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

We are proud to share OCO’s Impact Report for 2023-24. This year marks a significant milestone as we conclude our 2021-2024 Strategic Plan, a period characterized by unwavering dedication and relentless pursuit of our purpose to improve the lives of Ontario’s estimated four million caregivers.

This past year can best be described by the words growth and momentum. The Ontario Caregiver Organization (OCO) saw a surge in the number of caregivers accessing its free programs and services, underscoring the significant need for caregiver supports. In some cases, the increase in program registration was almost 60%.

This year, the Spotlight Report explored changes in the caregiving experience over the past five years. We learned that caregivers are feeling tremendous emotional and financial strain, because of their caregiving role. In fact, 73% of caregivers said they weren’t sure they would be able to handle their caregiving responsibilities going forward. We have shared insights from the Spotlight Report with government, healthcare leaders, and organizations that interact with caregivers to help inform their work. When we think of the critical role caregivers play in the healthcare system and our society, we need to collectively focus on how we can make things easier so caregivers can thrive rather than just survive.

To that end, OCO hosted its first Partners in Care Roundtable, convening more than 90 leaders from across all aspects of the healthcare system, including the Minister of Health, the Honourable Sylvia Jones. The event was about sharing and building on the progress of OCO’s Essential Care Partner Support Hub, which was launched last year, in partnership with Ontario Health. The goal of the event was to build on the progress of integrating caregivers as essential care partners across all healthcare settings in Ontario and collaborate on future opportunities to advance the recognition and empowerment of caregivers. The event was a resounding success, and we are excited to see momentum building in the growing recognition and inclusion of caregivers as part of the care team. We are truly at a turning point, laying the
foundation for a whole system approach with caregivers as partners in care.

As we celebrate our achievements, we also embrace opportunities for further growth. The continued support of the Ontario Ministry of Health and support received from Ontario Health, the Canadian Centre for Caregiving Excellence and Petro-Canada Caremakers Foundation last year signifies not only financial investment in our work, but also a shared vision for a future where caregivers receive the recognition and support they need and deserve.

Looking ahead we eagerly anticipate the next phase of our journey and our new strategic plan. Armed with the lessons learned and the momentum gained, we remain steadfast in our commitment to improve the lives of caregivers.

On behalf of the entire organization, thank you to our partners and volunteers for your continued support. OCO couldn’t do this work without you. To the caregivers who connect with us for help and shape our ongoing work, thank you for putting your trust in OCO. Together, let’s continue to forge ahead, fueled by our passion, purpose, and unwavering resolve.

Sincerely,

David Mosher
Board Chair,
The Ontario Caregiver Organization

Amy Coupal
CEO,
The Ontario Caregiver Organization
The Ontario Caregiver Organization offers direct to caregiver programs and services, in addition to hundreds of downloadable resources on its website.

Many of the programs are self-directed, meaning they are accessed on demand, by thousands of caregivers. These resources include the 24/7 Caregiver Helpline, monthly educational webinars, and website resources including a unique website for young caregivers. Other programs are for caregivers who would benefit from greater support through OCO’s Peer Support Programs, Caregiver Coaching and/or the Caregiver Support Team.

This combination of self-directed learning and personalized support is helping caregivers feel more connected and empowered in their role.

“The 1:1 Peer Support program was an amazing experience for me. It was wonderful to have insights from someone who has so much lived experience with this. The initial intake was easy and efficient, my mentor was very well suited to me and met my needs, and I feel much stronger coming out of this. I would recommend this program to anyone in the position of caregiving. Thank you!”

*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.
EXPANDING CAREGIVER SUPPORTS IN THE COMMUNITY

In partnership with the Ministry of Children, Community and Social Services, OCO provided 42 capacity building grants to Family Support Networks (FSNs) across the province, to fund community-based initiatives that support caregivers and families of adults with developmental disabilities.

One significant aspect of these initiatives was the focus on expanding support within diverse communities including Black, Jewish, French-speaking, and Chinese-speaking populations. Additionally, many FSNs prioritized serving caregivers in rural communities, recognizing the unique challenges faced by those in remote areas.

By supporting activities from educational workshops to local events, these grants made it possible for caregivers to share information and connect with a community of peers who uniquely understand their experience.

“This grant has revitalized member engagement, strengthened social connections, and fostered a sense of belonging among families of adults with developmental disabilities. It has provided families with an opportunity to connect and share experiences, deepening the bonds within our community and enriching the lives of families”

– FSN Grant Recipient

Learn more about the Capacity Building Grants for Family Support Networks
A CAREGIVER’S EXPERIENCE WITH OCO’S HELPLINE

PROVIDING GREATER SUPPORT TO THOSE WHO NEED IT

Alex heard about OCO at his local Older Adult Centre and called the Caregiver Helpline. The Community Resource Specialist discussed Alex’s experience and needs as a caregiver to his spouse and registered Alex, with his permission, into OCO’s Caregiver Coaching Program; a program that provides up to six 1:1 sessions with a professional caregiver coach. The Community Resource Specialist felt he could also benefit from a greater level of support and processed a referral to the Caregiver Support Team (CST).

The CST followed up with Alex by phone and validated the information shared through Helpline. During this conversation, Alex shared more details which highlighted other needs. From here, CST was able to provide Alex with more information regarding home and community care services, financial supports, and local in-person connection opportunities. By contacting the Helpline, Alex was connected to the support he needed both through his community and through the Ontario Caregiver Organization.

The Ontario Caregiver Helpline provides caregivers with 24/7 support and one point of contact to resources in the community. Community Resource Specialists are specifically trained in caregiver needs and talk through supports and resources available, both in the community and through the Ontario Caregiver Organization. When a caregiver is identified as having more complex needs, they are referred to OCO’s Caregiver Support Team.

This year, Helpline calls increased by almost 13% for a total of 3,185 calls/chats. 10% of caregivers needed greater support and were referred to the Caregiver Support Team.
CAREGIVER VOLUNTEERS: THE HEART OF OCO

Caregiver volunteers play an integral role in the development of OCO programs and services.

There are currently 295 volunteers who support our work in a variety of ways including as peer support facilitators, in workshop groups, or as part of Caregiver Voices - OCO’s online platform where caregivers can share their insights and provide feedback on an array of topics. Here are just a few ways volunteers supported the work of OCO last year.

- Participated in workshops designed to improve OCO’s website
- Participated in evaluating OCO programs and services
- Provided feedback and insights on the topic of caregiver compensation
- Consulted on the creation of new content that would be helpful for caregivers
- Provided insights on better understanding caregiver supports in Ontario
- Contributed to the adaptation of the I am a Caregiver Toolkit to apply to long term care
- Contributed to the development of OCO’s Strategic Plan
- Provided input on volunteer engagement to further grow this program
- Participated as a Peer mentors, Online Support Group Facilitators, and/or Program Ambassadors
- Participated on OCO’s various working groups, Caregiver Advisory Group, and Caregiver Advisory Panel
- Participated as a member of OCO’s Board of Directors
VOLUNTEERING: GIVING BACK AS A WAY TO HEAL

“I couldn’t put my feelings into words until I started this work. I feel so seen. I’m thankful to have found the Ontario Caregiver Organization and I’m thankful to have the opportunity to help others”.

Lux, Young Caregiver Volunteer

Lux has been a caregiver volunteer with OCO for just over a year. As a young caregiver for her mother, who was diagnosed with a mental health condition when she was just 11, Lux navigated her responsibilities without ever hearing the term “caregiver.” It wasn’t until a care provider enlightened her about this role and the expansive community of individuals who had undergone similar experiences that Lux’s awareness expanded. Encouraged by this newfound understanding, Lux joined a young caregiver support group, where she unearthed a supportive network and discovered the wealth of resources offered by the OCO.

She later became a valued member of OCO’s Caregiver Advisory Group and actively engaged in various working groups, delving deeper into the distinct challenges that caregivers encounter. Drawing on her expertise as a research assistant, Lux provided valuable insights from her scholarly work. As a co-author of two publications in the International Journal of Environmental Research and Public Health, Lux explored the experiences of young caregivers and service providers during the pandemic. These insights directly influenced her input into shaping OCO programs and services, including its volunteer program, to better cater to the varied needs of caregivers.

Moreover, Lux utilizes her policy insights gained from her Master’s in Public Service and her position as a researcher at a non-profit centered on social policy, to strengthen her advocacy for caregivers and marginalized individuals. This comprehensive approach, supported by her lived experiences as a young caregiver and her volunteer engagement with OCO, highlights her unwavering dedication to effecting positive change. Lux recognizes how her journey as a young caregiver has not only inspired her but also fueled her passion to advocate tirelessly for others facing similar challenges.

Lux describes the work she’s doing for OCO as “soul work” and says that sharing her story and listening to the experiences of other caregivers has been “healing”.
AMPLIFYING CAREGIVER VOICES

While every caregiving experience is different, there are common and recurring themes that are known to impact caregivers’ mental health.

OCO engages with caregivers in a variety of ways and shares their insights with government, health system leaders, workplaces, and with the public to create greater awareness of the challenges they face and understanding of what we can all do to make a meaningful difference.

OUR IMPACT AT A GLANCE

172 M Media impressions
817 Media mentions
1,943 Downloads of the Spotlight Report

90 Cross sector delegates convened for Caregivers as Partners in Care Roundtable
17 Submissions and inputs to government and system leaders on topics of importance to caregivers
535 Meetings with organizations that interact with caregivers

“I felt so seen and heard today. I really appreciate the Ontario Caregiver Organization for giving me this space.”

Carla, Caregiver and Roundtable Participant
BRINGING CAREGIVERS AND HEALTHCARE LEADERS TOGETHER

“Whole system care starts with the whole person. We’re in this together. Let’s solve it together.”

Terrence Ho, caregiver keynote speaker

In February, the Essential Care Partner Support Hub hosted the Caregivers as Partners in Care Roundtable event, where over 90 delegates, including the Minister of Health, the Honourable Sylvia Jones, came together to talk about how to better recognize and support caregivers. Delegates who represented a cross section of the healthcare system included twenty caregivers and patients, as well as representatives from Ontario Health, home and community care, primary care, hospitals, long term care, academic, and front-line healthcare providers. The goal of the event was to build on the progress of integrating caregivers as essential care partners across all healthcare settings in Ontario and collaborate on future opportunities to advance the recognition and empowerment of caregivers.

With the support of keynote Terrence Ho, who shared his caregiving experience and the barriers he faced when caring for his mother and friend, and the challenges he continues to face caring for his brother, the event was a resounding success. Building on the work of the Essential Care Partner Support Hub it laid the groundwork for collaborative efforts to advance a “whole system” approach to caregiver integration and support within the healthcare system.

Explore insights from healthcare leaders about the pivotal role caregivers play in the healthcare system and learn more about the Caregivers as Partners in Care Roundtable.

“The system can change drastically... we need a system that supports family caregivers. We need a system that identifies them and actually includes family caregivers as key members of that care team and I see that role in primary care but then also across the care continuum as well.”

Dominik Nowak, President, Ontario Medical Association; Staff Physician, Women’s College Hospital; Assistant Professor, University of Toronto, Department of Family and Community Medicine
Excerpt from Terrence’s Keynote at OCO’s Caregivers as Partners in Care Roundtable.

I’ve been a caregiver since the age of 10, although it took 20 years for me to realize I was a caregiver. In my life, I care for my 36-year-old brother, Torrance who was diagnosed with Duchenne muscular dystrophy at the age of five. I also cared for my mother, through her cancer and mental health journey and a family friend, who was also Torrance’s personal support worker for many years.

What I’d like to impress on everyone here today is that we really need to start by seeing the caregiver as a whole being, a person who has emotional physical, mental, spiritual, and financial needs. So, as we think of a whole system of care and how family caregivers play a role in the ecosystem, we have to remember that caregivers are the people who see the patient as a whole person, knowing them intimately on a daily basis. We are the person who helps the patient navigate the whole system of healthcare. We are also likely untrained, but we learn as we go.

We may also come across as assertive, aggressive, demanding, and maybe sometimes seen as a nuisance. And this is mainly because we are grieving and are fearful of what our loved one is experiencing. As family caregivers, we are often the single source of patient information. But the constant need to repeat the story to each new healthcare professionals causes unnecessary stress.

We coordinate the care across multiple providers to ensure our loved one’s needs are met but we are not recognized or supported. We also save the Canadian healthcare system time and money. But we are sometimes regarded as a nuisance when we advocate for the patient. So today, as we learn from each other and collaborate on ways to integrate and understand the value of family caregivers know that we all want the best patient experience because it impacts all of us. Since all of us here in this room will either be cared for or be a caregiver in our lifetime, let’s remember we’re all in this together. So, let’s solve this together.
THE UNDERCOVER KINDNESS PROJECT

Caregivers often say they’re doing ok, even when they’re not.

They also say that when they’re feeling lonely and overwhelmed, it’s sometimes a small act of kindness that can make a meaningful difference in their day. After putting a public call out to nominate a caregiver in their life, we teamed up again with OCO ambassador, Erica Ehm, to deliver small and meaningful acts of kindness.

The Undercover Kindness Project made a significant impact in raising awareness of the challenges caregivers face and highlighting ways in which we can all contribute to supporting them in our communities. The campaign reached over 30 million people last year, through various media channels and drove more than 60,000 people to the dedicated webpage. The Undercover Kindness Project gave OCO a platform to share caregiver voices. By expanding our reach and ensuring more caregivers are aware of our organization, we are not only fulfilling our purpose but also facilitating greater access to our free programs and services. Ultimately, the success of the Undercover Kindness Project goes beyond mere numbers, it signifies a meaningful step towards building an understanding of caregiver’s needs and a more supportive and compassionate community for caregivers.

Watch A Special Meal for Terrence and Sakina’s Surprise Makeover.
OCO is working to effect change within the healthcare system.

This past year saw the launch of the Essential Care Partner Support Hub (ECP), greater collaboration with Ontario Health Teams, and a new partnership with the Canadian Centre of Caregiving Excellence that will enable a new program to support caregiver health and wellness.

“I don’t think we could have been able to do it without the help of OCO. The support has been phenomenal... all the resources have been excellent.”

Healthcare provider

**OUR IMPACT AT A GLANCE**

- 121 new hospital and long term care homes were engaged through the ECP Support Hub
- 5,208 visits to the ECP Support Hub webpage
- 502 downloads of ECP resources
- 2,066 individuals attended knowledge exchange, education events and learning opportunities provided by the ECP Support Hub
- 91% of care providers who accessed support through the ECP Support Hub said they applied the knowledge in their work
- 89% of organizations using the ECP Support Hub said it was useful or very useful
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Last year, in partnership with Ontario Health, OCO launched the Essential Care Partner Support Hub. The first of its kind in Ontario, the Support Hub supports healthcare organizations to implement and adopt essential care partner programs and practices that formally identify, include, and support caregivers as part of the care team.

Health system partners are engaging with the ECP Support Hub through participation in the Learning Collaborative, 1:1 guidance and coaching, visiting the website to read about and download resources, and through attendance at information sessions or educational events.

Its first year was one of remarkable momentum, with over 120 hospitals and long-term care homes newly engaged with the Support Hub. OCO plans to expand the ECP Support Hub’s work over the next four years to include home and community care, primary care, and community support services, engaging Ontario Health Teams throughout.

Learn more about how the ECP Support Hub is making a difference in the lives of caregivers.

“We didn’t know what we were looking for. The Essential Care Partner Support Hub team first did a brainstorming session with our Patient Experience Council and continues to support our workgroup and share knowledge about what’s happening in other places. It’s been a really good partnership in terms of hands-on support...moving something from an idea to implementation”

Hospital Manager
EXPANDING CAREGIVER SUPPORT THROUGH ONTARIO HEALTH TEAMS

Ontario Health Teams (OHTs) are a new way of organizing and delivering care across the province.

There are 58 Ontario Health Teams, each made up of multiple organizations focused on improving the experiences of patients and caregivers in their community with the goal of ensuring that everyone in Ontario can benefit from better coordinated, more integrated care. Our work with OHTs last year involved different collaborations aimed at building greater understanding and knowledge of the critical role caregivers play, building caregiver inclusion and support into Ontario Health Team models, as well as expanding access of OCO programs and services to caregivers.

This past year, OCO collaborated with Ontario Health Teams in different ways. A few examples include:

- The Couchiching OHT and Eastern York Region North Durham OHT now include OCO in their access and navigation model, while the Algoma OHT, Huron Perth Area OHT and others now have dedicated space on their websites to connect caregivers to support through the Ontario Caregiver Organization.
- The Lanark Leeds Grenville OHT launched Caregiver ID across its region.
- The Great River OHT developed a working group to implement Essential Care Partner Practices and Programs.
- North Western Toronto OHT has focused on the inclusion of caregivers as part of their best practice spotlight work which focuses on transitions and alternate level of care deliverables.
Last year, OCO proudly announced its partnership with the Canadian Centre for Caregiving Excellence – an initiative of the Azrieli Foundation, and the Canadian Institute for Social Prescribing to expand social prescribing across the province to better the lives of caregivers.

Social prescribing supports individuals in creating their own pathways to holistic well-being. Healthcare professionals and social service providers work collaboratively with clients to connect them with non-medical services that support basic needs, social and emotional well-being, and that foster community belonging.

The funding from the Canadian Centre for Caregiving Excellence will enable OCO to create pilot projects that build structured referral pathways that connect caregivers to support by way of integrated primary care teams and other community-based health system providers, and establish models for caregiver social prescribing that can be spread and scaled across the province.

[Learn more](#) about how social prescribing will support caregivers.
INCLUSION, DIVERSITY, EQUITY AND ACCESSIBILITY (IDEA)

OCO prioritizes inclusivity, diversity, equity, and accessibility in its work.

This past year OCO participated in a Leading Equitable and Accessible Delivery (LEAD) Assessment and Improvement Plan. This Improvement Plan covers seven themes: Leadership, Governance and Strategy, People Resources, Supplier and Partnership Management, Programs and Services Development and Delivery, Communication and Technology, and Facility Support.
As part of the LEAD work OCO participated in the following:

- **Pre-LEAD Survey**
  - To understand where OCO starts in making OCO more inclusive and accessible

- **Visioning Document**
  - To understand OCO’s mandate, purpose, and aspirations, and understand OCO’s competence related to accessibility and inclusion

- **Disability Inclusion Workshop**
  - To establish a common understanding of accessibility and inclusion terms and concepts used in LEAD

- **Self-Assessment**
  - To assess OCO’s strengths and improvement areas, based on the LEAD themes and indicators, with selected OCO staff, caregivers, and volunteers

- **Improvement Plan**
  - The Abilities Centre created an Improvement Plan and is working with OCO to review and prioritize recommendations to implement the plan

Since participating in the Lead Improvement Process, OCO has identified the following key areas of focus as an organization: Volunteer Engagement, Program and Service Accommodation, and Community Connection Diversification. Next steps include identifying action plans to move this work forward.

In addition to participating in the LEADS assessment, OCO’s IDEA working group holds regular discussion sessions with staff to generate better understanding of issues related to:

- Anti-oppressive practices
- LGBTQ2S+
- Women in caregiving
- Developmental disabilities
- Indigenous cultural safety and awareness
- Supporting Francophone caregivers
- Black caregiver experiences
- Supporting newcomer caregivers
CREATING CULTURALLY APPROPRIATE RESOURCES

In partnership with the Centre for Education and Research on Aging and Health (CERAH) at Lakehead University, OCO adapted its I am a Caregiver Toolkit for indigenous communities.

Within Indigenous cultures, caregiving is understood to be a part of traditional roles and values embedded within the collective and community responsibly to one another. Many people, therefore, may not consider themselves a caregiver. Instead, they are a family member, friend, or community member doing what needs to be done in providing wholistic support. This includes responding to people’s spiritual, emotional, mental, and physical needs. The adapted I Am a Caregiver toolkit reflects these considerations. This collaboration included extensive review and input from the CERAH advisory committee made up of Indigenous leads, elders, and community members to ensure that the language and content is meaningful for indigenous communities.

With the support of Petro Canada Caremakers, the language translation and cultural adaptation of the I am a Caregiver toolkit is underway. Through engagement of caregivers and partner organizations, the toolkit will soon be available in Cantonese, Mandarin, Punjabi, Tagalog, and Tamil.

As a team, we are committed to staying abreast of relevant conversations related to IDEA, to stay curious, learn, engage in meaningful dialogue, and take action.
WHAT’S NEXT?

We are excited about the progress and momentum that was achieved last year, both in OCO’s ability to support more caregivers, as well as our work with healthcare leaders across the province.

At a provincial level, the ongoing transformation of the healthcare system continues to present a significant opportunity for OCO to influence change in a way that not only makes a difference for caregivers, but also for the people they care for and healthcare providers. This area of work, as outlined in OCO’s new Strategic Plan, will help to ensure caregivers are identified, included, and supported across the healthcare system and will be enabled by new collaborations with Ontario Health Teams, Home and Community Care, Community Support Services, and Primary Care. The new Strategic Plan also reflects the work we need to do to connect more caregivers to support, amplify their voices, and create solutions with and for them.

At a national level, OCO is excited to see momentum build around a National Caregiving Strategy and will continue to support the work of the Canadian Centre of Caregiving Excellence who are leading this work. We are pleased to be part of this national conversation, sharing the insights and experiences of caregivers in Ontario, particularly on the topic of respite and the financial impact of caregiving.

It is undeniable that caregivers across the province are struggling, not just financially but also with their own mental health, and it’s only getting worse. OCO has ambitious goals to inspire the change needed to better support caregivers; we are excited to see momentum build and a commitment to supporting caregivers increasing within organizations and communities across the province.

On behalf of the entire organization, thank you again to caregivers, partners, and OCO volunteers for your continued support. This work cannot be done without you.
SPECIAL THANK YOU

Looking at the impact OCO has made in such a short time is a testament to Janet Beed, author of the Beed Report - Expanding Caregiver Support in Ontario and OCO's first Board Chair.

Six years ago, Janet was asked to provide recommendations to the provincial government on how to best coordinate and strengthen caregiver supports. After engaging with caregivers, a wide range of organizations that influenced caregiver supports, and literature related to models used by other jurisdictions, Janet’s recommendation was to create an organization, one that supported all caregivers regardless of the care recipient’s diagnosis, age or where they lived. The Ontario Caregiver Organization was Janet’s vision, and it wouldn’t exist today without her thoughtful approach to addressing the growing issue around caregiver distress.

The Beed Report became the catalyst to building an organization dedicated to improving the lives of Ontario caregivers and it was Janet who took the first steps to making her vision a reality, defining the organization’s mandate and structure, hiring its first staff, and recruiting volunteer Board Directors to provide governance oversight based on her understanding of the caregiving experience and what caregivers needed to help them in their role.

Janet, on behalf of the staff, volunteers of OCO, and caregivers across the province who are finding the strength to keep going because of OCO, thank you. While your tenure on OCO’s Board of Directors may be coming to an end, know that your vision will continue to be the foundation of our work and the contribution you made to ensuring OCO’s success will not be forgotten.