

Q&A: More than a visitor – care planning in a changing environment

The role of both the Alzheimer Society of B.C. and Family Caregivers of B.C. is to support family caregivers who care for a person living with dementia. While we work closely with health care providers and other organizations as partners in care, we are not legal experts, nor are we embedded within the health care system. Where a question extends beyond our scope of knowledge and expertise, we have included links to relevant resources to provide more information for your situation.

The information in this document is current as of November 18, 2020. Please note that information may change as guidelines and public health orders change.

Visitor guidelines for long-term care and assisted living

1. What is the difference between essential visitor, social visitor, and designated visitor?

According to the [BC Centre for Disease Control](#), there are two types of visits allowed in long-term care and assisted living residences:

Essential visits	Social visits
Visits for compassionate care (such as critical illness, hospice care, end of life and medical assistance in dying).	Visits made by a family member or friend of a resident.
Visits essential to patient/client care and well-being, including: <ul style="list-style-type: none"> Assistance with feeding, mobility and personal care. Communication assistance and supported decision-making for people with disabilities or cognitive impairment. 	Each visitor must: <ul style="list-style-type: none"> Schedule their visit in advance with facility staff. Socialize in the designated visiting areas.
Existing registered volunteers providing services as described.	Social visits can only take place if there is no COVID-19 outbreak in the facility.
Essential visits are limited to one visitor at a time . For palliative and end-of-life care, more than one visitor may be allowed at a time.	Only one designated family member or friend may visit.
All visitors must wear a mask, clean hands before and after visiting (using soap and water or alcohol-based hand sanitizer) and maintain a distance of two metres from others.	

The term “designated visitor” refers to the social visit policy. Only one designated family member or friend may visit at this time. **Note:** only essential visits, as defined above, are allowed in hospital settings at this time.

Relevant links:

- [Canadian Centre for Elder Law](#)
- BC Centre for Disease Control – [Visitor Policy](#)
- BC Centre for Disease Control – Section C: [Visitors](#)

2. Is it one designated visitor at a time or only one visitor per resident?

- Currently, social visits allow for **one designated visitor** per resident.
- According to the BC Centre for Disease Control, this one designated visitor rule was part of a phased approach starting in July 2020. The guidelines are meant to be reassessed to determine whether the policy can be expanded safely to include other visitors.
- If you need a special arrangement made for a social visit, speak to the Director of Care or another member of the care team to discuss a plan.

3. Can more than one person provide essential visits if they are not visiting at the same time?

- Yes, in certain circumstances, more than one person can provide essential visits. For example, more than one visitor may be allowed for palliative and end-of-life care.
- Speak to the care home staff, starting with Director of Care, to discuss the options in your situation.

4. How do I become an essential visitor for my mom who lives in a long-term care home?

- If you feel that your visit is essential, speak to the care home staff. Staff in long-term care homes and assisted living residences determine what visits are essential.
- Prepare for this discussion by making a list of the resident’s needs and how you can support the person. Make note of what legal documents you have in place (such as a Representation Agreement and/or Power of Attorney).
- To get acquainted with health and safety practices in long-term care homes and assisted living residences, it might help to take the self-paced, one-hour [COVID-19: Social Visitation Essentials](#) online course which has been developed by the Family Caregivers of BC and SafeCare BC.

5. I have a BC Representation Agreement (RA) and Power of Attorney (POA) for my dad. Does that mean I will get essential visitor status?

- Although having your documents ready is an important step in the planning process, it does not mean that you will automatically get essential visitor status.

- Facility or health authority staff make the decision to determine whether you qualify as an essential visitor. See the table in question #1 for criteria of who is considered an essential visitor.
- An important aspect of the Representation Agreement is the ability for the representative to make health care decisions on behalf of the resident. As a supportive decision-maker, you should be included in discussions with the care home when it comes to changes in medical care. Ensure the care home has a copy of this form and that they are aware of your role in supporting the resident in making decisions.

Relevant links:

- [Nidus Personal Planning Resource Centre](#)
- [Canadian Centre for Elder Law](#) (Health Care Laws in BC)

6. Does a long-term care facility have the right to 'ban' friends and family members from visiting their family member?

Long-term care homes can limit visitation of friends and family members during a public health emergency. As a result of the COVID-19 pandemic, decisions are made to promote the health and safety of all residents, family, and staff.

Additional points to consider:

- Long-term care homes are under the direction of the [Ministry of Health](#) to implement infection prevention and control guidelines for COVID-19, which outline the visitor restrictions.
- All licensed long-term care homes must follow the [Residential Care Regulation](#) which states that “a licensee must, **to the greatest extent possible while maintaining the health, safety and dignity of all persons in care**, ensure that a person in care may receive visitors of the person in care’s choice at any time, and communicate with visitors in private” (Section 57).
- Similarly, the Resident Bill of Rights outlines the rights for residents living in long-term care to receive visitors and communicate with visitors in private. However, there are situations, such as the COVID-19 pandemic, “**where necessary, a resident’s rights may need to be balanced with the need to protect and promote this resident’s health or safety, or the rights, health and safety of other residents.**” ([Resident Bill of Rights](#), Section 5 – Scope of rights).

7. Why are there differences between long-term care homes in terms of visitation rules?

We have seen significant differences across the province in how long-term care homes have adjusted to the current visitation restrictions. This is because, while the Ministry of Health has some regulations that *must* be followed by all licenced long-term care homes, the rest are recommendations that care homes can choose to adopt at their discretion. Because of this, we

recommend speaking with the Director of Care at the care home first before bringing your concerns to the health authority or Ministry of Health.

Other differences between care homes that can impact how recommendations are put into practice include:

- Staffing capacity
- Physical environments (how much indoor/outdoor space is available? Are residents in private or shared rooms?)
- Number of residents
- Established resident or family councils
- Access to personal protective equipment
- Clear infection prevention and control policies

To learn more about practices in long-term care that help to reduce the risk of outbreaks, [read this report](#) published by the Canadian Foundation for Healthcare Improvement and the Canadian Patient Safety Institute.

8. Are visitor rights different between provinces?

- Yes, visitation guidelines vary across Canada. For example, in B.C. long-term care homes, currently only one essential visitor is allowed per resident. Social visits allow for one designated visitor per resident. In contrast, [Ontario](#) is currently allowing two essential visitors to visit at a time. For social visits, they are also allowing two visitors at a time. However, in areas identified as having a higher community spread, general visitors for social visits are not allowed, but one essential visitor is allowed.
- To learn more, consult this helpful [document](#) produced by the Public Health Physicians of Canada in June 2020 to show the differences between provinces in terms of visitation policies.

9. What kind of research can be cited to support family as essential partners in care?

Historically, public policy makers saw family caregiving as a personal choice or moral obligation despite the role also being an extension of the workforce¹. In more recent years, there has been a shift to viewing family caregivers as essential partners in care. The emerging evidence² shows that family presence improves:

¹ Institute of Medicine (US) Committee on the Future Health Care Workforce for Older Americans. Retooling for an Aging America: Building the Health Care Workforce. Washington (DC): National Academies Press (US); 2008. PMID: 25009893.

² Reinhard SC, Given B, Petlick NH, et al. Supporting Family Caregivers in Providing Care. In: Hughes RG, editor. Patient Safety and Quality: An Evidence-Based Handbook for Nurses. Rockville (MD): Agency for Healthcare Research and Quality (US); 2008 Apr. Chapter 14. Available from: <https://www.ncbi.nlm.nih.gov/books/NBK2665/>

- the quality, experience, safety, and outcomes of care;
- provides support to the resident; and
- reduces burden on health care staff.

Here are some resources that you can refer to in your discussions with health-care providers as you find ways to work as a team:

1. Infection prevention and control [guidelines](#) for long-term care and assisted living.
2. Canadian Foundation for Healthcare Improvement and Canadian Patient Safety Institute report entitled [“Reimagining Care for Older Adults: Next Steps in COVID-19 Response in Long-Term Care and Retirement Homes”](#).
3. [The Best Visit Possible: A guide for supporting family visits during COVID-19](#) (BC Care Providers Association).
4. [Staying Apart to Stay Safe: The Impact of Visit Restrictions on Long-Term Care and Assisted Living Survey](#) (Office of the Seniors Advocate).
5. Canadian Foundation for Healthcare Improvement’s recent report: [BETTER TOGETHER: Re-Integration of Family Caregivers as Essential Partners in Care in a Time of COVID-19](#) and hashtag **#morethanavisitor**.
6. Take the one-hour [COVID-19: Social Visitation Essentials](#) online course developed by Family Caregivers of BC and SafeCare BC. This course provides a certificate you can show to demonstrate your commitment to health and safety.

Relationship building and making a personal connection to care home staff is an important way to be recognized as an essential partner. It may help with conversations when sharing these types of resources.

Self-advocacy

Self-advocacy is what you can do to improve a situation for ourselves, a family member or another individual.

10. I have all the documents in place and have tried to communicate with the care home, but I haven’t had any success in getting the essential visitor status. What do I do next?

It’s always best to find a solution directly with the care home staff, if possible. Start by reflecting on your communication strategies by considering these tips:

- Try something new. Is there another staff member you can talk to? If you haven’t already spoken to the Director of Care, ask to speak to them directly.

- Try to get the care home’s decision in writing. This will help with future conversations and facilitate communication and understanding.
- Follow up on decisions in due course.
- The language you use is important. Humanize your concern by focusing on the needs of the resident, rather than your needs as a caregiver.
- Treat care staff with empathy and understanding of their needs as individuals. A gentle reminder: they don’t make the rules, but they are the ones that have to implement them. They are having an equally difficult time during the pandemic.
- While you share your concerns, try to present creative solutions.
- Provide relevant local information/facts to support your case, such as low COVID-19 case numbers in your region and assurance of your own low risk (i.e. very small personal bubble, understanding of safety protocols, etc.).
- Review the Alzheimer Society of B.C.’s Advocacy Fact Sheet on [Dealing with Conflict](#).

You can also reach out to community organizations and offices to share your story or concerns:

Organization	Description	Phone number
The Alzheimer Society of B.C.’s First Link® Dementia Helpline	Call the helpline to speak to a staff member about your situation if you’re supporting someone affected by dementia.	1-800-936-6033
The Family Caregivers of BC Caregiver Support Line	Call the caregiver support line to speak to a staff member about your situation.	1-877-520-3267
Patient Care Quality Office	To make a formal complaint regarding the quality of care you or a person you’re supporting has received, and appeal a denied essential visitor request.	Vancouver Coastal: 1-877-993-9199 Vancouver Island: 1-877-977-5797 Interior: 1-877-442-2001 Fraser: 1-877-880-8823 Northern: 1-877-677-7715 Provincial Health Services: 1-855-660-2757
Provincial Seniors’ Phone Line	For seniors and their families, or other concerned individuals in their lives, to report concerns about care.	1-877-952-3181

Three other options for advocating for an essential visitor status include:

1. Providing feedback to the [Seniors Advocate](#) by filling out the [Seniors Advocate Public Input Form](#).
2. Writing a letter to your Member of the Legislative Assembly (MLA). It is important that MLAs hear the needs of their constituents. Visit the Alzheimer Society of B.C.'s [provincial advocacy webpage](#) to learn more.
3. Contact Caregivers4Change, an organization that aims to inspire individuals and communities to support family caregivers. You can read more about their [mission and awareness here](#).

If you're supporting a person living with dementia and want to learn more about self-advocacy or to share a story or experience, contact advocacy@alzheimercbc.org

11. How do I decide if my family member should stay in a long-term care home or return home?

This decision is very personal and often complex, with many considerations to be made. To highlight a few:

- Consider the reasons why the person moved into care in the first place. This is often due to care needs exceeding what can be reasonably managed within the home. Have these care needs changed? The likely answer is often no.
- Consider what resources you have available to support the person at home – both human and financial. Who will care for the person at home? If the answer is *you*, can you realistically manage their current needs? How quickly can you re-engage with your local health authority for home support services? Who will provide care to the person if something were to happen to you? Are other family members or friends available to jump in and fill-in the gaps? Would additional care need to be hired, and if so, does your financial situation allow for this?
- Consider also the impact of a move back home for the person living in care. For some, an additional move may be too challenging.
- It can be helpful to use a decision aid to guide you through what to think about and what to put into place before making the decision to bring someone home. Below is a list of decision aids that you may be helpful for you:
 - [Decision aid and considerations](#) for caregivers (written notes)
 - [Decision aid and considerations](#) for caregivers (interactive checklist)
 - [Decision aid and considerations](#) for people living in long-term care or assisted living

- [25 important questions to consider before a removal from care](#) – CanAGE resource
- Speak to your case manager or contact your Home and Community Care Office to discuss the questions you may have. Having community-specific answers can help you make an informed decision with or on behalf of the person. For example, a case manager can provide you with information on what to expect if someone does transition out of care, such as discharge timelines and what types of care services can be available in the home, especially during the COVID-19 pandemic.

What if the person keeps asking to go “home”? The idea of what “home” is to the person may no longer be where they lived before moving into care. If the person keeps asking to go home, acknowledge that “home” may be a feeling of comfort, rather than a physical location. Try to validate this for the person in the moment before redirecting them. For example, “Of course you want to go home, I would too. I would love it if you could come home with me. The doctor said that you need to stay a few more days until your [knee gets better / blood sugar stabilizes / another health issue that may be known to them]. Just a few more days.”

Also consider that, with changes in communication, “home” could also be a different physical location than what you’re thinking of – a childhood home, the dining room if the person is hungry, etc.

As the person with dementia’s Representative, how can you utilize this position to influence health care decisions by doctors at institutions?

- Depending on the areas of authority given in the Representation Agreement, the Representative has the right to access the information necessary to support decision-making with or on behalf of the adult.
- As a person’s Representative, you should be included in all health-care decision making for that person. If you feel like you have not been included, contact the care home and respectfully remind them about your representative status. As a Representative, you have a duty to uphold the personal wishes of a person living with dementia and this means being involved in all decisions about their healthcare.
- Nidus (Personal Planning Resource Centre and Registry) has some excellent resources on this topic:
 - Review Nidus’ tips for using the agreement for health care and personal care matters in the [Making and Registering a Representation Agreement Section 9 – Self-Help Preparation Guide](#) (see page 17).
 - [Representation Agreement](#) – helpful links including [Role of a Representative](#) and [Access to Information and Representation Agreements](#).

Communicating with Care Home Staff

12. I haven't been able to receive a status update on my husband. Do family members have the right to see care plan changes or know if a doctor's visit has taken place?

If you are a supportive decision-maker, you have the right to access information that will help the person make an informed decision and express their views about their care. This includes the care plan and other documentation that shows whether a doctor's visit has occurred, and what discussions or decisions took place because of that visit.

13. What are the alternatives when outside bathing services or dental visits are not currently allowed? For example, if you find out that your dad's gums look inflamed, and this is an area of care you provided for him before the restrictions, how can you ensure that he continues to have this need met if you are not able to provide it for him?

Speak to the care team about your concerns and your family member's needs. It is possible that there are additional services being offered within the care home. If you used to take care of certain care needs, such as teeth brushing, provide tips to the care team on the best approach. This information can be recorded in the care plan so that staff adopt this practice.

Outside appointments that are essential, such as a medical appointment, are currently allowed so long as there is no active COVID-19 outbreak in the care home. Consider booking an appointment with a medical professional if you are concerned. Speak to the care team prior to making an appointment to understand all the steps and precautions that must be followed.

14. How do I ensure that my family member, who recently moved into a complex care facility (i.e. long-term care), receives an assessment?

It is required through the Residential Care Regulation, section 81, that a person admitted to the community care facility (i.e. long-term or complex care) for a period of longer than 30 days must have a care plan made within 30 days of their admission. The paperwork completed at admission will be used to help inform the care plan.

While you may not get to see the care plan within this 30-day period, it will be reviewed with you at your first care conference, typically within six weeks following admission. At this time, you can offer feedback to help inform the care plan (for example, the best approach for a successful bath). Providing additional information about the person's daily routine and personal history can also help to inform the care plan.

If a care conference does not happen within six weeks of admission, contact the care home administrator and express your need to be informed of the care plan based on the person's

assessment. For more information about what is stated in the regulation, you can [view the policy here](#).

Keep in mind that care plans can be very complex and involve many details that will evolve with the needs of the person. Do your best to document what you know to be important to the person, so that the staff has the information they need to create a care plan that is as person-centred as possible. The person's care plan will be reviewed if there is a substantial change in their circumstances, or annually if no substantial changes have occurred. Document any observations of change in the person so you are prepared for your care conferences. These are your opportunity to be involved in the assessment of the person and the care they receive.

If you are unsure of what to expect at the care conference, speak with your case manager about what this process looks like. You can also call the **Alzheimer Society of B.C.'s First Link® Dementia Helpline** at **1-800-936-6033** or **Family Caregivers of BC's Caregiver Support Line** at **1-877-520-3267** to speak with a staff member about ways you can prepare.

15. When communicating with staff at a long-term care home, do emails count as a legal document?

- It is a good idea to record or save all communication with the care home, whether it's in person, over the phone or in email format.
- For information about legal matters and what is considered a legal document, visit the British Columbia Law Institute's [legal services and information page here](#).
- You can also find more information about health-care consent for people living with dementia in [this summary report](#).

COVID-19 impact on quality of life

16. Has the quality of life for patients and family members decreased due to the COVID-19 pandemic?

While we cannot speak for all families, we have heard from many families that the current restrictions have had a negative impact on their quality of life due to less time spent with their family member(s). While some caregivers have shared with us positive outcomes resulting from the restrictions (for example, being relieved of the guilt of not visiting every day), others have shared a great increase in stress and anxiety; and for some, depression or feelings of trauma.

The recent publication *"Staying apart to stay safe: The impact of visit restrictions on long-term care and assisted living survey"* on November 3, 2020 by Isobel Mackenzie, BC Senior's Advocate, offers insight into the experiences of more than 13,000 residents and family

members who completed a month-long survey on the impact of visitation restrictions on families.

To view the report, visit www.seniorsadvocatebc.ca/reports. To read the news release, which offers background for the report and a summary of survey findings, [click here](#).

Care quality and maintaining abilities for the person living with dementia

17. Do people living with dementia experience a decline in function when they move into long-term care?

There is typically an adjustment period for most – if not all – people when they move into assisted living or long-term care. How long this lasts for will vary depending on the individual. Some may take a few months to settle, while others may adjust right away. It is not uncommon to notice a change in the person’s cognition immediately following a move into care, such as increased disorientation, confusion, agitation, or increased trouble with memory. You may personally recall an experience of waking up in bed in a new home and, for a split second or two, think you are in your own home. If you are not experiencing cognitive changes, you may quickly realize you have moved and be unphased by this experience. However, if you are a person living with dementia, your brain may not register this change immediately, if at all, until more time has passed and the routines of the care home become familiar.

If your family member experiences a decline in their health that is more significant or that you find concerning in any way, share your observations with the care team. There is a difference between being unhappy with a move and feeling depressed – let the care team know how the person usually acts and what their personality is like. Share with them your observations and why it is a concern for you. Knowing what is “normal” for the person can help the care team determine if the person’s behaviour is out of the ordinary and if it is outside the realm of what is expected while the person adjusts. For more information on preparing for a move into long-term care, visit the Alzheimer Society of B.C.’s [webpage on this topic here](#).

18. What can family members do to ensure that people living with dementia in long-term care receive appropriate care?

One of the best things you can do as a partner in the person’s care is to help the staff get to know the person so they can provide person-centred care. Provide them with some key information about their life history (e.g. what they did for a living), what is important in their life (e.g. dogs, jazz music), and who is important to them (e.g. bring photos of close

family members with the names on the photos). This can greatly improve the staff’s ability to respond to the person in a more person-centred way.

For example, if Mary keeps leaving her room every morning at 4 a.m. to wake up some of the other residents, it might be helpful for the staff to know that when Mary was a teenager, it was her responsibility to wake up her siblings for school. Without this insight, it can be challenging for staff to understand the *why* behind the behaviour. When they know the *why*, they can respond in a way that best reduces the chance of upset for Mary and, quite possibly, the need for medications if the behaviour cannot be managed with communication. For example, “Mary, so lovely of you to help out this morning. It’s a holiday though so no school today! Let’s head back to bed so you can get some extra sleep too.” Or perhaps Mary has always been an early-riser and is used to waking up at 4 a.m., so she may be looking for something to eat for breakfast at this time before she ‘leaves for work’. If this is the case, the most appropriate care in this situation could be for the staff to put out a small snack of a banana and some crackers next to Mary’s bed before she wakes up, so she no longer has the need to seek out something to eat at 4 a.m.

Check in regularly with the care team about how your family member is doing and if there are any behaviours that are new or are causing some challenges in the staff’s ability to provide the best care. While staff typically do the best they can – no one knows your family member like you do. Help the care team to identify what might be causing any challenging behaviours and possible solutions for responding.

If you are concerned with anything you have observed during your visits (for example, you notice your family member’s teeth aren’t as clean as they should be or their clothing smells unwashed), politely bring it up with the care team to see if there is a misunderstanding of what is required for the person’s care or whether it was a one-off incident. If a resolution is not achieved after this, document your observations and note the date and frequency of them so you have this information available at your next care conference.

For more information and support, contact us:

Alzheimer Society of B.C.

www.alzheimerbc.ca

1-800-936-6033

Family Caregivers of BC

www.familycaregiversbc.ca

1-877-520-3267