



OFFICE OF THE  
**SENIORS** ADVOCATE  
BRITISH COLUMBIA

# STAYING APART TO STAY SAFE

The Impact of Visit  
Restrictions on Long-  
Term Care and Assisted  
Living Survey

November 2020



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November 3, 2020

This pandemic has taught us many things beyond the basic science of infectious diseases. We have learned much about ourselves and each other as we unite to make it through this pandemic together. These troubled times have made us reflect on what we value in life and we have found that, for many of us, the top priority is the time we spend with our family and loved ones. It is currently predicted that it may be a year or more before life gets back to normal. This time frame is sobering when we think of those seniors who live in long-term care, many of whom are in the last year or 18 months of their lives.

British Columbia experienced the first COVID-19 outbreak in a long-term care home in Canada and we recorded the first death from COVID-19 in that same care home. We saw how quickly COVID-19 can spread in long-term care and we saw the devastating impact of this virus on the older population. In response, we reacted swiftly with a suite of measures that quickly brought COVID-19 outbreaks in long-term care in B.C. under better control. While we are still experiencing outbreaks, currently more than 80% of long-term care and assisted living sites have not yet experienced an outbreak. Of those that have experienced an outbreak, more than 60% are contained to a single person (mostly a single staff person) and there have been no deaths yet in over 70% of our long-term care/assisted living (LTC/AL) outbreaks.

One of the first measures we implemented to control transmission of the virus in our LTC/AL sites was to restrict all visits. This was an important measure to take at the beginning of the pandemic as the system needed time to ensure the necessary staffing stability, personal protective equipment (PPE) provisions and public health supports were in place to better manage COVID-19 in our long-term care system. However, the impact of these visit restrictions over the longer term are having a profound effect on many of our LTC/AL residents and their family members and we need to examine our current policy and practices as we look at the many months of this pandemic that still lie ahead.

No single issue has dominated the phone calls, emails and letters we have received here at the Office of the Seniors Advocate as that of the current visit restrictions in LTC/AL. The stories from families that have been separated, some for over six months, are nothing short of heartbreaking. Initially when visit restrictions were implemented, families and residents supported the need for such measures as they realized they needed to stay apart to stay safe while the health care system learned how to manage this virus in LTC/AL; however, as weeks became months, concerns began to rise.



In response, my office launched a survey, *Staying Apart to Stay Safe: the Impact of Visit Restrictions on Long-term Care and Assisted Living*, at the end of August. More than 15,000 people participated in the survey. The stories we heard have made it clear that residents need to spend more time together with the people they love and they cannot wait another year or more until this pandemic is over for this to happen.

While some pre-pandemic LTC/AL visits by family were purely social, the survey found that more than half of visiting family members were performing necessary tasks such as personal care, grooming, assistance with feeding, and mobilization. Despite this, the survey found that very few residents received an essential visit during the first phase of visit restrictions. Less than half of respondents applied for an essential visit and almost half of these requests were denied.

When the visit restrictions were amended at the end of June, many family members thought they would once again take up their role as a vital care partner for their loved one. However, two months after visit restrictions were relaxed, the survey found the majority of current visits are only once per week or less and many of these visits are 30 minutes or less. Prior to the pandemic, most family members were visiting several times a week or daily for much longer periods of time.

In the past, most family members would visit in the privacy of their loved one's room (75% of LTC residents live in a private room), but only two out of ten are currently able to enjoy these unobserved private visits. Currently, most visits are in common areas and almost one-third of visits are only permitted outside.

Sadly, during this pandemic, 151 residents of LTC/AL have died from COVID-19 to date. During this same time period, however, more than 4,500 residents have died from illnesses or conditions other than COVID-19. We learned that in their final months, weeks and days, most of these residents were not able to spend time with those they loved the most.

This pandemic has upended lives everywhere. However, for most, there is a post-pandemic world that will bring back the freedoms and choices we once took for granted. For residents of long-term care, however, this tomorrow may never come. Perhaps that is why we found that most residents of long-term care are not as worried about contracting COVID-19 as we might think. The comments we heard from hundreds of family members indicate there is a greater fear of death from loneliness. Many residents are despondent as the only thing they look forward to is receiving a visit from their family. There are also early warning signs of measurable health impacts. After recent years of stability, the rate of antipsychotic use for residents in LTC has increased 7% during this pandemic and initial reports from the quarterly interRAI assessments show troubling trends of unintended weight loss and worsening of mood among LTC residents.

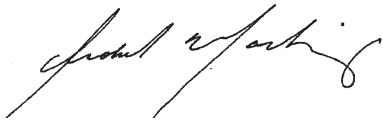
We implemented visit restrictions and other measures in long-term care and assisted living because we care. During this pandemic, the provincial government has dedicated significant financial resources to increase and stabilize the LTC/AL workforce, to ensure all LTC/AL sites have sufficient PPE, and to fund additional staff who can manage the safe screening and scheduling of visitors. The Provincial Health Officer has consistently and persistently made the safety of seniors a top priority as reflected in the swift measures we took at the beginning of the pandemic in response to the threat of COVID-19 in LTC/AL.

The challenge was and remains finding the balance between the risk from the virus and the need to have some quality of life. We cannot reduce the risk from COVID-19 to zero, but neither can

we reduce the risk to zero for a death in LTC due to a fall, a medication error, or infection. Our pandemic response measures are meant to keep our seniors safe, but what are we keeping them safe for if not to enjoy the limited time they have left with the ones they love? In the last eight months, our response to the pandemic has evolved and we now know much more about how the virus is transmitted, how to screen for the virus, and what are effective layers of protection. We need to apply this evolving knowledge as we allow greater flexibility for residents of long-term care and assisted living to spend time with their loved ones.

With compassion and kindness to temper clinical decisions around safety, we can thoughtfully respond to the needs of our seniors and their families. Finding the right balance will be challenging but it is the right thing to do as we seek to bring joy, comfort and an enhanced quality of life to British Columbia's seniors.

Sincerely,



Isobel Mackenzie  
Seniors Advocate  
Province of British Columbia

*"This survey would not have been possible without the incredible contributions from a number of talented and dedicated staff at the Office of the Seniors Advocate and the expertise of Lena Cuthbertson at the British Columbia Patient-Centred Measurement office. The support of the health authorities and the care home operators was paramount to allowing family members and residents to have their voice heard. I particularly want to thank the 49 volunteers who completed over 233 surveys with participants over the phone. Finally, I want to add my voice to the many who express appreciation for the steadfast guidance of our Provincial Health Officer, Dr. Bonnie Henry, and her team of Medical Health Officers. Their understanding of the fragility of our long-term care system and the need for swift and broad-sweeping action at the beginning of the pandemic along with consistent concern for the elderly throughout the past months has been appreciated by seniors everywhere and you have my profound gratitude."*

Isobel Mackenzie

# Background

On January 28, 2020, British Columbia identified its first case of COVID-19. On March 7, a North Vancouver care home declared the first COVID-19 outbreak in a Canadian long-term care home, and sadly, on March 9, this care home recorded the first death from COVID-19 in Canada. Two days later, on March 11, the World Health Organization declared COVID-19 to be a pandemic.

Within the initial days and weeks of our first care home outbreak, B.C. undertook a number of public health measures to reduce the possibility of the virus entering a long-term care (LTC) or assisted living (AL) setting and spreading. These measures have included:

- restricting visits to LTC and AL to “essential visits” only;
- lowering the threshold for declaring an outbreak in LTC/AL to one test-positive case of either a resident or a staff member;
- actively screening and/or testing all residents and staff at LTC/AL care homes with a declared outbreak;
- ensuring active on-site public health involvement at the beginning of a declared outbreak;
- restricting all staff who work in LTC/AL to work at one site only;
- developing COVID-19-specific sites to decant test-positive residents if necessary (has not been required to date);
- requiring care homes to develop outbreak management plans that included cohorting of test-positive residents;
- including all care homes in the provincial supply chain for personal protective equipment (PPE) to ensure sufficient supply of PPE for all LTC/AL sites; and
- dedicating significant financial resources to stabilizing the workforce and enhancing infection control practices at all LTC/AL sites.

The restriction on visits to LTC/AL was revised at the end of June. The revised policy allowed for all residents to receive one designated “social visitor.” This could be a current essential visitor if the resident had qualified for essential visits during the previous four months or, for those residents who did not have essential visits, they would now be allowed one designated “social visitor.” Other measures that were initiated at the beginning of the pandemic remain in place.

As of November 2, 2020, the experience of LTC/AL outbreaks in British Columbia is as follows:

- 20% of LTC homes have experienced a total of 87 outbreaks (71 sites);
- 7% of AL residences have experience a total of 15 outbreaks (14 sites);
- 59% of outbreaks have been contained to a single case (51% a staff member and 8% a resident);
- 72% of outbreaks have no deaths caused by COVID-19 to date;

- 97% of outbreaks and 100% of resident infections have occurred in the two largest of B.C.'s five regional health authorities (Vancouver Coastal and Fraser Health);
- 515 LTC/AL residents have been infected representing 1% of all residents and 3% of all cases;
- 351 LTC/AL staff have been infected representing less than 1% of all staff and 2% of all cases; and
- 151 LTC/AL residents have died from COVID-19, which is 56% of all deaths from COVID-19 in B.C..

Over the eight months since the pandemic was declared, the relationship between the number of new cases, the number of LTC/AL outbreaks and the hospitalization cases has shifted, as illustrated in the time series chart below:

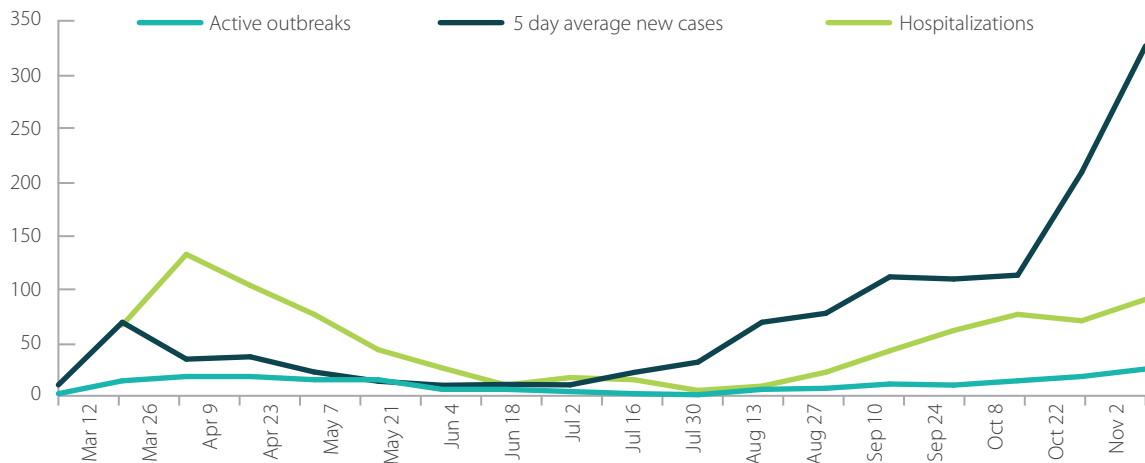


Figure 1: Active care home outbreaks, five-day COVID-19 case average, and active hospitalizations - B.C., biweekly

This graph illustrates that we are currently experiencing significantly lower rates of both hospitalization and outbreaks in LTC/AL relative to the five day rolling average of new cases than we were in the earlier part of the pandemic. This reflects in part the younger age of those infected as the pandemic has progressed and the measures implemented in the first two months of the pandemic to reduce the possible transmission of COVID-19 to and within LTC/AL settings.

Over the course of the pandemic, concerns have been expressed about the impact of visitor restrictions on the mental health and overall well-being of residents in LTC/AL, particularly those with dementia. There are many quality indicators that we measure in LTC and one of these is the use of antipsychotic medications. We examined the proportion of residents that were dispensed antipsychotics from March to the end of September 2020 and found the rate of use increased by 7%. As the graph below illustrates, when we look back at the past three years, this rate of increase is significant and is one indicator of the potential unintended consequences of the visitor restriction policies.

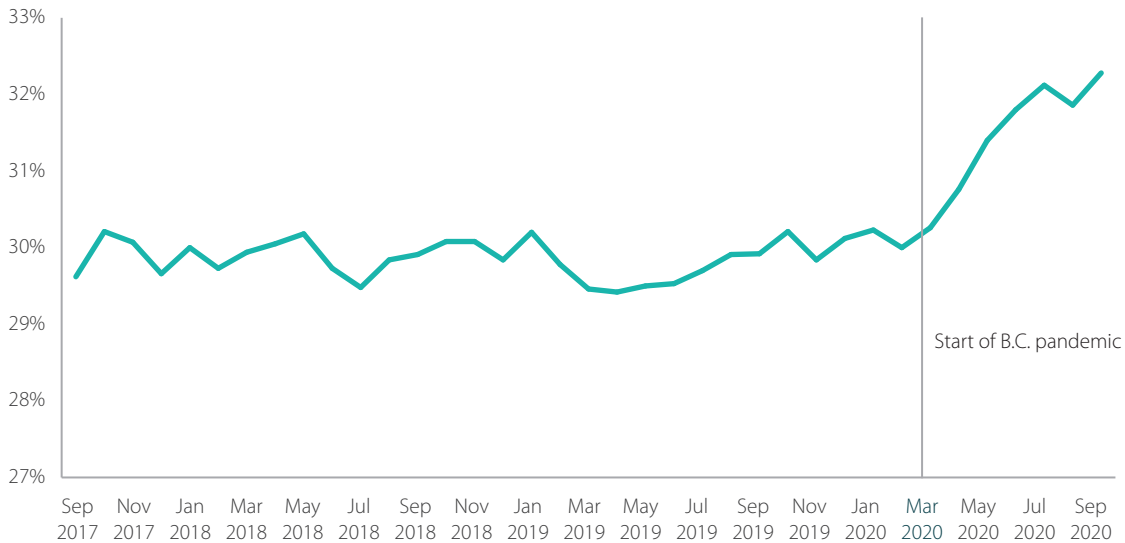


Figure 2: Proportion of residents on PharmaCare Plan B¹ that were dispensed antipsychotics

When the pandemic first began and visits to care homes were restricted to essential visits only, there was wide acceptance of the measures taken. During this time, everyone was being asked to stay at home, most businesses were closed, and the focus was on building capacity to manage the virus without allowing it to overwhelm our health care system.

However, as the period of time that families were separated began to stretch into months, many family members became increasingly distressed and the issue of care home visits came to dominate the calls and letters to the Office of the Seniors Advocate (OSA).

It became clear from the stories that individual care homes were taking very different approaches to managing both essential and social visits. We needed to gain a better understanding of the magnitude of the issue and, on August 26, we launched a survey specifically for family members and residents of LTC and AL to tell us about their experience.

1 PharmaCare Plan B provides drug coverage for residents living in LTC operated under the Community Care and Assisted Living Act, which is approximately two-thirds of all residents.



# The Survey

The survey was open from August 26, 2020, to midnight September 30, 2020. Respondents could complete the survey online, mail in a paper copy or answer over the phone. Over 15,000 people participated, producing over 13,000 valid responses

The survey received responses from all health authorities and from residents (or their visitors) living in all ownership types of long-term care and assisted living – health authority, not-for-profit society, private company with public funding, private company with no public funding – and all sizes of settings from those with less than 50 beds to those with 250 or more beds.

## Who Responded

We asked a number of questions to help us understand who was answering the survey and we learned the following about our the respondents:

- 49% are family members or close friends of a LTC resident;
- 14% are family members or close friends of an AL<sup>2</sup> resident;
- 9% are members of the public;
- 8% are residents of AL; and
- 6% are residents of LTC.

Of the visitor respondents:

- 11% are spouses of residents;
- 64% are adult children of residents;
- 4% are grandchildren of residents;
- 16% are some other relative of the resident; and
- 4% are a friend of the resident.

Overall:

- 77% of the respondents were female;
- the average age of the visitor respondent was 62 and the average age of the person they were visiting was 86;
- the average age of resident respondents was 83;
- 69% of respondents lived in the same city as the family member living in LTC/AL; and
- 92% communicated with their loved one in the English language.

<sup>2</sup> This includes both registered assisted living and seniors independent living sites.

## Visit Experience Pre-Pandemic

The survey asked a number of questions about the visiting experience prior to the pandemic. Respondents told us the following about their pre-pandemic visits in the LTC/AL setting.

When visiting their loved one prior to the pandemic:

- 20% assisted with personal care;
- 41% assisted with grooming (46% in LTC);
- 39% assisted with meals (45% in LTC);
- 65% took their loved one for walks, helped them with exercises/mobilization;
- 55% read to their loved one/updated on current events (60% in LTC); and
- 69% took their loved one out for appointments (62% in LTC).

These responses validate findings of previous surveys in terms of the type of assistance that family members provide for those who live in LTC. They also validate why family members see themselves as an integral part of the care team that is supporting their loved one.

When asked how frequently family members were visiting prior to the pandemic, respondents told us:

- 55% were visiting their loved one either daily or several times a week; and
- 65% were visiting for one hour or more.

## Essential Visit Experience

When visit restrictions were implemented in March 2020, a policy provision was made to allow for certain visits to continue, as they were deemed essential to a resident's health and well-being. These are termed "essential visits." The criteria for essential visits were defined by the Provincial Health Officer and are as follows:

Essential visits can include, but are not limited to:

- Visits for compassionate care, including critical illness, palliative care, hospice care, end of life, and Medical Assistance in Dying.
- Visits paramount to the patient/client's physical care and mental well-being, including:
  - assistance with feeding;
  - assistance with mobility;
  - assistance with personal care;
  - communication assistance for persons with hearing, visual, speech, cognitive, intellectual or memory impairments;
  - assistance by designated representatives for persons with disabilities, including provision of emotional support;
  - visits for supported decision making; and
  - visits for pediatric care, labour and delivery.
- Existing registered volunteers providing the services described above.
- Visits required to move belongings in or out of a client's room.
- Police, correctional officers and peace officers accompanying a patient/client for security reasons.

Who qualified for an essential visit was left to individual care homes to determine.

We asked respondents about whether they were aware of the essential visit policy, whether they applied for it and whether their application was successful. They told us:

- 14% of the respondents were an essential visitor;
- less than half (48%) of respondents were made aware of the potential for essential visits;
- less than half (42%) of respondents applied or had another family member apply for essential visits; and
- almost half (45%) of the essential visit applications were denied.

For those who were essential visitors, or were granted essential visits, we asked about the frequency and duration of the essential visits and we found:

- 9% of essential visits occurred daily, a further 16% were several times a week but not daily, and the majority were once per week or less; and
- 33% of essential visits lasted for 30 minutes or less and a further 32% were between 30 minutes and one hour.

## Current Visit Experience

Effective June 28, 2020, the visitor policy was changed from “essential visits only” to a policy that would allow all residents one designated “social” visitor. This appears to have been universally interpreted to mean that if you were receiving essential visits, your essential visitor would become your one designated visitor. Some residents had more than one essential visitor, so this in part explains why 18% of essential visitors did not become the designated visitor.

The requirement for designated visitors under public health directives are that they schedule their visit in advance and wear non-medical masks. Decisions related to where visits would occur, how frequently and how long a family member could visit were left to each care home operator to decide.

We asked both those who were currently the designated visitor (61% of respondents) and residents about their current visiting experience under the guidelines implemented on June 28. They told us:

- 20% of designated visitors are spouses;
- 51% are adult children; and
- 25% are another family relative.

Although change to the visitation policy was announced on June 28, care home operators were expected to need a week or two to make the necessary arrangements to accommodate increased visits. The majority (61%) of designated visitors completed their first designated social visit prior to the end of July; 28% did not have their first visit until sometime in August and 10% did not have their first visit until the month of September.

Currently:

- 30% of visits are outdoors only;
- 21% of visits are in the residents’ rooms;
- 65% of visits are observed by care home staff some or all of the time; and
- 18% of visits have plexiglass or some other physical barrier between the resident and visitor.

There is currently only one designated visitor allowed per resident. The frequency and duration of these visits are:

- 4% are daily;
- 56% are weekly (an estimated 10% of these are more than once per week, but not daily);
- 14% are every two weeks;
- 3% are every three weeks;
- 5% are monthly;
- 44% of visits are 30 minutes or less;
- 34% are 30 minutes to an hour; and
- 9% are one to two hours.

The reported visit frequency and duration of visits for the designated visitor are, on average, significantly shorter and less frequent than visits prior to the pandemic. For example, prior to the pandemic, 18% of LTC visits were daily, 41% were several times per week (but not daily), and only 4% were 30 minutes or less.

Upon first visiting their loved one after the visit restrictions were amended, 61% of family members reported their overall impression was that their loved one seemed worse than when they last saw them and specifically identified:

- 46% reported physical functioning was worse;
- 58% reported cognitive functioning was worse; and
- 58% reported their loved one's mood and emotional well-being was worse.

These observations would support the need to be concerned about the unintended consequences of the visitor restrictions on those living in LTC/AL. Each quarter in LTC, we regularly assess residents on a number of indicators including physical function, cognitive function, mood and behaviour. On average, we see a worsening of condition in about 25% of residents. The observation of family members doubles that number for the first quarter (April 1 to June 30). The 7% rate of increase in the use of antipsychotics (and an additional 3% rate of increase in the use of antidepressants) over the time period of the visitor restrictions is an added warning sign of potential health impacts from visitor restrictions.



## Current Infection Control Practices

Care homes were required to submit to health authorities, as part of their overall visitation management plan, the steps they were taking to mitigate the risk of COVID-19 for residents, visitors, and staff. We asked visitors what screening, detection, and prevention protocols were performed at the care home they visited.

Visitors report the following infection control practices at care homes:

- 93% are required to wear a mask;
- 90% schedule their visit in advance;
- 90% complete a health screening questionnaire in person or online prior to each visit;
- 88% are greeted by care staff upon arrival;
- 85% wash/sanitize their hands upon arrival;
- 76% have their temperature checked;
- 75% are required to remain six feet away from their loved one;
- 61% are physically escorted by care staff to the visiting area/resident room;
- 11% are required to wear a gown;
- 7% are required to wear gloves; and
- 4% are required to wear face shield.

In addition:

- 77% of visitors report they are not able to touch their loved one and this only drops to 72% when the visitor is a spouse; and
- 60% of visitors are not allowed to take their loved one out of the care home for social outings or appointments; this increases to 71% for LTC.

## What Do Residents and Visitors Recommend

We asked family members and residents their thoughts on how visit restrictions should be managed. We know a lot more about how to manage the risk of COVID-19 than we did when the pandemic began. More importantly, we know that we will be living with this virus in our community for the next year, perhaps more. Residents and family members have had six months or more of living with visit restrictions and it is important for us to know what measures they think are reasonable as they are the most directly affected.

While 75% support some form of visit restrictions while we have COVID-19 circulating in our communities, the majority of respondents do not support the current one visitor restriction. When asked how many visitors should be allowed, we heard:

- 16% support one visitor (current policy);
- 42% support two visitors;
- 36% support three to five visitors; and
- 6% support six or more visitors.

When asked about the frequency of visits that should be allowed during the pandemic, family members indicated the following support:

- 22% daily;
- 43% a few times a week; and
- 27% weekly.

When asked about how long visits should last during the pandemic, respondents indicated the following:

- 25% 30 minutes;
- 50% one hour;
- 17% two hours; and
- 7% four hours or more.

The survey asked visitors about what infection control practices they thought were appropriate. There was a high level of support for:

- 97% hand washing;
- 89% wearing a mask;
- 88% health question screening;
- 86% temperature checks;
- 85% greeted by care home staff upon arrival; and
- 77% scheduling visits in advance.

There was a lower level of support for:

- 25% thought visits should only be allowed in common areas (these respondents also generally indicate their loved one is in a shared room);
- 19% thought there should be no touching allowed;
- 12% supported outdoor visits only;
- 11% supported plexiglass or similar barriers between visitors and residents; and
- 9% thought visits should be supervised.

There was a high level of support for different visit restrictions for spouses (73% in favour) and for palliative/end of life residents (92% in favour). More frequent visits and the ability to hug or touch their loved ones were the top consideration for spouses.

In summary, while there is not a unanimous opinion for any question in the survey, there is a very strong consensus from the people who live in LTC/AL and their family members that we need to allow visits more than just weekly and we need to allow at least an hour or more for them to enjoy the company of their loved one at each visit.

We have also heard strong support that visits should not be observed by staff, that visits should be allowed in the resident’s room and that family members, especially spouses, should be able to touch their loved one. There is strong opposition to visiting only outside and to having plexiglass barriers between visitors and their loved one.

The survey responses highlight that family members act responsibly and want to reduce the possibility that they will transmit the virus to their loved one. They have told us they are more than willing to schedule their visits in advance, answer health screening questions prior to every visit, wash their hands thoroughly when they arrive, have their temperature checked, and wear a mask while they are visiting.

## Opinions on Quality

We asked visitors and residents a number of questions that provide an overall impression of their confidence in the quality of care and services they or their loved one are receiving. Many of these questions are identical to questions that we asked in our 2017 survey of care home residents and their family members.

Visitors were asked to rate the overall quality of the care and services received by their loved one before the pandemic and now. We asked this same question of family members in our 2017 survey; results are provided below for comparison.

	Pre-Pandemic	Currently	Previous Survey (2017)
Excellent	19%	15%	28%
Very good	39%	27%	39%
Good	25%	22%	22%
Fair	11%	15%	9%
Poor	3%	8%	2%
Don't know/unsure	1%	12%	n/a

We see decreases in the proportion who rate the quality as excellent or very good, and an increase in the proportion who don't know. This may be reflective of many things, including the inability of most family members to spend the time with their loved one that would allow them to be confident in the quality of care. We also found that:

- overall, visitors feel less confident that their loved one is safe when they are alone or that they will get the help right away if they need it than they did prior to the pandemic; and
- overall, visitors feel they are not kept up to date about their loved ones as much as they were prior to the pandemic and they are significantly less involved in decisions about their loved one's care now than before the pandemic.

When asked how well the care home managed the visit restrictions, respondents told us:

- 17% felt they were exceptionally well managed;
- 40% felt they were very well managed;
- 30% felt they were somewhat well managed; and
- 13% felt they were either not well or poorly managed.

It is to be expected that disruptions in care home operations as they manage the many restrictions brought on by COVID-19 would impact some quality indicators. It is interesting to see the majority of family members, while they acknowledge these impacts, believe the care home managed the visit restrictions very well or exceptionally well. This is reflective of a common theme throughout the survey responses of family members who, while they are very much wanting to see more of their loved one, are reasonable, rationale and consistent in their responses.

## Palliative Care Experience

Each year in British Columbia, approximately 25% of residents of long-term care pass away. Over the eight months of the COVID-19 pandemic in B.C., while 151 residents of LTC/AL have tragically died from COVID-19, over 4,500 residents passed away from illnesses, infections and conditions other than COVID-19 during the same time frame. We wanted to understand the impact of the visitor restrictions on how residents and their loved ones were able to experience the end-of-life journey.

We asked respondents to indicate if their loved one was designated palliative or had passed away since the pandemic was declared. These respondents were directed to specific questions on their palliative/end-of-life experience.

Overall, 10% of respondents reported that their loved one was either currently palliative or passed away during the pandemic. Here is what they have told us:

- half of the respondents (50%) indicated they were not allowed to spend as much time as they wanted with their loved one before their loved one passed away;
- 83% indicated there were restrictions on the number of people allowed in their loved one's room while they were palliative and over half were restricted to one visitor (48%) or no visitor (10%);
- most visitors (84%) were not required to stay six feet away from their loved one in the last 24 to 72 hours of their life but 23% were not allowed to touch them or kiss them good-bye; and
- 40% of respondents either do not believe (28%) or are not sure (12%) that their loved one passed away with dignity and the majority believe the visit restrictions are responsible.

We asked all respondents to tell us how long before death they would consider a person to be palliative. Over three quarters of people think a person is palliative if their death is expected in the next month or two. Yet, two-thirds had their loved one pass away a week or less after they were designated palliative.

This is an ongoing challenge in LTC, where, at any given time only 4% of residents are assessed as being expected to pass away within six months. With the frailty and comorbidities of those who live in LTC, end of life can come quickly and, under current visit restrictions, the valuable time one wishes to spend with their loved one in the final few weeks and days of life can easily be lost.

## Differences Between Assisted Living and Long-Term Care

The majority of responses were similar regardless of whether the respondent lived in or was attached to a LTC or AL site. There were, however, some key differences, as noted below.

Compared to long-term care, residents of assisted living were:

- more likely to reside in a single room;
- significantly more likely to have and to use a telephone without help;
- significantly less likely to have a spouse;
- less likely to have visitors that perform personal care, grooming or assist with feeding;
- less likely to have had daily visits pre-pandemic;
- less likely to use a wheelchair or be bed bound;
- on average, more likely to report better cognitive and physical function as well as better mood and emotional well-being;
- less likely to have received an essential visitor;
- much more likely to have moved out of the facility during the pandemic;



- significantly more likely to have been restricted to their room and for a much longer period of time than residents of LTC;
- much more likely to have been restricted from dining in the common dining room;
- less likely to have staff observing the visit and significantly less likely to be escorted to the visiting room;
- currently much more likely to be able to leave the facility for social outings and medical appointments; and
- on average, more likely to provide higher ratings across quality indicators.

These differences were, for the most part, to be expected as residents of AL are more independent than residents of LTC. The surprise, however, was the more severe lockdown in terms of confinement to their rooms and no use of the dining room that residents of AL experienced compared to those living in LTC.

## Differences Between Type of Visitors

Overall, the majority of visitors were adult children or other family members. However, 11% of visitors are the spouses of people living in long-term care or assisted living, and there were some statistically significant differences in their visit experiences including:

- spouses are significantly more likely to have visited daily prior to the pandemic;
- spouses are much more likely to assist with personal care/grooming and meals;
- residents whose visitor is a spouse are less likely to have a phone;
- residents whose visitor is a spouse are more likely to use a wheelchair or be bed-bound;
- spouses were more likely to have requested essential visits but no more likely to have been granted an essential visit;
- spouses are significantly more likely to be the current designated social visitor;
- spouses are much more likely, if they are not the current designated visitor, to have a paid companion as the designated visitor for the resident;
- spouses are more likely to be allowed to touch their loved one during the visit;
- spouses generally report better communication with the care home staff; and
- spouses are, on average, 14 years older than the average visitor to a resident in LTC/AL and the person they are visiting is far more likely to be male and is 7.6 years younger than residents who receive family visitors that are not the spouse.

## What Residents Told Us

Many questions were asked of both residents and visitors. Overall, most responses were similar. In resident responses, we had a higher proportion who indicated they reside in AL (54%) than in LTC (43%). This was not unexpected, as residents of AL would, on average, be better able to answer the survey without assistance, which was important given the range of accessibility options we were able to provide within the time limits of the survey.

Highlights of where we saw notable differences in responses from residents versus visitors include:

- LTC residents who responded to the survey were much less likely to be assisted with personal care, grooming, and feeding than residents who had a visitor respond to the survey;
- both LTC and AL residents who responded were more likely to have and use a personal phone and to use video calling such as Zoom or FaceTime;
- residents who responded are less likely to be worried about contracting COVID-19 than family members are worried about the resident becoming infected;
- residents felt more assured than their family members did that they were safe when alone and could get care when needed;
- relative to both family members and to residents of LTC, AL residents were much more likely to rate the quality of care they received during the pandemic as excellent or very good; and
- LTC residents wanted fewer restrictions on visits than AL residents.

# What Else Did We Learn

We asked a number of questions of both visitors and residents to gain a better understanding of the overall context in which they are experiencing visit restrictions.

One of the key questions we wanted answered was how worried are family about their loved one contracting the virus and how worried are residents about contracting COVID-19. Understanding that we know more today than we did at the beginning about how to manage this pandemic, we asked how concerned people were at the beginning and how concerned they are now. In all cases, the degree of concern is less now than it was at the beginning. Today, while we find that family members are more worried for residents than the residents are, the majority of both residents and families are only a little worried or not worried at all about contracted COVID-19. We also found that, overall, residents of long-term care were less worried than residents of assisted living.

We asked residents and their visitors the following:

*Given what we now know about the virus and our experience of the last six months, how worried are you now about getting COVID-19/your loved one getting COVID-19?*

	Visitors	Residents
Very worried	12%	6%
Somewhat worried	28%	19%
A little worried	38%	31%
Not at all worried	20%	41%

When the pandemic first hit and LTC/AL was closed to all but essential visits, there was a great effort made to promote virtual visiting through phone calls, Zoom, Skype or FaceTime. We wanted to know if some of these substitutes for in-person visits were helpful.

The first line of communication would be to call more often; however, we found that only about half of residents have a personal phone. The rate was much higher in AL, with 89% having a personal telephone (landline or mobile), while this fell to 41% for LTC residents.

The low rate of personal phones is explained, in part, by the over 85% of LTC visitors indicating their loved ones needed help either all the time (73%) or sometimes (15%) to use the phone. This pattern prevailed when questions about use of technology such as Zoom or FaceTime were asked.

Over eight in ten respondents (82%) indicated that, prior to the pandemic, their loved one had additional people such as a paid companion, physical therapist or hairdresser provide services for them.

## WHAT ELSE DID WE LEARN?

About two-thirds of family members appear to have email communication with the LTC/AL home and receive updates at least monthly on the activities of the care home. However, half of the respondents do receive any updates on the status of their particular family member.

When the pandemic began, there was significant public discussion about family members removing their loved one from LTC/AL. We found that 32% of respondents considered taking their loved one out of LTC/AL during the pandemic. However, only 9% did so, with 5% of families moving their loved one out of long-term care, and 20% out of assisted living during the pandemic.

Overall, 12% of respondents had a family member living in a care home that experienced an outbreak. For comparison, on September 30 (the last day for responding to the survey), 10% of LTC and AL homes had experienced an outbreak.

Overall, 37% of residents were restricted to their rooms at some point during the pandemic; however, the rate is much higher in AL, where 57% were restricted to their room versus 30% in LTC. For those who were restricted, the average duration was much longer in AL at 8.2 weeks than in LTC at 6.6 weeks.

# Personal Stories

The survey allowed all respondents to describe the impact of the visitor restrictions in their own words. Many described their first visit after restrictions were relaxed while others told of us of their overall experience. There were thousands of respondents, both family members and residents who took the time to tell their stories. They are difficult to read, but they must be told. Contained in this report is a random selection of twenty one of these stories. We are continuing to synthesize the thousands of responses and we will be producing a further compendium report that will more fully honour the voices of those affected.

*“During our first visit after the quarantine was lifted, she was very emotional. We used to live on the same street and she’s not used to being apart from her loved ones. I have to wear a mask now, which is understandable, but I sit 6 ft away from her and she is hard of hearing and can’t read my lips. I have to write everything down on paper and show it to her. She can see and read it. She has Alzheimer’s and doesn’t understand most of what I’m saying. It was so much easier when I could hold her hand and speak close to her. I miss hugging her. I’m everything to her and of course I don’t want her to get sick; however, I don’t think she wants to stay alive if I can’t be right by her side. She must be missing her other family members, her son and his wife, and her grandson and his wife. Very sad! Especially in the last chapter of her life! The care aides have a social bubble outside of the care home but they are caring for my mom in her room. I don’t understand why I can’t also be with my mom, caring for her emotional needs in her room.”*

*“My mom was very quiet during our first visit: she acted like her family had given up on her. All mom wanted was for me to hug her and for me to let her see me. I wasn’t allowed, I understood but she didn’t. I left crying...”*

*“Not sure how far in kilometers away I am but I have to take a 40-minute ferry ride to get there. While I agree with the one designated visitor it would be nice if they could come more than once a week and maybe stay longer than 30 minutes. I am sure most designated visitors wouldn’t mind doing extra precautions such as gowns gloves and face shields if they could spend more time with their loved ones and maybe even given the chance to hold their loved one’s hand. I know I would love to be able to get closer to my relative and hold their hands. Right now they often ask me to help them shift or get closer with family pictures and I feel bad that I have to call a worker to help them and they don’t understand why I can’t help them. I also don’t understand why I can’t visit in my relative’s room if they are in a private room.”*



*"I feel I am missing out of the limited time my husband has left. He doesn't speak so it is all the more important that he sees me. It's interesting that the assisted living residents have the freedom to come and go, from the same building/door, with no masks. And yet I can't get within 6 feet of my husband. I have asked several times to be considered an essential visitor. I need help!"*

*"My mother is 98 years old and I am her daughter. Unfortunately, because there can only be one designated visitor, my sister is the only one allowed to visit. This has put a burden on my sister as she tries to visit twice a week. I have asked if we could alternate monthly - one month my sister, the next month me; however, this was refused. My mother can't understand why I don't visit her. I was not allowed to go and do her hair or cut her toenails, even though I have done that for her the past two decades, yet a stranger was allowed to come and do those services. Thank you for the opportunity to express our thoughts."*

*"I'm not the designated visitor due to the distance I live from the place my Mom lives. My sibling is. This has been the most stressful and guilt evoking time I have ever gone through. My mom has some dementia which has gotten so much worse since the COVID-19 closures. Not being able to comfort my mom is heartbreaking. She believes she is in an actual prison and that she has done something wrong to be there, but can't remember what. She says she is lonely all the time. Denying her hugs and closeness is torture for my sibling, and myself. My mom can't carry on a phone call. Just recently we tried Zoom and it was such a bittersweet event. Heartbreaking to see my mom's sadness in her eyes. Dad died six months before COVID-19, Mom has no husband and thinks he's on a mission. She has never been alone and they were married over 60 years. COVID-19 has made me feel like I have deserted my Mom who was the kindest and at most times, happiest woman. There is no longer a shred of happiness on her face. Confusion, and frustration as to what has happened to her life is all that there is. Traveling to visit my mom has to be planned, and before this I'd visit a couple of times a year for a few weeks. Not be assured of a visit, and to see her only through a door is not the answer as in my mom's case she is upset when my sibling stood outside during the first part of COVID-19 and couldn't come in and that took over the whole visit. I have never felt so hopeless about anything in my whole life as what it would take to hug my mom again."*

*"I think care homes should be more flexible dependent on the circumstance. We were only allowed a window visit through tinted glass. They would not allow us to see her on her actual 99th birthday. I worry about the winter months and if there is a plan in place to see loved ones. When the winter weather hits, it will be even more difficult to see them. It is tough to hear your loved one say 'I'm not living I'm just existing.'"*

*"The care is good and I haven't noticed much of a change. I just miss my weekly visits from my daughter and young grandson that she babysits. I am worried about how we will visit in the colder winter months as we won't be able to sit outside."*

*"My loved one is very deaf. He used to wear a cochlear implant before becoming ill. When I was dressed up in full PPE and taken to him and made to sit 6 feet apart, he could not HEAR ME AT ALL!!! He is used to reading lips...he couldn't do that. He got angry about it and wanted me to remove the PPE which I couldn't. He was angry that the visit was chaperoned and flipped out on them. He thought I was sick because I had all this PPE on. I spent my full 30 minutes of my one and only visit trying to calm him. Window visits are not possible due to deafness and video is not much better same reason. If a resident is deaf how are they expected to hear anyone 6 feet from them with a mask and face shield? "*

*"As he has dementia, video calls were quite meaningless for dad but were more beneficial to family so we could see him to get a read on his state of well being. Going from visiting every other day to an occasional video call to now distanced visits has resulted in him no longer recognizing family. Most of his time now is spent in a wheelchair which he can 'walk' through the hallways, whereas we would get him up for walks, often outdoors, with his walker at almost every visit, so several times per week."*

*"Since our loved one suffers from a terminal illness and progressively gets worse, we are very sad that she (and we all!) missed out on a summer in which new memories with loved ones could have been made. It is a summer that she will never get back, and neither will we. Is it worth it? We don't believe it right to make the quantity of life so superior over the quality of life."*

*"I feel I have no control and it makes me nervous to not even know what her room looks like. I know she feels my uncertainty at times and that effects the way she responds when she is having bad days. I need to be able to go to her when she calls me upset. She just needs to know she is safe and that I am there for her. When I cannot do this we both feel stressed and unsafe. I believe the impact of mental stress due to COVID-19 has a negative impact on our physical health also. It is not normal for anyone not to be held or touched for such an extended period of time. While we are aware of the cautions that are necessary during these unprecedented times, we must also keep in mind the quality of life people are experiencing. I believe with caution and mandated practices regarding visiting loved ones in care homes, it can be done safely. It is possible to do but you have to take the time, effort, and spend what is necessary for this to happen. If something happens to her before I am able to be with her in person, it will be of no solace to me that we have been kept apart for her safety. I fear that something may happen to her before this is over and all this time keeping her safe will actually be moot. It has been 6 months which is an excessive amount of time to expect the elderly and families to be patient."*

*"My mother has dementia and is unable to read, unable to follow TV programs and not interested in games. However, she always enjoyed getting her hair done every week. I certainly don't understand whereby aide staff and others go home after their shift and are then in contact (other family members) when carrying out everyday activities i.e., grocery shopping, etc. and yet the hairdresser that was hired and work at my mother's facility was not allowed in."*

*"Thank you for this opportunity, I live in an independent apartment. My sweet husband of 55 years is in the LTC section. My reason for moving here was to be close to him and support him in our journey with dementia. It has been very hard on him to be separated from me, our daughters and grown grandchildren. It has been doubly hard on me. It has been six months since I was up to his room. I realize how hard everyone has worked to protect us, but time is not on our side and staff, who are excellent, come and go from the building. I live here and just want to support my husband."*

*"I work as a HCA in Long Term Care. The morale of my residents has greatly declined. Their lives have come to a halt. Aggression is on the rise and depression is on the rise. People in assisted living can come and go as they wish however my residents, some of whom would go for drives with family, are trapped inside. Their quality of life has decreased. Quite often their reason for living is family and that has been taken away. It is heartbreaking and unfair. Personally, it has greatly affected me. Watching my people decline is one thing but now with COVID-19, watching them decline without the support of their families at their sides until the point when death is near breaks me. On average, a person lasts 12-18 months (probably less now) in long term care. These are the last moments they have: we need to make them count. I have never experienced anxiety before but I'm disappointed to say that because of COVID-19, and the rules surrounding my residents, my heart is going nuts. My stress levels are through the roof and I cry - a lot. I'm wondering how much longer I can carry on with this job if this continues. And I know it will. I bet given the choice, family would risk COVID-19 to see their loved ones. Thank you for this survey. Perhaps one geared directly to caregivers (as we see what most don't) would be beneficial."*

*"My grandmother is my best friend and my world. It hurts not to be able to hug her or at least hold her hand. I would gladly take a COVID-19 test and quarantine until my results are back just to hold her hand. I feel a lot of guilt and helplessness not being able to be there for her and ensuring she is being properly taking care of."*

*"I am fortunate that my mother is in a very good care home, with excellent staff. I do not worry about her daily care, but I do worry that she will no longer recognize her family when they can eventually come back to visit. I feel that isolating our seniors, and often leaving them to die without their family around them, is much worse then risking them getting sick and having their family with them. Every resident should have their own room where their family can visit and/or care for them."*

*"I was even denied window visits as his room looked out on an outside courtyard. Ridiculous! Like I could pass anything on two feet away from his window and through a glass panel. He celebrated his 75th birthday (his last) through a window. No cake, no balloons, no semblance of a celebration at all. And my 70th birthday we couldn't even get together. But the crowning touch was when we celebrated our 50th wedding anniversary outside, six feet away, through a wire fence. NO TOUCHING! How could it get any more inhumane than that! Let me add, I was keeping to myself at home, only going out for groceries, staying away from people, washing my hands always, just in case I would have to go into him in an emergency (palliative care). It makes me wonder what would have happened if I had had a cold when they finally called me to say he was "palliative"? I'm pretty sure I would have been saying goodbye through a window! How is that for inhumane? This excuse for all this behaviour was said to be to keep our seniors "safe". Safe from what? What good does it do to keep them safe if, ultimately, they die of loneliness? How would you feel if your loved one was in this situation and they feel that they have been abandoned? My husband didn't know why I couldn't come in. He was way beyond understanding what was happening. But let me tell you, had I been able to hold his hand and tell him that I still loved him and that I was not abandoning him, he might still be alive today. He simply chose to stop eating or drinking. I believe he lost all hope of ever seeing me again. And what is the purpose of living if you have no hope?"*

*"Before COVID-19, my mom was an active 92-year-old. She moved into an independent living home, in part, for the socialization. When they started requiring people to stay in their apartments, even for meals, she found it very lonely and isolating. We are very lucky my Mom could still come out for walks with us if the weather was good. My sister and I really feel COVID-19 has hastened a downturn in her mental and physical abilities because of the restrictions at her home. She longs for a hug, for the opportunity for the two of us to visit her in her apartment and have tea together. Winter is coming and Mom has already said she won't walk in the cold: how do you decide between two daughters who is designated visitor? She is lonely, as are we. What an awful way to spend your last years: lonely and alone. Quality of life?"*

*“Visitor restrictions have had a terrible impact on my life. I am a 94-year-old WW2 veteran. I broke my hip here in a fall in March and the doctor decided I couldn’t go the hospital even for an x-ray. If my family could have visited to help me with that decision I would have had an operation by now instead of being stuck forever in this lodge in a wheelchair. The lodge has lost my hearing aids and my family was not allowed to come in to help look for them, so they are still lost. My family hasn’t even been allowed to come in to see my new room or help set things up so I can reach the phone. My family has not been allowed to help me go out for injections for macular degeneration so my vision is getting worse. I am very lonely. This form of being ‘confined to barracks’ is the worst.”*

*“Long term care homes have become prisons for the residents with no choices. It is hard to assess if the place is providing the proper care and if their needs are being met. This has led to a decrease in functioning. There is a struggle with the care home to ensure glasses are on, hearing aids are in and other things that assist them to stay connected. This isolation also decreases their ability to feel part of, and not lose their connections to time, place, people and society. More could be done if money were made available and staffing was increased. Who would want to live this way? Is it living?”*

# Summary and Recommendations

Through this pandemic, we have learned that many residents of long-term care and assisted living have dedicated family members who are essential to delivering the care and emotional support needed to ensure the final years, months and days of a resident's life are filled with comfort, meaning and joy. Many family members have been frustrated by visit restrictions that are now in their eighth month and there is emerging evidence these restrictions are having a negative impact on residents' health.

Residents have told us that contracting COVID-19 is not their biggest fear. We need to listen to and respect their voices. Residents have not surrendered their right of agency because they live in LTC/AL. Their bodies and minds may be diminished in function but they can still, in many cases, understand risk, know they are nearing the end of their life and know, with absolute certainty, that spending time – meaningful time – with the people they love is what they want most.

Family members have told us how much they care about their loved ones in LTC/AL. They care enough to visit many times a week, sometimes daily, and ensure their loved ones get the care and assistance they need. Not only are these family members essential to their loved ones, they are essential to an overburdened long-term care system that is further stretched by the daily realities of this pandemic. We need to see these dedicated family members as a resource that can help us and not as an issue to be managed.

The survey offered no unanimous opinions, although some came fairly close. There are some residents and family members who support the current visit restrictions. This is a minority of respondents, however, and they are, on balance, much more likely to find the current policies are meeting their needs. In large part this speaks to the widely divergent practices in care homes across the province. Some family members are able to visit frequently and in the privacy of the residents' rooms; however, most family members are more heavily restricted. Some residents only have one person that visited them prior to the pandemic and, sadly, some residents have no visitors as family members live far away or are not involved in the residents' lives. However, the large majority of respondents – both residents and families – reported that the current visitor restrictions are not working for them and some referred to them as inhumane.

We now have several months of experience with managing restricted visits in our LTC/AL homes. We can take this experience and recalibrate existing policies and practices to better meet the needs of those family members who serve as care partners and to provide the opportunity for additional family members to spend time with their loved ones.



The key to making this manageable for care homes is to shift visits away from common areas and into the residents' rooms where possible. This will reduce the burden on care home staff to manage and monitor visits in common areas and reduce the need to keep visits short and infrequent (currently, 75% of residents live in a private room). For those residents who live in a shared room, there will need to be a plan that fits the unique circumstances of shared rooms, such as the total number of occupants, overall space, availability of alternative locations, and the physical abilities of the resident. With common areas less congested as more visits shift to single rooms, there may be more opportunity for visits with residents living in multi-bed rooms.

We need to more formally recognize the role that some family members play as essential care providers for their loved one. The survey highlights that we did not manage essential visits as well as we might have during the first phase of visit restrictions. We need to respect that family members and residents are better able than care home administration to determine if their visits are essential to the health and well-being of residents. The results of the survey have supported that we can trust family members to be objective and honest in their assessments.

Moving forward, we need to allow the opportunity for every resident to have a designated essential care partner who can have frequent visits of longer duration. This will primarily be those family members who were visiting several times a week or even daily prior to the pandemic. Not all residents will have a person in their life who fits the criteria of an essential care partner; some residents will have only social visitors and some, unfortunately, will have no visitors.

In addition to the essential care partner, we need to allow for social visitors. This will primarily be those family members who might have visited once a week, every couple of weeks or monthly prior to the pandemic. The number of social visitors allowed should reflect the need for immediate family members (adult children, spouses) who are not the designated care partner to see their loved one. At a minimum, we need to allow for at least one social visitor (in addition to the essential care partner visitor) with provision for additional social visitors as determined by individual circumstances.

The issue of visitor restrictions in LTC/AL revealed a lack of voice for residents and family members in the decision-making process of how we manage our LTC/AL system. This frustration came through very clearly in letters, phone calls and survey responses from family members and residents.

Those who operate care homes are represented by industry associations or health authorities. Staff who work in the care homes are represented by their unions and safety association. These groups are often who the government will consult when they refer to "stakeholders" in the care sector. Currently, there is no similar standard bearer who speaks for residents and family members. LTC and AL homes may have a resident and/or family council. However, these councils are unique to each care home and have no collective voice at the health authority or provincial level. This was a gap that existed prior to the pandemic but, as with many things, the pandemic revealed why it is a gap we need to close.

To achieve this, it is recommended that the Ministry of Health work with the Office of the Seniors Advocate to establish a *Long-Term Care & Assisted Living Resident and Family Council Association*. This association would have as members the resident and family councils from all LTC and AL homes operated under the *Hospital Act* or the *Community Care and Assisted Living Act*. The Association would work with health authorities and the province to promote best practices and advance the quality of life for residents of LTC and AL by bringing together the voices of residents and their families. The Association would bring to the table the voice of residents and their family members in equal measure with those who own and operate care homes and the staff who work there.

As management of this pandemic has evolved, we need to return to the issue of visits in long-term care and assisted living, using the knowledge and experience we have gained to implement three key actions.

1. All residents need the opportunity to identify an essential care partner who can visit frequently and provide those supports and services that are essential to the health, physical and emotional well-being of the resident.
2. In addition to the essential care partner, residents need social visitors, and the number allowed needs to balance the risk of COVID-19 with the risks to resident health, happiness, and quality of life that results from long-term family separation.
3. The voice of residents and their family members must be embedded in decisions on how we shape our long-term care and assisted living system in British Columbia going forward. The Ministry of Health needs to collaborate with the Office of the Seniors Advocate to create a provincial association of long-term care and assisted living resident and family councils.

The voices of residents and family members have been heard through this survey and they have told us many things. First, we have learned the capacity of family to care for one another is boundless. We also learned that the wisdom and perspective that comes from aging is clarifying and, when we know our time is limited, we focus on what is most important. We also learned that, for many of us as we near the end of our life, what is most important is spending time with the ones we love. This knowledge must guide us as we focus on the ultimate goal...quality of life.

# Survey Methodology

The Office of the Seniors Advocate launched *Staying Apart to Stay Safe: The Impact of Visitor Restrictions on Long-Term Care and Assisted Living Survey* on August 26, 2020. The survey closed on September 30, 2020.

*Staying Apart to Stay Safe* was available as an online survey with options for paper (mail in) and telephone responses. The survey was open to all visitors and residents who wished to participate. In addition, recognizing that many people may have opinions about the visitation experience in care homes even if they do not have a loved one in care, responses were accepted from the general public to a limited, relevant set of questions around perspectives on how visits should be handled during the COVID-19 pandemic.

Responses were received from over 15,000 people, from which we obtained 13,142 valid responses. Surveys deemed incomplete or where potentially fraudulent response patterns were observed were excluded from our final pool of responses. We received 2,053 valid responses from residents (15.6% of all valid responses), 9,870 valid responses from visitors/family members (75.1%), and 1,219 valid responses from the general public (9.3%).

Of the 13,142 valid responses, 11,707 (89.1%) were collected through the online platform, 1,202 (9.1%) were collected from paper-based surveys, and 233 (1.8%) were collected over the phone. The average completion time for the online version of the survey was 33 minutes for the visitor survey, 25 minutes for the resident survey, and 8 minutes for the general public survey.

## Survey Instrument Design

Survey design was carried out by the OSA with advice from the British Columbia Patient-Centred Measurement (BCPCM) office, which directs strategy for the measurement of patient-centred care in British Columbia. Survey design was informed by a consultative group of residents, families, and care home operators. Some survey questions and design decisions were carried over from the OSA's *Every Voice Counts* (September 2017) survey of LTC residents and family members. *Every Voice Counts* was the most extensive survey of LTC residents ever conducted in Canada. Bringing over elements from this survey allows for a "pre-COVID" baseline on some resident experience items such as staff responsiveness, quality of care, and quality of life.

Feedback from the consultation group and the OSA's experience from the information and referral line suggests that residents and families may be reluctant to share views about care homes when there is potential for identification. Our survey, therefore, is anonymized, with no personally identifying information collected and no way to re-identify respondents or link to other data sets. The collection of personal information in the form of opinions was conducted under sections 26(c) and 26(e) of the *Freedom of Information and Protection of Privacy Act*.

The visitor survey consists of a minimum set of 77 questions, with additional sets of questions depending on the respondent's answers. For example, respondents who indicated that their loved one was palliative at any point during the period of March to September 2020 were directed to a set of palliative care-specific questions, while respondents who indicated they were a "designated visitor" answered additional sets of questions around visits during the pandemic. The resident survey consists of a minimum set of 53 questions (with optional set of questions depending on answers to certain questions) and the general public survey consists of 13 questions. A copy of each survey instrument is available on the OSA's website ([www.seniorsadvocatebc.ca](http://www.seniorsadvocatebc.ca)).

## Survey Implementation

*Staying Apart to Stay Safe* is the OSA's first survey to be primarily web-based. We partnered with the Ministry of Citizens' Services Citizen Engagement team to launch our survey on an industry-standard survey platform. While the majority of respondents engaged with our survey through the online platform, we also offered paper (mail in) and telephone options. In partnership with BC Mail Plus, the provincial government's mailing and distribution division, we facilitated requests for mailouts of survey packages to individuals and care homes. A group of 49 trained volunteer telephone interviewers were available to facilitate telephone surveys with residents and visitors, including language services in Mandarin, Cantonese, and Punjabi.

## Engagement and Promotion

To increase awareness of the survey, the OSA employed multiple communications strategies. On August 26, 2020, a media conference was held at the British Columbia Legislative Press Gallery announcing the release of the survey. This media conference was live-streamed; a link is available on our website. For ease of access, a dedicated website was created for the survey – [www.CareHomeVisits.ca](http://www.CareHomeVisits.ca). The OSA also communicated directly with over 560 care homes in B.C., encouraging them to provide information to residents and their families/visitors about the survey. A letter was enclosed for dissemination to residents and visitors.

We also promoted the survey on social media and on radio stations across B.C. In addition, a mailout to the "financially responsible party" for residents of subsidized LTC and assisted living was coordinated with the five regional health authorities. In approximately 80% of cases, the financial responsible party is a person other than the resident (typically a spouse or adult child; in rare cases, a guardian such as the Public Guardian and Trustee or bank employee). Health authorities were directed to use their distribution lists (mail or email) to contact the financial responsible party and deliver information about the survey. This action was approved by the Health Information Privacy and Security Operating Committee (HIPSOC), a provincial joint committee with the purpose of supporting and improving safe information exchange in health care.

# Characteristics of Respondents

Understanding the demographic characteristics of respondents is key to understanding the external validity of a survey and what biases it may exhibit.

The largest group of respondents were visitors of long-term care residents. This group represents 49.0% of respondents. The table below shows the distribution of respondents by care level.

Long-term care (LTC) – visitor	49.0%
Long-term care – resident	6.1%
Assisted living (AL) – visitor	14.4%
Assisted living – resident	7.7%
Other care level/unspecified – visitor	11.7%
Other care level/unspecified – resident	1.9%
General public	9.3%

In the visitor and resident surveys, we asked respondents to identify the health authority the care home is located in.

Health Authority	Visitors	Residents	B.C. distribution of LTC and AL beds
Interior	29.2%	34.0%	22.2%
Fraser	27.9%	20.2%	32.6%
Vancouver Coastal	15.5%	15.1%	21.6%
Island	21.9%	23.0%	19.7%
Northern	4.4%	5.8%	4.0%

Note: the data above has been tabulated over responses that indicated the care home to be subsidized LTC or AL and where the health authority was known.

Interior Health, Island Health, and Northern Health (to a lesser extent) contributed more visitor and resident responses than would be expected given their share of beds provincially. Fraser Health and Vancouver Coastal Health contributed fewer responses than would be expected.

Visitors and residents were also asked about the ownership of the care home.

Ownership	Visitors	Residents	B.C. distribution of LTC beds
Health authority	44.3%	53.9%	29.1%
For-profit (subsidized)	30.6%	20.2%	35.0%
Not-for-profit	18.6%	18.2%	29.1%
Private pay	6.6%	7.7%	6.8%

Note: the data above has been tabulated over responses that indicated the care level to be LTC and where ownership was known. 8.5% of visitors and 22.0% of residents did not know care home ownership.

We asked about the age and gender of visitors and residents.

	Visitors	Visitors' loved ones	Residents
<b>Gender</b>			
Male	21.4%	30.7%	29.9%
Female	77.9%	68.7%	69.3%
Other	0.7%	0.5%	0.9%
<b>Age</b>			
0 to 44	6.4%	0.6%	1.0%
45 to 54	12.7%	0.6%	1.3%
55 to 64	39.8%	1.5%	4.9%
65 to 74	30.5%	7.1%	12.0%
75 to 84	8.6%	22.5%	25.9%
85 to 94	2.0%	49.8%	46.4%
95+	0.1%	17.9%	8.5%





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