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Société **Alzheimer** Society
NIAGARA REGION

'Home-Sense' for Dementia

Helping You at *Home*

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A Resource Guide

ALZHEIMER SOCIETY NIAGARA
FOUNDATION

THERAPEUTIC
LIVING CENTRE

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For more information about ‘Home-Sense’ for Dementia or to order a copy* of this resource guide please contact the Alzheimer Society of Niagara Region at 905- 687-3914.

*A $15 fee to cover the cost of printing will apply.
This resource can also be downloaded from our website at no cost.

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‘Home-Sense’ for Dementia

Table of Contents

Introduction to ‘Home-Sense’ for Dementia 1
  What Makes an Environment Supportive? 2
  What ‘Home-Sense’ is about… 3
    How ‘Home-Sense’ is organized… 4
    Your Home and You 5
    Home-Sense: A Snapshot 6
    Home-Sense and You 7
Part One: Life at Home: Perspectives on Dementia 8
  About Dementia 10
    Common Questions 10
    Symptoms you May Experience with Dementia 11
    How Can I prevent Dementia or slow its progression down? 14
    If you have just been diagnosed with Dementia… 15
    WORDS OF WISDOM from others who know… 17
  Caring and Communication 18
    Dealing with Challenging Behaviours 20
    General Caregiving Strategies 21
    Living a Life with Meaning 23
  Dementia - Some Considerations 28
    Participating in future planning 28
    Decision Making and the ‘Noble Lie’ 28
    Consent, Capacity and Decision-making: The Basics 30
    Elder Abuse 32
Part Two: ‘Home-Sense’: A Guide to Home Adaptations 33
  ‘Home-Sense’ for You 34
    Simplifying and Task Analysis 35
    The use of CUES 36

Colour and Dementia 36
General Household Activities 41
Home Safety Checklist 41
Getting In and Out of the House 42
Moving Around the House 44
Using the Stairs 45
Keeping the House Clean and Doing the Laundry 47
Outdoor Maintenance 51
Daily Living Activities 53
Kitchen Safety 53
Eating and Maintaining a Healthy Weight 56
Choking 58
Weight Loss or Gain 59
Meal Preparation 60
Bathroom Safety 61
Using the Toilet and Incontinence 66
Grooming 67
Getting in and out of Bed and Restlessness 69
Dressing 70
Medication 71
General Community Activities 72
Community Safety Checklist 72
Grocery Shopping 73
Finances 75
Keeping Active and Involved 77
Concerned about Getting Lost? 79

Introduction to ‘Home-Sense’ for Dementia

> *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 72 year old man describing what it’s like to live with dementia
>
> **There are things YOU CAN DO to support *life after dementia***

Dementia affects a person’s thinking abilities (e.g. memory, problem solving and language abilities) making it difficult to do the things in life that are usually a part of everyday routine - things like managing finances, remembering people and events, making meals and getting around the community independently.

Dementia is <u>NOT</u> a normal part of aging and it can affect people younger than sixty-five. Sadly, it is becoming more common. About 500,000 Canadians have dementia, 180,000 live in Ontario. These numbers are expected to double by 2020 with one person diagnosed every minute according to a study commissioned by the Alzheimer Society of Canada called the “Rising Tide: The Impact of Dementia on Canadian Society” (2009).

We are all at risk of getting some form of dementia in our lifetime. Alzheimer’s disease is the most common type of dementia, but there are others such as vascular dementia, mixed dementia and frontal-temporal lobe dementia to name a few. Age, high cholesterol and high blood pressure, stroke and diabetes are just some of the risk factors.

There is not yet a cure for dementia, but there are things you can do to build your RESILIENCE

DEMENTIA WISDOM →

SUPPORTIVE home ENVIRONMENT
A HEALTHY LIFESTYLE
GREATER AWARENESS
EARLY DIAGNOSIS AND TREATMENT

What Makes an Environment Supportive?

To find out just what a supportive home environment looks like we asked people with dementia along with their care-partners what home meant to them. This is what they said…

'Home is Where the Heart is…'

- *It's life; if you don't have a home, then you don't have a life*
- *It's where you have people around that care for you*
- *To me, it's togetherness; it's so many things*
- *Where you're comfortable- where you feel safe*
- *Its where all your memories are*

' An environment can help or hasten a person's decline…'

A supportive home environment is more than just a house or physical space; it involves people, relationships, possessions and communities.

Supportive environments are the key to resiliency in that they:

Enable a healthy lifestyle

Maximize abilities and independence

Encourage involvement in life

Compensate for loss of abilities

Promote safety, security & belonging

What 'Home-Sense' is about…

'*Home-Sense'* is a term used to describe a number of strategies that you can use to create a supportive home environment that has a positive impact on your quality of life, in a physical, emotional, mental, and social sense. Home-Sense simply means making small changes or adaptations to keep **home feeling like home and your life your own- *in spite of* dementia.** It acknowledges that there are many losses associated with dementia but by adopting supportive strategies you will strengthen your resilience. These strategies are based on maintaining independence for as long as possible, enhancing safety, and encouraging ongoing involvement in life.

'Home-Sense' for dementia is intended to be a resource for people affected by dementia. This includes individuals diagnosed with dementia and those who care about them. We developed this resource together with a small group of people affected by dementia. We hope that it will help others to support *life after dementia.*

The tips and strategies offered in this booklet reflect the changing nature of dementia. They are not a 'blueprint' for home adaptation. Every experience is unique; what makes sense for one person may not work for another. We encourage you to seek additional support from your local Alzheimer Society and connect with others who have been or are going through a similar experience.

What Makes *'Home-Sense' for Dementia* Unique?

The development of this book has been a collaborative project. As such it reflects personal and professional knowledge and experiences. Stories or 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.

Note: The term 'caregiver' and care-partner are used interchangeably throughout this resource to reflect the fact that some people identify with one term or the other. The term 'dementia' is also used to represent all forms of dementia.

How ‘Home-Sense’ is organized…

‘Home-Sense’ for Dementia contains two parts:

Part One: Life at Home: Perspectives on Dementia gives general information about dementia, including an outline of its symptoms and common problems that impact everyday activities. People living with dementia and their caregivers share their thoughts, feelings and experiences about living and coping with dementia. Challenges are discussed as well strategies for promoting health and well-being.

Part Two: A Guide to Home Adaptations provides ‘Home-Sense’ Strategies - practical information about simple changes or adaptations that can be made around the home and community to better support a person with dementia. It is divided into three sections.

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

Each section is further divided into common problems that people with dementia and caregivers face. **Tips or strategies** to help manage these problems are listed.

Your Home and You

More than likely, your home means more to you than just a physical space; it is a place where you feel comfortable- a place where you belong. And the many possessions in your home reveal something about you, your life and your history. Some say that dementia is like experiencing a theft to your home where those possessions are stolen one by one over time. On the outside everything may appear normal, at first, but on the inside something is different. Things may be turned upside down or seem unfamiliar; items might be missing, unrecognizable or are in the wrong place.

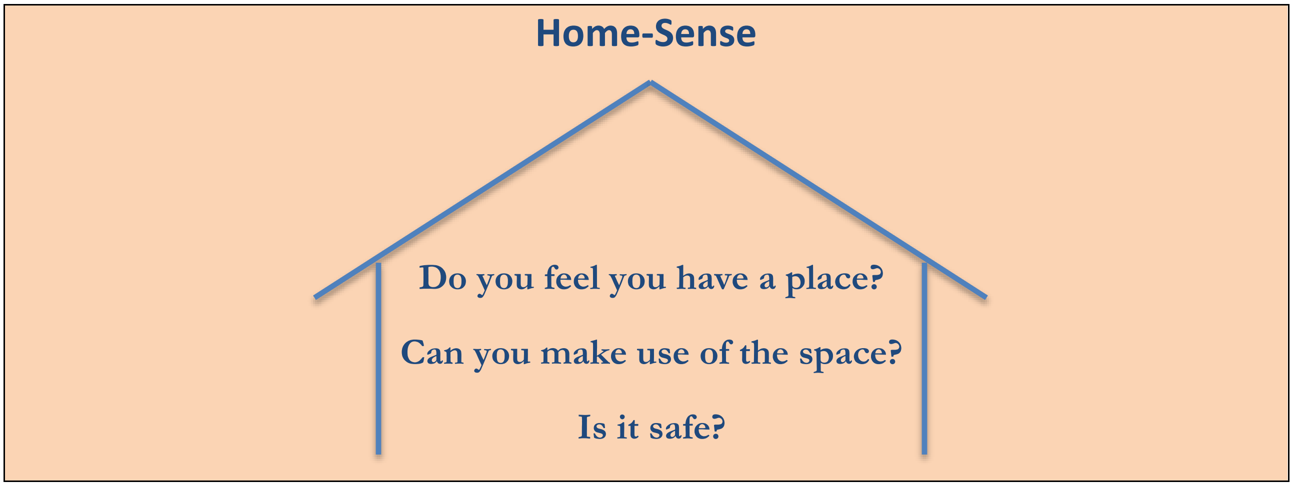
People with dementia and those who care about them have said that dementia intrudes upon their lives, robbing them of freedoms they once enjoyed and threatening feelings of stability and security. They are left with the tremendous challenge of adapting to ongoing change and loss – all the while trying to maintain some sense of order and sense of normalcy in life. Dementia is a difficult journey that no one can really understand unless they are going through it, but there is hope and there are supports to draw upon for help.

'Home-Sense' for dementia is a strategy for support along this journey. It involves making small changes to your home and the way in which you do things. It is about simplifying your home environment so you as a person with dementia or a care-partner can continue to engage in valued roles and activities for as long as possible. Home-Sense is also about making things safer without taking away a person's right to express themselves and exercise some degree of choice or control in their life. The main idea behind Home-Sense is **ADAPTATION**. As a person loses their abilities the environment around them flexes or adapts (changes itself) to accommodate the loss. This supports a person's continued involvement with people, activities, and tasks in whatever way they still can.

> ***It is not the strongest of the species that survives, nor the most intelligent. It is the one that is the most adaptable to change.***
>
> ~Charles Darwin

Home-Sense: A Snapshot

‘Home-Sense’ involves looking at the environment in a physical sense, a social sense, and a mental and emotional sense in terms of how it impacts upon a person’s quality of life. Three simple questions guide ‘Home-Sense’ and should be asked from the perspective of each person living in the home with special attention given to the experience of the person with dementia.



Do you feel you have a *place*?

Feeling that you have a place implies that you feel comfortable and ‘at home’ in your environment. It means you can express yourself and feel acknowledged or valued. It also means that your personal space and possessions are respected.

Can you make use of the space?

Making use of space is about being able to do what you need to do or want to do in any one area of the home or more broadly, the community. It implies that you can exercise some choice in your activities and have the support needed to accomplish things. ‘Making use of space’ enables involvement in everyday life and the continuation of valued roles and lifestyles. For people with dementia this often means that the environment, including people in it, adapt by making up for any loss of abilities and supporting independence as much as possible.

Is it safe?

The question to ask about safety is not only about whether a person with dementia is protected from harm but whether the environment supports their independence and continued involvement in life? Are they able to take reasonable risks that are consistent with their lifestyle and habits? Or, does the environment protect them to the extent that they are cut- off from the world around them, including activities they once enjoyed? **Asking these questions helps to identify barriers in the home that impact quality of life. From there supports can be put in place.** **Tools** for adapting the home are discussed in **Part Two: A Guide to Home Adaptation** followed by practical examples of adaptations.

Home-Sense and You

What 'Home-Sense' looks like for you may be different from another person depending upon your situation and the types of difficulties that you may be experiencing. This may include self-care activities such as bathing or meal preparation, leisure activities including hobbies and socializing, or work related activities such as managing finances and home maintenance. Home-Sense involves looking at your home environment to determine how it helps or hinders your activities and involvement in life and then finding ways to adapt it. Adapting the environment or the activity keeps the focus on remaining abilities.

Some things to consider…

Look at your home as a whole and then consider each room or area. *Can a person move from room to room with ease? Can they find things they need? What is the atmosphere of the room like? How does it make a person feel? Does the layout of the room and furniture make sense for the types of activities that typically take place in it? Are there private places?* Asking these types of questions gives clues to how the physical environment can be can changed to support a person's activities and enhance safety.

Perhaps the furniture could be re-arranged to create more space and prevent falls. Maybe the colour of the walls could be changed to make a room more calming. Perhaps assistive devices could be used like grab bars or raised toilet seats to help in the bathroom. Or maybe visual cues (e.g. labels, lists, pictures…) could be used as reminders or to give direction. These are just some of the examples of simple ways to adapt the home.

Is it costly?

The cost of 'Home-Sense' depends upon what types of changes or adaptations you need to make. Most changes are simple adaptations that do not involve costly home renovations. Often it involves reorganizing and "de-cluttering" the house, general *safety proofing* and learning to simplify daily activities. Adaptive aids or assistive devices 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 canes, walkers, toilet raises, grab bars and bath seats. Aids and assistive devices can be purchased from your local pharmacy or equipment vendor at reasonable costs or may be purchased second-hand through a local equipment re-processing agency. The cost of some items (e.g. walkers, wheelchairs) is partially funded by the government's 'Assistive Devices Program' (ADP) following an assessment by an occupational therapist or physiotherapist. Check with your local Community Care Access Centre (CCAC) for more information.

Part One

Life at Home: Perspectives on Dementia

Naturally, as a person ages, physical changes can make it increasingly difficult to move around the house and manage activities without some assistance. 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.

People with dementia do not only experience the physical changes associated with aging but also faces changes in cognitive (thinking) abilities that impacts on their ability to do those everyday things they have spent a lifetime doing, including socializing. Changes in the brain make the world around them increasingly difficult to understand. Familiar things and people become foreign. A person experiencing these difficulties may withdraw or retreat from the world, neglect themselves, or fail to notice problems within or around them.

Perspectives on 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." "It's 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 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." "It's 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 people affected by dementia are aware that something may be wrong well before they are given a diagnosis. Sometimes they question their observations or feelings and wonder if they are 'going crazy.' Often problems with memory are wrongly considered to be a normal part of aging. This period of questioning can be a very stressful and confusing time for everyone involved. It may be helpful to know something about dementia to better understand what is happening and how to give or get support.

What is Dementia?

Think of dementia as an end point along a continuum of memory loss and changes in other cognitive abilities (e.g. attention, problem-solving, judgment). At the one end there are some small changes in thinking ability associated with 'normal aging.' In the middle, there is mild cognitive impairment- a term used to describe when memory loss is noticeable but does not affect a person's ability to function (their independence) or relate to people around them in any significant way. At the other end there is dementia. Dementia is marked by a change in a person's ability to function, take care of themselves and manage the relationships around them. There are many forms of dementia including Alzheimer's disease, vascular dementia, Frontotemporal dementia, Dementia with Lewy Bodies, Parkinson's disease dementia, or dementia of a mixed type, to name a few. Alzheimer's disease is the most common form of 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 and relationships.

How do I Know if someone has Dementia?

If you are concerned that you or someone you know may have dementia it is best to consult with your family doctor as soon as possible.

There are some warning signs associated with dementia:

- 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 judgment and abstract thinking
- poor initiative

Symptoms you May Experience with Dementia

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.

Symptoms you May Experience with Dementia (cont.) …

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.

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."

Symptoms you May Experience with Dementia (cont.) …

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.

What Can I Do to Help Myself?

If you or someone you care about 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 early 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 Can I prevent Dementia or slow its progression down?

The Alzheimer Society of Canada outlines the importance of 'Healthier Living' in slowing the progression of dementia, improving quality of life and coping capacity.

Aspects of Healthier Living:

Make Healthy Food Choices

- Eat a wide variety of foods including fruits, vegetables and whole grains
- Limit salt, alcohol and caffeine
- Drink plenty of water
- Avoid smoking

Be active- Keep your brain active

- Make physical activity part of your everyday routine
- Keep up hobbies
- Play games (word puzzles, jigsaws, memory games)
- Try something new

Stay connected

- Find opportunities to interact with people and stay engaged

Take Charge of your health

- See your doctor regularly
- Get enough sleep - sleep affects memory, mood and function

If you have just been diagnosed with Dementia…

First Steps to Take

You have been told by your doctor or specialist that you have dementia. What can you do to understand and cope with the diagnosis?

Learn About Dementia

- Learn as much as you can about dementia. You can speak to your doctor. Speak with a counsellor at the Alzheimer Society nearest you. They will meet with you or talk with you on the telephone. Ask questions and discuss your thoughts, feelings and concerns with the counsellor.
- Look at the Alzheimer Society of Canada website (www.alzheimer.ca). There is a section specifically for persons living with dementia.

Meet with Your Doctor

- Discuss a plan with your doctor. Look at medication options. Consider having a friend or family member attend each doctor's appointment with you to help remember details of the visit and to offer support and assistance.
- Consider writing down your questions for the doctor on a notepad ahead of time

Stay Active

- Stay physically, mentally and socially active. This includes healthy living, hobbies, social outings, activities you enjoy

Talk to Others

- Each person reacts differently to the idea of sharing a diagnosis of dementia. You may or may not feel comfortable sharing this information with others
- Consider telling the people closest to you that you are living with dementia. Share as much information as you are comfortable with. Let people know what is important to you and what you need, and how they can help.

Plan for the Future

- Make plans for the future. Review your finances, set up Powers of Attorney
- Consider registering for the Safely Home Program

Seek Support

- You may experience a variety of emotions during this time
- Seek support of family, friends, faith leaders and your local Alzheimer Society
- Join a support group or coffee club or discussion group for persons with early stage dementia

Stay Positive

- Stay positive! Focus on what you CAN do. Focus on what makes you feel good, what brings joy, meaning and fulfillment into your life. Stay positive! Focus on what you CAN do. Focus

How long can I Live at Home with dementia?

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 your ability to care for yourself and maintain your 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 you to live at home.

" People do not exist by memory alone.

People have feelings, imaginations, desires, drives,

Will and moral being…"

~ Cohen and Eisdorfer, 1986

Sources: Shared Experiences: Suggestions for those with Alzheimer's Disease. Alzheimer Society of Canada made possible through an education grant from: Pfizer, Manulife Financial, Novartis, Janssen-Ortho Inc.

WORDS OF WISDOM from others who know…

If you have Dementia:

- you aren't crazy; you have a medical condition
- it's not you, it is dementia
- realize that you are not alone 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.
- 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
- you may feel lost; you may even get lost
- give yourself time to get familiar with things
- 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;
- if you can't do what you want; do what you can
- if it doesn't work, try a different approach
- 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:

- 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, its 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, and 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

We talked to a group of people in the early stages of dementia and their care partners about their thoughts and experiences on what it is like living with dementia, including giving and receiving care. This is what we found out:

In the beginning, people with dementia are often aware of their changing abilities and struggle to accept the reality of these changes and the impact it has on their lives and independence. They expressed how they felt more and more dependent and were sensitive to the demands being placed on people close to them, often a spouse or adult child. Although they feel it, they 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?"* Feelings of gratitude may also alternate with feelings of frustration and even resentment for needing help or being offered assistance.

> "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. And you know it gets me, but I've got to learn to accept it."

Caregivers expressed how they are continuously shifting and adapting to the changes around them, often uncertain how and when to give help. There can be a tension between them and the person they care about - a sort of 'pushing and pulling', resisting or accepting help; holding on or letting go. As one gentleman with dementia said:

> "She's in the same seat 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…."

The Paradox of Dementia[1]

Dementia doesn't just change abilities; it changes roles and it changes relationships. Both people with dementia and caregivers expressed how it is incredibly hard to face change and uncertainty. Both were concerned about what would happen when the person with dementia lost any awareness or insight into the changes. This is the paradox of dementia…

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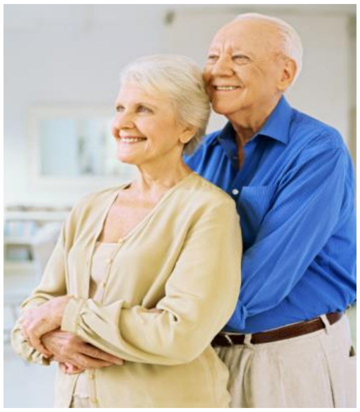
[1] Dempsey, M. (1998). Latent Grief: The unique and hidden grief of carers of loved ones with dementia.American Journal of Alzheimer's Disease

As the disease progresses and the person with dementia loses insight into the effects of their illness, the caregiver continues to experience the consequences of dementia and endures loss on multiple levels. These losses include the loss of a 'parent' or 'sibling' or 'partner.' It's also the loss of hopes, dreams and expectations. Ultimately it is the loss of their (the caregiver's) own sense of self or personal identity as the day-to-day demands of caregiving can consume their lives. In essence, the caregiver acts as a *lifeline* for the person with dementia.

> "I think it's harder for my wife and my children. I don't want to be a burden. It's not just about changing roles, its dragging her down…I want to let go when I'm dragging her down."

Caregiving



Watching, worrying, anticipating, intervening interpreting, empathizing, remembering - these are just some of the things described by caregivers as they tried to maintain their family member'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.

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."

'Remember Me'

It's important to remember that even though a person with dementia will lose thinking abilities and their perception of time and space may change - they will ***STILL feel*** and live in a world where relationships, objects and situations matter. People living with dementia continue to have the same basic needs that all people have—the same needs they had before dementia. This includes needs such as love, nourishment, security, belonging and personal identity.

It is also important that both caregivers and people diagnosed with dementia access information on dementia and become familiar with supports within their communities such as respite, homecare, support groups and counselling. These are all things that help to build networks of support and strengthen resilience.

Dealing with Challenging Behaviours

Trying to meet a person's needs is a fundamental part of the role of a caregiver. But it can be incredibly hard to do so when someone is exhibiting challenging behaviours such as restlessness, agitation, shadowing or inappropriateness. This is often the most stressful aspect of caregiving and can contribute to burn-out and compromise a caregiver's health. These difficult behaviours reflect the changes that dementia is causing to the person's brain. Although it is not possible to avoid them all together, it is possible to manage them through effective communication, medication and a supportive environment.

Here are some general communication strategies, easily remembered as "The R's," that were developed by the Canadian Association of Occupational Therapists in partnership with the Alzheimer Society of Canada.

'The R's of Response'

- **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)**

Other Tips for Communication

- 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
- 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

General Caregiving 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

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

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.

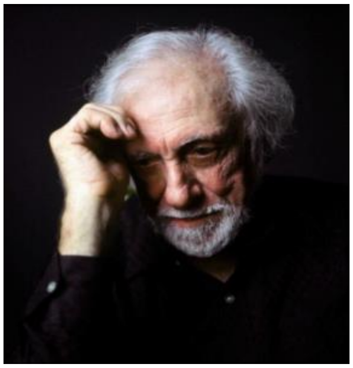
Agitation and Aggression

- 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

Living a Life with Meaning

Just because a person has dementia does not mean that all meaning is lost from life. In fact it's important to look for ways to keep a sense of purpose and meaning in life. Meaningful activities promote health and quality of life.

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 a 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 for Meaning

Creating opportunities for meaningful activity requires a caregiver to consider the relationship between the **person**, his **environment**, the **activity** and the **approach**. All of these things are factors that influence a person's capacity to participate in meaningful activities 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 the 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 the day. What activities did the person with dementia 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 Activities

- 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 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 the person 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 her 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 she 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 the person you are caring for. It gives you a break or time to get some things done independently and it offers opportunity for him 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.

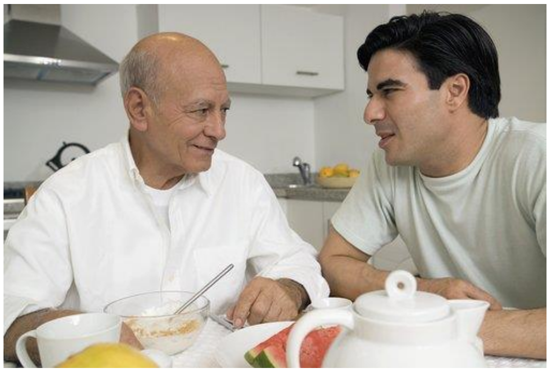
Your Approach

Your approach can have a significant influence on how a person responds to you, a particular task or request. 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 internal and external factors such as how they are feeling or what events preceded your approach, and for people in the later stages of dementia, where their mind is occupied, such as a particular time or event in the past. The ability to adapt your approach (body language, tone of voice) to suit the present circumstances is key to encouraging a person's engagement. Sometimes, however, adapting your approach means recognizing the person's present limits and trying again later or momentarily playing the role he believes you are a part of.

What's in an Encouraging Approach?

Add Structure to the Day

- 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.

Example of Routine

Morning Activities	**Afternoon Activities**	**Evening Activities**
• wash, brush teeth, get dressed • prepare and eat breakfast • coffee and conversation • discuss newspaper, reminisce • make something • take a break/quiet time • do chores together	• 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 neighbours or family • take a break or a nap	• 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

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 important to you
- wishes and expectations for care

Dementia - Some Considerations

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. If you have not already done so it is important to establish a continuing power of attorney (POA) for finances and personal care. "A continuing power of attorney is a legal document in which a person gives someone else the authority to make decisions about their property if they become unable to make those decisions themselves." [2] Your POA is not necessarily a lawyer but someone who you trust to act on your behalf with your best interests in mind if and when you are no longer capable of making decisions for yourself. This is an important topic that goes beyond the scope of this resource. Further information and support is available from your local Alzheimer society and it is recommended that you consult with a lawyer to discuss and set up your POA.

Decision Making and the 'Noble Lie'

Truth telling is a major ethical issue in dementia care. Clearly it is important to respect an individual's legal 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. Capacity, however, is the critical issue. There does come a time when individuals with dementia may become mentally incapable (of making decisions) if they lose their capacity to understand and, more importantly, appreciate their own circumstances. It is at such times that a substitute decision maker such as a POA has an important role to play. Most often substitute decision makers are family members. Making decisions for a person with dementia, while including them in the process, can be a difficult responsibility. Due to the damage to their brain, people with dementia typically lose the ability to recognize that there is anything wrong with them and as a consequence they can

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[2] A guide to the substitute decisions act. Publications Ontario 880 Bay Street, Toronto, Ontario: Available online: www.gov.on.ca

no longer make good decisions for themselves. They lack insight into the impact of their behaviour not only on others but also on themselves and may not see that they need help to make decisions. 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" (telling an untruth for the greater good), has relevance. The "Noble lie" represents a strategy for overcoming a person's resistance to support and intervention when that person requires that assistance and is mentally incapable of deciding whether or not to have it. **It is important to note, however, that a diagnosis of dementia does NOT make a person mentally incapable** and that the "Noble lie" is otherwise inappropriate.

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 were 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 put themselves 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.

Consent, Capacity and Decision-making: The Basics [3] [4]

A person with dementia has the right to make decisions for themselves about their personal care (e.g. treatment, admission to LTC, shelter, hygiene, nutrition, safety etc.) and property/finances (e.g. making a will, managing money, investing, etc.) as long as they are mentally capable of making decisions.

Mental capacity refers to the ability make decisions and to **"understand" and "appreciate."** For example, a person would be incapable of managing property if he or she is not able to understand information that is relevant to making a decision in the management of his or her property, or is not able to appreciate the reasonably foreseeable consequences of a decision or lack of decision.

Dementia and Capacity

Just because someone has been diagnosed with dementia does NOT mean they are mentally incapable. Mental Capacity is a legal construct, not a clinical one; it is not a clinical diagnosis or condition. Because it is a legal construct a clinical assessment involving particular tests, for example, the Mini Mental State exam, does not determine a person's capacity to make decisions. It is important to know that even if a person does not have full cognitive ability that person can still have the capacity to make important decisions.

A person with dementia is presumed capable unless there are reasonable grounds to believe the contrary based on evidence garnered through observation and questioning.

Who Assesses Capacity?

Capacity assessments are carried out by different types of people depending on the circumstances. It is a common misconception that capacity assessment must be done by a physician or a "capacity assessor". In some circumstances, there is no need for any type of formal capacity assessment by a professional before determining that a person is not mentally capable. Sometimes a statute specifies who must determine capacity. Sometimes a document such as a power of attorney specifies who must determine capacity. The Advocacy Centre for the Elderly (ACE) in Toronto, Ontario is an excellent resource for more information on human rights and issues like capacity.

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[3] Judith Wahl. B.A. LL.B Consent, capacity and substitute decision-making: The Basics. Advocacy Centre for the Elderly (ACE). Toronto, Ontario. Available online: http://www.acelaw.ca

[4] There are three Ontario statutes that are relevant to a discussion of these issues: the *Substitute Decisions Act*, the *Health Care Consent Act* and the *Mental Health Act*. If you have access to the internet, copies of all three acts may be found on the Government of Ontario's e-laws website at www.e-laws.gov.on.ca.

What happens when a person is mentally incapable?[5]

If a determination is made that a person with dementia is not mentally capable of making a particular decision, then someone else, a person known as their **substitute decision-maker (SDM),** would be entitled to make these decisions for them. A person can be incapable for making decisions within one area (e.g. decisions related to finances) but still be capable for making decisions in another area (e.g. health care decisions). Under the substitute decision makers act:

Personal Care Decisions

If a person with dementia becomes mentally incapable for **personal care decisions** their SDM is:

a) A Guardian appointed by the Superior Court of Ontario
b) A **Power of Attorney for Personal Care.**
c) The **highest-ranking person in their** life on the list of SDMs set out in the *Health Care Consent Act. (*a spouse or partner; a parent or child, a brother or sister, any other relative of the incapable person, or the Public Guardian and Trustee (if none of the above meet the qualifications, or in the event two or more equally ranked substitutes cannot agree)

Property/Financial Decisions

If a person becomes mentally incapable for **property/financial decisions** their SDM is:

a) Someone appointed by the Superior Court of Ontario. That person would be called their **Guardian of Property.**
b) **Continuing Power of Attorney for Property** (chosen by them)
c) **A Statutory Guardian** of Property. This would happen if the person had not prepared a Continuing Power of Attorney and they were assessed by a **Capacity Assessor** and found incapable of managing property. The Office of the Public Guardian and Trustee of Ontario (PGT) would then become the Statutory Guardian. Family members can then apply to be the Statutory through the PGT.
d) A **Trustee**. If their only income and assets are from government pensions (Old Age Security or the Canada Pension Plan) or social assistance (Ontario Works or Ontario Disability Support Program), another person can apply to the appropriate authority (either Human Resources and Skills Development Canada or the social assistance office) to be appointed as their Trustee to manage these benefits. The process to apply is set out in the applicable legislation (*Old Age Security Act, Canada Pension Plan Act*, *Ontario Works Act* or *Ontario Disability Support Program Act*).

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[5] Judith Wahl. B.A. LL.B Consent, capacity and substitute decision-making: The Basics. Advocacy Centre for the Elderly (ACE). Toronto, Ontario. Available online: http://www.acelaw/ca

Elder Abuse

Elder abuse is harm done to an older person by someone in a special relationship to the older person. Abuse can take many forms including physical, financial, sexual, emotional, and neglect. Failure to provide the necessities of life to older adults is a crime. Necessaries of life refer to those things necessary to preserve life, such as food, shelter, medical attention and protection from harm.

Forms of Abuse:

- **Physical abuse:** slapping, pushing, beating or forced confinement
- **Financial abuse:** stealing, fraud, extortion or misusing a power of attorney
- **Sexual abuse:** sexual assault or any unwanted form of sexual activity
- **Neglect** as failing to give an older person in your care food, medical attention, or other necessary care or abandoning an older person in your care
- **Emotional abuse:** humiliating, insulting, frightening, threatening or ignoring an older person.

If you are an older person who is being abused tell at least one person you trust such as your doctor, a friend, or a family member. If you see an older adult being abused report the situation. Too many people assume that someone else will take care of it or that the person being abused is capable of getting help if he or she really needs it. This may not be the case.

Part Two: 'Home-Sense'

A Guide to Home Adaptations[6]

This section outlines 'Home-Sense' strategies. It gives practical examples of simple changes or adaptations that can be made around the home and community to better support a person with dementia. It is divided into three sections.

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

Common difficulties with dementia are highlighted and correspond with a variety of strategies including making adaptations to the home itself or the way everyday activities are performed.

The guide is designed to enable you to easily identify tips and strategies for dealing with problem(s) you may be experiencing on any given day.

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[6] The guide to home adaptations is based on the ideas of the participants in the study, staff at the Alzheimer society in Niagara, 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.

‘Home-Sense’ for You

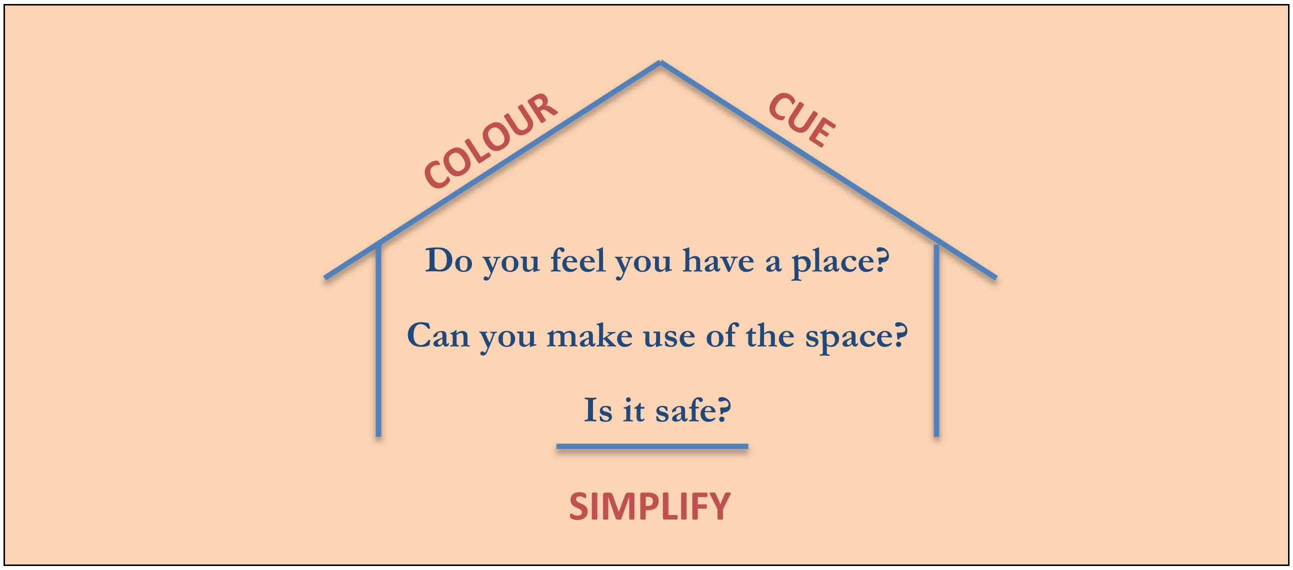
The home adaptations you choose will depend upon what makes sense for you- including your home and your daily routine as well as your individual needs or priorities. There are many possible adaptations identified in this guide. Remember the three key ‘Home-Sense’ questions:

1. **Do you have a place?**
2. **Can you make use of the space?**
3. **Is it safe?**

Consider these questions from the perspective of the person with dementia. Asking yourself these questions will help you to notice barriers within the home environment and the determine strategies and adaptations that may work best for you. Once you have identified some barriers, there are three basic **‘Home Sense’ tools** that will help to address them. They are:

- **SIMPLIFY**
- **CUE**
- **COLOUR**

These tools are a part of most simple home adaptations. Simplifying the environment often involves cueing and the use of colour. These tools will help to maximizes independence and enhance a person’s safety.



Simplifying and Task Analysis

Much of 'Home-Sense' involves simplifying the environment so that it 'makes sense' to a person with cognitive (thinking), sensory or physical limitations. Part of simplifying an environment is looking at tasks or activities themselves and asking **"how could this be made easier?"** If a person cannot manage to do all of an activity that they once did, such as cooking, can they do part of the activity? Would it help to place items out first in a particular order or list the components of the activity? Or perhaps simplifying means eating pre-made meals that only require heating in a microwave. It could also mean increasing the 'hands-on' support so that a person can continue to cook with help. Simplifying is about looking for different ways of doing something to make it easier and building support into the activity. It enables a person to keep active and use their remaining abilities. Remember the saying…

"If you don't use it, you lose it."

Many of the day-to-day activities we perform we do so without thinking, for example, brushing our teeth, getting our breakfast, or opening the front door. But a closer look at these activities reveals that they are actually quite complex and comprise of several singular specific sub-actions or behaviours that we perform in a certain order.

One of the symptoms of dementia is that a person may lose their knowledge of how to do familiar activities, for example, forgetting how to use your keys in a door, or open a window. One day a person with dementia may perform the activity just fine, but the next forget how. Instead of eliminating the activity from the person's life because it presents a challenge, **TASK ANALYSIS** offers an opportunity to look at how the activity is performed, what issues are getting in the way of performing it, and where supports can be added to help.

TASK ANALYSIS is basically a set of instructions about how to get from point A to point B - for example, how you get from the keys in hand to the opened door. The type of support needed depends on what is contributing to the person's difficulty performing the steps of a task. It could be a physical problem, a memory problem or maybe a sensory problem to do with low vision. Part of analyzing the task is trying to determine just where the problem lies and then trying out different adaptations to see what helps. Adaptations are a form of support. In the example of opening the front door, adaptations could involve posting the steps as reminders with pictures to give cues about what to do next. Or perhaps assistance may be required with a component of the task, such as identifying the right key to open the door. A colour- coded key chain may be another simple adaptation that helps a person to identify the correct key.

The use of CUES

A cue is defined as 'a stimulus that provides information about what to do.' There are different types of cues that can be used based on a person's senses to stimulate a given response, for example the smell of baked cookies could stimulate eating, or the sight of the toilet from a person's bed could cue that person to use the bathroom.

Some examples of cues:

Visual: body language (gesture, eye gaze, facial expression), signs, clocks, calendars and lights, or diagrams and representations of process.

Auditory: Tone of voice, verbal expressions, alarms or warnings, audio-recorded instructions

Colour and Dementia[7]

Colour plays an important part in our lives. Without colour not only would everything seem appear drab but would we would have difficulty distinguishing one thing from another. **Colour can be used as a tool to simplify environments and to cue a person to the appropriate action or direction.** Colour is a key aspect of 'Home-Sense.' What follows is some basic information about colour that can help in supporting a person with dementia.

FACT

As people age they require 3x the amount of light to see as well as younger people and they are more sensitive to glare

There are three primary colours**: red, blue** and **yellow,** and three secondary colours: **green, orange** and **violet.**

Primary Colours	Secondary Colours
RED	**GREEN**
BLUE	**ORANGE**
YELLOW	**VIOLET**

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[7] Calkins, M. Using colour as a therapeutic tool. Innovative Designs in environments for an aging society. IDEAS consulting Inc. http://www.ideasconsultinginc.com/pages/ColourTool.asp

Colour and Dementia (cont)…

The way we perceive colour is actually a combination of the pigment colour in the objects, and the colours in the light that reflect off the objects in our environment. What the eye actually perceives are the light waves that bounce off objects, and the colour we perceive is the colour of light that is not absorbed by objects, but reflected off of them.

Colours vary along three dimensions: **HUE, VALUE**, and **CHROMA.** HUE is what is typically referred to as colour, and is made up of one or more of the primary and secondary colours. VALUE is the lightness or darkness of the colour. And CHROMA is the brilliance of the colour. By varying colours along these three dimensions, we create what is called CONTRASTS

Contrast: Golden Rules

Black on White
Light Green on Dark Red
Light yellow on Dark Blue

Signage:
60 pt. Font
Times New Roman
Upper and Lower Case

Research[8] is beginning to show that not only is colour contrast important for people with dementia but so is the value of colours (lightness and darkness of a colour).

People with dementia have difficuty interpreting the world around them. Low light, 'loud' or complex patterns and lack of contrast (e.g. walls that blend in with floor or furniture) can make it unnecessarily difficult and impact on a person's ability to function. Colour contrasts can be used to emphasize important features in a room to enhance safety (e.g. contrast at the edge of stairs or level changes so they are easy to distinguish and minimize falls). Contrasts can also be used to focus on important doors or to camouflage or make doors 'disappear.'

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[8] Verity, J. Colour your world and theirs. Spark of life. Dementia Care Australia. http://www.dementiacareaustralia.com

Colour and Dementia (cont)…

Research suggests that colours themselves can also have an impact upon a person's emotions, however evidence is limited. Here are some commonalities about colour based on the available literature[9]

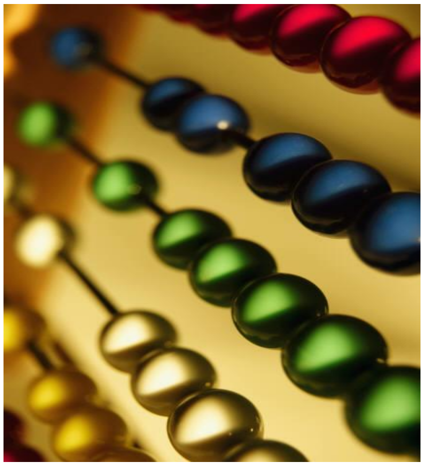
Blue: A restful colour with a calming effect. Research suggests that painting a room in shades of blue can lower blood pressure. Blue makes a room appear larger

Red: A stimulating colour that increases brain wave activity and the production of adrenalin in the blood

Green: A colour associated life and growth. It is also a restful colour and research suggests it decreases central nervous system activity. Green makes a room appear larger.

Orange: A stimulating colour that denotes energy, warmth and sun. It has been associated with appetite.

Yellow: A highly visible colour that is often used to carry important messages. Research also suggests that it is helpful for people suffering from mental lethargy.



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[9] Calkins, M. Using colour as a therapeutic tool. Innovative Designs in environments for an aging society. IDEAS consulting Inc. http://www.ideasconsultinginc.com/pages/ColourTool.asp

Take a Colour-Walk[10]

Try the following exercise to see whether there is effective colour contrast in your home. Alternatively, take photographs of different areas and print them in black and white. Using a piece of yellow cellophane walk around your home from room to room and answer the following questions:

- How well can I distinguish the floor from the walls?
- Do I feel confident walking around at my normal speed?
- Can I see important objects like chairs, doors, door handles, television, table tops, toilet seats, dinner plates, cutlery, steps and grab rails?
- Do I know particular areas from the colours and patterns used, for instance dining room, lounge room, public toilet?
- Is the main entrance door invisible?
- Is it easy to find doors to outdoor spaces
- Are paths easy to see?
- Am I able to walk at my normal speed outdoors?
- Are there landmarks that help me walk about easily? Is colour a part of the landmark?
- Are there particular colours I can see better than others?
- Is glare a problem anywhere?

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[10] Dementia-friendly environments. A guide for residential care. Victorian government health information. Victoria Australia. http://www.health.vic.gov.au/dementia/strategies/index.htm

Be Realistic

Changes can be difficult and it's important to be realistic. Even small changes made to an environment can be a big deal and a source of stress if they are made without sensitivity to the perspectives and experiences of all people involved, including the person living with dementia but also caregivers and families. When simplifying involves increasing the support to help a person do an activity, more demand is often placed on the caregiver. It takes time and energy to provide hands on support or to prepare activities in advance. While it is important to simplify to support ongoing engagement in everyday activities, it is equally important to do so in a manner that is not intrusive. People need to work with what they have got and use the resources available to them, including time and energy. As a caregiver you can only do so much, but some is better than none. It may mean that you pick and choose those activities that are most important or look for other people who can help (e.g. respite worker or friendly visitor).

You may find that you need to try a few adaptations before you notice improvement or give them time. 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 strategies may be the 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 this guide will relate to your particular circumstances and needs.

General Household Activities

Home Safety Checklist

- ✓ **Fire safety protocol** established (smoke alarms, water in ashtrays, fire extinguisher, and automatic shut off features on appliances)
- ✓ **Emergency numbers displayed** clearly near the telephone with step-by-step instructions: 'In case of an emergency call…'
- ✓ The person with dementia is registered with **MedicAlert® Safely Home®** 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)
- ✓ **Clutter-free home**
- ✓ **Home adaptations for cognitive & physical** problems
- ✓ **Colour contrast** used to identify obstacles/define edges and depth
- ✓ **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 professional

Getting In and Out of the House

Helpful Strategies

Tips for person with dementia

If you get disoriented and have trouble finding your way in/out of your home:

- 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

If you have difficulty climbing the stairs:

- 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

If you often misplace your keys:

- 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

If you have trouble seeing or grasping door handles/unlocking doors:

- colour contrast handle to distinguish it from door
- use lever style door handle for easy grasp
- use adaptive aids (for example, handle grip)

Tips for caregivers

Getting lost/disoriented:

- 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 colour 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 at all times
- register for and wear a MedicAlert® 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

Trips/ loss of balance:

- 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 if required to prevent falls
- have an occupational therapist assess your entranceway for safety and modifications (for example, ramp, handrails)

Using the elevator:

- put instructions inside the elevator or always accompany the person
- get to know neighbours
- use the elevator consistently to help maintain the skill

Carrying items into the home:

- 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

If you get confused and have trouble finding your way around the home:

- 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

If you get anxious or restless and feel you cannot stop moving:

- 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

Tips for caregivers

Trouble finding way around the home:

- 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

Pacing and Restlessness:

- 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 it

Using the Stairs

Helpful Strategies

Tips for person with dementia

If you feel insecure using the stairs:

- 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

Tips for caregivers

Risk of falling down stairs:

- 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

Preventing stair use/access:

- minimize need for stair use; for example, relocate bedroom to main level of home if possible
- attract activity on main level to 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; avoid soft treads
- keep tread coverings thin and tightly fixed to maximize usable tread size
- improve lighting on steps & stairs; stairs should have equal lighting to 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
- 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 on 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
- do not place any objects on the steps and make sure objects or landings do not distract or obstruct

Preventing Falls

- 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 helps someone with dementia see the change in height
- 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

If you are having difficulty organizing, performing and/or completing cleaning tasks:

- 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)

If you are having trouble physically doing the task:

- 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 needed
- 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

Tips for caregivers

Difficulty organizing, performing and completing cleaning tasks:

- 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

Trouble recognizing cleaning items or using items appropriately:

- 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

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

Difficulty organizing, performing or completing outdoor tasks:

- 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: push or pull sacks rather than lift; use smaller bags; use garbage cans on wheels; use movable cart for moving bags

Trouble remembering how to use machinery (for example: snow blower, and lawn mower):

- avoid risking personal injury. Hire outside help or seek assistance from a friend, family, or superintendent

If you are having trouble physically doing the task:

- 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)

Tips for caregivers

Difficulty organizing, performing and completing cleaning tasks:

- 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

Trouble physically managing the task:

- have an occupational therapist observe him/her performing the task; he or she can make suggestions on how to make the task easier (example, energy conservation techniques, proper posture, adaptive aids, simple home modifications)

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 every day?
- 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 the person enjoys or was always part of her/his role. A professional can help you to adapt the kitchen and simplify activities to enhance safety. They 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 will 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
- 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

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

Eating and Maintaining a Healthy Weight

Helpful Strategies for Coping with Difficulty Eating

Tips for person with dementia

If you have trouble remembering to eat regularly:

- 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

If you experience difficulty when eating:

- 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)

Tips for caregivers

Getting him/her to eat:

- cook hot foods with aroma to stimulate appetite; cook favourite foods, particularly food enjoyed in the 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 the same time/place every day 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

Difficulty eating:

- 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

If you have problems swallowing your food or you choke when eating:

- 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)

Tips for caregivers

Problems swallowing/choking

- 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

Weight Loss or Gain

Helpful Strategies

Tips for person with dementia

If you have lost your appetite:

- 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

Tips for caregivers

Loss of appetite:

- 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

If he or she refuses to eat:

- 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

If he or she eats excessively or eats inappropriate items:

- 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

If you are concerned about safety in the kitchen (for example, leaving stove on):

- 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

Tips for caregivers

Kitchen safety:

- 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

Risks accident or injury:

- 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 one 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

Tips for persons with dementia and their caregivers

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)

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

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

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-slide 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 matt 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, and 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?

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)
- 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)
- 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)

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 water or being drawn down the drain
- 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!

Helpful Strategies

Tips for caregivers

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

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
- 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

If you have difficulty making it to the toilet on time:

- 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

If you have trouble getting on/off toilet:

- 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

Tips for caregivers

If he or she is incontinent:

- 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

Please 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 the person 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.

If he/she gets disoriented (for example, can't find way to bathroom or inappropriately uses bathroom):

- 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

If you are worried you might forget to groom yourself (for example, brush hair or teeth, shave, and dress appropriately) before leaving the house:

- 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

If you are concerned about oral hygiene, nail-care, hair-care or shaving:

- 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

Tips for caregivers

If you are concerned about oral hygiene:

- 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

If you are concerned about nail care:

- 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

If you are concerned about shaving:

- 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

If you are concerned about hair care:

- 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)

If you are concerned about hygiene/grooming in general:

- 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

Getting in and out of Bed and Restlessness

Helpful Strategies

Tips for person with dementia

If you have trouble sleeping at night and feel restless:

- 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

Tips for caregivers

Difficulty getting in/out of bed:

- install grab bars or vertical poles in convenient locations
- install a trapeze over the bed
- install a bed rail

Getting up frequently at night or experiences disorientation at night:

- 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

If you have trouble finding or selecting the right clothes for the day:

- 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

If you have difficulty putting clothes on:

- 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

Tips for caregivers

Problems dressing/dresses inappropriately:

- 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

Problems dressing/dresses inappropriately:

- 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

If he/she does not distinguish between clean and dirty clothes:

- 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 pajamas or 'night clothes' at night)
- give gentle reminders that it's time to change

Medication

Helpful Strategies

Tips for person with dementia and caregivers

- 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 container
- discard old or expired medication
- 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 or keep a copy of medications in a purse or wallet.

General Community Activities

Community Safety Checklist

- ✓ register with the MedicAlert® 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

If you become OVERWHELMED or DISORIENTED in the grocery store:

- 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

Tips for caregivers

Difficulty putting items away in the right place in the kitchen:

- 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

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

Difficulty identifying items to buy:

- re-organize your kitchen space
- 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

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

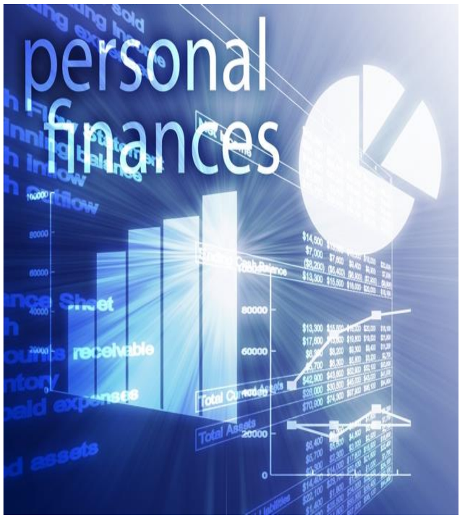
Getting confused when paying for items:

- 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 that 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

Finances

Helpful Strategies

Tips for caregivers



If you are worried about financial security and are concerned that you or the person you care about 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, veteran's 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 person 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

- 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

Tips for caregivers

- 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

On Staying Involved….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 disease 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

"John feels more comfortable with people who know his situation. That's why he likes coming to the REBEL group [support group through the Alzheimer Society of Niagara Region]. 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 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 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 license due to a medical condition such as dementia is a difficult reality facing many families. It is especially difficult when you have been driving for many years and rely on a car for transportation. While people with moderate to severe dementia should not drive, the fitness to drive of people with mild dementia should be tested on an individual basis.

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 are worried about your own driving or a family member's driving talk to your family doctor and ask about available supports offered in your area or contact your local Alzheimer Society.

Concerned about Getting Lost?

> "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*

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

Tips for person with dementia

- always carry personal identification with you
- carry the name and number of two emergency contacts with you
- register with MedicAlert® 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

Tips for caregivers

- 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 neighbors or Neighborhood Watch
- put identity cards and contact numbers in wallet or purse
- alert neighbors, 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
- 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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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 at 1-800-434-2268 ext. 232.

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

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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.

For more information about 'Home-Sense' for Dementia please contact the Alzheimer Society of Niagara Region

To order a copy of this resource for $15 call 905- 687-3914. This resource can also be downloaded from our website at no cost at www.alzheimerniagara.ca

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