Conversations About

Dementia and Responsive Behaviours

The Alzheimer Society of Canada's "Conversations" series was created to help people with dementia, caregivers and health-care providers have conversations about complex and sensitive topics related to living with dementia. This sheet provides information on things to consider when having conversations about responsive behaviours. To read other issues in the Conversations series, please visit www.alzheimer.ca/brochures

People with dementia, caregivers and health-care providers are encouraged to have conversations about all of the topics in this series early and throughout the progression of dementia. Even though talking about these topics can be difficult, it is only by having open conversations that it will be possible to be better prepared for any challenges.

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This information sheet will help answer some of the questions that you might have about dementia and responsive behaviours, including:

- How does dementia impact a person's behaviour?
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- How should I respond to the behaviour?
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Dementia and responsive behaviours

Dementia can have an effect on how a person behaves. These changes in behaviour can be upsetting and frustrating for both the person with dementia and those around them.

Responsive behaviours and **reactive behaviours** are terms commonly used to refer to actions, words or gestures presented by a person with dementia as a way of responding to something negative, frustrating or confusing in their social and physical environment.

Some common examples of responsive behaviour include:

- Aggression
- Agitation
- Wandering
- Restlessness
- Hallucinations
- Paranoia
- Making unexpected noises
- Becoming more withdrawn

How does dementia impact the person's behaviour?

The brain is one of the most complex and important organs in the human body. The brain helps us understand what is happening around us, provides us with our language skills and guides us in how to act in specific situations. Changes in a person's behaviour can be a sign of damage to the brain caused by dementia.

Dementia is an overall term for a set of symptoms that is caused by disorders affecting the brain. Dementia affects people in different ways, and as the condition progresses, a person with dementia may experience changes in their behaviour. These changes are often due to challenges understanding the world around them and increased difficulty with communication, which makes it hard for the person to express their needs. Changes in behaviour can be a way of communicating:

- Distress
- Pain
- Frustration
- Loneliness
- Boredom
- Unmet needs (such as thirst)

Learning about responsive behaviours and the other changes that may occur as the dementia progresses can help prepare you. As you experience new changes, remember that the person with dementia, like anyone else, still has the need for engagement and human connection — simple things like a smile or holding their hand can go a long way.

Responsive behaviours may be caused by any of the following:

The disease	Changes in a person's behaviour can be a sign of damage in a specific area of the brain. For example, the limbic system is involved with memory, emotions and basic needs (such as sleeping and eating). If the limbic system is affected by the dementia, the person may become suspicious, irritable, depressed or anxious. For more information on how changes in the brain may impact the person's abilities and behaviours, please go to www.alzheimer.ca/aboutthebrain
Lost communication skills	As the dementia progresses, the person with dementia may no longer be able to verbally communicate their basic needs, such as the need for food, drink, sleep or the need to use the toilet. When communication becomes difficult, the person will start using behaviours to communicate their needs to those around them. For example, the person may be pacing back-and-forth as a way of communicating that they need to use the toilet. For more information on how to communicate with a person with dementia, please go to www.alzheimer.ca/communication

Physical discomfort and pain	If the person with dementia is unable to use words to communicate their pain, they may start using behaviours as a way of communication. Some of their behaviours may include becoming agitated or withdrawing from others. Sometimes, families or staff may find these behaviours disruptive, resulting in the use of treatments such as antipsychotic medication. Pain may be present as part of a chronic condition, such as arthritis, or due to something new, like a recent fracture. Pain should be assessed routinely and should be considered as a possible cause of any change in the person's behaviour. Often times, treating underlying pain reduces behaviours.
Depression, delusions and delirium	People may also experience depression, delusions (false beliefs about someone or something) or delirium (intense episodes of confusion) and respond with behaviours that others may find difficult to understand. For example, a person with dementia may have the delusion that their food is being poisoned. This may result in the person pushing food away or refusing to eat, even though they are hungry. For more information about delusions and hallucinations, please go to www.alzheimer.ca/delusionsandhallucinations
Inability to understand what is going on around them	The person with dementia may have a hard time recognizing their physical surroundings and get lost. Or, they may not understand what to do in a particular setting, such as how to use the toilet. Changes in the senses (such as sight and hearing), can also make it difficult for the person to understand what is happening, which may cause anxiety, anger, withdrawal or self-protective behaviours.
Inability to understand or perform a task	People may not understand what they are being asked to do and at times may be overstimulated, under-stimulated or feel rushed. This may cause frustration or boredom, which may result in a responsive behaviour, like hitting or refusing to accept help.

Why is it important to understand the meaning behind the behaviour?

The information presented in this document is based on a person-centred approach to understanding and responding to responsive behaviours. A person-centred philosophy views people with dementia first and foremost as individuals with unique attributes, personal values and life history. Learning about the person will help you understand why they might behave as they do, allowing you to provide better care. Consider using the resource booklet "All About Me" to record information such as likes, dislikes, routines, habits, and other things that make the person with dementia unique. This resource is available at www.alzheimer.ca/allaboutme.

To help you understand why a person is behaving a certain way, remember that[1]:

- **All behaviour has meaning.**
- Behaviour is usually a response to something.
- Behaviours are complex.
- You need to consider whether the behaviour is upsetting or a risk for the person or others. If it isn't, does anything need to be done?

[1] Adapted from the U-First!® Workbook, Alzheimer Society of Ontario (2019)

- The person is not trying to be difficult.
- We need to try and understand and make the connections between the behaviour and what the person is trying to tell us.
- It is only after understanding the behaviour that we can find solutions to address it.

What should I consider when trying to understand the person's behaviour?

- Because many of the behaviours can be the result of physical health problems, it is always recommended that the person with dementia have a full medical assessment in order to rule out infections (such as a urinary tract infection), treatable conditions (such as depression or constipation), and to review medications.
- Sensory impairments such as hearing and vision loss can cause confusion, fear and anxiety which may result in responsive behaviours. Because of this, it is very important that people with dementia have annual hearing and vision evaluations and that they use assistive devices, like hearing aids and eye glasses, as needed.
- Are the person's physical needs being met? For example, think about the last time the person had something to eat or drink. Could they be hungry or thirsty?
- Is the person being engaged in meaningful activities? A person may display responsive behaviours if they are feeling restless or bored.
- Are there patterns to the behaviour? For example, are you noticing that the person seems to always be anxious and agitated in the same place, at the same time of day or when engaged in certain activities?
- Does the person's environment meet their needs? As the dementia progresses, noisy and crowded environments may make the person with dementia anxious and confused, resulting in responsive behaviours.
- As dementia progresses, the person may believe that they are living in the past. For example, they may think that they are still working, even if they retired years ago. To help you understand their behaviour, think about the person's life story, such as their routines, career, education and hobbies.

Nancy is 83 years old. She was diagnosed with Alzheimer's disease five years ago. She moved to a long-term care home six months ago. Staff have noticed that every day around 4:00 p.m., Nancy gets very anxious and paces the same hallway back-and-forth. This behaviour usually lasts 30-40 minutes. When trying to understand Nancy's behaviour, the staff asked Nancy's children about her routine, hobbies and career. The staff found out that Nancy was a stay-at-home mom. As part of her daily routine, Nancy used to pick up her kids from school every day at 4:00 p.m. When the staff learned this, they realized that Nancy was probably anxious and pacing the hallways at 4:00 p.m. every day because she believed that she needed to pick up her children from school. To help reduce this behaviour, the staff decided to change Nancy's daily routine. At 4:00 p.m. a volunteer was in charge of meaningfully engaging Nancy to go for a walk or attend an activity taking place in the home. Once this strategy was applied, Nancy's anxiety and pacing back-and-forth diminished.

How should I respond to the behaviour?

After considering all of the reasons why the person may be behaving a certain way (pain, thirst, medication side effects, physical environment, etc.) try using the problem-solving approach to help you respond to the behaviour.

1. **Identify the problem:** Take a step back and objectively pinpoint the problem. It is important to ask yourself if the person's behaviour is really a problem, or just an inconvenience.
2. **Analyze the problem**: Use a person-centred approach to help you understand what the person is trying to communicate.
    - What factors might be contributing to the person's reaction? For example, could the person be in pain?
    - What is happening and why?
    - Could the person be reacting to something or someone in the environment? For example, are they struggling at bath time because they are afraid of water?
3. **List possible strategies:** Think of all the ways to possibly solve the problem. When listing strategies, consider the life history of the person, their likes and dislikes, and the person's environment. What is likely to "fit" with their usual routine?
4. **Choose a strategy:** Weigh the pros and cons of each strategy. Select one.
5. **Take action:** Put the chosen strategy into effect.
6. **Assess the results:** Did the chosen strategy work? If not, why? Should another strategy be tried?

What strategies can I try to reduce responsive behaviours?

The chart[2] below suggests strategies that you can try to reduce responsive behaviours. Knowing the unique background, preferences and characteristics of the person with dementia can help you determine which options are most likely to help. Please note that these strategies may not work for everyone. Sometimes the first strategy is not successful, or it may work the first time but not with subsequent attempts. Talking to other caregivers, a doctor or someone from your local Alzheimer Society may provide explanations about why the strategy may have been unsuccessful. They might also have suggestions for other possible approaches.

Agitation	• Make an appointment for the person with dementia to have a full medical assessment to rule out infections, treatable conditions and to review medications. • Give the person something to hold. • Distract the person with music, a picture book or a simple game. • Assess the environment. Is it too noisy or bright? Is the person overstimulated, under-stimulated or tired?

[2] Adapted from the Shifting Focus Guide, brainXchange & Alzheimer Society of Ontario (2014)

Walking around (wandering)	• Ask the person if there is anything that they need. For example, are they looking for the washroom? Is the person thirsty? Are they constipated? • If it is unsafe for the person to leave the home alone, consider putting their coat out of sight. • Ensure that the person gets some exercise during the day.
Sexual behaviours	• Try to redirect sexual expression and sexual tension to activities that will help the person focus on something else, such as inviting them to join a physical exercise program. • Learn about the person's patterns of sexual expression and intimacy in order to understand their current behaviour. • Invite the person to go to their room and give them privacy.
Hallucinations	• Make an appointment for the person with dementia to have a full medical assessment to rule out infections, treatable conditions and to review medications. • Validate the person's fear by using phrases such as, "That must be frightening." • Increase lighting to remove shadows that could be misinterpreted. • Distract the person with music, exercise or photos. • Make sure the person has routine sight and hearing tests. If the person uses an assistive device, such as hearing aids, make sure they are wearing them and check to see if the batteries are working.
Paranoia	• Make an appointment for the person with dementia to have a full medical assessment to rule out infections, treatable conditions and to review medications. • Validate the person's feelings. Do not argue or correct. • Look for the "stolen" object to help alleviate their distress. • Investigate suspicions that could be true. For example, the person may be a victim of abuse (financial and physical).

What should I know about responsive behaviours and restraints?

Restraints are often thought to protect the safety of the person with dementia and others and reduce the risk of harm. However, restraints themselves can cause harm and reduce a person's ability to move around and express themselves. **The care strategy of choice is to use no restraints.** Understanding the reasons for some of the behavioural changes is the first step towards developing care strategies that meet the person's needs, thus providing alternatives to the use of restraints. When any restraints are being considered, the positive and negative consequences for the person with the disease and others must be carefully measured and monitored.

Types of restraints

There are three main types of restraints:

- **Physical restraints** that restrict or control movement or behaviour. They may be attached to a person's body or create physical barriers. For example, chairs that prevent a person from standing up or full bed rails are forms of restraints. Similarly, baby gates on stairs are a form of restraint and should not be used to prevent a person from accessing the stairs. The person may try to climb over the baby gate, increasing their risk of falls.
- **Chemical restraints** are medications used to modify or restrict behaviour, such as tranquilizers and sedatives.
- **Environmental restraints** change or modify a person's surroundings to restrict or control movement, such as keeping the person in a locked room.

Sometimes, an item that is meant to help a person move independently can also act as a restraint. For example, a lap tray might limit a person's ability to get up from their chair. However, if it is used to make it easier for a person to eat, and is removed immediately after the meal, then it is not considered a restraint.

Issues to consider when deciding if a restraint should be used

- **Reducing the person's freedom:** Restraints can decrease a person's ability to be physically active and to function independently. Restriction of freedom can also lead to a loss of confidence and self-esteem. For example:
  - A chemical restraint may leave a person sedated, confused and less able to move.
  - A physical restraint (such as a lap tray) may prevent a person from moving freely, which can lead to boredom, frustration and muscle stiffness.
- **Risk of harm or injury:** Despite good intentions, restraints can cause injuries. For example, when a bed rail is used, a person may try to climb over the rail to get to the bathroom and fall.
- **Loss of abilities:** The restrictions created by the restraints may cause the person to lose cognitive and physical abilities. For example:
  - A person who is sedated for long periods may lose muscle strength and balance.
  - Someone who is restrained in their chair because of a risk of falling, may become weaker and therefore at a higher risk for falls and injury.

It is important to remember that a physical, chemical or environmental restraint should not be used as a substitute for safe and well-designed environments, for the proper care of a person with dementia or solely for the convenience of caregivers.

The information provided in this resource by the Alzheimer Society is for general purposes only. It is not meant to replace any diagnosis, treatment or medical advice and does not replace your relationship with your health-care providers. The Alzheimer Society encourages you to talk to a qualified health-care provider before making any health-related decisions.

Useful Resources:

brainXchange.ca - this website has resources available on various topics related to brain health, including on responsive behaviours.

Where can I get further information?

You can find your local Alzheimer Society at www.alzheimer.ca/helpnearyou.

Alzheimer Society

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