

# SPOTLIGHT REPORT

**5 YEAR**  
RETROSPECTIVE  
2019-2023



THE ONTARIO

**caregiver**  
ORGANIZATION

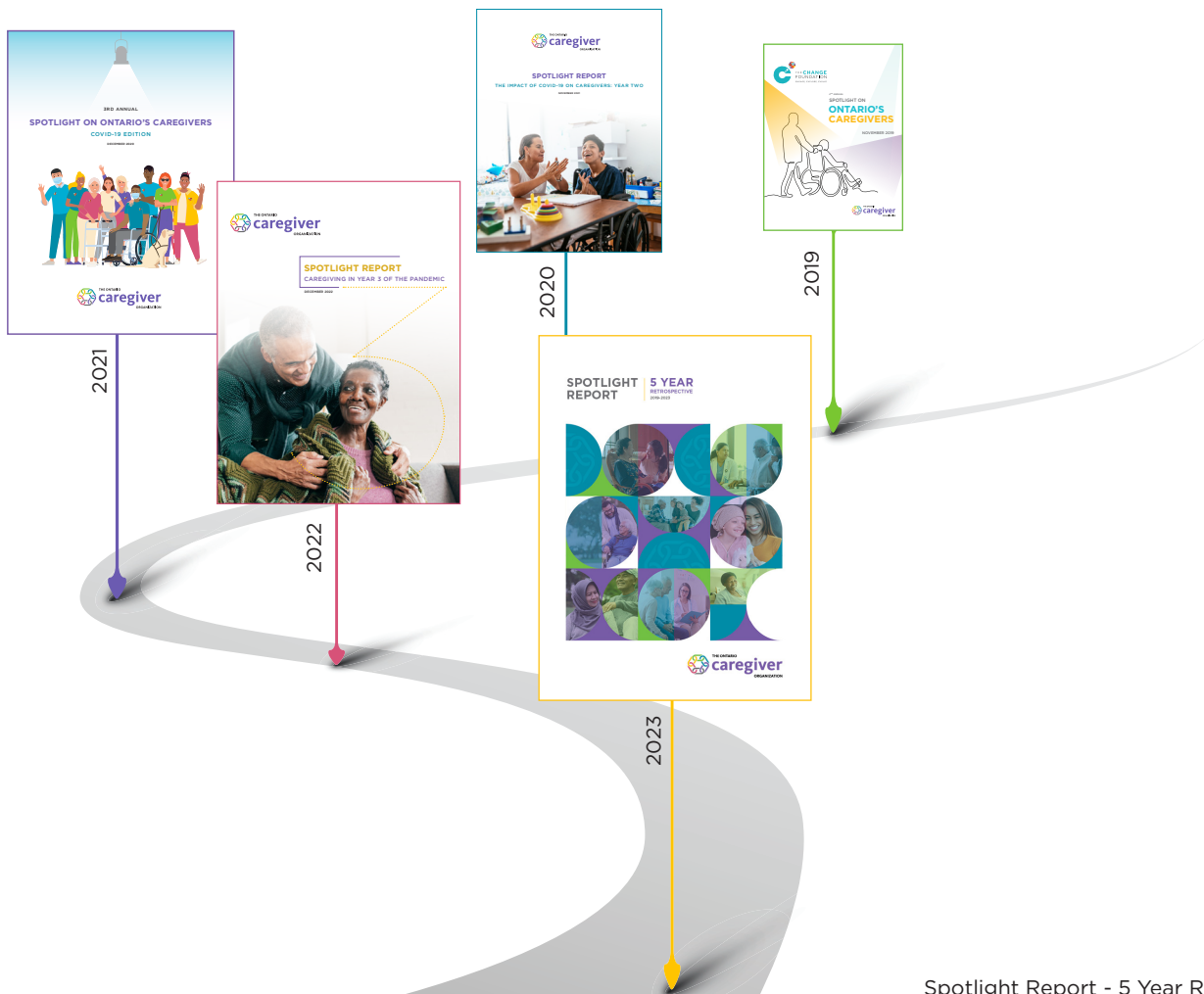


### **About the Ontario Caregiver Organization**

The Ontario Caregiver Organization (OCO) exists to improve the lives of Ontario's estimated 4 million caregivers; ordinary people who provide physical and/or emotional support to a family member, partner, friend, or neighbour. The OCO provides caregivers with one point of access to information, services and supports that empower and help enable caregivers to be successful in their role. Where gaps exist in caregiver programs and services, the OCO partners with caregivers, health care providers and other organizations to find new and innovative ways to bridge those gaps so all caregivers, regardless of age, condition or geographic location have access to the help they need.

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## MESSAGE FROM THE CHAIR AND CEO

Dear Friends and Colleagues,

This year marks the fifth anniversary of OCO's Spotlight Report. For the first time, the report provides a retrospective look at the caregiving experience today, compared to 2019. The question we considered was how have factors such as COVID-19, our aging population, the health human resource crisis, and the economic downturn influenced the caregiving experience over the last five years?

Every year, the Spotlight Survey shows caregiver stress and burnout is on the rise, the financial impact of caregiving is growing, and working caregivers are struggling to balance work and care responsibilities. These continue to be predominant themes.

For the first time in five years, caregivers say their workplace environments have improved. More caregivers say they feel understood by their employer and colleagues. While this is positive, there is still more to be done for the sixty-one per cent of working caregivers who still wish for more support from their employer.

This year, caregiver stress and feelings associated with burnout increased again. Caregivers are taking on more responsibilities and investing more time in their caregiving role. Added to that is the increased financial burden that goes along with providing care.



**43%** of caregivers say they feel depressed, compared to 37% five years ago.



**45%** of caregivers say they are currently experiencing financial hardship due to caregiving responsibilities, compared to 36% in 2019.



**52%** say they need to take a break from caregiving, compared to 38% in 2019.



**73%** say they are concerned they are not going to be able to handle all their caregiving duties going forward, up from 65% last year.

In 2017, the Beed Report highlighted that effective caregiver support must include initiatives at the individual, organizational and system levels. The creation of the Ontario Caregiver Organization was an essential first step, providing caregivers with one point of access for information, services, and support like the 24/7 Caregiver Helpline, Peer Support and



Caregiver Coaching. Caregivers who access these programs and services say it's made a profound difference in their lives.

At an Organizational level, OCO is working with health system partners and employers to identify caregiver support gaps and help implement the evidence-based caregiver friendly policies that make a difference. The Essential Care Partner Support Hub is an example of OCO's work in this area. While change takes time, there is great momentum happening in hospitals and long term care homes across the province and we look forward to expanding this work in other care settings.

At a system level, OCO continues to engage with government on important issues for caregivers, provide public education and raise awareness about the value, importance, and challenges of caregiving, including sharing data via the Spotlight Report.

Change isn't easy. It requires a commitment at the system, organizational and individual level to better support the family members, partners, friends and neighbours who selflessly provide care, often at the expense of their own health and wellness. OCO cannot do this work alone. If you are reading this and you or your organization interacts with family caregivers, reach out to OCO. We want to work with you.


Sincerely,

**David Mosher**

Board Chair,  
The Ontario Caregiver Organization

**Amy Coupal**

CEO,  
The Ontario Caregiver Organization



**“I never know if the Personal Support Worker will show up. It’s stressful because I have no help, no support.”**

***Caregiver***



## CAREGIVING RESPONSIBILITIES

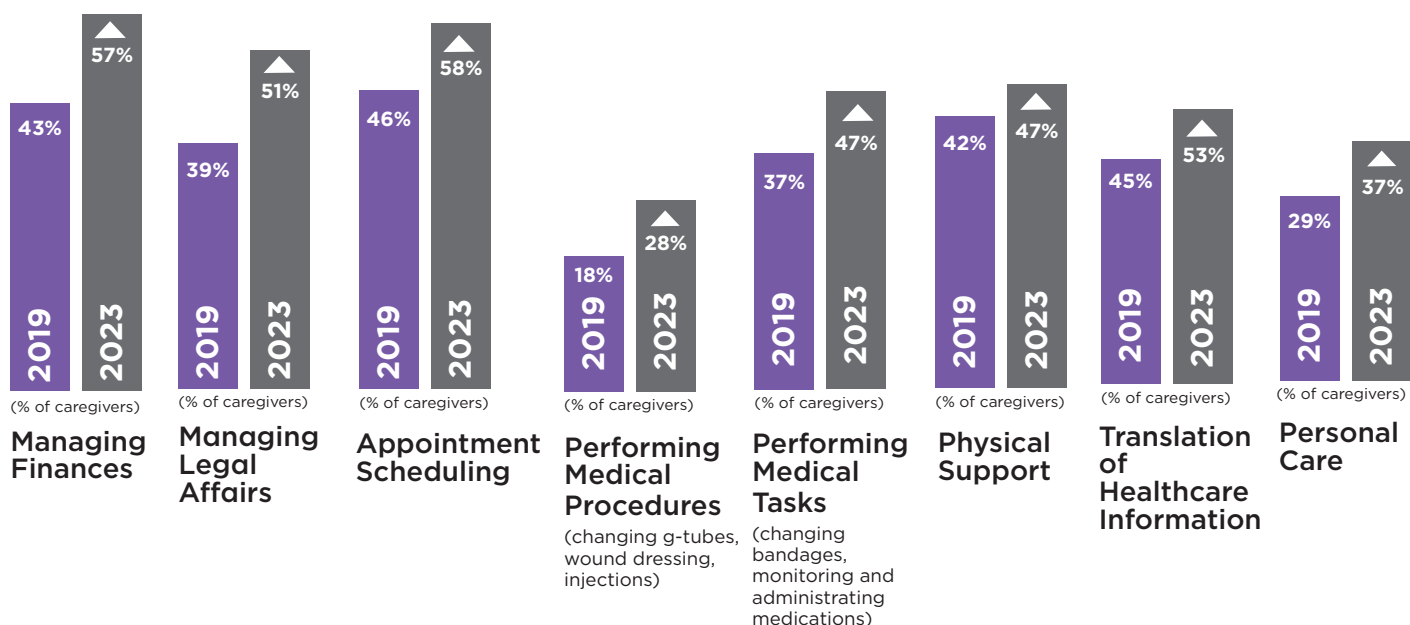
Compared to five years ago, there is a significant increase in the support caregivers provide for the person they care for, particularly across 10 critical tasks. More than half of caregivers say they have more caregiving responsibilities, compared to last year. The greatest increase is related to appointment scheduling, managing the financial and legal affairs of the care recipient, and carrying out medical procedures which caregivers say were once done by a nurse or personal support worker.



**35%** of Caregivers provide 10 or more hours of care, up from **30%** in 2019



**76%** of caregivers say they have taken on a task that otherwise would have been done by a Personal Support Worker or Nurse





**“I have no friends, no time to meet anyone, I am alone with my son and can’t do this alone anymore.”**


*Caregiver*






## CAREGIVER WELLNESS

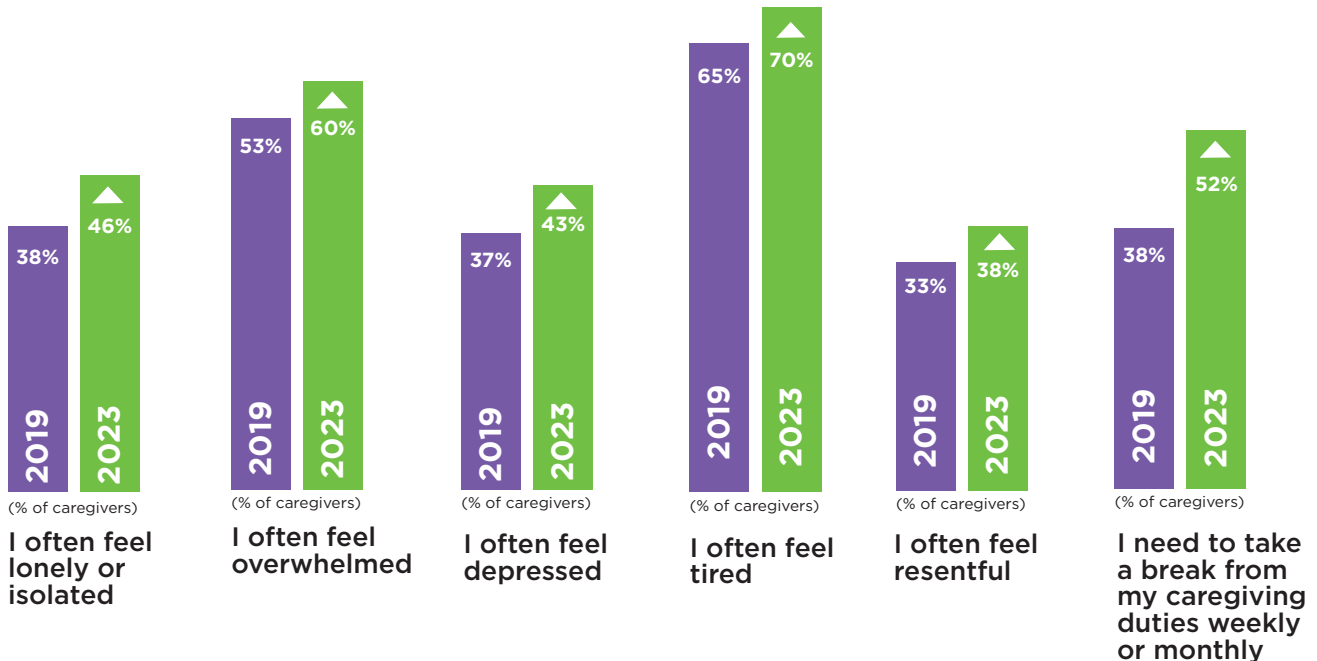
Caregiver mental wellness has been a predominant theme for years, however this year, 73% of caregivers say they are concerned that they are not going to be able to handle all of their caregiving responsibilities going forward and 74% say they can't take on any more than what they already have. Caregivers say that in addition to financial support, they need respite (32%) and mental health support (30%), in order to continue in their role.



**67%** of caregivers say they hit their breaking point but know they have no choice but to keep going, up from 63% in 2019.



**73%** of caregivers say they are concerned they are not going to be able to handle all of their caregiving duties going forward.





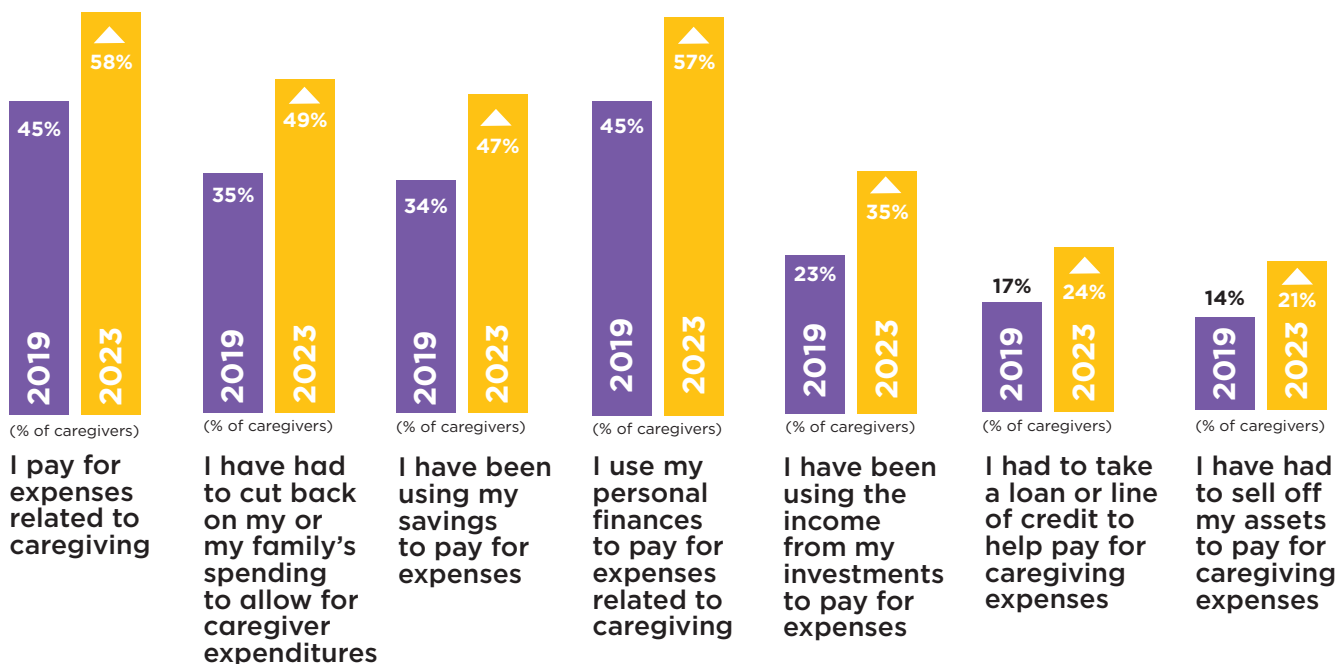
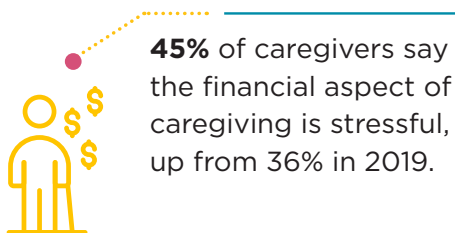
**“We have done everything we were supposed to do, paid off our home, saved for what was going to be the best time of our life, now we can’t do anything and I can’t afford groceries.”**


***Caregiver***



## FINANCIAL IMPACT OF CAREGIVING

Four-in-ten (39%) caregivers are facing financial hardship because of their caregiving responsibilities, up from 32% in 2019. In addition, more caregivers are using their savings or investments to cover expenses associated with caregiving. The financial impact of caregiving is one of the top reasons caregivers say they feel stressed.





**“Leaving my job may be the only option for me. Financially, I don’t know how I’ll do it, but working and taking care of my father is too hard and he’s my priority right now”**

*Caregiver*



## BALANCING WORK AND CARE

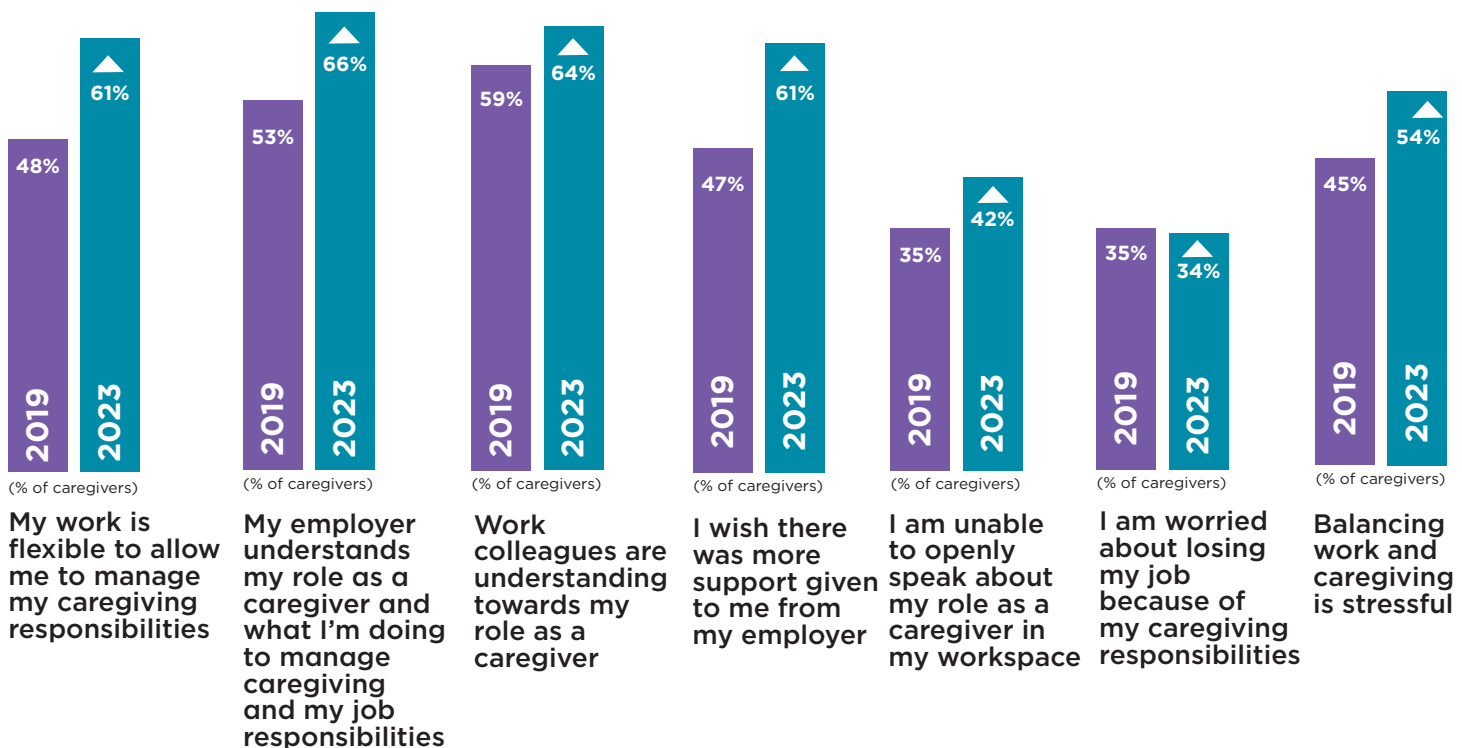
Greater flexibility and employer understanding of the caregiving role are two areas of improvement in the workplace. While this is positive, there is still room to improve as 61% say they wish they had more support at work (up from 47% in 2019) and 42% say they are unable to speak openly about their caregiving role at work (up from 34% in 2019).



**67%** of Ontario's 4M caregivers work



**40%** of working caregivers say they have considered quitting their job to provide better care



## FORGING AHEAD

The Spotlight Survey provides a quantitative snapshot of the caregiving experience, however it can't compare to the stories and personal experiences that caregivers share with the OCO team each and every day. It's these moments of vulnerability and connection that inspire the entire team to work to keep the momentum going. Looking ahead, OCO will continue to enhance and expand caregiver supports at an individual, organizational and system level. It will continue to work with organizations, its leaders, and staff to help improve the lives of Ontario caregivers.

OCO cannot do this critical work alone. If your organization interacts with family caregivers, we want to work with you.

On behalf of everyone at the Ontario Caregiver Organization, thank you to the more than 800 caregivers who participated in the Spotlight Survey and to the caregivers who collaborate and/or provide feedback through OCO's advisory group, working groups, caregiver panel and more. OCO would also like to thank its partners in the health system and beyond who share OCO's vision of improving the lives of caregivers.



## CAREGIVER PROFILE - WHO DO THEY CARE FOR?

Two in five caregivers (39%) care for their parents or in-laws. A quarter (25%) are caring for extended family members such as grandparents, siblings, or other relatives, and 6% are caring for children.

Caregivers are most commonly supporting someone over the age of 65, with a condition related to aging, including physical and mobility issues, cognitive issues like dementia or Alzheimer’s and cardiovascular issues. Caregivers providing care to their children are usually caring for mental health related issues (41%), and cognitive issues (41%).

Half (51%) of the caregivers belong to the “sandwich generation”. They are caring for children under the age of 18, while also supporting a parent or in-law.

PROVIDING CARE TO	
Parent/Step-parent	39%
Spouse/Partner	19%
Grandparent/Step grandparent	15%
Friend/Neighbour/Colleague	9%
Child/Step-child (18 years or older)	6%
Parent in-Law/Step-parent in-Law	6%
Sibling/Step-sibling	5%
Extended family	5%
Child/Step-child (under 18 years of age)	5%
Prefer not to answer	1%

CARE RECEIVER AGE	
Under 13	4%
13-17	2%
18-24	3%
25-34	6%
35-44	5%
45-54	8%
55-64	11%
65-74	18%
75+	46%
Don't know	4%

## METHODOLOGY

An online survey was conducted among N=820 self-reported caregivers in Ontario, 16 years of age and older. 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, mental health challenge or disability, or an aging 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, assisting with meals, assisting with the washroom, 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 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.

Surveys were conducted between September 19 – 28, 2023

While quotas were put in place to ensure representation across demographics and regions, 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 N=812 would be +/- 3.4%, 19 times out of 20.



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Phone: 416-362-CARE (2273) or 1-888-877-1626

[www.ontariocaregiver.ca](http://www.ontariocaregiver.ca)



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