

RESEARCH REPORT

External Research Program



Adapting your Home to Living with Dementia

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



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Adapting Your Home To Living With Dementia

A Resource Book For Living At Home And Guide To Home Adaptations

Canada Mortgage and Housing Corporation

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Cette publication est aussi disponible en français sous le titre : *L'adaptation de votre logement en fonction des besoins d'une personne atteinte de démence* Opims 66496

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 Web site www.cmhc.ca or contact the Project Officer, Responsive Programs by e-mail at 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.

Library and Archives Canada Cataloguing in Publication

Rushford, Nancy

Adapting your home to living with dementia : a resource book for living at home and guide to home adaptations / principal investigator: Nancy Rushford.

(Research report)

Issued also in French under title: L'adaptation de votre logement en fonction des besoins d'une personne atteinte de démence.

ISBN 978-1-100-12554-1

Cat. no.: NH15-437/2009E

I. Dementia--Patients--Dwellings--Safety measures. 2. Dementia
--Patients--Home care. I. Canada Mortgage and Housing Corporation
II. Title. III. Series: Research report (Canada Mortgage and Housing
Corporation)

RC521 R87 2009

362.196'83

C2009-980110-8

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Printed in Canada
Produced by CMHC

It seems we all feel about the same. It's a similar experience. You've lost part of yourself, you know. When you think about it... it's what makes a man a man, a person a person... You can't think. But there's nothing you can do...

A gentleman describing what its like to live with dementia

There may not be a cure for dementia itself but there are things YOU CAN DO to help yourself or the person you are caring for...

By creating a supportive home environment that builds on a person's remaining abilities and compensates for the disabilities associated with dementia, a person can live safely, comfortably, and more independently at home longer

Home is Where the Heart is...

A group of caregivers and individuals with dementia were asked what home meant to them. This is what they considered home to be:

Thoughts about Home

It's life. If you don't have a home, then you don't have a life.

A place where the family can gather.

It's where you have people around that care for you. If you don't have that, what do you have?

Home is life. That's where you find everything -- your wife, your children ...

To me, it's togetherness; it's so many things.

Family

Wherever you happen to be

Where you're comfortable

Safety

Familiarity more than anything else

You struggle to get it and you want to hold onto it because you were successful in getting it

Every piece of furniture has a history

Home is...well... I've lost my home

It's where all your memories are

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About Adapting Your Home to Living with Dementia

Adapting Your Home to Living with Dementia contains two parts.

“Part One: A Resource Book for Living at Home” gives general information about dementia, including an outline of its symptoms and common problems that impact everyday activities. Individuals with dementia and their caregivers share their thoughts, feelings and experiences about living and coping with dementia. Communication and behaviour is discussed as well strategies for sustaining participation through meaningful activity.

“Part Two: A Guide to Home Adaptations” contains three elements

1. General Household Activities
2. Activities of Daily Living
3. Community Activities

Each section is further divided into relevant topics and associated difficulties experienced by people with dementia and caregivers. Tips or strategies to help manage these difficulties are listed. At the end of each section, there is a “Self Assessment Form” and “To Do List” designed to help the reader list and prioritize the home adaptations selected.

Target Audience

Adapting Your Home to Living with Dementia is primarily intended for people with dementia living at home and their caregivers. It is designed to complement other available community resources. Community-based health professionals may also find it a useful tool to help individuals and their families:

- identify and prioritize issues related to home/community safety and the performance of daily activities;
- facilitate home adaptations to enhance safety, security and comfort; and
- maximize independence and create opportunities for meaningful participation in everyday activities.

Operational Definitions

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

Introduction

Your home is more than just a physical space; it is that place where you feel you belong; where each of its contents reveals a life and history that is unique to you. Dementia is like experiencing a theft from your home in which your possessions are stolen one by one over time. On the outside everything may appear normal but on the inside there is disorder, constant change and confusion. Things are turned upside down and seem unfamiliar; items are missing, unrecognizable or are in the wrong place.

As a caregiver or someone diagnosed with the condition, dementia acts like an intruder upon your life. It threatens your sense of safety and security at home and robs you of freedoms you once enjoyed. You are left with the tremendous challenge of adapting to and accommodating these changes while trying to maintain some sense of order and normalcy.

The Objective of This Book

This book is designed to help you through the process of adapting your home and to remind you that you are not alone in your experience. Its ultimate goals are to improve household safety and security, enhance comfort, independence, and participation in meaningful activities. It is also intended to help people with dementia and their families strengthen their ability to cope with everyday challenges.

As a guide to making home adaptations this book provides tips and strategies that reflect the changing nature of dementia. It does not have a blueprint for living with dementia or caring for someone with the disease, as each home and experience is unique. However, it does provide options that can be applied to your individual circumstances.

Additional support is recommended from your local Alzheimer Society, and an occupational therapist who has expertise in maximizing safety and independence through home or “environmental” adaptation.

What Makes *Adapting Your Home to Living with Dementia* Unique?

The development of this book has been a collaborative project involving caregivers, people living with dementia and staff at the Alzheimer Society of Niagara Region. As such it is a reflection of personal and professional knowledge and experiences. Narratives have been included and represent those who have been there, those who are currently going through it and those who have supported many through their experience.

Part One— A Resource Book for Living at Home

What is Home Adaptation?

Home adaptation involves making changes to the home environment to make the performance of every day activities safer and easier to manage. The environment includes the physical structure of the house as well as the activities and tasks being performed within and around the home and community.

Naturally, as a person ages, physical changes can make it increasingly difficult to move around the house and manage activities independently. Activities such as grocery shopping, preparing meals, cleaning, doing the laundry and general home maintenance can bring with them new challenges. Self-care activities including bathing and grooming can also be a problem.

A person with dementia does not only experience the physical changes associated with age but also faces changes in cognitive abilities (thinking) including memory, attention, problem solving and language. These difficulties can greatly impact on their safety, independence and participation in the home and community.

Home adaptations, including making changes to the house and the way in which everyday activities are performed can enhance safety and help to maintain a person's independence at home longer.

If you or your loved one is *living at home with dementia* this resource is designed to help you identify appropriate home adaptations and develop additional coping strategies to help you manage at home. A variety of tips and strategies are offered that correspond with the difficulties you may be experiencing either as a caregiver or as someone living with dementia.

Living with Dementia

What People with Dementia Have to Say

I had a hard time dealing with that one question— “Why me?”

It's pretty hard but what are you going to do? I wish I'd get better.”

“You can't do what you'd like anymore”

“I get angry at myself because I can't remember the name of someone. It's embarrassing. You feel dumb.”

“You can't remember what happened 5 minutes ago.”

“It's frustrating.”

“The hardest part for me was telling my wife “I forget” She didn't believe me at first. She thought I just had a selective memory.”

“After a while, you laugh at your problems because you have to accept it”

“I used to do so much. I've stopped enjoying things.”

“If I put something down or stop doing something I'll forget about it.”

“Its hard to admit you need help.”

“I got lost and don't want it to happen again.”

“I don't' know what happened. I look but can't find it.”

I am so grateful for my wife. I'd be lost without her.

“Sometimes you don't see right away.”

“I'm being second-guessed all the time. All the time. And you know it gets me, but I've got to learn to accept it.”

What Caregivers Have to Say

“Today he doesn’t act like he remembers yesterday.”

“It’s frustrating. You just said it, you turn around and repeat it again. You go to the bathroom and come back and you have to repeat it again...”

“It’s draining.”

“Sometimes it’s like being a parent again. You have to show them the right way and keep repeating”

“It’s hard when you haven’t got any patience. I feel bad. I feel guilty.”

“I am his daughter. He is my father. I ask myself, what would he want?”

“I find the mood swings difficult to deal with.”

“Caring for him just becomes a normal part of everyday life”

“Its hard to watch...when you see her comprehending what she is not capable of...when she feels humiliated”

“I want to care for him. He would do it for me.”

I didn’t have the patience when I was doing it all by myself. I had no time to do everything so I got help.”

“The key is diligence and acceptance.”

About Dementia

Common Questions

Many times families affected by dementia are aware that something may be wrong well before they are given a diagnosis but question the validity of their observations or feelings. They often

attribute problems with memory to be a normal part of ageing. This can be a confusing time characterized by self doubt, denial and what some describe as a feeling that either you or your loved one is ‘going crazy.’

What is the Difference between Dementia and Alzheimer’s Disease?

Dementia is generally a group of symptoms involving difficulties with thinking abilities, including memory, language, concentration and judgment. Alzheimer’s disease is just one of the dementias. It is the most common type. Most of the problems seen in Alzheimer’s disease are also seen in other types of dementias. Other types include vascular dementia related to having had a stroke, Parkinson’s disease, dementia with Lewy bodies or frontal-temporal dementia.

What is Alzheimer’s Disease?

The experience of Alzheimer’s disease is different for everyone but typically it follows three stages (early, middle and late) with an average progression of 8-12 years. When you have Alzheimer’s disease different parts of your brain are affected including your memory, language ability and behaviour. These problems make it increasingly difficult to perform activities of daily living without support, including looking after yourself and maintaining your home.

How do I Know if I or My Loved One has Dementia?'

If you are concerned that you or your loved one may have dementia it is best to consult with your family doctor.

¹ Reproduced, in part, from *Living at Home with Alzheimer's Disease and Related Dementias: A Manual of Resources, References and Information*, with permission from the Canadian Association of Occupational Therapists (CAOT). All rights reserved.

The following are some warning signs that may indicate that you or your loved one needs to be assessed further:

- Memory loss that affects daily life
- Problems performing familiar activities
- Problems with language
- Disorientation to place and time
- Changes in personality and behaviour
- Frequently losing and misplacing things
- Problems with judgement and abstract thinking
- Poor initiative

What Can I Do to Help Myself?

If you or your loved one has been diagnosed with dementia you need to continue to see your doctor to determine the treatment that is best for you. People who receive treatment have been shown to improve, stabilize or decline at a slower rate. There are several different medications available in Canada to treat symptoms of dementia, depending on its cause and presentation. Your doctor should be able to provide you with information about community services and organizations such as your local Alzheimer society that may be of help to you further.

How Long can My Loved One or I Continue to Live at Home?

There is no single answer to this question. Although most people prefer to live in their own homes for as long as possible, it depends upon individual circumstances such as how greatly dementia is affecting one's ability to care for oneself and maintain the home and what supports are available. It is important to know

that community supports, including a supportive family and friends and simple home adaptations can help people with dementia to live at home longer.

What Types of Home Adaptations can Help a Person with Dementia Live at Home Longer?

This depends upon the types of difficulties that the person with dementia is having around the home, including activities such as bathing and using the toilet, dressing appropriately, meal preparation, managing finances and home maintenance.

Adapting a home to dementia means creating a supportive home environment that maximizes a person's strengths or remaining abilities while compensating or minimizing their disabilities.

Simple adaptations include physically changing the home environment to make task performance simpler and safer (for example, installing grab bars to help one get in and out of the shower; minimizing clutter to prevent falls or changing the way that one performs a particular activity to make it easier).

How Much Will it Cost to Adapt My Home to Dementia?

The cost of adapting your home to dementia depends upon what types of adaptations you require. Most adaptations for dementia will be relatively simple and will not involve costly home renovations. Often adaptation involves reorganizing and "de-cluttering" the house, general *safety proofing* and learning to simplify daily activities. Adaptive aids for people with dementia are usually simple and inexpensive and may include memory and orientation cues (for example, signs and labels) or adaptive equipment for physical limitations such as toilet raises, grab bars and bath seats. These items can be purchased from your local pharmacy or

vendor at reasonable costs. They may also be available on loan from your local Alzheimer society or other community agencies at reduced cost or no cost. Funding may be available for adaptations such as ramps, lifts and handrails. Check with your health care provider for more information.

Canada Mortgage and Housing Corporation (CMHC) offers programs and financial assistance for low-income households, seniors and persons with disabilities. Financial assistance can be a loan, a forgivable loans or a non-repayable contribution, and can be used to fund accessibility modifications and home adaptations.

Contact CMHC for eligibility requirements before making home adaptations.

For more information, visit www.cmhc.ca or call 1-800-668-2624.

Symptoms you May Experience with Dementia²

Symptoms associated with dementia that you or your loved one MAY experience:

Memory loss

At first this may seem like ordinary forgetfulness but the frequency of it increases and begins to affect familiar activities and routines.

Aphasia

Aphasia is a term to describe difficulty with understanding, speaking and expressing language. You may notice that you have difficulty naming people and things, or trouble writing or reading, or you say the wrong words when you are speaking.

Apraxia

Apraxia refers to a problem using objects properly or difficulty carrying out body movements. You may feel clumsy and have difficulty doing routine things such as putting on your shirt on or getting food off your plate despite 'knowing' how to do it.

Perceptual problems

Perception is the awareness of the environment around you. You may find that you frequently bump into things and have trouble distinguishing objects. Things may look like one thing but actually be something else. You may find that sometimes you do not recognize familiar objects or people, or you may have problems with body perception such as positioning your body to sit in a chair.

Attention

You may have difficulty focusing and paying attention to things around you and what is being said. It may be hard to follow a television program or conversations.

Abstract thought

Abstract concepts, such as those involved in financial planning, may confuse you.

Judgment

You may find it difficult or feel overwhelmed trying to make decisions, even ones that involve minor matters such as where or what to eat. As the disease progresses you might find it hard to determine what is appropriate or not.

Problem solving

Solving problems can present a challenge, such as what to do when your vehicle breaks down, how to handle an emergency, or how to fix things. You likely feel that you should know what to do.

² Reproduced, in part, from *Living at Home with Alzheimer's Disease and Related Dementias: A Manual of Resources, References and Information*, with permission from the Canadian Association of Occupational Therapists (CAOT). All rights reserved.

Catastrophic reactions

You may feel extreme emotions in response to things that typically would not have bothered you and behave in ways that are not like you.

Depression

You may feel depressed as you try to cope with the losses associated with dementia. It is important to seek medical attention for depression. It can make symptoms of dementia appear much worse than they are.

Delusions and hallucinations

A delusion is a false belief. Delusions may accompany dementia. Hallucinations involve seeing, smelling, feeling or tasting something that is not perceived by others. It is not a common symptom and can often be treated.

Disruption of sleep/wake

You may have difficulty sleeping at night and/or have trouble staying awake throughout the day.

Perseveration

At times you may get stuck and keep repeating a particular phrase, action, or activity.

Restlessness

You may feel restless, like you want to keep moving and cannot relax. This may be worse in the late afternoon and early evening, a phenomenon called “sun-downing.”

Suspiciousness

Particularly during the middle stages of Alzheimer’s disease you might suspect others are trying to steal from you or are hiding things. Increasing problems with memory can lead to suspiciousness as you try to make sense of things around you.

Getting Lost

You may become disoriented. You may leave home and get lost despite having travelled the same route many times before.

Physical symptoms

Individuals with Alzheimer’s type dementia usually do not experience physical symptoms (for example, loss of muscle control) until the middle-to-end stages of the disease. Other types of dementia (Parkinson’s, Huntington’s chorea) have physical symptoms early on.

If you have Dementia: Words of wisdom from others who know

- You aren’t crazy. You have a medical condition.
- It’s not you, it’s dementia.
- Realize that you are not alone- about 435,000 people a year are living with dementia in Canada alone.³
- The hardest part is admitting and accepting you have it.
- It’s only natural to want to cover it up.
- You did nothing to deserve this. Dementia can affect anybody. No one knows yet exactly why or how someone gets it.
- Help is just around the corner. Ask for it.
- Join a group. Talk about it. Or just be around people who know.
- You may not remember what happened 5 minutes ago. Carry a small pad of paper and a pencil in your pocket or purse.

³ National Post. Jan.15, 2007 vol.9 no.97

- You may feel lost. You may even get lost. Give yourself time to get familiar with things. And always carry your ID with you.
- You won't be able to do things you once could; just do it for as long as you can. Do it the best you can.
- If you can't do what you want; do what you can.
- If it doesn't work, try a different approach.
- Take things as they come.
- Hold onto what you have. Count your blessings
- You will make mistakes, but so does everyone else. Be patient with yourself. Try to find something to laugh about.
- Don't give up. You've got to fight it until you can't fight it anymore.

If you are Caring for Someone with Dementia: Words of wisdom from others who know

- Caring for someone with dementia is demanding. Be gentle with yourself.
- Dementia can be unpredictable. Take things as they come.
- What doesn't work today may work tomorrow.
- It's not him, it's dementia. If you think about the person as they were 10 years ago and who they are today—the *difference* between the two is the disease.
- If you reach an impasse, don't fight it; try a different approach or try again later.
- Realize that you are not alone. Join a group. Talk about it.

- It's okay to feel frustrated, angry and depressed.
- Your world has also been turned upside down by dementia. You too face multiple losses. Give yourself permission to grieve.
- You may repeat yourself a thousand times a day. Take a deep breath, then say it again.
- Patience doesn't come instantly. It is something you have to work on.
- Just do the best you can. You can't do it all. Accept help.
- Try to find humour. It is a lifeline.
- Plan for possibilities but live one day at a time.
- Take care of yourself. Your physical, emotional and spiritual well-being is also important.
- Your focus will switch. Your activities and role will change. Somewhere in there find something for you.

Caring and Communication: Dealing with Difficult Behaviour

Caregiving is like a balancing act, particularly when it comes to dementia. Some have said the experience is like an emotional roller coaster ride, unpredictable and ever-changing with no clear beginning or end. In the case of a progressive dementia like Alzheimer's disease, the ride is marked by gradual decline, with fluctuations in behaviour and abilities as well as periods of confusion and lucidity. Naturally, the caregiver and the person with dementia attempt to maintain their balance in the best way they know how with whatever resources are available to them.

Maintaining balance involves continuous shifting and adapting to change. But with dementia a person has difficulty adapting to change because he loses the ability to interpret the environment and respond with the appropriate action or behaviour. The caregiver then compensates for this loss and bears the weight in added roles and responsibilities. This dynamic is often characterized by episodes of “pushing and pulling;” resisting or accepting help; holding on or letting go.

As one gentleman with dementia says:

She’s in the same seat as I’m sitting in.
How far do I push it and how far do
I pull? It is just as difficult for them
as it is for us. Probably more for them
because we forget....

In the beginning, individuals with dementia are often aware of their changing abilities and struggle to accept the reality of their diagnosis and the implications on their independence. They feel their increasing dependence and are sensitive to the demands being placed on their caregiver, often a spouse or adult child, but may have trouble expressing it. In the shadow of doubt, they fight to hold onto their independence. **“Do I ask for help or do I take a chance and stab at it myself?”** questioned one woman with dementia. Feelings of gratitude may also alternate with feelings of frustration and even resentment for needing help or being offered assistance.

Caring and Communication

“She takes care of me like a baby. I depend on her. But maybe sometimes too much, you know? And I kind of get frustrated.”

“I’m being second-guessed all the time. All the time. And you know it gets me, but I’ve got to learn to accept it.”

It’s incredibly hard to face changes that threaten to take away life as you have known it. Those habits, roles and routines that make up your life are often what give you a sense of purpose, meaning and security.

Not only is it difficult for those with dementia to cope with change and loss but it is hard on the people who love and care for them. Dementia is indeed a family affair. It is often the family proving care long after the person they know has faded. This is the paradox of dementia—the psychosocial self fades but the body lives on. As the disease progresses and the person with dementia loses insight into the affects of his illness, it is the caregiver who continues to experience the consequences of dementia and endures loss on multiple levels. This includes the loss of the ‘person’ with dementia, the loss of hopes, dreams and expectations and ultimately the loss of their own sense of self or personal identity as the day to day demands of caregiving consume their lives.⁴

“I think it’s harder for my wife and my children”

“I don’t want to be a burden. Its not just about changing roles, its dragging her down...I want to let go when I’m dragging her down.”

In essence, the caregiver acts as a *lifeline* for the person with dementia and is caught in a perpetual cycle of action-reaction. *Watching, worrying, anticipating, intervening, interpreting, empathizing, remembering*—these

⁴ Dempsey, M., Baago, S. (1998). “Latent Grief: The unique and hidden grief of carers of loved ones with dementia.” *American Journal of Alzheimer’s Disease*.

are just some of the tasks of the caregiver as she tries to maintain her loved one's connection to the world.

When he cannot remember, she remembers for him; when he can no longer think, she thinks for him, and when he cannot speak, she is his voice. As the demands of caregiving take the forefront of a person's life, a caregiver's own needs for her health and well-being can fade to the background. In a sense the caregiver risks losing sight of herself as a person with needs, desires and wishes.

Loss of a connection to oneself can present barriers to feeling and grieving the losses that a caregiver experiences on a daily basis. This may be a major factor in caregiver stress and burn out. It is important that caregivers not only access information on dementia to help them develop coping strategies for effective caregiving, but that they accept support through resources available to them such respite, homecare, support groups, and grief counselling.⁵

My husband says, "Please don't work so hard. Lie down. I need you. Without you, I have no life. I can't live without you. You are everything to me. Please take care of yourself."

Dealing with Challenging Behaviours

Dealing with challenging behaviours is often the most stressful aspect of caregiving and can contribute to burn-out. These difficult behaviours reflect the changes that dementia is causing to the brain. Although it is not possible to avoid them all together, it is possible to

manage them through effective communication and a supportive environment. Here are some general strategies, easily remembered as "The R's," that were developed by the Canadian Association of Occupational Therapists in partnership with the Alzheimer Society Canada.⁶

- Remain calm
- Redirect
- Reassure
- Repeat (in new ways)
- Revise (adapt tasks)
- Respond (to the emotional content)
- Reference (validate the person's point of view)
- Remind (encourage reminiscence)
- Reflect back the person's feelings
- Reinforce (support positive behaviours)

Tips for Communication⁷

- Avoid arguing, confrontations and questions with right or wrong answers, negatives, direct commands.
- Respond to the emotional expression of a communication even if you don't understand what the person is saying
- Avoid testing recall. Try not to begin or end a conversation with "Do you know? Or "Do you remember?"
- Never speak or act as if the person isn't there even if he cannot understand.

⁵ Dempsey, M., Baago, S. (1998). "Latent Grief: The unique and hidden grief of carers of loved ones with dementia." *American Journal of Alzheimer's Disease*.

⁶ Reproduced, in part, from *Living at Home with Alzheimer's Disease and Related Dementias: A Manual of Resources, References and Information*, with permission from the Canadian Association of Occupational Therapists (CAOT). All rights reserved.

⁷ Reproduced, in part, from *Living at Home with Alzheimer's Disease and Related Dementias: A Manual of Resources, References and Information*, with permission from the Canadian Association of Occupational Therapists (CAOT). All rights reserved.

- Always treat the person as an adult.
- Maximize the use of touch and non-verbal communication.
- Use humour.
- Maintain normal conversational structure (turn-taking in conversation).
- Minimize distractions; Speak clearly and face-to-face.
- Give the person time to respond.

Some General Strategies

- Keep the environment organized to lessen chance of misplacing things
- Have duplicates of favourite things
- Learn where the person's favourite hiding places are
- Provide safe and secure places for treasured personal items (for example, wall near the bed, in a 'fanny pack' that the person can wear)
- Check vision and hearing regularly
- Explain sounds or events that might cause alarm and confusion
- Provide reassurance and respond to the emotion of the concern
- Avoid playing into the misperception or hallucinations or attempt to reason the person out of it.

Behaviour Management Strategies⁸

Pacing and Restlessness

- Focus on redirecting energy and ensuring a safe space to move rather than stopping the behaviour.
- If the behaviour is new, have a medical check
- Provide reassurance that the person is safe and cared for
- Ensure that personal needs are attending to that the person may have difficulty communicating (for example, hunger, thirst, toilet and so on)
- Avoid telling the person about planned activities too far in advance as this may cause increased anxiety.
- If a person has left the house walk with him or her and begin a non-confrontational conversation that focuses on a favourite topic and serves to distract. Gradually change direction and return home.

Repetitive Questioning and Behaviours

- Look for the emotional need and meaning behind repeated questions and use affirming statements "you are worried that you are going to miss something..."
- If the person gets stuck on a phrase try to redirect him or her with interesting or distracting materials
- Provide orienting cues in the environment such as calendars and clocks. Some caregivers find it helpful to write the day's schedule on the whiteboard near an easily visible clock.

⁸ Reproduced, in part, from *Living at Home with Alzheimer's Disease and Related Dementias: A Manual of Resources, References and Information*, with permission from the Canadian Association of Occupational Therapists (CAOT). All rights reserved.

Shadowing

- People with dementia often become anxious and fearful of being abandoned. The caregiver is like a lifeline, when he or she leaves the room, anxiety heightens and so the person with dementia follows *like a shadow*. As a caregiver this can be frustrating but it is important to provide constant reassurance and a consistent routine that helps them to feel secure. It may help to tell the person about where you are going and what you are doing, to work in areas where you are visible.

Suspiciousness and Hallucinations

- People with dementia may become suspicious that family, friends and caregivers are taking things from them or trying to harm them. This is their way of making sense of things around them because they cannot remember things and have trouble understanding and interpreting their environment.

Agitation and Aggression

- Remain calm
- Remove any potentially harmful objects from the environment
- Reduce stimulation (turn off TV or music)
- Do not approach or move the person unexpectedly. This could startle them.
- Avoid confrontation except in the case of safety. In such a case, get immediate help
- Speak calmly and respond to the person's emotional concerns. Do not argue, rather be affirming of their feelings and experience

- Offer a distraction such as a favourite activity, a snack or a walk
- Call for help if you are concerned for your safety or others. Caregivers should have a pre-arranged plan for emergencies (family member, police, neighbour)

Catastrophic Reactions

Catastrophic reactions are extreme and inappropriate responses accompanied by anger and crying to what may seem like a simple or insignificant event. These reactions may occur when the person feels overwhelmed. These reactions are best avoided by looking for signs of increasing distress and eliminating them.

- Avoid challenging the person beyond their capacity to act or respond
- Avoid over-stimulating environments
- Try to figure out what caused the reaction to prevent it in future
- Speak calmly and be reassuring
- Move slowly
- Don't restrain but use reassuring physical touch
- Move to a calmer environment
- Use gradual distraction

Inappropriate Sexual Behaviour

This behaviour can be especially embarrassing and distressing for caregivers. Try to think about how misinterpretation or misunderstanding may lead to these behaviours in order to prevent them. The person with dementia may not know that his behaviour is socially inappropriate due

to damage to the brain associated with dementia, particularly in the frontal lobe. Touch can be misinterpreted as a sexual gesture. Sometimes the person may mistake his own actions or the caregivers as sexual behaviour, such as manipulating buttons or zippers. Or, he may need to use the bathroom.

- Be aware that the person with dementia has continuing needs for caring and affection which may be unmet. Provide caring and personal touch to meet those needs but be sure the touch is appropriate.
- Help the person find ways of expressing affection that are appropriate and comfortable for both.
- Protect personal dignity. Never make a joke of sexual overtures.
- Provide opportunities for bolstering self esteem and receiving positive attention.

Participation and Belonging

Home is ... “where you have people around that care for you.”

Feeling at home with “a place” in the world is like having a sense that you *belong* and that you are worthwhile with capabilities and experiences to contribute. That feeling of belonging is something that is cultivated within the context of your relationships and interactions with people. It becomes the *secure base* from which to participate in the world around you.

When a person has dementia and begins to lose memory and familiarity with everyday experiences, that secure base is threatened.

This tests their confidence and meaningful participation in life through everyday activities and interactions. With the added loss of insight associated with dementia the person may no longer be aware of changes to their capabilities and appreciate the impact of their actions. But this does not mean that a person with dementia loses the ability to *feel* and experience the world through activities and relationships.

Participation and Belonging through Meaningful Activity

Meaningful activity is any purposeful activity through which a person derives pleasure, satisfaction, or a sense of accomplishment and value. Engaging in meaningful activity connects a person with others and reminds him that he is worthwhile regardless of what he can or cannot do. It also gives a sense of control, dignity, self worth and achievement and is entirely personal in that it reflects individual preferences, skills, experiences and culture. Creating opportunities for a person with dementia to engage in meaningful activity requires the caregiver to have insight into their likes and dislikes, present abilities and past interests and roles. These things become a source of opportunity for meaningful and ongoing participation in everyday life.

Creating Opportunities: Considerations for Participation

Creating opportunities for meaningful activity requires the caregiver to consider the relationship between the **person**, the **environment**, the **activity** and their **approach**. All of these things are factors that influence a person’s capacity to participate and have positive experiences.

The Person

Think about the person as you have known them over the course of their life or your lives together. What roles have they had (for example, family roles, work roles, community roles)? What hobbies have they enjoyed or what things have they taken pride in? What gives them hope? What skills have they used in past and what skills do they currently have? Consideration of their past and present abilities and interests will give ideas for present day activities that can help to normalize a person's life and give them hope.

The Activity

Activities take on many facets of our lives including **self care** (bathing, and grooming), **productivity** (for example, paid or unpaid work, such household maintenance) and **leisure** (socializing with friends and family, community outings, participation in recreational groups and so on).

The best activities are those that support the continuation of lifelong roles and are “over-learned” and familiar. These types of activities are part of a person's memory that is retained the longest. In the later stages of dementia, when these activities may be too complex and demanding, simple, repetitive activities and ones that emphasize the ability to appreciate sensory experiences are best.

Activities can also be a way of positively influencing a person's mood and behaviour and diverting attention away from something negative or deconstructive to something positive and constructive. For example, if a person is restless and paces, engaging in a pleasurable activity can replace that behaviour and have

a calming effect. Instead of trying to stop unwanted behaviours directly, give an alternative activity.

Choosing the Right Activity

Think about how you typically structure your day. What activities did your loved one used to do and enjoy that he no longer does? What seem to be the obstacles to doing those activities? Could any of those obstacles be removed? Could he perform all or part of an activity with some help?

Tips for Activities⁹

- Make activities safe and part of the routine
- Minimize distractions that can frighten or confuse
- Set up the environment for success (make it manageable by breaking down the activity into simple easy to follow steps that match the person's present abilities)
- Assist with difficult parts of the task
- Encourage self expression
- Involve the person through conversation
- Try again later

The Environment

The home environment can be structured or organized to encourage meaningful activity and reveal opportunities for the person with dementia to contribute in whatever way he *still* can. This helps to reinforce to him that

⁹ "Tips for Activities" is reproduced, in part, from an Alzheimer Society Niagara Region presentation, with permission from the director of education, Jo O'Brien.

he is still needed and is important. In situations where all household tasks are taken care of and everything is done for the person with dementia, that person, in the early stages, may feel as if he no longer has a role and is a burden to those caring for him. A person in the later stages of dementia may have little or no insight into his problems and behaviours, having nothing to do or occupy himself. This can contribute to destructive habits or unwanted behaviours such as pacing and rummaging.

It is important to shift your focus from the outcome of activities (how well your loved one performs them), to the experience of doing the activity (whether he enjoys or values it). This will limit experiences of failure and frustration. Often times the activity needs to be tailored to the person's present abilities and modified or made easier to avoid frustration or failure.

Setting up your home environment

Have a look at the home and surroundings. Does it look inviting? Can you identify activities or tasks that he could safely get involved in? Is it easy for him to access those activities? Is there a comfortable place for him to identify as his (for example, his "spot" or chair) where he could safely do his own thing. Are there items in the room that may capture his interest and become a topic of conversation (for example, magazines, books, old pictures, or favourite items)? Are there things that you do around the house that he could help with?

The challenge as a caregiver is to find a balance between encouraging involvement and participation, which naturally takes time,

and getting the daily chores and tasks that need to be done each day accomplished. You may find it necessary to re-evaluate what tasks are of high priority and need to be done immediately and which ones can wait. Many caregivers find that their priorities change to accommodate the demands of their role as caregivers. What you were able to accomplish yesterday may not be realistic for today's circumstances.

It is also important to note that setting up your home environment *includes* inviting other people and supports into your life and weekly routine. This can have a positive effect on both you and your loved one. It gives you a break or time to get some things done independently and it offers opportunity for your loved one to connect with others. For example, weekly visitor drop-ins or community outings (recreation or support groups) can be arranged to provide opportunities for socializing.

Your Approach

Your approach can have a significant influence on a person's willingness to participate or get involved in daily activities. Although the approach you take may not vary much day to day, the person's response to you might vary depending on a variety of intrinsic and extrinsic factors such as how they are feeling or what events preceded your approach. The ability to adapt your approach (body language, tone of voice) to suit the present circumstances is key to encouraging a person's participation. Sometimes, however, adapting your approach means recognizing the person's present limits and trying again later.

What's in an Encouraging Approach?¹⁰

Structuring the Day

Tips

- Consider the time of day
- Help get the activity started
- Offer support and supervision
- Help the person to remain independent
- Concentrate on the process not the product
- Be flexible
- Be realistic
- Be relaxed
- Be patient
- Don't criticize, correct or 'test' the person
- Offer opportunity for choice
- Provide encouragement and praise
- Respond to the person's feelings

Structuring the day by establishing a reliable routine that balances rest with activity can help to alleviate anxiety and give the person with dementia a sense of security. It is an excellent way to make each day more manageable for you both.

Getting Started

Think how you organize the day. Think about the past week. Make notes about activities and experiences that worked and didn't work in the form of a journal. Ask yourself, what worked best and why? Was there too much or too little going on? Which activities were enjoyable and easily completed? Set up a schedule according to what seems to work and have everything you need to follow that schedule.

You will likely find that in time you need to change your routine to reflect changing abilities and needs. Continue to evaluate the activities that make up your daily routine by observing how the person responds to the activity. Are they getting bored, irritated, or distracted? Can you still engage them in the activities or is it time to take a break or introduce something different? Most importantly, the activities need to continue to meet both of your needs.

¹⁰ "What's in an Encouraging Approach" is reproduced, in part, from an Alzheimer Society Niagara Region presentation, with permission from the director of education, Jo O'Brien.

Example of Routine*

| Morning Activities | Afternoon Activities | Evening Activities |
|---|---|--|
| <ul style="list-style-type: none"> ■ Wash, brush teeth, get dressed ■ Prepare and eat breakfast ■ Coffee and conversation ■ Discuss newspaper, reminisce ■ Make a craft ■ Take a break/quiet time ■ Do chores together | <ul style="list-style-type: none"> ■ Prepare and eat lunch, read mail, clear and wash dishes ■ Listen to music, do a crossword, or watch television ■ Do some gardening, take a walk. Visit a neighbour or family ■ Take a break or a nap | <ul style="list-style-type: none"> ■ Prepare and eat dinner, clean up ■ Reminisce over coffee, dessert ■ Play cards, dominos, watch a movie ■ Give a massage ■ Take a bath, get ready for bed ■ Read a book or magazine together |
| <p>*“Example of Routine” is reproduced, in part, from an Alzheimer Society of Niagara Region presentation, with permission from the director of education Jo O’Brien.</p> | | |

Memory Books and Memory Boxes

Some people in the early stages of dementia and their families decide to preserve memories by creating a memory book or memory box together containing the person with dementia’s (and the family’s) life story. Not only is a memory book a great conversation piece and opportunity for reminiscence, it becomes a keepsake for many families. A memory book can also help others who may be involved in the care of someone with dementia to learn about their life and past interests. What you decide to include in your memory book is entirely up to you, but, here are some ideas to get you started.

Things to Include in a Memory Book

- Family tree
- Timeline with significant events
- Your life story
- Highlights (highs and lows)
- Previous job(s) and roles

- Biggest accomplishment
- Things you are most proud of
- Likes and dislikes
- Talents and hobbies
- People and things that are important to you
- Wishes and expectations for care

Participating in future planning

Thinking about the future can seem quite overwhelming when coping with the present is challenging enough. But it is very important that you take the opportunity, while you have it, to discuss as a family your expectations and wishes for the future, for yourself and each other, either as a person with dementia or as a caregiver. This topic is beyond the scope of this resource. Further information and support is available from your local Alzheimer society. A skilled person may be available to meet with you as a family to facilitate discussion and future planning and preparation.

The Noble Lie

Truth telling is a major ethical issue in dementia care. Clearly it is important to respect an individual's right to know about their own health and the implications of having a diagnosis of dementia, in order that they can make the necessary plans for their future, while they still have the capacity to do so. With that in mind, this resource has been written for and with caregivers and individuals with dementia.

Capacity, however, is the critical issue. There does come a time when individuals with dementia lose their capacity to understand and, more importantly, appreciate their own circumstances. Due to the damage to their brain, they lose the ability to recognize that there is anything wrong with them and as a consequence they can no longer make good decisions for themselves. They lack insight into the impact of their behaviour not only on others but also on themselves. All this, coupled with the fact that they forget that they have a memory problem, leads to the reality that there are times when truth telling is no longer always a kindness. This is when Plato's concept of the "Noble Lie"¹¹ (telling an untruth for the greater good), has relevance.

Families often struggle in getting individuals with dementia to agree to accept the resources they desperately need to maximize their quality of life and that of their family members who love and care about them. Accepting homecare services and making simple home adaptations to maximize personal safety is often met with resistance, particularly as the disease progresses.

They don't remember that they have any problems so they refuse assistance with personal care when they are no longer able to bathe and groom themselves. They refuse to utilize respite

services when their care partners need time to themselves, such as in home support and day programs. If, as they believe, there is nothing wrong with them, why would they need any of these things?

Family members, particularly spouses who have always made decisions together, feel they must ask them if they are willing to agree. They feel it is only right to allow them to decide. Of course this is appropriate when the person still has the capacity to understand and to appreciate consequences and when options can be considered and discussed.

But when the person angrily refuses all interventions and puts himself or others at risk of harm, the Noble Lie has its place for the greater good—to protect one's health and well-being.

For example, if the doctor orders medicine to slow the progression of dementia, and she no longer remembers that she has dementia, it is "a pill to help her feel less distressed." If she needs supervision but is no longer aware of changes in her abilities, it is "to help a family member learn the skill" or "to keep someone else company." If it is a locked cabinet to prevent him from ingesting harmful substances it is "to prevent things from getting lost." If it's a necessary adaptation to the house, it is to "make it safer for the family," or to "improve the value of the house" or "in case we need it in the future."

Some caregivers find that initially they are met with resistance when they try to introduce a change within the home but if they avoid confrontation and suggest trying something just for a while, they can incorporate the new resource into a routine and their loved one comes to accept it.

¹¹ Sylvia Baago of the Alzheimer Society Niagara Region identifies Plato's concept of the "noble lie" as a potential strategy in dementia care that could help families caring for people with dementia at home.

Part Two—A Guide to Home Adaptations

The guide to home adaptations is based on the ideas of the participants in the study, staff at the ASNR, the author and relevant literature. Some of the tips and strategies outlined have been reproduced from *The SAFER Tool Manual*, with permission from COTA Health, all rights reserved; and *Living at Home with Alzheimer's Disease and related Dementias, A manual of resources, references and information*, with permission, all rights reserved.

Why is Home Adaptation important?

Most people want to continue to live in their own homes and independently for as long as possible where they feel comfortable, safe and secure. Naturally as people grow older, physical limitations can make it increasingly difficult to live at home without some support including family help, community services and/or privately paid assistance.

For those experiencing dementia, changes in cognitive abilities such as loss of memory, language skills, and problem-solving ability can make living *and feeling* at home a tremendous challenge. Home adaptation involves making simple changes to the home environment to maximize safety, security, comfort *and* independence. Making these changes can support a person with dementia to live at home longer.

Part Two is a guide to home adaptations including tips and strategies to help manage difficulties associated with dementia and

caregiving at home. Common difficulties with dementia are highlighted and correspond with a variety of solutions, including making adaptations to the home itself or activities in and around the home and community.

This guide is designed to enable the reader to easily identify tips and strategies for dealing with a particular problem(s) they are experiencing on any given day without having to read through the entire book.

The strategies provided reflect both cognitive (for example, thinking) and physical issues that may make the performance of an activity difficult. As such, some of the information provided in this resource may also benefit people with age-related limitations or cognitive difficulties associated with other conditions/diagnoses (for example, brain injury, mental illness).

In addition, each section offers general information including safety checklists and considerations, and general tips for simplifying the environment or activity.

Identifying the Right Home Adaptations for You

When a person has dementia there are many things that may contribute to the difficulties experienced in performing daily activities. Loss of memory, perceptual problems, limited insight and poor judgement all may limit his ability to do everyday things. These difficulties may be further compounded by physical limitations associated with ageing or with particular types of dementia (for example, Alzheimer's type dementia in the later stages or vascular dementia).

The strategies or type of home adaptations you choose will depend upon which factors are contributing to your particular problem (for example, if it's a perceptual problem, memory problem, physical limitation or a combination of things). By adapting your home environment, be it making changes to the house or the activity itself, you are creating a better fit between the person's present abilities and the environment's demands.

There are many possible adaptations identified in *A Guide to Making Home Adaptations*. It is not necessary to make all the suggested adaptations, but you may find that you need to try a few before you notice improvement. If you find you are having trouble identifying the right adaptation(s), an occupational therapist or other health care professional can help determine what factors may be contributing to your problem and which adaptation(s) would likely be most appropriate to your circumstances and needs. Contact your doctor or local Community Care Access Centre (CCAC) (in Ontario) for an assessment.

Please note that not all the issues presented in *A Guide to Making Home Adaptations* will relate to your particular circumstances and needs. No two experiences of dementia are exactly alike and this resource is by no means an indicator of what is to come. As well, there is no guarantee that the tips and strategies provided will resolve the problems. Rather, they provide options for managing difficulties, enhancing communication and promoting safety and security as it relates to a person's activities and participation in the home and community.

I—General Household Activities

General Home Safety Checklist

- FIRE SAFETY PROTOCOL established (smoke alarms, water in ashtrays, fire extinguisher, automatic shut off features on appliances).
- EMERGENCY NUMBERS DISPLAYED clearly near the telephone with step-by-step instructions: 'In case of an emergency.'
- The person with dementia is on the 'SAFELY HOME ®¹² REGISTRY; or registered with NEIGHBOURHOOD WATCH.
- EMERGENCY CONTACT INFORMATION carried on person.
- ALARM SYSTEM or bells on exit doors have been installed if there is a risk of leaving home and getting lost; LOCKS INSTALLED on exit doors/windows; LOCKS REMOVED from inside of doors to prevent locking oneself in.
- COMMUNITY RESOURCES IDENTIFIED (for example, Alzheimer Society, CCAC).
- HOME SAFETY ASSESSMENT by health professional.
- HOME ADAPTATIONS FOR PHYSICAL impairments (for example, ramps, grab bars).

¹² Safely Home® assists police in finding a person who is lost and returning them safely to their home. It is a nationwide program developed by the Alzheimer Society of Canada in partnership with the Royal Canadian Mounted Police. For more information see www.safelyhome.ca English and French, retrieved November, 2008.

- ❑ CLUTTER-FREE HOME with clear well lit pathways for walking; mats and throw rugs are removed; Reflections are minimized (glare on floor, mirrors); Furniture is stable with rounded corners.
- ❑ HOME ADAPTATIONS FOR COGNITIVE impairments (for example, orientation/memory cues are used around the home including clocks, signs, white board indicating date/reminders; stairways not to be used are blocked with an accordion or swinging gate).
- ❑ COLOUR CONTRAST used to identify obstacles/define edges and depth (for example, in bathroom);
- ABSTRACT DESIGNS REMOVED (flooring, artwork, furniture coverings) to minimize confusion
- ❑ PRECIOUS AND/OR DANGEROUS ITEMS REMOVED (for example, pills, cleaners, needles).
- ❑ MEDICATION/MEDICATION COMPLIANCE ADDRESSED with doctor.
- ❑ POWER OF ATTORNEY ESTABLISHED (finances and personal care).
- ❑ DRIVING SAFETY ADDRESSED with the doctor/health professionals.

Getting in and out of the House

Helpful Strategies

| Tips for person with dementia | Tips for caregivers |
|---|--|
| <p>If you get disoriented and have trouble finding your way in/out of your home:</p> <ul style="list-style-type: none"> ■ Put a sign, your name or decoration on the door to identify it as yours. ■ Carry a note in your wallet with your address, directions or reminders. ■ Write your floor number on your key if you live in an apartment. ■ Put signs over doors (for example, 'exit' or '↑ to toilet'). ■ Tell someone in your home or apartment complex who you trust that you may need help at times. ■ Try to leave the home with someone in case you need assistance. <p>If you have difficulty climbing the stairs:</p> <ul style="list-style-type: none"> ■ Ensure a handrail is placed on either side of stairs for safety. ■ Have a ramp installed (an occupational therapist can help you with this). ■ Have a physiotherapist assess your mobility: consistently use a cane or walker if recommended. <p>If you often misplace your keys:</p> <ul style="list-style-type: none"> ■ Attach a large bright key ring to them for easy identification. ■ Put key on an elastic wrist band to prevent losing it. ■ Put key in designated spot clearly marked. ■ Attach keys to purse handle for easy access. ■ Give someone you trust a copy. <p>If you have trouble seeing or grasping door handles/unlocking doors:</p> <ul style="list-style-type: none"> ■ Colour contrast handle to distinguish it from door. ■ Use lever style door handle for easy grasp. ■ Use adaptive aids (for example, handle grip). | <p>If your loved one is at risk of getting lost/disoriented:</p> <ul style="list-style-type: none"> ■ Place door and window locks in invisible or unusual places such as the tops of doors, above the normal line of vision to prevent/conceal exit. ■ Use color contrast to conceal features and prevent exit (door lock, door handle). ■ Install door bell to indicate when door opens/closes to warn of exit. ■ Have your loved one carry ID /Safely Home® bracelet in case he gets lost. ■ Put name or decoration on the door to identify your house/apartment. ■ Have someone accompany your loved one. <p>If your loved one often trips/ loses balance:</p> <ul style="list-style-type: none"> ■ Install light fixtures or flood lights to illuminate entrances, steps and walkways. ■ Install easily accessible light switches or sensors to control outside lights. ■ Have balance assessed by a health professional: always use a cane or walker <u>if required</u> to prevent falls. ■ Have an occupational therapist assess your entranceway for safety and modifications (for example, ramp, handrails). <p>If your loved one has trouble using the elevator:</p> <ul style="list-style-type: none"> ■ Put instructions inside the elevator or always accompany the person. ■ Get to know neighbours. ■ Use the elevator consistently to help maintain the skill. <p>If you or your loved one have difficulty carrying items into the home:</p> <ul style="list-style-type: none"> ■ Add a grab bar or handle near threshold. ■ Install a delayed action door closer. ■ Install small shelves inside/outside entrances at elbow height to place parcels while opening doors. |

Moving Around the House

Helpful Strategies

| Tips for person with dementia | Tips for caregivers |
|---|--|
| <p>If you get confused and have trouble finding your way around the home:</p> <ul style="list-style-type: none"> ■ Use nightlights. ■ Post signs for orientation. ■ Close doors between rooms (limits confusion). ■ Give yourself time to familiarize yourself with your surroundings. ■ Look for environmental cues (familiar items or sounds that tell you where you are). ■ Ask for assistance. <p>If you get anxious or restless and feel you cannot stop moving:</p> <ul style="list-style-type: none"> ■ Follow a consistent routine to minimize anxiety. ■ Participate in calming activities, activities that you enjoy, or activities that are the least demanding (for example, go for a walk, listen to soothing music, do some gardening, wash dishes). ■ Consult your doctor if it persists. | <p>If your loved one gets confused and has trouble finding his way around the home:</p> <ul style="list-style-type: none"> ■ Use nightlights. Use glow tape on light fixtures for orientation. ■ Post signs or pictures for direction. ■ Close doors between rooms to limit confusion. ■ Offer assistance. ■ Remove objects that look like something else or cause confusion (for example, waste paper basket beside toilet). ■ Minimize reflection and glare. <p>If your loved one paces and gets restless:</p> <ul style="list-style-type: none"> ■ Replace the behaviour with an activity. ■ Use environmental cues to distract/encourage familiar activity (for example, place a newspaper or other familiar object on the table to grab attention/ provide opportunity for reminiscence). ■ Reduce stimulation. Play calming music. ■ Follow a regular routine to minimize anxiety. Orient person to time/place and activity. ■ Ensure pathways are clear to prevent falls. ■ If person rummages, allocate a rummage drawer rather than trying to stop the behaviour. |

Using the Stairs

Helpful Strategies

| Tips for person with dementia | Tips for caregivers |
|---|--|
| <p>If you feel insecure using the stairs:</p> <p>Climbing the stairs:</p> <ul style="list-style-type: none"> ■ Consult your doctor to assess your strength, balance and mobility. ■ Use a cane if needed. Ensure proper use of cane following health professional’s recommendations. ■ Hold onto handrails. ■ Take time and be extra cautious. ■ Wear shoes or slippers that fit properly and have a non-slip sole. ■ Avoid being distracted when using stairway. ■ Remove reading glasses when you climb stairs. ■ Never carry objects such as laundry baskets. ■ Avoid talking while on stairs. ■ Minimize the number of times you have to climb stairs each day. | <p>If you are concerned your loved one may fall down stairs:</p> <p>Giving physical assistance on stairs:</p> <ul style="list-style-type: none"> ■ Consult with your doctor. Request a referral to a physiotherapist for a mobility assessment at home. ■ When giving assistance on stairs stand slightly behind and to one side. ■ If person has a weaker side, the strong leg leads going up and the weaker leg leads going down. To remember: ‘good (leg) goes to heaven; bad (leg) goes to hell.’ ■ Ensure proper use of a cane if needed. ■ Install a stair lift for significant physical limitations (preferably prior to significant cognitive decline). An Occupational therapist can help you with this. ■ Always make sure that the person is wearing well fitted slippers or shoes with tread. ■ Avoid talking while person is on stairs. <p>Preventing stair use/access:</p> <ul style="list-style-type: none"> ■ Minimize need for stair use. For example, relocate bedroom to main level of home if possible. ■ Attract activity on main level: Redirect person away from stairs. ■ Secure gates at top or bottom of stairs to prevent unintended use of stairs: ensure gate is high enough to prevent tripping over. |

Ensuring a Safe Stairway

- Paint a contrasting colour stripe on the nosing of each tread to define steps (do not use tape).
- Use slip-resistant, rough finish on treads.
- Improve lighting on steps and stairs. Stairs should not have less light than adjacent areas.
- Install a light switch at both the bottom and the top of stairs.
- Provide low intensity night lighting that does not need to be switched on.
- Use colour contrast to highlight light switches near stairway.
- Keep tread coverings thin and tightly fixed to maximize usable tread size. Soft treads should be avoided.
- Steps should be a uniform size and height. Rise no higher than 178 mm (7 in.); run not shorter than 279 mm (11 in.).
- Install handrails one each side of the stairway. Position handrails at elbow height (900–965 mm [35 ½–38 in.]).
- Install a phone on each floor or call bell/intercom system.
- Do not place any objects on the steps and make sure objects or landings do not distract or obstruct.

Preventing Falls

If you or your loved one risks falling:

- Use chairs with arms to help get up/down.
- Make swinging chairs stationary and remove rocking chairs to prevent falls.
- Have clear unobstructed pathways from room to room.
- Move furniture away from middle of rooms for persons using walkers or wheelchairs to access entire room.
- Remove scatter rugs to avoid slipping. Eliminate clutter.
- Purchase furniture with rounded corners, not sharp edges in case of falls.
- Use colour contrast or changes in floor texture wherever there is a change in floor level to prevent tripping. This will help someone with dementia to see the change in floor level.
- Eliminate glare and shadows. Illuminate pathways.
- Install swing-clear hinges on doors to widen doorways for greater access.
- Install handrails or grab bars where there are significant changes in floor levels to help maintain balance if you/your loved one has physical limitations.
- Avoid ‘loud patterns’ on furniture, walls or carpet to minimize confusion and agitation. Heavily patterned furniture can be difficult for a person with dementia to see properly. They can misjudge the height or depth of the furniture and may fall.
- Purchase a fall alert alarm system for persons who live alone.
- If you or your loved one tends to fall, consult your doctor and inquire about attending a ‘fall prevention’ program.
- Ensure medication compliance and prevent medication mix up.
- Request a referral to an occupational therapist for a home safety assessment and a physiotherapist for a mobility assessment. Have a health professional show you how to safely get up or help someone up from a fall.

Keeping the House Clean and Doing the Laundry

Helpful Strategies

| Tips for person with dementia | Tips for caregivers |
|---|---|
| <p>If you are having difficulty organizing, performing and/or completing cleaning tasks:</p> <ul style="list-style-type: none"> ■ Have someone help you with cleaning tasks. ■ Organize tasks into a schedule (on a calendar) and follow a consistent routine. ■ Prioritize. Do only what needs to be done. ■ Post reminders for yourself on how to do a task if you tend to forget (illustrations or simple instructions). <p>If you are having trouble physically doing the task:</p> <ul style="list-style-type: none"> ■ Conserve your energy. Stop. Rest. Then continue. Set a timer, post a reminder, or leave cleaning items out in visible spot to remind you to complete the task if you tend to forget once you stop an activity. ■ Identify simpler ways to do task (for example, from a seated position rather than standing). ■ Have an occupational therapist observe you performing the task. He or she can make suggestions on how to make the task easier. (for example, energy conservation techniques; proper posture; adaptive aids; simple home modifications). | <p>If your loved one is having difficulty organizing, performing and completing cleaning tasks:</p> <ul style="list-style-type: none"> ■ Organize cleaning tasks into a schedule to maintain a consistent routine; prioritize. Do only what needs to be done. Post schedule or 'to do' list in a visible area. ■ Have him/her do tasks that are familiar, repetitive and are the least likely to cause frustration. ■ Simplify the task. (for example, set up equipment/cleaning items for each task; break task down into steps and do one step of task at a time). ■ Do cleaning activities together to provide subtle cues/support to perform the task. ■ Hire outside help and/or determine if your loved one is eligible for homecare support. <p>If he/she is having trouble recognizing cleaning items or using items appropriately:</p> <ul style="list-style-type: none"> ■ Label items according to use. ■ Lock away or throw out potentially harmful items. ■ Store cleaning items together and away from food items (for example, in laundry room). ■ Post simple step-by step directions on or beside the appliance. ■ Label or colour contrast the controls for easy identification. ■ Post an illustration of the appliance in use. |

Simplifying House Cleaning

Washing Floors

- Replace flooring with slip resistant, easy-to-clean flooring material.
- Use hard floor surface or tight pile carpeting to minimize effort required.
- Use movable carts/bucket on wheels.
- Put a storage cart and cleaning supplies all in one place and in different parts of the house (kitchen, bathroom, etc).
- Purchase light weight mop easy to squeeze.
- Mop with a long flexible handle.
- Buy detergent which does not require rinsing.
- Purchase kneeling helper device.

Washing Windows

- Reduce dirt exposure from inside (hood fan over stove, dehumidifier).
- Improve system for opening windows to facilitate cleaning.
- Use removable sliders.
- Use easy to operate hardware.
- Purchase a long handled window wiper.

Vacuuming and Sweeping

- Use a lighter vacuum cleaner with electric carpet brush, easy to use and move.
- Consider investing in a central vacuum system.

- Modify the height of electrical outlets for easy access.
- Rearrange furniture.
- Purchase a light weight long handled dust pan and brush.

Dusting

- Obtain shelves with doors for holding ornaments.
- Use an air conditioner in areas exposed to high dust.
- Clean air ducts and change filter.
- Buy a long handled feather duster.
- Use a dust mitten.

Simplifying Doing the Laundry

Hand-washing Items

- Rethink location of equipment for hand-washing.
- Clear space below sink to allow you to sit to do hand-washing (insulate plumbing to avoid burns).
- Use products for pre-soak.

Carrying Laundry Bag or Basket

- Use a movable cart to transport clothes.
- Install handrails on stairs to laundry room.
- Relocate washer-dryer to main level to minimize stair use.
- Use a belt to pull basket or hold laundry bag on shoulder.

Filling/Emptying the Laundry Machine

- Adjust or increase lighting task lighting.
- Place mirror at angle to see inside washing machine.
- Use a long reacher to help remove items from washing machine.
- Store a flashlight near laundry machine to help see items in machine.
- Use a net bag for small items.
- Purchase a front loader washer and dryer for easier access.

Read/work washing machine or dryer controls

- Install task lighting.
- Colour and texture code controls for easy identification.
- Use lever-type controls for easy grasp.
- Relocate controls within easy reach.
- Use aids or reacher to help access controls.

Filling or Emptying a Dryer

- Purchase a small dryer with front opening, place on counter for easy access.
- Ensure sufficient space in front of dryer to allow easy reach.
- Use easy-to-grasp door handle.
- Create space to place or fold clothing.

Ironing

- Purchase wash-and-wear clothing.
- Use adjustable ironing board to sitting position.
- Use a stable board/stable iron.
- Ensure easy access to wall outlet.
- Purchase an iron with automatic shut off.

Hanging up washing

- Stand on a wide and stable platform.
- Adjust height of clothesline.
- Use portable, lightweight clothes rack.
- Use non-spring pegs.

Having Trouble with Technology

Some Tips for Using Appliances

- Place **SIMPLE INSTRUCTIONS** on or beside the appliance.
- **COLOUR CONTRAST** on/off switches and important numbers for easy identification (dark background with light numbers helps to see). Purchase remotes with large numbers.
- **USE** the appliance **REGULARLY** to help maintain the skill.
- **AVOID** purchasing **COMPLICATED APPLIANCES**. Buy ones with easy to handle or read controls.
- If it's too confusing and presents a safety risk, stop using it! **RETURN TO A SIMPLER WAY** of doing things.

Outdoor maintenance

Helpful Strategies

| Tips for person with dementia | Tips for caregivers |
|--|--|
| <p>If you are having difficulty organizing, performing or completing outdoor tasks:</p> <ul style="list-style-type: none"> ■ Have someone help you with outdoor tasks to lessen the workload (for example, cutting grass, shovelling snow, gardening, taking out garbage). ■ Organize tasks into a schedule (on a calendar) and follow a consistent routine if you have trouble remembering to do it. ■ Prioritize. Do only what needs to be done. ■ Post reminders for yourself on how to do a task if you tend to forget (illustrations or simple instructions). ■ Make the task easier. For example, for taking out the garbage: <ul style="list-style-type: none"> ■ Push or pull sacks rather than lift ■ Use smaller bags ■ Use garbage cans on wheels ■ Use movable cart for moving bags <p>If you are having trouble remembering how to use machinery (for example, snow blower, lawn mower):</p> <ul style="list-style-type: none"> ■ Avoid risking personal injury. Hire outside help or seek assistance from a friend, family, or superintendent. <p>If you are having trouble physically doing the task:</p> <ul style="list-style-type: none"> ■ Conserve your energy. Stop. Rest. Do only a bit at a time. Consult with your GP if you feel faint, dizzy, short of breath or pain. ■ Identify simpler ways to do task (for example, from a seated position rather than standing). | <p>If your loved one is having difficulty organizing, performing and completing cleaning tasks:</p> <ul style="list-style-type: none"> ■ Organize outdoor tasks into a schedule to maintain a consistent routine; prioritize. Do only what needs to be done. Post a schedule or 'to do' list in a visible area. ■ Have him/her do tasks that are familiar, repetitive and are the least likely to cause frustration or risk injury. ■ Simplify the task rather than eliminate it (unless there is an immediate safety risk), especially if it is something that your loved one enjoys doing. (for example, set up equipment; break task down into steps and do one step of task at a time). ■ Do outdoor activities together to provide subtle cues/support to perform the task. ■ Hire outside help, particularly for tasks that involve machinery or tools that could cause injury. <p>If your loved one is having trouble physically managing the task</p> <ul style="list-style-type: none"> ■ Have an occupational therapist observe him/her performing the task. He or she can make suggestions on how to make the task easier. (for example, energy conservation techniques, proper posture, adaptive aids, simple home modifications). |

2—Daily Living Activities

Kitchen Safety Checklist

- Install smoke and heat detectors near the kitchen and bedrooms.
- Install fire extinguisher near kitchen exit with step-by-step instructions.
- Place “In case of fire” and emergency notice near fire extinguisher.
- Purchase automatic shut-off appliances.
- Remove and hide sink stoppers to avoid overflow accidents.
- Install plastic safety latches in all kitchen cupboards if dangerous items and substances are not removed, or put locks on cupboards.
- When not working in kitchen, remove stove switch knobs or take fuses out or switch off circuit breaker.
- Lock up sharp knives.
- Put complex appliances out of sight.
- Install lever-style faucets or a faucet with a single lever to control flow and temperature.

Safe or Unsafe in the Kitchen

Key Considerations

- Is the individual able to plan a nutritious meal (for example, identify what ingredients are needed) and locate and set up ingredients for cooking?
- If the individual requires a special diet (for example, diabetes) does he or she prepare food according to this diet?
- Does the individual use sharp utensils or hot objects properly?
- Does the individual remember to turn off the stove and appliances?
- Does dementia limit the individual’s ability to determine whether food is properly cooked?
- Does the individual keep rotten food in the refrigerator or food past the expiry date?
- Does the individual store and reheat items properly?
- Does the individual prepare and eat the same thing everyday?
- Does meal preparation and clean up physically exhaust the individual?
- Can the individual carry items from kitchen counter to table without difficulty?
- Can the individual identify and use kitchen items appropriately?
- Does the individual hoard food; rummage through kitchen cupboards or the fridge?

Please Note

If the person with dementia has issues related to any one of these areas seek further help/advice from a health professional. Ensuring kitchen safety does not necessarily mean eliminating ALL activity in the kitchen, particularly if meal preparation is something your loved one enjoys or was always part of her/his role. A professional can help you to adapt the kitchen and simplify activities to enhance safety. She can also provide suggestions to help you include someone with dementia in everyday activities such as meal preparation.

Kitchen Help

Memory Tips

- Organize items in cupboards in meaningful way (for example, most often used items most accessible; similar food types or items together, and so on).
- Label cupboards of contents.
- Minimize clutter (get rid of items and food you do not use regularly).
- Remove cupboard doors to reveal contents; place picture of contents on door.
- Label and date food items.
- Keep counter tops bare.
- Place items you do not want used or misplaced in difficult-to-reach, non-visible areas.
- Place whiteboard with erasable marker on fridge or cupboard door to create visible grocery list and to post reminders.
- Place simple instructions above regularly used appliances.
- Post reminders (for example, turn off stove) in visible and meaningful spaces.

Physical Tips

- The sink should be at a height requiring minimal bending.
- There should be knee space and the sink and faucets should be positioned to require minimal stretching.
- Countertops should all be one level.
- Pull out shelves enable you to carry out food preparation in a seated position.

- U- or L- shaped counters minimize walking distances between tasks.
- Install pivoting or revolving shelves in corners, pull out storage units and large vertical cabinets make storage more accessible.
- Relocate storage space to facilitate access to key items.
- Adapt appliances for easier use (for example, colour/texture code controls).
- Use movable carts, easy to push pull shelves.
- Increase lighting, particularly in fridge.
- Use chairs with armrests to ease getting up/down.
- Raise chairs with wooden blocks to ease getting up/down.
- Use lightweight, unbreakable dishes.
- Cut down distance between work areas.
- Use labour saving techniques (for example, pre-sliced bread and cheese; take breaks)
- For physical limitations (for example, arthritis, limited grasp) there are adaptive aids available to help perform kitchen tasks. See an occupational therapist for further help.

Kitchen Cleaning Tips

- Use easy-clean stove and pans.
- Rinse dishes after use.
- Adapt controls on dishwasher to facilitate use.
- Purchase a self cleaning oven and self defrosting fridge.
- Install a hood fan.
- Use a countertop with easy cleaning material.

Eating and Maintaining a Healthy Weight

Helpful Strategies for Coping with Difficulty Eating

| Tips for person with dementia | Tips for caregivers |
|--|---|
| <p>If you have trouble remembering to eat regularly:</p> <ul style="list-style-type: none"> ■ Eat at the same time every day. ■ Eat with family/friends if possible. ■ Set a watch or timer for meals. ■ Look for signs that it is time to eat (smell of food cooking, table set) or signs that you have eaten already (dishes). ■ Arrange with Meals-on-Wheels to bring prepared meals. ■ Organize pre-made meals and date them. ■ Follow a weekly meal plan. ■ Mark on the calendar or on a white board on the fridge when you have eaten. ■ Ask family to remind you. ■ Write a note for yourself and post in a visible spot. ■ Carry easy-to-eat snacks with you/ eat when you are hungry. | <p>If you have trouble getting your loved one to eat:</p> <ul style="list-style-type: none"> ■ Cook hot foods with aroma to stimulate appetite: cook favourite foods, particularly food enjoyed in person’s past. ■ Provide food choice to stimulate interest. ■ Set table to cue person to eat. ■ Eat together to encourage eating. ■ Set timer for meals or give a reminder call/have clock visible/post reminders. ■ Arrange for meal delivery service if you are not at home. ■ Prepare meals in advance with note indicating when to eat. ■ Eat at same time/place everyday to cue memory. ■ Avoid introducing drastic changes to diet. ■ Encourage him/her to assist with meal preparation to stimulate appetite and interest. ■ Serve simple and familiar meals. ■ Have easy-to-eat snacks available. |

Eating and Maintaining a Healthy Weight

Helpful Strategies for Coping with Difficulty Eating

| Tips for person with dementia | Tips for caregivers |
|--|---|
| <p>If you experience difficulty when eating:</p> <ul style="list-style-type: none"> ■ Remove distractions (for example, turn off TV, radio, ask people to talk quietly). ■ Look for hints in the environment about what to eat/how to eat (for example, watch other people). ■ Allow yourself plenty of time to eat. ■ Get someone to show you what to do if you feel confused. ■ Switch to finger foods if using utensils is frustrating you. ■ Eat simple meals. ■ If you're feeling anxious or confused allow yourself time to get oriented before eating (sit down quietly at the table). ■ If you are having difficulty grasping utensils or getting food off your plate use adaptive aids such as plate guards to help get food off plate or built up utensils to help with grasp (you can buy these from the drug store, home health care shops or pharmacy). | <p>If your loved one experiences difficulty when eating:</p> <ul style="list-style-type: none"> ■ Maintain an adult atmosphere. ■ Encourage independence. ■ Use simple tableware. ■ Minimize distractions. ■ Eat in familiar places that will give cues for appropriate eating. ■ Present one food item at a time. ■ Purchase adaptive aids (for example, built up utensils, plate guards, modified cup) if person has difficulty grasping utensils, getting food off plate or drinking. ■ Sit across from each-other to demonstrate how to eat or that food is safe (if person is suspicious). ■ Ask if he/she would like assistance; Demonstrate; Provide hand over hand guidance for first few bites if needed. ■ Use finger foods if cutlery is too difficult. ■ If drinking from a cup is difficult use a straw. ■ If total feeding is required; feed slowly and don't overload spoon. ■ Ensure he/she is seated properly (sitting upright with head flexed slightly forward). ■ If he/she is using a wheelchair ensure that a proper wheelchair has been prescribed by an occupational therapist (a seating assessment). ■ Allow plenty of time to eat. |

Choking

Helpful Strategies

| Tips for person with dementia | Tips for caregivers |
|--|---|
| <p>If you have problems swallowing your food or you choke when eating:</p> <ul style="list-style-type: none"> ■ Consult with doctor and speech pathologist to assess your swallowing. ■ Eat soft foods (mashed potatoes, casseroles, scrambled eggs, porridge). ■ Eat foods that are well-moistened and avoid mixing different textures (for example, chunks of vegetables in soup). ■ Cut up food in small, bite-sized pieces before eating. ■ Try to avoid eating alone in case you choke. ■ Begin with a small portion and add more when finished. ■ Avoid talking while eating. ■ Allow plenty of time; eat slowly. ■ Eat while sitting in proper upright position (never lying down). | <p>If your loved one has problems swallowing food or chokes when eating:</p> <ul style="list-style-type: none"> ■ Serve soft foods that are familiar adult foods. (mashed potatoes, casseroles, scrambled eggs, porridge). ■ Serve foods that are well-moistened and without pieces of different textures (for example, nuts or chunks of vegetables). ■ Puree or soft diet; thicken liquids with thickener. ■ Cut up food before serving in small bite sized pieces before serving/eating. ■ Try to avoid letting the person eat alone in case he chokes. ■ Begin with a small portion and add more when finished. ■ Avoid talking while eating. ■ Allow plenty of time. ■ For a person at choking risk thin liquids should be avoided (They are actually harder to swallow since they offer less resistance than slightly thickened drinks such as milkshakes and pureed soups). ■ Gelatin may be used for thickening. ■ If eating too fast is a problem, cue to chew and swallow. ■ Eat while sitting in proper position (never lying down). ■ Allow plenty of time. ■ Consult with doctor and speech pathologist to assess swallowing. ■ Learn first aid. |

Suggestion: Learn Basic First Aid and CPR so you will know how best to respond if choking occurs. Look in your local telephone directory for courses in your community.

Weight Loss or Gain

Helpful Strategies

| Tips for person with dementia | Tips for caregivers |
|---|---|
| <p>If you have lost your appetite:</p> <ul style="list-style-type: none"> ■ Cook your favourite foods/participate in meal preparation to stimulate appetite. ■ Avoid eating the same thing every day: Eat a range of foods that you enjoy. ■ Eat hot foods as the aroma will help to stimulate your appetite. ■ Eat breakfast daily. This may increase your appetite for the day. ■ Eat at regular times (for example, three meals/day). ■ Eat in a quiet room without too much stimulation. ■ If large meals are too difficult to manage, eat little and often. ■ Have healthy snacks available and within sight at all times. ■ Carry snacks with you. ■ Exercise regularly. | <p>If your loved one has lost his/her appetite:</p> <ul style="list-style-type: none"> ■ Cook favourite foods. ■ Serve hot foods as aroma stimulates appetite. ■ Focus on sensory aspects of foods. ■ Provide simple food choices. ■ Encourage participation in meal preparation to stimulate appetite. ■ Maintain consistent routine for eating. ■ Have healthy and easy to eat snacks available and visible. ■ Encourage daily exercise. <p>If he or she refuses to eat:</p> <ul style="list-style-type: none"> ■ Sample food to demonstrate that is safe/ok if suspiciousness is a problem. If suspiciousness persists (for example, fear of poisoning) contact a doctor. ■ Provide choice and maximize their sense of control. ■ Avoid conflict. Do not force feed. Try again later. ■ Eat together. Create normal mealtime atmosphere. <p>If he or she eats excessively or eats inappropriate items:</p> <ul style="list-style-type: none"> ■ Limit access to food between meal times. ■ Distract. Help person to engage in another functional activity. ■ Throw away or lock up potentially harmful items (if possibility of ingestion). ■ Consult with your doctor. |

Meal Preparation

Helpful Strategies

| Tips for person with dementia | Tips for caregivers |
|---|---|
| <p>If you are concerned about safety in the kitchen (for example, leaving stove on):</p> <ul style="list-style-type: none"> ■ Have meals delivered. ■ Eat pre-made meals that can be heated in the microwave. ■ Purchase automatic shut off appliances. ■ Post reminders (for example, reminder to turn off stove placed on wall beside stove). ■ Cook only when others are home. | <p>If you are concerned about his/her safety in the kitchen:</p> <ul style="list-style-type: none"> ■ Have an occupational therapist perform a kitchen safety/ functional assessment (contact your doctor, local CCAC, or the Alzheimer society for a referral). The OT will observe how he/she manages tasks such as meal planning, preparing items, cooking/ using appliances and clean-up. <p>If your loved one is unsafe in the kitchen and risks accident or injury:</p> <ul style="list-style-type: none"> ■ Supervise kitchen activities as un-intrusively as possible (for example, offer to help or do another task nearby. Avoid making an issue out of mistakes made. This will likely only add to confusion, frustration and defensiveness. ■ Have your loved one make meals only when someone is home. ■ Plan ahead. If dementia is at a stage where your loved on is unsafe in the kitchen, ‘Safety proof’ (see page 95) the kitchen whenever he/she is left alone and leave pre-made meals and snacks clearly visible to discourage cooking. |

Meal Preparation

Helpful Strategies

Tips for persons with dementia and their caregivers

If you or your loved one has TROUBLE REMEMBERING how to make meals:

- Follow the same weekly menu and use recipes to prepare meals.
- Prepare simple meals that require fewer steps.
- Prepare meals together.
- Post simple 'how to use' instructions beside appliances.
- Purchase frozen dinners or freeze and store meals.
- Have meals delivered to your home (for example, meals on wheels).
- Determine whether you qualify for homecare support (light meal preparation).

If you or your loved one MISPLACES ITEMS when cooking or can't find ingredients in the kitchen:

- Simplify your kitchen space. Throw out what you rarely use. Have items that you routinely use easily accessible and visible.
- Identify the contents of cupboards by labelling the inside of cupboard doors.
- Categorize and store items according to their use (for example, pastas and breads together; spices together; canned foods together).
- Set up the ingredients needed prior to preparing the meal.

If you or your loved one GETS TIRED while preparing meals or has difficulty standing, bending or lifting:

- Set up ingredients/ items needed in an easy to reach place.
- Prepare meals in a seated position.
- Take breaks. Do one thing at a time (for example, cut up vegetables in the morning to be used for dinner).
- Modify kitchen space to minimize walking, reaching, standing.
- Use adaptive aids (for example, reacher, lightweight pots/pans, rollator (wheeled walker) with basket or cart to carry items).

Bathroom Safety

Bathroom Safety Checklist

- Use adaptive aids/equipment to compensate for limited strength or balance.
- (for example, shower chair, bath bench, grab bars, lever-type tap, shower hose).
- Install a grab bar beside the toilet and tub and a shower hose to ease bathing.
- Place slip-resistant flooring inside/outside shower stall (or bath) using non-slippery coating, abrasive strips or rubber mats.
- Improve floor drainage to help prevent falls.
- Set the hot water temperature to 46°C (115°F) to avoid burns.
- Use colour contrast (contrasting colour tape) around the tub, toilet and fixtures to make them stand out (this helps if someone has difficulty judging depths).
- Use non-slip flooring and tiles that contrast with the tub.
- Remove unsafe appliances.
- Install a call bell in the bathroom.
- Remove bath mats; replace with non-slip rubber mat in contrasting colour to help with poor vision or perceptual problems.
- Relocate storage of personal care items (soaps, creams, razors and so on) to a safe place.
- Keep pills out of reach and locked in a cupboard to avoid accidental ingestion.
- Keep shampoo and other liquids out of the bathroom so that they cannot be swallowed.

- Remove lock from bathroom door to prevent person getting locked in.
- Remove and hide sink stoppers to avoid overflow accidents.
- Remove waste paper basket from bathroom so that it is not confused with a toilet.
- Install socket with ground fault indicator (GFI).
- Cover mirror if it adds to confusion as they may not recognize themselves in the mirror.
- Mark hot tap with tape or nail-polish for easy identification

Safe or Unsafe in the Bathroom?

Key Considerations:

- Does the individual require reminders to bathe?
- Does the individual look or smell unclean?
- Does the individual have any physical limitations (for example, pain, poor balance, limited strength)?
- Has the individual fallen recently?
- Is the individual impulsive?
- Does the individual get confused while bathing? (for example, forget what to do next)
- Does the individual wash thoroughly?
- Can the individual get into/out of the bathtub or shower?
- Does the individual tire easily and/or have trouble standing for long periods?

- Does the individual identify and use objects appropriately? (for example, shampoo, shower hose, soap etc)?
- Can the individual distinguish between hot and cold?
- Is the individual able to manipulate the taps and shower hose?
- Is the individual resistant to bathing?
- Set up items needed prior to bathing in a visible and accessible space.
- Follow a consistent bathing routine (for example, same time of day, same sequence of tasks) to encourage bathing.
- Colour code items if the bathroom is shared (for example, his/her blue and red toothbrushes, towels and so on).

Please Note

If the person with dementia has trouble in any one of these areas seek further help/advice from a health professional. Simple modifications can be made to the bathroom to make it safer. Homecare support is also available to help with bathing. Contact your local community care agency or your doctor for more information.

Bathroom Help

Memory Tips

- Organize items in bathroom cupboards in a meaningful way (for example, most often used items most accessible; similar types or items together, and so on).
- Label bathroom cupboards of contents.
- Minimize clutter (get rid of items you do not use regularly).
- Keep counter tops bare.
- Place items you do not want used or misplaced in difficult to reach and non visible areas.
- Post reminders and/or simple instructions in visible and meaningful spaces (use words or diagrams give cues about steps involved in a task).

Physical Tips

- Install grab bars beside toilet and tub.
- Install a hand-held shower mounted on a vertical rod or on a low bracket to make washing and rinsing easier; water control knob on shower head for easy use.
- Use a long handled sponge or brush to reach better.
- Purchase a single lever handle for shower and bath to help with grasp.
- Use a shower chair or bath bench if the person has difficulty with balance or getting into tub.
- Keep towels and items needed easily within reach.
- Clear space under basin/sink and insulate plumbing for seated activities.
- Raise/lower basin to appropriate height.
- Use task lighting.
- Buy a pump soap dispenser.
- Create space for clothes.
- Place dividers in drawers for easy location of items.
- Allow for activity in sitting position.

- Use an adapted toothbrush, hairbrush, easy to pump toothpaste if problems grasping objects.
- Mark chain on plug/ outline drain in contrasting colour.
- Ensure shower controls are easy to reach, read and operate.

Cleaning Tips

- Use easy-to-clean wall surfaces.
- Treat tub enamel; fungus-proof caulking.
- Ensure adequate ventilation to prevent moisture.
- Use a hand held shower head to facilitate rinsing/cleaning tub or shower stall.
- Use a long-handled cleaning brush for easier reaching.

Having Problems with Bathing?

“It’s the first time yesterday that a man came from homecare to give my husband a bath and I appreciate that so much. I am too weak. He was so happy. He said, “I never had such a good bath.”

If you are caring for someone who resists bathing it is important to consider what may be causing the person’s resistance, including the effect of dementia on his ability to bathe and the bathing context (for example, the bathing environment, quality of interactions between yourself and the person you are caring for).

Here are some possible reasons for resistance to bathing.

- Embarrassment or frustration with being unable to manage bathing.
- Feeling a loss of personal control.
- Feeling exposed or cold.
- Different standards of hygiene.
- Fear of being drawn down the drain.
- Fear of water.
- Failure to recognize the caregiver.
- Unable to see the bottom or sides of the tub due to perceptual problems.
- Difficulty with balance or coordination.

If bathing presents ongoing difficulties for you then frequency should be reduced to the minimum necessary. While you may wish as a caregiver that the person would bathe daily, it is not necessary unless the person is incontinent. Try other methods for bathing such as a sponge bathe or seek outside help through homecare support.

Many caregivers find at first their loved one refuses bathing help from an outside person. However, once they are familiar with the helper and have a regular bathing routine they often stop resisting. They may even enjoy it!

Having Problems with Bathing?

Helpful Strategies

Tips for caregivers

If the person with dementia refuses to bathe consistently and/or refuses help:

- Follow a consistent bathing routine.
- Set up bathing items to cue for the activity and simplify it.
- Post a reminder in a meaningful place.
- Break the activity down into simple steps and post steps on tub wall to serve as a reminder (if you are concerned your loved one is not bathing properly).
- ‘Set the scene’ to promote compliance with bathing by increasing the positive aspects and providing pleasant experiences leading up to and during the activity (for example, favourite robes, towels, soaps etc).
- Use humour.
- Give a positive reason for having a bath. Give positive reinforcement after the bath (for example, breakfast and a coffee, a compliment, an activity she enjoys).
- Offer outside help. Sometimes people are more willing to accept help from others.
- Wash hair separately (washing hair may be frightening).
- Keep him/her warm (for example, warm towels, warm the room by turning the hot water; eliminate draft).
- Protect privacy: If person requires help with bathing, avoid having him totally naked (drape a towel or robe over shoulders).
- Encourage the person to do as much as possible. Provide choice throughout bathing.

Tips for persons with dementia and caregivers

If you or your loved one has PHYSICAL DIFFICULTY bathing:

- Install a grab bar on the tub/shower wall for support.

NOTE: a vertical grab bar provides support when entering the tub, while an angled bar helps you to complete the entrance and lower yourself onto a shower seat or to the bottom of the tub). Alternatively, a removable grab bar can be clamped to the side of the bathtub.
- Purchase a removable shower seat or bath bench to enable bathing while sitting. A bath bench is best if you are using the bathtub and have difficulty climbing in/out. Sometimes it can be difficult to keep the water in the tub when using a bath bench. A solution is to cut slits in the shower curtain so it can drape over the bench.

Having Problems with Bathing

Helpful Strategies

Tips for persons with dementia and caregivers

If you or your loved one has PHYSICAL DIFFICULTY bathing:

- If you enjoy bathing submerged in the tub but cannot safely get up/down, consider purchasing a hydraulic bath lift; a simple device that lowers you into the tub.
- Colour-contrast the tub to define its edges and depth to make it easier to get in/out (for example, black on white or use a coloured rubber tub mat in tub).
- Use adaptive aids (for example, long handled sponge, easy to use soap/shampoo dispenser, wash mitt, back brush with curved handle).
- A Hand held shower head, mounted on a vertical rod or on a low bracket will make washing and rinsing easier.
- Ensure all bathing items are set up before bathing and are easy to reach.
- Install shelves within reach.
- Get assistance. Home care support is available.
- Sponge-bathe at the sink while sitting on a chair or stool if bathing in a tub or shower is too difficult.
- Install non-slip surface in bathtub and non-slip flooring throughout the bathroom.
- Take breaks. Modify bathroom space to minimize walking, reaching, standing.
- Replace bathtub with shower stall.

Getting the Help you Need

An Occupational Therapist can recommend the type of equipment that is best for you, coordinate trials, installation and determine if you are qualified for some funding to purchase equipment. Contact your doctor or local CCAC (in Ontario) for an assessment.

Using the Toilet and Incontinence

Helpful Strategies

| Tips for person with dementia | Tips for caregivers |
|--|---|
| <p>If you have difficulty making it to the toilet on time:</p> <ul style="list-style-type: none"> ■ Inform your doctor. This is a common problem. ■ Limit fluid intake prior to bed. ■ Use the toilet immediately prior to bed. ■ Use the toilet frequently to prevent accidents. ■ Wear easy to remove clothing (for example, pants with elastic waist band). ■ Have a commode (toilet seat with pail) near the bedside, bedpan or urinal. ■ Use adult protective underwear in case of accidents. <p>If you have trouble getting on/off toilet:</p> <ul style="list-style-type: none"> ■ Install a grab bar beside the toilet, transfer pole or versa-frame (arm rests/handles attached to toilet). ■ Attach a removable toilet raise to the toilet to give it more height or set the toilet on a pedestal. ■ Get assistance. Set up a call bell in bathroom. | <p>If he or she is incontinent:</p> <ul style="list-style-type: none"> ■ Limit fluid intake prior to bed. ■ Use a urinal or have a commode with pail at the bedside if the person has physical limitations. ■ Establish a toileting routine using timers and reminders to help prevent accidents. ■ Install a call bell. ■ Provide assistance. ■ Wear easy to remove clothing. ■ Use plastic mattress cover, bed pads or chair pads to keep the mattress dry and prevent infection and bedsores. ■ Get urological examination and bladder re-training. ■ Use a nightlight and close all other doors at night. ■ Ensure clear pathway to toilet. ■ Try to have a bathroom door open to keep the toilet visible. <p>Note: Introducing new items/equipment such as urinals or commodes may add to confusion. This will depend on the person's level of confusion. On the other hand, if your loved one has physical limitations and you are getting up at night to help him use the toilet, a commode or urinal can ease the task considerably.</p> |

Using the Toilet and Incontinence (continued)

Helpful Strategies

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|--|---|
| | <p>If he/she gets disoriented (for example, can't find way to bathroom or inappropriately uses bathroom)</p> <ul style="list-style-type: none">■ Post a sign on bathroom door labelling the room (use a familiar bathroom symbol).■ Remove items in bathroom that may be confused for something else (for example, trash bin).■ Colour toilet water blue or colour contrast toilet seat to prevent urine from getting on the toilet seat (helps him to direct the flow).■ Post reminder on wall beside toilet to cue for flushing or install flush activating sensor.■ Keep bathroom light on at night or use a night-light.■ Ensure he uses the toilet immediately prior to bed.■ Install a call bell beside the bed.■ Keep closet doors shut at night.■ Use adult diapers/pads at night.■ Keep a familiar path to the toilet. |
|--|---|

Grooming

Helpful Strategies

| Tips for person with dementia | Tips for caregivers |
|--|---|
| <p>If you are worried you might forget to groom yourself (for example, brush hair or teeth, shave, dress appropriately) before leaving the house:</p> <ul style="list-style-type: none"> ■ Maintain a consistent bathing/grooming routine. ■ Post reminders to yourself at the back of the front door (for example, 'did you remember to...?'). ■ Ask a family member or someone else you trust to help/give reminders. <p>If you are concerned about oral hygiene, nail-care, hair-care or shaving:</p> <ul style="list-style-type: none"> ■ Use homemaking services to assist with these activities. ■ Get a referral to a chiropodist/podiatrist for nail care. It may be possible to have a health professional come to your home for nail care. ■ Have regular dental checks. | <p>If you are concerned about oral hygiene:</p> <ul style="list-style-type: none"> ■ Ensure he/she has regular dental checks. ■ Establish consistent routine (for example, brush teeth immediately after breakfast and before bed). ■ Post a reminder in a meaningful place. ■ Set up the toothbrush with toothpaste to cue him to brush his teeth. ■ Check fit of dentures. <p>If you are concerned about nail care:</p> <ul style="list-style-type: none"> ■ Get a referral to a chiropodist/podiatrist for nail care. ■ Refer to visiting professionals who will provide nail care or educate you about proper nail care techniques. <p>If you are concerned about shaving:</p> <ul style="list-style-type: none"> ■ Use a safety razor/ battery operated electric razor. ■ Use homemaking services to assist with shaving. ■ Ensure mirror is at correct height for shaving. A magnifying mirror may be best. ■ Make shaving part of weekly routine. ■ Give reminders. Use humour to encourage shaving. <p>If you are concerned about hair care:</p> <ul style="list-style-type: none"> ■ Try a home hairdressing service. ■ Wash hair separately. ■ If the person is bed-bound use a hair washing container with drain or use leave-in-hair washing solution (check at your local pharmacy). ■ Remove hair appliances if person can no longer use them safely. ■ Make hair grooming a part of everyday routine. Wash hair as needed (for example, once a week). |

Grooming (continued)

Helpful Strategies

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| | <p>If you are concerned about hygiene/grooming in general:</p> <ul style="list-style-type: none"> ■ Maintain a consistent routine. ■ Give a reason for grooming: for example, remind him where he is going and why it is important to look presentable. |
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Getting in and out of Bed and Restlessness

Helpful Strategies

| Tips for person with dementia | Tips for caregivers |
|---|--|
| <p>If you have trouble sleeping at night and feel restless:</p> <ul style="list-style-type: none"> ■ Reduce stimulation before bed (limit activity). ■ Avoid caffeine or eating just prior to bed. ■ Play soothing music. ■ Turn the TV off at night. Avoid watching violent programs. ■ Avoid sleeping for long periods during the day. ■ Get some exercise each day. ■ Consult your doctor if sleeplessness persists. | <p>If your loved one has difficulty getting in/out of bed:</p> <ul style="list-style-type: none"> ■ Install grab bars or vertical poles in convenient locations. ■ Install a trapeze over the bed. ■ Install a bed rail. <p>If your loved one gets up frequently at night or experiences disorientation at night:</p> <ul style="list-style-type: none"> ■ Place a touch-sensitive light beside the bed. ■ Use a nightlight. ■ Place a call bell beside the bed. ■ Purchase a digital clock with illuminated numbers that can be seen at night. ■ Post a message board (for example, whiteboard) in bedroom with orientation information and directions (for example, place; instructions to remain in bed until specified time etc). ■ Place pictures or simple reading material at bedside to encourage a calming functional activity. ■ Verbally orientate the person to time and place. Provide reassurance. |

Dressing

Helpful Strategies

| Tips for person with dementia | Tips for caregivers |
|---|--|
| <p>If you have trouble finding or selecting the right clothes for the day:</p> <ul style="list-style-type: none"> ■ Have someone help you select clothes or lay them out for you. ■ Label your cupboards and drawers with words or pictures to reveal contents. ■ Store clothes in an easily accessible place. ■ Organize your closet/simplify it (have hooks or drawers installed in the closet; add shelves, add or lower rods in the closet, install a light in the closet). ■ Get rid of what you no longer need wear/put away clothes that are out of season. ■ Purchase many pairs of the same colour of socks to avoid mismatch. <p>If you have difficulty putting clothes on:</p> <ul style="list-style-type: none"> ■ Get homecare assistance. ■ Dress while sitting. ■ If one side of your body is weak or less mobile (for example, from a stroke, arthritis or injury) dress your weaker side first when putting on a shirt or pants. ■ Purchase loose fitting clothing. ■ Select clothing with Velcro fastenings, elastic waistbands and front openings to simplify getting dressed. | <p>If your loved one has problems dressing/ dresses inappropriately:</p> <ul style="list-style-type: none"> ■ Hang the day's clothes in a visible place. ■ Install an accordion closet door (this discourages rummaging and minimizes confusion when selecting clothes). ■ Remove unnecessary clothing from view. ■ Put away clothing that is not in season. ■ Label shelves or drawers. ■ Install lights in the closet. ■ Add or lower rods for easy access. ■ Simplify arrangements of clothes in closet. ■ Add floor shelves in closets or entrances for shoes and boots to reduce clutter. ■ Install hooks or drawers in the closet for better organization. ■ Purchase easy clothing: loose fitting, Velcro fastenings, front openings, elastic waistbands. ■ Purchase slip- on shoes for your loved one. ■ Sequence clothes in order ready for dressing to reduce frustration. ■ Button all shirts to a certain level so they can be slipped on easily. ■ Dress while sitting. ■ Break task into small steps to minimize frustration. ■ Get homecare assistance. |

Dressing (continued)

Helpful Strategies

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| | <p>If he/she does not distinguish between clean and dirty clothes:</p> <ul style="list-style-type: none">■ Once clothes are removed for the night take them to the laundry and out of sight.■ Avoid having a laundry basket in the bedroom to prevent wearing dirty clothes.■ Maintain a consistent bedtime routine (change into pyjamas or 'night clothes' at night).■ Give gentle reminders that it's time to change. |
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Medication Tips

- Use pre-filled blister packs (This organizes daily pill intake).
- Ask your pharmacist to prepare this for you.
- Use a medication organizer (dosette). There are several varieties including a lock feature. Check at your local pharmacy.
- Arrange for family or a friend to supervise medications or fill dosette. Monitor medication intake.
- Ask the doctor to simplify medication and times taken.
- Use a medication alarm as a reminder to take medication.

- Store medication in a locked cabinet or child-proof containers.
- Discard old or expired medication.
- Have the drug store deliver medications.
- Carry a list of medications on your person and post one at home.

Please Note

Some people find it useful to store all medical information in one binder that can be taken to each doctor's appointment, including medication lists, test results, medical precautions, appointment times and updates from doctor's appointments.

Daily Living Activities Self-assessment Form

| Area of difficulty | Possible solutions or strategies to try |
|--|---|
| Eating and maintaining a healthy weight | |
| Meal preparation | |
| Bathing and grooming | |
| Using the toilet and incontinence | |
| Getting in and out of bed and restlessness | |
| Dressing | |
| Medication | |

| To-do List |
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3—General Community Activities

Community Safety Checklist

- Register with the Safely Home® registry. Contact your local Alzheimer Society.
- Keep identification in a purse or wallet at all times.
- Wear a bracelet with name and contact person.
- Alert neighbours, shopkeepers about risk of getting lost.
- Get to know your local community.
- Stick to familiar places and routes.
- Travel with another person or let someone know where you are going.

- Utilize community resources (day programs, friendly visitor programs etc).
- Address driving safety with your doctor.
- Carry a SMALL amount of money at all times.
- Carry bus route information at all times/bus pass.
- Carry a card that explains your condition.
- Avoid going to places alone.
- Avoid going out in rush hour when traffic is heavy.
- Use calendar and date book to keep track of appointments.
- Set up memory centre with keys, phone, emergency numbers in one place.

Grocery Shopping

Helpful Strategies

| Tips for person with dementia | Tips for caregivers |
|--|--|
| <p>If you become OVERWHELMED or DISORIENTED in the grocery store:</p> <ul style="list-style-type: none"> ■ Stop. Rest. Allow yourself time to get familiar with your environment. ■ Look for signs/directions in the store. ■ Ask for help from a staff member wearing a uniform. ■ Carry your ID with you and emergency contact numbers. ■ Carry a pocket book/appointment and have the day's tasks written down. This will help remind you of why you are there and what you are to do next. ■ Try to avoid shopping alone. | <p>If the person with dementia has difficulty putting items away in the right place in the kitchen:</p> <ul style="list-style-type: none"> ■ Label kitchen cupboards using words or pictures. ■ Cupboards should be easily accessible/within reach. ■ Break down the task into steps and/or have the person do part of the task (for example, empty all bags). |

Tips for persons with dementia and caregivers

If you or your loved one gets tired grocery shopping:

- Do the shopping together or have someone else help with the task.
- Use a bundle buggy/ wheeled basket or wheeled walker with a basket.
- Have groceries delivered to your home.
- Do a little bit of shopping per day vs. weekly shopping.
- Shop at stores that are nearby and easily accessible.
- Familiarize yourself with the location of items in the store: Organize your grocery list according to location of items to minimize walking.
- Shop at a time of day when you have the most energy.
- Use a bundle buggy to carry groceries from car into house.

If you or your loved one has difficulty identifying items to buy:

- Re-organize your kitchen space (See KITCHEN HELP, page xx for details).
- Label each cupboard to indicate contents.
- Place a small whiteboard (one you can write on with a marker and erase) on the fridge:
 - List the contents of the fridge and cupboards using the whiteboard (for example, dairy products, vegetables, meat, canned foods, pasta/bread...)
 - Each week check off/list what items are needed
 - Write 'master' grocery list based on items checked off as needed.

If you or your loved one has TROUBLE FINDING ITEMS in the store:

- Shop at the same store every time.
- Select a smaller grocery store where you can get to know the staff.
- Look for signs in the aisles.
- Follow the same route each week (for example, dairy products first, then fruit/veggies, then canned foods etc).
- Shop with your partner, friend/family.

If you or your loved one GET CONFUSED when paying for items:

- Stick to a weekly budget for groceries.
- Only carry the approximate amount of cash you will need to purchase the groceries.
- Do not take credit cards.
- Try shopping on the same day(s) each week to get to know regular staff who can help/understand.
- Alert grocery store manager to your condition.
- Do not shop during busy times.
- Take your time. Try not to get anxious if there is a line of people behind you.

4—Finances

Managing Finances

Helpful Strategies

If you are worried about financial security and are concerned that you or your loved one may be taken advantage of financially:

- Establish power of attorney for finances.
- Increase level of support to accomplish financial tasks (independence with safe limits).
- Inquire about eligibility for financial support (pension, old age allowance, medical benefits, veterans benefits).
- Contact your local Alzheimer society for information, support and guidance.
- Seek financial advice from a professional; arrange for income tax services.
- Set up direct deposit of pension cheques into your account.
- Set up automatic bill payment.
- Budget withdrawals. Go to the bank weekly or every two weeks.
- Avoid using credit cards—do not carry them with you.
- Carry only small amounts of cash in your wallet.
- Avoid using ATM cards to take money out of your bank account. Go directly to the bank teller. Get to know the tellers at the bank.
- Alert the bank to your condition.
- Do not allow door-to door salespersons to enter your home. Post a reminder on the back of your door not to let them into your house.
- Request that junk mail not be delivered to your home.
- Do not give any personal information over the phone. Post a reminder of this beside the phone.
- Purchase a phone with call display and an answering machine that allows you to hear the messages being left as the call is going through. When home alone, screen calls by letting them go through to the answering machine.
- Avoid shopping alone.

Tips for Persons with Dementia

If you keep losing track of your money:

- It may be time to get some assistance with managing finances. Your spouse may be able to do this; or ask a trusted family member for help.
- If you do not trust a family member or a friend, an objective third party can do this. Refer to a public trustee. Your local Alzheimer society can provide more information about this.

- Take only what you need when you go out. Stick to your shopping list.
- Establish and follow a weekly budget.
- Take money out of the bank once a week according to your weekly budget. If you are worried you might lose or spend your money all at once, put the money in an envelope in a safe place (always the same place) and take from the envelope what you require daily. Let someone you trust implicitly know where the envelope is.
- Have contact information in your wallet in case it is lost.

If you are having trouble sorting out the correct amount of money to pay for items:

- Take your time.
- Keep your receipts.
- Shop at quiet times with few crowds.
- Shop at the same places.
- Get to know the cashiers and ask for help.
- Avoid shopping alone.

If you are having difficulty organizing bill payments:

- Arrange for automatic withdrawal from your bank account.
- Have someone you trust assist you with this task.

Keeping Active and Involved

Helpful Strategies

| Tips for person with dementia | Tips for caregivers |
|--|---|
| <ul style="list-style-type: none"> ■ Focus on what you still can do and keep doing it! ■ Have someone help you to create a ‘memory book’ that contains information that is important to you. This may include photos and stories from your past and/or a present day journal, calendar and ‘to do’ lists. Such a book can help you to organize daily activities and re-visit the past. It can also help you to communicate with others as it is a good conversation piece. ■ Join a local support group or activity group through your Alzheimer’s society. This will give you an opportunity to talk to others who are going through a similar experience, to get information and to feel supported. ■ Try to follow a consistent routine that balances rest with activity. Make social contact a part of that routine. If you have trouble feeling motivated to get out, try to do things with a friend who can encourage you. (for example, a walking partner) ■ Care for a well-trained pet. Many people find that caring for a pet helps to keep them active, follow a routine and get out daily for some physical activity. ■ Get support to continue to do activities and hobbies you enjoy. You may not be able to do these activities in the way that you used to, but that does not mean you have to stop altogether. Activities can be modified! ■ Have regular visitors to your home (for example, friends or someone from a ‘friendly visitor program’ through your Alzheimer society. | <ul style="list-style-type: none"> ■ Provide opportunities for reminiscence (photo albums, family pictures, vintage items and other memorabilia). ■ Provide opportunities to engage in familiar activities. Have items/materials visible in the environment that invite involvement in familiar activity. ■ Follow a consistent routine that balances rest and privacy with activity and socialization. ■ Strive for ‘the just right challenge’ where the person can exercise some choice and experience success. Avoid over-stimulation and stressful situations that lead to failure. This often involves setting up the environment or task for success. A counsellor from the Alzheimer’s Society or health professional such as an occupational therapist can help you with this. ■ Investigate past interests and explore volunteer programs (day centres/senior centres). ■ Make sure that you as the caregiver are not the only source of social contact. ■ ALLOW OUTSIDE HELP. Not only will it give you a break but it will provide more opportunities for socialization. Often resistance to outside help and activity is overcome once it is no longer threatening and becomes a part of a regular routine. |

Personal Accounts and Narratives

I just moved into a new home, I'm happy, I've got a little garden, so I've got to try to get a positive attitude towards what I've got, that's all.

72-year-old gentleman diagnosed with Alzheimer's expressing what he has and what he can still do

He fought me every step of the way but now he loves it and looks forward to going.

A caregiver overcoming her spouse's resistance to joining a group

Johnny feels more comfortable with people who know his situation. That's why he likes coming to the Rebel group (support group through the Alzheimer's Society). When we go someplace else, he asks, "Do they know about me?" There are some people who don't know and don't understand, but in the group they all understand. He feels accepted.

A caregiver talking about the value of a support group for people with dementia

Think about what it would be like if this place weren't here (referring to the Alzheimer's society). It would be awful, wouldn't it? Because we can talk about it and realize what's going on. Without coming here, like say, go back 30 years ago, something was happening to you, and everybody would be thinking you're crazy. At the time, that's how they'd think, compared to now. Nowadays, we know we've got a disease that can't be helped. It must have been extremely hard for people at that time. And I even remember when I was a kid, we'd say, "Hey, this guy's crazy." Now I say, "Hey, this guy has a disease."

A 66-year-old man diagnosed with dementia referring to the Alzheimer's society and the importance of social support.

My husband had a friend he plays cards with.... When we start to play games, he'll say, "I don't know if I remember how to play this anymore," but at the end of the night, he always seems to be the winner. His friends say, "For a guy who doesn't know how to play, he sure wins a lot!"

A caregiver identifying her spouse's concern about memory loss but keeping active in spite of it

Keeping Active When You Can No Longer Drive

Losing a driver's licence due to a medical condition such as dementia is a reality facing many families. It is especially difficult when you or your loved one have been driving for many years and rely on a car for transportation.

If you are no longer able to drive it is important to explore other options for transportation that will enable you to continue to participate in your regular community activities.

Most communities have taxi services that offer reduced rates for seniors, people with disabilities and medical conditions such as dementia. Contact your doctor, local Alzheimer Society or provincial-territorial transportation department for further information.

Please Note

Driving is an issue that needs to be discussed with your family doctor. If you or your loved one is having difficulty dealing with the loss of a driver's licence, ask your doctor about support groups that may be offered in your area or contact your local Alzheimer's society.

I was downtown the other day, shopping, and it was four blocks away. I got lost. “I got lost! Holy! It’s only four blocks away! I can’t believe it. I don’t ever want that to happen again.

A man in the early stages of Alzheimer’s Disease

Concerned about Getting Lost?

You are not alone. The risk of getting lost is a very real threat to carers and persons with dementia. Here are some tips to help minimize the risk.

| Tips for person with dementia | Tips for caregivers |
|--|---|
| <ul style="list-style-type: none"> ■ Always carry personal identification with you. ■ Carry the name and number of two emergency contacts with you. ■ Register with Safely Home®. ■ Always carry a small amount of money with you. ■ Carry a card that describes your condition with you. ■ Have a list of your current medications in your wallet or purse. ■ Before you leave home, write down where you are going and who to refer to if you get confused. ■ Wear a watch. ■ Avoid going out alone. If you have to, make sure someone knows where you are going and when you will return. ■ Stick to familiar routes and places. Let people in those places know that you are at risk for getting lost. | <ul style="list-style-type: none"> ■ Place door or window locks in invisible or unusual places, such as the top of doors, above the normal line of vision. ■ Install second locks on exit doors to make the process of unlocking complicated. ■ Add a fence to the backyard and lock its gate. ■ Install alarm system (this can be simple, like bells on door knobs). ■ Consider keypad entry lock, door alarm or portable buzzer activated by movement. ■ Ensure person with dementia is on the Safely Home® registry. ■ If a registry is not available notify local police department and have a recent photo available. ■ Have bracelet engraved with appropriate information and contact person. ■ Inform the neighbours or Neighbourhood Watch. ■ Put identity cards and contact numbers in wallet or purse. ■ Alert neighbours, superintendent and local shopkeepers of possibility of getting lost. ■ Make sure car keys are hidden. ■ Do not leave your loved one alone in the car. ■ Cover mirrors and keep curtains drawn at night. ■ Camouflage windows with decorations and coverings. |

Concerned about Getting Lost? (continued)

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| | <ul style="list-style-type: none"> ■ Place a symbol or sign on doors in the house to identify the room. ■ Identify the triggers that initiate the person leaving home and try to eliminate them. ■ Provide escorts for safe walking. ■ Support the emotional need behind the wish for experiences such as going out to work by talking about it. ■ Provide enough stimulation and exercise during the day. ■ Put away items that might cue a person to go out (coats, boots and so on). |
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Community Activities: Self-assessment Form

| Area of difficulty | Possible solutions or strategies to try |
|-------------------------------------|---|
| Grocery shopping | |
| Managing finances | |
| Keeping active and getting involved | |
| Leaving home and getting lost | |

| To-do List |
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Acknowledgements

Adapting Your Home to Living with Dementia was carried out with the assistance of a grant from the Canada Mortgage and Housing Corporation (CMHC) under the External Research Program.

The resource was developed in collaboration with the Alzheimer Society of Niagara Region [ASNR] and a group of extraordinary individuals living with dementia and their caregivers.

A special thanks to Marge Dempsey and Gina Bendo for their knowledge and expertise and to the staff at ASNR for their contributions.

The author is especially grateful to the participants who volunteered to share their time, experiences and wisdom.

Five publications served as key references in the development of this resource. With permission, some of their material has been included in this 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.

For further information and/or to order this resource visit www.caot.ca or call Canadian Association of Occupational Therapists Publications Manager, Ph: 1-800-434-2268 ext. 232.

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

For further information and/or to order the SAFER, visit www.cotahealth.ca or call 416-785-9230, ext. 1174.

Visit our website at www.cmhc.ca