



shifting focus

**a guide to
understanding
dementia behaviour**

Introduction

People with dementia are like the rest of us. Each person has a story, a unique personality, life experiences, interests and preferences. Like the rest of us, they need caring people to help them stay relaxed, feel safe and maintain their dignity. Their perception of reality, however, can differ from ours.

This booklet is for the family, friends and co-residents of people who live with dementia and are acting in ways that create distress. The tips and tools are designed to help you improve the relationship with a person with dementia living with responsive or challenging behaviour.

What is dementia?

Dementia is an umbrella term for many brain disorders. Changes in a person's behaviour can signal damage to the brain caused by a dementia. Dementia affects everyone differently, but it commonly diminishes these abilities:

- Language
- Recognition
- Memory (including knowledge of the disease)
- Purposeful movement
- Sensory perception
- Reasoning

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

What are responsive behaviours?

Responsive behaviours is a term that is used to describe the challenging behaviours of people with dementia, such as agitation, wandering or depression. The term shows how the actions, words and gestures of people with dementia are a **response** to their current environment and often unpredictable and intentional.

When trying to understand your friend or family member's behaviour, keep in mind:

- All words, gestures and actions communicate meanings, needs and concerns.

Ask yourself:

- What external factors may be influencing the behaviour?
- Is the behaviour a problem for the person diagnosed or for me?
- Will the "solution" cause more anxiety than the problem?

Ultimately, we can't expect the person with dementia to change; ***we must change***. We need to accept the individual as he is ***in this moment***.

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

~ Sharron Cooke, the voice of a resident

Why do they happen?

When the person with dementia is showing responsive behaviours, ask yourself these questions about what happened before, during and after the event.

Physical: Does she seem to have discomfort or pain?

Intellectual: Has he experienced memory changes?

Emotional: Does he seem lonely or has he acted in unusual ways, like being suspicious of others, hearing or seeing things we don't?

Capabilities: Can he do more than you realize?

Environment: Is there too much noise or too large a crowd nearby?

Social: Does her childhood, prior employment or early adulthood offer any clues?

Actions of others: What am I doing or not doing to contribute to her behaviour?

“ If I could put a stop to this behaviour - I would.”

~ Art Garrison, Person living with dementia

The following are examples of responsive behaviours with suggestions for what to do and not to do when they occur.

Agitation

During a visit with his wife, Jim fidgets, picks at his clothes and is restless.

Do ✓

- Give him something to hold.
- Distract him with music.
- Talk about a happy moment in his life.
- Is it too noisy or bright?
- Is he getting tired?

Don't ✗

- Ask him to stop.
- Tell him to calm down.
- Raise your voice.



Wandering

Susan gets out of bed and wanders the halls of her long-term care home at night.

Do ✓

- Ask why she does this: Does she need the washroom? Is she thirsty?
- Put slippers and house coat out of sight.
- Ensure Susan gets light exercise during the day.

Don't ✗

- Ask the nurse to give Susan a sleeping pill before bed, which results in her sleeping most of the day.

Sexual behaviours

Bill is found masturbating every morning in the common area.

Do ✓

- Take him to his room, close the door and give him privacy.
- Offer an activity to occupy his hands and mind like sorting screws from washers, folding washcloths etc.

Don't ✗

- Yell at him to stop.
- Explain this is inappropriate.
- Restrain his arms.
- Make him feel upset.

James approaches female residents and attempts to grope them as they pass.

Do ✓

- Inform the staff of your concerns and each new situation.
- Avoid the same space and buddy-up when you must pass him.
- If you see him coming and cannot exit, try to talk to him about his life.

Don't ✗

- Explain that his actions are inappropriate.
- Get angry with him.
- Restrain his arms.
- Make him feel embarrassed.

“ 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

After a short visit, around 4:30 pm, Hannah becomes upset, paces the room and says, “I want to get out of here NOW.”

Do ✓

- In the late afternoon, turn on lights and any lamps.
- Close the drapes to lessen shadows.
- Request a light exercise program for the morning.
- Have her set the table for the evening’s meal.
- Visit in the morning.

Don’t ✗

- Request that Hannah is prescribed a medication to calm her, which results in her sleeping much of the day.

At dinner, you begin to cut your father’s food. He lets you for a minute and suddenly grabs your wrist and threatens to “smack you if you try that again!”

Do ✓

- Remain calm and don’t react.
- Let your arm go limp, apologize and find a topic of conversation or an object to distract him.
- Once he lets go of your arm, slowly give him space.
- Think about why he got angry. Could he have been embarrassed?

Don’t ✗

- Grab his hand and force him to let you go.
- Yell out in surprise.
- Explain that you were only trying to help.

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.



Don't ✗

- Tell her nothing is on her walls. “You see, nothing is there. Time to go to bed.”
- Get angry with her.
- Argue.

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 ✗

- 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 Southon, Family Care Partner

“I want to go home”

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

Do

- Acknowledge his feelings.
- Ask about his home or where he grew up.
- Reminisce, even if you know all the answers.

Don't

- Explain to him that this is his new home and he has nowhere else to go.

Dora becomes distraught and grabs her husband when he gets ready to leave after a visit.

Do

- Provide a reason for your departure.
- Walk her to her next activity, join in for a few minutes and then say a quick goodbye.
- Don't say “goodbye.” Instead try “see you soon” or “bye for now.”

Don't

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

“ You do not need to be perfect to be loved.”

~ Alice Walker

Talking to someone 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.

Do ✓

- Introduce yourself, even if it feels awkward.
- Use humour and smile.
- Go at her pace.
- Use visual cues and gestures for direction.
- Accept inappropriate answers or nonsense words.

Don't ✗

- Argue.
- Ask her to reason or problem solve.
- Say, "Don't you remember."
- Correct his ideas or scold him.



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

~ Carl W. Buechner

More information and a full version of this guide is available at:

www.ShiftingFocus.ca

or by calling the **Alzheimer Society** at **211**

Alzheimer *Society*
ONTARIO

www.alzheimerontario.ca



**Alzheimer
Knowledge
Exchange**

www.akeontario.org



Behavioural Supports Ontario