



THE ONTARIO

**caregiver**  
ORGANIZATION

# Empower. Support. Connect

2022-23 IMPACT REPORT

## **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.



Two thirds of caregivers say they have experienced feelings of **helplessness**, **burn out**, and find it **difficult to continue** with their caregiving responsibilities.

## MESSAGE FROM THE CHAIR AND CEO

**Last year, 67% of Ontario's 4 million caregivers said they reached their breaking point but knew they had to keep going.**

Coming out of the pandemic, caregivers continue to struggle. More caregivers are investing more hours each week providing care, the majority are also raising a family and working. Providing care is getting harder and the number of caregivers who feel burnt out is steadily increasing.

The stories and experiences that caregivers share are authentic, raw, and sometimes heartbreaking. Some went through the pandemic with limited access to the family member, partner or friend they care for, others stepped up and provided more care when community services weren't available. Many continue to do so in the face of ongoing health human resource challenges.

Knowing that caregivers provide 75% of care in the health system and more are struggling to cope, creates a tremendous sense of urgency to reach more caregivers with programs and services that can help them through their caregiving journey. It also underscores the need to work with system partners to positively influence change in the health system and in the workplace. We must also continue to raise awareness among the public about the caregiving role and what we can all do to make a difference.

This was the focus of our work over the past year. We are proud of what was accomplished and the impact the OCO is making on the caregiver experience at the individual, organizational and system level. Here are just a few highlights:



- **Achieved a 50% increase in participation in OCO's activities**, programs, and services



- **Launched the Essential Care Partner Support Hub** in partnership with Ontario Health. This initiative means caregivers will be recognized, included, and supported as essential partners in care in hospitals and long term care homes, even during times of system pressures



- **Awarded 37 grants to family support networks** that support those caring for an adult with a developmental disability, with funding from the Ministry of Community, Children and Community Services



- **Created the Undercover Kindness Project** with brand ambassador Erica Ehm, which has been instrumental in raising awareness of the caregiving role, educating the public on the challenges of being a caregiver and inspiring people to help a caregiver in their life

At the heart of everything we do are caregivers. We would like to extend a special thank you to OCO's Caregiver Advisory Group, advisory panel members of Caregiver Voices and the many working group members who participated and provided the feedback that continues to shape our work. Thank you to all the caregivers who shared their experience with the OCO team to inform our work, including this report, and to our partners in the health system and beyond for sharing our passion and commitment to improving the lives of caregivers.

**David Mosher**

Board Chair, Ontario Caregiver Organization

**Amy Coupal**

CEO, Ontario Caregiver Organization

## 2022-23 AT A GLANCE



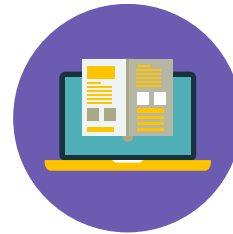
**168,553**  
Client  
encounters\*



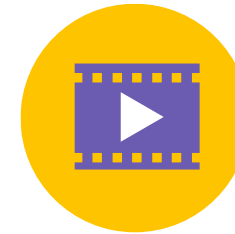
**2,756**  
Helpline Calls/  
Chats



**50,604**  
Views of Online  
Events



**133,526**  
Website  
visits



**66.4M**  
Media  
Impressions



**5,623**  
e-Newsletter  
Subscribers



**141**  
Stakeholder  
Collaborations



**9**  
Partnerships  
with Ontario  
Health Teams



**22**  
Submissions to  
government/  
system leaders



**62**  
Employers Engaged  
to Adopt Workplace  
Tools/Practices

\*Encounters are defined as engagement, information, education, training, or support provided to a caregiver or professional intermediaries through a variety of activities, programs, and services.

# EMPOWERING, CONNECTING AND SUPPORTING CAREGIVERS

OCO provides free programs and services to caregivers with diverse experiences and backgrounds. Whether it's the Helpline, Peer Support, or an educational session, the goal is to empower, connect and support caregivers with the information they need. When asked about their experience with an OCO program or service, more than 3 in 5 caregivers said it increased their confidence in maintaining their physical and mental health and 76% of caregivers said the program increased their awareness of how to access resources and supports. Others benefited from sharing and hearing from other caregivers about their experiences.



## THE ONTARIO CAREGIVER HELPLINE - 1-833-416-2273

As a caregiver, it can be challenging to find information about programs and services that are available in the community or online. This was the inspiration behind [the Ontario Caregiver 24/7 Helpline](#) – a one-stop resource for information and referrals that connect caregivers to the support they need. This might include respite, a community support group, a program for the care recipient or an OCO program that may benefit the caregiver themselves.

Professional Community Resource Specialists in English and French answer the Helpline. Interpretation services are available in 150 languages upon request. Helpline Specialists are trained to understand the unique needs of caregivers and help connect them with the support they need.



**2,756 people contacted the Ontario Caregiver Helpline where Community Resource Specialists made 3,777 referrals to local supports and services.**

## THE CAREGIVER SUPPORT TEAM

Through the Helpline or another OCO program, caregivers who could benefit from greater support are referred to the Caregiver Support Team. These caregivers may be experiencing burn out, system navigation challenges, or they may be struggling with current services that are not meeting their needs.

The Caregiver Support Team is comprised of OCO staff with diverse professional backgrounds who work together to provide a supportive and inclusive approach to identifying immediate next steps to meet a caregiver's needs. This can include informed consultation and suggestions for helpful resources or support and meaningful connection to others who are facing similar situations. The Caregiver Support Team can be accessed through the Helpline or other OCO programs.



**202 caregivers were referred to The Caregiver Support Team and 409 referrals were made to a program or service to meet the unique needs of these caregivers.**

*"Thank you for not passing me onto someone else...I have talked to so many people about this and no one has helped me come up with a plan before, thank you."*

*- Caregiver*



# PEER SUPPORT

Caregivers tell us that sometimes just knowing that someone else understands what they're going through makes a difference. The Ontario Caregiver Organization's [Peer Support program](#) provides caregivers with a safe space to share their experience. Taking an empathetic and non-judgemental approach, Peer Mentors share their own relevant caregiver experience, provide neutral and supportive advice, and suggest helpful resources. The OCO offers online group peer support groups and a 1:1 Peer Support program.



**224 new caregiver participants registered for the 1:1 Peer Support Program. 82 new mentor matches were made, and 26 new Peer Mentors were trained.**

## Meet Katherine

*“The Ontario Caregiver Organization is like a 411 for caregivers.”*



Click on video or [here](#) to watch on YouTube

## CAREGIVER COACHING PROGRAM

The [Caregiver Coaching Program](#) offers individualized support for caregivers showing signs of burn out or distress in their role. Potential participants are either referred internally from other OCO Programs and Services (such as Peer Support or Helpline) or through a self-referral form on the OCO website. All participants are assessed by OCO staff, who are part of the Caregiver Support Team (CST), for program eligibility, based on established criteria. Caregivers can receive up to six coaching sessions. The program aims to improve resilience and leverage personal strengths to meet the challenges of caregiving.



**82 caregivers collectively accessed 509 coaching sessions. 80% of participants said they felt less distressed after the coaching sessions.**



### Meet Sara

I would describe my caregiving journey as a slow burn. For many years after my dad passed away, my mom lived independently. Shortly after turning 80, her health evolved, and I would help my mom with appointments and groceries. It was all manageable at first, but when my mom was diagnosed with Alzheimer's, my caregiving responsibilities became more complex. More care was needed, more people were involved, and coordinating all of it felt like a full-time job. When the pandemic hit, everything just became so much harder, and caregiving took an even more emotional and mental toll. Even though my wonderful siblings and I were a cohesive team of caregivers, and I have wonderful, supportive friends, I still felt very isolated, alone, and powerless. I eventually had no coping mechanisms left to keep me going. I wasn't sleeping well or taking care of my health; I was just trying to keep up with all aspects of my life. While I loved being able to care for and spend time with my mom,

I was showing all the signs of burn out. I took a leave from my job to focus on my wellness. I came across the Ontario Caregiver Organization by chance - an ad in my Instagram feed. It never crossed my mind that there was an organization solely focused on supporting caregivers. I joined the SCALE program and 1:1 counselling.

Being with people who were having the same experiences as me, at the same time, became a huge source of support. I learned that it was ok to feel how I was feeling. I was reminded that I can't pour from an empty cup. I would never have thought that just a couple of sessions would enable me to get back on my feet. I felt empowered and stronger mentally and emotionally.

My mother has now passed away and my caregiving journey has ended. I'm now working through my grief and just missing my mom. When I look back over the past year, I know I couldn't have done it without the help of the Ontario Caregiver Organization. I am so truly grateful.

## SCALE

The [SCALE](#) Program (Supporting Caregiver Awareness, Learning and Empowerment) aims to empower caregivers with practical information and skills to focus on their own mental health and well-being. The program offers caregivers weekly psychoeducational webinars (live or recorded), divided into two 4-week sessions with strategies, tools, and resources to help caregivers better cope with difficult caregiving emotions. The program also provides access to a confidential online group and/or individual counselling which is optional.



**There were 10,930 caregiver encounters throughout the SCALE experience. Recorded SCALE webinars were viewed over 3,798 times over this fiscal year.**

### *Meet Susan*

*“OCO has been a life-saver for me. They have made my caregiving journey so much easier. I want other caregivers to know there are supports available that can empower you as a caregiver.”*



Click on video or [here](#) to watch on YouTube

# WORKING WITH PARTNERS TO IMPROVE THE CAREGIVING EXPERIENCE

Delivering free direct-to-caregiver programs and services is only part of the work we do at the Ontario Caregiver Organization. In collaboration with system partners, OCO is working to ensure caregivers are included as essential partners on the care team and supporting organizations in building their capacity to support caregivers.



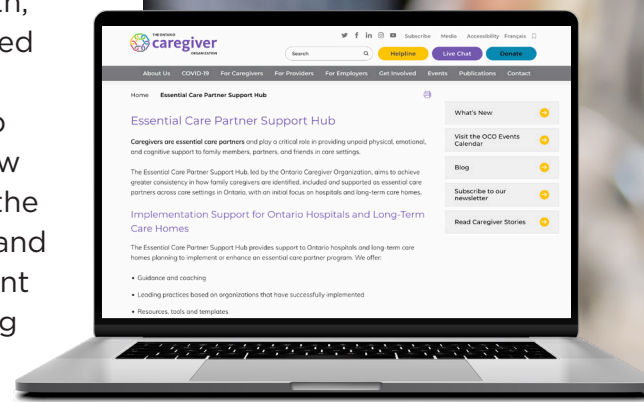
## ESSENTIAL CARE PARTNER SUPPORT HUB

Access restrictions put in place during the pandemic had a devastating effect on many caregivers and the person they care for. The Ontario Caregiver Organization envisions a future where caregivers are engaged as part of the care team, providing the critical physical and emotional support to a family member or friend, even during times of system pressure.

In partnership with Ontario Health, the OCO launched its [Essential Care Partner Support Hub](#). The new Support Hub team is actively working with hospitals and long-term care homes to either enhance or implement their Essential Care Partner Program policies and leading practices that enable caregiver inclusion by formally identifying, including and supporting caregivers as part of the care team. The Support Hub team provides coaching and guidance, as well as

access to ready-to-use resources such as Caregiver ID, created in collaboration with caregivers and care providers. Through the Support Hub, organizations can also connect with peer organizations that have implemented an Essential Care Partner Program with success.

“We can’t do it without our Essential Care Partners. They provide incredible support to our patients and residents” says Paula Doering, Senior Vice President Clinical Programs, Chief Nursing Executive and Allied Health, Bruyère. “We believe our Designated Care Partners have the potential to reduce the risk for falls and help improve health outcomes. We know that understanding the impact of the designated care partner program and fostering its continued improvement will be just as important as creating the program.”



## FAMILY SUPPORT NETWORK GRANTS

For the second year, the Ontario Caregiver Organization (OCO) received funding from the Ministry of Children, Community and Social Services (MCCSS) to enable capacity-building grants to help support, strengthen and expand the peer networks of families and caregivers that provide support to adults with developmental disabilities in Ontario.

Of the 37 applicants selected for funding:

- Eight grants were awarded to support the creation of new Family Support Networks and build capacity for those that are less established.
- Twenty-two grants were awarded to build capacity of Family Support Networks that are already established but need funding to sustain, strengthen and expand.
- Seven grants were awarded to support collaborative initiatives that will have higher impact and will benefit families and caregivers of adults from more than one Family Support Network or reach multiple communities across the province.

*“The grant allowed us to develop marketing materials and create a website to be able to share our story with the broader community...and it has allowed us to purchase a zoom membership - an important platform to be able to bring families from far and wide together. This grant has helped us to connect with more families than we could have ever imagined and to help these families feel less isolated. - Clovis and Sherron - Sawubona Afrocentric Support Network*

## SUPPORTING CAREGIVERS IN THE WORKPLACE

64% of caregivers are balancing work and caregiving responsibilities. A third are worried about losing their job because of their caregiving role and half wish for more support from their employer. In order to better support [working caregivers](#), the OCO has workplace specific tools, guidance, e-Learning, and virtual information sessions for working caregivers focused on achieving better balance between work and caregiving demands.



**62 employers were engaged this year to support adoption of caregiver-inclusive practices and tools. 1,300 people either attended a workplace information session or downloaded working caregiver resource materials from the website.**

*“I can’t believe how many other co-workers are going through this too” - Working Caregiver*

# RAISING AWARENESS OF THE CAREGIVING ROLE

The Ontario Caregiver Organization engages with media and social media influencers to help ensure the conversation about caregiving stays top of mind. This year, the Ontario Caregiver Organization was mentioned 221 times in media and earned over 66 million media impressions. The organization also launched a new initiative that asked the public to nominate a caregiver in their life for a random act of kindness.



## THE UNDERCOVER KINDNESS PROJECT

A little kindness towards a caregiver can go a long way, which is why the OCO partnered with Erica Ehm to launch the [Undercover Kindness Project](#). Each video shares the experience of a caregiver and shows what small acts of kindness can do to recognize them. The impetus for this project was caregiver feedback around the stigma related to their role. While they need help, they rarely ask for it because they don't want to be judged, or worse, they fear that the help won't be there. We all know a caregiver, so the underlying message of The Undercover Kindness Project is to recognize and support a caregiver in your life. Don't wait to be asked, just do something meaningful for them. Stop by with coffee, pick up groceries, mow the lawn – it's the small things that make a difference. Just ask Marisa.

### *Meet Marisa*

The Undercover Kindness Project was featured on [Global News](#), [Breakfast Television](#) and many other news outlets.



Click on video or click [here](#) to watch on YouTube



# ENGAGING CAREGIVERS IN OUR WORK

At the centre of everything we do is caregivers. Nothing about them, without them. Through the Caregiver Advisory Group, the Caregiver Advisory Panel and numerous working groups, the OCO engages with caregivers to understand their lived experience and what needs to be done to improve the lives of caregivers. Caregiver engagement not only helps the OCO improve its programs and services, but it helps to ensure the caregiver voice is heard as a part of regional and provincial dialogue, particularly at this time of health system transformation.



The Caregiver Advisory Group meets regularly with OCO leadership. In the past, the group has generated ideas and provided input on various topics including, primary care – pathways to support for caregivers, caregiver terminology, the essential role of caregivers and support after the caregiving role ends.

The Caregiver Advisory Panel is open to all caregivers, through [Caregiver Voices](#), who would like to provide feedback on OCO’s program and resource development and other initiatives. The panel has provided new content ideas for OCO’s webinar series, as well as important feedback to Health Canada on caregiver concerns related to Covid-19 Home Rapid Antigen Tests. The panel also provided insights on Bill 7 which were shared with the Ontario government and system partners.

## ***Meet Bhavini***

*“As a group we share our lived experiences and talk about solutions that will push the agenda forward to improve the supports for caregivers. Being a part of the advisory group has greatly influenced my caregiving journey because I know there is an organization making the effort to help caregivers.”*



Click on video or click [here](#) to watch on YouTube

## IDEA

The Ontario Caregiver Organization is committed to **Inclusion, Diversity, Equity** and **Access** (IDEA) in our work. While there is more work to do, the OCO implemented a number of initiatives to help ensure we offer a space that is inclusive to all.

- Board and staff IDEA working groups
- Board and staff anonymous IDEA surveys conducted, reviewed and feedback implemented
- Organizational IDEA policy developed and approved by the Board
- Board and staff IDEA training on key topics and issues with external subject matter experts and content
- Board and staff recruitment processes refined from an IDEA standpoint
- Language and content updates to reflect most inclusive, person centered language and best practices
- A wide range of equity-deserving communities to ensure programs, services and practices are refined appropriately

Both the board and staff of OCO will continue to work in collaboration with a wide range of experts, organizations and individuals with lived experience to advance our commitment to IDEA at OCO.



## LOOKING FORWARD

As we look forward to the year ahead, we're excited about the new opportunities to reach more caregivers with supports and services that can help them in their caregiving journey.

We look forward to our continued work with system partners on caregiver issues and the expansion of the work being done through the Essential Care Partner Support Hub within hospitals and long-term care homes and dialogue with other system partners to expand that work into other care settings. With this being the final year of OCO's current [strategic plan](#), we are also excited to undertake caregiver and stakeholder engagement to start to envision the new opportunities that lay ahead for the Ontario Caregiver Organization. There is much more work to be done to improve the lives of caregivers and we will build on feedback, insights and emerging priorities to work with and for caregivers on what they need most.



Ontario Caregiver Helpline: 1-833-416-2273

Email: [info@ontariocaregiver.ca](mailto:info@ontariocaregiver.ca)

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

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



Funded by:

