



shifting focus

A Guide to Understanding Dementia Behaviour

(full version)

Table of Contents

Introduction.....	4
About your brain	5
Specific kinds of responsive behaviours and what to do when they occur:.....	9
Agitation.....	10
Wandering	11
Sexual behaviours	12
Sundowning	14
Repetition.....	15
Anger or aggression.....	16
Hallucinations and paranoia:	17
Strategies to enhance communication with people living with dementia	18
Creating a meaningful visit	20
Your role as a care partner in the long-term care home	22
Communicating and working with the staff	23

Terminology

He, she, husband, wife, mother, father, friend or co-resident –These terms are used interchangeably and are meant to be generic.

Care partner or partners in care – Non-paid family members, friends or volunteer companions who provide some aspect of care or support to persons with dementia.

Dementia – A general term that refers to many different diseases including Alzheimer's disease, Vascular dementia, Frontotemporal dementia, Lewy Body dementia, Mixed dementia and others. Different types of dementia are caused by different physical changes to the brain. Some dementias are reversible, meaning that they can be treated and cured. Some are irreversible, meaning that there is no cure as of yet.

Alzheimer's disease – The most common form of dementia (64% of all dementias in Canada). Alzheimer's disease causes a gradual (slow) onset of memory loss and a continuing decline. There are also changes in judgement and reasoning, and performing everyday tasks becomes harder.

Introduction

When you are diagnosed with a dementia, you become a member of a club. And knowing someone who has been diagnosed makes you an honorary member. The disease affects you too, whether your husband forgets your name, your Mom doesn't recognize you or your friend can no longer sit and chat.

But challenging situations become more so when your friend or family member displays what we call "responsive behaviours," that is, the challenging difficult behavior that usually seems so out of character with the person you know. It's hard to know what to do. Sometimes, out of fear of doing something wrong or making it worse, we stop visiting. But that outcome benefits no one.

This booklet is meant to help family members, friends and co-residents of those who live at home or in a long-term care home and behaving in unpredictable ways that create unease or distress. It helps care partners and fellow residents learn about the brain and how dementia affects it; recognize your family member's actions and their meaning; offer ways to respond; and increase patience and acceptance for those living with a dementia.

But remember these are suggestions. Dementia is always changing and unique for each person. One suggestion may work today, but not tomorrow.

The goal is to give you tools to improve the relationship with your family member or friend and everyone's quality of life. After all, isn't that what we all want for ourselves and those we support?

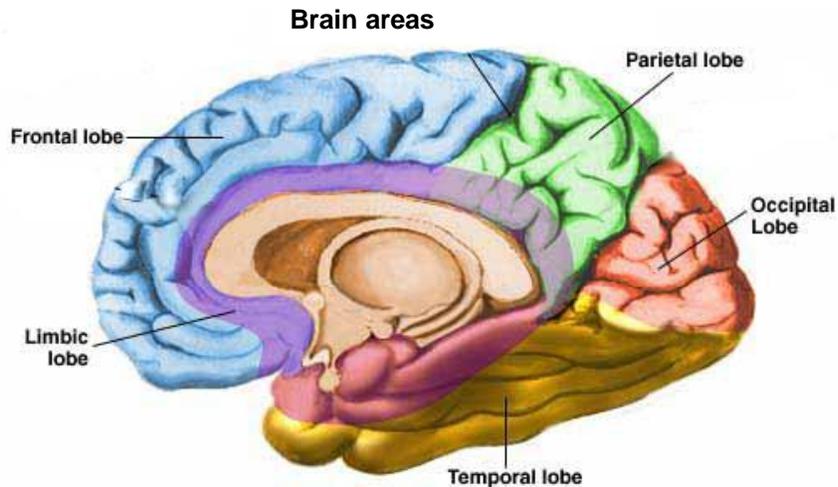
Before we begin, things to consider:

People with dementia are no different than the rest of us. They need caring people to help them stay relaxed, feel safe and maintain their dignity. They want a sense of purpose and significance. Their perception of reality can differ from ours. This does not mean they are wrong; it just means that their context is different.

Disclaimer: This guide is intended for information purposes only and is not intended to be interpreted or used as a standard of medical practice.

About your brain

Changes in a person's behaviour can be a sign of damage to the brain. Below are descriptions of each area of the brain, its function and how damage can cause specific changes.



Limbic System

- Affected early in Alzheimer's disease
- Involved with memory and emotion
- Links the lobes of the brain, enabling them to connect behaviour with memories
- Controls emotion and basic needs, such as sleeping and eating

Hippocampus and Temporal Lobes

- The Hippocampus processes verbal and visual memory. Verbal memories relate to what we read, say or hear; visual memory lets us recognize objects, faces and places to guide us around our environment.
- Temporal lobes control new learning and short-term memory.

Parietal Lobes

- Help us sequence actions, such as getting dressed in the right order or starting and driving a car
- Control our ability to understand spatial information, such as our location in a specific environment and where other objects are

Frontal Lobe

- Initiates activity and lets us plan and organize our actions
- Regulates social judgement and behavior, such as knowing appropriate behaviour for a situation, interpreting others' feelings and monitoring our actions

Occipital Lobe

- Controls vision and the ability to see and combine colours, shapes, angles and movement into meaningful patterns

What happens to the brain with dementia?

- **Loss of language** – The person with dementia may lose the ability to speak or comprehend language. Care partners often fill in the blanks. You may be right some days but not others, frustrating you both.
- **Loss of recognition** – The person with dementia may lose the ability to recognize people, usually in the order they came into his life. Those who entered first, such as during childhood, are the last forgotten and those who entered last, like grandchildren, the first. As the disease progresses, your friend will only remember his remote past.
- **Loss of purposeful movement** – The person with dementia will lose the ability to plan, sequence and execute the steps of a particular task. For example, when getting dressed, she may put on her pants on first, then her underwear.
- **No knowledge of your disease** – “You don’t know that you don’t know.” She is not in denial; she believes she has the same abilities as always. She lacks the insight to know she needs help and is more likely to resist care.
- **Loss of perceptual acuity** –Your family member can experience hallucinations (seeing things that aren’t there) or, more often, illusions (misperceiving what is there). For example, clothes on a coat hook may be interpreted as a person, particularly when shadows form late afternoon or early evening.
- **Loss of initiative** – While often mistaken for being “lazy” or “sleepy,” loss of initiative is common and begins early. She may lose interest in participating in activities. For example, she may sit all day in silence with her chin on her chest, but if approached she makes eye contact and smiles.
- **Loss of memory** – Your fellow resident is losing her short term memory, sensory memory, long-term memory, habitual memory and unconscious memory. She has no control over this. Awareness of her loss will vary day to day and moment to moment.

Responsive behaviours: What are they and why do they happen?

“Responsive behaviours” is a term, preferred by persons with dementia, representing how their actions, words and gestures are a response, often intentional, that express something important about their personal, social or physical environment.

They are the result of changes in the brain affecting memory, judgement, orientation, mood and behaviour.

Responsive behaviours follow these principles:

1. All personal expressions (words, gestures, actions) have meaning.
2. Personal expressions communicate meanings, needs and concerns.
3. To understand their meaning, you must consider the factors influencing his behaviour (physical, emotional and environmental elements etc.).

When someone exhibits a responsive behaviour, reflect on whether it is a problem for the person diagnosed or for *you*? Will the “solution” cause more anxiety? Will changing your expectations affect “the problem”?

While the guide offers strategies for “in the moment” behaviours, think about their true meaning. Consider these questions regarding what happened *before, during and after* the event:

- **Physical** – Are her basic needs met? Is she in discomfort or pain? What changes in her physical condition do you see (e.g. grimacing, eating patterns, energy level)?
- **Intellectual** – Has he experienced recent changes in his memory? Has he been showing impulsive behaviour (swearing, sexual behaviour)? Is he struggling with speech or sequenced tasks (getting dressed)?
- **Emotional** – Have you noticed increased tearfulness or anxiety? Does he seem lonely? Has he exhibited any new unusual behaviour (e.g. suspicious of others)?
- **Capabilities** – Can your Mom do more than you realize? Does your husband understand that he may need help?
- **Environment** – Is there too much noise or too large of a crowd around your friend? Is the lighting poor, making it hard for him to navigate? Is there *enough* stimulation?
- **Social** – Do her childhood, early adulthood or employment experiences offer insight? What do you know about his religion or culture?
- **Actions of others** – What are you doing or not that may contribute to her behaviour?

A responsive behaviours philosophy needs to:

- Understand the meaning of personal expressions (words, gestures, actions).
- Understand the layered nature of these expressions, including at the individual level (subjective experience of the physical body, cognition, emotional experiences, spirituality and cultural beliefs), the experience of the social environmental (the nature of caring and interpersonal relationships and broader cultural issues such as organizational policies and practices) and the experience of the broader physical environmental (built environment, temperature, lighting).
- Develop skills in active listening, be truly present and communicate using alternative ways.
- Be open, non-judgemental and compassionate.
- Understand the person with dementia and his experiences, the meanings of personal expressions and how best to offer support.

The impact a responsive behaviour can have on family, friends and co-residents:

Families and care partners commonly feel guilt, grief, loss, frustration, helplessness and anger. It's normal if you do too. Try to recognize your emotions as they surface and leave the room. While he no longer has the same ability to communicate, most people with dementia still read body language and respond accordingly.

Use local resources (your long-term care home's Family Council, Residents' Council, Social Worker, your local Alzheimer's Society etc.) for support and encouragement. **You are not alone.** Many have walked this path before you and are willing to share if you let them.

“The very biggest lesson I’ve learned is to see things through my husband’s perspective, not my own.”

~Judy Southon, Family Care Partner

Specific kinds of responsive behaviours and what to do when they occur:

In the following pages are examples of specific responsive behaviours and what to do/not do when addressing them. The most common responsive behaviours are:

- General restlessness or agitation
- Pacing or aimless wandering
- Sexual behaviour or behaviours perceived as sexual
- Sundowning
- Constant unwarranted requests for help or attention
- Repetitive sentences or questioning
- Outbursts of anger
- Cursing or verbal aggression
- Seeing things that aren't there
- Paranoia
- Screaming
- Complaining or whining
- Grabbing onto people
- Difficulty with saying goodbye

As stated earlier, the tips and strategies in this guide are suggestions; dementia affects everyone differently at different times.

Ultimately, we can't expect the person with dementia to change; ***we must do the changing.*** We need to understand the disease, be patient and accept who the person is *in this moment.*

If a responsive behaviour begins to impact the quality of life of your family member or those around him (co-residents), consult with the professional staff to adjust his plan of care.

It is important to note that if your personal safety is at risk, leave the room for a safer place, even the hallway. Don't get into a position where you can't leave the room. Once you've left, get staff assistance immediately.

Agitation

Possible triggers/causes:

- Environmental, such as changes to living arrangements or in caregivers
- Fear of bathing, unknown surroundings or having clothes changed
- Dehydration
- Fatigue
- Feeling overwhelmed or confused

Strategies:

- Redirect person's attention; remain calm and positive.
- Use visual and verbal cues (gestures).
- Simplify tasks and routines.
- Whenever possible, give him options. But offer one or two choices to avoid overwhelming him. (e.g. do you want to wear this blue shirt or this red shirt? vs. what shirt do you want to wear?).

Example: During a visit with his wife, Jim fidgets, picks at his clothes and seems restless. He can't sit still and his wife is getting upset with his behaviour.

Don't: Ask him to stop picking, tell him to calm down or raise your voice.

Do: Give him something to hold, distract his attention with music, talk about a happy moment in his life or go for a walk. Consider the environment; is it too noisy or bright? What time of the day is it? Is he tired?

“He is not the problem. He has a problem.”

~Sharron Cooke, the voice of a resident

Wandering

There are different kinds of wandering. Active wandering includes pacing, searching for something or attempting to keep busy. Passive wandering occurs when the person seems to pace aimlessly and is easily distracted.

Possible triggers/causes:

- Stress and anxiety
- Inability to recognize people, places or objects
- Desire to fulfill former obligations
- Boredom
- Searching for something familiar
- Her need to find the bathroom, a special person or a lost object

Strategies:

- Encourage movement and exercise to reduce anxiety.
- Maintain regular routines.
- Remove visual reminders (coat, purse, hat) from sight.
- Involve him in productive activities.
- Help her connect with familiar items and objects (photos, personal items).
- Reassure where he is.
- Accommodate wandering. It may be the last independent skill she has.

Example: Susan gets up and wanders the halls of her long-term care home throughout the night. She is often found in another resident's room and is creating a disturbance among those she lives with.

Don't: Ask the nurse to give Susan a sleeping pill before bed.

Do: Address triggers and ask questions about *why* she might be engaging in this behaviour (e.g. is she in need of the washroom? Is she thirsty? Did she used to get up early in the morning?). Make the environment less encouraging to wandering (e.g. put slippers and house coat out of immediate sight), shut the door or ask that a yellow privacy band be placed over her fellow residents' doors. Ensure Susan engages in light exercise throughout the day to increase the need for rest at night.

Sexual behaviours

Interest in sex does not decrease as we age, even when a person has dementia. In some cases, her actions will be interpreted as sexual when she is trying to communicate. When behaviour expresses a sexual desire, give her privacy. She is an adult and has the right to be left alone.

Sexual behaviour involving a couple (when one or both has dementia) is a difficult subject, especially if not with a spouse. While it may be tempting to try to stop the relationship, keep in mind he likely no longer remembers his partner or even being married. Allowing it to continue may hurt his spouse and family, but further responsive behaviours may occur if he is either prevented from seeing his new companion or made to feel guilty. Distraction can work to disengage the behaviour, at least for a period of time.

Please keep in mind that this refers to **consensual** behaviour. If the sexual behaviour is not consensual (i.e. resident to resident or resident to staff member), use the following strategies.

Possible triggers/causes:

- Less control over urges due to changes in the brain
- Disinhibition
- Disrobing because of tight clothing, an overheated room, the need to use the washroom or disorientation of time and space

Strategies:

- Provide privacy.
- Stay calm and don't judge or scold.
- Distract with activities that suggest comfort (cuddling a pet or stuffed animal or looking at family photos) or keep hands busy (folding, sorting or holding stress balls).
- Change his wardrobe with shirts that close in the back or provide suspenders if he takes off his pants.
- If she makes sexual advances on a visitor or co-resident, try to distract her or remove her from the situation.
- Avoid approaching him in ways that might be misunderstood (e.g. stroking his knee or putting your arm around his waist).
- Gently touch or hug the person in a way that will not be perceived as sexual.
- Offer a body pillow to cuddle in bed (if the person goes into other people's beds at night). A stuffed animal or a hot-water bottle wrapped in a towel can also provide comfort and satisfy the need for a warm body.
- Put a pillow on his lap for a barrier between his hands and genitals.
- Contact staff immediately if your physical well-being is in danger.

- Provide her with an apron to wear with pockets full of objects to touch. This might divert her from touching herself or at least allow her to do so more discreetly.

Example: Roger continually removes his pants at the breakfast table, exposing himself.

Don't: Tell him that his actions are inappropriate, restrain his arms or make him feel upset or embarrassed.

Do: Return him to his room quietly and check for physical triggers (e.g. his pants may not be fitting correctly, a tag may be bothersome, the material may be irritating to his skin or he may be hot). Consider his past history. Does he seem irritated or anxious? Consider dressing him in zipperless pants or with suspenders.

Example: Bill masturbates every morning in the common area of the long-term care home, which is causing distress to his fellow residents.

Don't: Yell at him to stop, explain this is inappropriate, restrain his arms or make him feel upset or embarrassed.

Do: Quietly take him to his room, close the door and provide privacy. Offer an activity that may redirect his attention by occupying his hands and mind (e.g. sorting screws from washers, folding washcloths etc.).

Example: James approaches female residents and attempts to grope them as they pass. Most now avoid being in the same room as him or walking down the hallway at the same time.

Don't: Explain that his actions are inappropriate; become angry; restrain his arms or make him feel upset or embarrassed.

Do: If you are a co-resident, inform staff immediately of your concerns and notify them of each situation. Whenever possible, keep your distance, avoid sharing the same space (e.g. hallway) and perhaps buddy-up when you must approach him (e.g. bedroom, dining room etc.). If you see him coming and cannot exit, talk to him (if he was a farmer, ask him what he farmed, where he grew up).

“This [sexual] behaviour is natural. It can happen. Some people think it is bad behaviour, but it’s not.”

~Sharron Cooke, the voice of a resident

Sundowning

When people with dementia become agitated, specifically in the late afternoon and evening, it is known as sundowning. They may become suspicious, upset or disorientated, see or hear things that are not there and believe things that are not true.

Possible triggers/causes:

- End of day exhaustion (mental and physical)
- Boredom, sleeping a lot during the day and lack of routine
- Wanting to go home
- Disorientation
- Mix up between the day and night
- Reduced lighting can cause shadows, often resulting in confusion, fear or anxiety

Strategies:

- Discourage napping or keep naps short.
- Ask recreation staff to schedule calming activities when agitation usually occurs.
- Work with staff to restrict sweets and avoid caffeine at night.
- Provide adequate lighting to help him identify objects and people.
- Provide items of comfort like a favourite pillow or blanket.
- Plan and encourage activities during the day.
- Provide reassurance and reminisce as a distraction.

Example: After a short visit, Hannah struggles to maintain a conversation with her daughter. She becomes upset, paces in her room and says, “I want to get out of here NOW.” Her daughter notes that her mom experienced similar distress yesterday and the day before around 4:30pm, as she arrives for a visit after work.

Don't: Request that Hannah is prescribed a medication to calm her, which results in her sleeping much of the day.

Do: As late afternoon approaches, turn on bedroom lights and lamps. Close drapes to limit shadows. Request a morning exercise program to reduce restlessness in the afternoon. Consult with staff for strategies that provide a sense of purpose, like setting the dining room tables or putting vases out for that evening's meal. Visit in the morning.

Repetition

Repetition is verbal (also referred to as perseverating, where your wife may repeat the same question) or physical (repetitive movements like rubbing hands together again and again). Unfortunately, people who perseverate are often characterized as “attention seekers.” In truth, she has little insight or control over this.

Possible triggers/causes:

- Feelings of insecurity or loss
- Loneliness
- Separation from a loved one
- Under- or over-stimulation
- Inability to express a need (e.g. someone fidgeting with clothes may need to go to the bathroom)

Strategies:

- Distract with activities he enjoys like a walk or snacking.
- Respond to the emotion behind her question.
- Give him something to occupy his hands.
- Consult with staff to see if you can fit the repetitive action into household chores (e.g. dusting the same area over and over again).
- Speak calmly and answer the question like the first time.

Example: Lily continually asks why her mother hasn't visited, even though she passed away many years ago.

Don't: Say things like, “Don't you remember? Your mother died 25 years ago. You know better than that. Your mother would be 113 if she were still alive!” She will respond as if she were hearing it for the first time, every time, and grieve.

Do: Respond to the emotion behind the question. Is she feeling insecure? Family photos and stories often restore a sense of intimacy and feelings of warmth in place of the person.

Example: Adam taps his fingers on the arm of his wheel chair...tap, tap, tap... from morning until bed.

Don't: Ask him to stop repeatedly or restrain his hands.

Do: Ask yourself who is bothered by the behavior. If it isn't bothering anyone else, do nothing! Turn the behaviour into an activity (e.g. give him a cloth and ask for help with dusting) or play music and get his tapping to match the beat.

Anger or aggression

Anger reflects many feelings and occurs for reasons that aren't clear. We can try to figure out why but we must respond to the behaviour.

Possible triggers/causes:

- Fatigue or disruption of sleep pattern
- Grief as his world becomes less and less familiar
- Pain or physical discomfort
- Sensory overload
- Feeling lost, insecure or forgotten
- Fear of a situation or a person he finds threatening
- Dementia may lessen his control over emotions.
- As dementia progresses, he may struggle to express anger and will do so physically (hitting, biting, kicking) or verbally (shouting, name-calling).
- May happen suddenly without any apparent reason or after a stressful event

Strategies:

- Watch for a sudden increase in movement to indicate anxiety.
- Respond in a supportive manner and reassure in a gentle voice.
- Reduce noise.
- Ensure that staff maintain a consistent routine.
- Speak slowly and use repetition.
- Break activities into manageable steps.
- Distract him.
- Approach slowly from the front at the same eye level.
- Leave the room for a "time out." Remember it is the disease, not the person.
- Avoid arguing or expressing anger or irritation, verbally or non-verbally.

Example: You are having dinner with your father. You watch your father struggle to cut his meat and get the food to his mouth. You offer to help and begin to cut his food. He lets you for a minute, but then grabs your wrist and threatens to "smack you if you try that again!" Your father has never laid a hand on you and you are horrified that this just happened.

Don't: Grab his hand and try to force him to let you go, yell in surprise or explain that you were trying to help.

Do: Remain calm and don't react. Let your arm go limp, apologize and distract him with conversation. Once he lets go, give him space to cool down. Later, think about what was behind his anger. Was he embarrassed? Could he have thought you were taking his food?

Hallucinations and paranoia

When someone hallucinates, he sees or hears things no one else does (e.g. kittens walking on the floor). As a rule, if the hallucination is not upsetting, don't intervene. Delusions are beliefs contrary to fact. Delusions remain persistent despite all evidence to the contrary (e.g. a paranoid delusion is that a nurse in the home took all of your money).

Possible triggers/causes:

- Sensory changes (hearing and vision diminishes)
- Medications or physical illness
- Unrecognized environment or caregivers, inadequate lighting
- Disruption of routines
- Removal of items from the person (e.g. money or jewellery)

Strategies:

- Meet with her physician to review medications and schedule hearing and vision tests.
- Seek medical evaluation for illness, infection, bowel impaction, urinary tract infection etc.
- When she is suspicious, look for lost articles and remind her where the valuables are stored. Don't scold for losing or hiding things and keep a spare set of frequently lost items (if possible). Investigate suspicions that might be true.
- Increase lighting in the room.
- Do not directly disagree with a false idea.
- Use physical touch as reassurance.

Example: Kate is fearful at night because she sees spiders crawling on her bedroom walls.

Don't: Tell her nothing is on her walls or say, "You see Kate; nothing is there. Go back to bed."

Do: Validate the fear by saying, "That must be very frightening for you." Do not get angry and argue. This is real to her. Check for shadows that could be misinterpreted as spiders and try to remove them (e.g. increase lighting). Distract with music, exercise, playing cards or photos. It may be useful to see if she has any hearing or vision problems at this time.

Example: Josie is convinced that a staff member has stolen her purse. She always keeps it in her bedside table and this morning it was gone! She is sure that "new girl with the funny eyes" took it.

Don't: Gently explain no one stole her purse and, just like last time, she lost her bag.

Do: Validate her feelings. Try to alleviate the distress (e.g. look for the "stolen" purse and then distract her). Investigate suspicions that could be true. She could be a victim. But if this paranoia continues, have similar purses ready as replacements.

Strategies to enhance communication with people living with dementia

The more dementia progresses, the more difficult conversation becomes. While feeling disheartened is normal, don't give up! Here are helpful tips that might improve the relationship:

- Introduce yourself. It may feel awkward but you can no longer assume that your Dad remembers who you are. (i.e. "Hi Dad, it's your daughter Sarah.")
- Smile.
- Be calm and gentle. You set the mood.
- Use humour.
- Use visual cues for directions (e.g. pointing in the desired location or patting the appropriate chair).
- Go at her pace. People with dementia need more time to respond.
- Give instructions one at a time.
- Use pampering (massage hands, manicure, comb her hair).
- Remember he responds to you and your body language.
- Be flexible and respond to his mood changes.
- If he repeats the same question, answer like the first time.
- Wait for a response.
- Be accepting of inappropriate answers and nonsense words.
- Be aware of your body language. Use it to communicate relaxation and reassurance.
- Try not to argue.
- Do not ask her to reason or problem-solve.
- Do not ask, "Don't you remember?" This can cause agitation.
- Do not correct his ideas or scold him.
- If she experiences a hallucination or delusion, it is best not to re-orientate him, unless it causes harm. For example, your friend tells you that her mother is coming to visit tomorrow. Don't explain she has long passed; instead, distract her with a new topic of conversation.

"They may forget what you said, but they will never forget how you made them feel."

~Carl W. Buechner

Example: “I want to go home.”

How do you feel coming home after a long day? For most of us, it's a sense of relief or contentment. You are in a safe place and surrounded by people and things that put you at ease. When a people with dementia say, “I want to go home,” they want these same feelings.

Possible triggers/causes:

- Fatigue
- Over stimulation
- Asking the person to complete an unfamiliar task

Strategies:

- Watch your tone of voice and body language. Speak calmly and use short sentences.
- The home your wife speaks of may be where she grew up. Use this to start a conversation: “Where was home? Did you grow up in the city or the country? What was your favourite thing to do when you were there?” Even if you know the answers, still ask.
- Acknowledge his anxiety.
- Provide reassurance.

Example: Frank has recently moved to a long-term care home and is constantly asking to go back “home.”

Don't: Explain to him that this is his home now and he has nowhere else to go.

Do: Acknowledge his feelings. “It must be hard to want to go home. Can you tell me about your home? Where did you live? What did you like doing there as a kid? Do you have any siblings?” Reminisce even if you know all the answers; you want him to feel safe and at ease as if he was at home. You might even hear a new story!

Creating a meaningful visit

As dementia progresses and responsive behaviours increase, visits become challenging. You may struggle to connect with her. Below are activities for you and your friend. Like the other tips, what works one day may not the next. Learn to observe (body language, tone of voice) and listen, even if he can no longer say words. *Remember to be flexible and change strategies when necessary.*

- Familiarize yourself with the facility`s schedule and the person`s routine. When do they have lunch? When do they nap? For most, morning visits are better than evenings.
- Visits between a half-hour and an hour are best, especially for those who tire easily.
- Give a manicure, massage hands and feet with cream, wash and set hair, give a facial, shave or apply make-up. Such activities help the person to feel cared for.
- Look at newspapers and magazines together, taking time to read and discuss items depending on his capacity and interest.
- Help with phone calls, birthday cards and gifts. Try to let her participate.
- Keep a family diary or visitor`s book in her room. Visitors can write notes, providing a social record. They can leave messages for each other or record observations.
- Plant an herb garden in window sill pots.
- Exercise together.
- Create a sensory box organized by theme, like jewellery, cookbooks, spices, newspaper clippings, gardening, old family pictures, potpourri, fishing, farming, sewing, etc.
- Go for a walk or drive.
- Go for a favourite treat or bring one to her.
- Look through family pictures. Be sure to say “tell me more” when he talks about a memory.
- Read out loud.
- Listen to music.
- Make a scrapbook.
- Draw maps of travels, home or garden to spark reminiscence.
- Attend religious services.
- Bring a child or pet along and just watch.
- Eat in the dining room or outside to make him feel like the host.
- Bring a bouquet of flowers and arrange them in a vase together.

Saying goodbye after a visit

A family member becoming distraught when you attempt to leave isn't a responsive behaviour. But it is common and causes anguish for you both. To ease the transition:

- Give a reason. If your spouse knows that you have to leave (e.g. you have a doctor's appointment or need to pick up your child), he will be more accepting of it. This suggests that you *have* to leave but do not *want* to.
- Plan your departure to coincide with an event (e.g. lunch or a planned activity). Get your Mom settled there and quietly leave. You don't need to announce your departure.
- Plan a quick exit. Compared to a longer goodbye, your wife has less time to digest it.
- Don't say "goodbye," which has a sense of finality. Try "see you soon" or "bye for now."

Example: Dora becomes distraught and grabs her husband when he goes to leave after a visit. Her husband feels guilty and questions whether moving her into a long-term care home was the right decision.

Don't: Explain that you will be back in a few days and she doesn't need to cry.

Do: End your visits in time for her daily activity session. Walk her there and even join in for a round or two. When she is enjoying herself, say a quick "see you soon" in her ear and leave. Ensure that the staff member running the session knows of your intent.

"If I could put a stop to this behaviour, I would"

~ Art Garrison, Person living with dementia

Your role as a care partner in the long-term care home

Care partners feel many emotions when a family member moves into a long-term care home. Some are relieved to share the care while others feel guilty, especially if promises were unkept. Some no longer know what role to play. But *you have not lost your role; you are sharing the responsibility of care with others.*

Now you can focus on giving him what only you can. You are once again his wife or son instead of his nurse, social worker, case manager and banker. You can also share your knowledge about his life, daily routines and your own coping strategies. Include these in his plan of care so that all who care for him have access to it.

Another option is getting involved with the long-term care home's Family Councils or Residents' Councils. Both encourage mutual support among members, facilitate learning about issues related to long-term care and allow individuals with common goals and concerns to speak with a collective voice. These councils provide support with challenging situations like responsive behaviours. Speak to the administrator at your long-term care home for more information or consult the reference list at the end of this guide.

“Moving a family member into a long-term care home is not something you do to them; it is something you do for them.”

~ Education Department,
Alzheimer Society of Kingston, Frontenac, Lennox & Addington

Communicating and working with the staff

You are now a partner in care with the staff. Your role is to inform, advise, recommend and encourage the best quality care for your family member.

- Get to know the staff and maintain regular contact.
- Find out about daily routines, programs and services. Obtain a calendar of activities and participate when you can.
- Attend care conferences, which occur six weeks after admission and then annually.
- Have realistic expectations. Differences from the care you gave are inevitable.
- Help develop the plan of care, which lays out a strategy for the resident's needs.
- Day to day notes or a communication book in the room can ensure important information is passed on to the staff on all three shifts.
- Participate in the Family Council where the day to day running of the home is discussed.

Difficult discussions

At times, you must have a difficult conversation with a staff member. It could be because a fellow resident is creating distress for mother or you believe a staff member is failing to respond appropriately to her.

When raising concerns, an established relationship with one or two members of the team caring for wife is essential. To create one, try to keep in touch with the staff and be ready to discuss issues as they arise.

Communication and documentation are key components in resolving conflicts and expressing concerns. The best methods to help meet your needs and your mother's are to:

1) Wait 24 hours after an event, unless you fear for your family member's safety, to allow you to reflect before further action. If you feel an event merits discussion, ask yourself the following questions and write your answers, which will help you present your concerns. Remember to be frank but respectful.

- What troubles me about the care? (e.g. my wife gets upset around the same time each day and the staff just seems to ignore her).
- Where does this problem occur? (e.g. in her room, right before dinner).
- When did I realize that something wasn't right? (e.g. I've observed this for a few weeks).
- Why is this happening? (e.g. she may be sun downing, but I think the lack of attention from staff makes it worse).
- How often does this problem occur (e.g. every day)?
- Clarify what you want (e.g. I want the staff to take my wife's behaviour seriously and recognize her distress; I want them to do something specific to help her).

- Clarify what you don't want. (e.g. I don't want an argument with the personal support worker that creates a bad relationship. I worry that they will take it out on my wife).
- Think about what you want and don't want and search for a creative and productive option. (e.g. how can I have a conversation with the staff to ensure they listen and respond to my wife and avoid creating bad feelings)?

2) Present your written concerns to the right person and wait to hear back. Try not to voice them to other staff members. Keep it between you and your contact.

Converting ideas into actions

How do you ensure change from your concerns and a meeting? The first step is to have clear expectations about how decisions will be made. The second step is to consider the following to turn a decision into action:

- Who?
- Does what?
- By when?
- How will you follow up?

This allows all parties to leave the meeting with the next steps, who will initiate them and what the follow up will be.

You can also consult with the Family or Residents' Council of the long-term care home. They work to improve quality of care in the home with management.

Councils provide information and support when dealing with an issue. Connect with your home's Family or Residents' Council for more information on sharing concerns.

Making an official complaint

Long-term care in Ontario is governed by the regulations of Ontario's Long-Term Care Homes Act (2007). This means that under law your role as a care partner can be direct. You can be involved in:

- Care conferences
- Discussions about the care plan
- Reassessments of needs
- The identification of behavioural triggers
- Planning intervention strategies

There are also requirements for responsive behaviours for the home. While ideally a positive partnership between the staff and the care partners exists, a provision in the law allows for complaints, both oral and written, and requires management to respond. The Act also provides for Resident and Family Councils, which are both additional sources for bringing concerns and suggestions to management.

Final words

Who better to provide an end to this guide than those with dementia? While their voices may no longer be heard, their words will live on.

- Please don't correct me. I know better; the information just isn't available to me at the moment.
- Remember my feelings are intact and I get hurt easily.
- I usually know when the wrong words come out and I'm as surprised as you are.
- Try to ignore my off-hand remarks that I wouldn't have made in the past. Focusing on it won't prevent it from happening again. It just makes me feel worse.
- I may say something that is real to me, but may not be factual. I am not lying, even if the information is not correct. Don't argue. It won't solve anything.
- If you can anticipate that I am getting into difficulty, please don't draw attention to it. Try to carefully help me through so nobody else will be aware of the problem.
- I don't mean to frustrate you. I know you get impatient and tired of telling me things three times in a row. Please be patient.
- Ask me what I think or want. Don't assume you know.
- Believe I still love you, even if I am having trouble showing it.

(Members of Memory Problems, An early stage support group in the North/Central Okanagan Region of the Alzheimer Society of B.C., Canada)

"You do not need to be perfect to be loved."

~Alice Walker

Additional resources

- Alzheimer Knowledge Exchange: www.akeresourcecentre.org
- Alzheimer Society of Ontario: www.alzheimerontario.ca
- Alzheimer Society of Toronto: www.alheimertoronto.org
- Canadian Coalition for Seniors' Mental Health: www.ccsmh.ca
- Canadian Dementia Resource and Knowledge Exchange (CDRAKE):
www.dementiaknowledgebroker.ca
- Concerned Friends of Ontario Citizens in Care Facilities:
www.concernedfriends.ca
- Family Councils' Program: www.familycouncils.net
- Java Music Club: www.javamusicclub.com
- Kenneth G. Murray Alzheimer Research and Educational Program (MAREP):
www.marep.uwaterloo.ca
- Montessori Methods for Dementia: www.dementiability.com
- Ontario Association of Residents' Councils: www.ontarc.com
- P.I.E.C.E.S. Canada: www.piecescanada.com

More information and a full version of this guide is available at:
www.ShiftingFocus.ca
or by calling the **Alzheimer Society** at 211

References

About Your Brain:

- Alzheimer Society of Canada: www.alzheimer.ca/en/About-dementia/About-the-brain

What happens to your brain when you have a dementia?:

- Alzheimer Society of Canada: The 7 A's of Dementia: www.alzheimer.ca/en/About-dementia/Dementias/What-is-dementia/Seven-A-s-of-dementia

Responsive Behaviours: What are they and why do They Happen?:

- MAREP: <https://uwaterloo.ca/murray-alzheimer-research-and-education-program/research/projects/responsive-behaviours>

Responding to Responsive Behaviours:

- P.I.E.C.E.S.: <http://u-first.ca/u-first-curriculum/about-p-i-e-c-e-s>

A Responsive Behaviours Philosophy:

- MAREP: <https://uwaterloo.ca/murray-alzheimer-research-and-education-program/research/projects/responsive-behaviours>

Specific kinds of Responsive Behaviours & Strategies for When They Occur:

- Alzheimer Society of Canada: www.alzheimer.ca/en/About-dementia/Understanding-behaviour
- Managing and Accommodating Responsive Behaviours in Dementia Care, A Resource Guide for Long Term Care, MAREP, 2005
- Alzheimer Society of Toronto, Behaviours www.alheimertoronto.org/behaviours

Communicating & Working With the Staff:

- After the Move: Communicating & Working With the Staff: Alzheimer Society of Ottawa and Renfrew County, Nov. 2012

Difficult Discussions:

- Friends of Residents in Long term Care: www.forltc.org/cms/getting-hel/resolving-a-conflict
- Patterson, Kerry et al. Crucial Conversations: Tools for Talking When Stakes Are High. McGraw Hill Professional, 2011. Print.

Strategies to Enhance Communication with People Living With Dementia:

- RAO: Long Term Care Mental Health Framework: http://www.toronto.ca/ltc/pdf/how-to-guide_mental-health.pdf
- Alzheimer Society of Canada: www.alzheimer.ca/~media/Files/national/brochures-day-to-day/day_to_day_communications_2010_e.ashx

Final words:

- Members of Memory Problems, An early stage support group in the North/Central Okanagan Region of the Alzheimer Society of B.C., Canada: www.alzheimerbc.org/getdoc/19c68af4-e2d7-4c5c-b058-ab4db3ba54b6/MemoryProblemsBooklet.aspx

Acknowledgements

The Alzheimer Knowledge Exchange is grateful to the following health care professionals, resident advocates, care partners and those living with dementia that were members of the advisory panel and participated in the production and review of this guide:

- **Jillian McConnell**, Knowledge Mobilization Lead and Project Coordinator, Canadian Dementia Resource & Knowledge Exchange (CDRAKE)
- **Sharron Cooke**, Vice President, the Ontario Association of Residents' Council; President of the Residents' Council of Newmarket Health Centre
- **Art and Myrna Garrison**, care partner and person with dementia
- **David Harvey**, Chief, Public Policy and Program Initiatives, Alzheimer Society of Ontario (ASO) and Co-Chair of the Alzheimer Knowledge Exchange (AKE)
- **Dr. Phyllis Hymmen**, Former President, Concerned Friends; Care partner
- **Dr. J. Kenneth LeClair**, Providence Care & Queen's University, Chair & Co-Chair of the AKE and CDRAKE
- **Dee Lender**, Director of Education, Ontario Association of Residents' Councils
- **Lisa Loiselle**, Assoc. Director of Research, The Kenneth G. Murray Alzheimer Research and Education Program, University of Waterloo (MAREP)
- **Caroline Mole-Brooks**, President, Residents' Council, Hawthorne Place Care Centre; Board Member for the Ontario Association of Residents' Councils
- **Samantha Peck**, Program Coordinator, Family Councils' Program
- **Vicki Poffley**, Director of the Alzheimer Society of Kingston, Frontenac, Lennox and Addington
- **Shawn Souder**, Manager, South East Local Health Integration Network , Behavioural Supports Ontario Project
- **Judy Southon**, Chair, Home Advisory Committee, Seven Oaks long-term care home; Certified in Montessori Methods for Dementia & Care Partner
- **Kim Wilson**, Executive Director of Canadian Coalition for Seniors' Mental Health
- **Ryan MacKellar**, Communications Assistant, Alzheimer Society of Ontario
- **Karen Parrage**, Resources Coordinator, Alzheimer Knowledge Exchange

More information and a full version of this guide is available at:
www.ShiftingFocus.ca
or by calling the **Alzheimer Society** at 211

This guide is brought to you by:



Alzheimer Society
ONTARIO



Behavioural Supports Ontario

Contributing partners include:

- Alzheimer Society of Kingston, Frontenac, Lennox & Addington
- Canadian Coalition for Seniors' Mental Health
- Concerned Friends
- Family Councils' Program
- Murray Alzheimer Research and Education Program
- Ontario Association of Residents' Council
- South East Local Health Integration Network