A Guide to Understanding Dementia Behaviour

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Shifting Focus:
A Guide to Understanding Dementia Behaviour

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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 (LTC) and are presenting with responsive behaviours that create unease or distress.
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.
Goals 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 and providing ways in which to recognize a resident’s actions and their respective meaning.
  • Providing strategies on how to respond to specific responsive behaviours.
Goals of the guide:

- 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 and volunteers.

NB: While all scenarios and subsequent strategies provided in the guide take place in the LTC setting, much of the guide would easily translate and be useful in a community / home environment.
Things to Consider

• 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.
Research & Development:

I. A thorough literature review was conducted to ensure that similar-minded guides were not already available to the general public.

Determined:

• 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.
Research & Development:

II. 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.
Research & Development:

III. The author initiated the assistance of others who had a vested interest in this guide and requested their participation in the form of an advisory panel.

• This 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.
Advisory Panel:

- Geriatric Psychiatrists: Drs. Ken LeClair & Dallas Seitz
- 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)
- 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.
IV. Upon completion and sign off from all panel members, the guide was distributed throughout the province of Ontario for field testing with a request to complete a survey following its review.

Participants included:

- Clinical staff of the *Reitman Centre for Alzheimer’s support and training including director* Dr. Joel Sadavoy
- Clients of the Alzheimer Society of Kingston, Frontenac, Lennox & Addington
- BSS Operations Team (Ontario)
- Four LTC homes in the South East Local Health Integration Networks
- Behavioural Supports Ontario staff and care partners, North East Local Health Integration Networks
- Clinical leads of Alzheimer Knowledge Exchange, Canadian Dementia Resource & Knowledge Exchange
- Alzheimer Society of Ontario
Survey Questions & Responses
(mean response):

Content: 1=poor 2=fair 3=good 4=very good 5=excellent:

– Rate the clarity of the content (4.35)
– Rate the usefulness of the content within the Family and Friend Resource Guide (4.25)
– Rate the impact you believe this guide may have (4.25)

Language Level: 1=poor 2=fair 3=good 4=very good 5=excellent:

– Given its expected audience, how would you rate the language level chosen for the Shifting Focus Guide? (4.0)
– Do you feel the guide is presented in a manner that would be easy to understand for most family members and/or friends? All participants selected AGREE
Survey Questions & Responses
(mean response):
Would there be any further resources you would add to the existing Resource List?

- Gentle Persuasive Approach (GPA) training
- Dementia Network
- Reitman Centre

Suggested methods of dissemination:
- Family Physicians office (including Family Health Teams)
- Magazine advertisements
- Alzheimer Chapters
- Day Programs
- Community Care Access Centres
Survey Responses:

Option to add additional comments (What did they like most? What needs improvement? Is there anything that needs to be added?)

What did you like most about the guide?

- The simple language used. When I looked at the guide - size, content etc - I felt discouraged at the task of reading it. However, I quickly realized that it was written for me - an average caregiver and not for professionals. I am sincere in relating to you the task I had in studying this guide. It is extremely well done. If your goal was to disseminate this guide to all caregivers, you have attained it.
Survey Responses:

Option to add additional comments (What did they like most? What needs improvement? Is there anything that needs to be added?)

What did you like most about the guide?

The most that I liked about this guide is that the language is very appropriate for family and caregivers. I also like that examples are used for the responsive behaviour.

I really like the 'Communicating & Working with the Staff Section.' I believe most of the caregivers struggle with how to communicate and advocate for their love ones with staff.
Survey Responses:

Option to add additional comments (What did they like most? What needs improvement? Is there anything that needs to be added?)

What did you like most about the guide?

I really enjoyed the way the guide was broken down to easily follow and understand. Specifically, I liked how each described behaviour was separate and could be printed off and provided separately from the rest. Since there is an overwhelming amount of reading for a caregiver, having the ability to break it down according to their needs is very valuable. I also liked how the information was mostly provided in a point-form format for a quick read.

Also, having “ineffective” strategies listed is important so caregivers are aware of any strategies being done by the LTCF may not be the best.
Survey Responses:

Option to add additional comments (What did they like most? What needs improvement? Is there anything that needs to be added?)

“The guide explained how to communicate clearly with staff in LTC as well as the person with Dementia, whether it is verbal or non-verbal. I also liked that the guide gave an explanation about different responsive behaviours and certain interventions or strategies to try.”
Shifting Focus:
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(full version)

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Shifting Focus: A Guide to Understanding Dementia Behaviour (condensed version)

Hallucinations
Kate becomes fearful and anxious at night because she sees spiders crawling on her walls.

Do
- Validate the fear, "That must be frightening."
- Remove shadows that could be misinterpreted (e.g. increase lighting).
- Distract her with music, exercise, playing cards or photos. It may be useful to see if she has any hearing or vision problems.

Paranoia
Josie is convinced that someone has stolen her purse.

Do
- Validate her feelings.
- Alleviate the distress by looking for the "stolen" purse and then distract her with another activity.
- Investigate suspicions that could be true. She could be a victim.
- If this paranoia continues, have similar looking purses available as replacements.

Don't
- Tell her nothing is on her walls. "You see, nothing is there. Time to go to bed."
- Get angry with her.
- Argue.

Don't
- Explain no one has stolen her purse and, just like last time, she lost her bag.

"The very biggest lesson I've learned is to see things through my husband's perspective, not my own."
- Judy Toulben, Family Care Partner
**Shifting Focus: A Guide to Understanding Dementia Behaviour**

- **2 versions** of the guide are available:
  - **Full version**: 28 page booklet
  - **Short version**: 8 page booklet:
    - a definition of Responsive Behaviours
    - why these types of behaviours tend to happen
    - strategies of some of the most common responsive behaviours:
      - agitation
      - Wandering
      - sexual behaviours
      - Sundowning
      - Hallucinations & paranoia
      - “I want to go home”
    - communication strategies.
Shifting Focus – Content:

• **About your brain**: Brief descriptions of each area of the brain, its function and how damage can cause specific changes to the Limbic system, Hippocampus and Temporal Lobes, Parietal Lobes, Frontal Lobe & Occipital Lobe.

• **What happens to your brain when you have a dementia**: Loss of: language, recognition, purposeful movement, perceptual acuity, initiative, memory and having no knowledge of your disease.
Shifting Focus – Content:

• Defining Responsive Behaviours:
  • What are they and why do they happen?
  • Ask care partners / co-residents to reflect on whether the behaviour is a problem for the person diagnosed or for “you” and will the “solution” cause more anxiety?
Shifting Focus – Content:

• Ask care partners to 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?
Shifting Focus – Content:

• Identify specific Responsive Behaviours & Provide Strategies and case study examples:
  • Agitation
  • Wandering
  • Sexual behaviour or behaviours perceived as sexual (consensual / non-consensual)
  • Sundowning
  • Repetition (verbal and physical)
  • Anger or aggression
  • Hallucinations & Paranoia
  • “I want to go home”
  • Saying Goodbye after a visit
Example: *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
Example: *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.
Example: *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.
Shifting Focus – Content:

Strategies to Enhance Communication:

• Introduce yourself
• Go at their pace
• People with dementia need more time to respond; be patient and wait for a response
• Remember he responds to you and your body language
• Be accepting of inappropriate answers and nonsense words
• Do not correct his ideas or scold him.
Shifting Focus – Content:

• Create a Meaningful visit:
  • Includes suggested activities for the visitor and the resident to do together
  • Highlights the importance of knowing the best time to engage the person with dementia
  • Observing body language to give clues that they are no longer engaged
  • The need to be flexible and change strategies when necessary.
Shifting Focus – Content:

• The role of the Care Partner in the Long Term Care Home: Address the many emotions people feel when a family member moves into a Long Term Care Home as well as the role care partners can now play:
  • Can once again be his wife or son instead of his nurse, social worker, case manager and banker.
  • Able to share their knowledge about his life, daily routines and coping strategies.
  • Have input into his plan of care and ensure that all those who care for him have access to it.
Shifting Focus – Content:

• How to communicate & work with LTC staff:
  • Care partner’s role 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
  • Attend care conferences, which occur six weeks after admission and then annually
  • How to convert ideas into actions with clear expectations of who does what by when and how each person will follow up.
Shifting Focus: Distribution:

• **Condensed booklet:**
  • 10,000 copies were published and 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).
  • Webinar offered province-wide to paid and unpaid care partners.

• **Longer, full version:**
  • A PDF version was sent 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.
  • Seniors Health Strategic Clinical Network of Alberta Health Services.
Shifting Focus: Distribution:

- www.ShiftingFocus.ca

Access tip sheets, strategies, video vignettes and how to access / purchase both full and condensed versions of the guide (available in 7 languages).
Shifting Focus: Distribution:

- www.ShiftingFocus.ca
Acknowledgements:

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- Public Policy and Program Initiatives
- Alzheimer Society of Ontario (ASO)
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Thank you...Questions?

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