

Long-Term Care in Canada

Introduction

This survey is about some important issues in your province (Province) and Canada today. It should take about 10 to 15 minutes of your time.

Part 1: Epidemiology – proximity/profile

[text screen]

Our main focus is long-term care facilities and some of the challenges posed by the Covid pandemic.

For the purposes of this survey, we're defining long-term care (LTC) facilities as places that are:

- provincially licensed and regulated
- provide living accommodation for elderly people
- provide on-site nursing and personal care 24 hours a day, 7 days a week

We're NOT talking about "assisted living" retirement residences where there may be meals and other services but not nursing staff always on-site.

Q1.

Base=All

[Single choice]

In the last year, is there (or was there) a family member or close friend of yours living in a long-term care facility (LTC)?

Yes, currently have family/close friend in long-term care

Not currently, but did have in past year

No, do not

[If Yes, currently have – Proceed with A1 series, skip B1 series, and continue.

If Not currently, but in past year – Skip to B1 series and continue.

All others skip to Part 4]

[A section only ask those who currently have family/friend in care (option 1) at Q1]

[Text screen]

Base=Currently have family/friend in care (option 1) at Q1.

We have a series of questions regarding that family member/friend's experience at their long-term care residence.

A2.**Base=Currently have family/friend in care (option 1) at Q1.****[Single choice]**

First, what is that person's relationship to you? (If you know more than one person currently living in long-term care, please consider the one you are closest to. If it's a couple, please consider the one who has the next birthday.) Is this person:

Your parent

Your spouse/partner

An in-law

Another relative (aunt, uncle, etc.)

A friend, not related

Other (Specify):

A3.**Base=Currently have family/friend in care (option 1) at Q1.****[Single choice/Open-ended number]**

What is their gender and age?

Gender:

Male

Female

Age: (Your best estimate is fine if you're not entirely sure of their exact age.)

Under 60

60-69

70-79

80-84

85-89

90-94

95-99

100+

Not Sure

A4.**Base=Currently have family/friend in care (option 1) at Q1.****[Single choice]**

How long have they lived in their current long-term care residence?

Less than 6 months

6 months to a year

1 to <3 years

3 to <5 years

5+ years

A5.

Base=Currently have family/friend in care (option 1) at Q1.

[Multi-choice]

Does that family member/close friend in long-term care have any of the following conditions:

(Select all that may apply)

Extreme frailty

Dementia (Alzheimer's or other)

Disability/Chronic health problem

Other serious health conditions

None of the above/Just elderly **[Exclusive]**

A6.

Base=Currently have family/friend in care (option 1) at Q1.

[Single choice]

Based on their current physical and mental health, would it be possible for your loved one to still be living in an at-home situation, or not?

Yes, relatively easily

Yes, with some help

Not really without massive help

No way that would be possible

A7.

Base= "some help" (option 2) or "Not without massive" (option 3) at A6.

[Multi-choice]

What kind of at-home support would this person need to live outside long-term care? (Select all that may apply)

Nursing support – a few hours per day

Nursing support – most of the day/night

Doctor visits

Wheelchair access

Medical equipment (i.e. lifts, home oxygen, etc.)

Personal assistance (bathing, toileting, meals)

Supervision/Secure environment

Social interaction/Other people around
Other support (specify):

A8.

Base=Currently have family/friend in care (option 1) at Q1.

[Single choice]

Does your loved one share a room with another resident(s) or have their own room?
(If they share a room with just their spouse, please select “own room”.)

Shares a room

Own room

Not sure

A9.

Base=Currently have family/friend in care (option 1) at Q1.

[Single choice]

As far as you know, is that long-term care facility operated by:

The government (provincial or municipal)

A community or religious group

A private company

Don't know/Not sure

A10.

Base=A private company (option 3) at A9.

[Single choice]

Is that private company:

A large company operating a “chain” of multiple residences

A smaller company (possibly family-owned) operating just the one residence

Don't know/Not sure

A11.

Base=Currently have family/friend in care (option 1) at Q1.

[Single choice]

Long-term care homes can have complicated financing structures: residents pay some costs such as accommodation themselves; the provincial government covers other care-related costs.

As far as you know, is the portion of costs your loved one pays for living in long-term care a source of financial stress for them and/or their family?

No, not at all
 A bit
 A fair amount
 Yes, the cost is a big stress
 Don't know/Can't say

A12.

Base=Currently have family/friend in care (option 1) at Q1.

[Single choice]

As far as you know, does your loved one in long-term care pay any extra money of their own (or their family's) for additional care/services not included in the "basic" level of care that the province covers?

Yes, pays extra for more services
 No, does not
 Don't know/Can't say

A13.

Base=Currently have family/friend in care (option 1) at Q1.

[Single choice]

Thinking back to when the family was looking for a long-term care arrangement for this person, as far as you know, was it easy or difficult to understand the process and options available?

Very easy
 Fairly easy
 Fairly difficult
 Very difficult
 Don't know/Can't say

A14.

Base=Currently have family/friend in care (option 1) at Q1.

[Single choice]

What about finding information on the financial costs of different options? Would you say that was:

Very easy
 Fairly easy
 Fairly difficult
 Very difficult
 Don't know/Can't say

[B Section for those who did have family/friend in care in past year (option 2) at Q1]

B0.

Base=Did have family/friend in care in past year (option 2) at Q1.

[Text screen]

You've indicated that you had a loved one in care last year but not currently. We have a series of questions regarding that family member/friend's long-term care residence and their experience there.

B1.

Base=Did have family/friend in care in past year (option 2) at Q1.

[Single choice]

Could we first please confirm the reason they are no longer living in a long-term care residence?

They now live elsewhere (hospital, a family member's home, etc.)

They have died this past year

B2.

Base=Did have family/friend in care in past year (option 2) at Q1.

[Single choice]

What is (or was) that person's relationship to you? (If you knew more than one person living in long-term care this past year, please consider the one closest to you.) Is or was this person:

Your parent

Your spouse/partner

An in-law

Another relative (aunt, uncle, etc.)

A friend, not related

Other (specify):

B3.

Base=Did have family/friend in care in past year (option 2) at Q1.

[Single choice/Open-ended number]

What is (or was) their gender and age?

Gender:

Male

Female

Age: (Your best estimate is fine if you're not entirely sure of their exact age.)

Under 60
60-69
70-79
80-84
85-89
90-94
95-99
100+
Not Sure

B4.

**Base=Did have family/friend in care in past year (option 2) at Q1.
[Single choice]**

How long did they live in their last long-term care residence?

Less than 6 months
6 months to a year
1 to <3 years
3 to <5 years
5+ years

B5.

**Base=Did have family/friend in care in past year (option 2) at Q1.
[Multi-choice]**

Does or did that family member/close friend living in long-term care last year have any of the following conditions: (Select all that may apply)

Extreme frailty
Dementia (Alzheimer's or other)
Disability/Chronic health problem
Other serious health conditions
None of the above/Just elderly **[exclusive]**

B6.

Base=Did have family/friend in care in past year (option 2) at Q1 AND "they now live elsewhere" at QB1 (ie if deceased, skip to B8)

[Single choice]

Based on their current physical and mental health, would it be possible for your loved one to still be living in an at-home situation, or not?

Yes, relatively easily
 Yes, with some help
 Not really without massive help
 No way that would be possible

B7.

Base= “some help” (option 2) or “Not without massive” (option 3) at B6

[Multi-choice]

What kind of at-home support would have been or was needed for your loved one to live outside long-term care? (Select all that may apply)

Nursing support – a few hours per day
 Nursing support – much of the day/night
 Doctor visits
 Wheelchair access
 Medical equipment (i.e. lifts, home oxygen, etc.)
 Personal assistance (bathing, toileting, meals)
 Supervision/Secure environment
 Social interaction/Other people around
 Other support (specify):

B8.

Base=Did have family/friend in care in past year (option 2) at Q1.

[Single choice]

Did your loved one share a room with another resident(s) or have their own room?
 (If they shared a room with just their spouse, please select “own room”.)
 (If they had both arrangements, please select the one they had for the longest period of time there.)

Shared a room
 Own room
 Not sure

B9.

Base=Did have family/friend in care in past year (option 2) at Q1.

[Single choice]

As far as you know, is the long-term care facility they were living at operated by:

The government (provincial or municipal)
 A community or religious group
 A private company

Don't know/Not sure

B10.

Base=A private company (option 3) at B9.

[Single choice]

And is that private company:

A large company operating a "chain" of multiple residences

A smaller company (possibly family-owned) operating just the one residence

Don't know/Not sure

B11.

Base=Did have family/friend in care in past year (option 2) at Q1.

[Single choice]

Long-term care homes can have complicated financing structures: residents pay some costs such as accommodation themselves; the provincial government covers other care-related costs.

As far as you know, was the portion of costs your loved one paid for living in long-term care a source of financial stress for them and/or their family?

No, not at all

A bit

A fair amount

Yes, the cost was a big stress

Don't know/Can't say

B12.

Base=Did have family/friend in care in past year (option 2) at Q1.

[Single choice]

As far as you know, did your loved one in long-term care pay any extra money of their own (or their family's) for additional care/services not included in the "basic" level of care that the province covers?

Yes, paid extra for more services

No, did not

Don't know/Can't say

B13.

Base=Did have family/friend in care in past year (option 2) at Q1.

[Single choice]

Thinking back to when the family was looking for a long-term care arrangement for this person, as far as you know, was it easy or difficult to understand the process and options available?

- Very easy
- Fairly easy
- Fairly difficult
- Very difficult
- Don't know/Can't say

B14.

Base=Did have family/friend in care in past year (option 2) at Q1.

[Single choice]

What about finding information on the financial costs of different options? Would you say that was:

- Very easy
- Fairly easy
- Fairly difficult
- Very difficult
- Don't know/Can't say

Part 2: Ratings of that LTC

[Section asked of those who currently do/did have a loved one in LTC (options 1 or 2) at Q1]

C1.

Base=Currently do/did have a loved one in LTC (options 1 or 2) at Q1.

[Text screen]

Now some specific questions about the actual long-term care residence your loved one is (or was) living in.

C2.

Base=Currently do/did have a loved one in LTC (options 1 or 2) at Q1.

[Single choice]

Thinking about the time before COVID-19 and its restrictions – generally speaking, how often did you visit this long-term care residence?

- A few times a week or more
- Weekly
- Once or twice a month
- A few times a year
- Less often than that

C3.

Base=Currently do/did have a loved one in LTC (options 1 or 2) at Q1.

[Single choice grid]

Based on your own experience and observations visiting, and based on what you've heard from resident(s) or others, how would you rate this long-term care facility on each of the following:

[rows][Randomize items]

The residents' own space (their suite or room)

The shared spaces in the residence (for dining, socializing, entry, etc.)

Professionalism of the staff

Staffing levels – i.e., the number of workers there at any given time

Overall cleanliness and upkeep of the building

Quality of the food served

Amenities/services/activities

Quality of nursing care for residents e.g. amount of time/attention

Quality of medical care provided e.g. doctor visits/follow-up

The social atmosphere within the residence

A comfortable home for your loved one and other residents

The overall quality of care provided at that long-term care residence **[Anchor]**

[columns]

Excellent

Good

Poor

Terrible

C4.

Base=Currently do/did have a loved one in LTC (options 1 or 2) at Q1.

[Single choice]

Would you recommend this long-term care residence to someone else who needed care?

Yes, definitely recommend

Yes, probably

No, probably not

No, definitely not recommend

Don't know/Can't say

Part 3: COVID-19 and that LTC residence

Section asked of those who currently do/did have a loved one in LTC (options 1 or 2) at Q1.

C5.

Base=Currently do/did have a loved one in LTC (options 1 or 2) at Q1.

[Single choice grid]

Now, a few questions about long-term care facilities and COVID-19. Over this past year, given the pandemic, what kind of job would you say this long-term care facility has done in each of the following areas:

[rows][Keep this order]

Their implementation of public health measures

Communication/updates to residents' families

Effectiveness at protecting residents from COVID-19

[columns]

Excellent job – hard to do any better

Good

Poor

Terrible job -- major failures that should not have happened

C6.

Base=Currently do/did have a loved one in LTC (options 1 or 2) at Q1.

[Single choice]

Would you say your province's rules/restrictions for visiting residents at long-term care facilities during the COVID-19 pandemic have been too strict, too relaxed, or about right overall?

Way too strict
 Too strict
 Too relaxed
 Way too relaxed
 About right overall

C7.

Base=Currently do/did have a loved one in LTC (options 1 or 2) at Q1.

[Single choice]

In the specific long-term care facility where your loved one is (or was), would you say the rules regarding visiting during the COVID-19 pandemic have been applied fairly and consistently for all residents and families?

Yes, consistently and fairly
 Mostly
 Not really
 Not at all – were unfair and inconsistent
 Can't say/Not sure

C7B.

Base=Currently do/did have a loved one in LTC (options 1 or 2) at Q1.

[Single choice]

Overall, what kind of impact, if any, have the visiting restrictions during Covid had on your loved one living in long-term care?

No real impact on them
 Modest impact – missed visiting but okay
 Some impact – loneliness, maybe some confusion
 Serious impact – isolation during Covid had serious effects on them

C8.

Base=Currently do/did have a loved one in LTC (options 1 or 2) at Q1.

[Single choice]

How would you describe your own level of concern or stress about your loved one in long-term care during the Covid pandemic? ~~over the past year?~~

Low stress/Felt under control
 Some stress at times
 Pretty stressful overall

Really stressful/Lots of worry

C9.

Base=Currently do/did have a loved one in LTC (options 1 or 2) at Q1.

[Single choice grid]

Did you or any of your family members do any of the following in response to concerns about COVID-19 and your loved one in that long-term care facility?

[Keep this order]

Contact the LTC residence with specific concerns/questions about COVID-19

Make a complaint (to management, the board, a provincial body etc.)

Become more involved in providing care yourself during COVID-19 (feeding, bathing, sleeping over)

Seriously consider moving your loved one out of the residence

[columns]

Yes, did that

No, did not

C10.

Base=Currently do/did have a loved one in LTC (options 1 or 2) at Q1.

[Single choice grid]

During the COVID-19 pandemic, to what extent would you say each of the following could be trusted?

[Randomize items]

The long-term care home's management

The long-term care home's staff

Your provincial health officers

[columns]

Could trust a great deal

A fair amount

Not much

Could not trust at all

C11.**Base=Currently do/did have a loved one in LTC (options 1 or 2) at Q1.****[Single choice]**

Did this long-term care residence have any cases or outbreak of COVID-19 this past year? (Select all that may apply.)

No, did not [Exclusive]

Isolated case(s), staff only

Isolated case(s), residents

Yes, significant outbreak among residents

Not sure

C12.**Base=Resident cases of COVID-19 (options 3 or 4) at C11.****[Single choice]**

Did any residents of that long-term residence die of COVID-19?

Yes

No

Not sure

C13.**Base=Resident cases of COVID-19 (options 3 or 4) at C11.****[Single choice]**

Did your loved one get COVID-19?

Yes

No

C14.**Base=Loved one caught COVID-19 (option 1) at C13.****[Single choice]**

Did they end up in the hospital or ICU?

No, did not

Yes, hospital but not ICU

Yes, ICU

C15.**Base=Loved one caught COVID-19 (option 1) at C13.****[Single choice]**

Did they survive COVID-19?

Yes, survived

No, did not

C16.**Base=Loved one survived COVID-19 (option 1) at C15.****[Single choice]**

Have they fully recovered from it?

Yes,

No, not fully/Still feeling effects

C17.**Base=Currently do/did have a loved one in LTC (options 1 or 2) at Q1.****[Single choice]**

Has everyone in that LTC residence been offered at least a first vaccination for COVID-19?

Yes, vaccinated

No, not yet

Not sure

C18.**Base=Currently do/did have a loved one in LTC (options 1 or 2) at Q1.****[Single choice]**

All things considered, including what was known back at the beginning of the pandemic about COVID-19 and how it spreads, would you say this long-term care residence:

Did everything that could be expected

Did well enough overall

Fell short

Failed to do what should have been done