



THE ONTARIO

caregiver

ORGANIZATION

SPOTLIGHT REPORT

CAREGIVING IN YEAR 3 OF THE PANDEMIC

DECEMBER 2022



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.

Read our [2021-2024 Strategic Plan](#)

Acknowledgements

We greatly appreciate the time and openness of the 820 caregivers from across Ontario who participated in this survey. We would also like to acknowledge Pollara Strategic Insights, who conducted the survey and prepared the background report on which this report is based. Their expertise and insights have been invaluable. We want to also take this opportunity to thank the caregivers who are part of OCO's Caregiver Advisory Group, the online caregiver panel, and many working groups which give us an opportunity to generate ideas, collaborate on projects and apply their insights to everything we do.

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MESSAGE FROM THE CHAIR AND CEO

Dear Friends and Colleagues,

A lot has changed since we published last year's Spotlight Report. Most Ontarians are vaccinated, Covid-19 restrictions have eased, and many programs and services have re-opened. What hasn't changed is the impact caregiving is having on caregivers. There are far too many Ontarians struggling to cope physically and emotionally.

Our health care system is in crisis. There are fewer nurses and personal support workers adding more pressure on caregivers to deliver care that would otherwise fall to a health care professional. While 66% of caregivers are fairly new to the role (less than 3 years), many find themselves on the brink of collapse, feeling helpless and burnt out. In fact, 63% of caregivers say they reached their breaking point over the past year but still had to keep going.



This year's Spotlight report has uncovered notable insights on the caregiving experience at this point in the pandemic:

One in four caregivers say their caregiving responsibilities have become more difficult since the easing of Covid-19 restrictions

A third of caregivers are spending 10 or more hours a week providing physical or emotional support to someone in their life. This number spiked during the pandemic and hasn't decreased significantly with the re-opening of community programs and services

Two thirds of caregivers say they have experienced feelings of helplessness, burnout, and find it difficult to continue with their caregiving responsibilities. Almost half of caregivers who have been in the role for less than 2 years are saying they feel this way

A third of caregivers are experiencing barriers to accessing the support they need

One in four caregivers say their mental health is worse now, compared to when we were in the midst of the pandemic

A third of caregivers are worried about losing their job because of their caregiving responsibilities



This year, the OCO took a closer look at the experience of caregivers depending on where they live in the province. As health system transformation continues, we hope these regional insights (Appendix A) are of value to health leaders and provide a window into the caregiver profile and experience in their community.

As always, the Ontario Caregiver Organization (OCO) is here to support caregivers with its free direct-to-caregiver programs and services, including 1:1 and group peer support, caregiver coaching, educational resources, a 24/7 helpline and more. As we look forward, we are pleased to be working with government and health care partners to support the development of a provincial Essential Care Partner Program in hospitals and long term care homes and beyond. This program was originally created in response to access restrictions implemented during the pandemic and has been successfully piloted in more than 30 health care settings. A special thank you to the 60+ organizations who have helped to evolve this program, as part of OCO's Essential Partners in Care Learning Collaborative. While this work will take time, the impact will be a significant step forward in ensuring caregivers are recognized as part of the care team and have the information and support they need, when they need it.

We would also like to extend a sincere thank you to caregivers who continue to share their experiences and insights and collaborate with us so the Ontario Caregiver Organization can continue to improve and expand its programs and services, amplify your voices, and contribute to health care system transformation.

Sincerely,

David Mosher

Board Chair, The Ontario Caregiver Organization

Amy Coupal

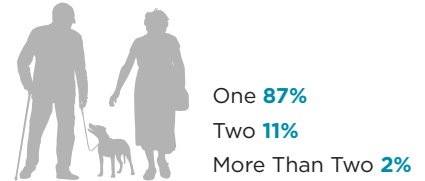
CEO, The Ontario Caregiver Organization



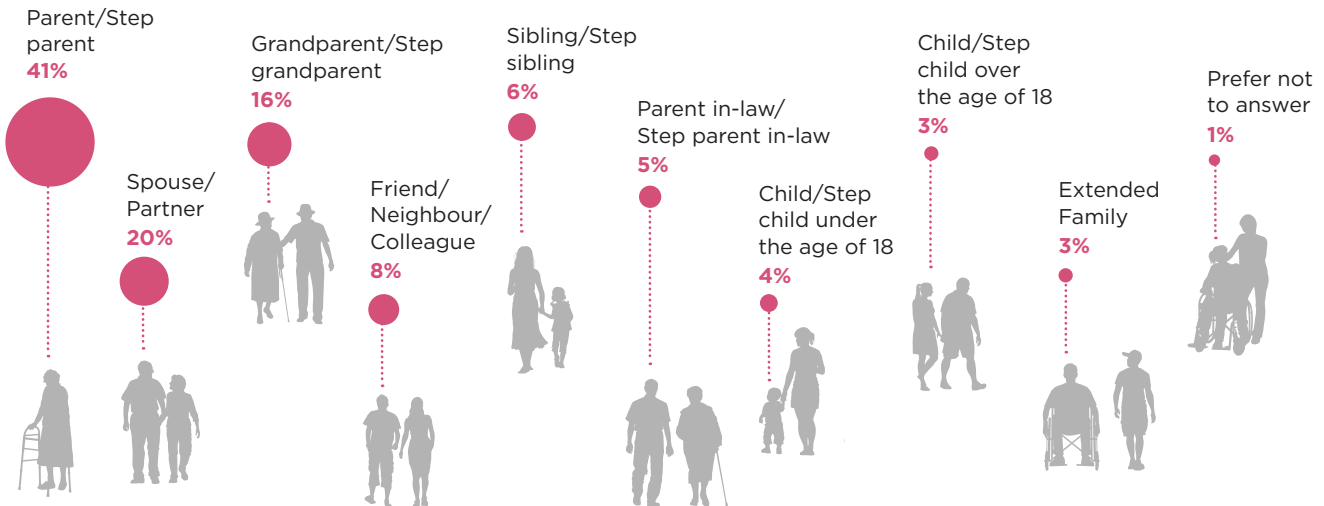
CAREGIVER PROFILE

There are an estimated 4 million caregivers in Ontario who are providing physical and/or emotional support to someone in need. Half (48%) are part of the “sandwich generation”, caring for their own parent(s) or in-laws while also raising children under the age of 18. A third of caregivers are new to the role, taking on the responsibility over the last two years.

How many people do caregivers support?



Who are caregivers caring for?



| HOW LONG HAVE CAREGIVERS BEEN PROVIDING CARE? | |
|---|-----|
| Less than 6 months | 16% |
| 6 months to less than 1 year | 19% |
| 1 year to less than 2 years | 17% |
| 2 years to less than 3 years | 14% |
| 3 years to less than 5 years | 11% |
| 5 years or more | 22% |
| Prefer not to answer | 1% |

| HOW OLD IS THE PERSON THEY SUPPORT? | |
|-------------------------------------|-----|
| 75+ | 50% |
| 65 - 74 | 19% |
| 55 - 64 | 9% |
| 45 - 54 | 6% |
| 35 - 44 | 4% |
| 25 - 34 | 5% |
| 18 - 24 | 2% |
| 13 - 17 | 2% |
| Under 13 | 4% |
| Don't know | 4% |

| WHERE DOES THE CARE RECIPIENT LIVE? | |
|--|-----|
| With the caregiver | 49% |
| In another private home | 37% |
| In health care facility or other health care setting | 11% |
| In other type of housing | 3% |

THE CAREGIVING ROLE



Four million caregivers across Ontario provide an estimated 75% of the care in our health care system. Yet, despite the critical role they play, one in five caregivers say they are rarely or ever included in discussions about care. The reality is caregivers are often on their own, navigating a complex health care system and the complex emotions that come with the role.

The caregiving experience changed throughout the pandemic. This past year, 25% of caregivers say their caregiving responsibilities have become more difficult even with the easing of Covid-19 restrictions, and since the pandemic, more agree they have taken on responsibilities that would otherwise have been provided by a personal support worker (PSW) or nurse.

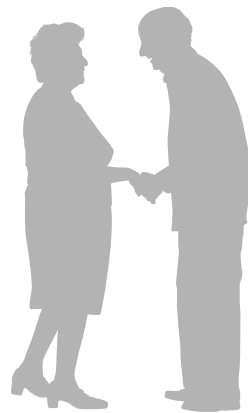
32% invest 10+ hours of care per week (26% pre-pandemic)

1/3 say they are never or rarely asked what supports they may need for themselves



79% agree that they have taken on a responsibility that otherwise would have fallen into the hands of PSWs or nurses

CAREGIVER HEALTH AND WELLBEING



25% say their caregiving tasks are getting more difficult since the easing of pandemic restrictions

Over two-thirds have found it difficult to continue with their caregiving tasks

63% feel they have hit their breaking point

One in 3 caregivers face barriers in accessing the support they need including long wait times or services not being available in their geographic area

The pandemic put a spotlight on the urgency of addressing caregiver well-being, but the fact that caregivers are not coping well in their role was a reality long before the pandemic and it continues to be a reality today. One in five caregivers (22%) say their mental health is worse than it was in the midst of the pandemic, and 63% feel they hit their breaking point last year but had no choice but to keep going. The top three things that caregivers say they need are respite, mental health support and peer support, however, one in three face barriers in accessing these services. One in four caregivers say they don't know what they need.



ACCESSING CARE FOR THE CARE RECIPIENT



One of the roles as a caregiver is to act as a bridge between health care providers and the care recipient. They gauge when urgent care is needed and accompany the care recipient to appointments including trips to the emergency department. Half of caregivers say the person they care for visited an Emergency Department or urgent care clinic in the past 12 months. One in 5 say they accessed care via Emergency and/or urgent care monthly.

| REASONS FOR EMERGENCY DEPARTMENT VISITS | |
|--|-----|
| Problem was too serious for the family doctor to treat | 44% |
| Needed care or services not available at the family doctor | 24% |
| Needed care when family doctor's office was closed | 20% |
| Wanted to get care faster | 19% |
| Family doctor directed patient to go to the hospital | 17% |
| Caregiver was overwhelmed and did not know where to turn | 11% |
| Family doctor was only offering virtual care and in-person care was needed | 9% |
| Couldn't get an appointment at the family doctor's office | 7% |
| Don't have a family doctor | 6% |
| Other | 3% |

ACCESSING SUPPORT FOR THE CAREGIVER

Caregivers are not always taking advantage of programs or services that are available to them. While half use in-home care or physical rehabilitation, less have used day programs, mental health services or community-based programs. The biggest barrier to using these programs is often that services are declined by the care receiver.

When asked what support caregivers need, the top three supports are respite, mental health support, and peer support. However, one in 10 say they can't access these programs and services because of wait lists or they are not available in their area.



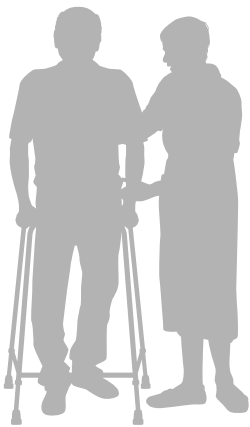
| THE SUPPORTS CAREGIVERS SAY THEY NEED | |
|---------------------------------------|-----|
| Respite care for the care recipient | 27% |
| Mental health counselling services | 27% |
| 1:1 support from another caregiver | 22% |
| Caregiving coaching services | 20% |
| Caregiver support groups | 17% |
| Don't know | 25% |

CONCERNS ABOUT THE FUTURE OF HEALTH CARE

| CAREGIVERS CONTINUE TO BE CONCERNED ABOUT THE FUTURE OF HEALTH CARE, SPECIFICALLY: | |
|--|-----|
| Longer wait times for tests, procedures, diagnosis, or treatment | 80% |
| Shortage of family doctors | 78% |
| Shortage of nurses | 76% |
| Less beds/spaces in hospital | 74% |
| Less availability and access to home care | 72% |
| A shortage of personal support workers | 72% |
| Less beds/spaces in long term care | 69% |

WORKING CAREGIVERS

Working caregivers are spread thin, having the added stress of balancing work and caregiving responsibilities and often, young families of their own. Sixty-four per cent or an estimated 2.5 million caregivers work. Those who worked from home during the pandemic are concerned about how they will manage their caregiving responsibilities when they return to a physical workspace. A significantly higher number are considering quitting their jobs because of their caregiving role.



62% are concerned about how they will manage caregiving when they return to a physical workspace.

More caregivers say their employer is understanding of their role, still more are considering reducing their working hours or quitting their jobs (37% vs 30% in 2021)

1 in 3 are worried about losing their job because of their caregiving responsibilities

51% wish for more support from their employer



WHAT WE CAN ALL DO

Care Providers:

1. Include caregivers as part of the care team. Include them in decision making and provide them with the information they need to be successful. Ask caregivers what support they need. [Learn more about how to engage caregivers in a meaningful way.](#)
2. Point them to the [Ontario Caregiver Organization](#) to access direct-to-caregiver programs and services, including the [24/7 Ontario Caregiver Helpline](#) - 1 833 416 2273 (CARE) for resources in their community.
3. Contact the [Ontario Caregiver Organization](#) and ask about how you can bring the Essential Partners in Care Program to your workplace.

Employers

1. Create a caregiver-friendly workplace by demonstrating your commitment to caregiver employees through enhanced HR policies, supportive conversations, and flexible work options.
2. Work with the Ontario Caregiver Organization to host training and information sessions for your managers and staff. Share information about the Ontario Caregiver Organization; our [24/7 Helpline](#) at 1 833 416 2273 and point them to resources available.
3. Check out our [Guide for Employers](#) and [Employer e-Module](#) to determine what strategies may be helpful in your workplace.

Educators

1. Caregivers are children and youth too. Identify caregivers in your classrooms. Ask how they're doing and what support they may need. It can make a difference.
2. Provide reasonable accommodations to your students who are caregivers. Flexible deadlines, recorded lessons, and notetakers can help these students keep up with their educational responsibilities while balancing their caregiver responsibilities.
3. Refer young caregivers to [YoungCaregiversConnect.ca](#) and the [Ontario Caregiver Organization](#) where they can access information, programs, and supports including the Peer Support Program.

Family Members, Friends and Neighbours

1. Ask caregivers how they are doing. It's a simple thing that makes a significant difference.
2. Tell caregivers about the [Ontario Caregiver Organization](#) and let them know we have resources and programs that may help.
3. Offer practical help and support to the caregiver(s) you know. Caregivers are often reluctant to ask for help but providing practical or emotional support may make a significant difference. This could include errands, day to day tasks, providing food or a simple phone call to check in with the caregiver on how they are doing. Here are a few [more ideas](#).

OCO PROGRAMS AND SERVICES

Free programs and services are available to Ontario caregivers:



24/7 Helpline
(1-833-416-2273)



Helpful Webinars
(Live and Recorded)



e-Learning and
Educational Resources



Dedicated Resource
for Young Caregivers:
youngcaregiversconnect.ca



Group and 1:1 Peer Support
(online or by phone)



Group and 1:1 Counselling



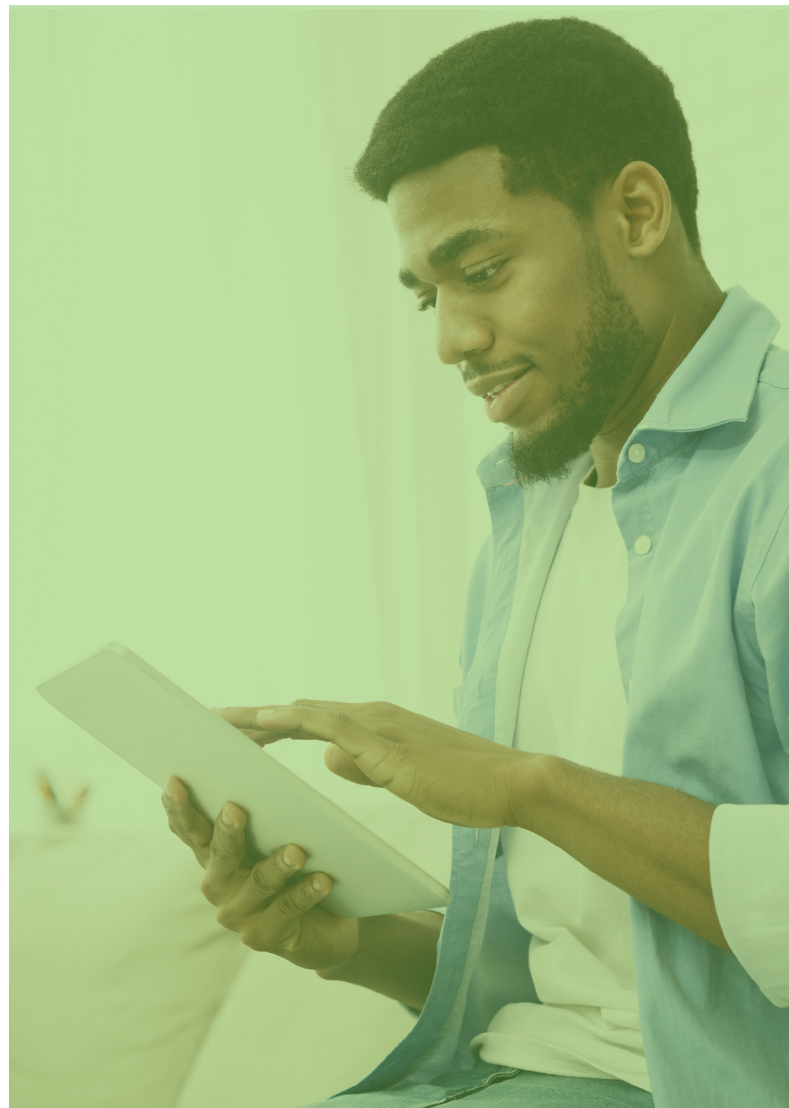
Toolkits for Caregivers
(For New and Working Caregivers)



Time to Talk Podcast



90Second Caregiver

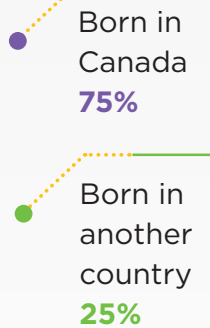
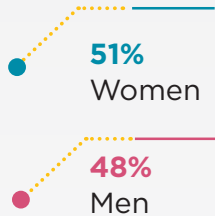


CONCLUSION

The Ontario Caregiver Organization exists to improve the lives of caregivers so they can do more than just survive in their role. The OCO team works to help caregivers thrive in their role. While there is much work to be done, the OCO is pleased to see the increasing support and engagement of healthcare leaders across the province. The opportunity to make a difference is now. It includes the care providers on the front line who interact with caregivers every day but there is also a role to be played by employers, who can implement caregiver friendly policies that enable caregivers to better balance work and home. There is also a role to be played by educators and the general public. There is something we can all do; steps we can take to let caregivers know they are recognized and supported. The OCO will use the insights in our Spotlight Report to continue to amplify the voices of caregivers, advance these conversations and support organizations to action change. Whether you are a healthcare leader, care provider, an employer, an educator or a family member or friend to a caregiver, we have resources that you can use to take action.



APPENDIX 1 – DEMOGRAPHIC PROFILE OF SURVEY RESPONDENTS



| AGE | Female | Male | Overall |
|-------|--------|------|---------|
| 16-25 | 12% | 17% | 15% |
| 26-44 | 28% | 35% | 31% |
| 45-63 | 40% | 33% | 36% |
| 65+ | 20% | 16% | 18% |

| MARITAL STATUS | |
|----------------------------|-----|
| Married | 50% |
| Common law partner | 10% |
| Widowed | 3% |
| Divorced | 6% |
| Separated | 2% |
| Single, never been married | 28% |

| CAREGIVER ETHNICITY | Caregiver Ethnicity | Care Recipient Ethnicity |
|--------------------------------|---------------------|--------------------------|
| White/Caucasian | 71% | 68% |
| Visible Minority | 32% | 34% |
| Chinese Heritage | 10% | 10% |
| South Asian | 6% | 6% |
| Black | 3% | 4% |
| Indigenous Heritage | 3% | 3% |
| Arab and/or Maghrebi | 2% | 3% |
| Southeast Asian | 2% | 2% |
| Latin American/Hispanic/Latino | 2% | 2% |

| CHILDREN IN HOUSEHOLD | |
|-----------------------|-----|
| Under 14 years | 19% |
| 14 - 17 years | 13% |
| 18+ years | 32% |
| No Children | 41% |

APPENDIX 2 - INSIGHTS BY REGION

Central Region - Mississauga Halton, Central West, Central, North Simcoe Muskoka

- In the Central regions, caregivers are more likely to be middle-aged (46-55 years; 25%). They are also most likely to be the youngest of caregivers (16-25 years; 18%) but are least likely to be 55+ year old (26%). These caregivers are most often caring for parents or in-laws (46%). A few care for their spouses (19%), while the younger caregivers are likely caring for grandparents (20%).
- Half (51%) have their care recipient residing in the same home as them, and a third (35%) have them living in their own home.
- Apart from old-age related ailments (39%), caregivers are most likely to be caring for physical ailments (28%) and cognitive issues such as Alzheimer's (20%) and cancer (16%). They are more often providing care for less than 10 hours per week (29-31%). However, there are also more recent caregivers who have started providing care since the past year and are caring for 10+ hours per week (12%). The incidence of this latter group of caregivers is highest in the Central region.
- Middle aged caregivers, and most likely to be younger caregivers, with very few older caregivers in this region. Their care recipients are often admitted to the hospital, and thus these caregivers are also often in touch with the health care team. They believe they are

seen as important by the health care team, but don't feel they are included in discussions. Both recipients and caregivers are most likely to use services such as respite care, home care services, mental health services, and supports from community-based and local organizations.

East Region - Central East, South East, Champlain

- Caregivers in the East are spread across all age groups, with slightly higher proportion of caregivers aged 36-45 (21%). They are least likely to be caring for their parents/in-laws (43%) compared to the other regions and are most likely to be caring for their spouses (22%). About one-in-ten care for their grandparents (15%) or a friend or neighbour (10%).
- Slight majorities (53%) have their care recipient residing in the same home as them. A third (35%) have their care recipient living separately in their own home.
- Four-in-ten (39%) care for an old-age related issue and are also providing care for physical ailments (34%), cognitive issues (23%) and mental health issues (17%). Most caregivers have been providing care for over a year and spend less than 10 hours per week caring (39%). They are also likely to be in an intensive caregiving situation where they have been providing care for over a year and spend 10+ hours caring in a week (26%).

- Mixed aged caregivers, who are in touch with the health care team, and feel like they are an important part of the team. They also feel included and agree that they are asked about what support they need as caregivers. They are likely to use different services for care recipients and themselves, but more often they need access to support groups and local organizations.

West Region - Erie-St. Clair, South West, Hamilton Niagara Haldimand Brant, Waterloo Wellington

- Caregivers belong to different age groups; however, younger caregivers (16-25 years) are most likely to be residing in the West (18%), similar to the Central region.
- They are more likely to caring for more than one person (18%) – with most caring for their parents/ in laws (42%), and a quarter caring for their spouse (23%) or caring for an extended family member (23%), such as a grandparent (13%) or a sibling (9%). Half (52%) live in the same home as their care recipient, and a third (35%) live separately.
- Most are dealing with old-age related issues (40%), physical ailments (37%), and cardiac issues (24%). This group is also most likely to be caring for mental health issues (20%). They are likely to be in this role for over a year and provide care for less than 10 hours per week (45%).

- Mixed aged caregivers and most likely to have younger caregivers in this region. Their care recipients are often admitted to hospitals or the ED, and they feel they are seen as important by the health care team, are included in discussions about care and are asked about what they need as caregivers. They are more likely to have accessed services for themselves, especially education materials on how to care for themselves as well as mental health support.

Toronto Region - Toronto Central

- Most caregivers are aged between 26-45 years (20-24%), and this region is least likely to have younger caregivers aged 16-25 (7%). They are least likely to be caring for more than one person (9%), most often care for their parents/ in-laws (47%), and also provide care to grandparents (16%), or friends or neighbours (14%). They are least likely to be caring for their spouse (11%).
- Care recipient usually live separately in their own home (49%), while a third (32%) live with the caregiver in the same home. 19% say their care recipient lives in a health- care facility or in some other living situation.
- Caregivers in Toronto are usually helping with aging issues (43%), along with physical ailments (33%) and accidental injuries or recovery from surgery (20%). They are more likely to have been providing care for more than a year and less than 10 hours per week (40%).

- Middle aged caregivers, and least likely to be younger caregivers. They are often in touch with the care recipient's health care team and are the most likely to feel that they are seen as important to this team. Despite this, they feel they are not always included in discussions about care. Their care recipients are more likely to have used different services, and these caregivers are also one of the most likely to have used services for themselves, especially mental health care services, and support from local groups.

North Region - North West, North East

- In North, caregivers are more likely to be 16-25 years old (17%), as well as most likely to be older, 55+ (58%). They are most likely to be caring for more than one person (17%) – other than caring for parents/in-laws (47%), caregivers also provide care to their spouse (22%), friend (12%), and are most likely to care for a child (9%) who is 18 years and older (6%).
- The housing situation is split – 44% care recipients reside in separate homes and 41% in the same home as the caregiver.
- Caregivers are mainly caring for individuals with old-age related issues (56%) and cognitive issues like Alzheimer's or dementia (26%), physical ailments (33%) or cardiovascular issues (21%). They are more likely to be long-term caregivers, that is they have been providing care

for over a year – more than a third (37%) provide care for less than 10 hours per week, but a third (31%) are also intense caregivers, providing 10+ hours of care. Caregivers in the North are most likely to be in an intense caregiving situation compared to the other regions.

- Caregivers are older in age. They are less likely to be in contact with health care professionals, and don't feel that they are seen as important compared to caregivers in the other regions. However, they do feel they are included in discussion about care. They are the least likely to use services for themselves or for their care recipient.

APPENDIX 3 – 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 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, and feeding, bathing and toileting needs, help with outdoor tasks, or anything else. It may also include providing physical support, assisting in certain health care 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.

Surveys were conducted between Oct 3 – 11, 2022. 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 N=820 would be $\pm 3.4\%$ 19 times out of 20.

Appendix 1 provides regional insights. Margin of error by region is provided below.

| REGION | | Interviews (Weighted) | Interviews (Unweighted) | Margin of error* |
|---------|---|-----------------------|-------------------------|------------------|
| Central | Mississauga Halton, Central West, Central, North Simcoe Muskoka | 241 | 203 | $\pm 6.9\%$ |
| East | Central East, South East, Champlain | 182 | 176 | $\pm 7.4\%$ |
| West | Erie-St. Clair, South West, Hamilton Niagara Haldimand Brant, Waterloo Wellington | 243 | 174 | $\pm 7.4\%$ |
| Toronto | Toronto Central | 98 | 162 | $\pm 7.7\%$ |
| North | North West, North East | 56 | 105 | $\pm 9.6\%$ |
| Ontario | | 820 | 820 | $\pm 3.4\%$ |



Ontario Caregiver Helpline: 1-833-416-2273

Email: info@ontariocaregiver.ca

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

www.ontariocaregiver.ca



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The views expressed in this publication are the views of the Ontario Caregiver Organization and do not necessarily reflect those of the Province.