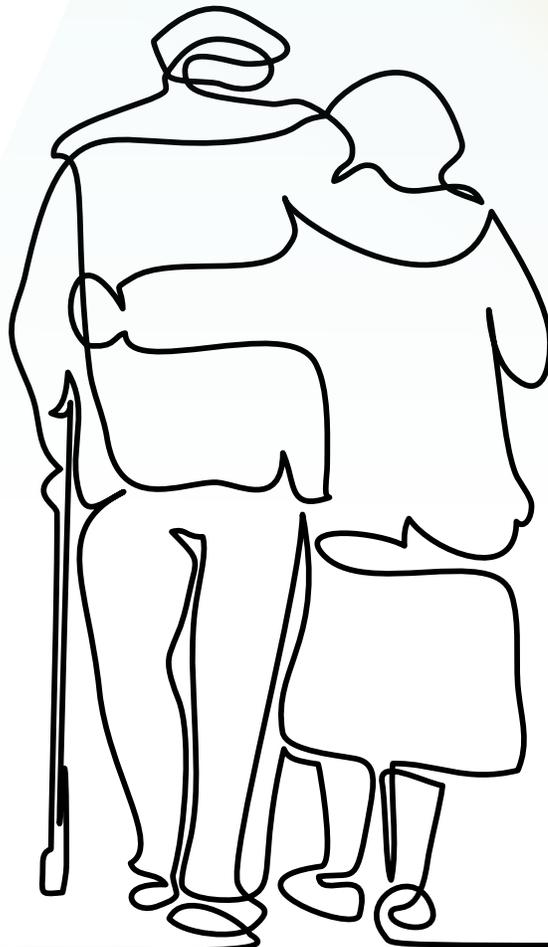




THE **CHANGE**
FOUNDATION
ENGAGE, EXPLORE, EVOLVE

SPOTLIGHT ON
ONTARIO'S
CAREGIVERS



NOVEMBER 2018

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 PATIENT ADVISORS NETWORK

The Patient Advisors Network (PAN) is a Canadian, independent, peer-led community of practice comprised of patient and family advisors, created in 2016. The members are people who have received health services or cared for those who have, and who are committed to improving health care for the good of all. Advisors devote time working within the healthcare system for improvement while maintaining their work and personal lives. PAN strongly believes that advisors can learn from each other and can bring the value of their collective understanding to improving the experiences of patients and caregivers working in collaboration with their healthcare partners.

ACKNOWLEDGEMENTS

This survey wouldn't have been possible without the participation of 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.

The Foundation would also like to acknowledge Pollara Strategic Insights, who conducted the survey of 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.

To complement the survey, The Change Foundation created an online caregiver advisory panel. We want to thank the 100+ caregivers who have 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 to shape this report and will continue to help us shape reports and products in the future.

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MESSAGE FROM THE PRESIDENT



Dear Friends and Colleagues,

We are pleased to release this report on the state of caregiving in Ontario—the first of its kind in our province. It was inspired by the annual State of Caring report developed by Carers UK, and it builds on our 2016 report, *A Profile of Family Caregivers in Ontario*.

In Canada, family caregivers provide roughly three quarters of all patient care. A 2009 estimate put their contributions to the healthcare system at \$25 billion per year¹. However, if we consider that caregivers provide an average of 11-30 hours of care per week, using the current minimum wage of \$14/hour in Ontario, **their contributions add up to between \$26 and \$72 billion a year.**

And yet, there isn't a lot of up-to-date information to explain the diversity of family caregivers, the breadth and depth of their contributions, and their views of their own caregiving experiences.

Through this report, and the survey it is based on, we set out to better understand the experience, profile and needs of family caregivers in Ontario.

The Change Foundation has been working in this area since 2015 with a specific focus on their interactions and experiences with the healthcare system.

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 diseases, physical or mental disability or old age-related disorder.

In keeping with our commitment to co-design, we included caregivers on our planning, selection, and review team from the outset. We worked closely with the Patient Advisors Network (PAN) to select our polling and communications vendors, and to develop the survey tool that would give us insight into the important aspects

¹Hollander, M.J., Liu, G., Chappell, N.L. 2009 Who cares and how much? The imputed economic contribution to the Canadian healthcare system of middle-aged and older unpaid caregivers providing care to the elderly. *Healthcare Quarterly*, 12(2); 42-49.



In Canada, family caregivers provide roughly three quarters of all patient care.



of caregiving. Together, we selected Pollara Strategic Insights to conduct a survey of 800 Ontario caregivers.

Our objectives for this study were to understand:

- 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 from this survey echo what we've heard through our other work, including our

Changing CARE projects, other research and policy work, and collaborations with other stakeholders. Specifically:

- Many caregivers don't self-identify as caregivers, often seeing their caring role as a spouse, child, parent or in-law, but once the role is explained they ultimately do understand the role they play in their family member's health care.
- Most caregivers feel they do not have a choice in taking on the role.
- Caregivers provide a wide range of care and support activities, including emotional support, help with household chores or tasks, and administering medicine.
- Most caregivers feel that their family member would not receive the same quality of care and would be in worse physical or mental

condition if they were not caregiving for them.

- Caregivers generally appreciate the time they are spending with the person they are caring for, believe they are improving the life of their family member and feel rewarded for what they do by their family members.
- Little to no formal supports are provided, and those that are provided, are not easy for caregivers to find.
- Many experience both positive and negative impacts of caregiving.
- Caregiving has a financial impact on caregivers – this includes added out-of-pocket expenses, having to take time off work, and turning down career opportunities.
- When initially asked, caregivers say they feel positive and optimistic about their role. However, when they are asked more specific questions about their caregiving responsibilities, it is clear there are many aspects of caregiving that cause stress and leave caregivers feeling overwhelmed, helpless and frustrated.

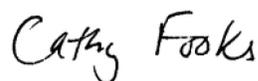
We are pleased that there is growing momentum focusing on better supporting family caregivers at the provincial and federal levels. **We believe that Ontario-specific data is imperative to better understanding the specific situation in our province, so that we can ensure that supports and services truly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

Our plan is to take the pulse of the caregiver experience every year for the next few years. This year's report will act as a baseline for comparison and give us a sense of whether the momentum in Ontario for the caregiver experience is taking us in the right direction.

In addition to the survey, which provides us with the caregiver experience in quantitative form, we've also set up an online panel of caregivers who we turn to on an ongoing basis to help us bring the qualitative side of the caregiver experience to life. This group also helped to provide us with feedback on issues and themes that we highlight in this report. Although our survey and report will be done annually, the website will be updated regularly, so please check back often for caregiver stories and different takes on the survey data. We've even created a section on the site where you can manipulate the data yourself.

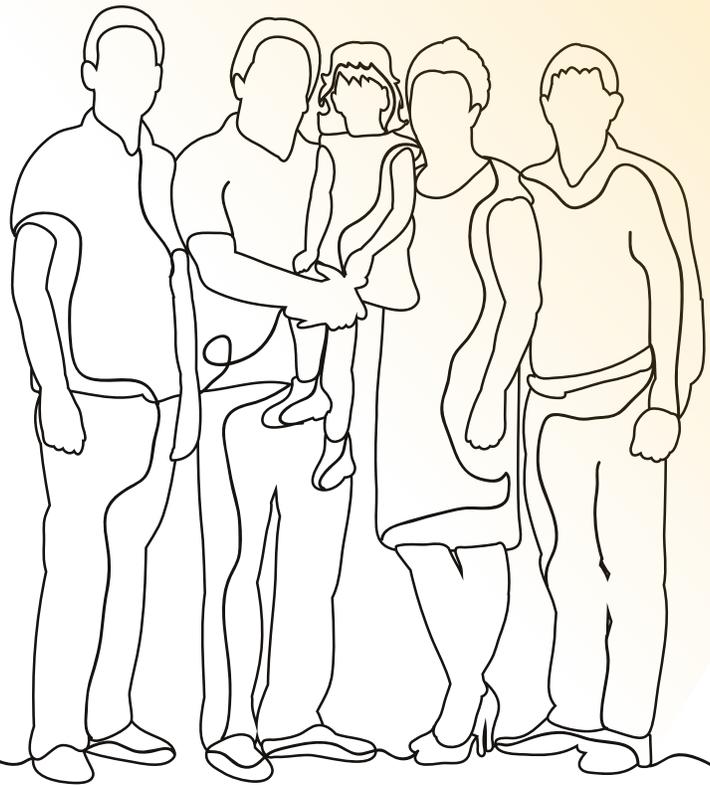
This work – taken as a whole – underscores that supporting caregivers should remain an urgent priority. The Change Foundation will continue to focus on making positive change for caregivers within the healthcare system, and we'll continue to make our knowledge, insights and results widely available to inform other efforts happening in the healthcare system.

We plan to work towards a vision where caregivers are properly supported. We know that, together with our diverse stakeholders, we can make this vision a reality.



Cathy Fooks
President and CEO
The Change Foundation

OVERVIEW



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

In 2016, we published *The Profile of Caregivers in Ontario*, based on the 2010 General Social Survey data collected by Statistics Canada. Although 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 health care system. The analysis and findings of our *Spotlight on Ontario's Caregivers* survey align with the themes, data and take-away points from our past work. More importantly, we now have a baseline of understanding by which to measure growth and change year over year.

In this overview, we highlight our findings from our *Spotlight on Ontario's Caregivers* by topic.



WHO ARE THEY CARING FOR?

- 83% of caregivers are caring for one person. However, 17% are taking care of more than one person.
- 46% are caring for a parent or in-law.
- Almost two-in-ten are caring for their spouse or partner (18%) and 15% are caring for their grandparents.
- 7% are caring for children with exceptional needs, such as a disability or chronic illness.
- Caregivers provide support for a number of ailments, with 44% indicating that they care for someone with aging issues; 17% provide care for a patient with Alzheimer's and an additional 17% care for someone with a physical disability.
- 44% of those receiving care live in the caregiver's home and 37% live in their own private residence. 11% live in a healthcare facility or institution. 59% of caregivers who travel to provide care are 30 minutes or less away.
- 41% of caregivers have been caregiving for at least three years, while 29% have only been doing it for a year.
- Though 90% of caregivers speak English as their primary language, only 67% of those they care for speak English as their first language.

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A CLOSER LOOK

TIME THEY SPEND AND TASKS THEY ARE RESPONSIBLE FOR

45%

of caregivers living in the same house as the person they are caring for spend more than 10 hours per week providing care.

// *Caregiving does not only happen during the day. More than half say they at least occasionally stay up at night to provide care.*

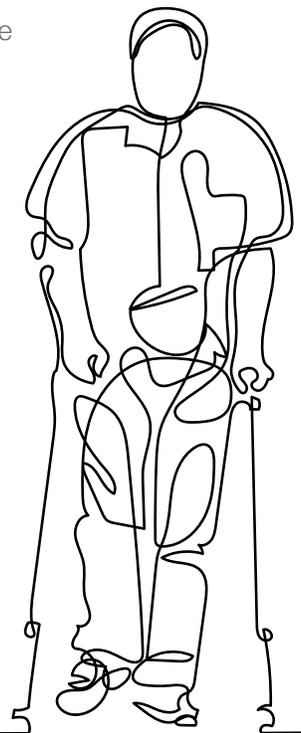
- Caregiving can be time-consuming.
 - While 45% say they spend less than 4 hours a week, 31% are intensive caregivers who spend 10 or more hours a week.
 - One in ten caregivers spend so much time caring, they can't estimate the hours.
 - 45% of caregivers living in the same house as the person they are caring for spend more than 10 hours per week providing care.
 - If the person who is being cared for lives separately or in a healthcare institute, 58% of caregivers spend less than 4 hours a week caregiving.
- Caregiving does not only happen during the day. More than half say they at least occasionally stay up at night to provide care. This is true of those who have other responsibilities such as children or work. 72% of caregivers with children under 14 years old report providing overnight care with 21% of those saying this is a regular occurrence.
- 72% of caregivers provide emotional support and 68% provide transportation – the top two tasks. However, 59% are also involved in activities around the home and 52% schedule appointments.
- 42% of caregivers provide basic medical tasks such as changing bandages, monitoring or administering medications, or giving reminders about appointments, and 21% take part in medical procedures such as changing G tubes, changing wound dressings and giving injections.
- More than two-thirds of caregivers believe that the person they are caring for would be in a worse situation if they were unavailable to provide care. At least half of caregivers believe those they look after would not have the same level of activity or quality of care if they were not involved.

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 this 2018 *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 2018 survey found the following:

- While the majority of caregivers recognize they are not the most important member of the healthcare team, they do feel they play an important role. Luckily, many believe healthcare providers also see them in this light.
- Most see themselves as fully or partially responsible for organizing the circle of care, including accessing community and/or home care, financial aid and medical equipment. While this organizing is not seen as a difficult task, half do admit to feeling overwhelmed by it and a strong majority wish there was somewhere they could go for advice and to ensure they were using all available resources.
- Most caregivers have been in the situation of having to transition their family member/friend from the care of one provider to another in the past year. Transitioning between primary care and other physicians or between facilities is not seen as particularly difficult. However, moving from a specialist to another type of care and between homes and facilities are more difficult. Bringing a loved one home from a facility without home care help is particularly hard, as it requires juggling and special arrangements to cover caregiving and other life responsibilities.

Half do admit to feeling overwhelmed by it and a strong majority wish there was somewhere they could go for advice and to ensure they were using all available resources.





A CLOSER LOOK

ROLE ON THE HEALTHCARE TEAM

45%

of caregivers feel they play an important role as a member of the healthcare team. However, only 17% see themselves as the most important member of the healthcare team.



Patient transitions within the healthcare system are less difficult for caregivers than transitions from a healthcare facility to home (without home care) or from home to a health care facility.

- 45% of caregivers feel they play an important role as a member of the healthcare team. However, only 17% see themselves as the most important member of the healthcare team.
- 42% to 48% believe that healthcare providers also see caregivers in this light.
- 63% of caregivers who view their role as most or equally important to the rest of the team, believe that primary doctors view their role as important. Similar proportions feel that nurses (63%), therapists (63%), PSWs (66%), nurse practitioners (58%) and specialists (55%) see their role as important.
- 48% of long-term caregivers (> 1 year) believe their primary doctor views them as at least equally important to the team. 69% of intense caregivers (> than 100 hours a week) feel the same, with 51% of them feeling that they are seen as the most important member, and 18% feel equally important.
- 60% of caregivers see themselves as fully or partially responsible for organizing the other members of the healthcare team.
- 54% admit to feeling overwhelmed by this task and 75% wish there was somewhere they could go for advice. 61% want to know of and access all available resources.
- 80% of caregivers providing care to their spouses and 66% of caregivers who live in the same house as the person they are caring for are solely responsible for managing and organizing all the caregiving tasks.
- Patient transitions within the healthcare system are less difficult for caregivers than transitions from a healthcare facility to home (without home care) or from home to a healthcare facility. 26% of caregivers rate transitions involving a primary physician as difficult. In contrast, specialists make the transition harder for caregivers - 43% say it was difficult moving between specialists, 48% between specialist to hospitals and 48% between multiple providers.
- 51% to 54% of caregivers find transitioning to or from a healthcare facility and home to be difficult. 59% of caregivers who brought a family member home from a facility without home care help said it was hard. 55% had to juggle other responsibilities with the added-on caregiving, and 53% had to arrange support from other healthcare providers.
- For 65% of caregivers who live in a separate home from the person they care for, transition between hospital and home without home care services was difficult, since they had to arrange for care, set up and pay for equipment and find a way to manage the delays in the provision of home care. Whereas, 49% of those who live in the same house as the person they care for said the transition was difficult.

INFORMATION AND SUPPORT

Caregivers have many information and support needs – and often those needs aren't met. This is a major focus within our [Changing CARE](#) projects. The 2018 survey showed:

- Caregivers are given information about the health condition 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, less than one-in-five caregivers receive hands-on training.
- There is less information provided when it comes to emotional support, either for the caregiver or care receiver, or on how to access financial support.
- Most support was given at the start of caregiving and has not been repeated in the past 12 months.
- Cost, followed by lack of information, are the biggest barriers to getting needed additional support.
- When more information is needed, caregivers are more likely to depend on the internet or friends and family than they are on healthcare providers.

57% of those who needed information on how to access financial support through special agencies, government agencies or tax credits did not receive information. 49% did not get any information to access legal support for managing legal affairs.





A CLOSER LOOK

45%

of caregivers say cost was the biggest barrier to getting additional support, followed by 32% who said it was lack of information.



Those who found transitioning between a hospital and home without home care services to be a difficult process were provided less information about home care services, caregiving support and respite care than those who found the process easier.



INFORMATION AND SUPPORT

- 91% of caregivers say they are informed about the health condition of the person they are caring for with 52% believing they are very informed.
- 64% of caregivers who needed information on how to provide physical support received it (written materials, verbal instructions and/or hands-on training). Only 37% received actual hands-on training, and 36% of caregivers who needed information didn't receive any.
- 53% of caregivers received information on emotionally supporting their family member or friend, whereas only 43% received information to help support themselves emotionally.
- 57% of those who needed information on how to access financial support through special agencies, government agencies or tax credits did not receive information. 49% did not get any information to access legal support for managing legal affairs.
- Caregivers who have been providing care for more than a year or put in more than five hours per week caregiving or have to travel for longer times to the person they care for are more likely to require information about home services, respite care or caregiving support than other caregivers.
- Those who found transitioning between a hospital and home without home care services to be a difficult process were provided less information about home care services, caregiving support and respite care than those who found the process easier.
- 45% of caregivers say cost was the biggest barrier to getting additional support, followed by 32% who said it was lack of information.
- When more information is needed, 58% of caregivers turn to the internet, 44% turn to friends and family, and 28% turn to healthcare providers. Surprisingly, only 9% approach disease-based charities for information.
 - A distinct difference is seen with rural caregivers. 34% turn to the primary healthcare provider of the person they are caring for and 32% turn to government agencies.

HOW CAREGIVERS FEEL ABOUT CAREGIVING

The caregiver role has both positive and negative impacts, but there are clear tolls on the caregiver. The 2018 survey results confirm this:

- Overall, most caregivers feel that being a caregiver strengthens their relationship and commitment to their loved one and makes them feel rewarded. That said, three-fifths admitted they are doing this because they have no choice, and two-fifths feel trapped, helpless and frustrated at times.
- Three-quarters feel they are coping at least generally well with their caregiving responsibilities. However, only one-fifth feel they are coping very well. There are many aspects of caregiving they find to be stressful, particularly dealing with the declining health of their family member, meeting the needs of their family member as well as managing their own emotions.
- Three-fifths consider caregiving to be physically strenuous. About half of the caregivers had talked to their doctors about their ability to physically and emotionally handle this job, either at the beginning of the process or occasionally throughout. Half, on the other hand, have never had this conversation.
- About half feel their personal time, social life and ability to care for themselves have been negatively impacted. While fewer have felt a toll on their physical health, almost half have seen a negative impact on their mental health.



Two-thirds wish there were more financial or day-to-day supports from government agencies.





A CLOSER LOOK

42%

self-identify as caregivers.

// *While 64% were happy to step in and provide care, 18% felt intimidated by what was expected of them.*

HOW CAREGIVERS FEEL ABOUT CAREGIVING

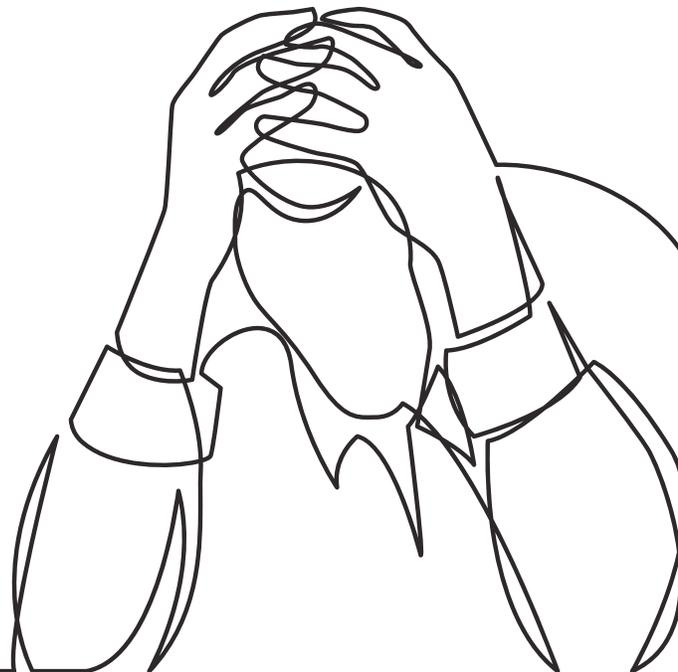
- 42% self-identify as caregivers. While the rest are less likely to see themselves in this way, when it is explained to them, an additional 35% agree that this is what they are. 24% don't see themselves as caregivers, have never considered it, or prefer not to say.
- While 64% were happy to step in and provide care, 18% felt intimidated by what was expected of them.
- 74% believe being a caregiver strengthens their relationship to the person they are caring for and 75% feel rewarded by the experience. 87% say that they took up this role as part of their commitment towards the relationship, and 64% feel they are appreciated for what they do. That said, 61% admitted they are doing this because they have no choice, and 41% feel trapped, helpless and frustrated at times.
- 20% feel they are coping very well and 58% feel they are coping generally well with their caregiving responsibilities.
- 78% enjoy spending time with their loved one and 76% say they are learning about how much they have to give. 64% feel tired, 55% feel frustrated, 54% feel anxious and 51% feel overwhelmed. 36% feel depressed and 33% feel resentful.
- Caregiver stress is caused by multiple factors: 60% of caregivers say it comes from dealing with the declining health of the person they are caring for, half say it comes from trying to meet their needs and half say it comes from trying to manage their own emotions.

THE IMPACTS OF CAREGIVING

Caregiving has an impact on friendships and employment:

- While caregiving has had some impact on family relationships, it has affected friendships for about half. Two-fifths have also seen a negative impact on their financial situation, particularly those looking after a child or a spouse.
- Many have had to take time off work for caregiving responsibilities, and some have even lost their jobs. More than half of workplaces try to make concessions to allow their employees to handle these other responsibilities, but one-third of caregivers say their workplace does not even try.
- Two-fifths have had to finance the person they are caring for. For a third of caregivers, this means using savings or cutting back on family expenditures.
- One-quarter are receiving some funds or financial support from family or government supports and for one-quarter their health benefit plan covers most of the expenses.
- Two-thirds wish there were more financial or day-to-day supports from government agencies.

More than two-thirds of caregivers believe that the person they are caring for would be in a worse situation if they were unavailable to provide care.





A
CLOSER
LOOK

57%

of workplaces try to make concessions to allow their employees to handle these other responsibilities. But 32% say their workplace doesn't even try.



Most caregivers are able to manage their caregiving duties by requesting or making special work arrangements: 39% left work early, 35% took days off, 34% took time off during the day, and 25% went late to work.

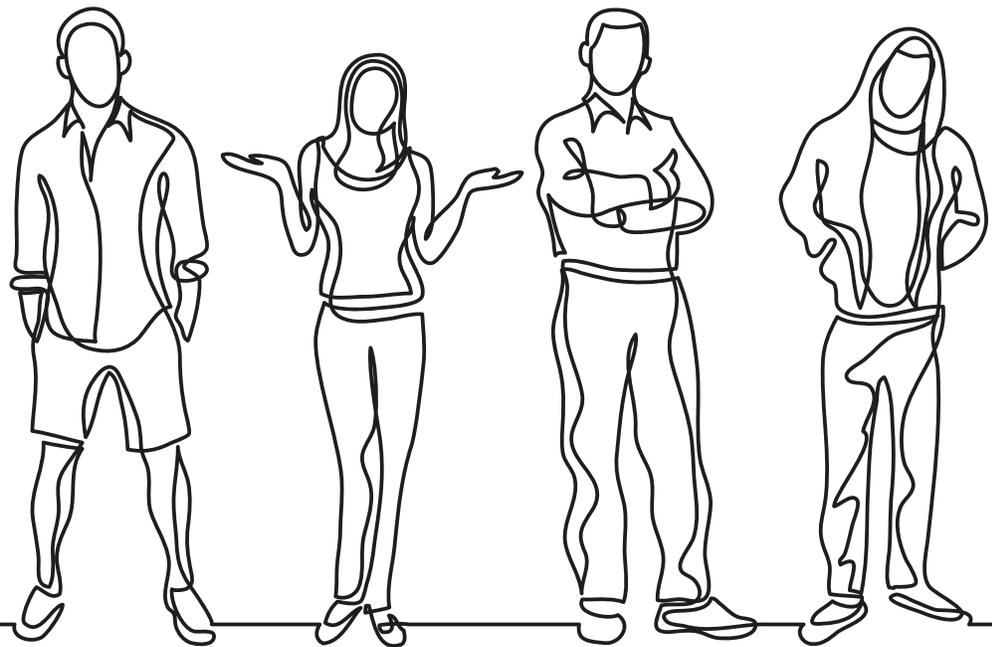
THE IMPACTS OF CAREGIVING

- 51% of caregivers feel negative impacts on their personal time, 49% say travel plans have been disrupted and 48% have seen impacts on their social life – including spousal relationships and friendships. 41% say it has impacted their physical health and 49% say it has had mental health implications.
- 37% to 40% say that caregiving has had an impact on family relationships, and 48% say it has affected friendships.
- Most caregivers are able to manage their caregiving duties by requesting or making special work arrangements: 39% left work early, 35% took days off, 34% took time off during the day, and 25% went late to work.
- 57% of workplaces try to make concessions to allow their employees to handle these other responsibilities. But 32% say their workplace doesn't even try.
- 8% of caregivers lost their jobs as a direct result of their caregiving responsibilities.
- 15% of caregivers postponed enrolling in an education or training program because of their caregiving duties.
- 38% of caregivers have seen a negative impact on their financial situation, particularly those looking after a child (54%) or a spouse (46%).
- 44% of caregivers have had to finance the person they are caring for. For 32% of caregivers, this means using savings or cutting back on family expenditures. Only 26% are receiving funds from family members, 24% from benefit plans and 23% from government supports.
- 22% of caregivers have faced some financial hardship due to caregiving. Of these caregivers, 74% have used personal funds, 71% have used savings, 78% have cut back on other family expenses, 52% have used their income from investments and 45% have taken a loan. However, 44% have received aid from family and 43% from government, community centers, etc.
- 66 to 68% of caregivers wish there were more financial or day-to-day supports from government agencies.

YOUNG CARERS

Young Carers² are a distinct group of caregivers, whose experience is equally important to understand. Our 2018 survey heard from 71 young carers. Our findings include:

- Young carers (ages 16 to 24³) play an active role as caregivers. While they often have help, they are likely to consider themselves primary caregiver on at least one task, with no task being off limits to this group. While they are less likely to be involved in financial support, some of this group is responsible for paying for their loved one, and some find it difficult to meet work responsibilities and feel their career growth is impacted by their responsibilities.
- Young carers tend to downplay their role. They are less likely to consider themselves a caregiver and do not feel they are an important member of the healthcare team. Similarly, they do not feel healthcare providers see them as important. While many know they are having a positive impact on the life of the person they are caring for, this group is less confident in the strength of the role they play.



²A note on terminology: In Canada, the term family caregiver is commonly used. However, when it comes to younger caregivers, the young carer term has been adopted from the UK. It creates an inconsistency.

³Young carers are those between the ages of 5 to 24 years of age. However, due to age of consent, data from this survey is only available for those between 16 and 24 years old.

A CLOSER LOOK

60%

of young carers say arranging for support from other healthcare providers was most difficult while transitioning between hospital and home.



Young carers are more likely than their older counterparts to be an interpreter for the person they are caring for, with 17% saying their loved one does not speak English.



YOUNG CARERS

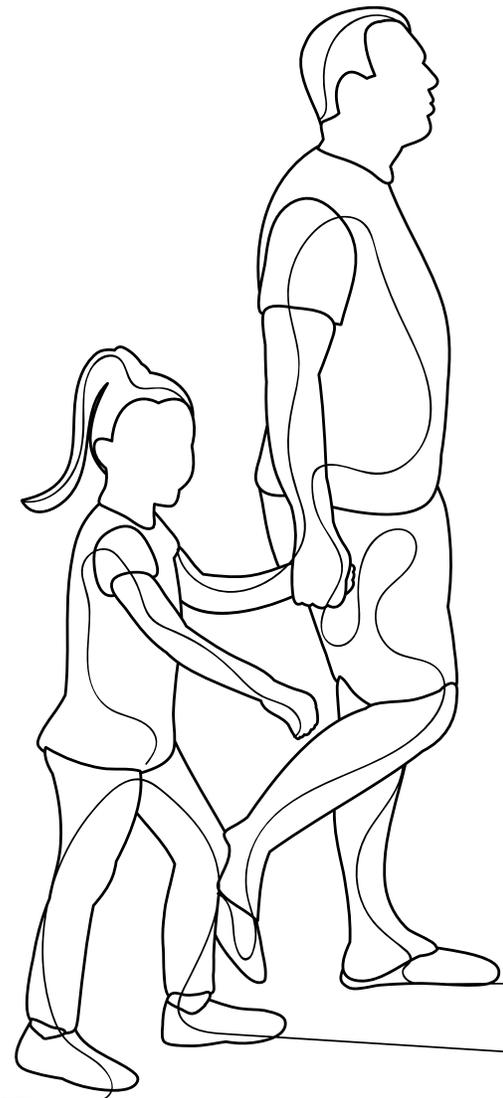
- 60% of young carers say arranging for support from other healthcare providers was most difficult while transitioning between hospital and home. This may be related to them feeling that they are not as important a part of the healthcare team.
- Young carers do not generally self-identify as caregivers. 70% said they had not considered themselves caregivers before the survey. While 59% were happy to take on this role, 24% felt intimidated and 13% did not want to do it but felt it was expected.
- While 68% of young carers enjoy spending time with their loved one and 66% feel they are learning about how much they have to give, 51% also feel tired, 50% feel anxious, 45% feel overwhelmed, 44% feel frustrated and 41% feel short tempered. 26% say they feel resentful and depressed, which is lower than for older caregivers.
- Young carers are less likely to feel stressed overall than older caregivers, with only 37% feeling stressed about managing their own emotions, 49% for dealing with declining health, and 34% in trying to balance caregiving and work. That said, approximately one-third feel stressed about many of their responsibilities.
- Young carers believe their caregiving duties could have the following long-term impacts on their lives: 36% on ability to fulfill work responsibilities; 34% on career growth; 30% on their physical health and 36% on their financial situation.
- One quarter of young carers are either using personal finances or their savings to pay for caregiving expenses themselves. While a third received some financial aid from family, a quarter also had some help from government agencies, community centres, etc.
- 90% provide care to only one person: 50% care for a grandparent; 23% for a parent; 15% provide care to a sibling.
- Young carers provide care support for a number of ailments, with 39% listing aging issues, 22% Alzheimer's or dementia, 22% arthritis, 18% recovery from surgery and 17% accident injuries. 8% care for someone with mental illness, 7% with developmental disorders/disabilities and 1% with addiction.
- Young carers are more likely than their older counterparts to be an interpreter for the person they are caring for, with 17% saying their loved one does not speak English.
- While young carers are more likely than older caregivers to say another person is primarily responsible for coordinating the team, 23% take on this role themselves. 40% find this process to be difficult, 52% find it overwhelming and 68% wish there was one place to go for information.

CAREGIVERS WITH YOUNG CHILDREN

Caregivers with young children, some of who are the sandwich generation, are often overlooked as family caregivers. Our 2018 survey showed that their experience is unique, showing the following:

- Despite conflicting responsibilities, caregivers with young children spend many hours and sleepless nights caregiving. They are responsible for many tasks, often being the only one to take on these responsibilities.
- This group is confident and understand the worth they are providing. They feel they are an important part of the healthcare team and are likely to believe providers see them in the same light. They know that their work is helping the quality of life of the people they are caring for and feel appreciated.
- Despite this group's strength and confidence, they do need help. They find it difficult to manage work and family responsibilities along with caregiving. They feel the financial strain of raising a family and paying for caregiving expenses. They are more likely than other groups to feel overwhelmed, tired, frustrated and even depressed.
- Caregivers with young children are more likely to feel that caregiving responsibilities have a long-term impact on their life.

Despite conflicting responsibilities, caregivers with young children spend many hours and sleepless nights caregiving. They are responsible for many tasks, often being the only one to take on these responsibilities.





A CLOSER LOOK

58%

of caregivers with young children find balancing their caregiving and family and work responsibilities much more stressful than the rest of the caregivers surveyed. 50% are stressed about finances and 40% about legal affairs.



Caregivers who are parents of young children feel more stressed than other caregivers when it comes to these responsibilities.

CAREGIVERS WITH YOUNG CHILDREN

- 68% of caregivers with young children were happy to take on a caregiving role; 21% felt intimidated and 10% were not keen to take on this role.
- Despite having the responsibility of children and taking care of a parent or other family member, they have a positive outlook. 80% feel they are coping at least generally well, with 21% saying they are coping very well. While 84% believe they are doing as much as they can, 59% feel they are appreciated for the amount they do.
- Although 75% enjoy spending time with their loved one, most also feel negative emotions. 63% feel tired, 62% frustrated, 55% anxious, and 50% overwhelmed. 47% have disturbed sleep, 46% feel irritable, 41% depressed and 38% resentful— all higher than average for the caregivers surveyed.
- Caregivers who are parents of young children feel more stressed than other caregivers when it comes to these responsibilities: 59% when dealing with the declining health of the person they are caring for, 45% for meeting their needs, 45% for making decisions for them, and 58% for dealing with their own emotions.
- 57 - 58% of caregivers with young children find balancing their caregiving and family and work responsibilities much more stressful than the rest of the caregivers surveyed. 50% are stressed about finances and 40% about legal affairs.
- 35% believe this responsibility has torn apart their family and 51% say it has had a negative impact on their personal time.
- 43% say it had a long-term negative impact on fulfilling their family and work responsibilities and on their financial situation, and 36% on career growth.
- 54% of caregivers with children under 14 are considered to be from the *sandwich generation*, representing 9% of all caregivers.

URBAN, SUBURBAN, RURAL AND REMOTE CAREGIVERS

Each of the 800 respondents were asked to self-declare whether they lived in an urban, suburban, rural or remote area of Ontario. Our analysis shows there were geographic impacts on the caregiving experience including:

- Though both rural and urban caregivers spend more time caregiving, it is urban caregivers who need to travel the most to provide care.
- Rural caregivers are more invested and understand their role and its impact but find coordinating care to be more stressful and are more likely to feel overwhelmed by it.
- Urban caregivers feel the negative impact of caregiving on their family and social life. Suburban caregivers do face the stress of caregiving but not as much as the other two groups.
- Urban caregivers, in particular, feel the financial stress and need support in terms of finances and help from family and friends.

Though both rural and urban caregivers spend more time caregiving, it is urban caregivers who need to travel the most to provide care.





A CLOSER LOOK

44%

of urban and 48% of rural caregivers self-identify as caregivers compared to 38% of suburban caregivers. 76% of urban and 70% of rural caregivers are happy to accept this role compared to 60% of suburban caregivers who are hesitant.



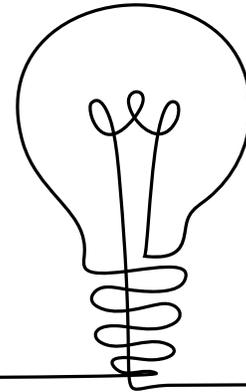
Although rural caregivers overall report being less stressed than other caregivers, there are a few key activities that are notably more stressful for them: coordinating care (50%), finding services for the person they are caring for (47%) and the financial expenses of caregiving (41%).

CAREGIVERS BY GEOGRAPHY

- 44% of urban and 48% of rural caregivers self-identify as caregivers compared to 38% of suburban caregivers. 67% of urban and 70% of rural caregivers are happy to accept this role compared to 60% of suburban caregivers who are hesitant.
- 95% of rural caregivers have a higher sense of commitment towards their role. 22% of urban and 25% of rural caregivers feel they are coping very well, compared to 17% of the suburban caregivers.
- 80% of rural caregivers enjoy spending time with their loved ones and 87% feel they are learning about how much they have to give, which is higher than the urban, suburban and remote caregivers. However, 64% say they feel anxious and frustrated and 60% report feeling overwhelmed.
- Although rural caregivers overall report being less stressed than other caregivers, there are a few key activities that are notably more stressful for them: coordinating care (50%), finding services for the person they are caring for (47%) and the financial expenses of caregiving (41%).
- 83% of caregivers live in an urban or suburban area. Rural caregivers are usually older and when compared to the rest of the sample are more likely to be caring for their spouses (33%) along with caring for parents (33%).
- 35% of urban caregivers have their loved one living in a separate private home, compared to 41% of rural and 39% of suburban caregivers. Urban caregivers travel for longer to reach their loved one. 45% travel for more than 30 minutes compared to 36% of suburban and 33% of rural caregivers, who generally travel less than half an hour.

WHAT WE LEARNED

Although many of the stats we've outlined in this 2018 report mirror what we have been hearing since 2015, there were a few elements that we feel are important.



Self-identification by caregivers remains a big obstacle.

If caregivers don't think of themselves in that role, they are unlikely to look for supports for caregivers. We believe the solution to this challenge is two-fold: helping caregivers to understand their role through general public awareness efforts and working with healthcare providers to identify and recognize family caregivers in their role within the team.



There are distinct differences in the caregiver experience when we look at where caregivers live, who they are caring for and what other responsibilities they have in their lives.

This information provides insights into how we can better support different groups of caregivers. We have always known that a one-size-fits-all response will not be effective.



Family caregivers are hesitant to admit they are struggling.

When asked generally how they are coping, or if they are responsible for organizing the many aspects of care – both in the community and with the healthcare providers – they are quick to say they are doing okay and coping fine. However, when we dig deeper, and ask specific questions, many say they are struggling in more than one way. This is an important reminder that building relationships with caregivers is imperative to understanding what they need.



Those who are in long-term or very intense caregiving situations have different experiences.

It is intuitive to understand that a caregiver who cares for someone with an acute illness over a period of six months would be different from someone who has been caring for someone with a chronic illness, disability or mental illness for many years. However, the differences go further than the impacts of intensity and length. We need to consider the life-altering implications of these long-term caregiving situations.



The financial, social and educational impacts of caregiving are real.

It's important that consideration be given to the longer-term impacts of caregiving, even though we have only asked about these impacts in the short-term. There are life-long implications, for example, for a young carer who delays education or a mother of a young child who puts off going back to work due to caregiving responsibilities.



Caregivers intrinsically understand their value and believe the person they care for would not receive the same level of care or attention if they weren't providing care.

Despite this understanding, society as a whole has not given caregivers the attention or support they need. Caregivers truly are the glue that keeps our healthcare system together. If there was a collective caregiver strike tomorrow, our system would come to a grinding halt. We need to invest in them, so that they can play their important role without burning out, getting sick themselves, or feeling hopeless.



When caregivers need help, they turn to the internet and their friends and family long before looking to the healthcare system for help.

Although support services exist for caregivers, they are hard to find for many caregivers. Our goal should be that caregivers are proactively offered supports rather than waiting until they are desperate and finally seeking support. There are other jurisdictions we can look

to for models of where this is done more effectively, including the UK, Australia, and many European countries, including the Netherlands, Spain and Germany.

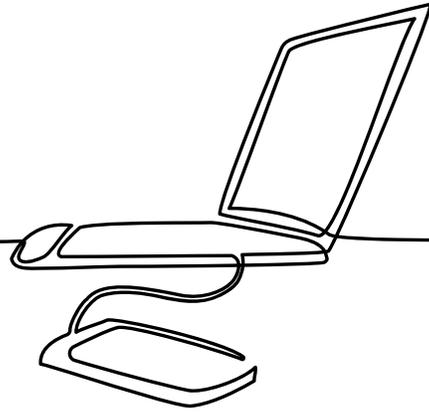
Each one of these points require deeper review and consideration. We will probe many of these with our standing panel, and through our next survey.

As we review this data, there is one longer-term data point that could be very insightful, albeit likely difficult to track. We continue to hear anecdotes about the longer-term impact of caregiving on the caregiver's health, including many stories about the fact that the caregiver passes away before the one they are caring for. If there was an opportunity to track the OHIP information for caregivers, and look at this with a longer view, we believe that caring for caregivers would be clearly an urgent priority.

It's only with a clearer understanding of the caregiving situation in Ontario that we can work with caregivers to figure out how they can be supported in this critical role at the individual, organizational and system level.

It is our hope that we will see improvements in the caregiver experience in Ontario year-over-year, and that this report will serve to inform and measure change over time.

APPENDIX



Methodology

An online survey was conducted by an independent third-party polling firm (Pollara Strategic Insights) with 800 self-reported caregivers in Ontario, 16 years of age and older, in May 2018. All 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, neighbour 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 800 would be +/- 3.5%, nineteen times out of twenty.



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