

## Everyone should have someone

### Learning from caregivers' experiences of long-term care visitation during COVID-19

Families and friends provide the essential support, care and love that people living with dementia need to live well with the disease. The COVID-19 pandemic cut many people living with dementia off from their support networks. This was particularly true for people living in long-term care.

When the pandemic began, caregivers supporting people in long-term care throughout B.C. were shut out – with no idea when they'd be able to see residents again. In addition to being unable to support crucial daily care, they were unable to offer the reassurance, comfort and familiarity that helps maintain sense of self and well-being. Despite care home staff working with them to find creative solutions – like video calls and window visits – many families saw a decline in residents' quality of life. Guidelines were developed early on – including a clause for an “essential” visitor – but were revised multiple times throughout the pandemic.

After essential visitor status was introduced, families reached out to the Alzheimer Society of B.C. for support in navigating the challenges they faced in applying. Every story was different but there were common threads. After visitation was once again restricted in January 2022, we launched a survey to learn more about people's experiences of the process.

What we heard from families illustrates a disconnect between how guidelines were written and how they were applied. Within a health-care system already stretched by the pandemic, people navigated changing policy, inconsistent communication and confusing application/appeal processes. Family members who were denied access felt the trauma of physical separation from their

spouse or parent. Additionally, those who were granted essential visitor access had to shoulder the weight of their caregiving duties without the support of other family members. Still others were unaware they might be eligible to apply.

As we look ahead, it is important not to lose sight of the challenges we've collectively faced and what we've learned from them. We can better define what essential care means to residents' quality of life and recognize the vital role families play in providing it. We can advocate for making decisions based on a person-centred approach, instead of a strictly biomedical one. We can work together to make system-level changes to better support people with a family member living with dementia in long-term care. We are pleased to share our findings and accompanying recommendations.



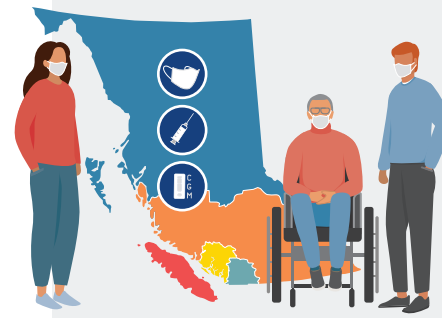
Jen Lyle  
Chief Executive Officer  
Alzheimer Society of B.C.

“My husband is living with dementia... when I visit him, **my main aim is to make him feel loved.** I cut his hair, massage him, give him a manicure and pedicure. I keep an eye on his appearance and well being.”



# Everyone should have someone

Learning from caregivers' experiences of long-term care visitation during COVID-19



## Who completed the survey?

A total of 499 surveys completed:

- Fraser Health: 34 per cent
- Vancouver Coastal Health: 21 per cent
- Island Health: 21 per cent
- Interior Health: 17 per cent
- Northern Health: Five per cent

Note: Two per cent of respondents did not indicate their health authority.

- Forty-five per cent of respondents were adult children or children-in-law. Spousal caregivers accounted for 33 per cent, other family members for 15 per cent and friends/neighbours for another seven per cent.

- 250 respondents applied but only 164 received essential visitor status.

## The policy

The guidelines for visitation in long-term care included a limited definition of “essential” that did not reflect the full breadth of the support that families provide, because that support can’t be easily quantified.

Between March 2020 and February 2022, these guidelines were revised multiple times with designations (such as “social designated visitor” and “single designated visitor”) added as new categories.

## Communication

Provincial policy allowed care homes flexibility but required them to give caregivers advance guidance on how and when they could visit. Our survey found only 52 per cent of respondents received instructions on how to apply for essential visitor status.

## Application instructions

People who received instructions applied to be essential visitors at twice the rate of those who didn’t receive instructions. They were also twice as likely to be granted essential visitor status. Of those who did not receive instructions, only 26 per cent were granted essential visitor status and 40 per cent weren’t aware applying for the status was an option.

## Why did people apply for essential visitor status?

While 28 per cent of respondents listed assistance with physical care as the sole or partial reason for applying, 59 per cent of respondents indicated that assistance with mental health and well-being was the sole or partial reason for applying. Such a pattern speaks to the role families and friends play in supporting residents’ quality of life.

## What was the application experience like?

“There was no process – I was simply denied.”

“The resident had no input into the decision. They wanted to see me but weren’t allowed.”

“My mother is living with dementia and she was not involved in the decision-making process. It was strictly made by management.”



## Who are the social visitors?

Of people visiting, 23 per cent had social visitor status.

“I was asked to assist with Mom’s bathing routine, which gave me essential status. Now she’s calmed down and I am seldom there for bathing but they keep my status as essential for the Friday visits. Any other day I visit, I am considered a social visitor.”

## Who are the essential visitors?

Of people visiting, 40 per cent had essential visitor status.

Eighty-two per cent of essential visitors were spouses, while 66 per cent were adult children or children-in-law.

While an application should include a reason for applying, 22 per cent of respondents were never asked for one.

At least five per cent reported that they were prevented from entering during outbreaks, despite ongoing access being a primary feature of essential visitor status.

## Why were people denied?

The most common reason for having one’s essential visitor status denied was that the care provided by staff was considered sufficient or the applicant was not considered essential.

Just under 50 per cent appealed the decision directly with the care home or health authority. Nearly 29 per cent did not appeal at all.

## Why didn’t people apply?

Fifty per cent of respondents did not apply to be essential visitors.

“No one was considered essential. The facility told me they don’t have any essential visitors. The reason given was that all ‘essential’ services for residents are being provided by staff!”

“It feels like applying and being denied would create more emotional difficulty than not applying at all. I don’t want to jeopardize relationships with staff or create conflict. If other people can only be social visitors, it feels unfair to think that I am more deserving of extra time with my loved one than they are. Fairness matters.”

“My initial request to be an essential visitor was made because my husband was having difficulty swallowing, but I was declined. It wasn’t until he had a seizure that it was granted...I was able to stay with him until he passed away seven days later. I felt fortunate to be able to be with him but in what world should we feel privileged to hold the hand of our dying spouse?”

# Everyone should have someone

Learning from caregivers' experiences of long-term care visitation during COVID-19

## Recommendations based on survey results

Based on the trends that emerged from our survey findings, we have three key recommendations to put forward on how people's lived experience of the COVID-19 visitation guidelines can better inform policies and processes that would balance safety protocols with the needs of people living with dementia in care, as well as their families and caregivers.

### Families must be involved and engaged

Families are not just "visitors." They are essential partners in dementia care. They hold valuable knowledge about how the delivery of care can be centred around the resident's needs and personal wishes. In many cases, family members act as substitute decision-makers and must remain informed so they can make the best possible decisions on behalf of the resident living with dementia. Future policy must recognize that families play an essential role in not only delivering person-centred dementia care but also augmenting resident quality of life.

"I was told it didn't apply to me because my mom does not require assistance with feeding or other duties beyond what the staff are providing. She doesn't need me – except as a social support, which I was told was not included in essential visitor status."



"Applying feels like a hassle. You have to meet certain criteria and the doctor needs to sign off, but it seems to come down to whether or not you provide daily care needs. My mother's cognitive decline seems to qualify her for an essential visitor, if you ask me. I still have to apply, never mind how lonely and isolating it's been for her."



### Family access must be determined with a person-centred approach

The processes determining access to long-term care should centre on the person's wishes. This means asking the resident and their substitute decision-maker who they would like to visit, when and how often. If this conversation takes place when residents move in, it will help ensure everyone has a designated support person who can visit to attend to their psychosocial needs, even in times of outbreak.

### Communication must be clear and proactive

All provincial policy affecting families needs to be clearly communicated with them at provincial and local levels. They need to be informed of their options so that they can ensure that residents can have the best quality of life possible.

"I wasn't informed of the process of being designated an essential visitor. If you did not know the designation existed, you would never be an essential visitor."



Learn more about how you can advocate for people affected by dementia at [alzbc.org/advocacy](https://alzbc.org/advocacy).