

## Home and Community Care Caregiver Experience Survey

This survey will help us understand your experience as a caregiver and point out where we can make services better. It will take approximately 20 minutes to complete. What you tell us is confidential and taking part is voluntary. Your responses will not have an impact on <client name>'s current, or future, home care service(s) in any way.

This survey uses "*home care provider*" to refer to the Local Health Integration Network (LHIN) care coordinator who arranges <client name>'s care plan, as well as any agency care coordinators, and all service providers who come to <client name>'s home to deliver services.

### INSTRUCTIONS:

- Put an 'X'  clearly inside one box that best describes your experience using a **black or blue pen**.
- If you make a mistake, just strike out the mistake ~~by~~ and put the 'X'  in the correct box.
- If you cannot answer a question, or do not want to answer it, please leave it blank and move on to the next question.
- Please **DO NOT** write your name, address, or the names of providers anywhere on the questionnaire.
- When you have completed the survey, please return it in the prepaid envelope provided.

*We thank you for your time.*

### NEED MORE HELP?

For help completing this questionnaire, *or if you wish to complete the survey online or over the telephone*, please call the survey helpline at <insert helpline number> or email us at <insert email address>.

Are you familiar with the home care services that <client name> received or is receiving through the LHIN?

- Yes
- No → if you answered “No”, please *do not* complete the rest of this survey. However, *please do* place this survey in the postage paid self-addressed envelope and return the survey by mail.

***Being a Caregiver...***

***We first want to ask you about your activities as a caregiver.***

1. What is your relationship to <client name>? ***“They are my...”***
  - Spouse / Partner
  - Parent / Step-parent / Parent-in-law
  - Child / Step-child / Foster child / Child-in-law
  - Sibling / Half-sibling / Step-sibling
  - Grandchild / Step-grandchild / Grandchild-in-law
  - Grandparent / Step-grandparent / Grandparent-in-law
  - Friend / Neighbour
  - You do not have an option that applies to me.
  
2. In an average week, how many hours of help do you provide to <client name> (including travel time)?
  - Less than one (1) hour per week.
  - 1-5
  - 6-10
  - 11-20
  - More than 20
  
3. In addition to yourself, how many other unpaid caregivers are you aware of that provide at least one (1) hour of support each week to <client name>?
  - None, I am the only caregiver.
  - 1-2 others
  - 3 or more
  
4. What kind of care do you provide <client name> in your capacity as a caregiver? **Please select all that apply.**
  - Personal support (including mobility and personal care such as toileting, dressing or bathing)
  - Nursing and medical treatments (e.g., managing medications, wound care, etc.)
  - Care coordination (i.e., scheduling and/or attending medical appointments)
  - Emotional support
  - Transportation (helping them to get to appointments, or other important places)
  - Paying bills, managing finances and/or business
  - Housekeeping, shopping, cooking
  - Using the phone or email/internet to communicate with others
  - Other care, not listed here.
  
5. Do you also receive home care services to support your own needs?
  - Yes, including publicly funded home care services.
  - Yes, but only services that I pay for myself.
  - No

### ***Caregiver supports...***

***The following questions ask about your experience with the supports available to you as a caregiver.***

6. When home care services started for <client name>, how well prepared did you feel for your caregiving role?
- Not at all
  - Somewhat
  - Mostly
  - Fully
7. Do you feel well supported by home care providers as a caregiver?
- Not at all
  - Somewhat
  - Mostly
  - Fully
8. At any point in time, if you needed further support, as a caregiver, did a home care provider connect you to other services (e.g., transportation, day programs, Meals on Wheels, etc.) that were helpful to you?
- Not applicable / I did not need further support.
  - Yes, I was connected to enough of the right services.
  - Yes, I was connected, but they were not the right ones.
  - Yes, I was connected to the right ones, but I needed more services.
  - No, I was not connected to other services.
  - Do not know / Do not remember

### ***Accessing home care...***

***The next questions about your experience, as a caregiver, when <client name> first started receiving home care services.***

9. Were you involved in planning <client name>'s home care as much as you wanted to be?
- Not at all
  - Somewhat
  - Mostly
  - Fully
  - I did not want to be involved.
  - I wanted to, but <client name> did not want me to be involved.
10. Do you understand what home care services <client name> should receive?
- Not at all
  - Somewhat
  - Mostly
  - Fully

***Now thinking about the services currently provided to <client name> ...***

11. How often are home care visits arranged at a time that works for you as a caregiver?
- Never
  - Sometimes
  - Usually
  - Always

12. Are you able to make changes to <client name>'s home care services if needed?
- Not applicable / <Client name>'s needs have not changed.
  - Never
  - Sometimes
  - Usually
  - Always
13. How often do changes in appointments/service times by home care providers negatively affect you as a caregiver?
- Never
  - Sometimes
  - Usually
  - Always
  - Not applicable / There have not been any changes in the timing of appointments.
14. Do you have all the equipment and supplies you need for <client name> to continue to live at home? (e.g., walker, incontinence supplies, etc.)
- Not applicable / We do not need any equipment or supplies.
  - Yes, we have all the equipment and supplies needed.
  - We are missing important equipment and supplies, and I do not know how to obtain them.
  - We are missing important equipment and supplies because we cannot afford them.
  - We are missing important equipment and supplies for other reasons.
15. What **additional** help does <client name> need? (including current home care services, as well as additional things that are not funded) **Please select all that apply.**
- Not applicable / <Client name> does not need any additional help.
  - Personal support (including mobility and personal care such as toileting, dressing or bathing)
  - Nursing and medical treatments (e.g., managing medications, wound care, etc.)
  - Physiotherapy
  - Other special therapies (e.g., speech/swallowing therapy, occupational therapy, counseling, etc.)
  - Social visits and/or recreational activities
  - Housekeeping, shopping, cooking services
  - Transportation (e.g., getting to appointments, vehicle modification, taxis, parking for medical appointments, etc.)
  - Other home support services, not listed here.
16. In the past year, what services have you, or your family, paid for yourselves? **Please select all that apply.**
- Not applicable / I do not have to pay for any home care services.
  - Home care equipment (e.g., shower bars, hospital bed, walker, etc.)
  - Home modification and/or equipment installation (e.g., wheelchair ramp, bathroom grab bars, etc.)
  - Personal support (including mobility and personal care such as toileting, dressing or bathing)
  - Respite services (e.g., in-home, adult day program, etc.)
  - Nursing and medical treatments (e.g., managing medications, wound care, etc.)
  - Physiotherapy
  - Other special therapies (e.g., speech/swallowing therapy, occupational therapy, counseling, etc.)
  - Transportation (e.g. vehicle modification, taxis, parking for medical appointments, etc.)
  - Housekeeping, shopping, cooking services
  - I cannot afford to pay for additional services.
  - Other home support services, not listed here.

17. Do you have enough money to pay for everything needed to support <client name>'s care?
- Not applicable / I do not have to pay for anything to support their care.
  - Never
  - Sometimes
  - Usually
  - Always

***Responding to your needs...***

***The following questions are about your needs, as a caregiver, and how well they are met by the home care providers.***

18. What help do you need to support yourself as a caregiver? (including services that are and those that are not funded) **Please select all that apply.**

- Not applicable / I do not need any additional help.

**Care and services for you:**

- Personal support for you (including mobility and personal care such as toileting, dressing or bathing)
- Nursing and medical treatments for you (e.g., managing medications, wound care, etc.)
- Special therapies for you (e.g., speech, rehab, counseling, etc.)
- Housekeeping, shopping, cooking services for you
- Transportation needs for you (e.g. getting to appointments, vehicle modification, taxis, parking for medical appointments, etc.)

**Other supports for you:**

- Instrumental support (i.e., practical help with your caregiving duties)
  - Respite services (e.g. in-home, adult day programs, etc.)
  - Social visits and/or recreational activities for you
  - Peer support from other caregivers
  - Emotional support
  - Informational support (e.g., information, advice, etc.)
  - Training to treat medical conditions, procedures, and/or administering of medication
  - Financial support
- Other supports, not listed here.

***Communication...***

The following questions ask about your experience, as a caregiver, communicating with <client name>'s home care providers.

19. Is there someone who is reliable in responding to any questions or issues that you may have about <client name>'s home care?

- Not applicable / I have not had any questions.
- Never
- Sometimes
- Usually
- Always
- Do not know / Do not remember

20. Do home care providers explain things in a way that is easy to understand?
- Not applicable / I have not communicated with providers.
  - Never
  - Sometimes
  - Usually
  - Always
21. If you were **not able** to understand what the home care providers said, was it for any of the following reasons? **Please select all that apply.**
- Not applicable / I have no difficulty understanding.
  - Language barrier
  - Use of jargon/technical terms
  - Spoke too fast
  - Not listening/paying attention
  - Other reasons, not listed here.
22. How often do you feel that the home care providers listen carefully to you?
- Not applicable / I did not speak with providers.
  - Never
  - Sometimes
  - Usually
  - Always
23. How often do you observe a lack of communication between different home care providers that negatively affects <client name>'s home care? (e.g., one staff member not informing other providers about the care plan)
- Never
  - Sometimes
  - Usually
  - Always
24. How often do you understand the next steps in <client name>'s home care? (e.g., the services that will be provided and the things that you need to do to support <client name>)
- Not applicable / I have not discussed <client name>'s home care.
  - Never
  - Sometimes
  - Usually
  - Always

**Home care providers...**

The next questions ask about your experience with home care providers, both staff members who organized <client name>'s care as well as providers who come to <client name>'s home to provide care.

25. Please complete the following statement indicating which of the following characteristics you have experienced to be true of the home care providers: "**Generally, home care providers...**" Please select all that apply.

- ...are punctual.
- ...are courteous and respectful.
- ...keep us informed.
- ...are efficient in the use of allotted time.
- ...have the necessary skills.
- ...are emotionally supportive.
- ...pay attention to detail.
- ...communicate clearly.
- ...are friendly.
- ...are safety oriented.
- ...are responsive to needs.
- ...are reliable.

26. Do you believe <client name> was harmed because of an error, mistake or by something the home care providers did not do?

- No
- Yes, and there was a good follow-up to address the problem.
- Yes, but there was not good enough follow up to address the problem.

27. What is your experience with the complaint process?

- Not applicable / I have not needed to complain.
- I do not know how to make a complaint.
- I know how, but it is difficult to make a complaint.
- I know how, but I do not feel comfortable making a complaint.
- I made a complaint, but not enough was done to address my complaint.
- I made a complaint and it was resolved to my satisfaction.
- Do not know / Do not remember

**After a Hospital Stay... [only asked for caregivers of hospitalized clients]**

The following questions are about coming home after being in hospital. **If <client name> was not discharged from hospital at the start of their recent home care or in the past 6 months then please skip to question 32.**

If <client name> **was** hospitalized at the start of their recent home care, or in the past six (6) months...

28. When <client name> left hospital, how well prepared did you feel for your caregiving role?

- Not applicable / <Client name> was not hospitalized at the start of their recent home care, or in the past six (6) months.
- Not at all
- Somewhat
- Mostly
- Fully

29. When <client name> left the hospital, did you know whom to contact if you had a question about <client name>'s condition or treatment?
- Not applicable / <Client name> was not hospitalized at the start of their recent home care, or in the past six (6) months.
  - Yes
  - No
  - Do not know / Do not remember
30. After <client name> left the hospital, did <client name>'s home care start when you needed it?
- Not applicable / <Client name> was not hospitalized at the start of their recent home care, or in the past six (6) months.
  - Yes
  - No
  - Do not know / Do not remember
31. After <client name> left the hospital, did the home care providers seem well informed and up-to-date about the care <client name> received in the hospital?
- Not applicable / <Client name> was not hospitalized at the start of their recent home care, or in the past six (6) months.
  - Not at all
  - Somewhat
  - Mostly
  - Fully
  - Do not know / Do not remember

***After Home Care Ended... [only asked for caregivers of discharged clients]***

The following questions asks about your experience, as a caregiver, when Home and Community Care for <client name> ended. Please consider the time when <client name> was discharged from home care. **If <client name> has not been discharged, please skip to question #35 in the section entitled "About you ..." below.**

32. After <client name>'s home care services ended, if you needed further support, as a caregiver, did the home care providers help connect you to other services in the community?
- Not applicable / <Client name> has not been discharged from home care.
  - I did not need further support.
  - Yes, I was connected to enough of the right community services.
  - Yes, I was connected, but they were not the right ones.
  - Yes, I was connected to the right ones, but I needed more services.
  - No, I was not connected to other community services.
  - Do not know / Do not remember
33. How prepared did you feel, as a caregiver, for <client name>'s home care services to end?
- Not applicable / <Client name> has not been discharged from home care.
  - Not at all
  - Somewhat
  - Mostly
  - Fully
  - Do not know / Do not remember
34. Do you know whom to contact if <client name> needs home care again?
- Not applicable / <Client name> has not been discharged from home care.
  - Yes
  - No

### **Overall**

Please rate of your experience, as a caregiver, with home care.

35. Please complete the following statement: "**Overall, I am satisfied with...**" Please select all that apply.

- ...the supports available to me as a caregiver.
- ...the type of care that <client name> is eligible to receive.
- ...the amount of care that <client name> is receiving.
- ...the way care is provided by the home care providers.

36. Did the home care services that <client name> received help them stay at home?

- Not at all
- Somewhat
- Mostly
- Totally

### **About you...**

The following questions are for us to know more about the caregivers of the clients we serve.

37. What best describes your race/ethnicity? **Please select all that apply.**

- White
- Black
- East or Southeast Asian
- South Asian
- Latino
- You do not have an option that applies to me.

38. Do you self-identify as a Francophone?

- Yes
- No

39. Do you self-identify as an Indigenous person?

- No
- Yes, First Nation (Status/Non-Status Indian)
- Yes, Métis
- Yes, Inuk (Inuit)
- Yes, I use an alternative term to describe my Indigenous ancestry and/or identity (e.g., Anishinaabe, Treaty #3).

40. What is your age?

- Under 18
- 18-24 years old
- 25-34 years old
- 35-44 years old
- 45-54 years old
- 55-64 years old
- 65-74 years old
- 75-84 years old
- 85-94 years old
- 95+ years old

41. What sex were you assigned at birth?

- Male
- Female

42. Which of the following describes your present gender identity?

- Woman
- Man
- Two-spirit
- Trans woman
- Trans man
- I identify as something other than the options listed above (e.g., genderqueer, crossdresser, etc.).

43. Do you consider yourself to be...?

- Heterosexual / Straight
- Homosexual / Gay / Lesbian
- Two-Spirit
- Bisexual
- I identify as something other than the options listed above (e.g., asexual, demisexual, etc.).

***The next questions ask about how you feel in your current living situation.***

44. How often do you feel isolated from others?

- Never
- Sometimes
- Usually
- Always

45. How often do you feel left out?

- Never
- Sometimes
- Usually
- Always

46. How often do you feel that you lack companionship?

- Never
- Sometimes
- Usually
- Always

47. Do you ever worry about losing your home or place to live?

- Never
- Sometimes
- Usually
- Always

48. Do you ever have difficulty making ends meet/paying your bills at the end of the month?

- Never
- Sometimes
- Usually
- Always

49. After paying your monthly bills, do you typically have enough money left for food?

- Never
- Sometimes
- Usually
- Always

***Comments***

***We are interested in any additional comments you might have about home care service and providers (Please avoid sharing your name and the name of any providers).***

50. Do you want to share anything about your experience with home care that works well for you as a caregiver?

51. Do you want to share anything about your experience with home care that does not work well for you as a caregiver?

52. Do you have any suggestions for how home care services could be improved?

***Thank you for your time!***