


shifting focus




A Guide to Understanding Dementia Behaviour

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Shifting Focus

- Brief overview of the guide
- Goals
- Disclaimers
- Initial steps
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- Content of the guide
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Shifting Focus: Brief Overview

What is it?

- An information guide that is meant to be used as a tool by the family members, friends and co-residents of those who live in a Long Term Care Home and are presenting with responsive behaviours that create unease or distress.

Shifting Focus: Brief Overview

This guide seeks to help those care partners, volunteers & co-residents who are unsure on how to respond to some of the new situations and/or remarks that a person with dementia might present.

The goal of the guide:

Assist care partners and fellow residents by:

- Providing information about the brain and how dementia affects it and subsequent behaviour
- Defining responsive behaviours
- Suggesting ways in which to recognize a resident's actions and their respective meaning

The goal of the guide:

- Provide strategies on how to respond to specific responsive behaviours
- Offer ways to enhance communication with people living with dementia and create a meaningful visit
- Inform care partners on their role in the Long Term Care (LTC) Home
- Provide suggestions on how best to communicate and work with the LTC home staff

Disclaimers:

- But remember these are suggestions. Dementia is always changing and unique for each person. One suggestion may work today, but not tomorrow.
- 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), you should 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 and get staff assistance immediately.

Initial Steps:

- A thorough literature review was conducted to ensure that similar-minded guides were not already available to the general public. What we found:
 - Considerable amount of information geared toward care partners who are caring for a family member / friend at home; however little information was available to those who had members of their family living in a LTC home.
 - There was a significant lack of information directed to those who are sharing a residence (i.e. roommate / dining partner etc.) with a person who had been diagnosed with a dementia and was presenting with responsive behaviours.

Initial Steps:

- Once it was determined that there was a significant need, a general outline of what was to be included, the target audience, the goal of the document etc., was drafted in consultation with clinical and administrative leads.

Advisory Panel

- The panel met monthly to discuss the content and direction of the guide.
- Upon completion, all members endorsed the guide and gave their support for its publication.
- Members of this advisory panel included representatives and/or executive members from:
 - Ontario Association of Residents' Council
 - Public Policy and Program Initiatives
 - Alzheimer Society of Ontario (ASO)
 - Alzheimer Knowledge Exchange (AKE)
 - Concerned Friends
 - Canadian Dementia & Resource Knowledge Exchange (CDRAKE)

Advisory Panel

- MAREP (The Kenneth G. Murray Alzheimer Research and Education Program – University of Waterloo)
- members of local LTC home residents' councils and home advisory committees
- Family Councils' Program
- Alzheimer Society of Kingston, Frontenac, Lennox & Addington (KFL&A)
- Canadian Coalition for Seniors' Mental Health (CCSMH)
- Former and current care partners
- current residents of long term care homes
- Individuals diagnosed with a dementia.

Field Testing

- Once the final draft was complete and all members of the panel had signed off, the guide was sent out for field testing.
- Participants included:
 - Dr. Joel Sadavoy (*Head of Geriatric Psychiatry, the Reitman Centre for Alzheimer's support and training, and head of community psychiatry services at Mount Sinai Hospital*) and team.
 - Clients of the Alzheimer Society of Kingston, Frontenac, Lennox & Addington
 - BSS Operations Team (Ontario)
 - Four area LTC homes in the South East LHIN
 - BSO staff and care partners, North East LHIN
 - Clinical leads of Alzheimer Knowledge Exchange, Canadian Dementia Resource & Knowledge Exchange
 - Alzheimer Society of Ontario

Content: *About your brain*

- Brief descriptions of each area of the brain, its function and how damage can cause specific changes:
 - Limbic system
 - Hippocampus and Temporal Lobes:
 - Parietal Lobes
 - Frontal Lobe
 - Occipital Lobe

Content: *About your brain*

- What happens to your brain when you have a dementia?
 - Loss of language
 - Loss of recognition
 - Loss of purposeful movement
 - No knowledge of your disease
 - Loss of perceptual acuity
 - Loss of initiative
 - Loss of memory

Content:
Defining Responsive Behaviours:

- What are they and why do they happen?
- Reflect on whether the behaviour is a problem for the person diagnosed or *for you* and will the “solution” cause more anxiety?

Content:
Defining Responsive Behaviours:

Consider these questions before, during and after the event:

- Physical – Does she seem to be in any discomfort or pain?
- Intellectual – Is he struggling with speech or sequenced tasks (getting dressed)?
- Emotional – Have you noticed increased tearfulness or anxiety?
- Capabilities – Can she do more than you realize?
- Environment – Is there enough stimulation?
- Social – Do her childhood, early adulthood or employment experiences offer any insight?
- Actions of others – What am I doing or not doing?

Content:
Responsive Behaviours & Strategies

- Identifies specific Responsive Behaviours and what to do/not do when addressing them:
 - Agitation
 - Wandering
 - Sexual behaviour or behaviours perceived as sexual (consensual / non-consensual)
 - Sundowning
 - Repetition (verbal and physical)
 - Anger or aggression
 - Hallucinations & Paranoia

Content: *Responsive Behaviours & Strategies: 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 be 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

Content: *Responsive Behaviours & Strategies: Wandering*

- 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 him.
 - Accommodate wandering. It may be the last independent skill she has.

Content: *Responsive Behaviours & Strategies: Wandering*

- **Case Study:** 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:**
 - Request the nurse give Susan a sleeping pill before bed.
 - Do:**
 - Address triggers and ask questions about why she might be engaging in this behaviour (i.e. 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 (i.e. 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.

Content: *Responsive Behaviours & Strategies - "I want to go home:"*

- **Possible Causes/Triggers:**
 - Fatigue
 - Over stimulation
 - Asking the person to complete an unfamiliar task

Content: *Responsive Behaviours & Strategies - "I want to go home"*

- **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?"
 - Acknowledge her anxiety.
 - Provide reassurance.

Content: *Responsive Behaviours & Strategies - "I want to go home"*

- **Case Study: Frank has recently moved to a long term care facility 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!

Content: *Responsive Behaviours & Strategies – Saying Goodbye after a visit*

- **Strategies** to ease the transition:
 - Give a reason. If your spouse knows that you have to leave (i.e. you have a doctor's appointment or 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 (i.e. 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."

Content: *Responsive Behaviours & Strategies – Saying Goodbye after a visit*

Case Study: Dora becomes distraught and grabs her husband when he goes to leave after a visit. Her husband feels guilty too 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.

**Content:
*Strategies to enhance communication***

- Introduce yourself
- Go at her pace. People with dementia need more time to respond.
- Remember he responds to you and your body language.
- Wait for a response.
- Be accepting of inappropriate answers and nonsense words.
- Do not correct his ideas or scold him

Content: *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:
 - Relief
 - Guilt
 - Unsure of what role they now play
- 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. Y
 - 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.

Content: *Your role as a Care Partner in the Long Term Care Home*

- Get 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
- Allow individuals with common goals and concerns to speak with a collective voice.
- Provide support with challenging situations like Responsive Behaviours.

Content: *Communicating & 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.

Content: *Communicating & working with the staff*

- 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.

Content: *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.

Content: *Difficult discussions:*

The best methods to help meet your needs and those of the person living in LTC are to:

1. Adhere to the 24 hour rule, unless you fear for your family member's safety, and reflect before further action.
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.

Content: *Difficult discussions:*

If you feel an event merits discussion, ask yourself the following questions:

- What troubles me about the care?
- Where does this problem occur?
- When did I realize that something wasn't right?
- Why is this happening?
- How often does this problem occur?
- Clarify what you want.
- Clarify what you don't want.
- Search for a creative and productive option.

Content: *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?
- You can also consult with the Family or Residents' Council located within the Long Term Care Home. They work to improve quality of care in the Long Term Care Home with management.

Content: *Final Words*

- 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.
- Try to ignore my off-hand remarks that I wouldn't have made in the past. If you focus on it, 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.
- 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.

Distribution:

- **2 versions** of the guide will be made available:
 - **Long version:** the complete 25 page document; set to be released by 1st of November.
 - **Short version:** 8 page booklet that focuses specifically on responsive behaviours and the respective strategies for each behaviour only; set to be released within the next 2 weeks.

Distribution:

- Participants of today's webinar will have access to both the long form and the short form today via the AKE website.

Distribution:

- Short, 10 page version will be distributed and promoted through a variety of avenues, including:
 - Publication and dispersion of 10,000 that is to be distributed to local and provincial Alzheimer societies, all Long term care homes within the province of Ontario, regional and local partners of the Alzheimer Society of Ontario (ASO) and Alzheimer Knowledge Exchange (AKE).

Distribution:

- Long, full version will be sent out to:
 - All LTC homes within the province of Ontario, regional and local partners of the Alzheimer Society of Ontario (ASO) and Alzheimer Knowledge Exchange (AKE) and advisory panel partners via a **pdf**.

Distribution:

- A url: **ShiftingFocus.ca** is also being created:
 - Access tip sheets
 - Videos featuring a series of short clips offering practical strategies of how to respond to a variety of responsive behaviours will also be available on the website in the future.
 - Information on how you access both the short and long versions.

Questions?

