politiques et recherche

**Rapport de recherche :** *L'adaptation de votre logement en fonction des besoins d'une personne atteinte de démence : un manuel de référence pour vivre chez soi et un guide pour l'adaptation des logements*

**Chercheuse principale :** Nancy Rushford (M.A., M.Sc.) (ergothérapie)

**Membres de l'équipe de recherche :** Personnel de la Société Alzheimer de la région de Niagara (SARN) et un groupe extraordinaire de personnes atteintes de démence et leurs soignants habitant dans la région de Niagara.

Ce projet a été réalisé (ou réalisé en partie) grâce au soutien financier de la Société canadienne d'hypothèques et de logement (SCHL) dans le cadre de son Programme de subventions de recherche, subventions qui sont octroyées au terme d'un concours annuel. Les idées exprimées sont toutefois celles de l'auteur (ou des auteurs) et ne représentent pas la position officielle de la SCHL. Pour en savoir plus sur ce programme, visitez le site Web de la SCHL à [www.schl.ca](http://www.schl.ca) ou communiquez avec l'agent de projets, Recherche d'initiative privée, par courriel, à [erp@cmhc-schl.gc.ca](mailto:erp@cmhc-schl.gc.ca), ou par la poste à : Agent de projets, Recherche d'initiative privée, Programme de subventions de recherche, Division de la recherche et des politiques, Société canadienne d'hypothèques et de logement, 700 chemin de Montréal, Ottawa (Ontario) K1A 0P7.

Pour consulter d'autres feuillets *Le Point en recherche* et pour prendre connaissance d'un large éventail de produits d'information, visitez notre site Web au

**[www.schl.ca](http://www.schl.ca)**

ou communiquez avec la

Société canadienne d'hypothèques et de logement

700, chemin de Montréal

Ottawa (Ontario)

K1A 0P7

Téléphone : 1-800-668-2642

Télécopieur : 1-800-245-9274

Bien que ce produit d'information se fonde sur les connaissances actuelles des experts en habitation, il n'a pour but que d'offrir des renseignements d'ordre général. Les lecteurs assument la responsabilité des mesures ou décisions prises sur la foi des renseignements contenus dans le présent ouvrage. Il revient aux lecteurs de consulter les ressources documentaires pertinentes et les spécialistes du domaine concerné afin de déterminer si, dans leur cas, les renseignements, les matériaux et les techniques sont sécuritaires et conviennent à leurs besoins. La Société canadienne d'hypothèques et de logement se dégage de toute responsabilité relativement aux conséquences résultant de l'utilisation des renseignements, des matériaux et des techniques contenus dans le présent ouvrage.



National Office

Bureau national

700 Montreal Road  
Ottawa ON K1A 0P7  
Telephone: (613) 748-2000

700 chemin de Montréal  
Ottawa ON K1A 0P7  
Téléphone : (613) 748-2000

Puisqu'on prévoit une demande restreinte pour ce document de recherche, seul le résumé a été traduit.

La SCHL fera traduire le document si la demande le justifie.

Pour nous aider à déterminer si la demande justifie que ce rapport soit traduit en français, veuillez remplir la partie ci-dessous et la retourner à l'adresse suivante :

Centre canadien de documentation sur l'habitation  
Société canadienne d'hypothèques et de logement  
700, chemin Montréal, bureau CI-200  
Ottawa (Ontario)  
K1A 0P7

Titre du rapport: \_\_\_\_\_  
\_\_\_\_\_

Je préférerais que ce rapport soit disponible en français.

NOM \_\_\_\_\_

ADRESSE \_\_\_\_\_

rue

App.

ville

province

Code postal

No de téléphone ( ) \_\_\_\_\_



# ADAPTING YOUR HOME TO LIVING WITH DEMENTIA

## TABLE OF CONTENTS

### **VOLUME 1: RESEARCH REPORT**

Background	11
Introduction	12
Objective	13
Methodology	13
Participants and Recruitment	13
Phases and Data Collection	15
Data Analysis	17
Findings	18
Discussion	20
Conclusion & Implications	21
Limitations	22
References	23

### **VOLUME 2 (separate volume)**

PART 1: A RESOURCEBOOK FOR LIVING AT HOME

PART 2: A GUIDE TO HOME ADAPTATIONS



## BACKGROUND

This research was inspired by families who sought support from the Alzheimer's Society of the Niagara Region, Canada, to deal with the many challenges associated with dementia. Individually the families had unique stories to tell but collectively they shared a common experience and represented a wealth of knowledge and strategies developed to cope with the disease. Combined with the expertise of family support counselors at ASNR, and information gained through the literature, it was anticipated that the experiences and perspective of these families could be incorporated into an education resource designed to give practical support to others going through a similar experience. The document titled *'Adapting your home to living with dementia. A resource book for living at home and guide to home adaptations* is the primary output of this research. It was developed through assistance from a grant given by the CMHC, and in collaboration with individuals living with dementia, their families, and the ASNR.

The document complements previous CMHC publications on this topic (CMHC, 1989; 1998; 2002; 2003; 2008) and other resources available to families through the Alzheimer Society of the Niagara Region and the Canadian Association of Occupational Therapist (1998). In particular, it builds upon ASNR's 'Therapeutic Living Centre' [TLC], an educational centre designed to model adaptations to the home environment that are relevant to dementia. This resource is unique in that it combines home adaptations for cognitive limitations (memory, problem solving, attention) with adaptations for physical limitations commonly associated with age-related changes. As such it is not only useful for families coping with dementia, but may be relevant to individuals with cognitive or intellectual impairments associated with other health conditions such as acquired brain injury, intellectual disability/developmental delay, and cognitive difficulties associated with psychiatric diseases or disorders.

## INTRODUCTION

There are an estimated 364,000 Canadians over the age of 65 who have some form of dementia (Alzheimer Society Canada, 2007), 50% of whom live in the community, 29% of whom live alone (Alzheimer Society Canada, Canadian Study of Health and Aging Working Group, 1994). Each person experiencing dementia faces challenges that potentially compromise their safety and quality of life at home. A supportive environment is crucial for individuals with dementia since the disease affects not only physical capabilities but the ability to adapt behaviour to the environment (CAOT, 1998).

*Environmental adaptation or modification* can be defined as a means of re-establishing a balance between a person's abilities and the environment's demands through structural changes, special equipment, assistive devices and behavioural changes (Messecar, 2000). Although many issues for creating a supportive environment are similar to the safety and accessibility concerns of people with physical disabilities, cognitive and behavioural symptoms also need to be considered for persons with dementia, as well as the appropriate selection, introduction and timing of physical adaptations (CAOT, 1998). As it is often the family caregiver who provides most of the supportive care for people living with dementia in the community [Messecar, 2000; Cumming et al., 2001], the caregiver's ability to understand how to adapt the environment is critical to enhancing safety and security and maximizing independence and participation in and around the home and community.

The Canada Mortgage and Housing Corporation have published resources to assist families with home adaptation relevant to dementia (CMHC, 1998; 2002). These resources provide caregivers with suggestions for how they can make simple changes to their homes to accommodate the behaviours associated with Alzheimer's Disease. However, given that the presentation of symptoms of dementia may vary from person to person and change over the course of the disease process, not all suggestions for adaptation are appropriate at any given time. Thus, home adaptation requires that one engage in a process of assessing individual needs or functional limitations, selecting appropriate environmental strategies and reassessing needs throughout the course of the disease.

Typically, a professional such as an Occupational Therapist guides the process of environmental adaptation and makes recommendations for the family or caregiver to implement within his or her home. Adherence to recommendations is a complex process including factors such as purpose and meaning attributed to aspects of the home environment, caregiver skills and ownership of ideas, personal resources, and formal and informal supports (Cumming et al; 2001; Messecar, 2000). Consequently, health care professionals need to promote a collaborative approach to home adaptation that fosters joint decision making, provides clients with information, options and choices and ensures that the caregiver and care receiver's needs and preferences are respected (Messecar, 2000; Clemson et al., 1999).

In order to foster a collaborative approach to home adaptation it is not only important to understand the needs and preferences of people with dementia and their family caregivers; it is equally important to identify and strengthen the resources they already

have available to them. Family caregivers and individuals in the early stages of dementia naturally develop a range of coping strategies to manage the difficulties associated with dementia. Combining their knowledge and experiences with professional expertise and available literature in the form of a practical and easily accessible resource will potentially serve a few important functions: 1) It helps to bridge the gap between research and practice 2) It potentially empowers families to access and use formal supports according to their needs 3) It supports and encourages individuals and families to further develop their skills and strategies to cope with dementia 4) It reminds people that they are not alone in their experience.

## **OBJECTIVE**

The purpose of this research was to collaborate with individuals with dementia and their families to develop an educational resource on home adaptation that could be meaningfully applied to their individual circumstances and needs over time. The primary outcome of this research is the resource titled “**Adapting your Home to Living with Dementia: A Resource Book and Guide to Home adaptations.**” It provides practical information and strategies for individuals and families to help them cope with the challenges associated with dementia.

## **METHODOLOGY:**

This research followed a practical action research approach (FMECD, 2003; Somekh, 2006) including focus groups and semi-structured interviews with family caregivers and persons in the early stage of dementia. This included an exploration of the lived experience (Silverman, 2006) of dementia and care giving, including difficulties and functional implications, as well as coping strategies. Action research integrates research and action (Somekh, 2006). It provided an opportunity for people living with dementia and their family caregivers to collaborate with the researcher to develop a meaningful resource that builds upon their experiences and responds to their changing needs.

Two primary research questions served to guide this qualitative study and resource development:

1. What are the experiences of individuals with dementia living at home and caregivers providing home based care?
2. What specific difficulties do they experience in the home and community and how do they cope with these difficulties?

## **PARTICIPANTS & RECRUITMENT**

Participants were selected by purposive sampling and were recruited through the ASNR. This involved posted advertisement at ASNR, presentation of the study to caregiver and early stage dementia support groups operated by ASNR, and through the organization’s

family support counselors who provided home-based support to families. Persons who identified an interest in participating were contacted by the research assistant by telephone to schedule a meeting to determine eligibility, describe the study in detail and obtain informed consent from appropriate parties.

**Inclusion Criteria:**

1. Be a caregiver of a person living at home with dementia who lives with the person with dementia or within close proximity [within Niagara region]
2. Be diagnosed with Alzheimer Disease or a related dementia and have participated in discussions with a physician during which the diagnosis of dementia was disclosed.
3. Live within the Niagara community
4. Be able to speak English and express thoughts and feelings

**Exclusion Criteria:**

1. Be living in a retirement home or long term care facility

**Site Description:** The research was conducted at the Alzheimer Society of Niagara Region, and in the participants’ homes, also in the Niagara region. The Alzheimer Society is a non-profit agency operating nationally, provincially and locally in Canada. The Alzheimer Society of the Niagara Region serves as a source of education, support, and advocacy for persons with dementia, their family members, health providers and the general public.

**Background Demographic Data**

Fourteen participants were recruited through ASNR; seven caregivers and seven persons with dementia. Individual demographic data was collected through a questionnaire administered to each participant at the onset of the study.

**Carer Profile**

Gender	Age	Relationship to person with ADRD	Carer health issues	Mobility aid (carer)	Type of home	Live alone
female	79	spouse	Heart; high blood pressure, high cholesterol	No	House/owned	No
male	76	spouse	Arthritis, asthma, heart (bypass surgery)	No	House/owned	No

female	62	spouse	Arthritis, connective tissue disease, fibromyalgia	No	House/rented	No
female	48	Adult child	none	No	House/owned	Yes
female	85	spouse	Anemia, arthritis, ovarian cancer	Yes/cane	Condo/owned	No
female	44	Adult child	Menopause (severe symptoms)	No	House/rented	Yes
female	78	spouse	Blindness R eye; hypertension	No	House/owned	No

### Profile: Individuals with ADRD

Gender	Age	Relationship to Carer	Type of dementia	Onset	Health issues	Mobility aid (carer)	Type of home	Live alone
male	67	Gender			Relationship to carer	No	House/rented	No
female	74					No	House/owned	No
male	78	spouse			Hypertension, angina	No	House/owned	No
male	87	spouse			respiratory	No	condo/owned	No
female	68	daughter			none	No	House/owned	Yes
male	83	spouse			none	No	House/owned	No
male	84	daughter			Arthritis, emphysema, cataracts	No	House/rents	Yes

## PHASES AND DATA COLLECTION

**Phase One:** The initial phase comprised of two focus groups to explore the lived experience of dementia from the perspective of family caregivers and individuals diagnosed with dementia [one caregiver group; one person with dementia group]. A semi-structured questionnaire was developed for each group to serve as a facilitation guide. These questionnaires were piloted with a person with dementia and a caregiver and revisions were made accordingly. An experienced facilitator with extensive knowledge

and skills in the area of dementia /psychosocial support collected data from both focus groups. Each focus group was audio-taped and subsequently transcribed. Field notes were collected by an additional research assistant who attended the focus groups and recorded her observations. The data was analyzed by the primary investigator and the first draft of the reference guide was developed. This draft consisted of a list of categorized data and emerging themes as well as everyday activities around the home and community from which participants would verify and elaborate upon in phase two.

**Phase Two:** Two additional focus groups were facilitated with the same participants (1 caregiver group; 1 persons with dementia group) to verify emerging themes and elaborate on the list of everyday activities in terms of the participants' experiences (difficulties and coping strategies). These groups were audio-taped and transcribed and a research assistant collected field notes. The procedure for collecting data differed slightly for each group in phase two in that the caregiver group was introduced to the draft together as a group. They were asked to reflect further on their experiences as a group. In contrast, the 'persons with dementia' group were asked to verify and elaborate on emerging themes as a group, but was introduced to the draft through 1:1 interview in their home environment. The interviewer recorded their responses to the draft in writing. Adapting the method of data collection to 1:1 interviews in the home provided a more comfortable and appropriate environment where individuals with dementia could concentrate and more easily express themselves. The home environment also provided a meaningful context to elicit responses to questions related to their activities around the home.

Seven staff members of the ASNR including family support counselors, the clinical services director and the educational specialist were given a copy of the initial draft. They were asked to elaborate on the issues presented in terms of difficulties experienced with activities around the home and community as it related to their experience with people with dementia and their caregivers. They identified common difficulties they had observed that were not represented in the draft and added their suggestions and recommendations for adaptive strategies/home modifications.

**Phase Three:** Focus group and interview data from the second phase was analyzed by the primary investigator. The researcher also conducted a literature review on environmental adaptations for dementia, and the experience of dementia from the perspective of caregivers and individuals living with the disease. Common themes, issues, and adaptive strategies that emerged from the study were compiled with relevant literature on the topic, and the input from the ASNR staff. This information was then integrated into the second draft of the reference guide.

**Phase Four:** A feedback form was developed for participants and ASNR staff to critique draft two of the reference guide in terms of content and relevance, style and layout. A copy of the draft was distributed to each participant, ASNR staff, and the CMHC for review. One week later the research assistant met with each participant in their home to discuss the draft and complete the form. ASNR staff completed the form independently and the CMHC representative provided verbal feedback over the phone.

**Phase Five:** The primary investigator reviewed the feedback and made revisions accordingly. Draft 3 of the resource included the revisions and was piloted with members

of the target audience who were unfamiliar with the resource (including 3 family support counselors; 3 caregivers and 3 individuals with dementia, one who lived at home). The research assistant met with participants of the pilot phase on a 1:1 basis in their homes. They were introduced to the resource and were given a copy to review along with a feedback form to complete. Two weeks later the research assistant returned to obtain feedback. Where assistance was needed the research assistant helped the participant to complete the form.

**Phase Six:** Further revisions were made according to the feedback received. Draft four was piloted with one caregiver and one ASNR family support counselor who had never seen the resource.

**Phase Seven:** Final revisions were made according to the feedback and the final product “**Adapting Your Home to Living with Dementia: A Resource Book for Living at Home and a Guide to Home Adaptation**” was completed. The final version was then submitted to CMHC.

### ***Rigor and Trustworthiness***

To ensure data was collected and analyzed accurately the following procedures were employed: 1) Multiple data collecting strategies including focus groups, 1:1 interviews, and feedback questionnaires. 2) Focus groups were audio-taped and transcribed and supplemented by field notes 3) Member checking procedures were optimized throughout the research process. Participants were given repeated opportunities to verify themes and elaborate on their experiences. 4) The researchers had clinical expertise in dementia and research experience.

Triangulation was used to ensure trustworthiness including multiple methods of data collection (focus groups and 1:1 interview) and a variety *sources/data* (audio-taped recordings, field notes, feedback questionnaires; separate focus groups involving caregivers and persons with dementia).

## **DATA ANALYSIS:**

The method of analysis used to interpret the data followed a system based on a constant comparative method (Burnard, 1991).

**Stage 1: Immersion in data.** Transcripts were read through and notes made throughout the reading on general themes within the transcripts.

**Stage 2: Open coding.** Transcripts were read again and as many headings as necessary were written down to describe all aspects of the content. The headings or category system accounted for the entire interview data.

**Stage 3: Collapsing categories.** The list of categories was surveyed by the researcher and grouped together under higher order headings. The number of headings was reduced by collapsing some of the ones that were similar into broader categories.

**Stage 4: Production of final list of Categories**

**Stage 5: Re-read transcripts.** Transcripts were re-read alongside the final list of categories and sub-headings to establish the degree to which the categories covered all aspects of the focus groups.

**Stage 6: Transcript coding by categories.** Each transcript was worked through with the list of categories and sub-headings and ‘coded’ according to the list of category headings. E.g. Memory loss and its impact = 1; Denial/Resistance to Change = 2.

**Stage 7: Cut and paste data into categories.** Data was then cut and pasted within appropriate categories for further analysis while maintaining a complete copy so as not to lose the whole meaning of the discussion.

**Stage 8: Identification of themes.** Themes were identified based on the information contained within the categories and compared across groups. These themes were used to develop outlines for the second phase of focus groups and the first draft of the self assessment guide.

**Stage 9: Analysis/comparison of new data.** The transcripts from the second phase of focus groups were read alongside the final list of categories and sub-headings to establish the degree to which the categories covered all aspects of the focus groups. Data that did not fit into the original list of category headings formed a new heading.

**Stage 10: Transcript coding by categories.** The data was cut and passed within appropriate categories.

**Stage 11: Revision/elaboration on themes.** Themes were further identified and elaborated upon. These themes were incorporated into the second, third, fourth, and final versions of the reference guide.

## **FINDINGS:**

Findings from the study revealed that the experience of dementia involves a process of adaptation experienced as a dynamic tension between the person with dementia and his or her caregiver. This tension manifested as 'holding on vs. letting go' (caregivers) and 'autonomy vs. self doubt' (persons with dementia). Empathy, gratitude and humor were the primary coping mechanisms by which both groups managed this tension.

## **ADAPTING TO DEMENTIA AS A DYNAMIC TENSION**

Persons with dementia and their caregivers were both engaged in a process of adapting to the changes to the quality and nature of their activities, relationships, and roles as a consequence of dementia. This had implications on their sense of identity and was experienced as a dynamic tension between them. In the context of the care giving relationship, this tension manifested for caregivers as holding on vs. letting go of their loved one in terms of encouraging independence in day to day activities or being protective. Individuals with dementia struggled in relationship with their caregiver, often a spouse or adult child, with exerting their autonomy vs. experiencing self doubt in relation to their performance of everyday activities.

Caregivers were primarily concerned with safety and security, particularly how to



minimize risks and protect their loved one from experiencing failure. They felt at times like a parent rather than a spouse or a daughter. Persons with dementia expressed concerns about wanting to maintain their independence, yet needing and being grateful for help, and related their experience to that of a child. Shifting perspective and *seeing beyond oneself* at a particular moment in time (or looking at the ‘big picture’) was used as a key coping strategy for both groups. Empathy and gratitude were the primary mechanisms through which both groups shifted perspective. Persons with dementia commonly used humour as another coping strategy.

## **INDIVIDUALS WITH DEMENTIA**

Individuals diagnosed with dementia were aware of the dichotomy between their abilities in past and at present, primarily impacted by memory loss. They were critical of themselves for failing to meet their own expectations. This was further compounded by anxiety over being seen to make mistakes and the impulse to deny or cover up these mistakes. They lived in a shadow of doubt, their own, and their caregivers, and fought to hold on to their independence and their self concept or identity. This sense of identity was tied to their abilities (what they were able to do) and their roles. At the same time they were trying to come to terms with the finality of their diagnosis and their increasing dependence on their caregivers which was met with a complex mix of gratitude (for their help), fear (of losing it) and frustration (over needing it; getting too much of it; or not wanting it). They worried about their caregiver’s health, feeling that dementia was harder on their families and caregivers than on themselves and were concerned about being a burden, not wanting to ‘drag them down’. They commonly *shifted perspective* as a strategy to deal with the challenge of adapting to dementia: Shifting perspective enabled them to see beyond themselves and their current circumstances. It manifested in *humour*, *empathy* and *gratitude* for what they still had (comparing themselves with others less fortunate and imagining how difficult life would be without support).

## **CAREGIVERS**

The caregivers acted as witnesses to their loved one’s experience and functioned as safety nets, absorbing the consequences of dementia in terms of added roles and responsibilities. They were in a constant state of vigilance and caught in a perpetual cycle of action-reaction; their loved one’s every move (actual and anticipated) dictating their next step. The caregivers were attuned to the needs and experiences of their loved one and ‘felt their pain’ but were helpless to prevent ‘the fall.’ When they experienced frustration and felt ‘drained’, they experienced guilt over not being patient enough. They were critical of themselves as caregivers, comparing themselves to an ideal of what a caregiver ‘should’ or ‘could be.’ This was compounded by the resistance they routinely experienced when providing care. The need to protect their loved one’s safety and security conflicted with his/her desire to be autonomous and independent, potentially leading to confrontations that they were trying to creatively circumvent. They often felt like a parent and had to move beyond their historical roles of ‘wife’ ‘husband’ or ‘adult child’ in order to supervise, set boundaries, and provide care. They altered their lifestyles considerably in order to accommodate their new role(s). They described an ongoing tension with wanting

to respect their loved one's desire for independence but needing to protect and make decisions for them. The caregivers were determined to care for their loved one but lived in doubt about how long they could keep providing care, resolving to live day by day. Similar to their loved ones, they shifted perspective and adopted the bigger picture as a coping strategy. This manifested primarily in *empathy* and helped them to manage the day-to-day challenges associated with providing care, including anticipating and interpreting their loved one's actions and needs.

## DISCUSSION

These findings are consistent with research into the subjective experience of dementia including coping strategies used by people in the early stages of Alzheimer's disease. In one particular study (Clare, 2003) responses to awareness of changes in memory functioning formed a continuum running from 'self-maintaining' to 'self-adjusting.' A self-maintaining stance related to attempts to normalize the situation and minimize the difficulties, thus maintaining continuity with prior sense of self. A self-adjusting stance related to attempts to confront the difficulties and adapt one's sense of self accordingly. (Clare, 2002) The ways that people tried to adjust fell into two categories along a continuum: self-protective and integrative responding. Self protective involved attempts to hold on and compensate. This reflected attempts to maintain a sense of self and normality. Developing a fighting spirit and coming to terms reflected attempts to confront the threats head on and respond in a way that balanced struggle with acceptance. This was seen as a way to integrate the changes within the self. The phenomenon of self-protective or self integrative responses (along a continuum) is consistent with the experiences of individuals with dementia in this study. They oscillated between feelings of autonomy and self doubt as they struggled to adapt to dementia. In particular, their use of humour as a coping strategy could be interpreted as a self protective function, helping to minimize their situation, thus preserve their sense of identity. Furthermore, research into the care giving relationship involving mothers being cared for by their adult daughters revealed the experience of 'grateful guilt' in response to the contradictory experiences of 'receiving care' while identifying with the role as a 'mother.' This is similar to the participants in this study who worried about being a burden and felt grateful for help.

In terms of the experiences of caregivers, the findings from this research contrast with other research where 'caregivers' and 'care receivers' are described as experiencing a progressive sense of asynchrony, loss of mutuality, personal disconnectedness and detachment from each other (Jones & Martinson, 1992; Lynch-Sauer, 1990). The caregivers and care receivers in this study expressed connectedness through empathy for the experiences and feelings of one another. Empathy helped them to cope with the daily challenges of dementia. Although their interactions and roles were changing as a consequence of the disease, they did not describe feelings of detachment from each other. However, the nature of their attachment to each other could be interpreted as changing. Attachment theory provides a descriptive and explanatory framework for discussion of interpersonal relationships between human beings. In infants it is primarily a process of *proximity seeking* to an identified *attachment figure* in situations of perceived distress or

alarm (Bowlby, 1980). It is also used as a theoretical framework to explain the behaviours of adults in interpersonal relationships and relationships involving care (Hazen & Shaver, 1994).

Understanding dementia and its impact on self identity and relationships may help to facilitate home adaptation, particularly in situations involving resistance to change. Caregivers in this study described resistance as a frequent occurrence impacting their activities and actions. The individuals with dementia acknowledged their denial of their need for help. This reflects, in part, research that shows that adherence to recommendations for environmental adaptation is a complex process including factors such as purpose and meaning attributed to aspects of the home environment, caregiver skills and ownership of ideas, personal resources, and formal and informal supports.

## **CONCLUSIONS: ADOPTING ‘THE BIG PICTURE’**

Dementia places major demands on individuals living with the disease and their family members providing care. Understanding the care giving relationship and particularly how people with dementia and family caregivers naturally attempt to adjust and cope is an important starting point in interventions involving environmental adaptation. *Adapting the Home to living with Dementia* involves more than simply making physical changes to the home, introducing assistive devices, simplifying tasks or adapting one’s approach. It is a process that occurs within the context of relationships that need to be appreciated and better understood. Health care professionals need to promote a collaborative approach to environmental adaptation that fosters joint decision making, provides people with information, options and choices and ensures that the caregiver and care receiver's needs and preferences are respected (Messecar, 2001; Clemson et al., 1999). Providing families with a variety of options to suit their individual circumstances and strategies to overcome resistance are key factors to enhancing their capacity to adapt their homes to dementia.

**“Adapting your Home to Living with Dementia: A Resource Book and Guide to Home Adaptations”** integrates the findings from this research into practice in that it incorporates a reference guide to home adaptation into the ‘bigger picture’ of the experience of dementia and the care giving relationship.

## **IMPLICATIONS**

Incorporating the knowledge and experiences of people living with dementia and family caregivers into a practical and easily accessible resource will potentially serve the following key functions: 1) Bridge the gap between research and practice 2) Empower families to access and use formal supports according to their needs 3) Support and encourages individuals and families to strengthen their skills and strategies used to cope with dementia.

## **LIMITATIONS**

As the development of this resource was based on a qualitative study with a small number of participants, it is not necessarily representative of the experiences of the population of persons with dementia and family caregivers as a whole. Further investigation may reveal other issues and themes that may be of relevance to home adaptation for dementia. Similarly, the practical strategies offered in this resource are not exhaustive. As such this resource should continue to evolve through collaborative processes and be followed by further editions.

## References

Alzheimer Society Canada (2007). Available online:

<http://www.alzheimer.ca/english/disease/stats-people.htm>

Alzheimer Society. Canadian Study of Health and Aging Working Group: Patterns of caring for people with dementia in Canada. *Can J Aging* 1994; Vol. 13 no. 4: 470-487. Retrieved August 2008 from

<http://www.alzheimer.ca/english/disease/stats-caregiving.htm>

Bowlby J (1980). *Loss: Sadness & Depression*, Attachment and Loss (vol. 3) London: Hogarth Press.

Burnard (1991). A method of analyzing interview transcripts in qualitative research. *Nurse Educ Today*, 11 (6): 461-466

Canadian Association of Occupational Therapists (1998). "Living at Home with Alzheimer's Disease and Related Dementias," a manual of resources, references and information. Ottawa, ON: CAOT Publications ACE.

Canada Mortgage and Housing Corporation (2008). Using the stairs. Available online at [http://www.cmhc.schl.gc.ca/en/co/maho/adse/masein/masein\\_002](http://www.cmhc.schl.gc.ca/en/co/maho/adse/masein/masein_002)

Canada Mortgage and Housing Corporation (1989). *Maintaining Senior's Independence: A Guide to Home Adaptations*. Canada Mortgage and Housing Corporation Publications.

Canada Mortgage and Housing Corporation (2003). *Maintaining Senior's Independence through Home Adaptations: A self Assessment Guide*. Canada Mortgage and Housing Corporation Publications.

Canada Mortgage and Housing Corporation (2002). *At Home with Alzheimer's Disease: Useful Adaptations to the Home Environment*. Canada Mortgage and Housing Corporation Publications.

Clare, L. (2003). Managing threats to self: awareness in early stage Alzheimer's disease. *Social Science & Medicine*, 57 (6): 1017-1029.

Clare, L. (2002). Developing awareness about awareness in early stage dementia. *Dementia* (1): 295-312.

Clemson, L. & Martin, R. (1996). Usage and effectiveness of rails, bathing and toileting aids. *Occupational Therapy in Healthcare*, 10 (1): 41-59.

Cumming, R.G., Thomas, M., Szonyi, G., Frampton, G., Salkeld, G., Clemson, L. (2001). Adherence to Occupational Therapist Recommendations for Home Modifications for Falls Prevention. *The American Journal of Occupational Therapy* 55 (6): 641-647.

Gitlin, L. & Corcoran, M. (1996). Managing Dementia at Home: The Role of Home Environmental Modifications. *Topics in Geriatric Rehabilitation, 12* (2): 28-29.

Federal Ministry for Economic Cooperation and Development (2003). International Education in Action Research Manual. Ed (Ian Hughes) Retrieved online May 18 2008 from [http:// www.afronets.org/files/Action-Research.pdf](http://www.afronets.org/files/Action-Research.pdf)

Hasselkus, B. & Murray, B. (2007). Everyday occupation, well-being, and identity: The experience of caregivers in families with dementia. *American Journal of Occupational Therapy, 61* (1): 9-20.

Hazan, C., & Shaver, P. R. (1994). Attachment as an organizational framework for research on close relationships. *Psychological Inquiry, 5*: 1-22.

Jones, P. S., & Martinson, I. M. (1992). The experience of bereavement in caregivers of family members with Alzheimer's disease. *Journal of Nursing Scholarship, 24*: 172-176.

Lynch-Sauer, J. (1990). When a family member has Alzheimer's disease: A phenomenological description of care giving. *Journal of Gerontological Nursing, 16*: 8-11.

Lubinski RL. Environmental considerations for elderly patients (1995). In: Lubinski R, (ed.) *Dementia and Communication*. San Diego, Calif: 257-278

Messecar, D. (2000). Factors affecting caregivers' ability to make environmental modifications. *Journal of Gerontological Nursing, 26* (12): 32-42

Messecar, D., Archbold, P., Stewart, B. & Kirschling, J. (2002). Home environmental modification strategies used by caregivers of elders *Research in Nursing and Health, 25* (5): 357-370.

Silverman, D. (Ed.) (2005). *Doing qualitative research: Second edition*. Sage Publications Ltd: London.

Skolaski-Pellitteri, T. (1983) Environmental adaptations which compensate for dementia. *Phys Occup Ther Geriatr. 3*(1):31-44

Somekh, B. (2006). Action research. A methodology for change and development. Open University Press. New York: NY

Ward-Griffin, C., Bol, N. & Oudshoorn, A. (2006). Perspective of women with dementia receiving care from their adult daughters. *Canadian Journal of Nursing Research* 38 (1): 120-146.

Visit our website at [www.cmhc.ca](http://www.cmhc.ca)