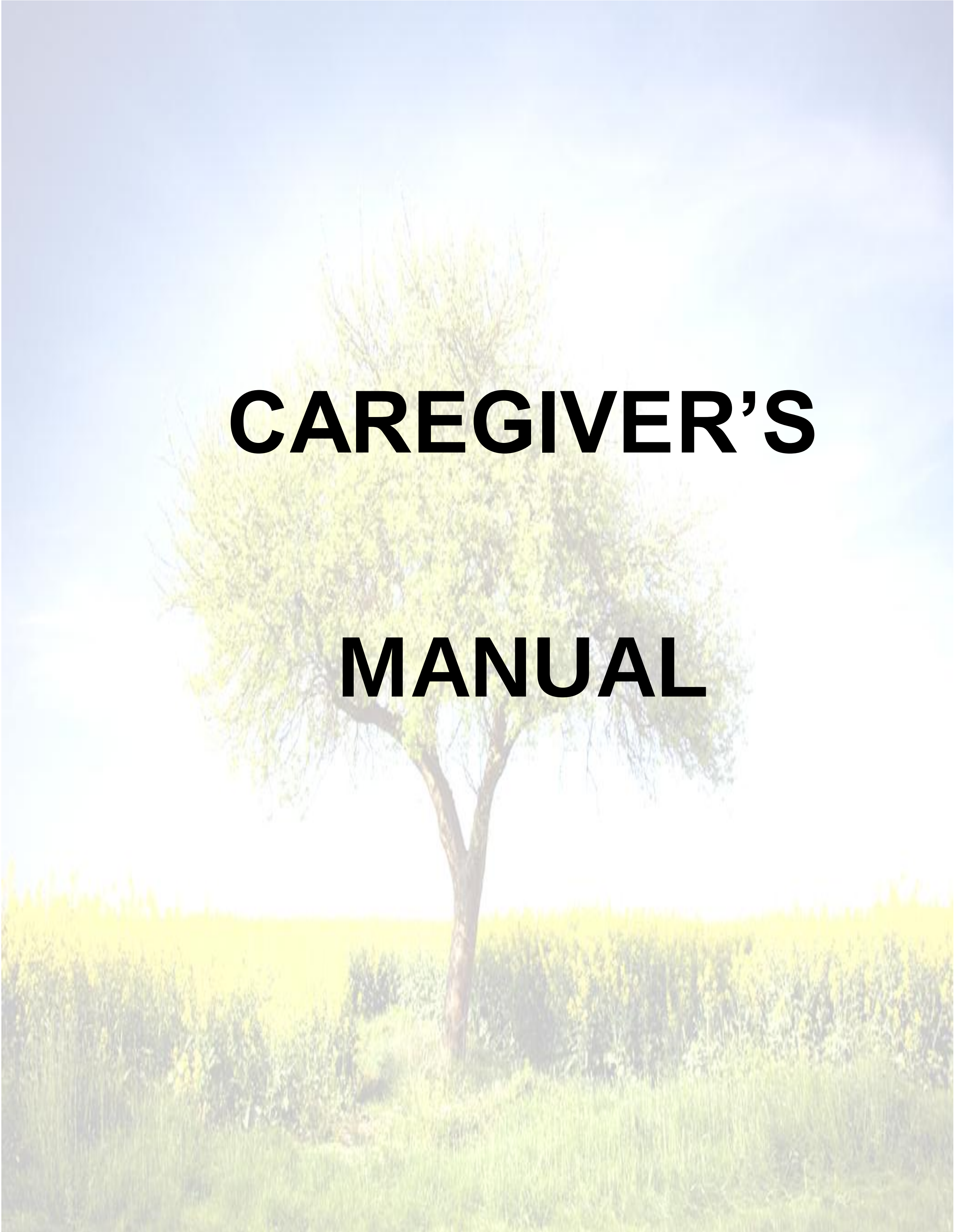

CAREGIVER’S

MANUAL

Produced by:

Sandra Somers CNS
Dementia, Seniors Mental Health, Education
Seniors and Spiritual Health
Island Health

Wendy Thompson, B.Sc. (Psych), B.Sc. O.T.

Edited by:
Alison Ritchie B.Sc. O.T. Laurel Steed B.Sc. O.T.
Seniors and Spiritual Health
Island Health

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INTRODUCTION: CARE FOR THE CAREGIVER

Caregivers often state the most important goal is to care for their loved one. However, sometimes they must be reminded to care for themselves, to remain physically and mentally able to care for others. Caregivers may experience feelings of frustration, discouragement and sadness. Sometimes a sense of being overburdened can create feelings of guilt or resentment. Fatigue is common and always a result of doing too much and not getting enough rest. Caregivers generally put aside their own need for rest, socializing and solitary moments.

Looking after someone with dementia is exhausting and you must take care of yourself by developing "survival strategies". The following are some suggestions:

➢ Don't keep the problem a secret. Tell those close to you so that you can share your feelings. Dementia is a distressing illness but not an uncommon one and people may understand and sympathize more than you expect.

➢ Consider joining a support group where you can meet other people who are in a similar situation; the support, education, and relaxation strategies offered can be helpful.

➢ When you feel things are getting on top of you **slow down**. Take a few deep breaths and tell yourself to let go of the tension. Concentrate only on today. Yesterday is over and what happens tomorrow will happen tomorrow.

➢ You are an individual with interests and needs of your own. Try to retain old acquaintances and hobbies and spend time doing activities you enjoy. This may mean taking time off from caring for your loved one. There are services available or respite care when you need time for yourself. Contact the Home and Community Care office to access services in your local community.

- ➢ Give yourself the occasional “gift”. A meal out, movie, indulge yourself with a new purchase: “**You** deserve it!”

- ➢ Protect yourself from situations you don’t think you can handle. Remember, it’s okay to say **“no”.**

- ➢ Recognize the warning signs of stress and “Burden”.

- Do you feel sad or depressed?
- Do you feel you are functioning in the way you think you should?
- Are you lying awake at nights worrying?
- Are you losing weight?
- Do you constantly feel overwhelmed?
- Do you feel isolated?
- Do you feel alone with the situation with no options or solutions?
- Are you treating your stress with alcohol use?
- Do you need pills such as tranquillizers or sleeping pills to get through the day or night?

- ❖ It is important to acknowledge these warning signs as they are an indication you are overburdened by your situation and need help to cope with your own needs as well as the needs of your loved one. Talk with your physician about services in the community that can assist you with these emotional responses.

- ❖ You are only human and can only do so much. There may come a time where you can no longer provide the amount of care your loved one requires. There are residences in your community with staff available who are specially trained to care for your loved one.

Tips to reduce caregiver stress:

- Learn about the disease
- Be realistic about the disease and your ability to cope
- Acknowledge and Accept your feelings
- Allow yourself time to grieve the many losses you and your loved one will experience through each transition of the dementia journey.
- Share your feelings and your situation with others
- Stay positive
- Look for the humor
- Take care of yourself

(From Alzheimer BC Caregiver Strategies)

For support contact: Alzheimer Society of BC.

www.alzheimerbc.org
1-800-667-3742

For more information on Grief and Loss go to the Dementia and Families Internet page Island Health:
http://www.viha.ca/seniors/dementia.htm

LEARNING

ABOUT

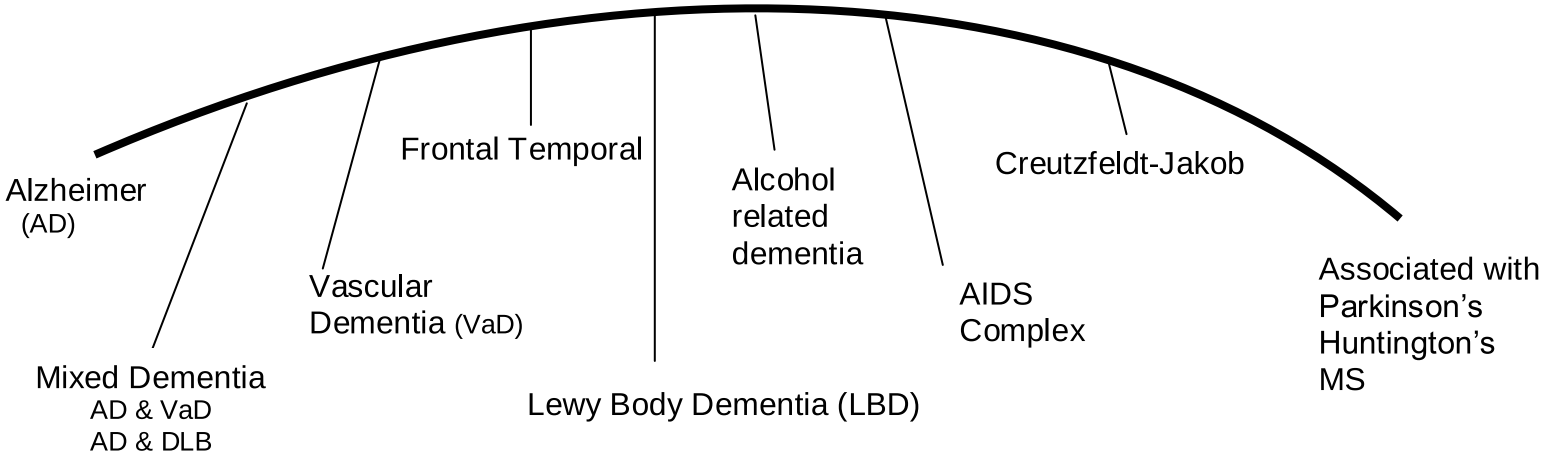
DEMENTIA

What is Dementia?

Definition

A progressive, irreversible neurologic disorder resulting from the death of brain cells. It is characterized by changes in mental function, and eventually by changes in physical function.

TYPES OF DEMENTIA



Symptoms

Loss of executive function

Loss of the ability to concentrate, plan, take initiative, make sound judgments, think abstractly, and problem solve.

The 7 A's are usually associated with dementia:

- **A**mnesia - memory loss
- **A**phasia - loss of language
- **A**praxia - impaired motor skills
- **A**gnosia - inability to recognize and identify objects or people
- **A**pathy-loss of initiative
- **Al**tered perception-misinterpret information from the senses; hearing, vision, touch, taste, smell
- **A**nosognosia-no longer able to appreciate that something has changed or is wrong; do not see their changes in abilities that others see.

Diagnosis

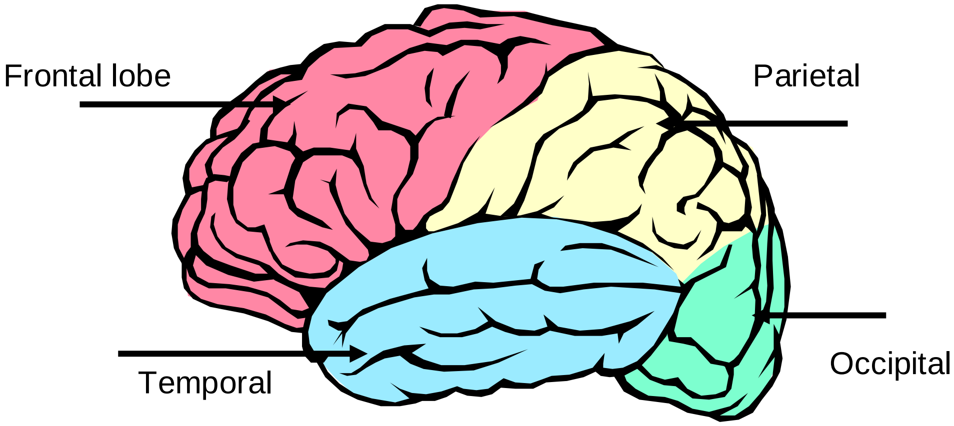
Absolute diagnosis of a dementia is not possible until autopsy and brain analysis. However, probable dementia diagnosis is made when all other possible causes of the cognitive decline have been ruled out.

Medical Workup:

A person may appear to be experiencing dementia, but may in fact be suffering from a reversible condition such as depression, delirium from acute infection, side effects of drugs, thyroid condition, B12 deficiency, etc. This is why thorough investigation prior to diagnosis is essential.

*DEMENTIA IS *NOT* A NORMAL PART OF AGING

Changes in Behaviour with Dementia



The Cerebral Cortex covers the head like a "cap". This is the most highly developed part of the brain, and is approximately 1/4 inch thick. It is the "grey matter"; the wiring network of axons. The Cortex is divided into a Right and a Left hemisphere (side) and four lobes, each with specific functions.

With dementia, cell death results in "shrinking brain tissue".

"Normal" Brain Function	Changes with Dementia
Frontal ▪ "The Boss" ▪ Thinking, planning, attending ▪ Speech activation ▪ Initiative ▪ Judgment	**Frontal** ▪ Neglect personal hygiene ▪ Wander into traffic ▪ Disinhibition ▪ Lost social skills ▪ Perseveration ▪ Emotional outbursts
Parietal ▪ Sensory information ▪ Touch / spatial ▪ Writing	**Parietal** ▪ Lost in familiar areas ▪ Decreased sensation to heat, pain, cold ▪ Can't draw picture ▪ Can't assemble (dressing, eating)
Occipital ▪ Visual interpretation (including writing)	**Occipital** ▪ Lack of recognition of objects, people ▪ Hallucinations
Temporal ▪ Memory (Hippocampus) ▪ Interpreting language, interpreting sound Interpreting patterns & numbers ▪ Regulation of emotions (limbic system) ▪ Regulation of temperature, appetite, thirst (hypothalamus)	**Temporal** ▪ Loss of short and long term memory ▪ Loss of words and meanings of words ▪ Loss of number skills ▪ Limbic system: deregulation of fear, anger, lust, jealousy ▪ Deregulation of body heat (wear excess clothing) ▪ Deregulation of thirst (risk of dehydration) ▪ Deregulation of appetite (loss of weight)

(Quinn, 1996;Restak, 1984;Lucero, 1992;Drance, 1990; Cummings, 2000; Sadavoy, Lazarus, Jarvik, 2006)
Monahan/Somers 2007
Creating Experts Education Series

THE SENSES

HEARING

SMELL

TASTE

VISION

TOUCH

HEARING

Hints at recognizing a hearing problem

You might observe the person to:

- Tilt his or her head to one side.
- Ask repeated questions.
- Misinterpret what was said.
- Withdraw from social encounters.
- Appear to have a short attention span.
- Have a blank stare.
- Not react to words or sounds in an expected manner
- Experience increased irritability and frustration.
- Experience increased anxiety or signs of fearfulness.
- Act in a way that indicates that he or she is suspicious.

TASTE

Strategies for helping someone with altered taste sensation

- Prepare attractive, colourful foods that are from all the food groups.
- Make sure that hot foods are hot and cold foods are cold.
- Try to use a variety of food textures with each meal.
- Use additional seasonings to increase food taste.
- Respect ethnic palates.
- Avoid putting too much food in the person’s mouth when assisting with meals. A teaspoon at a time is a manageable amount.
- Try not to rush a meal. Allow time for the person to eat at their own speed.
- Encourage the person to feed him/herself.
- Obtain adapted utensils, if necessary, from a medical supply store, pharmacy or contact an Occupational Therapist for advice.
- Encourage regular oral hygiene.

VISION

Strategies for helping someone with vision difficulties

- Ensure the person is wearing prescription glasses; clean the lenses regularly.

- Know if the person has other visual problems (for example: cataracts, tunnel vision, macular degeneration).

- Marks on the floor can be easily misinterpreted. The person may identify lines as stairs, etc. and make false moves according to what he/she interprets; this may cause accidents or falls.

- Visually identifying the bathroom door will assist the person in finding the bathroom correctly. Put a picture of a bathroom or toilet on the door or label "toilet" if the person is able to read.

- Ensure the colour characteristics of the room are different from the immediate object of attention; e.g. use a green toilet seat in a white bathroom to clearly identify the toilet.

- Keep clocks and calendars low enough to see.

- Adjust lighting to prevent the person from getting too much glare from shiny surfaces.

- Allow extra time for the person to adjust to a dark/light room.

- Know if the person can discriminate colours.

- Have the person dress in front of a straight, full-length mirror.

- Take extra time and use additional verbal and tactile (touch) cues to orient the person to the environment especially in unknown surroundings.

- Keep environment uncluttered.

SMELL

Strategies for helping someone with an altered sense of smell

- Eliminate smells that are unpleasant to the person.

- Label things well for the person who does not have a functional sense of smell (e.g. apple juice, iced tea).

- Install smoke detectors.

- Install carbon monoxide detectors.

- Install propane gas detectors.

TOUCH

Strategies for helping someone with altered touch sensation

- An altered touch sensation in the person's feet may affect their ability to drive safely.

- Provide mobility aids to ensure steady footing and balance while walking.

- Use caution in cutting toe nails too short; consider professional foot care.

- Adjust the temperature on the hot water tank to ensure the water is never hot enough to burn or scald the person.

- Monitor the use of electric blankets and heating pads as someone with an altered sense of touch will not be able to feel heat in the same way and has an increased risk of burns.

- Provide elbow length oven mitts and knives with safety handles if the person is still cooking.

- Assist with medications if lack of touch sensation to the hands interferes with their ability to pick up pills.

- Assist with changing hearing aid batteries, razor blades, light bulbs etc.

NOTE: *Occupational Therapists and Physiotherapists can recommend resources and equipment to support sensory loss.*

COMMUNICATION

“Preparing for Communication”

Speech

Communication

Orientation

PREPARING FOR COMMUNICATION

- Be aware of the person’s “best” ear.
- Speak to the person in a quiet room without T.V., radio, persons talking or other distractions.
- Be aware of ethnic language differences as many words have similar sounds but very different meanings.
- Hearing aid batteries should always be checked. A good battery will make the aid squeal when the aid is cupped in the hand.
- Identify yourself to the person each time if necessary.
- Use visual cues when possible; name tag, photo etc.
- Maintain eye contact to ensure the person is attending to the conversation.
- Do not chew gum when talking with a person.
- If glasses are usually worn, ensure the person is wearing them so he/she can see you are talking and can “see” the mouthing of words.
- Stop to answer the person’s questions.
- Do not talk to him/her when you are on the run as only part of what you are saying may be heard. Sit down, maintain eye contact.

- Use short sentences that come directly to the point.

- Try not to approach the person from behind. Gently touch the person before speaking to alert them to your presence and your intention to speak.

- Use simple words while talking slowly to prevent overwhelming the person.

- Be aware that sounds can easily be misinterpreted. Sounds like vacuums, clapping and pounding can cause fear or agitation if they are not accurately identified.

- Never talk over the person; include him/her in all conversations when he/she is present.

SPEECH

Loss of speech does not mean loss of mind or thinking ability…

- Only one person should talk at a time.

- Try not to overwhelm the person with too many words.

- Do not shout; speak slowly, calmly, clearly and as naturally as possible.

- Maintain eye contact and use tone of voice appropriate for an adult.

- Allow the person time to respond.

- Speak in simple, concrete sentences or phases.

- Use gestures and body language to reinforce communication.

- Use pictures when necessary to help the person understand.

- Make sure that the person is using their sensory aids (glasses, hearing aid) and wearing their dentures.

- Approach the person in a calm relaxed manner to keep him/her relaxed…this will enhance the ability to talk.

- Position yourself so that the person can see who is speaking.

- Take time to listen to prevent the person from withdrawing from family and life activities.

- Try not to quickly change the subject when talking; the person may need time to shift his/her thinking to go along with your story.

- Uses repetitious, simple words when teaching the person new tasks.

- The person’s emotions may change quickly with little or nor apparent provocation. Do not be upset by this, merely wait for the person to relax again.

- Accept swearing or profanity as meaningless as it is often involuntary.

- Be sure to praise the person for his/her efforts as well as for successes.

- Do not interrupt the person’s thinking process by unnecessary comments as this makes it hard for him/her to get back on track.

- When a person is having difficulty expressing an idea, fill in gaps, or make guesses. Try to work it out together.

- If the person is unable to communicate, establish a daily regular routine and use activity as a mode of communication.

- If the person tends to repeat requests or words over and over try using distraction:

For example:

- Change the subject.
- Sing a familiar song.
- Talk about the feelings behind the statement. For example, if the person says, *“I want to go home”*

Respond with: *“You must miss your home” “Tell me what your home was like”*

COMMUNICATION

- Avoid asking questions that rely on memory alone.

- The person may be persistent in expressing an irrational thought or idea. Try not to reason with the person, as he/she may no longer have the ability to rationalize. Reasoning or rationalizing with the person frequently leads to frustration and anger.

- Try not to express your anger or impatience verbally or with physical movements such as shaking your head, pointing your finger, etc. These responses are easily sensed and will likely increase confusion and agitation.

- Approach the person slowly from the front to avoid startling him/her. Make sure you have the person's attention before speaking or touching him/her and speak slowly and clearly using short, simple sentences.

- A person with dementia can often have a low frustration tolerance and can become agitated quite quickly if they feel confused or feel threatened. When communicating to the person around tasks or activities, try to:

- Give clearly stated directions for each step.
- Complete one step at a time.
- Avoid open ended questions instead offer a choice. (e.g. food, activities, or clothing). The person may no longer have the ability to think of several things at once and may be too overwhelmed to keep track of multiple events, statements, questions or directions. Decision-making may be overwhelming to the person and result in an agitated response. Example: *Would you like peas or carrots?*

- Offer activities and events that the person is capable of doing. You will need to regularly assess the person's capabilities and adjust your expectations accordingly.

ORIENTATION (time, place, person, event)

- Always talk to the person as a fellow human being.

- Avoid talking over the person as if he/she were not there.

- Avoid the use of medical terms with the person.

- Provide the person with verbal, factual help.

“Today is…, it’s time to…”

- Clocks and calendars should be placed at eye level, and numbers and letters should be large enough to read clearly.

- Mirrors should be placed at eye level.

- Write down information to help the person remember things.

- Write down regularly scheduled activities clearly on a calendar.

- If you leave the house to go outside or to go to the garage, leave a message with the person or on the table or fridge, (e.g., “Bob is in the garage”). Try to use the same area/place to leave messages-fridge, white board, chalk board, bulletin board, by the phone etc.

- Orient to day/night by making sure curtains/blinds/drapes are open during the day.

- Consider digital clocks that have large numbers that show the date time, and day of the week.

ACTIVITIES OF DAILY LIVING

ACTIVITIES OF DAILY LIVING

Activities of daily living include any activity a person wants to or needs to carryout on a daily basis – everything from brushing teeth, making a sandwich, shopping or going for coffee with a friend. The following are suggestions for family and other caregivers that can help the person continue to engage in daily life:

- Caregivers and family members should work as a team when caring for a person in the home situation; ensure a consistent approach and a structured consistent daily routine.

- Provide the opportunity for involvement in daily tasks. Some suggestions for doing so are:

- Consider the complexity of the task

- Simplify the task – if the person is having difficulty with a task simplify the task by breaking it down into simple steps. For example, if a person is having difficulty setting the table get necessary items out and give step-by-step directions (e.g., “Put the napkins on the table.” “Place the spoon beside the bowl.”).

- Encourage the individual to participate in tasks, which are of the appropriate complexity (e.g. heat up a frozen dinner rather than prepare dinner from scratch).

- Regularly evaluate the person’s ability to perform tasks and adjust your expectations accordingly. (i.e. give the person more or less direction).

- Structure the task

- Prepare the work area (e.g. if the person is washing up before bed, bring the toothbrush and toothpaste out of the drawer so they can be seen on the counter).
- If balance is an issue provide appropriate height surface with a sturdy seat/chair.

- Reduce clutter in the work area by removing objects not necessary for completing the task.

- Reduce distractions by turning off the television, radio or other potential sources of distraction so the person can concentrate on the task at hand.

- Ensure the individual is working in a well-lit area.

- Use colour and texture to distinguish furniture from rug, objects from counter top, etc. Blue chairs on a blue rug are very difficult for some people to see just as a white toothbrush on a white bathroom counter can be hard to see.

❖ Consider how to best assist the individual with carrying out the task:

- If the person can read and comprehend words, try writing down step-by-step instructions.

- If a person can understand the spoken word, try guiding them through the task verbally. Often only the first step needs to be said and the individual can carry on with the next steps independently.

- Demonstrate how the task is done first.

❖ Use a consistent approach

- By using the same approach when helping the individual with a specific task, you are helping the person remember how to do things with consistent cueing.

- Establish a daily routine so each day's structure is consistent for the individual and easier to remember; this also helps the person feel secure.

❖ Try to prevent discouragement by setting the person up for success.

- Incorporate the above suggestions into your daily routine so that the individual can be successful when participating in an activity (even if they are only able to carry out part of the task independently).

- Reflect on your own expectations of what the individual can do on a daily basis – if your own expectations are too high the individual may not be able to succeed.

- Remember that there may be fluctuations in the individual's mental and physical abilities – expect "good" days and "bad" days and assist the person based on how they are managing each day.

- Encourage the individual to participate in daily life – once he or she has a successful experience, this positive experience can foster a sense of purpose and help the individual to feel they are contributing.

- Praising the individual can be positively reinforcing.

- Allow the person extra time to do things for himself/herself rather than do it for him/her.

- Make the task fun and enjoyable for the person. A person with a dementia is more likely to remember an activity or event if it is attached to pleasant emotions.

THE HOME ENVIRONMENT

THE HOME ENVIRONMENT

BATHROOM

Although it is important to consider personal privacy, evaluation of the person's ability to safely bathe and toilet independently must be ongoing.

- Install grab bars by the tub and toilet.
- Place a contrasting coloured, non-skid mat in and beside the tub for the person to stand on, during and after a bath.
- Bath oil should not be used as it makes surfaces too slippery.
- Bath water should be warm, not hot, as hot water can cause fatigue and dizziness, which can lead to increased confusion or falls. Turn down the temperature of the hot water tank.
- It may be necessary to place a bath seat in the shower or tub especially when shampooing hair so the person can sit while showering to minimize risk or falls.
- It may be necessary to mark the shower stall lip with coloured tape to help reduce the risk of falls.
- Check toilet height when standing; it should be at least above the knee in height.
- Apply safety frame for arms.

- If bathroom door opens into the bathroom, consider rehanging door so that it opens outwards. This will prevent the person from blocking the door if they fall.

BEDROOM

- Bed height should not be too high or too low – just at the back of the knee. If falling out of bed consider half bedrail or place the mattress on the floor.

- A telephone should be placed by the bed and should have enlarged and/or illuminated letters and numbers. Ensure cords are tucked away to prevent tripping.

- 911 should be easy to read and posted on or around each telephone; the person's name, address and phone number should be on the same paper.

- Eyeglasses should be kept within easy reach of person but not in a place where they can easily be knocked to the floor.

- Remove hazards such as throw rugs to reduce the possibility of falls.

- Heating pads, electric blankets and hot water bottles should be used cautiously. The person may not be able to accurately feel heat intensity, or may not be able to see and manipulate dials.

- When getting out of bed, the person should sit before standing, place body weight on feet and rise slowly to standing position. Quick head elevation or movements by the person can cause sudden dizziness or fainting spells.

- Install a floor to ceiling bar beside the bed if necessary to provide extra support.

KITCHEN

Adapted kitchen gadgets can be obtained and will promote independence in the kitchen. Built-up handles, one handed beater, non-skid pads for under plates or bowls, wedge dishes, touchless can opener, a special board for peeling and cutting vegetables, etc. are some options. Other considerations are:

- The person should wear garments with snug sleeves.

- The person should wear non-skid shoes.

- Fitted kitchen mitts should be used instead of potholders.

- Curtains should not be near the stove.

- Make sure smoke detectors are installed, are in good working order and check batteries routinely. Make sure the person is familiar with the sound of the smoke detector and the meaning of the sound.

- A fire extinguisher should be easily accessible and visible and everyone should know how it is used.

- Frequently used items should be stored in an area close to waist height to prevent reaching above the head or bending over.

- Remove throw rugs.

- Remove clutter from counter tops to avoid distraction.

- A heat sensitive, automatic shut off system can be installed for stove tops, although these can be expensive. Break circuit knobs or fuses may need to be removed to disable stove.

- All small appliances including the kettle should be electric (not stove top) and have an automatic shut off switch.

- Simple timers with loud bells should be available for use.

- Stoves should have bright markers on the control dials and numbers should be large and easy to identify.

- Use labels or pictures of drawer or cupboard contents to help orient a person to the location of frequently used kitchen items.

- Arrange all items frequently used within arm’s reach to deter use of step stools or climbing on a chair.

STAIRS

- The person should wear non-slip shoes when using the stairs.

- Steps should be deep enough to place foot firmly and flatly on each step.

- Ideally have hand rails on both sides of the stair, both inside and outside of the home.

- Handrails should extend at least to the end of the stair treads.

- Texture changes can be used to mark the ends of the handrails (e.g. Velcro strips).

- Stairs should be free of miscellaneous articles, toys, etc.

- Mark each step with florescent tape for easy identification.

- Stairwells should be well lit.

- Scatter rugs and worn carpeting should be removed from stair areas.

- A gate with a complex lock can be placed at the top of stairs to prevent falls.

- Consider using a product with a mixture of sand and paint to apply to outside stair for increased traction.

- Keep outdoor walkways clear and well lit.

- Keep snow and ice cleared from entrances and sidewalk.

WANDERING

WANDERING BEHAVIOUR

Wandering is seen often in people with dementia. Both over-stimulation and under-stimulation can trigger it. Wandering is a common and often times serious problem that affects both the individual and the caregiver. There are different kinds of wandering behaviour and different reasons attributing to this behaviour.

Purposeful Wandering

- Reminiscent / fantasy wandering – attempts to carry out roles from the past such as visiting a childhood home or going to work

- Recreational wandering – pattern of activity matches pre-institutional clock

- Agitated wandering – frightened resident trying to escape – may escalate into aggression if resident is confronted

Purposeless Wandering

- Tactile wandering – use their hands to explore their environment as they walk, as if looking for clues

- Environmentally cued wanderers – have reflex-like responses to environment, e.g. door, exit.

Caution

Restraints may compound the problem. If wanderers are restricted they may fight the restraint and become more determined to get out or may become more anxious, tense and noisily disruptive than when allowed to wander freely.

Side effects of psychotropic drugs, especially antipsychotic, can cause akathesia, an internal restlessness that causes the person to want to move continuously.

The most important approach to management is identifying the causes of the behaviour itself. Some possible causes include:

PHYSICAL OR MEDICAL CAUSES

➢ Direct result of changes to the brain from the disease.

- Unable to identify or express hunger/thirst.

- Reaction to medications such as sedatives, tranquillizers, or the interaction of several medications in combination.

- Physical discomfort due to pain, infection, constipation (urinary tract infection and chest infection are common causes of wandering, agitated behaviour).

- Need to use the bathroom.

- Need to exercise and be active (wandering can become an expression of the person's need for sensory stimulation and socialization).

- Need for companionship and socialization (i.e. feeling lonely and isolated).

ENVIRONMENTAL CAUSES

The person:

- May want to escape from a noise or a crowd.

- May be afraid (possibly from new and strange surroundings, hallucinations or delusions).

- May be misinterpreting their environment (shadows can be interpreted as people or animals and can be quite frightening; noises can be misinterpreted and also lead to feelings of fear; smells are often misinterpreted and trigger old memories that induce fear or confusion).

- May be trying to make sense of a new environment (e.g., recent relocation, new daycare, facility placement, move to a new neighbourhood or city). Changes in the immediate environment: such as a new decorating scheme or moving furniture to a different spot can also create confusion and wandering behaviour.

- May be uncomfortable, (e.g., too hot or too cold, clothing too tight).

- May be triggered to want to leave by seeing outdoor clothing such as a coat, hat or shoes.

- May be acting out his/her past/old routines such as leaving for work, school, going to feed the cows, etc.

- May be looking for a friend or family member who is out of sight.

- May get lost while taking a walk even if surroundings were at one time familiar.

- May be searching for his/her past home or searching for people from the distant past.

Persons with a dementing illness such as Alzheimer's Disease best remember events/places/and people during the early years of their lives. The years that hold the most vivid memories are between 12-24 years of age.

NIGHT TIME WANDERING

May be caused by:

- Inability of the person to separate dreams from reality.
- Inactivity during daytime hours.
- Too much sleep during daytime.
- An infection or pain can cause sleep disturbances.
- Adverse reactions to medication such as sedatives and tranquilizers.
- Person may be cold as core body temperature is at it’s lowest 30 minutes after a person falls asleep.
- Inability of the person to appreciate time; when they awaken in the night they may believe that it is time to get up and dress.

*If the individual does wander one must ask the question “**is the wandering a problem, and for whom is the wandering a problem?**”*

If the person’s behaviour is not jeopardizing his/her or others safety, or disrupting the lives of others, the best approach is to try to identify the cause(s) and try to mange the behaviour. Medications to induce sleep in an attempt to prevent wandering can create a whole new set of problems, such as: falling, increased confusion, incontinence, constipation, irritability, and depression. Discuss options with your doctor if nighttime wandering is frequent and creates a risk to the person or caregiver.

HOW TO IDENTIFY CAUSES OF WANDERING BEHAVIOUR

Try to understand what leads to wandering behaviour. Keep a journal and write down any observation about the wandering behaviour over a period of several days.

For Example:

- Did anything happen just before the wandering episode that could have caused it?
- What is the person's mood, demeanor, are they grimacing, frightened etc.

- Is there a pattern to the time of day the wandering occurs?

- Is the person looking for activity or exercise?

- Does the person appear to have a goal?

- Does the person appear to know where they are going or what they are looking for (purposeful wandering)?

- What medication is the person taking?

- Is there a physical complaint that is the basis of the wandering?

- Did the person use pacing, exercise, or other repetitive behaviour as a coping mechanism at a younger age?

TO PREVENT WANDERING

- Wandering may be due to the person searching for a person, place or object from the past. Reminiscing about things from the past may be comforting. Photo albums, travel books and magazines are ways of introducing a reminiscence activity.

- For some people with dementia, wandering is a coping mechanism to release energy or reduce stress and tension. Trying to stop the wandering may increase agitation and cause anger and frustration.

- Anticipating an event such as a visit to or from a relative may contribute to wandering. Consider if the person needs to be advised of plans ahead of time and what amount of advanced notice is necessary without causing undue anxiety or restlessness.

- Wandering may occur when a change in location is anticipated. In the event of relocation slowly introduce the person to the idea of change. If possible, visit the new location several times prior to moving to help orient the person to new surroundings. Involve the person in the actual move if possible, by allowing them to pack and transport boxes.

- A person who wanders at the same time every day may be returning to a former schedule or routine. For example, a person may be trying to get back to work after lunch or fixing a snack for children coming home after school. Think of ways to accommodate this by going for a walk or a drive or provide other distractions during this time of day.

- Have the individual see a physician for a thorough medical examination to rule out medical causes contributing to the wandering behaviour.

- Avoid or limit daytime napping.

- Plan daily activities during the time a person tends to wander. This could include an exercise regime, participation in household activities, participation in gardening activities, walks to the store, etc.

- Decrease noise levels in the environment and the number of people interacting with the individual to prevent over stimulation.

- Remove items from view that may trigger a desire to wander such as shoes, boots, purse, coat rack.

- Make sure the person is not wandering because of a need to use the bathroom. Look for obvious signs such as fidgeting with clothes or holding onto themselves.

- At night time be sure the bathroom or a commode is easily accessible and visible. Direct/assist to regular toilet schedule.

- Use night-lights, floor lighting, signs and familiar objects to assist the person to move around an area safely, particularly for finding the bathroom at night.

- Place an extra blanket over the person after they are asleep to ensure they stay warm and comfortable.

- Reflector tape is useful around a bathroom door to assist in finding the bathroom.

- Put fences or hedges around your patio or yard; install gates on stairwells; consider electronic buzzers, motion sensor lights, chimes/bells on doors and windows, or a sound monitor with a transmitter or receiver.

- Camouflage some doors with a screen, curtain or a painted mural. Put a two foot square dark color in front of a door knob, or place a decorative plant stand at the level of the door knob.

- With wandering into others' rooms, try using a theatre rope barrier across the doorway, a Velcro sign across the door or keeping the door shut; use STOP or DO NOT ENTER signs; floor grid.

- Install locks that are difficult to operate and higher up on doorframe, out of field of vision or the person's reach.

- Frequently reassure the person who may be feeling lost or abandoned.

- Try communication techniques such as reassuring the person frequently about where he/she is and why.

- Speak in a calm, normal tone of voice.

- Try to follow the person or offer to walk with him/her until they are ready to be redirected towards home.

- Offer proper nutrition with frequent meals to accommodate for calories burned with increased activity. Finger foods such as sandwiches, cheese and fruit offer good nutrition for persons unable to always sit for a meal.

- On occasion, a successful substitute for wandering behaviour is a rocking chair.

KEEPING THE WANDERER SAFE

To ensure safety: limit the person's access to:

- Bodies of water
- Tunnels
- High balconies
- Bus stops
- Steep stairways
- Obstacles that might cause falls, such as loose scatter rugs, cluttered rooms
- Swimming pools
- Roadways where traffic tends to be heavy
- Dense foliage

- Deep ditches or hills

- Other things that could present hazards if this person wanders

- Make sure the house is accident proof by keeping medications, toxic substances such as cleaning supplies, sharp objects, alcohol and matches in locked cupboards or closets.

- Put locks on outside gates. Fenced in backyards allow people to wander safely and provide positive exercise and activity.

- Use a safety gate across doors and at the top of stairs. This may help keep the wanderer in a limited area where he/she can explore safely.

- Provide comfortable clothing such as jogging suits and tennis shoes.

- Give frequent drinks of water or juice or juice pops to prevent dehydration. The person with dementia will often forget to drink or will not recognize thirst. Dehydration can be dangerous and increase confusion, leading to delirium and increased potential for falls. *(see Delirium Information page 64)

- Have a current picture of the individual available with a matching description including name, age, address, any medical or physical conditions and a description of distinguishing characteristics such as scars, moles, glasses, etc.

- Provide the individual with a medic alert bracelet or necklace.

Provide the individual with an ID card in a wallet or purse that indicates that the individual has memory impairment and gives a list of names and phone numbers of several contact persons.

- Label clothing with a name and phone number.

- Whenever the person leaves the home place a pocket instruction card on their person. The card should carry a message to call home with a phone number as well as a message to stay calm and not to walk away. The information on the card should be individualized to the person and should be provided by a family member or friend who is aware of what the person may respond to.

- Use brightly coloured outdoor clothing such as a jacket, coat and pants when they are leaving the house. Reflectors can be sewn onto sleeves or pant legs, which may help motorists, identify a person in the night or assist police involved in searching for a missing person.

- Alert neighbours and police that a memory impaired person lives at this particular residence and keep a list of important phone numbers close to the telephone such as neighbours, police, physician, and family members**. *The Alzheimer Society of B.C. has developed a Wandering Package.*(page 47)**

Wandering Package

Alzheimer Society of B.C.

The ***Wandering Information Kit:*** a booklet containing information on wandering, how to reduce the person's risk of wandering and becoming lost and tips on what to do in the event of a wandering incident.

The ***Identification Kit:*** a useful tool to help families organize vital information on the person with dementia, such as a physical description and medical conditions, to have available in the event of an emergency. It is helpful for families to have a recent photograph immediately available if a person with dementia goes missing. Therefore, the ***Identification Kit*** also includes a spot to keep a current photo of an individual at risk of getting lost.

Tips for Police: a resource that families can share with police and other first responders if a person with dementia goes missing. Includes information for police about wandering and dementia and how to communicate with a person with dementia.

Locating Device Fact Sheet: If families are considering purchasing locating technology for a person with dementia, such as a GPS device, this resource is designed to help with the decision-making process.

Disorientation and Dementia: The Wandering Package also includes a fact sheet written specifically for people with early dementia. It provides some helpful suggestions on how to increase one's autonomy and safety.

Please phone **1-877-596-7750** to request a free copy of the ***Wandering Package***. When you phone this number, please leave your name and your mailing address and feel free to ask for a return phone call to answer any questions. You can also download the ***Wandering Package*** from the Alzheimer BC. Website www.alzheimerbc.org/wandering.

Safely Home Wandering Registry

Safely Home® is a Canada-wide program designed to help find a person with Alzheimer's disease or related dementia who is lost and assist in a safe return home. Developed by the Alzheimer Society of Canada in partnership with the RCMP, vital information on people at risk of getting lost is stored on the Canadian Police Information Centre database (CPIC). The program provides registered individuals with an ID bracelet engraved with a number that allows police to view the person's information, including their home address, using the CPIC database. www.safelyhome.ca.

PREVENTING FALLS

FALLS

As the individual's ability to anticipate danger declines, the potential for a fall increases. There are also changes in balance and movement that can increase the potential for falls. Although it is impossible for all hazards to be removed the following are suggestions for prevention and creating a low risk environment:

Throughout the household check that the following are attended to:

_____ 1. Properly fitting footwear with non-skid rubber soles are worn. Ensure shoelaces are properly tied or Velcro is tightly secured. "Flats" are preferred to shoes with elevated heels. Hip protectors can be worn to reduce injury for persons who are at higher risk.

_____ 2. Flooring and carpeting are in good condition without worn or curled edges that may cause tripping and falling.

_____ 3. Lighting is bright and free of glare.

_____4. Night-lights are strategically placed throughout the house, especially in stairways and between bedroom and bathroom. Floor lighting is recommended.

_____ 5. Telephones are positioned so the person does not have to hurry to answer a ringing telephone.

_____ 6. Electric cords are not located in walkways. When possible they can be shortened and tacked down to baseboards.

_____ 7. Clutter does not obstruct walkways or stairways.

_____ 8. Grab bars are installed in the bathtub and toilet areas.

_____ 9. Water drainage is appropriate to prevent the development of slippery floors after bathing.

_____10. A bath seat is available for use in the tub or shower.

_____ 11. Throw rugs are removed from all areas of the home.

_____ 12. Bedside table is accessible for placement of glasses, telephone and other important items.

_____ 13. A floor to ceiling pole is placed by the bed or favorite chair. (A commode or urinal can be placed by the bed for easy access at night)

_____ 14. The floor has a non-slip surface.

_____ 15. Spills are cleaned up quickly to prevent slipping.

_____ 16. Cleaning and cooking supplies are stored in locations that are not too high (to avoid reaching or standing on a chair) or too low (to avoid lightheadedness after stooping). Waist height is ideal.

_____ 17. Throw rugs are not placed over a carpet or scattered in high traffic areas.

_____ 18. Furniture is placed in positions that allow for wide walkways.

_____ 19. Chairs and sofas are of a height sufficient to permit easy sitting and standing. An electric lift chair recliner can help those who have difficulty getting in and out of a chair.

_____ 20. Sturdy railings are provided along both sides of all stairways.

_____ 21. Stairway steps are non-skid.

_____ 22. Objects are not placed on stair landings or thresholds.

_____ 23. When possible, florescent tape is placed on all steps to indicate where the steps begin and end.

_____ 24. A gate with a complex lock is placed at the top of the stairway.

_____ 25. Outside steps are in good condition. During the winter, sand and/or salt slippery surfaces to ensure safety.

_____ 26. Walkways are shoveled free of ice and snow in the winter to prevent slips and falls.

MANAGING INCONTINENCE

INCONTINENCE

The privacy and dignity of the person who may be experiencing problems with incontinence is of the utmost importance. Caregivers must be sensitive to the feelings of humiliation and embarrassment experienced by the individual who is losing control of their bodily functions. It is important to make every effort to preserve the person's self-esteem as individuals with dementia have some degree of awareness of the functions they have lost. Family members and other caregivers may also feel embarrassed or awkward when assisting with toileting. These feelings are normal under these circumstances and it is helpful for caregivers to discuss these feelings with other family members, physicians, nurses, Community Health Workers, or friends. At times caregivers may find the experience of assisting an individual to clean up to be a very difficult and unpleasant task. Try to remain calm and reassuring and recognize that both of you will probably feel quite uncomfortable in this new situation. Talk through the steps slowly and simply while having the individual assist as much as possible and remember to praise the person for their efforts. It is important to communicate with the person so that you may establish a routine that is comfortable for everyone.

- Persons with a progressive dementia may begin to wet themselves or have bowel movements in their clothing in the latter stages of the disease. This problem can be devastating and embarrassing for the individual as well as distressing for the caregiver. It is important for family members and professional caregivers alike to be aware of the strong feelings evoked by this behaviour and approach the problem in a sensitive, caring manner. There are many possible causes of urinary and bowel incontinence, therefore it is important to rule out any treatable causes of this behaviour. Some possible causes include:

Physical or Medical Causes

Infections such as urinary tract infection and urethritis.

Male	Female
➢ Prostate surgery may cause infection or urinary retention that leads to overflow	➢ Vaginitis can cause loss of urine control ➢ Constipation or fecal impaction can block the bladder so that urine leaks past the blockage point ➢ In older women weak pelvic muscles can sometimes cause “stress incontinence” or “leaking”, this may occur if a person sneezes, coughs or laughs.

- Chronic illnesses that limit physical mobility such as stroke, Parkinson’s disease, arthritis or chronic pain can hamper attempts to reach the bathroom.

- Changes to vision associated with normal aging or physiological conditions can hamper visibility and make it difficult to find the bathroom.

- Not drinking enough fluids may cause irritation of the bladder; if the person becomes dehydrated they may become incontinent because the physical signal or urge to use the bathroom may be lessened or no longer be understood. Promote hydration, as reducing fluids will not stop incontinence.

- Caffeinated fluids such as coffee, tea, cocoa, and colas as well as alcohol can have a diuretic (promotes the formation and excretion of urine) effect.

- Medications such as tranquillizers, sedatives, hypnotics, antidepressants and diuretics can affect bladder muscle function and/or reduce the person's sensitivity to body signals.

ENVIRONMENTAL CAUSES

- The bed may be too high or too low to the floor making it difficult for the person to get up and use the toilet.

- The distance to the bathroom may be too far as older adults are not always able to hold urine for extended periods of time.

- The person may be afraid of falling, particularly when walking during the night, and resist the need to walk to the bathroom.

- The person may have difficulty undressing to use the toilet.

- If the floor and the toilet seat are similar in colour it may make it difficult for a person with visual difficulties to find the toilet.

- Poor lighting may make it difficult for the person to find the bathroom or locate the toilet once they are inside the bathroom.

- The person may require cues or signs that orient them to the location of the bathroom.

OTHER CAUSES

- The task of using the toilet may have become too complicated for the person.
- The person may not remember what to do once they are in the bathroom.
- The person may require assistance to undress, sit on the toilet, wipe themselves, and/or get up from the toilet.
- The verbal instructions the person receives may not be simple or clear enough for them to understand.
- The person may feel they are being rushed which can cause confusion and lead to difficulties in using the toilet.
- The person may SENSE the need to go to the toilet but may no longer be able to EXPRESS the need to go to the toilet.

APPROACHES TO INCONTINENCE

- Use a written diary or journal to assist you in understanding the nature of incontinence. Document routine patterns of behaviour associated with bathroom activities so that alternate caregivers may also be of assistance. Write down any observations about the incontinent behaviour over several days.
- *Do accidents happen only at certain times of day or just at night?*
- *How often does the person use the toilet?*
- *Did the incontinence begin suddenly?*

- *Is the person urinating in improper places, such as flowerpots, wastepaper baskets, closets, the bathtub, or in the kitchen sink?*
- *Do accidents happen on the way to the bathroom?*

This information will be helpful to you and will also be helpful to your doctor in assessing for a treatable medical condition that may be causing the incontinence.

➢ Ensure that the person is given a thorough medical examination to rule out any possible infections or medical conditions that may be contributing to the incontinence.

➢ A urinary tract infection can often be accompanied by a fever or a **sudden change in the person's behaviour**. If a fever persists for more than 24 hours and/or behaviour changes are sudden with an increase in confusion and speech problems it is important to contact your physician, as this might be a delirium. A delirium is a serious medical condition that should be addressed immediately.

➢ Discuss with your physician medications that can be used to treat incontinence. Remember that all medications have side effects and if drugs are used the person must be carefully observed.

➢ Talk with your doctor about a Home Care Nursing assessment and non-medical recommendations or contact a Nurse Continence Advisor.

➢ After carefully observing the individual's toileting pattern during the day and night attempt to toilet the person just prior to expected the time you have documented.

➢ Consistently toilet the person before and after meals, before going to bed and immediately upon arising.

- An adequate water intake of 5-8 glasses daily is the minimum daily requirement for a healthy adult. At times it may be difficult for the person with dementia to remember to drink or they may have lost the recognition of the sensation of thirst. Caregivers can provide a great variety of substitutes for fluids such as; jello, popsicles, ice cream, or ice cubes.

- A regular routine schedule for providing fluids will be helpful.

COMMUNICATION APPROACHES

- Use simple precise messages, with short sentences and one step instructions.

- Watch for any visible clues that the person needs to use the toilet; such as reaching for a belt, tugging at a zipper, holding onto themselves, or taking down pants. Often time's restless behaviour or facial expression may signal a need to use the toilet. *Consider the person's use of slang or alternate expressions around using the bathroom. Ensure that alternate caregivers are familiar with the behaviour and words the individual uses when needing to use the toilet.

Examples of slang:

Tinkle, pee, take a leak, use the john, etc.

- Listen carefully, as the person with dementia may substitute a different word in his attempts to express his/her need to use the toilet.

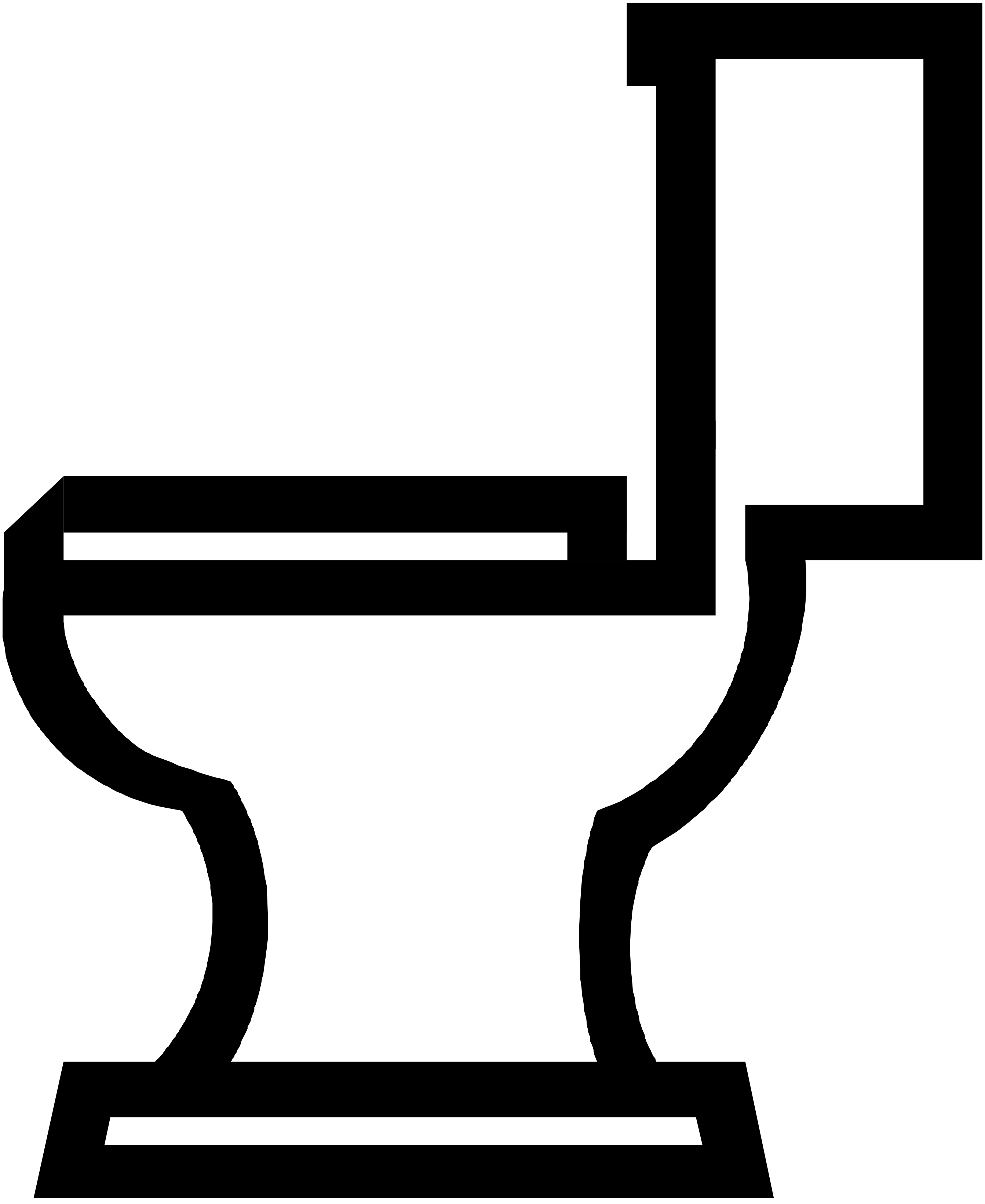
For Example:

“take a peek”, “I want tea”, “use the thing”, “the what’s it”

- Individuals with dementia, no matter how severe, have some degree of awareness of their inabilities. It is important to not focus on the incontinence itself but to focus more on providing assistance in a way that is reassuring and not reprimanding or punitive.

- It is sometimes helpful to use signs to assist the person in locating the bathroom, for example, the word “toilet” with letters that are boldly printed, in capital letters, and large enough to be easily read.

- If the person is no longer able to read, placing a picture of a toilet at eye level on the bathroom door can be helpful.



CLOTHING FOR INCONTINENCE

- Simplify clothing as much as possible by using pants with elastic waistbands or skirts. Velcro may be used instead of zippers or buttons.

- Select clothing that is washable and does not need ironing. Shoes that are also washable such as tennis shoes or good fitting slippers are much easier to keep clean.

- Clothing should be changed when wet to avoid the person becoming accustomed to wet clothing, as well as to avoid irritability, confusion and infection. Adult briefs or “undergarments” are readily available in stores. These briefs are washable or disposable and are recognizable to the individual as an undergarment. There are different brands and products, don’t give up after trying one.

SKIN CARE

- It is important to provide good skin care to prevent rashes or skin breakdown that can lead to irritability, discomfort, pain and medical complications. Allow the individual to participate as much as possible in his/her hygiene; giving the person a cloth to wash with is often a good distraction when assisting with changes of clothes and cleanup during periods of incontinence. This can also make the person feel like they are participating in his/her own care. Local drug stores supply products that act as both soap and skin conditioners to lessen the steps involved in assisting the individual as well as keeping the skin clean and dry.

BATHROOM AIDS

- A raised toilet seat with grab bars can make it easier for a person to safely get on and off the toilet.

- Ensure that the toilet seat is fastened securely to the toilet so that it does not slip when the person sits on it.

- A padded toilet seat is more comfortable for the person who may need to sit for a longer period of time.

- If the person is having difficulty getting to the bathroom because of stairs or distance, a commode chair placed near the person’s bed or in a private area can be helpful. The commode should be stable so that it does not easily slide or topple over and the toilet top should be left off or raised so the individual can easily identify it as a toilet.

- For an individual who is restless and has difficulty sitting for extended periods of time, it is often helpful to give them something to do with their hands when they are using the toilet. Giving them face cloths to fold, a book or magazine with meaningful pictures to look at, or playing music are a few examples of activities that may be of assistance. It is important to know the individual well and give them an activity that will both hold their attention and is meaningful to them.

- Urinals and bedpans are readily available through medical supply stores and for men there are spill proof urinals, which can be kept in the bed.

DELIRIUM

Delirium in the Older Person: A Guide for Families

What is delirium?

Delirium is a sudden, temporary onset of confusion that causes changes in the way people think and behave. Older people are most at risk. Knowing what to look for and treating the causes early can help save lives.

What causes delirium?

Infection
Medication side-effects
Not taking medications as prescribed
Recent surgery with anaesthetic
Worsening of a chronic illness
Dehydration
Poor nutrition
High or low blood sugar
Constipation or diarrhea
Pain
Alcohol use or withdrawal
Recent injury or fall
Recent move or hospital stay
Grief over a recent loss, for example death of a family member, friend, or pet
Poor fitting hearing aids or glasses
Low blood levels of Vitamin B12

What puts someone at risk for getting delirium?

People are more likely to get delirium if they have:
Had delirium before
Memory or thinking problems
Severe illness resulting in hospital stays
Dehydration
Problems with seeing or hearing, or
Are taking 5 or more medications

What are the signs of delirium?

Confusion
Restlessness
Being upset
Slurred speech
Not making any sense
Seeing or hearing things that are not there
Mixing up days and nights
Drifting between sleep and being awake
Forgetting things
Trouble concentrating
More alert than normal
Not knowing where they are
Trouble staying awake

How is delirium diagnosed?

Delirium is diagnosed by:

Noticing signs of delirium
Learning the person’s medical history
Learning the person’s usual thinking ability, daily routines, communication style, moods, behaviours and sleep habits.
Doing a physical examination.
Doing blood, urine, and X-ray tests to find the cause.

How is delirium treated?

Treating delirium means treating the underlying cause. It is very important to figure out the cause of delirium as soon as possible. This usually means doing tests and asking questions. Once the cause is known, the most effective treatment can be given. This may include medication as well as changing the person’s surroundings.

For many people, delirium can clear in a few days or weeks. Others may not respond to treatment for many weeks. Some people never fully return to their normal selves. You may see some problems with memory and thinking that do not go away. Each person is different.

What can you do to help?

1. Learn about delirium

Know the signs of delirium listed in this handout.

Tell the doctor or other health care team member if you notice any signs of delirium.

Understand that delirium is not dementia. Dementia is the gradual loss of brain cells over time that results in decline of day-to-day thinking. Dementia cannot be cured.

2. Support healthy rest and sleep by:

Reducing noise and distractions.
Keeping light low or off when resting.
Improving comfort with a pillow, blanket, warm drink or back rub.
Not using sleeping pills if possible.

3. Support physical activity by:

Helping with sitting and walking.
Talking with the health care team about safe exercise and activities.

4. Support healthy eating and drinking by:

Encouraging and helping with eating.
Offering fluids often.

5. Support good hearing by:

Encouraging the wearing of hearing aides.
Making sure hearing aides are working.

6. Support good seeing by:

Encouraging the wearing of glasses or use a magnifying glass.
Keeping glasses clean.
Using good lighting.

7. Support mental stimulation by:

Arranging for familiar people to visit.
Keeping sentences short and simple.
Gently reminding them where they are and what is happening. Please do not argue with them.
Talking about current events and what is going on around the person.
Reading out loud or using large print or talking books.
Bringing in a clock, calendar or pictures from home.

Where can I learn more?

Delirium resources on the VIHA Website:
www.viha.ca/mhas/resources/delirium/

HealthLinkBC - Health advice you can trust 24/7.
Tel: 8.1.1 from anywhere in BC.
Tel: 7.1.1 for deaf and hearing-impaired assistance (TTY)
Web: www.HealthLinkBC.ca

UNDERSTANDING PROTECTIVE AND RESPONSIVE BEHAVIOR

UNDERSTANDING RESPONSIVE BEHAVIOR

- Behaviours seen in persons with dementia are almost always in response to something in the person's environment. The trigger or cause of the behaviour is where you need to look in order to determine the cause of the person's distress. Responsive behaviours include: agitation, restlessness, apathy, disinhibition, sleep disturbance, pacing, wandering, verbal outbursts or acting out. These behaviours are a persons best response to what they understand is happening in their environment. All behaviour has meaning and to understand the meaning of the behaviour it is important to see the world from the perspective of the person with dementia.

  "Stepping out of our reality and into theirs means accepting that our clock runs way too fast. It is not they who should cooperate with us, but we who should cooperate with them" *(*Dunne, 2002).

- Anger and irritability are often signs that a person is feeling a loss of control over his or her life. Calmly acknowledging these feelings even when you do not understand what it is that has upset the person can be helpful in reducing the behaviour. As it is often difficult to predict these episodes, it is useful to keep a diary or a journal to help identify situations when a person may become upset. Write down everything that happens each time a person reacts this way. Write down what time of day it was, who was present, whether noise or over stimulation was a factor and what immediately preceded the outburst. As a caregiver, you will often see a pattern emerge that can help you think about how to alter the environment and prevent an angry outburst from occurring.

- Persons with dementia will often sense a caregiver's frustration or anger and become anxious or angry themselves. A gentle, supportive, simple approach will almost always be more successful than lengthy explanations or rationalizing.

- After the episode is past, try not to remind the person of the incident. He or she will probably soon forget that it occurred. Caregivers should carefully consider what could be changed to avoid a reoccurrence.

- Work out an emergency procedure for yourself in the event that you feel your physical safety is threatened.
  - Stand out of reach of the person.
  - Leave the room to prevent injury to yourself.
  - Leave the house and return in a few minutes.
  - Call for help from family members, friends, a family physician

POSSIBLE CAUSES

Physical

- Fatigue at the time of a request, activity or event.

- Disruption of the sleep pattern, sleepless nights or day and night reversal, which can cause sleep deprivation. This can lead to a delirium and will increase confusion and decrease function.

- Physical discomfort, such as pain, fever, illness or constipation is often expressed as agitation and can lead to delirium if not treated.

- Side effects from medications, especially tranquilizers, sedatives, and antidepressant medications and can lead to delirium if not brought to the physician's immediate attention.

- Impairment to vision or hearing which can cause a person to misinterpret sights and sounds in his/her environment.

- Expectations that are too difficult for the person's current level of understanding and function.

Environmental

- Sensory overload – too much noise, activity, clutter or too many people in the environment at one time.

- Unfamiliar people, place or sounds.

- Sudden movements or startling, unexpected noises.

- Feeling lost, insecure, or forgotten. When the familiar family caregiver is out of sight the impaired person may feel abandoned and frightened.

- Difficulty adjusting to darkness from a well-lighted area and visa versa can cause confusion and agitation.

- Poor lighting, dark hallways, which may cause misinterpretations of surroundings.

Other Causes

- Being asked to respond to several questions or statements at once.
- An emotional reaction to arguments, stress, irritability, or frustration of others.
- Being scolded, confronted, or contradicted.
- Feeling embarrassed.
- Being surprised or startled by unexpected physical contact.
- The frustration of being unable to perform what was once a simple task.
- Unable to understand what they are expected to do.
- Instructions that are unclear or too complicated.
- Any change in schedule or routine.
- Attention might be too short for the task that is expected of them.
- The activity is perceived as too child-like or insulting.

COPING STRATEGIES/ADAPTIONS/MANAGEMENT

- Begin with a complete medical evaluation to rule out physical or medication problems as the cause of angry or agitated behaviour.

- Discuss possible side effects of the person’s current medications with the physician.

- Have vision and hearing checked and optimize using clean glasses and properly working hearing aids.

- Alternate quiet times with more active periods during the day.

- Plan outings and activities when the person is well rested.

- Make sure that the person is comfortable, that clothes are not too tight, that the person is not too hot or too cold, and that the person is not experiencing any pain.

- Keep the environment simple by reducing noise level, the number of people in the person’s immediate surroundings and unnecessary clutter.

- Daily routine should be as consistent as possible; persons with dementia become quickly disoriented and confused if there are any changes or surprises in their daily routine. Try scheduling meals, bathing, socialization and other activities at the same time everyday.

- If change in routine is necessary (this may be especially important for caregiver respite or daycare relief) the person should be introduced to the new caregiver or new place as gradually as possible.

- Ensure that the person is protected from hurting him or herself.

- Remove sharp utensils, tools, and other dangerous objects from the person's environment.

- Regular exercise, including daily walks, helps in reducing stress and promoting relaxation.

- Gentle distraction with a favorite food, topic of conversation, or meaningful activity is useful approaches in reducing anxiety or agitation. Music, pleasant smells, massage, quiet reading, rocking chair or gentle physical touch such as holding hands and hugging may be comforting and help to calm the person.

- A heated beanbag or heavy blanket placed over the back of the neck and shoulders can help promote relaxation.

Remember:
"You cannot control the disease. You can control your reaction to it"
Liz Ayres

Dementia Care

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