

Canada Carer Well-Being Index

Who Cares for Carers? Perspectives on COVID-19 Pressures and Lack of Support



Table of Contents



Caring for a person with a compromised immune system is very challenging during times like this pandemic... This has created heightened anxiety in myself and the individual I care for."

 25-year-old female from Canada taking care of someone with kidney disease

U 3	Setting the Stage
04	Research Approach and Methodology
05	Five Key Themes Emerged from the Global 2020 Carer Well-Being Index
06	Key Findings Canada
07	Rising Demands
10	Changed Responsibilities
13	The Toll on Carers
16	Inequities in Caregiving
20	Path to Solutions
23	Conclusions and Opportunities
28	Appendix

Satting the Stage

Setting the Stage





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According to the International Alliance of Carer Organizations (IACO), there are more than 63 million carers internationally*. In order to illuminate the challenges carers face, Embracing Carers, a collaboration with leading carer organizations around the world, conducted a Global State of Care survey in 2018 to determine the unmet needs of carers and the impact that caring for others has on their own health and well-being. The collaboration and key findings from the research sought to increase awareness, discussion and action about the often-overlooked needs of people who provide unpaid care for others.

Around the globe, many of the stresses on carers have long existed, but in 2020, the uncertainty of the pandemic has made them even greater for carers across countries. It has significantly affected global healthcare systems and has caused substantial disruption for unpaid carers around the world, in ways that put their economic, physical and psychological well-being at risk.

In producing the 2020 Carer Well-Being Index, Embracing Carers aims to detail the ways in which the pandemic disproportionally harms carers around the globe—and to identify key societal solutions and specific actions that can address their needs during the pandemic and beyond.



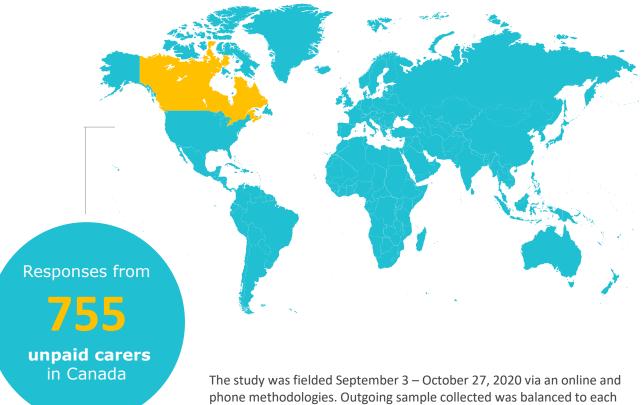
Research approach and methodology



The Carer Well-Being Index is a **global** research study commissioned by Embracing Carers and fielded in partnership with an independent, third-party market research provider and non-governmental organizations across 12 countries: United States, Canada, United Kingdom, France, Germany, Italy, Spain, Australia, Brazil, Taiwan, India and China.

Respondents included more than 9,000 unpaid carers across the countries surveyed, of which 755 were unpaid carers in Canada. Unpaid carers were defined as caring for someone with a long-term illness, physical disability, or **cognitive/mental condition**. The conditions they care for included cancer, Multiple Sclerosis, Parkinson's Disease, Dementia, Alzheimer's, Spinal cord injury, Muscular Dystrophy, cognitive/mental condition or Congestive Heart Failure.

The content in this report highlights key learnings specific to carers within Canada*.



country's Census to allow qualifying respondents to fall out naturally. Light weighting was applied in select countries to achieve better national representation. At the 95% confidence level, the full, 12-country average global unpaid carer sample has a margin of error of +/- 1.03 percentage points. The Canada unpaid carer sample has a margin of error of +/- 3.6 percentage points.

Five key themes emerged from the 2020 Carer Well-Being Index





Rising Demands

The pandemic sent shockwaves across the globe and placed added pressure on carers. More than ever before, they are shouldering heavy burdens.



Changed Responsibilities

Carers around the world have long faced hurdles, but the pandemic has elevated specific tasks, amplifying their responsibilities.



The Toll on Carers

Though being a carer can be rewarding, it comes at a cost. The physical, mental and financial implications can combine to erode carers' well-being.



Inequities among Carers

All carers are facing difficult times, but in Canada, women and those caring for someone with ongoing cognitive conditions face their own unique struggles when it comes to support.



Path to Solutions

Supporting carers is a global issue and a societal responsibility. Across public and private sectors, everyone has a role to play.



Key Findings Canada



Compared to the 12-country global average, Canadian carers are more likely to provide emotional support, manage appointments and home maintenance services as key responsibilities as a caregiver.

- 72% of Canadian carers say that their primary responsibility is to provide emotional support, compared to 65% of the 12-country average
- 64% of Canadian carers say that their primary responsibility is to manage doctors' appointments, compared to 57% of the 12-country average
- 64% of Canadian carers say that their primary responsibility is home maintenance, compared to 55% of the 12-country average.

With that, there is a higher incidence of Canadian carers feeling that being a carer negatively impacts their lives.

- 66% of Canadian carers say that being a carer negatively impacts their emotional/mental health, compared to 58% of the 12-country average.
- 56% of Canadian carers say that being a carer negatively impacts their financial health, compared to 52% of the 12-country average.

And the coronavirus pandemic has exacerbated the distress Canadian carers feel on their well-being.

- 70% of Canadian carers say that the pandemic has worsened their emotional/mental health, compared to 61% of the 12-country average
- 61% of Canadian carers say that the pandemic has worsened their physical health, compared to 46% of the 12country average



I: Rising Demands

"I feel that the number of hours that I spend taking care of my father has increased since it is hard to get someone who is willing to come in to help me with the care and I am also afraid of the possibility of infection."

-62-year-old Canadian male caring for one individual with Dementia



The pandemic has increased the demand for carers in Canada and has put added strain on their role



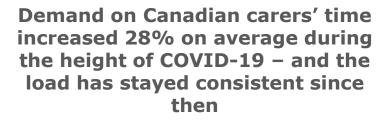
As the pandemic spread across the globe, some became carers for the first time



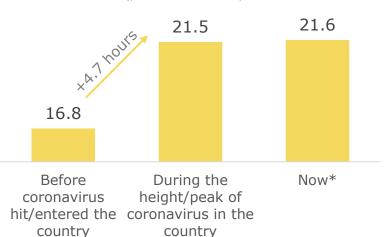
12%

Of Canadian carers began caring duties for the first time as a result of the pandemic





Average Hours Carers Spend Caregiving (per week, Canada)



Similar to experiences in other countries, the pandemic has made caregiving in Canada more difficult

66%

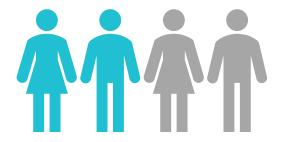
say the pandemic has made caregiving harder





Canadian carers are being relied on more than ever, especially when it comes to providing emotional support





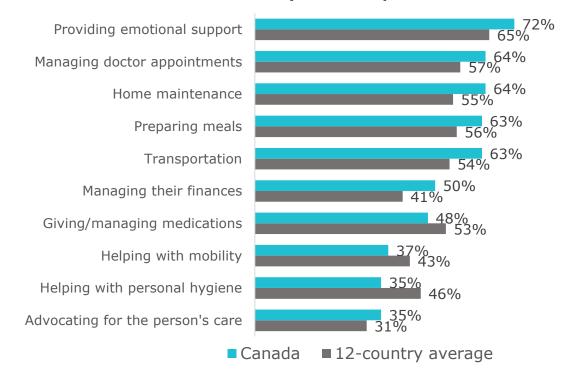
48%

of Canadian carers say the person(s) they care for is/are relying on them more than ever before



Carers in Canada bear the weight of key responsibilities, such as providing emotional support, appointment scheduling, and home maintenance.

Primary Carer Responsibilities





II: Changed Responsibilities

"Before the pandemic, other family members + her friends would visit and help – whether it was to entertain her or for emotion support. Now that COVID-19 is happening, they aren't able to come over and therefore I have to fill in for that."

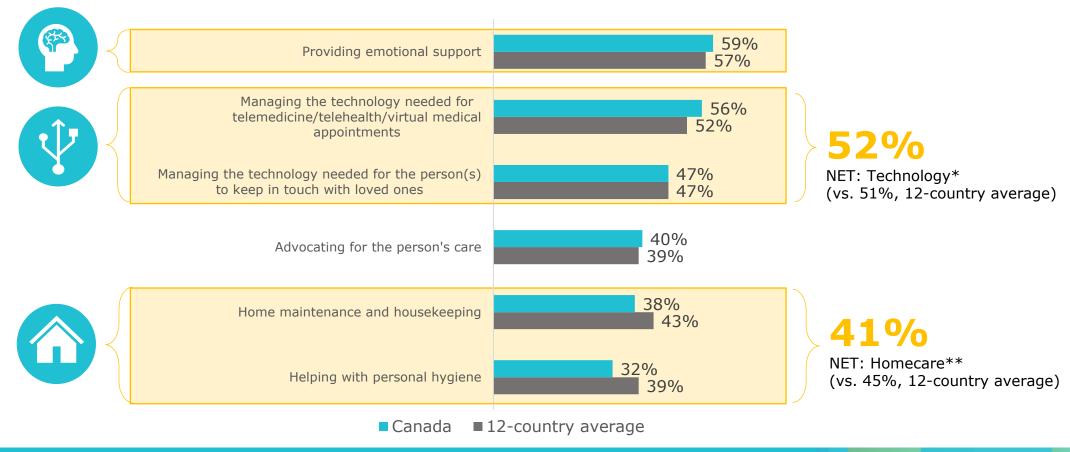
 25-year-old Canadian female caring for one individual with an Ongoing/Long-Term Cognitive/Mental Condition



Due to the pandemic, Canadian carers have taken on greater responsibilities surrounding emotional support, managing technology, homecare, and advocating for their loved one



Top Responsibilities That Have Increased Due to the Pandemic:



As Canadian carers' responsibilities increase, there is little time for respite and their own needs are being neglected



Canadian carers are providing significantly more emotional support for their loved ones — and their own needs are taking a back seat

59%

have provided more emotional support due to the pandemic



12-country average

say they've put the needs of the person(s) they are caring for above their own during the pandemic



12-country average

Canadian carers' telehealth and technology usage has also surged, fueling a desire for specific technology trainings

52%

report increased responsibility managing technology* due to the pandemic



12-country average

of carers need additional quidance/training on how to use telehealth/online tools/mobile apps for caregiving



12-country average

Canadian carers' responsibilities at home have only grown leaving little opportunity for a break

41%

report increased homecare** responsibilities due to the pandemic



12-country average

say the **biggest challenge** they've faced as a carer during the pandemic is the inability to take a break

12-country average





III: The Toll on Carers

"Being home full time and little income has put a tremendous financial strain on my household and relationship. It has really stressed me out and wearing on me emotionally. I am physically getting tired and worn out by end of every day and I feel less happy as I don't see my grown children much or friends due to pandemic."

– 58-year-old Canadian female caring for someone with Congestive Heart Failure



In Canada, the pandemic is causing burn out and taking a toll on carers' emotional, financial and physical well-being



Most carers are experiencing unprecedented levels of burnout



71%

of Canadian carers say caring for someone during the pandemic has caused them to feel more burnt out than ever before



Top aspects of carers' well-being impacted in Canada

Emotional/Mental
Well-Being

70%

of carers say the pandemic has worsened their emotional/mental health



Financial Well-Being

55%

of carers say the pandemic has worsened their **financial health**



Physical Well-Being

51%

of carers say the pandemic has worsened their **physical health**



Isolation, lack of support, increased demand for supplies, and lack of sleep are contributing factors to Canadian carers' worsening well-being



70%

of carers say the pandemic has worsened their **emotional**/**mental** health, because:

Physical distancing and sequestering orders have made me feel isolated and alone	44% vs. 34% , 12-country avg.
I have even less time to spend with my friends and family	39% vs. 31% , 12-country avg.
I don't feel like I have anyone to turn to for support	34% vs. 27% , 12-country avg.
I am severely lacking sleep because I am constantly worried about the person(s) I care for	34% vs. 30% , 12-country avg.
I am more afraid than ever before that the person(s) I care for is going to die	33%

In Canada,

55%

of carers say the pandemic has worsened their <u>financial</u> health, because:

More of my money is going toward supplies and resources I need to provide care	33%
Government, social services, and/or insurance provided financial support is not enough to cover my caregiving expenses	24%
My professional or paid working hours were reduced or cut back	23%
My salary was reduced	18% vs. 23% , 12-country avg.
I've had to reduce my professional/paid working hours because of my caregiving duties	16% vs. 22% , 12-country avg.

51%

of carers say the pandemic has worsened their **physical** health, because:

I am lacking sleep	58%
I am exercising less	51% vs. 45% , 12-country avg.
I have postponed my own medical appointments	37%
I have adopted unhealthy eating habits	36%
I can't afford nutritious food (e.g. fruits and vegetables, etc.)	19%

12-country averages provided only in cases where Canadian results vary in a statistically-significant way





IV: Inequities in Caregiving

"I am unable to take the usual transportation that I do to my Grandmother (carpool), and because she is immunocompromised, I feel unsafe taking public transit, so naturally there is a raised cost with having to take Uber. It is also difficult to provide emotional support when things can seem admittedly bleak, not being able to take her for walks at the park due to her immune system, etc."

 21-year-old Canadian female caring for someone with Alzheimer's

Female carers and those caring for someone with an ongoing cognitive condition are facing unprecedented challenges







- Half (52%) of Canada's female carers say that uncertainty caused by the Coronavirus/COVID-19 is causing anxiety (vs. 37% male carers).
- Half (48%) of Canada's female carers whose emotional/mental health has worsened say it is due to physical distancing orders making them feel isolated and alone (vs. 38% male carers).
- Almost all (97%) agree that there needs to be more mental/wellness resources readily available for carers (vs. 91% male caregivers).



Ongoing cognitive condition carers in Canada have fewer financial resources and aren't receiving enough support

- Two-thirds (65%) of ongoing cognitive condition carers say that being a carer has had a negative impact on their financial health (vs. 56% average Canadian carer).
- Almost all (97%) say that more financial tools from the local/state government are important in ensuring they are able to properly provide the care needed (vs. 92% average Canadian carer).

^{*}Ongoing cognitive health conditions include bipolar disorder, chronic depression, autism, down syndrome, schizophrenia, psychosis, among others





Canada's female carers have taken on more emotional support duties, and now face increased mental/emotional challenges of their own



79%

of female carers report providing emotional **support** as one of their primary responsibilities as a carer



(Male Canada carers: 62%)

In rates higher than Canadian male carers, the pandemic has left female carers feeling anxious and isolated

52%

say that uncertainty caused by the Coronavirus/COVID-19 is causing anxiety for both/all of them

(Male Canada carers: 37%)

48%

of those whose mental/emotional health has worsened due to the pandemic, say physical distancing orders have made them feel isolated and alone

(Male Canada carers: 38%)

Female carers strongly feel that more can be done to support them



97%

agree that there needs to be more mental/wellness resources readily available for carers

(Male Canada carers: 91%)

77%

believe avenues to connect with other carers (e.g., social media) are important to ensure they can properly provide care

(Male Canada carers: 69%)

18



Ongoing cognitive condition carers are being disproportionately impacted by the financial burden of the role – and look to government and social/care sources for support



Ongoing cognitive condition carers are more likely to face financial problems:

Say that being a carer has had a negative impact on their financial health

(Average Canadian carer: 56%)

74%

Are concerned that they are not going to be able to afford to provide proper care

(Average Canadian carer: 65%)

They are not receiving enough support

66%

Believe that carers are not receiving enough support from the federal/national government

(Average Canadian carer: 58%)

61%

Believe that carers are not receiving enough support from social services/care professionals

(Average Canadian carer: 53%)



97%

Say that more financial tools from local government are important in ensuring they are able to properly provide the care needed

(Average Canadian carers: 92%)



19



V: Path to Solutions

"Please keep in mind all of the people out there that give selflessly to so many people. We are not loud... but we do have voices and we do need help! Financially, medically and emotionally."

 48-year-old Canadian Female caring for someone with diabetes and chronic knee pain



In addition to worries about increased infections due to reopening, Canadian carers have financial, employment, and technology concerns



Concerns extend beyond the immediate health threat that COVID-19 poses to caregivers:



87%

I am concerned about the increase in Coronavirus/COVID-19 infections from re-openings



Affordability

65%

I am concerned that I will not be able to **afford to provide** proper care



Employment Pressures*

64%

I am concerned that I will have to **work full time remotely** while also caregiving for the foreseeable future



Technology Demands

53%

I am concerned that I will need to use **more technology and digital tools** to manage care properly





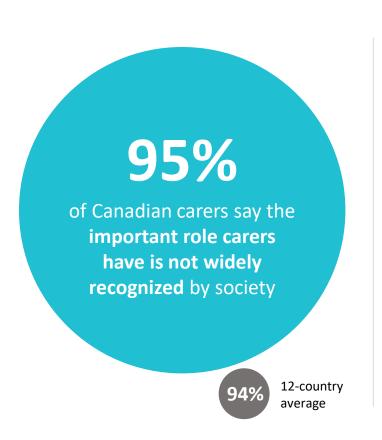




21

Canadian carers lack support from crucial entities and feel they are not receiving the recognition they deserve





Carers need help to provide care; solutions can be found in public and private settings

Canadian carers believe they do not receive enough support from:

Federal/national government	58%	57%	12-country average
Local & state/province government	58%	56%	12-country average
Social services/ care professionals	53%	51%	12-country average
Insurance organizations	52%	51%	12-country average
Local communities	49%	50%	12-country average
Private companies	47%	52%	12-country average
Healthcare professionals	47%	45%	12-country average



Conclusion & Opportunities



The global pandemic has had a dramatic impact on carers around the world





Rising Demands

In every nation surveyed, including Canada, the pandemic is requiring carers to do more. These demands will likely continue long after the pandemic is addressed.



Changed Responsibilities

While the nature of new expectations of carers varies around the world, all need urgent support to navigate and address the new challenges they face.



The Toll on Carers

Carers around the globe are feeling overwhelmed, facing burnout that is aggravated by financial strains and growing fears of the lasting impact of the pandemic. They require tools and resources to survive and thrive.



Inequities Impacting Carers around the World

The pandemic has exacerbated the challenges facing women carers and those caring for people with ongoing mental conditions in Canada. Specific steps must be taken to address these imbalances.



Path to Solutions

Canada must ensure carers receive early and continuing support to emerge safely – and as soon as possible – from the grip of the pandemic. Across public and private sectors, everyone has a role to play.



Carer Advocacy Priorities





Embracing Carers, along with its partners, has recognized five advocacy priorities that address universal needs for unpaid carers. These priorities form the framework for recommended actions – by governments, civic organizations, employers and communities – highlighted by the results of the Global Carer Well-Being Index.

Global Carer Priorities

- Safeguard the health and well-being of unpaid carers.
- Minimize the financial burden placed on unpaid carers.
- Enable access to user friendly information and education.
- Support unpaid carers who are employed.
- Invest in research to ensure carers' needs and contributions are recognized and addressed.

See global report for specific actions we can take to address each of these priorities.



The march forward in supporting carers





When the pandemic hit, the entire world was impacted. Countless countries shuttered their borders, businesses and families found themselves under stay-at-home mandates and quarantine orders. These new pressures made the care journey more challenging, both for carers living with someone in their care and those caring from a distance. Younger adults and parents were especially likely to step into caregiving roles, despite having to manage their own, interrupted obligations.

Carers haven't been alone in experiencing the pressures of the pandemic but many faced pressures, demands and time commitments that others may not understand. As health and social care providers move to rapid responses to control COVID-19, carers must navigate fast-changing care delivery models, learn new telehealth and technology, provide emotional support despite their own emotional needs, and handle increased responsibilities at home—all at once.

The question remains: Who is caring for the carer? The carers in this survey reported that they often sacrifice their own health and well-being for the sake of people they love. They deal with emotional isolation. Financial strife hits hard as unemployment spikes and salaries are imperiled. Many lack the time to care for their own physical and emotional health. There are even more nuanced challenges when looking at female carers and those taking care of someone with ongoing cognitive health conditions. In taking a hard look at how the pandemic has affected the globe, carers have faced unprecedented challenges – they are undercounted, unheard and struggling.

The question ahead, is **what are we going to do about it?** Now more than ever, federal and provincial governments, public entities, the private sector and all citizens of the globe have a role to play in addressing that problem. In moving forward, **carers should not have to face these hardships and inequities alone.** As a society, we can help them, together.

Resources & Acknowledgments



To learn more about caregiving and resources available for carers, as well as those advocating for carers, please visit our partner organizations' websites.

Embracing Carers' success comes through a collaborative effort by many. Thank you to the Embracing Carers partner organizations for their continued support and counsel on the 2020 Carer Well-Being Index. The completion of this research would not have been accomplished without the support of:





















Appendix



Detailed research methodology



Merck KGaA, Darmstadt, Germany (operates its biopharmaceutical business in the U.S. and Canada as EMD Serono) has conducted proprietary research to determine the adverse and disproportionate affects the Coronavirus pandemic has had on unpaid carers around the world, including their economic, physical and psychological well-being. Building on the five global priorities established in the Global State of Care report, Merck KGaA, Darmstadt Germany/EMD Serono and its Embracing Carers partner organizations commissioned this research to give a clear mandate to leaders within the public and private sector of the concerns of unpaid carers and key solutions to best support them.

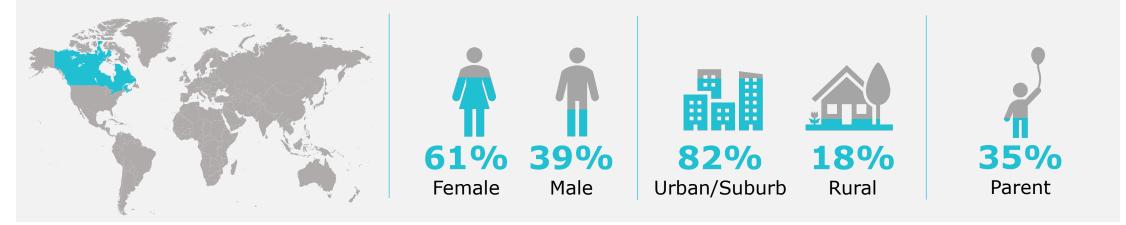
In partnership with a third-party global leader in multinational market research, a survey was fielded online from September 3 – October 27, 2020 across 12 countries, of which included the United States, Canada, United Kingdom, France, Germany, Italy, Spain, Australia, Brazil, Taiwan, India and China. The study consisted of 9,044 unpaid carers (n=750 in each country surveyed). Unpaid carers were defined as those who are caring for someone with a long-term illness, physical disability, or cognitive/mental condition (including cancer, Multiple Sclerosis, Parkinson's Disease, Dementia, Alzheimer's, Spinal cord injury, Muscular Dystrophy, cognitive/mental condition, Congestive Heart Failure, etc.). Outgoing sample collected was balanced to the Census of each respective country to then allow qualifying respondents to fall out naturally. Light weighting was applied in select countries to achieve better national representation. At the 95% confidence level, the total for the unpaid global, 12-country average carer population has an estimated margin of error of +/- 1.03 percentage points and each individual country has an estimated margin of error of +/- 3.6 percentage points. The survey length was approximately 20-25 minutes.

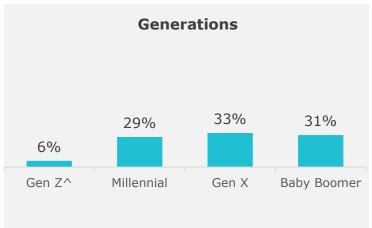


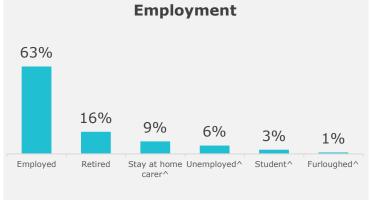
Canada Demographic breakout

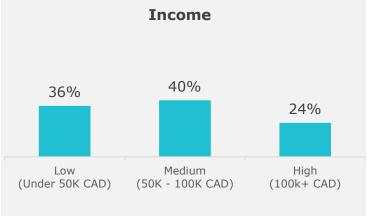


Demographic breakout of sample (n=755)









Canada detailed breakdown of conditions and people(s) cared for



About the people they care for (n=755)

