

3RD ANNUAL

SPOTLIGHT ON ONTARIO'S CAREGIVERS

COVID-19 EDITION

DECEMBER 2020



THE ONTARIO

caregiver

ORGANIZATION

About the Ontario Caregiver Organization

The Ontario Caregiver Organization (OCO) exists to support Ontario's 3.3 million caregivers; ordinary people who provide physical and/or emotional support to a family member, partner, friend or neighbour. The OCO helps to improve the caregiving experience by providing one point of access to information, services and supports that empower and enable caregivers to be successful in their role. Where gaps exist in caregiver programs and services, the OCO partners with caregivers, health care providers and other organizations to find new and innovative ways to bridge those gaps so all caregivers, regardless of age, condition or geographic location have access to the help they need. Established in 2018, the OCO is a not-for-profit entity funded by the Government of Ontario.

Acknowledgements

COVID-19 has disrupted and added stress to all our lives. The question this report tries to answer, is how much has it disrupted the experience of caregivers, whose lives are already impacted in many ways? The only way to understand this is by hearing from these caregivers directly. We greatly appreciate the time and openness of the 825 caregivers from across Ontario who participated in this survey. This report wouldn't have been possible without them.

We would also like to acknowledge Pollara Strategic Insights, who conducted the survey and prepared the background report on which this report is based. Their expertise and insights have been invaluable.

We want to also take this opportunity to thank the caregivers who are part of our online caregiver advisory panel, and many working groups which give us an opportunity to road-test ideas, get real-time feedback on our approach, and explore caregiver issues and themes with caregivers themselves. Their shared experiences help us shape all of our work, including our reports, programs and services, and emerging priorities.

TABLE OF CONTENTS

MESSAGE FROM THE CHAIR AND CEO [4](#)

OVERVIEW [6](#)

KEY TAKEAWAYS [8](#)

ONTARIO CAREGIVER ORGANIZATION [12](#)

SUPPORT, RESOURCES AND EDUCATION [13](#)

CAREGIVER DEMOGRAPHICS [14](#)

THE IMPACTS OF COVID-19 ON CAREGIVERS AND CAREGIVING [17](#)

INTENSE AND EXPERIENCED CAREGIVERS [18](#)

MENTAL HEALTH [19](#)

CAREGIVERS CARING FOR MENTAL HEALTH AND ADDICTION ISSUES [20](#)

THE FINANCIAL IMPACT OF CAREGIVING [21](#)

INFORMATION AND SUPPORT [22](#)

HOW CAREGIVERS FEEL ABOUT CAREGIVING [23](#)

IN SUMMARY [24](#)

METHODOLOGY [25](#)

MESSAGE FROM THE CHAIR AND CEO

Dear Friends and Colleagues,

We will never forget 2020. The COVID-19 pandemic that hit Ontario in mid-March changed all of our lives forever.

But what about Ontario's 3.3 million caregivers — those family members, friends and neighbours who support someone with an illness, chronic disease or acute health care situation?

The restrictions implemented in Ontario were a primary defense to try to stop COVID-19 from spreading uncontrollably in our province and overwhelming our healthcare resources. But it also turned the lives of many caregivers upside down.

At the Ontario Caregiver Organization (OCO), our primary role is to support family caregivers in Ontario. Like many organizations, the OCO immediately pivoted and responded when COVID-19 changed Ontarians' lives dramatically in mid-March. We quickly mobilized, adapted and increased our programs and services to reflect the new realities that caregivers were facing because of the pandemic. Thanks to our virtual caregiver panel, we were able to get real-time input into our new and adapted offerings. Through this work and

our ongoing engagement with caregivers, we gained insight into their constantly changing experiences since the onset of the pandemic.

It's been heartbreaking. It's been enlightening. It's been inspiring.

We've heard anecdotes, spoken with caregivers, even done mini-surveys to better understand the caregiver experience. We also drew on our own experiences, as caregivers. But for us to adapt and create resources that are truly meaningful, we needed to get a big picture view, across all caregivers in Ontario, and to do a deep dive into the themes that were emerging.

That opportunity presented itself in the 3rd annual 2020 Spotlight on Ontario's Caregivers – our inaugural stand-alone report. Last year, we partnered with The Change Foundation on the 2019 report, and this year we are leading the whole process. We will continue to issue this report every year, as a way to measure our progress, the changing landscape of caregiving and identify new and emerging trends in caregiver needs.

This report is based on a survey of 825 caregivers across Ontario and gives us the opportunity to compare the experiences of many different caregivers, as well as track changes year-over-year. It helps us to better understand how caregivers are actually faring during this pandemic.

This year's survey was completed in late September, right before the second wave of COVID-19 hit Ontario. This report is released at a time when important decisions are being made regularly to manage the virus. The insights and learnings from this data are extremely relevant to those of us working in the healthcare system and the extended community as we continue to respond in an informed manner to this wave, and beyond.

While we don't know how long this pandemic will last, we do know that the caregivers who are shouldering an outsized burden need our support and will continue to do so well after it is over. At the Ontario Caregiver Organization, we understand the relevance and importance of our role and we take our responsibility very seriously. Along with many partners and collaborators, the OCO is committed to being a leading

source of support for caregivers and to continually evolve our approach to meet their changing needs.

Sincerely,

Janet Beed

Board Chair, Ontario Caregiver Organization

Amy Coupal

CEO, Ontario Caregiver Organization

DEFINITION OF FAMILY CAREGIVER:

We define family caregivers as people who provide physical and emotional support to family members, partners, friends or neighbours without pay. Care and support can be given for many reasons including frailty, palliative care, long-term illness, long-term recovery from accident or surgery, degenerative disease, physical or mental disability or age-related conditions.



OVERVIEW

This is the third annual Spotlight on Ontario's Caregivers, but this year our approach, and questions, had to be adapted to reflect the reality of 2020: we are living through a global pandemic.

COVID-19 has put the caregiver role in the spotlight more than ever before. With the many restrictions on personal interactions currently in place, people living with a chronic illness, who are frail or elderly, or have recently fallen ill, are naturally even more reliant on family caregivers as demonstrated by this year's data.

In looking at the results of this year's survey, some themes surprised us, while others were expected. Being at home is easing the pressure on half of working caregivers, because they are taking less time off and employers are more understanding and flexible. On the flip side, there is little or no opportunity for a break, in large part because there is less outside help available. There is a notable increase in the financial burden of caregiving, due in part to the pandemic.

Additionally, based on our mini-surveys in the spring and summer of 2020, we can anticipate that there will be an entirely

new group of caregivers emerging as a result of COVID-19. For those who had COVID-19, there are some who are dealing with long-term effects of the illness. The temporary suspension of health services, while necessary to ensure capacity within the healthcare system may put some at risk for more progressed health issues and concerns.¹ The reality is family caregivers will continue to play a significant role in our healthcare system during COVID-19 and beyond.

In so many ways, the pandemic has had immeasurable impact on close family members and friends who are providing care and additional support. The Ontario Caregiver Organization is committed to monitoring these impacts, and providing resources and supports to meet the continually evolving needs of caregivers.

“ We can anticipate that there will be an entirely new group of caregivers emerging as a result of COVID-19... family caregivers will continue to play a significant role in our healthcare system during COVID-19 and beyond. ”

¹[https://www.thelancet.com/journals/lanpub/article/PIIS2468-2667\(20\)30201-2/fulltext](https://www.thelancet.com/journals/lanpub/article/PIIS2468-2667(20)30201-2/fulltext)
<https://www.intelligencer.ca/news/local-news/dont-delay-care-because-of-covid-19-officials>



**54% OF CAREGIVERS SAY IT
HAS BECOME MORE DIFFICULT
TO MANAGE THEIR CAREGIVING
RESPONSIBILITIES SINCE THE
COVID-19 OUTBREAK**

KEY TAKEAWAYS



Caregiving responsibilities are more time consuming due to COVID-19

31% of caregivers are providing more than 10 hours of care per week, which is up from 26% before the pandemic. Those added hours are being spent providing emotional and behavioural support, providing transportation and completing tasks around the home. This isn't surprising, given the physical distancing, isolation and other restrictions in place as a direct result of COVID-19.



Caregivers are more in need of respite during the pandemic, but have a harder time getting a break

The demands on caregivers have grown, and it is hard and sometimes impossible, to hire external help or get support from other family members in caring for an ill family member. Naturally, this has more caregivers feeling like they need a break. Unfortunately, it is also much harder to get a break, due to many factors, including day program cancellations, people choosing to stay in isolation to reduce the risk of COVID-19, and school and summer children's program closures.



Caregiver mental health is a major concern during the pandemic

The mental health of caregivers has always been a concern, but it has been amplified due to COVID-19. Caregivers are concerned about being able to meet the care recipient's needs during isolation, as well as protecting themselves and other family members from being exposed to COVID-19. The pandemic has left many caregivers feeling lonely, isolated and depressed.

In looking at the mental health impacts of past health and economic crises, we can anticipate that mental health concerns for caregivers will continue to increase even after the pandemic is under control.¹

¹<http://www.camh.ca/-/media/files/pdfs---public-policy-submissions/covid-and-mh-policy-paper-pdf.pdf>



Caregivers for those with mental health or addiction issues face additional challenges during the pandemic

77% of caregivers who support someone with a mental health or addiction challenge say it is difficult to access support for the care recipient due to COVID-19 restrictions.

These caregivers have a particularly heavy load to carry, spending much more time providing emotional and behavioural support compared to other caregivers. They are also spending more hours caregiving since the pandemic came to Ontario. Since these caregivers are doing more with less, they are more likely to feel overwhelmed, short-tempered, trapped/helpless, depressed, not appreciated and resentful than other caregivers.



The pandemic has notably increased the financial impact for caregivers

Four in ten caregivers reported that they are incurring higher costs related to caregiving and have to use more of their personal finances to pay for expenses due to COVID-19. Among caregivers aged 26-64, 39-42% are using their savings to help pay for expenses related to caregiving.



Even during a pandemic, caregivers are hesitant to admit they are struggling

As in past years, most caregivers are quick to say they are coping well. However, when they are asked about how tired, anxious, overwhelmed or frustrated they are, it becomes clear that more than half of caregivers have high stress levels. The stress is particularly high when it comes to managing their emotions and balancing the needs of the care recipient with work and family responsibilities (including keeping everyone safe due to COVID-19) while in isolation.



Working remotely has eased the pressure on some working caregivers during the pandemic

Although many caregivers have had to manage their caregiver duties by adjusting their work schedules, this is notably less prevalent than last year. For caregivers working from home, some say their responsibilities are easier to balance with work responsibilities and that their employers are understanding and helpful, compared to last year. Even so, the majority of caregivers say their employer does not have formal policies for flex hours to deal with caregiving tasks.



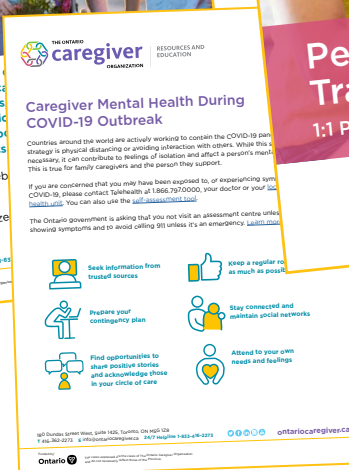
Intense and experienced caregivers are a small but incredibly important group who have unique needs, especially due to Covid-19

Everything is harder for experienced caregivers, and those who are providing intense levels of caregiving (10 hours or more a week). The financial impact is bigger, their stress levels are higher and they are struggling more to balance their caregiving with work and other family responsibilities. They are also worried about meeting their care recipient's needs during isolation.

ONTARIO CAREGIVER ORGANIZATION: ONE POINT OF CONTACT FOR CAREGIVERS

Helping Ontario caregivers be successful in their role

We've heard anecdotes, spoken with caregivers, even done mini-surveys to better understand the caregiver experience since the pandemic hit. In the early days of COVID-19, the Ontario Caregiver Organization quickly pivoted to develop programs and services, in collaboration with caregivers, for caregivers. The following is a list of programs and services that are available, free of charge, to family caregivers across the province. **For more information visit ontariocaregiver.ca**



SUPPORT, RESOURCES AND EDUCATION

Meeting the needs of caregivers during COVID-19 and beyond:



24/7 Ontario Caregiver Helpline & Live Chat

- one place to go to find information and support in the community 1-833-416-2273 (CARE)



SCALE Program

(Supporting Caregiver Awareness, Learning and Empowerment) - weekly webinars, online group coaching and one-on-one telephone counselling



OCO webinar series

- providing information on a range of topics including finances, privacy and caregiver wellness



Toolkits - including Caregiver Starter Kit and Work & Caregiving - A Balancing Act



COVID-19 Tipsheets

- including contingency planning, caregiver mental health and effective use of technology



Peer Mentoring Program

- connect with another caregiver and share experiences, challenges and solutions



Online Support Groups

- connecting caregivers with similar lived experience on a weekly basis.

Helping caregivers and providers work together:



Partners in Care: Pandemic Toolkit

- a toolkit developed to respond to COVID-19, with resources that support the safe presence of caregivers in healthcare settings. These resources have a long-term purpose in achieving the ultimate goal to support, recognize and integrate caregivers into healthcare teams in all settings



Resources - to help providers understand, engage and support caregivers, tailored to the hospital, long-term care and community-based care



Accredited online training for providers: Caregivers as Partners

CAREGIVER DEMOGRAPHICS

Caregivers truly represent Ontario's population, and caregiving knows no demographic bounds. Of particular interest now and in the future, is the entirely new group of caregivers who are emerging as a result of COVID-19.

Stats

There are slightly more female caregivers (54%) than male caregivers (45%).

The largest age category - 41% of caregivers - is between the ages of 46 and 65.

59% of caregivers are either married or have a common law partner.

More than half (54%) of caregivers are parents, with 35% who have children who are 18 years or older, and 27% who have children under the age of 17.


58% of caregivers are employed, and 41% are employed full time. More men (47%) than women (36%) are employed full time, and more women (12%) than men (9%) are employed part time.

30% of caregivers are visible minorities*.

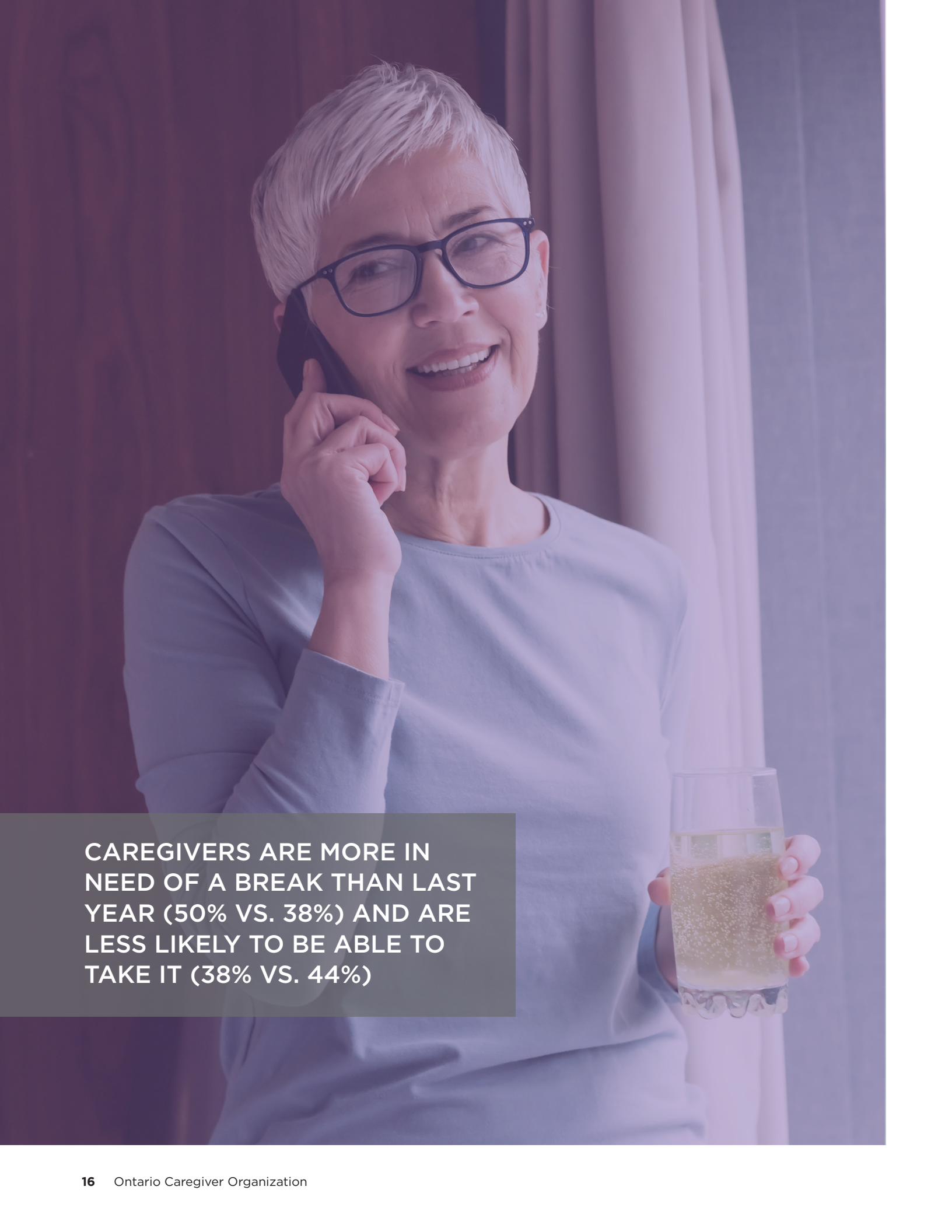
Nearly half (48%) of caregivers were either born outside of Canada, or their parents were born outside of Canada.



* Visible minority refers to whether a person belongs to a visible minority group as defined by the Employment Equity Act and, if so, the visible minority group to which the person belongs. The Employment Equity Act defines visible minorities as 'persons, other than Aboriginal peoples, who are non-Caucasian in race or non-white in colour.' Categories in the visible minority variable include South Asian, Chinese, Black, Filipino, Latin American, Arab, Southeast Asian, West Asian, Korean, Japanese, Visible minority, n.i.e. ('n.i.e.' means 'not included elsewhere'), Multiple visible minorities and Not a visible minority.



**80% OF CAREGIVERS SAY
THEY ARE RESPONSIBLE FOR
PAYING FOR THE EXPENSES
OF THE PERSON THEY ARE
CARING FOR.**



CAREGIVERS ARE MORE IN NEED OF A BREAK THAN LAST YEAR (50% VS. 38%) AND ARE LESS LIKELY TO BE ABLE TO TAKE IT (38% VS. 44%)

IN DEPTH REVIEW: THE IMPACTS OF COVID-19 ON CAREGIVERS AND CAREGIVING

Due to COVID-19, many caregivers have to do more with less. Not only that, but many of the in-person supports, and ways to de-stress, that they normally rely on for their own well-being aren't available.

- Overall, caregivers are concerned about being able to meet the needs of the person they are caring for during isolation, as well as keeping everyone safe from COVID-19, including themselves. Many caregivers are feeling lonely, isolated and depressed.
- More than half (54%) of caregivers feel their responsibilities became more difficult due to COVID-19. This is particularly true for those between 45 and 64 years old, and those with children under 18.
- Six-in-ten caregivers feel that it has become more difficult to get in touch with primary healthcare providers, and two-fifths are unsure who to turn to for information.
- More than half of caregivers find it more difficult to manage caregiving responsibilities since COVID-19. Of those caregivers, a third attributed the shift to virtual medicine. Caregivers are providing more emotional and behavioural support to their care recipients compared to last year. This is may be due to the lack of available services during the pandemic and is especially true for caregivers who care for someone with additional COVID-19 complications.
- 50% of caregivers say they need a break at least once a month, which is up from 38% last year. These caregivers also say breaks are harder to get than before. Only 38% say they can take a break when they need to, down from 44%.
- Most caregivers find it particularly difficult that other family members cannot come to help, and that caregiving has become more of a full-time responsibility. That said, at least four-in-ten caregivers say they are getting some additional help from other family members during these times.
- Caregivers who have been working from home since the beginning of the pandemic are more likely to agree that their work is flexible, and that it allows them to better manage caregiving.
- These caregivers are concerned about being exposed to COVID-19 when returning to work outside the home.
- 6 in 10 caregivers have a plan in place or have thought about who would care for their family member if they get COVID-19. 33% haven't even thought about it.

INTENSE AND EXPERIENCED CAREGIVERS

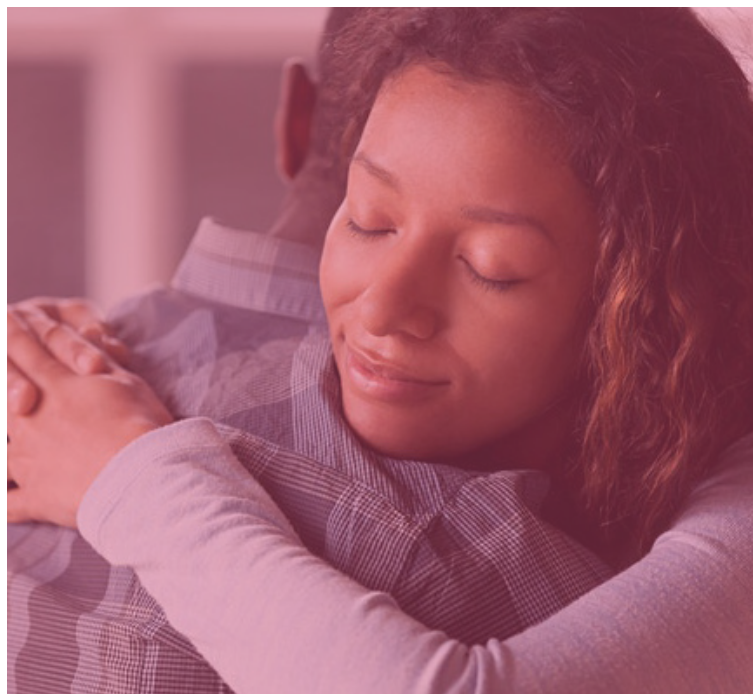
For many caregivers who have been doing so for a long time, and those who take on the role for many hours a week, caregiving was already difficult. COVID-19 added an extra level of intensity to their situations, and their needs are distinctly different from other caregivers.

- Nearly half of those caring for a child are experienced caregivers, with 47% being a caregiver for five or more years. Most of these caregivers care for a child with a cognitive health problem, such as a developmental disability (41%) or mental illness (22%).
- Experienced caregivers also tend to spend more hours caregiving per week. Roughly a third of those caregiving for more than 3 years spend more than 10 hours per week, compared to roughly 28% of those caring for less than 3 years.
- Not surprisingly, all aspects associated with caregiving are, on the whole, more stressful for those who provide care for more than 10 hours per week. More than half are stressed with the overall management of caregiving (58%), stressed emotionally (55%), and stressed juggling work and family responsibilities (55%). They are also worried about being able to meet their care recipient's needs during isolation (60%) and about finances associated with caregiving (44%).
- Intense and experienced caregivers feel that the main barrier to additional support is cost. Other barriers include policies or limitations of community support, and the inability to get the right kind of support.
- 77% of intense caregivers and 78% of those who provide care to their child, feel that doctors see them as important members of the healthcare team, compared to 67% of other caregivers who feel this way.
- Caregivers who care for a child are more likely to feel short-tempered and irritable (66%), overwhelmed (59%), isolated (54%), trapped, frustrated (53%) and depressed (51%). They are also less likely to feel rewarded (53%) and more likely to feel unappreciated (43%).
- Caregivers who care for a child are relatively stressed overall (52%) and are struggling to manage their own emotions (61%), balance work (56%) and other home responsibilities (54%) with caregiving, find services for their child (45%) and manage finances (48%).
- Those who are providing care to a child during the pandemic are much more likely to have reduced their regular working hours (37%) or taken days off (32%) to help manage their caregiving role.
- Caregivers caring for children find managing finances difficult. 72% had to pay out-of-pocket using their personal finances, 57% used their savings, and 24% took out a loan. 53% of these parents face financial constraints, and some even feel they can't afford their child's treatment.

ISOLATION AND CAREGIVER MENTAL HEALTH

For caregivers, taking care of their own mental health should be a top priority, however, it is often a challenge to do so. During COVID-19, this has become even more difficult than before.

- Caregiving puts stress on the caregiver's own mental health. Nearly half (47%) of caregivers are dealing with the care recipient's anxiety and stress over COVID-19 and its restrictions and are unable to take the breaks or access the social interaction they need. As a result, more than half (52%) find it stressful to manage their own emotions.
- More than three-quarters (77%) of caregivers dealing with mental health challenges find it difficult to access mental health support for the person they are caring for.
- Half of caregivers are much more involved in providing emotional support than before the pandemic and 25% are providing more behavioural support than before. This support includes dealing with anxiety, depression and emotional outbursts.
- Caregivers are more in need of a break than last year (50% vs. 38%) and are less likely to be able to take it (38% vs. 44%).
- Caregiving is more difficult this year for more than half of caregivers because they aren't able to get social interaction or physical activity for those they are caring for and aren't able to arrange visits with other family members.
- Roughly half of caregivers find it stressful to make sure the needs of the person they are caring for are met when they were in isolation.
- Many caregivers are also dealing with their own isolation, including not being able to see others. 43% say they often feel lonely and isolated.
- Many are having a harder time getting in touch with healthcare providers. Those dealing with mental health issues are having an extremely hard time due to the pandemic, with most saying they do not have access to the support they need.



CAREGIVERS CARING FOR MENTAL HEALTH AND ADDICTION ISSUES



Caring for someone with mental health or addiction challenges is a distinctly different caregiving experience. The pandemic has put a spotlight on the differences, and has amplified the challenges in accessing care, getting support and being able to afford treatment services, as some treatment options are not covered or have caps on how many hours of service people can access.

- 21% of mental health caregivers say they can't find healthcare providers, compared to 12% of other caregivers.
- Compared to 50% of other caregivers, 67% of mental health caregivers are spending more time providing emotional support, and nearly half (47%) are spending more time providing behavioural support (compared to 25% of other caregivers).
- There are added barriers for caregivers for those with mental health or addiction challenges, including the cost of paying for care (43% vs. 32% total), the person with mental health problems not accepting help from others (38% vs. 27% total) and limitations on community/home care (25% vs. 17% total).
- 59% of caregivers say they cannot always afford the treatment options that are really necessary. 58% said they are dealing with financial hardship, compared to 41% of other caregivers.
- Social isolation is having a bigger impact on mental health caregivers. 55% say caregiving is more difficult since the pandemic. 60% say the difficulty comes from a lack of social interaction for their loved one and 55% say it comes from their inability to get a break since they are at home.
- Mental health caregivers have higher rates of negative emotions than other caregivers – 64% feel overwhelmed, 62% are short tempered, 55% feel trapped/helpless, 54% feel depressed, 51% did not feel appreciated and 50% are resentful.
- Two-thirds (65%) say it is difficult to get support when a person transitioned from child to adult care.
- In general, seven-in-ten (71%) caregivers in Ontario feel that the police and other first responders need better training on supporting someone with mental health issues; 42% feel very strongly about this.

THE FINANCIAL IMPACT OF CAREGIVING

COVID-19 impacted the employment and finances of many people in Ontario. Many of those people who are also caregivers face extra financial hardship this year.

- While caregivers feel more financial hardship, as a whole, over last year (41% vs. 32%), these hardships are not entirely related to caregiving. That said, 37% incurred higher costs for caregiving this year, and had to use more of their personal finances to pay for expenses due to COVID-19.
- 47% say they are using their own finances to pay for caregiving expenses. 38% are using their savings, and 25% are dipping into their investments.
- 80% of caregivers say they are responsible for paying for the expenses of the person they are caring for.
- 42% of those caring for someone with COVID-19 are spending more of their own money than the rest of caregivers.
- While taking financial responsibility is normally more of a primary task for older caregivers, even young caregivers (34%) are now having to pay for expenses out of their own pocket.

Working caregivers

- Among employed caregivers, more than a quarter have taken time off during the day or have taken one or more days off, while one-fifth have reduced or altered their working hours to manage caregiving. Overall, they are less likely to take time off or alter their hours than last year, likely due to working at home and flex time, both effects of the pandemic.
- 60% of caregivers say their employers are somewhat accommodating of their caregiving responsibilities.
- Those who are working from home during the outbreak are more likely to say their employers are accommodating. 22% of employers have an official policy and 42% say there is no official policy, but their employers have helped when they could.
- More caregivers feel that their work is flexible in terms of working hours and working from home compared to last year. However, 40% of caregivers don't have that flexibility. Nearly half (48%) wish their employer gave them more support.



INFORMATION AND SUPPORT



This year, information and supports – the lifelines of many caregivers – were even harder to find due to COVID-19.

- Caregivers turn to the internet, and friends and family, as their primary source of information.
- In general, caregivers feel informed about the health condition of their family member, with only a small change in this number after COVID-19 (86% to 81%). Notably, young caregivers (16 to 25 years old) are considerably less informed (76%) than they were before the outbreak (85%).
- Caregivers for people who live in a healthcare facility feel less informed about the health of the person they are caring for than before the outbreak.
- When it comes to information about emotional support, just 31% who need it for the person they cared for received it, and 26% of those who need it for themselves received it. More than 30% need this information but haven't received it. Among intense caregivers, 65% say they need emotional support, but only 28% received it.
- While roughly half of caregivers feel they could benefit from information about how to access financial support, only a quarter say this information is available to them.
- 26% of caregivers say they need information on occasional relief and respite care but didn't receive it.
- This year, caregivers are most likely to identify COVID-19 restrictions as the reason for not receiving supports. Other factors are cost, lack of information, policy limitations and inability to find support.
- 27% of caregivers feel that the person they care for will not accept help or support from others, which is similar to last year's findings (30%).

HOW CAREGIVERS FEEL ABOUT CAREGIVING

The added stress, anxiety and hardship of COVID-19, along with fear that they or the person they are caring for will contract the virus, is having an impact on how caregivers feel about their role this year.

- Experienced caregivers are more likely to be aware of their role.
- 49% of those who have been caring for 3 to 5 years, 58% of those who have been caring for more than 5 years, and 27% of those have been caring for less than a year agreed up-front to be a caregiver.
- 40% of caregivers were initially intimidated or didn't want to take on the caregiver role. Those caring for someone with COVID-19 felt most intimidated.
- Willingness to accept the caregiving responsibility increases with age. 77% of those 65 or older are happy to take on this responsibility.
- During the pandemic, caregivers continued to feel negative emotions. A majority are worried, overwhelmed and tired. Many feel irritated and frustrated, and are more likely to feel lonely, or isolated and depressed compared to last year. However, six-in-ten (57%) feel they are appreciated for the work they do.
- 51% of caregivers find that balancing caregiving responsibilities and work is stressful, compared to 45% last year. About half of caregivers working at home say this helped ease the pressure of caregiving. Interestingly, both groups cite

the same reason for the change – that being at home means they are closer to the person they are caring for and less scheduling is needed; however, some get more help from family, while others can't rely on people (family or paid support) outside of their household.

- During the pandemic, caregivers are not only stressed about ensuring the needs of the person they are caring for are met while in isolation, but also about keeping themselves and their family members safe while providing care and following proper social distancing protocols.

Role of caregivers in the healthcare system

- 4 in 10 of caregivers believe that healthcare providers see them as at least equally important members of the healthcare team.
- 2 out of 3 caregivers of someone who is staying in a home or facility say they think these facilities see them as important members of the healthcare team.

IN SUMMARY



In September 2020, the Ontario Caregiver Organization set out to better understand how COVID-19 is impacting family caregivers in our province. The insights in this report, along with what we learned through smaller surveys and conversations with caregivers since the pandemic hit, reveal that caregivers are facing unique challenges as a result of COVID-19; with more than half saying it has become more difficult to manage their caregiving responsibilities since the outbreak.

While caregiver burn-out and mental health have always been a concern, caregivers say they feel more lonely and isolated than ever before and are more worried about their own mental health compared to years prior. In addition, they say the financial impact is bigger, their caregiving responsibilities are greater and more time consuming, and there is greater worry about meeting the care recipient's needs during isolation.

The themes in this report, along with what we've heard from caregivers throughout the pandemic, continue to guide the OCO in developing the supports and resources that family caregivers need right now. As a response to COVID-19, the OCO has a number of free resources, created with caregivers, for caregivers, to help support the family members, friends and neighbours who continue to go above and beyond for their care recipient. These resources include toolkits, tip sheets, and webinars. They also include our peer support program that provides 1:1 and group online support. In addition to providing caregiver supports, the OCO has made the Partners in Care Toolkit available to hospitals, long term care, and other congregate settings to support re-engaging caregivers in a meaningful way.

The OCO will continue to use the voice of caregivers to inspire our work. We hope these insights will inspire others who also want to find new and innovative ways to support family caregivers. Lastly, we would like to extend a heart felt thank you to family caregivers across the province. You play an incredibly important role in Ontario's healthcare system and in keeping your family members and friends safe during these unprecedented times.

METHODOLOGY

An online survey was conducted by an independent third-party polling firm (Pollara Strategic Insights) with self-reported caregivers in Ontario, 16 years of age and older, from September 10 to 25, 2020. 825 participants answered 'yes' to the following question:

During the past 12 months, have you cared for someone who needed support due to frailty, palliative care, long-term illness, long-term recovery from accident or surgery, degenerative disease, physical, mental health challenge or disability, or old age-related disorder? The need for this care could be due to COVID-19 diagnosis or be unrelated to it.

By this we mean providing help or care, usually without pay, to a family member, friend, neighbor or anyone else. This help may be personal and can include certain tasks such as helping with housework, cooking meals and feeding, bathing and toileting needs, help with outdoor tasks, or anything else. It may also include providing physical support, assisting in certain healthcare related tasks such as monitoring medication, coordinating for or attending doctor's appointments or conducting basic medical procedures. This care can also be social or psychological such that you are providing support or company to the person to enable them to be more socially included, driving them, shopping with or for them, or anything else.

83% of respondents care for someone in their home or in the care recipient's home.

While quotas were put in place to ensure representation across demographics and region, results have been weighted to be reflective of the total population of caregivers in Ontario.

Margin of error is not applicable to this study due to its online methodology. However, as a guideline, the margin of error on a representative sample of 825 would be $\pm 3.4\%$, nineteen times out of twenty.



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