

Staying Apart to Stay Safe

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

This version of the survey is intended for people who visit somebody living in a care home.

Thank you for taking the time to tell **your story**, in **your voice** of the impact from living with the visit restrictions in long-term and assisted living that have been required in response to the COVID-19 pandemic.

The survey will ask you some questions about your visits before the pandemic. We want to know what type of activities you did during the visits and what the health and well being of residents was like. We want to know a little bit about your experience when the visit restrictions were mandated. How did you find out, what did you do during the first few months?

We also want to know what your visits look like now. Visit restrictions were eased on June 30th to allow for one designated visitor for each resident and we want to know how that is working for you. We also want to hear your ideas and suggestions as both residents and family members on where we might improve and if we have achieved the right balance between risk and the need to find a way to live through this pandemic for the next year or so.

Your experiences and insights are very important. This is **your** lived experience and hearing directly from residents and family members will help us better understand the overall impact of the COVID-19 pandemic on residents living in long-term care and assisted living and the people who love them.

Feedback will be accepted until September 30, 2020 at 11:59pm (PDT).

If you have any questions about completing the survey or would like to speak with the Office of the Seniors Advocate, please call us at **1-877-952-3181**.

Please proceed question-by-question. Some questions may lead to different lines of additional questions depending on the answer. Where this happens, instructions for which question to proceed to are included. Please remember that you may choose to NOT answer a particular question if you are uncomfortable or do not wish to provide an answer.

Please mail your completed survey to:

Office of the Seniors Advocate

PO Box 9651 STN Prov Govt

Victoria, BC V8W 9P4

Q1) What is your relationship to your loved one who you visit in long-term care or assisted living?

- Spouse
- Child
- Grandchild
- Other family relative
- Friend
- Paid companion
- Spiritual advisor (e.g., Reverend, Priest, Rabbi)

Q2) Does your loved one live in:

- A private room
- A shared room with one other person
- A shared room with more than one other person

Q3) Did your loved one pass away in care since the declaration of the COVID-19 pandemic on March 11, 2020?

- Yes
- No

Q4) Before this pandemic, how often did you visit your loved one?

- Daily
- Several times per week, but not always daily
- Weekly
- Every other week
- Monthly
- Other

5) When you visited before this pandemic, on average how long did you stay?

- 30 minutes or less
- 30 minutes to one hour
- One to two hours
- Two to four hours
- More than four hours
- Other
- I don't know/I am unsure

Q6) When you visited before this pandemic, what types of activities did you do with your loved one during visits? Please check all that apply.

- I assisted with personal care such as help to the toilet, bathing, and dressing
- I assisted with grooming such as hair combing, shaving, nail care
- I assisted at meal times to help/encourage my loved one to eat
- I assisted by taking my loved one for walks or doing exercise with them
- I read to my loved one and/or helped them keep up with current events
- I took my loved one out for appointments and social outings

Q7) Does your loved one have a private phone line in their room or a mobile phone?

- Yes
- No
- I don't know/I am unsure
- Prefer not to answer

Q8) Before this pandemic, did you regularly talk with your loved one on the phone?

- Yes [GO TO Q9]
- No [GO TO Q10]

Q9) How often did you talk on the phone?

- Daily
- Several times per week, but not always daily
- Weekly
- Every other week
- Monthly
- Other

Q10) Before this pandemic, did you ever use video-calling (such as FaceTime, Zoom, or Skype) to talk with your loved one?

- Yes [GO TO Q11]
- No [GO TO Q12]

Q11) How often did you use video-calling?

- Daily
- Several times per week, but not always daily
- Weekly
- Every other week
- Monthly
- Other

Q12) Does your loved one need help from staff or volunteers to use video-calling or to talk on the phone?

- Always
- Sometimes
- Rarely
- Never
- Prefer not to answer

Q13) Before this pandemic, did your loved one have additional people (such as a paid companion, podiatrist, physical therapist, or hairdresser) provide care or services to them either in or out of the care home?

- Yes
- No
- I don't know/I am unsure

Q14) In the six months before this pandemic, was your loved one's health:

- Getting much better
- Getting slightly better
- Staying about the same
- Getting slightly worse
- Getting much worse

Q15) Is your loved one currently designated palliative?

- Yes
- No
- I don't know/I am unsure

Q16) In March 2020 (when this pandemic was declared), how would you describe your loved one's physical mobility?

- Could walk without any assistance
- Needed to use a cane/walker either always or sometimes
- Sometimes used a walker and sometimes a wheelchair, but needed someone to help them
- Used only a wheelchair
- Was bed-bound
- I don't know/I am unsure

Q17) In March 2020, how would you describe your loved one's cognitive functioning?

- They had no impairment.
- They had slight impairment that sometimes affected short-term memory and sustained concentration, but they were completely aware of themselves, their surroundings and people around them. They could follow current events and conversations.
- They had mild impairment. They still knew who they were and remembered family members, but the ability to follow more complex conversations and remember recent events and engage in meaningful conversations fluctuated.
- They had moderate impairment. They knew who they were and where they lived and recognized close family members (but not always more distant relatives and friends), but it was becoming increasingly difficult to sustain meaningful conversations.
- They had more severe impairment. They sometimes thought they were living in another time and place and could not always remember close family members. Their ability to engage in meaningful conversations was very limited.
- They were severely cognitively impaired with almost no awareness of current time and place and could not obviously recognize family members.
- They were completely unresponsive.
- I don't know/I am unsure

Q18) In March 2020, how would you rate your loved one's mood and emotional well-being?

- Excellent. They were happy, optimistic about the future, and engaged in activities around them
- Very good. They were generally happy but would occasionally express feelings of sadness and/or anxiety. They usually participated in activities
- Good. They were sometimes happy and sometimes participated in activities but had increasing episodes of sadness and/or anxiety.
- Not that good. They often were unhappy, they had withdrawn from most activities, and they displayed sadness and/or anxiety most of the time.
- Poor. They were mostly unhappy, they withdrew from all activities, and consistently displayed sadness and/or anxiety.
- I don't know/I am unsure

Q19) Before this pandemic, did you feel your loved one was safe when he/she was alone?

- Always
- Sometimes
- Rarely
- Never
- I don't know/I am unsure

Q20) Before this pandemic, did you feel if your loved one needed help right away, he or she would get it?

- Always
- Sometimes
- Rarely
- Never
- I don't know/I am unsure

Q21) Before this pandemic, did you know who to talk with at the care home to get information about your loved one?

- Always
- Sometimes
- Rarely
- Never
- I don't know/I am unsure

Q22) Before this pandemic, did you feel the staff kept you up-to-date about your loved one?

- Always
- Sometimes
- Rarely
- Never
- I don't know/I am unsure

Q23) Before this pandemic, how often did the care home communicate with you about your loved one's overall general and physical health?

- Every day
- At least once per week
- Every other week
- Once a month
- No communication is offered
- I prefer not to answer

Q24) Before this pandemic, did you feel you were involved as much as you wanted in decisions about your loved one's care?

- Always
- Sometimes
- Rarely
- Never
- I don't know/I am unsure

Q25) Before this pandemic, how often did the care home communicate with you about general updates on the care home and its activities?

- Every day
- At least once per week
- Every other week
- Once a month
- No communication is offered
- I prefer not to answer

Q26) Before this pandemic, how would you rate the overall quality of care and services provided to your loved one?

- Excellent
- Very good
- Good
- Fair
- Poor
- I don't know/I am unsure
- I prefer not to answer

Q27) When visitor restrictions were implemented during this pandemic, how were you notified about the restrictions? Check all that apply.

- I received an email and/or text message from the care home
- I received a phone call from the care home
- I received a letter sent by regular mail from the care home
- A notice was posted on the care home's website
- Other
- I was not notified by the care home

Q28) If you were notified by your loved one's care home about the restrictions on visits during this pandemic, did the notification include information about essential visits?

- Yes
- No
- I don't know/I am unsure
- I wasn't notified about restrictions on visits

Essential visits have been defined by the Provincial Health Officer 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.

Source: <https://www2.gov.bc.ca/assets/gov/health/about-bc-s-health-care-system/office-of-the-provincial-health-officer/reports-publications/covid-19-infection-prevention-control.pdf>

Q29) Do you feel your visits with your loved one meet the above criteria for essential visits?

- Yes
- No
- I don't know/I am unsure

Q30) Did you make a request to be an essential visitor?

- Yes [GO TO Q31]
- No [GO TO Q35]

Q31) Were essential visits allowed?

- Yes [GO TO Q38]
- No [GO TO Q32]

Q32) Were you advised how to appeal the decision?

- Yes [GO TO Q33]
- No [GO TO Q40]

Q33) Did you appeal?

- Yes [GO TO Q34]
- No [GO TO Q40]

Q34) Was your appeal successful?

- Yes [GO TO Q38]
- No [GO TO Q40]
- I don't know yet; the decision is pending [GO TO Q40]

Q35) Did somebody else make a request?

- Yes [GO TO Q36]
- No [GO TO Q40]
- I don't know/I am unsure [GO TO Q40]

Q36) What was their relationship to your loved one?

- Spouse
- Child
- Grandchild
- Other family relative
- Friend
- Paid companion
- Spiritual advisor (e.g., Reverend, Priest, Rabbi)

Q37) Were they successful in getting essential visits?

- Yes [GO TO Q40]
- No [GO TO Q40]

Q38) As an essential visitor, how often did you visit during this pandemic?

- Daily
- Several times per week, but not always daily
- Weekly
- Every other week
- Monthly
- Other

Q39) As an essential visitor, how long were you able to visit your loved one each time you visited?

- 30 minutes or less
- 30 minutes to one hour
- One to two hours
- Two to four hours
- More than four hours
- Other
- I don't know/I am unsure

Q40) During this pandemic, have you considered taking your loved one out of the care home?

- Yes [GO TO Q41]
- No [GO TO Q42]
- I don't know/I am unsure [GO TO Q42]
- I prefer not to answer [GO TO Q42]

Q41) Did you take your loved one out of the care home?

- Yes
- No

Q42) At the beginning of this pandemic, how worried were you that you might get COVID-19?

- Very worried
- Somewhat worried
- A little worried
- Not worried at all
- I prefer not to answer

Q42) At the beginning of this pandemic, how worried were you that your loved one might get COVID-19?

- Very worried
- Somewhat worried
- A little worried
- Not worried at all
- I prefer not to answer

Q43) During this pandemic, has the care home where your loved one lives experienced an outbreak of COVID-19?

- Yes [GO TO Q44]
- No PGO TO Q46]
- I don't know/I am unsure [GO TO Q46]

Q44) Did your loved one test positive?

- Yes [GO TO Q45]
- No [GO TO Q46]

Q45) Did your loved one recover?

- Yes
- No
- Still recovering

Q46) Were you tested for COVID-19?

- Yes [GO TO Q46A]
- No [GO TO Q47]

Q46A) Did you test positive?

- Yes
- No
- I don't know yet; results pending
- I don't know/I am unsure

Q47) During this pandemic, has your loved one been restricted to their room within the care home?

- Yes [GO TO Q48]
- No [GO TO Q49]
- I don't know/I am unsure [GO TO Q49]

Q48) For how long were they/have they been restricted to their room?

[] weeks

Q49) During this pandemic, has your loved one been allowed to participate in activities within the care home?

- Yes, always
- Yes, sometimes
- No
- I don't know/I am unsure

Q50) During this pandemic, has your loved one been allowed to dine in common dining areas?

- Yes, always
- Yes, sometimes
- No
- I don't know/I am unsure

Q51) During this pandemic, do you regularly talk with your loved one on the phone?

- Yes [GO TO Q52]
- No [GO TO Q53]

Q52) How often do you talk with your loved one on the phone?

- Daily
- Several times a week but not always daily
- Weekly
- Every other week
- Monthly
- Other

Q53) During this pandemic, do you ever use video-calling, such as FaceTime, Zoom or Skype, to talk with your loved one?

- Yes [GO TO Q54]
- No [GO TO Q55]

Q54) How often do you use video-calling?

- Daily
- Several times a week but not always daily
- Weekly
- Every other week
- Monthly
- Other

Q55) During this pandemic, has your loved one needed help from staff or volunteers to use video-calling or talk on the phone?

- Always
- Sometimes
- Rarely
- Never
- Prefer not to answer

Q56) During the essential visitor-only restrictions, did you or family and friends visit with your loved one by standing outside a window?

- Always
- Sometimes
- Rarely
- Never
- I don't know/I am unsure

Q57) During this pandemic, how often does the care home communicate with you about your loved one's overall general and physical health?

- Every day
- At least once per week
- Every other week
- Once a month
- No communication is offered
- I prefer not to answer

Q58) During this pandemic, how often does the care home communicate with you about general updates on the care home and its activities during this pandemic?

- Every day
- At least once per week
- Every other week
- Once a month
- No communication is offered
- I prefer not to answer

Q59) How were you informed by your loved one's care home of the change to visitor restrictions on June 30th? Please check all that apply.

- I received an email and/or text message from the care home
- I received a phone call from the care home
- I received a letter sent by regular post from the care home
- A notice was posted on the care home's website
- I was not notified directly by the care home

Q60) Are you the designated visitor for your loved one?

- Yes [GO TO Q62]
- No [GO TO Q61]

Q61) Who is the designated visitor?

- Spouse [GO TO Q81]
- Child [GO TO Q81]
- Grandchild [GO TO Q81]
- Other family relative [GO TO Q81]
- Friend [GO TO Q81]
- Paid companion [GO TO Q81]
- Spiritual advisor (e.g., Reverend, Priest, Rabbi) [GO TO Q81]

Q62) When was the date of your first visit?

Q63) Now that you can visit again, how often do you visit with your loved one?

- Every day
- At least once per week
- Once every two weeks
- Once every three weeks
- Once a month
- Other

Q64) Now that you can visit again, on average how long are you allowed to stay per visit?

- 30 minutes or less
- 30 minutes to one hour
- One to two hours
- Two to four hours
- More than four hours
- Other
- I don't know/I am unsure

Q65) Where are you allowed to visit with your loved one? Please check all that apply.

- Outside
- In a designated common area within the care home
- In your loved one's room

Q66) Are there staff from the care home observing you during the visit?

- Yes, always
- Yes, sometimes
- No
- I don't know/I am unsure

Q67) What are the infection control protocols that you are required to follow? Please check all that apply.

- I must schedule the visit in advance
- I must complete either an online or paper-based health screening questionnaire prior to the visit or when I arrive
- I am greeted by care home staff when I arrive for my visit and verbally asked health screening questions
- I am greeted by care home staff to "check in" for visit but NOT asked health screening questions
- I have my temperature checked by care home staff
- Care home staff ask me a series of health questions each time
- I am asked to wash or sanitize my hands
- I am asked to wear a mask
- I am asked to wear a face shield
- I am asked to wear a gown
- I am asked to wear gloves
- I am physically escorted by care home staff to the area/room where I can visit
- I must stay 6 feet away from my loved one

Q68) Is there plexiglass or some other physical barrier between you and your loved one?

- Yes
- No

Q69) Are you allowed to hug your loved one or touch them during the visit?

- Yes
- No
- I don't know/unsure

Q70) Now that you can visit again, are you permitted to take your loved one outside the care home for social outings and/or medical appointments?

- Yes
- Yes, but with restrictions
- No
- I don't know/unsure

Q71) Were you provided any personal protective equipment, such as a face mask, by the care home?

- Yes
- No
- I prefer not to answer

Q72) What did they provide?

Q73) When you first saw your loved one after visits resumed, what was your overall impression?

- They seemed better than when I last saw them.
- They seemed about the same as when I last saw them.
- They seemed worse than when I last saw them.
- I don't know/I am unsure

Q74) Please describe, in your own words, what your first visit was like.

Q75) How would you describe your loved one's physical mobility now (after June 30, 2020)?

- Can walk without any assistance
- Needs to use a cane/walker either always or sometimes
- Sometimes uses a walker and sometimes a wheelchair, but needs someone to help them
- Uses only a wheelchair
- Is bed bound
- I don't know/I am unsure

Q76) Is your loved one's physical mobility, compared to before this pandemic:

- Better
- About the same
- Worse
- I don't know/I am unsure

Q77) How would you describe your loved one's cognitive functioning?

- They have no impairment.
- They have slight impairment that sometimes affects short-term memory and sustained concentration, but they are completely aware of themselves, their surroundings and people around them. They can follow current events and conversations.
- They have mild impairment. They still know who they are and remember family members, but the ability to follow more complex conversations and remember recent events and engage in meaningful conversations fluctuates.
- They have moderate impairment. They know who they are and where they live and recognize close family members (but not more distant relatives and friends), but it is becoming increasingly difficult to sustain meaningful conversations.
- They have more severe impairment. They sometimes think they are living in another time and place and cannot always remember close family members. Their ability to engage in meaningful conversations is very limited.
- They are severely cognitively impaired with no awareness of current time and place and cannot recognize family members.
- They are completely unresponsive.
- I don't know/I am unsure

Q78) Is your loved one's cognitive functioning, compared to before this pandemic:

- Better
- About the same
- Worse
- I don't know/I am unsure

Q79) How would you rate your loved one's mood and emotional well-being?

- Excellent. They are happy, optimistic about the future and engaged in activities around them.
- Very good. They are generally happy but occasionally express feelings of sadness and/or anxiety. They usually participate in activities.
- Good. They are sometimes happy and sometimes participate in activities, but have increasing episodes of sadness and/or anxiety.
- Not that good. They often are unhappy, they have withdrawn from most activities, and they display sadness and/or anxiety most of the time.
- Poor. They are mostly unhappy, they have withdrawn from all activities, and consistently display sadness and/or anxiety.
- I don't know/I am unsure

Q80) Compared to before this pandemic, how would you rate your loved one's mood and emotional well-being?

- Better
- About the same
- Worse
- I don't know/I am unsure

Q81) Compared to before this pandemic, do you feel your loved one is safe when they are alone?

- Always
- Sometimes
- Rarely
- Never
- I don't know/I am unsure

Q82) Compared to before this pandemic, do you feel if your loved one needs help right away, they will get it?

- Always
- Sometimes
- Rarely
- Never
- I don't know/I am unsure

Q83) Compared to before this pandemic, do you know who to talk with to get information about your loved one?

- Always
- Sometimes
- Rarely
- Never
- I don't know/I am unsure

Q84) Compared to before this pandemic, do you feel the staff keep you up-to-date about your loved one?

- Always
- Sometimes
- Rarely
- Never
- I don't know/I am unsure

Q85) Compared to before this pandemic, do you feel you are involved as much as you wanted in decisions about your loved one's care?

- Always
- Sometimes
- Rarely
- Never
- I don't know/I am unsure

Q86) Since the COVID-19 pandemic was declared, how would you rate the overall quality of the care and services provided to your loved one?

- Excellent
- Very good
- Good
- Fair
- Poor
- I don't know/I am unsure
- I prefer not to answer

Q87) Thinking about the visitor restrictions that were put in place during this pandemic, how confident are you that the restrictions worked in keeping your loved one safe from getting COVID-19?

- Not at all
- Partly
- Quite a bit
- Completely
- I don't know/I am unsure
- I prefer not to answer

Q88) Given what we now know about the virus and our experience of the last six months, how worried are you now about your loved one getting COVID-19?

- Very worried
- Somewhat worried
- A little worried
- Not at all worried
- I prefer not to answer

Q89) While the COVID-19 pandemic continues and the COVID-19 virus is circulating in the community, do you support putting some limits on visits in long-term care and assisted living?

- Yes
- No
- I don't know/I am unsure

Q90) Do you support the current (as of August 26, 2020) visitor restrictions of one designated visitor per resident?

- Yes [GO TO Q92]
- No [GO TO Q91]
- I don't know/I am unsure [GO TO Q92]

Q91) How many visitors should be allowed?

[] visitors

Q92) During this pandemic, how often do you think family and close friends should be able to visit their loved ones in long-term care and assisted living?

- Daily
- A few times per week
- Weekly
- Every two weeks
- Every three weeks
- Monthly
- Other

Q93) Given your answer in the above question, during this pandemic, for how long do you think family members and close friends should be able to visit their loved ones in long-term care and assisted living?

- 30 minutes
- One hour
- Two hours
- Four hours
- More than four hours

Q94) Do you think there could be different visit guidelines for spouses?

- Yes [GO TO Q95]
- No [GO TO Q96]
- I don't know/I am unsure [GO TO Q96]

Q95) Could these differences include:

- More frequent visits
- Ability to be physically close without a mask (i.e., touching, hugging)

Q96) Do you think there should be different visit rules for residents who are at the end of their life or designated palliative?

- Yes
- No
- I don't know/I am unsure

Q97) When do you believe someone becomes palliative? When death is expected...

- Within the next two months
- Within the next month
- Within the next two weeks
- Within the next week
- Within the next few days

Q98) While the COVID-19 virus continues to circulate in the community, which of the following infection control practices do you agree with? Please check all the apply.

- Must schedule the visit in advance
- Must complete either an online or paper-based health screening questionnaire prior to the visit
- Greeted by care home staff upon arrival
- Have temperature checked by care home staff
- Care home staff ask a series of health questions each time
- Asked to wash or sanitize hands
- Asked to wear a mask
- Asked to wear a face shield
- Asked to wear a gown
- Asked to wear gloves
- Physically escorted by care home staff to the area/room where visit occurs
- Stay six feet away from loved one and wear mask
- Stay six feet away from loved one or wear mask
- Plexiglass or some other physical barrier between resident and loved one
- No touching of loved ones
- Touching allowed with mask, face shield, gown and gloves
- Outdoor visits only
- Direct supervision of visits
- Visits only in common areas
- Visits in the residents' room

Q99) Overall, do you feel that visitor restrictions were well managed by your loved one's care home?

- Exceptionally well managed
- Very well managed
- Somewhat well managed
- Not well managed
- Very poorly managed

Q100) What gender do you identify with?

- Male
- Female
- Non-binary
- Trans
- Other

Q101) What gender does your loved one in care identify with?

- Male
- Female
- Non-binary
- Trans
- Other

Q102) What is your age?

[] years old

Q103) What is your loved one's age?

[] years old

Q104) In what language does your loved one primarily communicate with you?

- English
- Other [] (please specify)

Q105) Do you live in the same city as the loved one you visit?

- Yes [GO TO Q107]
- No [GO TO Q106]

Q106) How far away from your loved one's care home do you live?

[] kilometers

Q107) What type of care home does your loved one live in?

- A long-term care home
- An assisted living facility
- An independent living facility
- Other
- I don't know/I am unsure

Q108) To the best of your knowledge, who operates the care home your loved one lives in?

- It is owned and operated by the local health authority
- It is owned and operated by a not-for-profit society but offers publicly subsidized beds/units
- It is owned and operated by a private company but offers publicly subsidized beds/units
- It is owned and operated by a private company with only privately paying residents
- I don't know/I am unsure

Q108a) To the best of your knowledge, how many people live in the care home?

- Fewer than 50
- 50 to 99
- 100 to 149
- 150 to 199
- 200 to 249
- 250 or more
- I don't know/I am unsure

Q109) How long has your loved one lived in care?

[] years.

Q110) Which health region does your loved one live in?

- Interior Health Authority
- Fraser Health Authority
- Vancouver Coastal Health Authority
- Island Health Authority
- Northern Health Authority
- I don't know/I am unsure

Q111) As a consequence of the visitation restrictions imposed in response to this pandemic, do you feel your mental and emotional well-being, compared to before this pandemic, is:

- Significantly worse
- A little worse
- About the same
- A little better
- Significantly better
- I don't know/I am unsure
- Prefer not to answer

Q112) Is there any other information you would like to share about the impact visitor restrictions have had on you or your loved ones due to COVID-19?

Please complete the following section if you answered YES to Q3 or YES to Q15.

As a reminder:

Q3) Did your loved one pass away in care since the declaration of the COVID-19 pandemic on March 11, 2020?

Q15) Is your loved one currently designated palliative?

If you did not answer yes to either of these questions, you have reached the end of the survey. THANK YOU very much for your participation. Please refer to cover letter for mailing instructions.

The next questions ask about the experiences of family members whose loved ones living in long-term care or assisted living passed away and/or were designated palliative during the period of COVID visitor restrictions. Understanding and improving the quality of end of life care is important at any time and even more important during a pandemic. If you are the grieving family member of a senior who died in care during this pandemic, we offer you our heartfelt condolences and, if you are willing to respond to them, our deep gratitude for your willingness to answer the next questions

Q113) Before the COVID-19 pandemic, was your loved one designated palliative?

- Yes [GO TO Q115]
- No [GO TO Q114]

Q114) Were you advised by the care home that they were palliative?

- Yes
- No

Q115) Has your loved one passed away?

- Yes, and please accept our condolences [GO TO Q116]
- No [GO TO Q131]

Q116) How long after you were advised they were palliative did your loved one pass away?

- The same day
- Within a week
- A week or more later
- A month or more later

Q117) While they were designated palliative, could you spend as much time as you wanted with your loved one before they passed away?

- Yes [GO TO Q119]
- No [GO TO Q118]

Q118) Please describe details.

Q119) While they were designated palliative, were other family members allowed to spend as much time as they wanted with your loved one before they passed away?

- Yes [GO TO Q121]
- No [GO TO Q120]

Q120) Please describe details.

Q121) While your loved one was in the last 24 to 72 hours of their life, were there any restrictions on the number of people allowed in the room with your loved one?

- Yes
- No

Q122) How many people were allowed in your loved one's room in the last 24 to 72 hours of their life?

[] people

Q123) Were you limited in the choice of who could be with your loved one in the last 24-72 hours of their life?

- Yes [GO TO Q124]
- No [GO TO Q125]

Q124) Who was allowed to be in the room with your loved one? Check all that apply.

- Immediate Family only, such as a spouse, children, siblings
- Extended Family only, such as cousins, aunts, uncles
- Close friends

Q125) Did you or other visitors have to stay at least six feet away from your loved one during the last 24 to 72 hours of their life?

- Yes
- No

Q126) Do you feel your loved one passed away with dignity?

- Yes, completely
- Yes, somewhat
- No
- I am not sure

Q127) Do you think the restriction of visits prevented the final wishes of your loved one from being fulfilled?

- Yes, completely
- Yes, somewhat
- No
- I don't know/I am unsure

Q128) While you were with your loved one, did you have to wear any of the following personal protective equipment? (Check all that apply.)

- Face mask
- Gown
- Face shield
- Gloves
- I did not have to wear any personal protective equipment

Q129) While your loved one was palliative, were you required to keep six feet of distance from them?

- Yes, all of the time
- Yes, sometimes
- No
- I don't know/I am unsure

Q130) While your loved one was in the last 24-72 hours of their life, were you allowed to touch them or kiss them good-bye?

- Yes
- No

If you have finished Q130, you have reached the end of the survey. THANK YOU very much for your participation. Please refer to cover letter for mailing instructions.

Q131) Are you allowed to visit your loved one as much as you want?

- Yes [GO TO Q133]
- No [GO TO Q132]

Q132) Please describe details.

Q133) Are other family members allowed to visit your loved one as much as they want?

- Yes [GO TO Q135]
- No [GO TO Q134]

Q134) Please describe details.

Q135) While you are with your loved one, do you have to wear any of the following personal protective equipment? (Check all that apply.)

- Face mask
- Gown
- Face shield
- Gloves
- I did not have to wear any personal protective equipment

Q136) When visiting your loved one, are you required to keep six feet of distance from them?

- Yes
- No
- I don't know/I am unsure

Q137) When visiting your loved one, are you allowed to touch them or kiss them?

- Yes
- No

Q138) Do you think COVID-19 visit restrictions for those designated as palliative are appropriate?

- Yes, completely [GO TO END]
- Yes, mostly [GO TO Q139]
- Yes, somewhat [GO TO Q139]
- No [GO TO Q139]

Q139) Please describe why not

You have reached the end of the survey. THANK YOU very much for your participation. Please refer to cover letter for mailing instructions.