

THE **CHANGE**
FOUNDATION
ENGAGE, EXPLORE, EVOLVE

2ND ANNUAL

SPOTLIGHT ON

ONTARIO'S CAREGIVERS

NOVEMBER 2019



THE ONTARIO

caregiver

ORGANIZATION

ABOUT THE CHANGE FOUNDATION

The Change Foundation is an independent health policy think-tank that works to inform positive change in Ontario's healthcare system. With a firm commitment to engaging the voices of patients, family caregivers, and health and community care providers, the Foundation explores contemporary healthcare issues through different projects and partnerships to evolve our healthcare system in Ontario and beyond. The Change Foundation was created in 1995 through an endowment from the Ontario Hospital Association and is dedicated to enhancing patient and caregiver experiences and the quality of Ontario's health care.

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 will enhance 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, healthcare providers and other organizations to find new and innovative ways to bridge those gaps so all caregivers, regardless of age, disease or geographical 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

This survey wouldn't have been possible without the participation of over 800 caregivers across Ontario. We greatly appreciate their time and interest in completing the survey. It is only by collating and analyzing the data from all the participating caregivers that we can gain a better understanding of the Ontario-specific caregiver experience, highlighted in this report.

We would also like to acknowledge Pollara Strategic Insights, who conducted the survey of over 800 caregivers and prepared the background report on which this resource is based. Their expertise and insights have been invaluable in the creation of this report.

In keeping with our commitment to co-design, we included caregivers on our planning, selection, and review team at the outset of this project in 2018. We worked closely with the Patient Advisors Network (PAN) as we selected our polling and communications vendors, and developed the survey that we used in both 2018 and 2019. The voice of PAN's members played an important part in the creation of this project, and will continue to be heard as long as these surveys are conducted.

To complement the survey, The Change Foundation created an online caregiver advisory panel. We want to thank the caregivers who agreed to take part in the standing panel. This online forum gives us an opportunity to road-test ideas and explore caregiver issues and themes with caregivers themselves. Their shared experiences helped shape this report and will continue to help us shape our reports, products and direction in the future.

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MESSAGE FROM THE PRESIDENTS



Dear Friends and Colleagues,

We are pleased to release this report on the state of caregiving in Ontario – the second annual report released by The Change Foundation, and the first in collaboration with the Ontario Caregiver Organization (OCO). This report builds on the inaugural 2018 report and allows us to highlight trends in the caregiver experience in Ontario for the first time.

In Canada, 28% of the population is providing care to a family member at any given time. The expectations of family caregivers are growing to such an extent that their role is one of the most important ones in our society. We can even quantify it. Our research shows that caregivers provide between 11 and 30 hours of care a week, and some provide so much care they can't even count the hours. We estimate that these family caregivers contribute the equivalent of between \$26 and \$72 billion¹ to our society every year.

And yet, until last year's *Spotlight on Ontario's Caregivers* report, there wasn't a lot of in-depth data to understand the breadth and depth of their contributions and their experience with the healthcare system.

We believe that Ontario-specific data is imperative to understanding the specific situation in our province, so that we can ensure that supports and services truly address the needs of caregivers. We are pleased that there is growing momentum focusing on better support for family caregivers at the local, provincial and federal levels.

The creation of the Ontario Caregiver Organization in 2018 is a testament to this. Since opening, the OCO has engaged with caregivers to better understand their needs, and is inspired by caregivers, their stories and unique experiences. The OCO's commitment is to continue to work with caregivers, healthcare and service providers, as well as other organizations, to find new and innovative ways to support

¹Calculated by using Ontario's current minimum wage (\$14/hour) and multiplying the average hours per week of caregiving (11-30) by the number of caregivers in Ontario.

DEFINITION OF FAMILY CAREGIVER:

We define family caregivers as family members, friends or neighbours who provide care for someone, without pay, due to frailty, palliative care, long-term illness, long-term recovery from accident or surgery, degenerative disease, physical or mental disability or old age-related disorder.



all caregivers, regardless of age, diagnosis or where they live in the province. A key part of this commitment is to empower caregivers with information, tools and resources so they can be successful in their role.

The insights from the 2018 Spotlight report have already made a tremendous impact by identifying that caregivers want one point of access for information. To address this need, the OCO recently launched the Caregiver Helpline – a 24/7 resource that caregivers can call or engage in a live chat between 7 a.m. and 9 p.m., Monday to Friday, to find local supports, get information about caregiving and get other important knowledge that caregivers have told us they need.

The annual Spotlight data will continue to act as a foundation for the OCO's ongoing work and will

be used to inform further consultations and to co-design programming with caregivers. It will also provide a benchmark to measure the impact of the work of OCO and our partners as we all work towards improving the caregiving experience.

Our objectives for this survey are to better understand the caregiver experience, and see how it changes over time, in the following areas:

- who caregivers are caring for;
- what tasks caregivers are responsible for;
- where caregivers are turning for information and support;
- how caregiving impacts the lives of both the caregiver and the care receiver;
- how caregivers feel about their role as part of the healthcare team;
- what additional supports or information could help caregivers in their role.

Our findings echo what both organizations see and hear in our everyday work. It also offers new insights about the caregiver experience in Ontario. Most notably:

- Caregivers believe their family member would not receive the same level of care or attention if they weren't there.
- Many caregivers don't think of themselves as caregivers. Instead, they consider themselves spouses, children, parents, in-laws who are just doing their duty. Once they realize that they're not alone, and that they play an important role in their family member's health care, it is often very empowering for them.
- Many caregivers hesitate to admit they are struggling. They often don't ask for help or support because they feel guilty overshadowing the person they are caring for. And yet, the rates of stress and feelings of being overwhelmed paint an urgent picture of the need to recognize and support family caregivers in their role.
- The caregiving experience varies greatly and is influenced by many factors — where the caregiver lives, who they care for, the other responsibilities they have in their life, and the length and intensity of their caregiving experience.

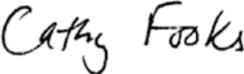
Last year's report served as a baseline for the caregiver experience in Ontario. Year over year, we will gather more and more information and we'll be able to glean better insights to see if efforts in Ontario to change the caregiver experience is taking us in the right direction.

In addition to the survey, which quantifies the caregiver experience, we've also set up an online panel of caregivers from across Ontario who we turn to regularly to help us bring the qualitative side of the caregiver experience to life. This group provides deeper insights and examples of issues

and themes that surface from the survey results. We also encourage you to visit the Spotlight 2019 website, which features caregiver stories and additional data.

This work, taken as a whole, underscores that supporting caregivers should remain an urgent priority. We will continue to make our knowledge, insights and results widely available to inform other efforts happening across Ontario and beyond.

Our vision is to see caregivers recognized and supported properly. We know that, together with our diverse stakeholders, we can make this vision a reality.

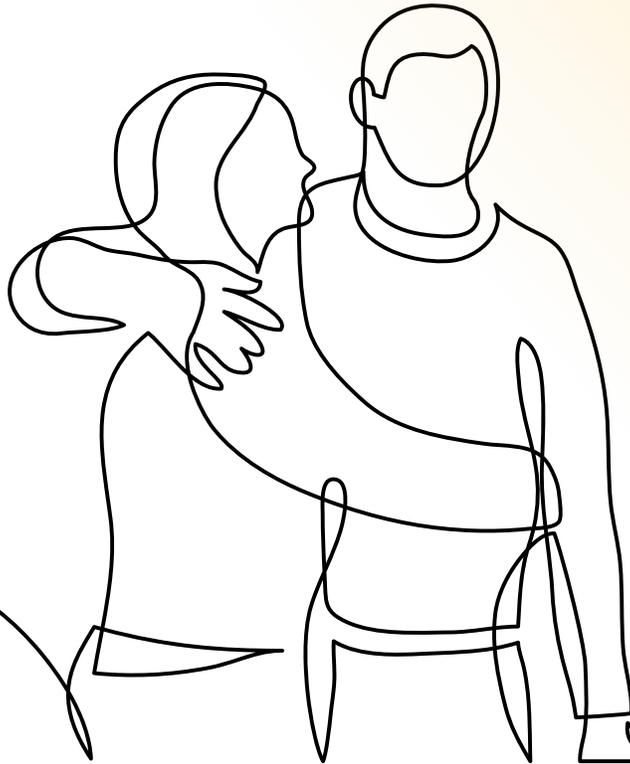


Cathy Fooks
President and CEO
The Change Foundation



Amy Coupal
President and CEO
The Ontario Caregiver Organization

OVERVIEW



Since 2015, The Change Foundation has been focused on informing change in the way family caregivers are identified, recognized and integrated into the healthcare team.

In 2016, we published *A Profile of Caregivers in Ontario*, based on the 2010 General Social Survey data collected by Statistics Canada. Our Profile report gave us a baseline of understanding of Ontario caregivers, the survey was very broad, covering all aspects of caregiving.

In 2016, we also travelled across the province to listen to and learn from caregivers and healthcare providers to understand their distinct views on caregivers as members of the healthcare team. Although each caregiver's experience is unique, there were common themes across all the stories we heard. Our reflections and findings from that province-wide consultation are outlined in our

Caring Experience reports: *Stories Shared, Voices Heard*.

Our 2018 *Spotlight on Ontario's Caregivers* survey was the opportunity to dig deeper into key topics that are relevant to our focus on the interactions and experiences of family caregivers within the healthcare system. The analysis and findings of our first *Spotlight on Ontario's Caregivers* survey aligned with the themes, data and take-away points from our past work. More importantly, it gave us a baseline of understanding by which to measure growth and change year over year.

In this overview – the first done in partnership between The Change Foundation and The Ontario Caregiver Organization – we highlight our findings from our *2019 Spotlight on Ontario's Caregivers* survey, including some comparisons of results from 2018.



It would make my life easier if all the systems were integrated so we didn't have to tell our stories over and over again.

- Caregiver
Advisory Panel
Member

WHAT HAS CHANGED

- **While similar numbers of caregivers are involved in organizing care, in 2019 56% of caregivers find the process difficult, compared to only 39% in 2018.**
- 31% of caregivers are primarily responsible for paying for expenses in 2019, compared to 41% in 2018.
- This year, slightly fewer respondents were primary caregivers than in 2018, and as a result, slightly more were sharing responsibilities.
- **The impact on finances is more pronounced in 2019 – 32% said they had faced financial hardships compared to 22% in 2018.**
- **79% of caregivers see their role in the healthcare system as important compared to 70% in 2018.** 18% of caregivers continue to think their role is the most important, and a similar percentage of caregivers feel that their healthcare providers see them as important members of the team.

WHAT HAS REMAINED THE SAME

- There are no differences in who the caregivers are caring for when comparing the results from last year. That is, most caregivers are caring for parents who are dealing with aging-related health conditions.
- In 2018, we found that just over half of caregivers were part of the sandwich generation – they care for an aging parent and are also parents to young children under 18 years old. That number remained the same in the 2019 survey.
- Emotional support and help with transportation are still the top tasks performed by caregivers, followed by household tasks and scheduling appointments.
- The proportion of caregivers who have the information they need about the health condition of the person they care for is similar to last year.
- **Emotional counselling for both the patient and the caregiver is still one area where more support is needed, with 77% of caregivers wishing for a 'one-stop-shop' that they can turn to for help and advice.**
- Most caregivers continue to have a positive outlook towards caregiving and are generally coping well. But 31% are not coping well emotionally, and the high levels of stress and negative emotions we found in 2018 remain unchanged.



CAREGIVER DEMOGRAPHICS

- Intense Caregivers – those who are long-term high-demand caregivers – are more likely to be 65 years old or older, to be caring for a child or their spouse and to be living with the person they care for.
- Short-Term-High Demand Caregivers are more likely to be caring for their spouse.
- There are slightly more female caregivers than male caregivers – 54% vs. 46%.
- The largest age category – 44% of caregivers – are between the ages of 46 and 65.
- 52% of caregivers are parents, with 35% having children who are 18 years or older and 21% having children under the age of 17.
- Two-thirds of caregivers are employed, and nearly half are employed full time. 55% of male caregivers are full-time employees, compared with 41% of female caregivers. 16% of women are part-time employees, compared to 9% of men.
- 45% of caregivers were either born outside of Canada, or their parents were born outside of Canada. Among those, the majority have been Canadian residents for more than 15 years.

WHO ARE CAREGIVERS CARING FOR?

- Caregivers are most likely to be caring for older family members, often parents (44%).
- Nearly 20% of caregivers are caring for more than one person.
- The people receiving care most often live in their own homes, rather than with the caregiver. 13% are caring for someone who lives in an institution or facility.
- 45% of caregivers live in an urban area, while 29% live in a suburban area and 23% live in a rural area.
- Those who have to travel to provide care do so for half an hour or less, on average. However, 40% travel longer. Notably, **suburban caregivers spend the most time travelling, with 46% taking 30 minutes or more to travel to the person they are caring for.**
- While one-in-three caregivers have been in this role for a year or less, the majority (65%) of caregivers have been in the role for much longer. 38% have been caregiving for at least three years.
- Most caregivers who responded to the survey speak English as their primary language, and the same is true for the people they care for. However, about 20% of those receiving care speak little to no English.



Caregivers have a wealth of knowledge about the patient's issues and their input is invaluable to appropriate care.

- Caregiver
Advisory Panel
Member



My pledge is always for more mental health. When we are in a good place, we can do anything. We need more mental health support and respite care.

- Caregiver
Advisory Panel
Member

TIME THEY SPEND AND TASKS THEY ARE RESPONSIBLE FOR

- Caregiving can be a time-consuming job. While 43% spend up to four hours a week caregiving, one-third spend 10 or more hours a week. These hours are not only during the day – **50% at least occasionally stay up at night to provide care.**
- Caregivers take on a number of different tasks. While emotional support and transportation are the most common, 50% of caregivers are also involved in activities around the home, scheduling appointments and physical support.
- Caregivers have financial responsibilities as well. Nearly half say they are involved in paying care-related expenses themselves.
- One third of caregivers take on basic medical care (changing bandages, monitoring or administering medications, reminders about physio, etc.), while 18% take on some medical procedures (changing G-tubes, changing wound dressings, giving injections, etc.).
- More than 40% are responsible for translating medical information for their family members.
- **Two-thirds of caregivers believe the patient they care for would not get the same quality of healthcare or access to activities that promote mental and physical health if they were not available to provide care.**
- **The majority (59%) of caregivers feel they need to take breaks from their caregiving duties. However, nearly half of these caregivers aren't able to take a break as often as they'd like.**
- Many caregivers (56%) welcome the idea of respite care, but not if it would contribute to the cost of caregiving. Some caregivers don't use respite care because the person being cared for isn't willing to accept care from others (28%), or they feel guilty (21%) or lack confidence (18%) in leaving the care in someone else's hands.

ROLE ON THE HEALTHCARE TEAM

The Change Foundation's 2016 Caring Experience engagement project was our first opportunity to explore the role of caregivers within healthcare teams. We built on those findings through the 2018 and 2019 *Spotlight on Ontario's Caregivers* survey, where we probed further about experiences with different parts of the healthcare system, and the transitions between healthcare providers. The 2019 survey found the following:

- While very few caregivers feel they are the most important member of the healthcare team, they nonetheless believe they play an important role. Luckily, most believe healthcare providers also see them in this light.
- Most see themselves as fully or partially responsible for organizing the other members of the healthcare team and the majority find organizing the different team members and navigating through the system to be a difficult task. Most caregivers have been in the situation of having to transition their family member from the care of one provider to another in the past year.
- Transitioning between primary care and other physicians or between facilities is not particularly difficult. However, **moving from a hospital to another type of facility, or to specialists or home without help is more difficult.** Bringing a family member home from a facility without home care help is particularly difficult, as it requires juggling other life responsibilities, special arrangements to cover caregiving and providing physical care.

The system is extremely difficult to navigate and there is no guidance as to how to navigate it. There is not enough support for caregivers. Entering the caregiving process, caregivers are expected to find out information for themselves.

- Caregiver Advisory Panel Member

Transitions out of a protected environment into the community and home was another caregiver hurdle. Preparation was essential for success but connecting with a community team was painful.

- Caregiver Advisory Panel Member





ROLE ON THE HEALTHCARE TEAM

- While 61% of caregivers feel their role is important, only 18% believe they should be considered one of the most important.
- 39% of those caring for their spouse are more likely to feel they are the most important member of the healthcare team, while 53% of those caring for a child and 38% caring for a parent are more likely to feel they are equally important as other healthcare team members.
- **70% of caregivers feel that the primary doctor involved in care sees them as an important member of the healthcare team.**
- 39% of caregivers are responsible for organizing the different members of the healthcare team or different tasks involved in the patient's care. 16% share these tasks with another caregiver. Very few (4%) said a provider, government agency or coordinator takes on this role.
- 76% of caregivers providing care to their spouses and 63% of people caring for someone in the same house are solely responsible for managing and organizing all the caregiving tasks. 20% of those who live in a healthcare facility have a team of people managing these responsibilities.
- More than half of caregivers find the transition between long-term care facilities and a hospital or home to be difficult.
- **The most difficult transition for caregivers is between a hospital and home without home care, with multiple providers for the same health-related condition.** Juggling their other responsibilities with new caregiving responsibilities, coordinating care among other healthcare providers and providing physical care to the patient are the most difficult aspects of this transition.

// The most frustrating issue was the lack of coordination among specialists. My husband has complex medical issues requiring different areas of expertise and there was a lack of a holistic perspective, it felt fragmented. What was difficult was if it takes all these specialists to treat my husband how is it expected that I alone, with no medical background am competent to care for my husband. I needed someone to guide me, someone I could ask questions to. I still need this today.

– Caregiver Advisory Panel Member

INFORMATION AND SUPPORT

Caregivers have many information and support needs – and often those needs aren't met.

- Caregivers are given ample information about the health condition, medications and physical care for those they are caring for. However, this information is often given in verbal or written form. Even when the information is about physical care, only one-in-five receive hands on training.
- There is less information provided when it comes to emotional or financial support for either the caregiver or the patient.
- The biggest barrier to getting proper support is the cost for getting external help, followed by lack of information or not knowing where to access support. While most caregivers don't blame their healthcare providers for the lack of support, they are also more likely to turn to the internet or family and friends than healthcare providers for information.
- There is a clear need for more and better access for caregivers to get support and information from the healthcare system. The majority want one place to go for advice, the system to be easier to navigate so patients can access the right kind of support and shorter wait times for care. Many caregivers wish for better support from the community for day-to-day care, and better support from healthcare professionals to help with their caregiving duties.

The most frustrating issue I had to deal with was navigating the healthcare system and its many different silos. Having an appointed navigator or 'one-stop-shop' for information; would have improved the guidance I needed to find resources, etc. It was very overwhelming to be thrown into an experience like caregiving without having a path laid out or something to help you get through the barriers to care.

– Caregiver Advisory Panel Member

The Ontario Caregiver Organization recently launched the 24/7 Caregiver Helpline, where caregivers can call or engage in a live chat to find information about caregiving and local supports, as well as other important information that caregivers say they need.

1-833-416-2273 (CARE)

The most difficult part in the beginning is to navigate the health care system, to understand the resources available, to learn about respite care, funding etc. No one volunteers the information and everyone assumes that the other health care provider already gave you the information.

– Caregiver Advisory Panel Member



I do get information from health care providers, but I always want more, and I turn to the internet for more and to find the support in specific areas. Sometimes when I get information from health care providers I have to absorb the information first and I don't have the questions right away. I go to groups/charities to gather lived experiences and bring back to the health care provider.
- Caregiver Advisory Panel Member

I would say a caregiver needs different kinds of support at different times depending on the condition of the person...eventually caregivers need the variety as the kind and amount of care changes as this will keep caregivers 'on the job,' longer than possible without support.
- Caregiver Advisory Panel Member

INFORMATION AND SUPPORT

- Just 47% of caregivers who needed information on emotional support and counselling for the care receiver, and 43% who needed this information for themselves, received it.
- 43% of intense caregivers were in need of emotional counselling for themselves and 42% felt the person they provide care to needed it too. Though 37% did receive some support for counselling the patient, only 29% received similar support for themselves.
- 37% of caregivers were given information about how to access caregiving support or home care services. But there is still 25% who say they did not get the information they needed.
- Of those who needed information about occasional relief or respite care, only about 30% received it, while 29% said they could have benefited from this information, but they did not have it.
- 60% of caregivers felt they could have benefitted from information about how to access financial support, but only 26% of caregivers had access to this information.
- Among intense caregivers, there are many major barriers to providing the best care. Barriers include the cost of external help for 51%, the lack of information for 46%, unwillingness of the person they are caring for to accept help from others for 35% and limitations in the community and home support systems for 34%. Notably, in this cohort, 26% feel that healthcare professionals do not understand their needs and 23% feel professionals don't understand the role of the family caregiver.
- Notably, paying for additional help is more of a barrier for 46% of urban caregivers and 47% of suburban caregivers, compared to 37% of those living in rural or remote areas.
- **For those who are in need of information, 49% turn to the internet, 45% to friends and family, and 10% turn to disease-based organizations. Surprisingly, less than 25% try to get information from professional healthcare providers. Among young caregivers, 62% approach friends and family first for getting information, and 57% search the internet.**
- 69% feel they need more support from the community to help with the day-to-day care of their family member. Almost 60% feel that even though supports are available, they are often not in their community or are too hard to get to.

HOW CAREGIVERS FEEL ABOUT CAREGIVING

Being a caregiver has both negative and positive impacts, but it's clear that it can take a mental, physical and emotional toll. The 2019 survey results confirmed this:

- While caregivers do not always see themselves as such, they do understand this is the role they have taken on. Most were happy to step in and help, but one-in-five were intimidated by what was expected of them.
- Only about half of the caregivers surveyed had talked to their doctors about their ability to physically and emotionally handle the job, either at the beginning of the process or occasionally throughout.
- Overall, the outlook on caregiving was positive, as many felt it was rewarding and it strengthened their relationship and commitment to the person they care for. That said, **three-fifths admitted they didn't have a choice in taking on the role.**
- Eight-in-ten felt they are coping at least generally well with their overall caregiving responsibilities and the physical aspect of caregiving. Fewer felt they were coping well emotionally. However, **only one-fifth felt they were coping very well on all aspects.**
- More than half find the overall management of caregiving stressful, particularly dealing with the patient's declining health, meeting the patient's needs, balancing caregiving with other responsibilities and managing their own emotions. **Many admitted that even though they enjoy spending time with the person they care for, caregiving does leave them feeling tired, anxious, worried, overwhelmed and frustrated, or trapped at times. For some, it leads to lack of sleep, depression and loneliness.**

When I first became a caregiver to my parents I have to say I didn't really realize that's what I was becoming. It was always natural to just help them with whatever they needed help with and it just progressed to a full time job due to multiple health issues.
- Caregiver Advisory Panel Member



I think in each case I've been a caregiver, I've grown a deeper bond with the person I was/am helping. I also think that those challenges we talk so much about also offer the opportunity for me to learn and grow.
- Caregiver Advisory Panel Member



Financial strain and our own mental health is a huge concern as well as regular respite and relief from our own situations.
- Caregiver Advisory Panel Member





I didn't realize I was a caregiver at the time. You just do what you need to do for your loved one.

- Caregiver Advisory Panel Member



Since my son was born, I've never not known what it's like to "not be a caregiver." I'm scared most days but keep moving on. I worry about the quality of his life when I'm gone. I continuously feel inadequate but still move forward.

- Caregiver Advisory Panel Member



When I first became a caregiver, I didn't realize that's what I was. I thought of myself as his wife and this is what marriage is about... 'in sickness and in health.' Having raised kids, I wasn't worried about taking care of my husband, I was confident I could handle it. However, as his health declined, I started to think I couldn't handle the growing number of issues I had to think about/juggle/resolve. But if I didn't, who would?

- Caregiver Advisory Panel Member

HOW CAREGIVERS FEEL ABOUT CAREGIVING

- 42% of the caregivers who participated in this survey accept that they have the responsibility of a caregiver. However, 35% admit they have not thought of it this way. Even after explaining the role of family caregiver, 12% still do not consider themselves as 'caregivers.' Only 21% of young carers are ready to accept their role as a caregiver.
- When asked about their initial feeling towards being a caregiver, 57% were happy to do it. 19% did not want to be a caregiver, but thought it was expected of them or felt they were the only person willing to do it.
- Those who are parents of young children (under 14 year old) were more intimidated to take on the added responsibility of being a caregiver. 24% of those who have a job were more likely to be worried about caregiving, compared to 13% of those who were retired or at home.
- Although 86% look at caregiving as part of their family commitment and 69% say it makes them feel rewarded and fulfilled, 64% feel like they did not have a choice in taking on these responsibilities.
- 58% of caregivers feel their loved one appreciates and recognizes the amount they do for them, but 45% also wish they would receive greater empathy and respect from healthcare providers.
- 50% of young caregivers feel they did not have a choice. Interestingly, 55% of young caregivers also do not feel fulfilled and rewarded in taking up these caregiving duties, making them the least likely to feel the positive aspect of caregiving.
- **51% to 54% of caregivers have never had a discussion with a healthcare provider about their own ability to physically and/or emotionally handle their role as a caregiver. Among those who have, less than a quarter have done so only occasionally.**
- Even though over half of the caregivers have not had a discussion with their healthcare providers on how to manage their responsibilities physically and emotionally, 80% say they are at least coping generally well with their responsibilities overall and 76% are coping well physically. However, 66% say they are coping well mentally or emotionally. Notably, only about one-fifth say they are coping very well either overall, physically or mentally.
- 64% of those caring for a person who lives in the same household say it is physically strenuous for them. 53% of those living in independent homes and 55% of those whose family member is staying in a healthcare facility feel the same.

- 72% of caregivers focus on the positive facets of caregiving. They say they are learning a lot about caregiving, while enjoying the available time they have with their family member. Moreover, more than half do not feel resentful, depressed, lonely or isolated.
- **54% admit to being anxious or worried, 53% are overwhelmed, 43% are frustrated and 48% are feeling irritable.**
- **53% admit that the overall management of their caregiving responsibilities is stressful.** 52% find balancing these responsibilities with those of the family to be stressful. In addition, 45% find balancing caregiving with work stressful, while 47% say dealing with family conflict regarding caregiving is stressful.
- Caregivers caring for their children are most stressed overall – with 63% saying they are stressed. Of this group, 76% are stressed about managing their own emotions, 72% are stressed about managing the needs of their child, 79% are stressed about finding services and 68% about balancing caregiving with work responsibilities.
- 59% of those caring for parents also have high stress levels, with 71% concerned about the declining health of their parent and 58% about balancing caregiver with family responsibilities.
- While those caring for a spouse are somewhat less stressed about most factors, 64% are highly stressed about the declining health of their spouse.

My pledge is for mental health. When we are in a good place, we can do anything. We need more mental health support and respite care.

– Caregiver Advisory Panel Member



As a caregiver for my child, I feel the impact on my own mental health and many other aspects of my life as an individual and as a family.

– Caregiver Advisory Panel Member



THE IMPACTS OF CAREGIVING

Caregiving has an impact on friendships and employment:

- Though caregivers generally take caregiving in stride, they are aware of the impact caregiving has had on their life. **More than half feel the negative impact on their personal time, social life, and ability to care for themselves.** While fewer have felt a toll on their physical health, half have seen a negative impact on their mental health.
- Caregiving has a negative impact on fulfilling family responsibilities for two-fifths of caregivers. However, the impact on the caregiver's relationship with the one they care for is generally positive.
- Though the impact on work-related aspects is not entirely negative, it has somewhat hindered career growth and new opportunities. Many have had to take time off work or take days off for managing their caregiving responsibilities and have had difficulties fulfilling their work responsibilities.
- **While more than half of respondents said their workplaces tried to make concessions to allow them to handle their caregiving responsibilities, only one-in-five said their workplace actually had a policy in place. Nearly two-in-five of respondents felt their company was not really helping them.** More than half feel their colleagues and employers understand their caregiving role, their timing is flexible, and the majority are not worried about losing their jobs because of their caregiving duties.
- **One-third have faced financial hardships in the past 12 months due to their caregiving** responsibilities. Two-fifths are paying for expenses themselves, and one-third have had to cut back on their family expenses and use their savings. Only one quarter say that some of their expenses are being covered by health benefit plans or that they have received some financial support from the government or family members.
- Three-quarters wish for more financial support from government agencies and half feel they are unable to always afford the treatment their family member needs.





As a caregiver, my biggest wish would be to have regular respite such as 1 weekend off per month to spend time with my husband. There is absolutely no time when caregiving to actually sit down and talk to your spouse.

- Caregiver Advisory Panel Member



Caregiving can be very isolating. I am fortunate to have a community of friends and neighbours who assist or provide emotional support. Although they cannot truly understand the extent of caregiving, it is helpful to stay emotionally and socially connected to others, even if it is rare.

- Caregiver Advisory Panel Member

THE IMPACTS OF CAREGIVING

- 57% of caregivers are unable to relax or take time off for themselves, 54% aren't able to make vacation plans and 52% aren't able to take part in social activities. The impact is also seen on their health – 53% say there's been a negative impact on their mental health and 44% say there's been an impact on their physical health.
- Caregiving has an effect on relationships. For 39%, it affects their relationship with their spouse or partners and 45% with other family members. 40% say it hinders them from fulfilling their family responsibilities. 30% of the caregivers who have children say it affects the time they are able to be a parent.
- 31% of caregivers who are parents to young children feel the responsibility negatively impacts on their housing situation and 26% feel it has a negative impact on their relationship with the person they are caring for.
- 24% say their relationship with their employer at work has been negatively affected and 33% find it difficult to fulfill their work responsibilities. 32% say their career has been negatively affected.
- Nearly 20% have difficulty in managing work and have reduced their weekly hours or taken a break from work to manage their caregiving duties.
- Three-in-four caregivers have taken time off from work to manage their caregiving duties, with 35% taking less than a week and 31% taking up to a month.
- For 52% of caregivers, their employers are accommodating of their caregiving responsibilities – 20% of employers have an official policy, while 32% of employers help when they can. For the remaining half, 37% do not have accommodations and 12% do not offer additional help.
- 52% of those caring for a child and 43% of those caring for their spouse have taken more than a week to almost a month off work due to caregiving.

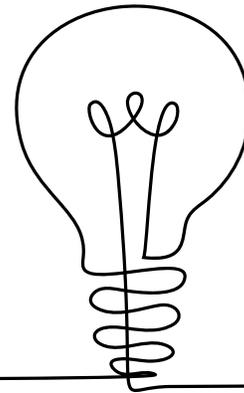
For professional support I have great benefits with my work and have utilized EAP. In my place of work we offer caregiver case management, this service is brief but offers support to help with service navigation and links the caregiver to support services in the area such as education groups, advisory tables and one to one counselling. The government needs to fund more services like these for communities.
- Caregiver Advisory Panel Member



- 57% of caregivers are not worried about losing their job because of their caregiving responsibilities as 53% to 59% feel their employer, manager and/or work colleagues understand their role as a caregiver. 54% say they are comfortable with speaking about their responsibilities at work. This positive outlook is offset by 35% who say they are worried about their job, and 31% who say they feel a lack of understanding from their employer.
- When it comes to flexibility with work hours, 48% agree they are flexible, which allows them to better manage their caregiving responsibilities. But 43% do not have accommodation at work and 47% wish for more support from their employer.
- 14% of caregivers postponed enrolling in an education or training program because of their caregiving duties. This is true for 19% of those 26 to 44 years old and 17% of male caregivers.
- **The 26 to 44 year old caregivers are most impacted financially. 50% use personal finances, 45% have had to cut back on expenses and 40% use savings.** 29% have used income from other sources like investments, 24% have used loans and 22% have sold off assets. The older caregivers (65+ years) manage the cost of caregiving differently – 24% have cut back on expenses and 27% use savings.
- Caregivers caring for children find managing finances difficult. 57% have cut back on family expenses, 59% are using savings and 41% have taken a loan, with 26% selling off assets.
- **32% have faced financial hardships in the past 12 months because of their caregiving responsibilities.**
- It is not surprising that **73% of caregivers wish for more financial support from the government. In addition, 55% feel they can't always afford the treatment their family member really needs.**

WHAT WE LEARNED

Although many of the statistics we've outlined in this 2019 report mirror what we learned in last year's report, there were a few key takeaways we feel are important.



HOW CAREGIVERS FEEL ABOUT CAREGIVING



The majority of caregivers feel they didn't have a choice in taking on the caregiving role.

In fact, most caregivers start their role thinking of it as a natural extension of their relationship as a spouse, a parent or an adult child caring for their aging parents, for example. In many healthcare settings, there is an assumption that the family member will take on a caregiving role without any assessment or discussion about their capacity to do so. When people don't feel they have options and the role is undervalued by society and the healthcare system, it is understandable that caregivers aren't quick to reach out for support.



Caregivers are hesitant to admit they are stressed about their responsibilities.

At a quick glance, it would be easy to assume caregivers are coping well. However, as soon as they are asked more detailed questions about whether they are stressed, feel depressed or overwhelmed, the reality of their situations become clear. Caregiving is the most stressful for those with added responsibilities such as their

own families with children under 14 and/or full-time employment. This underscores the need for a variety of supports to meet the diversity of caregiver needs.



Most caregivers want a single point of access for information and support.

Many caregivers don't know where to start looking for support, and often don't realize they need support until they are nearing or at the burnout stage. One point of access would simplify their search and would help to make them aware of the range of support options that are available.

There seems to be no set way to approach caregiving. All of us learn as we go.
– Caregiver Advisory Panel Member

HOW CAREGIVERS SEE THEIR ROLE



The needs of caregivers and the person they care for can sometime be at odds, adding to the stress that caregivers feel.

Caregivers feel especially stuck or burdened when the person they care for won't accept care from someone else. This creates a dichotomy between the needs of the patient and the needs of the caregiver, and it becomes difficult to determine whose needs take priority.



The costs of caregiving are growing.

This was one of the biggest changes from last year. Out-of-pocket expenses such as parking, travel and medical supplies can add up for caregivers. There are also financial implications related to taking time off work, holding off on applying for a promotion, delaying further education or even going from full-time to part-time employment. This means caregivers are cutting back on family expenses, tapping into their savings, taking out loans and even selling off assets to cover the costs associated with caregiving.



Caregivers are unlikely to see the healthcare system as a place to get support in their role.

Caregivers are still more likely to turn to the internet and friends and family before turning to a healthcare provider when they need help.

HOW CAREGIVERS FEEL ABOUT THEIR ROLE ON THE HEALTHCARE TEAM



Caregivers find it difficult to organize care and coordinate with the healthcare team.

Caregivers know very well that transitions between healthcare providers and/or organizations is when care continuity can fall through the cracks. This is one of the main reasons that many caregivers feel like the main hub for all of their family member's healthcare information. Many caregivers carry binders or stacks of papers to each appointment to ensure that everyone has the latest information about the patient's health. The lack of interconnectivity between electronic health information systems and the lack of communication between providers are two major contributors to this stressful task for caregivers and patients.



Caregivers don't feel their family member would get the same care if they weren't there

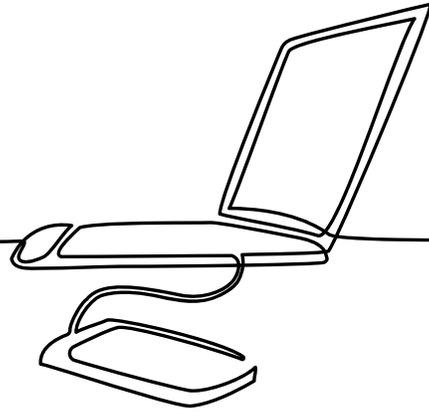
This is especially concerning as it is very stressful for caregivers to feel that they have to be at every appointment and/or home care visit. Caregivers should feel confident that the quality of care would be the same no matter who is at each appointment.



Caregivers are increasingly understanding the importance of their role as part of the healthcare team.

The growing profile of caregivers and their contributions to the healthcare system is helping to underscore the importance of the role of caregivers. However, caregivers still feel there is room for improvement in getting more recognition and empathy from healthcare providers.

APPENDIX



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, in June 2019. 805 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 or mental disability, or old age-related disorder?

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, 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.

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 805 would be $\pm 3.5\%$, nineteen times out of twenty.



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