



Survey Questions

From CCCE report *Caring in Canada: Survey insights from caregivers and care providers across Canada*



Below is the full set of questions included in the National Caregiving Survey. These questions were administered in both the panel and open link surveys. Please see the Methodology section on page 11 of our report for more information about survey administration. Note that this list of questions does not reflect survey logic pathways based on participant responses or randomization of response options.

Demographics

1. **Which of the following age groups are you in:**

- a) Under 14
- b) 14-17
- c) Under 18
- d) 18-24
- e) 25-34
- f) 35-44
- g) 45-54
- h) 55-64
- i) 65-74
- j) 75+
- k) I prefer not to answer

2. **Please indicate your gender:**

- a) Woman
- b) Man
- c) Non-binary
- d) Other – please state
- e) I prefer not to answer

3. **Which of these commonly used terms do you use to describe your sexual orientation?**

- a) Lesbian
- b) Gay
- c) Bisexual
- d) Pansexual
- e) Queer
- f) Asexual
- g) Heterosexual or straight
- h) 2spirit
- i) Uncertain or questioning
- j) My sexual orientation is not listed above (please specify)
- k) I prefer not to answer

4. **Which province or territory do you live in?**

- a) British Columbia
- b) Alberta
- c) Saskatchewan
- d) Manitoba
- e) Ontario
- f) Quebec
- g) Newfoundland and Labrador
- h) New Brunswick
- i) Nova Scotia
- j) Prince Edward Island
- k) Northwest Territories
- l) Yukon
- m) Nunavut

5. **What is the last year of education that you have completed?**
- a) Elementary
 - b) High school
 - c) College or technical/trades training
 - d) University certificates and diplomas
 - e) University Bachelor's degree (B.A.)
 - f) University Master's degree (M.A.)
 - g) University Doctorate (PhD)
 - h) I prefer not to answer
6. **What is your ethnic origin?**
- a) Black (African, Afro-Caribbean, African-Canadian descent)
 - b) East Asian (Chinese, Korean, Japanese, Taiwanese descent)
 - c) Latino (Latin American, Hispanic descent)
 - d) Middle Eastern (Arab, Persian, West Asian descent, e.g. Afghan, Egyptian, Iranian, etc)
 - e) South Asian (South Asian descent, e.g. East Indian, Pakistani, Sri Lankan, Indo-Caribbean, etc.)
 - f) Southeast Asian (Filipino, Vietnamese, Cambodian, Thai, other Southeast Asian descent)
 - g) White (European descent)
 - h) Other, Specify
7. **Are you First Nations, Métis or Inuk (Inuit)?**
- a) No, not First Nations, Métis, or Inuk (Inuit)
 - b) Yes, First Nations (North American Indian)
 - c) Yes, Métis
 - d) Yes, Inuk (Inuit)
8. **Which religion do you follow?**
- a) Catholic
 - b) Protestant

- c) Muslim
- d) Buddhist
- e) Orthodox
- f) Jewish
- g) Hindu
- h) Other
- i) Atheist (not religious)
- j) I prefer not to answer

9. **What is your immigration status?**

- a) Canadian Citizen
- b) Permanent resident
- c) Temporary Resident
- d) Refugee
- e) Asylum seeker
- f) I prefer not to answer

10. **Were you born in Canada?**

- a) Yes
- b) No
- c) I don't know
- d) I prefer not to answer

11. **How long have you been in Canada?**

- a) Less than one year
- b) 1 year to less than 5 years
- c) 5 years to less than 11 years
- d) 11 years to less than 21 years
- e) 21 years or more
- f) I prefer not to answer

12. **Which of the following categories best describes your relationship status?**
- a) Single
 - b) Married or living common law
 - c) Widowed
 - d) Divorced
 - e) Separated
 - f) I prefer not to answer
13. **Which of the following best describes the area in which you live?**
- a) Urban area
 - b) Suburban area
 - c) Rural area
 - d) I prefer not to answer
14. **Among the following categories, which one best reflects the total income, before taxes, of all the members of your household?**
- a) \$19,999 or less
 - b) Between \$20,000 and \$39,999
 - c) Between \$40,000 and \$59,999
 - d) Between \$60,000 and \$79,999
 - e) Between \$80,000 and \$99,999
 - f) \$100,000 or more
 - g) I prefer not to answer
15. **What language or languages do you speak on a regular basis at home? Please select all that apply.**
- a) English
 - b) French
 - c) First Nation/Indigenous (please specify)
 - d) Arabic
 - e) Chinese, Cantonese, Mandarin
 - f) Filipino / Tagalog

- g) German
- h) Indian, Hindi, Gujarati
- i) Italian
- j) Korean
- k) Pakistani, Punjabi, Urdu
- l) Persian, Farsi
- m) Russian
- n) Spanish
- o) Tamil
- p) Vietnamese
- q) Other (please specify)
- r) I prefer not to answer

16. **What is your current employment status?**

- a) Working full-time
- b) Working part-time
- c) Self-employed / freelance work
- d) Student
- e) Homemaker
- f) Unemployed
- g) Retired
- h) I prefer not to answer

Identifying caregivers, care receivers, and care tasks

1. **During the past 12 months, have you helped or cared for someone with a medical condition, mental health condition or disability?**
 - a) Yes, as part of a paid job
 - b) Yes, unpaid for a family member, friend, or neighbour (This would include care provided to your own children under the age of 15 years old if they have a medical or mental health condition or disability)
 - c) None of the above

2. **During the past 12 months, have you helped or cared for someone who had challenges related to aging?**
- a) Yes, as part of a paid job
 - b) Yes, unpaid for a family member, friend, or neighbour
 - c) None of the above
3. **If you care for more than one person, what is your relationship to those you care for other than your main care recipient. Please select all that apply.**
- a) Partner or spouse
 - b) Parent
 - c) Child
 - d) Sibling
 - e) Other family
 - f) Friend
 - g) Employer
 - h) Neighbour
 - i) Other
 - j) I only have one care recipient that I care for
 - k) I prefer not to answer
4. **How old is your main care recipient. If you are unsure, please provide your best estimate. If the child is less than 1 year old, please enter '0'.**
- a) _____
 - b) I don't know
5. **Does your main care recipient live with you?**
- a) Yes
 - b) No
 - c) I prefer not to answer
6. **What is the main health condition or problem for which your main care recipient receives help? Please select all that apply.**
- a) Intellectual or developmental disability
 - b) Physical disability

- c) Sensory disability (e.g. hard of hearing, D/deaf, blind, low vision, deafblind)
- d) Challenges related to aging
- e) Mental health condition
- f) Addiction
- g) Medical condition (heart disease, diabetes, etc.)
- h) Genetic disorder (Sickle Cell Disease, Cystic Fibrosis, Huntington's Disease, etc)
- i) Rare disease (Ehlers –Danlos Syndrome, Duchenne Muscular Dystrophy, etc)
- j) Cognitive decline (Alzheimer's, dementia)
- k) Cancer
- l) Long COVID-19
- m) Other, specify
- n) I don't know

7. How long have you been providing this care to your main care recipient?

- a) ___ year(s)
- b) Less than one year
- c) I prefer not to answer

8. How many active hours in a typical 24-hour period do you provide care to your main care recipient? (Active hours can be defined as assistance with activities of daily living such as personal hygiene or grooming, dressing, toileting, and eating or instrumental activity of daily living such as cooking, cleaning, transportation, laundry, and managing finances.)?

- a) ___hour(s)
- b) I prefer not to answer

9. What type of care and support do you provide to your main care recipient? Please select all that apply.

- a) Transportation (e.g., errands, get to medical appointments, get to social events)
- b) Meal preparation, meal clean-up, house cleaning, or laundry

- c) House maintenance or outdoor work (e.g., house repairs, lawn maintenance, snow shoveling)
- d) Personal care (e.g., bathing, dressing, feeding)
- e) Medical treatments or procedures (e.g., changing bandages or dressings, taking medications, performing blood sugar tests)
- f) Scheduling or coordinating care (e.g., organizing care schedule, making appointments, hiring professional help)
- g) Managing finances (e.g., banking, bill paying, managing health insurance claims)
- h) Emotional support (e.g., spending time with them, talking with and listening to them)
- i) Financial Support
- j) Access to recreational activities
- k) Access to faith/ spiritual community (e.g., attending church, synagogue, mosque, etc)
- l) Overnight support
- m) Other specify
- n) I don't know

10. **Is there someone under 18 in your household who assists in providing care? For example, children assisting with the care of aging grandparents.**

- a) Yes
- b) No
- c) I prefer not to answer

11. **In general, how is your physical health?**

- a) Excellent
- b) Very good
- c) Good
- d) Fair
- e) Poor
- f) I don't know

12. **In general, how is your mental health?**
- a) Excellent
 - b) Very good
 - c) Good
 - d) Fair
 - e) Poor
 - f) I don't know
13. **During the past 12 months, have your caregiving responsibilities caused you to feel or experience any of the following?**
- a) Tired
 - b) Worried or anxious
 - c) Overwhelmed
 - d) Lonely
 - e) Isolated
 - f) Short-tempered or irritable
 - g) Resentful
 - h) Depressed
 - i) Loss of appetite
 - j) Disturbed sleep
 - k) Other Specify
 - l) None
 - m) I don't know
14. **During the past 12 months, would you associate your caregiving responsibilities with any of the following?**
- a) Accomplishment
 - b) Appreciation
 - c) Learning
 - d) Making a difference
 - e) Fulfillment

- f) Pride
- g) A sense of importance
- h) Happiness
- i) Other specify
- j) None
- k) I don't know

Access

1. **In the past 12 months, have you sought out any information regarding support, services or benefits for caregivers?**
 - a) Yes
 - b) No
 - c) I don't know
2. **During the past 12 months, have you attempted to access supports, services, or benefits for caregivers?**
 - a) Yes
 - b) No
 - c) I don't know
3. **In the past 12 months have you received financial benefits for caregivers? Financial Benefits may include Tax Credits and Income Support or other services to assist you in your caregiving responsibilities.**
 - a) Yes
 - b) No
 - c) I prefer not to answer
4. **How satisfied or dissatisfied are you with the support or services you have received as a caregiver in the last 12 months?**
 - a) Very satisfied
 - b) Somewhat satisfied
 - c) Not very satisfied
 - d) Not at all satisfied

- e) I haven't received any support or services
- f) I don't know

5. **Where have you accessed information about support, services, or benefits for caregivers?**

- a) Walk in clinic
- b) Family Doctor
- c) Other Medical Practitioner (pediatrician, oncologist etc.)
- d) Phone
- e) Care Organization (Ontario Caregiver Organization, L'Appui Quebec, etc)
- f) Charities
- g) Family
- h) Pastoral care (e.g., church, synagogue, mosque, etc)
- i) Friend
- j) Online
- k) Hospital
- l) Community Centre
- m) Social Worker
- n) Other
- o) Could not access
- p) I don't know

6. **How easy or difficult has it been to find information and advice about support, services or benefits for caregivers?**

- a) Very easy
- b) Somewhat easy
- c) Somewhat difficult
- d) Very difficult
- e) I don't know

7. **In the past 12 months in your experience as a caregiver, have you**

- a) Requested information about how to get financial help

- b) Used respite services where someone would take over your care to give you a break
- c) Had an outside service provide transportation for the person you're caring for instead of you providing the transportation
- d) Had modifications made in the house or apartment where to make things easier for them
- e) Had a doctor, nurse, or social worker ask you about what you need to help you give care.
- f) Had a doctor, nurse, or social worker assess your well-being or ask you what you need to take care of yourself.
- g) Other specify.
- h) None of the above
- i) I don't know

8. In the past 12 months, have you done the following online for your main care recipient?

- a) Had a virtual or online visit with a healthcare provider who could care for the person you're caring for
- b) Created an online or shared calendar to organize caregiving schedules or activities
- c) Managed prescription refills or delivery on an app or website
- d) Placed an online order for groceries or household supplies
- e) Helped them use a ride service like Lyft or Uber
- f) Searched online for support services, aides, facilities, or other help
- g) Connected with other caregivers online using social media or support groups
- h) Watched videos to learn how to do different things you need to do to care
- i) Access test results
- j) Coordinate online patient history
- k) None of the above
- l) I don't know.

9. **How many hours a week on average do you spend researching supports and services or navigating systems to assist you in your caregiving journey.**
- a) Less than 1 hour
 - b) 1-2 hours
 - c) 3-4 hours
 - d) Over 5 hours
 - e) I don't spend time researching or navigating
 - f) I don't know
10. **Do you find it difficult to access or hire quality care providers and other paid care services in your area.**
- a) Very difficult
 - b) Somewhat difficult
 - c) Not very difficult
 - d) Not at all difficult
 - e) I have never attempted to get services
 - f) I don't know
11. **Are there any other services you would find useful that you would like to use but you do not currently have access to / don't know how to access?**
- a) _____
 - b) There are no other services I would like to use
 - c) I don't know

Policy

1. **In the past 12 months have you received support or services for your main care recipient to assist them?**
- a) Yes
 - b) No
2. **Overall, how satisfied, or dissatisfied are you with the support or services you have received for your main care recipient in the last 12 months?**
- a) Very satisfied
 - b) Somewhat satisfied

- c) Not very satisfied
- d) Not at all satisfied
- e) I don't know

3. **In the past 12 months, has your main care recipient used any of the support, services or benefits listed below?**

- a) Respite support or services allowing you to take a break from caring at short notice or in an emergency
- b) Respite support or services allowing you to take a break from caring for more than 24 hours
- c) Respite support or services to allow you to have a rest from caring for 24 hours or less
- d) Housekeeping
- e) Home care/home help (eg. Personal Support Work)
- f) Day centre or day activities
- g) Meals Services
- h) Equipment or adaptation to their home (eg. wheelchair or handrails)
- i) They are permanently resident in a care home
- j) Financial supports or other tax credits
- k) None of the above
- l) I don't know

4. **With regard to tax credits related to care, please select which of the following applies to you.**

- a) I am familiar with tax credits related to care and have used it
- b) I am familiar with tax credits but have not used as I am not eligible
- c) I am familiar with tax credits but have not used for some other reason
- d) I am not familiar with tax credits related to care
- e) I don't know

5. **Which of the following services or supports or benefits do you think would be / have been helpful to you? Please select all that apply.**
- a) Having respite services available, where someone would relieve your caregiving duties to give you a break
 - b) Requiring a doctor, nurse, or social worker ask you about what you need to fulfill your caregiving duties such as referral to home care medical support, transportation, etc.
 - c) Requiring a doctor, nurse, or social worker ask you about your wellbeing as a caregiver
 - d) Improved access to home care services
 - e) Long term care insurance
 - f) Monthly allowance to help with the costs of caregiving
 - g) Tax credits that are easier to access and more generous
 - h) Support from your workplace (days off, flexible work arrangements, etc)
 - i) Free counselling and other mental health supports
 - j) Formal training for caregivers on key care responsibilities
 - k) Other specify.
 - l) None of the above
 - m) I don't know

Prioritization

1. **What has been helpful information you have received from different organizations, such as voluntary organizations and private agencies as well as government services for your caregiving experience.**
- a) _____
 - b) I don't know
2. **There are many ways to support caregivers, how important do you think these types of caregiver supports are?**
- a) Very important
 - b) Somewhat important
 - c) Not very important

- d) Not important at all
- e) I don't know

Items:

- Having respite services available, where someone would relieve your caregiving duties to give you a break
- Requiring a doctor, nurse, or social worker ask you about what you need to fulfill your caregiving duties such as referral to home care medical support, transportation, etc.
- The development of national public long term care system
- Requiring a doctor, nurse, social worker, or other healthcare professional ask you what you need to take care of yourself and track your wellbeing
- Improved access to home care services
- Monthly allowances to help with the costs of caregiving
- Free counselling and other mental health supports for caregivers
- Formal training for caregivers on care responsibilities like giving medication, managing finances, and dressing wounds.

3. How helpful would you find each of the following ways to help caregivers financially?

- a) Very Helpful
- b) Somewhat helpful
- c) Not very helpful
- d) Not at all helpful
- e) I don't know

Items:

- An income tax credit to caregivers, to help offset the cost of care
- A partially paid leave of absence from work, for caregivers who are employed
- A program where caregivers could be paid for at least some of the hours they provide care
- Caregiving days off from work (Sick days for care responsibilities)
- Monthly care allowance
- Long term care insurance

Economic strain

1. **During the past 12 months, have you experienced financial hardship because of your caregiving responsibilities?**
 - a) A lot
 - b) A little
 - c) Not very much
 - d) Not at all
 - e) I don't know

2. **How difficult has it been to get affordable services in the local area or community that you are providing care in, such as delivered meals, transportation, or in-home health services?**
 - a) Very difficult
 - b) Somewhat difficult
 - c) Not very difficult
 - d) Not at all difficult
 - e) I have never attempted to get such services
 - f) I don't know

3. **In the past 12 months, what has your average out of pocket expense been (per month) to cover costs related to caregiving.**
 - a) Below \$200
 - b) Between \$200-\$999
 - c) Between \$1000-\$2999
 - d) Between \$3000-\$7999
 - e) Between \$ 8000 - \$9999
 - f) Between \$10000 - \$20000
 - g) Over \$20000
 - h) I don't know

4. **In the past 12 months have you experienced any of the following because of your caregiving duties?**

- a) Took on more debt (credit cards, loans, lines of credit)
- b) Missed or was late paying for a student loan
- c) Borrowed money from family or friends
- d) Filed for bankruptcy (medical or personal)
- e) Been unable to afford basic expenses like food
- f) Left your bills unpaid or paid them late
- g) Used your personal short-term savings
- h) Used long-term savings, like retirement or education, to pay for other things
- i) Stopped saving
- j) Moved to a less expensive home, apartment, or other living arrangement
- k) Was evicted or had a home foreclosed
- l) Put off when you planned to retire or decided to never retire
- m) Had to start working
- n) Had to work more hours
- o) Had to find a second job
- p) Other specify
- q) None of the above
- r) I don't know

Care providers

1. **What is your job title? [pick all that apply]**

- a) Direct Support Professionals (DSPs)
- b) Personal Support Workers (PSWs)
- c) Attendants for people with disabilities
- d) Respite worker
- e) Supervisor/manager of frontline care providers
- f) Other specify
- g) I don't know

2. **During the past 12 months, where have you primarily provided help or care to these people as part of your paid job?**
- a) A nursing home or senior's residence
 - b) A residential care facility (e.g., group home for people with disabilities or addictions)
 - c) Long-term care home
 - d) A hospital
 - e) The care recipient's home (e.g., home care worker, live-in caregiver)
 - f) Some other location
 - g) I don't know
3. **How long have you been working as a care provider?**
- a) ___ year(s) [HAS TO BE GREATER THAN 0]
 - b) Less than one year
 - c) I prefer not to answer
4. **Which of the following would make your job easier? Please select all that apply.**
- a) Adequate resources, such as medical supplies, equipment, and better facilities
 - b) Ability to choose to continue to support the same clients (continuity of care)
 - c) Better tools and resources to better serve your clients
 - d) Supportive work environment
 - e) Better recognition of the work I am contributing
 - f) Reasonable working hours / good work life balance
 - g) Higher pay
 - h) Flexible scheduling
 - i) Access to paid sick leave
 - j) Time off
 - k) Full time employment opportunity
 - l) Access to supports such as counselling or wellness activities

- m) Appropriate training and education, as well as continuing education
- n) Other specify
- o) There is nothing that would make my job easier
- p) I don't know

5. **Please indicate to which extent you feel supported. This could be through staffing, resources including tools and equipment, interactions with leadership, sufficient training.**

- a) Very supported
- b) Somewhat supported
- c) Not very supported
- d) Not at all supported
- e) I don't know

6. **What would make you feel supported at work?**

- a) _____
- b) I don't know

7. **How do you get help or support to do your job?**

- a) Colleagues and team support
- b) Supervisor and leadership support
- c) Employee assistance programs (EAP)
- d) Professional association and networks
- e) Continuing education and training
- f) Employee wellness programs
- g) Union
- h) Peer support groups
- i) Human Resources
- j) Mentor
- k) Other specify
- l) I don't receive any support
- m) I don't know

8. **How much do you agree or disagree with the following?**

- a) Strongly agree
- b) Somewhat agree
- c) Somewhat disagree
- d) Strongly disagree
- e) I don't know
- f) Not Applicable

Items:

- Care providers are included as part of the care team in the health care system
- I feel supported at work
- I feel supported by my colleagues and management
- I feel like I am paid fairly.
- There is an adequate amount of staff present throughout my shifts
- A union would increase the support I feel at work
- I feel supported by the government
- I feel my work is being appreciated by the people I care for
- I feel that continuing education leads to greater pay respect and opportunity for care providers
- I feel safe at work

9. **Have you considered changing careers for any of the following reasons?**

Please select all that apply.

- a) Poor work life balance, burnout or stress
- b) Not satisfied with current job
- c) No opportunity for career advancement
- d) No opportunity for training and education
- e) Not paid a high enough salary
- f) Lack of benefits
- g) Lack of job security
- h) Personal reasons, such as home life, family dynamics

- i) Abuse and discrimination
- j) Other specify
- k) I have never considered changing careers
- l) I don't know

10. **In the past 12 months, have you been discriminated against or abused at work? Please select all that apply.**

- a) Abused
- b) Discriminated against
- c) Neither
- d) I don't know

11. **I feel that I have been discriminated against based on:**

- a) Race or ethnicity
- b) Age
- c) Immigration status
- d) Gender or gender expression
- e) Disability
- f) Sexual orientation
- g) Religion
- h) Other, Specify
- i) I don't know

12. **I have experienced discrimination at the hands of**

- a) Employer
- b) Client
- c) Family of care recipient
- d) Colleague
- e) Management
- f) Rest of the health care team (e.g., nurses, doctors)
- g) Other, Specify
- h) I don't know

13. **I have experienced abuse at the hands of**
- a) Employer
 - b) Client
 - c) Family of care recipient
 - d) Colleague
 - e) Management
 - f) Rest of the health care team (e.g. nurses, doctors)
 - g) Other, Specify
 - h) I don't know

Indigenous caregivers

1. **Are you aware of any support services specifically designed to assist Indigenous caregivers? (Please select one option)**
- a) Yes (please specify)
 - b) No
2. **What support services or resources would you find beneficial as an Indigenous caregiver? (Please select all that apply)**
- a) Culturally appropriate counseling or therapy services
 - b) Respite care options
 - c) Financial assistance programs
 - d) Education and training opportunities
 - e) Access to support groups or peer networks
 - f) Other (Please specify)
 - g) I don't know
3. **How important is it to you that caregiving and support are delivered in a culturally sensitive manner for Indigenous individuals and families? (Please select one option)**
- a) Extremely important
 - b) Somewhat Important
 - c) Not very important

- d) Not at all important
- e) I don't know

4. **In your experience, what are some unique strengths or qualities that Indigenous individuals with autism bring to their communities? (Please select all that apply)**

- a) Cultural knowledge and understanding
- b) Strong sense of community and family support
- c) Connection to nature and the environment
- d) Resilience and adaptability
- e) I don't know
- f) Other (Please specify)

5. **Please indicate the extent to which you agree or disagree with the following: There is adequate representation and inclusion of Indigenous voices and perspectives in caregiver supports and policy discussions? (Please select one option)**

- a) Strongly agree
- b) Somewhat agree
- c) Somewhat disagree
- d) Strongly disagree
- e) I don't know



Canadian Centre for Caregiving Excellence

The Canadian Centre for Caregiving Excellence is a new initiative incubated and powered by the [Azrieli Foundation](#). The Foundation has long supported innovative initiatives to improve access to quality care. Following a period of building networks and convening stakeholders, the Centre will become a stand-alone organization.



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