Tips and additional resources



Context

This document describes some practical ways to support a person living with dementia who is experiencing additional challenges during the COVID-19 pandemic.

The COVID-19 pandemic has brought a unique set of challenges to people living with dementia and caregivers, including disruption to routines, isolation and in some cases, a need for increased supports. For health-care providers supporting people affected by dementia, the pandemic has created new challenges and many people have found creative ways to stay safe and overcome obstacles while providing person-centred care.

The Alzheimer Society of B.C. has responded to COVID-19 by continually adapting and reviewing

how best to provide support and education across the province. We have extended the hours of the First Link® Dementia Helpline and provide weekly dementia education webinars. We have also launched a COVID-19 webpage dedicated to health-care providers, which includes a link to our health-care provider survey.

The following tips are based on a person-centred philosophy that views people living with dementia first and foremost as individuals with unique attributes, personal values and history. A key to understanding behaviour and enhancing communication is providing person-centred care by meeting the person living with dementia where they are and accepting their reality.

Responsive behaviours

Responsive behaviour is a person-centred term used to describe actions, words or gestures that are a response to something important about the personal, social or physical environment of a person living with dementia. Responsive behaviours are a result of changes in the brain affecting memory, judgement, orientation, mood and behaviour.

Examples of responsive behaviours include agitation, confusion, loss of inhibition, hallucinations or delusions, reactive or repetitive behaviours, loss of initiative and pacing or wandering.

It can be difficult to manage the discomfort and negative emotions resulting from events that cause anxiety, fear, grief, pain, change or loss. The severity of events and the way they're managed affect a person's ability to cope with this discomfort. The symptoms of cognitive impairment associated with dementia can affect how a person perceives the event, the emotions that are triggered by the event and how they make sense and respond to the event.

Additional resources:

- Building a Strong Foundation for Dementia
 Care guidebook: <u>Understanding behaviour</u>
- Shifting focus: A guide to understanding unpredictable dementia behaviour (pages 7-19)



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While changes in behaviours can be frustrating, it is important to understand that **all behaviours have meaning**. Attempting to understand why a behaviour may be occurring can help you adapt your response in the moment and potentially help reduce the likelihood of the behaviour happening again.

Consider how these four factors may be driving the behaviour by asking yourself these questions:

Ability to communicate

- Can the person see and hear me?
- Am I offering too many choices?
- Does the person have difficulty with wordfinding or generating a response?
- Am I giving the person enough time to respond?

Task-related causes

- Is the task of interest to the person and fitting with their current abilities? Is the task too complicated?
- How do I present the task or activity? Is it familiar to the person?

Use your problem-solving skills!

When a person living with dementia exhibits a responsive behaviour, reflect on whether it is a problem for the person or for you: Will the solution cause more anxiety? Will adjusting expectations affect the problem?

Consider using "The 5 W's" to figure out what may be influencing the person's responsive behaviour:

- Is the person lonely or bored?
- Has the person lost a sense of initiative?

Physical state

- Is the person in pain?
- Have there been recent medication changes that may cause a change in behaviour?
- Does the person have an infection or another illness?
- Is the person hungry or thirsty?

Current environment

- Is the space too noisy, crowded or unfamiliar?
- Has the environment changed? Have things moved or are they out of reach? Are there high levels of stress around the person?
- Are there any cues that indicate what is expected or where things are located?

Additional resources:

- <u>Understanding behaviour changes</u>
 handout
- 4-step problem solving handout
- 1. What is going on?
- 2. Where is it happening?
- 3. When does it occur?
- 4. Who is involved?
- 5. Why is this happening?



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Strategies to enhance communication

We communicate most information verbally, through the words we choose, and non-verbally, through facial expressions and gestures. As dementia progresses, a person will experience a gradual deterioration of their ability to express themselves clearly and understand what others say. However, some form of communication does remain possible at every stage of the disease. When all else fails, people still maintain feelings, so communication on an emotional level is possible.

Tips for communicating:

- Speak slowly and clearly. Use simple words and short sentences to make the message clear. If the person has hearing problems, lowering the pitch of your voice is often better than increasing volume.
- Avoid open-ended questions. Close-ended questions can be answered with "yes," "no," "maybe," "I don't know" or "I don't remember"

- and are often easier to answer than open-ended questions. For example, rather than asking "What would you like for lunch?," ask "Would you like a sandwich for lunch?"
- Get the person's attention. Approach the
 person slowly and from the front. Introduce
 yourself and use the person's preferred name.
 Gently touch a hand or arm to help get their
 attention. Make eye contact or crouch down to
 get to eye level. Wait until the person is ready
 to listen before talking.
- Show as you talk. Use actions as well as words.
 For example, if it is time to go for a walk, point to the door or bring the person's coat or sweater to illustrate what you mean.

Additional resources:

- Understanding communication
- Communication handout

Strategies for responding

- Set the stage. To have a successful interaction, start by making sure that the environment is appropriate. Are there any distractions, like a radio or other noise? Ask yourself, "Can the person hear and see me?"
- Validate. Put yourself in the person's reality.
 Respond to the feelings and not to the issue.
 Rather than contradict them, acknowledge their concern.
- **Reassure.** Comfort the person. Tell them, "I am here for you," or "It is going to be OK." Use a caring touch or a hug, if appropriate.

- Distract/redirect. Offer an activity or a favourite snack. Engage the person in a calming activity such as looking at photographs, taking a walk or singing softly.
- Follow up. The solution comes in making changes and seeing if they make a difference.
 What works one day may not work the next.
 You may need to continue trying different things to get a response or to be understood. Discuss your plan with the care team, including family members. Re-evaluate the care plan often.



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Putting the strategies into practice during the COVID-19 pandemic

Wearing personal protective equipment (PPE)



Factors that influence behaviour

- PPE can affect a person's social and physical environment. Changes in environment can make it difficult to recognize the staff member or the space which can be frightening and disorienting.
- Consider the person's history. Can wearing PPE trigger a past experience that was negative?
- PPE can make communication challenging.
 For example, wearing a mask can make it harder to hear the words someone says and hide non-verbal facial expressions such as smiling.

Strategies to try

- Adopt strategies to enhance communication, such as speaking slowly and clearly.
- Use a laminated photo or name badge to introduce yourself.
- Acknowledge the presence of the mask (or other equipment). Use humour if appropriate.
 E.g. "Hi Walter, it's Jen. I'm here to help you get ready for the day. I know I look a bit strange, but I'm wearing this mask to keep us both healthy."
- Ask a trusted person to wear a mask, either in person or virtually, to add familiarity.

Supporting a person • on isolation



- Changes in the brain can make it difficult for a person to remember that they are in isolation and cannot leave their room, understand why certain people cannot visit or why they can't follow their normal routine.
- Dementia is already an isolating disease: any disruption to a person's daily routine, including decreased access to stimulating activities or sensing a heightened level of anxiety, can result in responsive behaviours, increased feelings of loneliness and may cause dementia symptoms to worsen.
- Come up with a strategy as a care team and include the family. Gather information about what you know about the person and create a new daily routine. Can a family member schedule phone calls or use virtual visits at times of the day when the person needs more reassurance?
- Be mindful of your body language. Check in with yourself before entering the person's home or room. Take a deep breath if necessary.
- Use visual cues. Add posters in key parts of a room to remind the person about the virus or use language or symbols that will deter the person from leaving the room (e.g. "Do not enter" or "Stop").





- Remember, all behaviour has meaning.

 People may pace/wander for many
 reasons, including medication side-effects,
 discomfort, over-stimulation, boredom or
 simply a need for a walk.
- Changes in space or routine due to COVID-19 can create a sense of confusion or disorientation that could lead to this behaviour.
- In the moment, distract or redirect the person to a positive activity that they enjoy doing (e.g. looking at family photos or having a cup of tea).
- Assess the situation and determine cause of wandering by using the 5W's.
- Modify the environment. Can the person's room be more stimulating? Can there be a designated space in the hallway for safe walking?



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Alzheimer Society of B.C. resources

First Link® Dementia Helpline

For anyone affected by dementia, whether professionally or personally. Helpline staff and volunteers give people the support they need, when they need it.

- English: 1-800-936-6033 (9 a.m. to 8 p.m.)
- Cantonese and Mandarin:
 1-833-674-5007 (9 a.m. to 4 p.m.)
- Punjabi: 1-833-674-5003 (9 a.m. to 4 p.m.)

For further information and support, visit the Alzheimer Society of B.C. website: www.alzheimerbc.org

COVID-19 resources

- COVID-19 resources for health-care providers
- <u>COVID-19 and dementia</u>: Resources for people living with dementia and families.
- Health-care provider COVID-19 survey

Other helpful links

- Health-care provider resources
- Webinars
- Guidelines for care: Person-centred care of people with dementia living in care homes

We want to hear from you!

How has your role changed in this time of increased measures to stop the spread of COVID-19? What resources would help you support people living with dementia in your care? Have you made adjustments worth sharing with others facing the same challenges in continuing care? Share your questions, stories and strategies with us by completing short survey at alzbc.org/HCPsupport.

Additional resources:

- <u>Care for caregivers: Mental health support for</u>
 <u>health care providers</u> (SafeCare BC &
 Canadian Mental Health Association BC)
- COVID-19 Ethics analysis: intervening when patients or residents pose a risk of COVID-19 transmission to others (BC Ministry of Health/ BC Centre for Disease Control)
- Guidance for supporting clients who wander and require physical isolation (Baycrest, Behavioural Supports Ontario and Regional Geriatric Program of Toronto)
- Non-pharmacological approaches to support individuals living with dementia maintain isolation precautions (Behavioural Supports Ontario)
- The person behind the mask: Communicating with clients living with dementia while protecting ourselves (Alzheimer Society of Peel; Mississauga Halton Behavioural Supports Ontario)
- <u>Taking care of your mental health during the</u>
 <u>COVID-19 pandemic</u> (BC Care Providers Association)

