Before the visit

Background

The last few months have been challenging for all who live and work in long-term care and assisted living. In July, the Ministry of Health released guidelines for care homes to reopen visitation for residents with the requirement that care homes also submit their safe visitation plan.

What can I expect?

As there will be some variation in visiting procedures between care homes, you can expect your care home to send you a communication outlining their procedures for visitation and precautions they are taking. What you can expect in all care homes:

- All visits must be booked in advance with the care home. This may be by phone or online – your care home will let you know how to arrange these visits.
- At this time, only one designated visitor is allowed for social visits.
- Wash your hands often and avoid visiting if you or the person you are visiting are showing any signs of illness.
- Bring a mask and expect to wear one during your visit.
- You will have a time limit for your visit to allow staff to accommodate visitors for all residents.
- If there is an active outbreak at COVID-19 at the residence, visitation will be suspended immediately.

For more information about social visiting guidelines, see the BC Centre for Disease Control's <u>infographic</u> or <u>guidelines</u> document, which are both available on the BCCDC <u>website</u>.

As the COVID-19 situation evolves, these guidelines will continue to be reassessed and may change.

Five questions to ask before your visit

- Are there any restrictions to what I can bring to my social visit? For example, disposable food containers or other items that can easily be cleaned, such as letters or cards.
- 2. What number can I call if I need to reschedule?
- 3. How far in advance will I be able to schedule my visit?
- 4. How much time will I have with the person I am visiting?
- 5. Can I hug or touch my person? What should I do if my person hugs or touches me?

Consider the perspective of the person living with dementia

- The limitations to visitation in long-term care means that a person living with dementia may not understand why you could not visit them over the past few months and may feel confused, angry, or frustrated by your visit.
- The person may not understand why you are wearing a mask and become anxious or disoriented. You may also experience greater troubles communicating than before restrictions were put in place.
- The person may tire quickly or not be able to maintain conversation for the visit duration.



Before the visit

Keep in mind:

People living with dementia are highly perceptive of emotions, and any feelings of fear or anxiety you have may indirectly transfer over to the person you are visiting. If you find your emotions become challenging during your visit, excuse yourself – if possible - and allow yourself time to pause and regroup so you can be fully present in your visit with the person.

Coping with the emotion

Seeing your family member again after months of being physically apart can be strange, even painful. It can be a reminder that things have changed and you may be feeling uncertain about how long these changes will last, or if there will ever be a return to the visits you had with your family member before the COVID-19 situation. You may experience a variety of feelings when you first see your family member after months of being apart:

- Shock at any changes to their appearance or health (such as weight or mental health). Keep in mind, appearance does not always reflect the level of care being received. For example, a person's hair may appear unkempt because of limited access to hair stylists before restrictions to visitation were reassessed. It can be tempting to blame care staff during your visit, however, if you are concerned with the care the person has received, take some time to reflect on your concerns and write down your observations. The emotion of seeing your person again may make it difficult to think logically about the situation.
- Anxiety or worry over the unknowns. You could

- feel anxious about the person's physical condition or their feelings over your absence when not understanding why it occurred. Depending on where the person is along the dementia journey, you may feel anxious about whether they recognize you.
- Guilt over their being in care. Remember that the decision to move a person into long-term care is not one that was taken lightly. There was a reason that decision was made. Each family's situation is as unique as the experience of the dementia journey. Perhaps you are feeling powerless because things are happening, and you are not able to step in and support or help your family member when they need it. You are left with the feeling of being torn between being there for the person and keeping them safe.
- Sadness and grief over the restrictions to visitation that are still in place. You may be grieving the loss of time with your family member or feeling anticipatory grief over the loss of time you know could occur in the future.
- Anger or frustration over the situation you are both in and the restrictions still in place. You may wish for things to return to normal so you can visit your family member as you did before the visiting restrictions were put into place.
- Relief that you can see your family member in person again, in any capacity.

Additional resource:

<u>"Personal protective equipment for family caregivers" training video</u> (Ottawa Hospital)



During the visit

What to do if the person does not recognize you

The person's ability to recognize you will depend on many factors, including their ability to recognize you before restrictions were put in place, their emotional state at the time of your visit, and for some, the level of interaction they had with you from a distance if visits through a door/window or video calling have been available to you.

For many people living with dementia, masks make it challenging to recognize a person or follow a conversation with them.

What you can do:

- Do your best to exaggerate the features in the upper portion of your face above your mask to communicate what it is you are saying; for example, widen your eyes, raise your eyebrows, furrow your brow, or nod your head while speaking. Remember to speak slowly, keep your sentences short, and allow the person additional time to process what you are saying.
- Try your best to use positive language when talking about COVID-19 and the precautions put in place to keep everyone safe. You might say, "This mask does look funny, doesn't it?" or, "How wonderful that we can see each other again."

While the person may not recognize your physical appearance, they may remember the way you make them feel and will still appreciate your company. For some, sensory cues such as hearing your voice or holding your hand may help to



remind them that you are a person who is important to them. Keep in mind that as the disease progresses, it is natural that a time will come when the person will no longer be able to recognize you.

What you can do:

Try to involve the person in a pleasant activity
that stimulates the senses and activates multiple
parts of their brain. For example, playing a
favourite song for them on your smartphone or
tablet; or showing photos while you talk about a
favourite memory from your past that the two
of you share.

It may just be a bad day. If the person is feeling tired or depressed, they may have greater difficulty recognizing you.

What you can do:

 If possible, try booking your next visit with the person when you can expect them to be at their best. You may find another time works better for your family member.



During the visit

What if the visit does not go well?

For the person living with dementia, it can be difficult to understand why you need to wear a mask, or why physical distancing needs to be practiced. They may not recognize you under the mask and become confused or agitated during the visit.

What you can do:

- Validate the emotion you are observing in the person you are visiting. Even if the person is no longer capable of communicating to you using verbal language, their body language or behaviour may communicate how they feel. For example, if you notice the person's brow is furrowed and their lips are pursed, you might say something like, "You look angry. I am so sorry. I will help you anyway I can."
- Reassure the person that you understand how they are feeling and that you are there to support them. For example, "I was nervous too when I first saw people wearing masks. It's okay, it's still your daughter under here."
- After you have validated how the person is feeling and reassured them that they are safe, try to redirect the person's attention to something positive that they typically enjoy.
 For example, "You always had the most beautiful flower garden. Should I plant purple marigolds or yellow marigolds in my garden?"
- If the person appears too agitated or confused to continue the visit, despite your best efforts to comfort them, try again another time. It may take time for the person to get used to seeing you again under new circumstances.



Ending your visit

Ending your visit might mean that a meaningful time together has now come to an end, and how the visit ends can have great potential for continuing or changing the tone of the visit long after it ends. With visiting restrictions still in place, saying "goodbye" can be a reminder that when the visit ends, you are not there, leaving the person sad or lonely. The longer the person has been living in care, the harder it may be when that visit ends.

- Where possible, try to avoid saying "goodbye" when ending your visit, and instead, choose language that is positive.
- Remind the person how much you have enjoyed their company and appreciate their time, and that you will call them again. For example:
- · "Seeing you is the best part of my day."
- "I can't wait to see you again."
- "I'll be back in a few days. See you soon!"
- "I need to pick up your prescription from the pharmacy. I'd better go."



After the visit

Adjusting to the changes to visitation

Give yourself time. Acceptance does not come overnight, nor does it persist each day. There may be times when you find it difficult to accept this new reality and limits to how and when you can visit your family member. Other times, it may come more easily.

While we cannot change the restrictions around physical distancing, we can learn how to adapt the way we visit. Recognize that you are doing the best that you can considering impossible circumstances. It will take some time to adjust and to figure out new routines. Keep in mind that the Ministry of Health will continue to reassess visiting guidelines as the COVID-19 situation evolves.

What can I do if I am unable to visit my family member?

It is hard when the restrictions have been eased in long-term care, but you are still unable to visit your family member. For some families, the new visitation guidelines may mean a reduction in the frequency of visits with their person, if virtual or window visits had previously been coordinated.

The decision as to which family member is the one person allowed to visit the person in care may stir up a variety of feelings for you and your family. It is normal to feel sad or angry at the situation, and to grieve the loss of your time with the person in care.

 Ask your visiting family member to take photos or a short video of their time with the person in care so you can see for yourself how they are doing.



- If allowed by the care home, ask the visiting family member to bring photos or videos of yourself to share with the person.
- Consider having the visiting family member facilitate a video call with the person in care.
 Try to keep an open mind, even if you have been unsuccessful in the past when video calling with your family member. You may find that, by having somebody who is close to the person living with dementia, the call has a more successful outcome.
- Remember that care homes have to take a cautious and phased approach to opening to visitors, and that these precautions are in place to protect the health and safety of all staff and residents.



After the visit

What to do if you are concerned with what you observe in your visit

- If you observe changes in the person's care plan (for example, medication, restraint use, etc.) or are concerned with what you observe during your visit, you should request a meeting to discuss these changes with the care team. Do your best to write down your observations and
- concerns before the meeting so the focus can be kept on the facts rather than assumptions. Keep in mind that this time has been challenging for care staff as well.
- While urgent decisions may have been made by the care team over the past few months, you are entitled to be involved in these decisions going forward if you are a substitute decision-maker.

Additional resource:

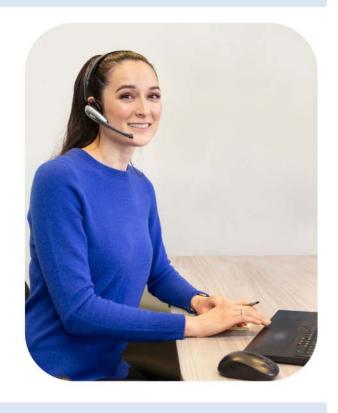
SafeCare BC and Family Caregivers of BC free, online educational program: "COVID-19: Social visitation essentials."

Alzheimer Society of B.C. resources

The First Link® Dementia Helpline is 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 (Monday to Friday, 9 a.m. to 8 p.m.)
- Cantonese and Mandarin: 1-833-674-5007 (Monday to Friday, 9 a.m. to 4 p.m.)
- Punjabi: 1-833-674-5003 (Monday to Friday, 9 a.m. to 4 p.m.)

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



We want to hear from you

How did your first visit go? Were you surprised by anything? Do you have any tips to share with other visitors? Are there any concerns that were not addressed? Share your stories, ideas or concerns with us by e-mailing advocacy@alzheimerbc.org.

