

Driving Meaningful Change

2024-25 IMPACT REPORT



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MESSAGE FROM THE BOARD CHAIR AND CEO

This year, OCO continued to see a significant increase in demand for its programs and services, with 50% more encounters* than the year prior. With almost three in every four caregivers experiencing signs of burnout, the spike in demand tells a clear story; the programs and services offered through OCO are critically needed right now and looking ahead, they will be even more so.

Over the next five years, the number of caregivers across the province may increase as much as 50%, from 4 million to 6.5 million people. This is, in part, due to the demographic shift but also the projected increase in chronic disease. As a result, our province is poised to face an unprecedented demand for healthcare, and this surge will place extraordinary pressure on unpaid caregivers who provide physical and emotional support to a family member, partner, friend, or neighbour.

Given the changes in the caregiving landscape, OCO refreshed its strategic plan last year in collaboration with caregivers, staff, and sector leaders. This plan is expanded from three to four priorities to better enable OCO's purpose of improving

the lives of caregivers. OCO's work over the past year focused on these key priorities:

- Connect more caregivers with the support they need to improve their experience and well-being
- Embed caregiving into the culture of healthcare to recognize and support caregivers as partners in care
- Generate solutions with caregivers and system partners to address issues that impact caregivers
- Amplify caregiver voices and evidence to influence change

Healthcare system transformation continues to provide a key opportunity for OCO to amplify the voices of caregivers across



the province. Whether it be informing government and system leaders on home and community care, long term care, transitions in care, aging in the right place, system navigation, and what to expect in the next five years, OCO has become a trusted advisor on issues related to caregiving in Ontario.

This year, OCO made significant gains working with health system leaders to ensure caregivers are recognized, included, and supported as essential partners on the care team. Through the Essential Care Partner (ECP) Support Hub, its learning collaborative, and many educational opportunities, 164 new healthcare organizations worked with the Support Hub, more than doubling its reach since the launch in 2023.

We are proud of what the entire team at OCO accomplished last year. We also recognize there is still significant work to do - work we couldn't do without the engagement of so many. On behalf of the entire organization, we want to thank caregivers across the province for all that you do, as well as OCO volunteers who inform our programs and services and act as peer mentors, advisors, and directors. We would also like to thank the many organizations that collaborate with OCO, and our funders who deeply believe in and support the work we do.

Together, we are driving meaningful change.

Sincerely,

Yves Savoie

Board Chair, The Ontario Caregiver Organization

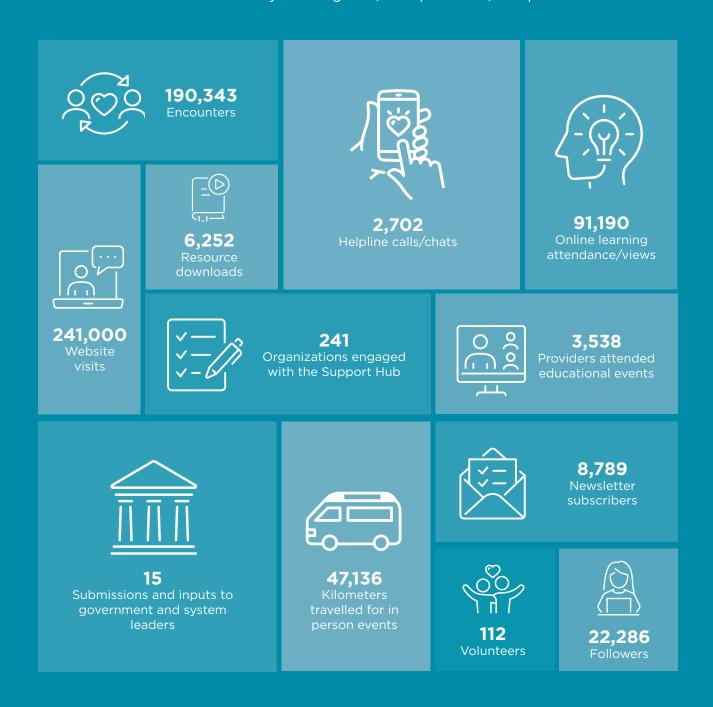
Amy Coupal

CEO, The Ontario Caregiver Organization

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

OUR IMPACT AT A GLANCE

Every day, OCO reaches thousands of caregivers, providing information, education, and support. Last year, we saw significant growth in many of OCO's programs and services, and within our online community of caregivers, care providers, and professionals.



HONOURING JANET BEED'S IMPACT



"I've had many wonderful opportunities in my career and in my personal life. But I have to say, being part of creating the Ontario Caregiver Organization is the one that I will treasure deepest in my heart. To have mv name attached to the Janet Beed Impact Award, I couldn't be more humbled."

- Janet Beed

Nine years ago, Janet Beed, a widely respected leader in the healthcare system, was asked to assess whether caregivers in Ontario had the support they needed. She initially thought the answer might be yes because there are many organizations offering various forms of help.

But Janet didn't stop at assumptions. Instead, she listened.

Through province-wide town halls and interviews with caregivers and community organizations, she uncovered a far more complex reality. Unless caregivers had a certain diagnosis, were a certain age, and lived in certain parts of the province, support varied and was often nonexistent.

According to Janet, Ontario caregivers didn't have much needed supports or opportunities to share their voice, and so with this in mind, the Ontario Caregiver Organization came to be.

In recognition of Janet's vision, values, and commitment to supporting caregivers, as well as her leadership as the organization's inaugural board chair, OCO launched the Janet Beed Impact Award. This award celebrates a caregiver who embodies Janet's values around raising awareness of the needs of caregivers and generating solutions to address those needs. This individual also calls for action, works to create impact, and collaborates with others to be a champion for caregivers.

CONGRATULATIONS TO RON BELENO



"I am so honoured and grateful to receive this award. It means so much to me and my family."

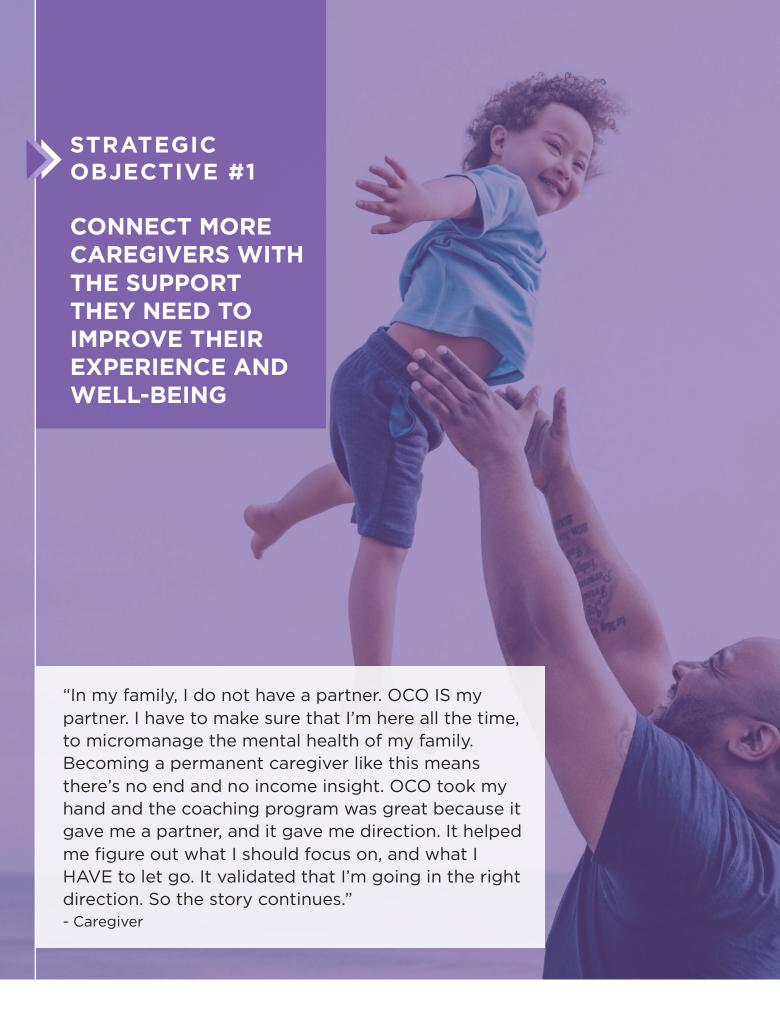
- Ron Beleno

OCO WAS THRILLED TO HONOUR RON BELENO AS THE FIRST RECIPIENT OF THE JANET BEED IMPACT AWARD.

As a family caregiver to his late father, who lived with Alzheimer's disease for over a decade, Ron brings lived experience, empathy, and advocacy to everything he does.

Ron is a tireless advocate in the dementia, caregiving, aging, and research communities. He is affiliated with AGE-WELL, Canada's technology and aging network, and served as co-chair of the Older Adult Caregiver Advisory Committee. He consults widely with governments, healthcare organizations, researchers, and innovators, always focused on improving the caregiver experience, especially through technology solutions. Whether educating caregivers, advising policy makers, or mentoring emerging leaders, Ron lives the values that this award represents.





CONNECT MORE CAREGIVERS WITH THE SUPPORT THEY NEED TO IMPROVE THEIR EXPERIENCE AND WELL-BEING

REDUCING BARRIERS TO SUPPORT FOR ONTARIO'S DIVERSE CAREGIVER POPULATION

Many caregivers face barriers to accessing the support they need. These barriers can often be the result of language, race, cultural background, or sexual orientation. To help bridge the gap and make resources accessible to diverse caregiver communities, OCO, with funding from Petro-Canada CareMakers Foundation, created the I am a Caregiver Toolkit for the Chinese, Punjabi, Filipino, Tamil, Gujarati, Farsi, Black, and 2SLGBTQIA+ communities.

OCO partnered with seven community organizations and engaged with more than 70 caregivers from different populations to better understand how caregiving is defined, how it's shared within families or communities, and what specific supports are needed most. Each toolkit features culturally relevant content designed to empower caregivers with the information they need to support their own health and well-being.

> 7,250 printed toolkits were distributed through community organizations, hospitals and other care settings, and libraries. Another 1,625 toolkits were downloaded from OCO's website. All eleven adaptations are available on OCO's website.

Special thanks to the following community partners for supporting this work: CareFirst Seniors & Community Supports Association, Kababayan Multicultural Centre, Indus Community Services, Scarborough Centre for Healthy Communities, TAIBU Community Health Centre, Aga Khan Foundation's National Council - Care for the Elderly Portfolio, as well as the multiple community organizations and caregivers who supported engagement with the 2SLGBTQIA+ community.



"These consultations have really helped me to focus on myself - it has showed me that I too can ask for support when helping my husband."

- Tamil speaking caregiver







EXPANDING SUPPORT FOR FAMILIES OF ADULTS WITH DEVELOPMENTAL DISABILITIES

Families caring for adults with developmental disabilities face unique challenges that are intensified by the need to navigate multiple systems while providing care and support. The Family Support Network (FSN) capacity-building grant program, made possible by the Ministry of Children, Community and Social Services, enable FSNs across the province to deepen social connections and build sustainable peer support for families in their communities.

The grants make meaningful engagement among members of the FSN possible, creating a safe space for families to support, mentor, and learn from one another and share information about local initiatives, resources, and developmental services. The grants also enable local programming and the creation of tailored caregiver resources.

>OCO awarded 41 community-based Family Support Networks. Whether supporting established networks or helping to spark new ones, this work is helping caregivers feel less isolated and more empowered.

RAISING AWARENESS OF OCO'S PROGRAMS AND SERVICES

To expand our reach and better support caregivers, OCO recognizes the importance of sharing its work with media partners across the province. Last year, OCO was featured by several media outlets including Global News, CTV News, CHCH, the Toronto Star, The Honest Talk, and others, to raise awareness on topics such as caregiver burnout, emerging trends in caregiving, and how individuals can prepare for future caregiving responsibilities. These efforts aim to inform both current and future caregivers about the realities of caregiving, the free supports and services offered by OCO, and how to access available resources.

OCO was featured in media 629 times, with a potential reach of over 90 million individuals. Throughout the year, our website received more than 240,000 unique visits—an increase of 38% compared to the previous year. Additionally, OCO saw an average of 43% growth in newsletter subscribers and followers on its digital channels.

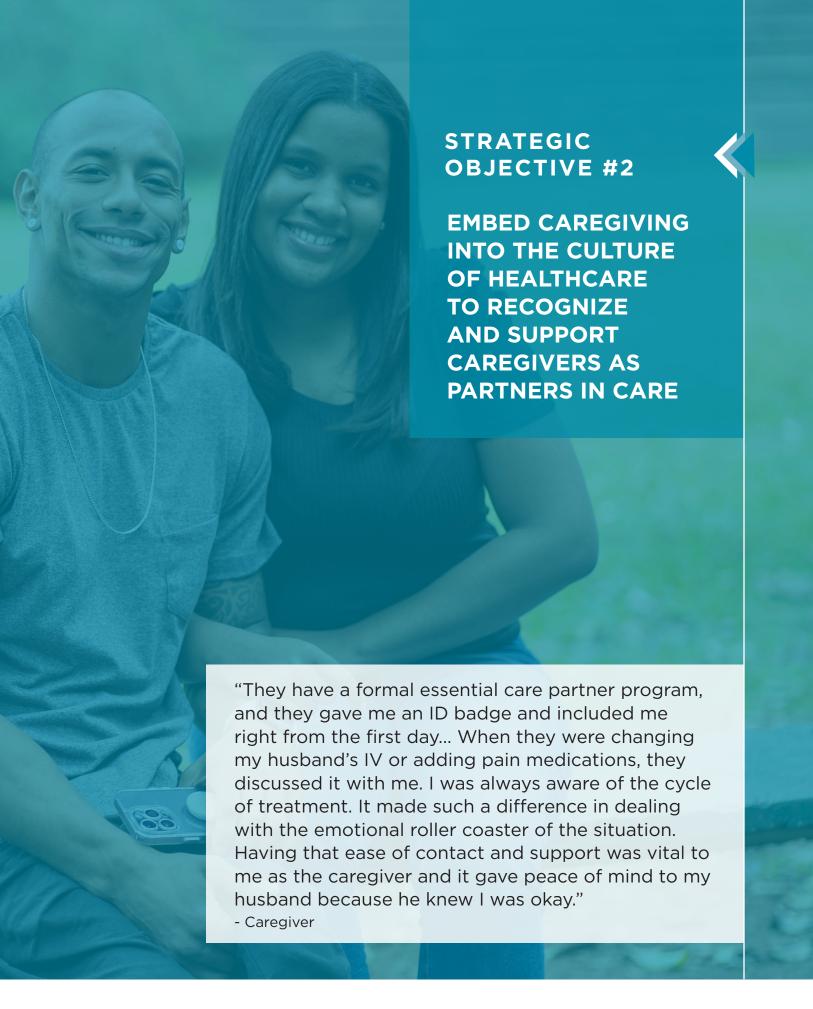
"Our social connections have deepened, and we are learning more about each other as well as the needs of our sons and daughters. Some of our members have challenges accessing information or getting help. This is a safe place. All our members are open and feel safe to share personal information."

 Maria DeMarco, FSN Lead, Danforth Family Network



TORONTO STAR



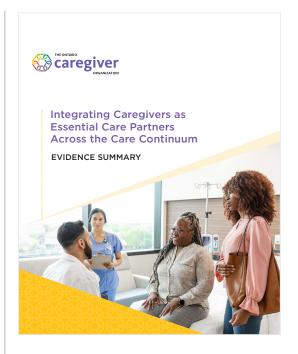


EMBED CAREGIVING INTO THE CULTURE OF HEALTHCARE TO RECOGNIZE AND SUPPORT CAREGIVERS AS PARTNERS IN CARE

ADVANCING THE ADOPTION OF CAREGIVER-INCLUSIVE PRACTICES IN HEALTHCARE SETTINGS

Through the support of OCO's Essential Care Partner Support Hub and in partnership with Ontario Health, healthcare organizations are embracing a culture shift where caregivers are recognized and valued as essential partners on the care team. The Support Hub provides care settings with free guidance and coaching, resources, education, and learning opportunities to support the implementation of evidence-informed caregiver-inclusive policies and practices. These evidence-informed policies and practices that recognize, include, and support caregivers have shown to improve patient outcomes, as well as the experience for caregivers and healthcare providers.

Last year, the Support Hub worked with 241 healthcare organizations, and made connections with 164 new healthcare organizations, more than doubling the reach of the Hub since its launch in 2023.



PARTNERSHIPS IN ACTION

Supporting Seamless Transitions Across Care Settings: Great River OHT's Essential Caregiver Pilot Program

Caregivers tell us one of the most stressful parts of their caregiving journey happens during transitions from hospital to home or to other care settings. In eastern Ontario, Great River Ontario Health Team (OHT) launched its Essential Caregiver Pilot Program with the support of the Support Hub to address this issue.

Caregivers receive Essential Caregiver education and are formally identified with a badge, so they can be recognized across hospitals and healthcare organizations within the OHT.

Staff at partner organizations receive education to understand what it means when a caregiver is wearing the Caregiver ID badge, and the importance of including caregivers as essential members of the care team. These seemingly simple acts help to ensure effective communication between healthcare providers and caregivers across different healthcare settings in the region.

Work is underway to review lessons learned with the pilot program and expand to more organizations in phase two of the project. The long term goal is to have Essential Caregivers be formally recognized across the entire healthcare system in the Great River OHT.

Making it Easier for Organizations to Provide Caregiver Support in Hospitals and Long Term Care

St. Thomas Elgin General Hospital: A Caregiver Guide for Complex Continuing Care

At St. Thomas Elgin General Hospital, caregivers now receive a caregiver guide upon admission to the complex continuing care unit. Developed in collaboration with the hospital's Patient Family Advisory Committee, staff, and the Support Hub, the guide includes information to better prepare families for what to expect, creating a more welcoming and well-informed experience for caregivers.



"This work has been incredibly important in ensuring caregivers are recognized across the healthcare system and has helped staff to have a better understanding of the essential role of caregivers."

- Tracy Crowder, Project Manager, Great River OHT

Shalom Village Long Term Care Home: Filling a Gap in Caregiver Support

Shalom Village Long Term Care Home used OCO's Supporting Caregiver Awareness, Learning, and Empowerment (SCALE) program to bring caregivers together in a meaningful way. The Support Hub worked with Shalom Village to pilot and deliver OCO's SCALE program in person, which filled a gap in support available to caregivers at the long term care home. Through the pilot, Shalom Village was able to offer 8-weekly psychoeducational webinars, followed by facilitated peer discussions with caregivers led by a Shalom Village team member. The success of the pilot has led to interest from participants in creating ongoing monthly support groups at the home, and other long term care homes eager to adopt a similar approach.

Supporting caregivers leads to better resident health outcomes, better caregiver experience, and makes it easier for care providers to provide better care. At Shalom Village, caregivers who were once isolated now have a community of support.

Provider Education and Knowledge Exchange: Learning Together, Leading Change

Last year, more than 3,500 healthcare providers, including leadership and front-line teams, participated in education and knowledge exchange offered by the Support Hub. Through keynote presentations, workshops, eLearning, webinars, and the Essential Care Partner Learning Collaborative - an interactive multisector forum for healthcare organizations - the Support Hub is increasing awareness and understanding of the caregiver experience and evolving practice at the provider level.

This year, for the first time, the Support Hub hosted its first "in person" Learning Collaborative in Ottawa, which brought together over 20 healthcare organizations and 30 providers to share and learn from one another.

"The Learning Collaborative is an excellent space to spread and scale how we can improve the lives of caregivers and patient experience and establish standardized strategy across the province."

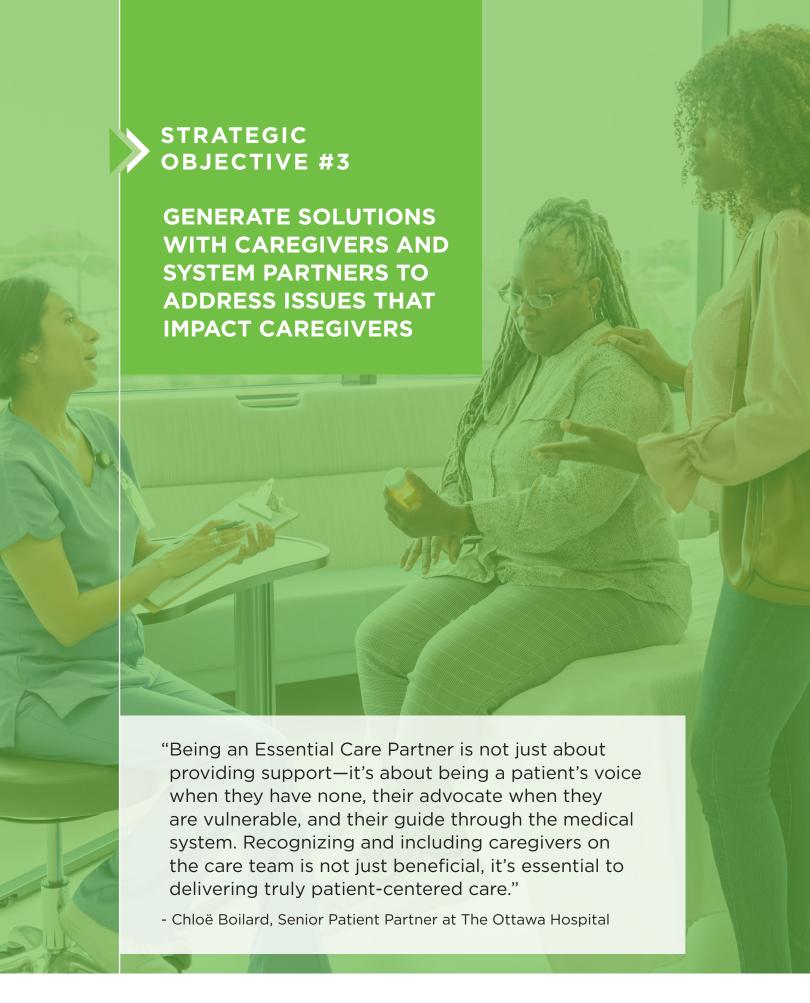
- System Leader at an Ontario Health Team





"Being part of today's event showed me how much stronger care becomes when caregivers and healthcare staff work as one team."

- Healthcare Provider



GENERATE SOLUTIONS WITH CAREGIVERS AND SYSTEM PARTNERS TO ADDRESS ISSUES THAT IMPACT CAREGIVERS

A SOCIAL PRESCRIPTION FOR CARE

With the support of the Canadian Centre for Caregiving Excellence, a program of the Azrieli Foundation, and in partnership with integrated primary care and paramedicine teams across 10 sites, OCO developed and implemented its Caregiver Social Prescribing Pilot Program in the Southwest and Northeast regions of Ontario.

Social prescribing is an evidence-based way to help individuals access non-medical services that support basic needs, social and emotional wellbeing, and that foster community belonging. For caregivers, social



WE'RE HERE FOR YOU AS YOU CARE FOR OTHERS.

Connect with your local Caregiver Link Worker for 1:1 support and navigation including help with:

experience and building next steps
Finding supportive services and
resources to meet your needs
Learning more about supports available
in your community for you and the
person you care for and support with
getting connected

Adrien McKenna
Caregiver Link Worker- Southwest
Phone: 416-558-5948
Email: adrienm@ontariocaregiver.ca



prescribing is about having the opportunity to focus on their well-being and prioritize their needs. This is done in collaboration with a Caregiver Link Worker who receives the social prescription and provides 1:1 guidance and support to the caregiver as they navigate their options and access programs and services that are right for them.

"The focus on connecting caregivers with relevant community resources, support networks, and activities tailored to their specific needs demonstrates a commitment to creating a supportive ecosystem around them."

- Care Provider

A SOCIAL PRESCRIPTION TO OCO

"I have been a caregiver on and off for my husband for over 30 years. I was referred to The Ontario Caregiver Organization through our Family Health Team. I received a telephone call from OCO's Caregiver Link Worker, we completed a questionnaire to understand my needs. She paired me with a Caregiver Coach who offered six one-hour coaching sessions. I have been a caregiver most of my life and at the beginning of the first session, I really thought that I was wasting this poor woman's time. I was so lost myself! My coach helped me see myself. my strengths above all. I will always be grateful to her and this program. Now, the in-person SCALE program is underway. It's giving me tools to move forward and tools to better understand the emotions we constantly struggle with. One step at a time, one foot in front of the other, forward march."

- Caregiver

CAREGIVER STORIES: SHARING FOR CHANGE

With healthcare transformation well underway, more and more caregivers are being asked to share their lived experience to inform decision making at a local and provincial level. This can feel daunting to many caregivers who have complex stories and want to ensure they are sharing in the most effective way, to have the most impact.

Last year, OCO offered Caregiver Stories, Sharing for Change workshops to 18 caregiver partners who are involved in advisory committees and working groups in healthcare organizations across the province, to help strengthen their confidence and ability to share their lived experience in an authentic and strategic way.



"I am confident that I will be better at sharing my stories in an effective manner at our OHT working groups."

- Caregiver

TAKING CARE OF SOMEONE?

OCO's caregiver resources are created in collaboration with caregivers. This past year, the Support Hub engaged caregivers through OCO's Caregiver Voices platform to inform the development of a visual resource that would help healthcare providers empower caregivers with information about their role as an essential care partner and how caregivers can self-identify to ensure they are recognized, included, and supported as part of the care team.

Caregiver input and feedback helped the resource come to life with examples of different variations of caregiving relationships, as well as the different types of support caregivers provide. "Taking Care of Someone?" is just one example of a resource created in collaboration with caregivers and care providers to help empower caregivers with the information they need and educate providers on what they can do to support caregivers in their organization.





AMPLIFY CAREGIVER VOICES AND EVIDENCE TO INFLUENCE CHANGE

PREPARING TO CARE: PERSPECTIVES OF FUTURE CAREGIVERS

Each year, OCO issues its Spotlight Report, which looks at the caregiving experience in Ontario. This past year, the work was expanded to understand the perceptions of future caregivers, those who expect to be in the role in the next five years.

By 2030, the number of unpaid caregivers in the province could increase by more than 50%. This dramatic increase poses a unique challenge for families, many of whom may not be ready to take on the financial, emotional, and practical challenges of caregiving. OCO learned that while future caregivers think it's important to start preparing for the role, the majority haven't started. This includes having conversations about living arrangements and legal and financial considerations. The report also uncovered that many people believe the healthcare system will provide all the care that's needed.

OCO is engaging with current and future caregivers to determine what resources are needed to empower future caregivers with information to help them start to prepare for the responsibility now. This is an upstream approach to mitigating the risk of burnout, getting to caregivers before they find themselves overwhelmed, or their own health begins to suffer.

Learn more in the **Preparing to Care Report**.



"I'm absolutely delighted with the support OCO offered me. They're a little gem that everyone should know about."

caregiver

- Caregiver

INFLUENCING SYSTEM CHANGE

The healthcare system in Ontario is transforming in many ways. As OCO's profile grows, caregivers are increasingly being recognized by health system leaders and OCO is being invited to key senior advisory groups and committees, bringing caregiver insights to the most senior leaders in the healthcare system.

Caregiver insights have been shared through reports, written submissions, and in meetings on topics of importance to caregivers including home and community care, palliative care, long term care, transitions in care, aging in the right place, system navigation and what to expect related to numbers and needs of people who expect to be prospective caregivers in the next five years.

OCO also engaged caregivers to gather insights about their lived experience related to caregiver distress and financial support. Insights were shared with key system leaders to enable better understanding of caregiver pain points and opportunities to work together towards solutions. OCO has also worked closely with national caregiving organizations to ensure strong alignment on synergies, roles, and opportunities to inform policy in Ontario and on a national scale.



THANK YOU TO OCO VOLUNTEERS

Caregiver volunteers play an integral role in OCO programs and services. There are currently 112 volunteers who support our work in a variety of roles including Peer Mentors, Online Support Group Facilitators, Program Ambassadors, and members of OCO's Caregiver Advisory Group and Board of Directors.

OCO also engages 294 caregivers on its Caregiver Voices platform, to share their insights and provide feedback on an array of topics. These are a few initiatives that OCO caregivers participated in last year:

- Contributed to OCO program and services evaluation
- Provided insights related to various caregiver 'pain points'
- Contributed to the adaptation of the *I am a Caregiver Toolkit* to 11 new diverse communities
- Participated in the Essential Care Partner Advisory Committe





MEET AANAM, PEER SUPPORT VOLUNTEER

OCO's Peer Mentor program is made possible by caregiver volunteers like Aanam, who volunteer their time and lend their insights and experience to caregivers who need support.

My name is Aanam and I'm an immigrant who moved from India to Canada in September 2019, just 17 years old and filled with excitement yet unprepared for the challenges ahead.

One of the most life-changing experiences for me was losing my beloved grandmother, whom I cared for deeply. During her time bedridden after a hip fracture, I was by her side every day, providing not just physical care but emotional comfort as well. We shared countless memories, laughter, and stories from her past, and I did everything I could to help her feel loved and supported.

Her passing was heartbreaking. I was left with a sense of deep loss, but it taught me an invaluable lesson: there are many others out there, like my grandmother, who need love, care, and a listening ear. Often, the greatest gift we can offer to someone is simply being present and hearing their struggles. Caring for others can be both rewarding and overwhelming, and I understand the feeling of neglecting one's own needs to care for others.

As a peer mentor with OCO, I want to ensure caregivers don't lose sight of themselves in the process. Peer mentors are here to listen to your worries, offer guidance, and be a constant source of support. Together, we'll work toward your personal growth and well-being. My commitment as a peer mentor is to be selfless, honest, and compassionate - ready to empathize, understand, and provide constructive feedback when needed. Caregivers are not alone on this journey, and we will walk beside you every step of the way.

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Last year, OCO trained 27 new caregiver Peer Mentors for a total of 70. Peer mentors made 681 connections via phone calls, emails, and in-person meet ups with caregivers.

INCLUSION, DIVERSITY, EQUITY AND ACCESSIBILITY (IDEA)

OCO is committed to IDEA and works in collaboration with caregivers, healthcare providers, and other organizations from diverse communities or those facing barriers to inclusion to address the challenges caregivers face so all caregivers, regardless of age, condition, or geographic location, have access to the support they need.

OCO continues to take actionable steps towards its commitment to IDEA. Here are the initiatives undertaken last year:

BOARD AND STAFF TRAINING:

- Maintained IDEA board committee and staff working group
- Continued IDEA training and learning for the Board, staff, and volunteers

PROJECTS AND PARTNERSHIPS:

- The Multi-Cultural Caregiver Resource Project will help to bridge the language and culture gaps that currently exist for caregiver resources in Ontario, including:
 - Multiple in-person community consultations conducted in partnership with local agencies serving diverse populations, which resulted in 11 new adaptations of the I am a Caregiver Toolkit in: Cantonese, Mandarin, Punjabi, Tamil, Tagalog, Gujrati, Farsi, and adapting the toolkit for 2LGBTQIA+ and Black communities
- Hosted the Indigenous Caregiver Webinar: Tools to Support Your Journey, in collaboration with Lakehead University's Centre for Education and Research on Aging & Health (CERAH)
- Provided webinars for caregivers on:
 - o Aidance arc-en-ciel : défendre les intérêts des personnes 2SLGBTQIA+
- Developed the Caregiving Across Cultures: Caregiver <u>Guide</u> in partnership with the Waterloo Wellington Older Adult Strategy and Camino Well-being & Mental Health to support professionals supporting older adults in newcomer or immigrant communities, and expanded the partnership with the Cambridge North Dumfries OHT to promote the guide on their website
- Continued review, prioritization, and implementation of LEAD improvement plan in concert with the Abilities Centre

PLANNING FOR THE FUTURE

As healthcare system transformation continues, OCO will continue to ensure caregiver voices are heard, sharing their lived experience with system leaders and decision-makers to influence system change. While supporting caregivers experiencing burnout and distress with programs and services is critical, so is mitigating the factors that contribute to this experience. The Essential Care Partner Support Hub will continue to work with healthcare settings and deepen its engagement with home care, primary care, and Ontario Health Teams.

As more Ontarians become caregivers, it will be important to connect with them early in their journey and even before their journey begins. OCO will explore the insights derived in its Preparing to Care report to find new and innovative ways to reach prospective caregivers so they can start to plan for the role. Educating future caregivers now is one way to help relieve burnout and financial strain.

OCO will continue to find new ways to reach caregivers and connect them to support. It will look to grow its capacity to support future demand for its "low touch" and "high touch" programs, from online educational resources that can be accessed through OCO's website to more intense programming that includes 1:1 coaching and support.

Regardless of age, condition of the person they care for, or geographical location. OCO will continue to advance its purpose and ensure all caregivers across the province can access support.



About the Ontario Caregiver Organization

The Ontario Caregiver Organization 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. 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, 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. OCO is funded, in part, by The Ministry of Health.

Ontario Caregiver Helpline

1-833-416-2273

The Ontario Caregiver Organization

Email: info@ontariocaregiver.ca Phone: 416-362-CARE (2273) or

1-888-877-1626

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