



The Ontario Caregiver Coalition (OCC) is the voice of caregivers in Ontario. We advocate for recognition and support for the family, friends, and neighbours whose unpaid care is the hidden backbone of Ontario's health system. Our members include both caregivers from across Ontario and organizations that support them. For more information about the OCC and our work, please see our website at www.ontariocaregivercoalition.ca, or follow us on social media.

April 2026 Newsletter

At the OCC

The OCC's Submission to the Ontario Human Rights Commission on Caregiving

While it is not widely known, caregivers do have some rights under the Ontario Human Rights Code. Protections against discrimination on the basis of family and marital status can apply to caregivers in the workforce, in housing, and in services such as health care and education. For example, working carers may have a right to accommodation in the workplace for their caregiving responsibilities. Approximately 20 years ago, the Ontario Human Rights Commission (OHRC) held a public consultation on human rights and family caregiving, which resulted in a report, *The Cost of Caring*, which made recommendations for changes to law and public policies that affect caregivers, as well as its Policy and Guidelines on Discrimination because of Family Status, which sets out official guidance on the interpretation of the provisions of the Code that address family caregivers.

The OHRC is now in the process of updating the Policy to reflect the changing context of caregiving in Ontario. The OCC collaborated with a number of our member organizations, including Dr. Alison Williams, the Ontario Association of Social Workers, the Young Caregiver Council of Canada and the Young Caregiver Association, to provide a detailed and comprehensive submission to the OHRC, recommending changes to strengthen its interpretation of the Code to better protect caregivers. We also had the opportunity for an in-person discussion.

The OCC Submission covered a broad range of issues, including:

- Reinforcing that caregiving is a human rights issue that deserves serious attention
- Recognizing that the lack of support for caregivers, and for those they care for, creates systemic barriers for caregivers in accessing work, housing and services
- Bringing a broad interpretation to the restrictive definition of "family status" in the Code
- Specifically addressing Indigenous understandings of care, the effects of colonialism and anti-Indigenous racism on access to supports for caregivers, and the importance of

Indigenous caregivers receiving supports in a manner that is culturally safe and respects connections to community

- Strengthening access to workplace accommodations for caregivers, including a greater emphasis on designing workplaces to include caregivers, and ensuring that caregivers are not pressured to seek solutions that would undermine the dignity and security of those they care for
- Clearly addressing the experiences of young carers in education systems
- Requiring health and community services providers to include caregivers within health equity frameworks and efforts

and more. The OCC's submission will soon be available on our [website](#).

The OHRC anticipates releasing a revised Policy in late 2026 or early 2027. The OCC will remain in communication with the OHRC and will share the updated Policy with our networks once released.

March General Members Meeting and In-Person Social Recap

Our latest General Members Meeting was held on March 26th and was hybrid. It was our first in-person gathering since 2019. It allowed those who wished to meet in person an opportunity to do so, while still offering the convenience and accessibility of an online meeting.

This meeting launched our 2026 Caregiver Day theme, *Care About Change*, a theme which builds on our unique commitment to advocacy, brings a hopeful message forward, and encourages our community to fight for change.

Ron Beleno, a new member of the OCC, gave us a beautiful and eloquent caregiver opening. He spoke about his experience caregiving for his parents and his activism in communities around dementia, ageing, and caregiving. His opening touched on the level of resilience required of caregivers and how it helps to build perspective, ending on a hopeful note and a call to action, tying wonderfully into our Caregiver Day theme—hope is not passive, it is action, collaboration, and community, to care about change is a decision.

Adrienne Scott of the Ontario Community Support Association spoke to the work of the OCSA to champion improvements to home and community care. Adrienne outlined the OCSA's key asks for the 2026 Ontario budget, including increased investments in home and community care, funding for training emerging leaders in the sector, investment in home care clinics, and funds to scale up care coordinators in Naturally Occurring Retirement Communities, and shared details on the OCSA's 2026 coordinated government relations campaign and grassroots mobilization to reach MPPs and regional media.

We also heard from Rebekah Gold of the Young Caregivers Council of Canada, who offered a thought-provoking presentation on young carers, leading a discussion on the impact of being a caregiver from such a young age. The YCCC is a national, grassroots, young carer-led advocacy organization for young carers (past and present) aged 14-30. Young carers have similar roles and responsibilities to adult carers, but lack access to the same recognition and support, and often face stigma and a sense of needing to hide their role. Rebekah emphasized the importance of recognizing young carers around us, learning from them, and creating space for support.

Additionally, Adriana Shnall of the Koschitsky Centre for Caregiving Innovation spoke briefly on caregiver mental health and how it is significantly impacted by the demanding nature of this role. Mental health needs often go unrecognized, and when they are, mental health supports are typically hard to access, driven by crisis rather than a proactive approach. Adriana emphasized the importance of research so we can better understand how to support caregivers and help them with their mental health, an essential issue for caregivers.

We also shared more on the OCC's upcoming Caregiver Policy Framework, which will draw from our Policy Brief series to provide a caregiver lens on public policy and will be a tool to support building, assessing, and strategizing on future policies to define how caregiver policy making should be approached.

Thank you to all of those who were able to attend, and a special thanks to the Alzheimer Society of Ontario for hosting this meeting. We appreciated the heartfelt discussion and the participation in our Caregiver Day campaign. We are so grateful for the opportunity to be able to connect this way, both face-to-face and virtually. OCC members will receive copies of presentations and formal meeting notes next week.



Caregiver Day 2026 Recap: How We Cared About Change

Caregiver Day was on April 7th. Every year, the OCC hosts our annual Caregiver Day Campaign to bring awareness to caregiver issues and advocate for change. This year, our theme was **Care About Change**. What makes the OCC unique is that it's a coalition — a community of people who are motivated and excited about the possibility of change. After a year of fear and uncertainty, we wanted to focus our Caregiver Day efforts on hope, within and outside of our coalition, paying attention to the work being done to support caregivers.

Throughout the day, we ran a social media campaign that we had such great success with. We were so happy to see so many people engaging with our message. We posted about our Policy Brief series and the challenges caregivers face, the collage we made (more on that below), our Caregiver Day survey submissions, and how you can fight for change alongside us.

Our OCC Chair, Lauren Bates, also spoke at the 2026 National Caregiver Day Symposium, hosted by the Canadian Home Care Association and our organization member, the Canadian Centre for Caregiving Excellence, a program of the Azrieli Foundation. This national event brought together a community of people who care about caregiving to explore how caregiving evolves across ages and stages and how we can better support caregiver wellbeing across Canada.

Lauren joined the panel, *Employer Supports for Caregivers - From Evidence to Action*, to discuss our [fifth policy brief](#), alongside OCC Member Allison Williams of McMaster University, Tyler Downey from SEIU Health, and caregiver Avijeet Palmar, moderated by the OCC's Amy Coupal. This event was an important opportunity for us to connect, learn, and share on the caregiving experience, and the OCC is grateful for the opportunity to join and speak on employer supports, a priority issue for the OCC and caregivers across Canada.

As part of our Caregiver Day campaign efforts, we also offered members an activity to participate in at our March General Members Meeting. Our in-person attendees filled out heart-shaped sticky notes, alongside our virtual ones, who were given a Zoom poll. We asked attendees to tell us what makes them fight for change and what is the change they want to see, and they delivered. Using these answers, we created a Caregiver Day collage that is filled with meaningful, thought-provoking answers.

Thank you to everyone who contributed to putting this together. Check out our collage below:



We also asked people to tell us what makes them fight for change in our Caregiver Day survey. Here's what they said:

- “Seeing how hard my mom works to care for my grandma.”
- “To be a voice for those of ALL ages who can't.”
- “Caregivers can feel invisible—that drives me to make change.”
- “The long-time advocates who inspire me every day!”
- “I fight for change because no caregiver should navigate alone.”
- “Knowing how badly caregivers need to be acknowledged and supported, whether through financial resources, mental health support or respite.”

Caregiver Day was a wonderful chance for us to highlight all the issues caregivers face daily, and how our community is fighting back. As we look back on Caregiver Day and the great success we had, we are reminded that it is not just on Caregiver Day that we fight for change; we must continue to fight every day. The OCC will be keeping this message in mind throughout the rest of the year as we continue to advocate for caregivers across Ontario, and we hope you will too. Just because Caregiver Day is over, doesn't mean we have to stop caring about change.

Here are some things you can do to fight for change:

- **If you have 5 minutes:** Engage with our posts and follow the OCC on social media to take a closer look at the collage and see the rest of the campaign.

- **If you have 10 minutes:** Sign the [petition](#) for an Ontario Caregiver Support Benefit
- **If you have 30 minutes:** Visit our website and read our [Policy Briefs](#)
- **If you have 1 hour:** Write to your MPP and tell them to fight for change for caregivers in Ontario!

We look forward to celebrating Caregiver Day next year on April 6th, 2027!

Celebrating Volunteer Week 2026

Canada's National Volunteer Week ran from April 19th to 25th. Volunteer Week is an opportunity to recognize the incredible work and invaluable impact of volunteers across Canada. The Ontario Caregiver Coalition is a grassroots organization built by and continuing to thrive because of our volunteers. We want to thank our volunteers for their hard work and dedication. You are the backbone of the OCC, and we are forever grateful for your contributions to advocating for Caregivers. Your drive and passion are what keep the OCC strong and help us help Caregivers all across Ontario.

To celebrate the passion of our members, the OCC ran a social media campaign for Volunteer Week using baby photos submitted by our volunteers, showing off our adorable volunteers who have grown up to make such valuable contributions to caregiver advocacy and the OCC. If you'd like to see the campaign, follow us on social media. Links to our profiles are available at the bottom of this newsletter.

Thank you once again to all of our volunteers. With you by our side, we know change IS possible. Together, we can build a better Ontario for caregivers.

Continuing To Strengthen the OCC'S Culture Of Respect and Inclusion

As a coalition and as an organization built by people who understand the value of care, the OCC has always been built on a foundation of strong relationships and a culture of inclusion and respect. The OCC has always aspired to be a community where those from diverse perspectives and experiences could come together, find common strength, and work collaboratively towards meaningful change. Our 2025 Member Engagement Strategy identified three core values of caring, listening and empowering.

To create strong governance foundations for these values, the OCC has been developing a suite of organizational policies.

Our Rights and Respect Policy affirms that the OCC is founded on an ethic of care and respect. We work to build a coalition that can act as a voice of Ontario's caregivers in all of their diversity. It is essential that all who come into contact with the OCC are treated with dignity. We

are committed to the principles and requirements of the Ontario Human Rights Code, and to ensuring an environment where all can contribute and where many voices are heard. All those working to carry out the mandate of the OCC, including employees, independent contractors, and volunteers, have a responsibility to work to build and maintain a culture of care, respect and inclusion and refrain from any form of harassment or discrimination. Complaints about contravention of this Policy can be made to the Chair of the OCC's Membership and Governance Committee, who is currently Keena Naik.

The OCC understands that protecting the confidentiality and privacy of our membership is essential. We are often asked why we do not record our General Members Meetings, or allow others to record: this is because our members need to feel comfortable and confident in sharing experiences that may be difficult and deeply private. Our Confidentiality and Privacy Policy sets out standards and processes for protecting the private information of both our Organization and Caregiver Members, while ensuring that our work is transparent and accountable. We have taken important steps in recent years to improve our document storage and protection, and to ensure that volunteers and staff who have access to confidential information understand their responsibilities.

If you have questions about OCC governance policies, please reach out to us at ontariocaregivercoalitionocc@gmail.com.

Member Initiatives

Share your Experience on Blood Cancers and CAR-T Cell Therapy

Are you a patient or caregiver with experience surrounding CAR-T cell therapy to treat blood cancers like Non-Hodgkin's or B-cell lymphoma? Your lived experience can help shape research and improve care. [An evaluation of CAR-T cell therapies for B-Cell Lymphoma on cytokine release syndrome and neurotoxicity](#) is being conducted by Canada's Drug Agency (CDA).

Our members at the Canadian Cancer Survivor Network are helping the CDA with recruitment and are **seeking caregivers and patients** who have experience with CAR-T cell therapies for treating blood cancers (e.g., Non-Hodgkin's, B-cell Lymphoma, etc) for **one-on-one interviews**.

Why participate? Your perspective could help improve the future of cancer care.

Participation will be made as accessible as possible for those who need accommodations.

Contact Natalie at nbennett@survivornet.ca to learn more about how you can share your perspective.

Help MS Canada: Sign a Petition to Change the DTC for Canadians Living with MS

The Disability Tax Credit (DTC) is failing people with multiple sclerosis (MS). Barb, who has been living with MS for more than a decade, knows this all too well.

“I know firsthand how difficult accessing the DTC is. Many doctors don’t want to even fill out the paperwork for Canadians living with MS, because it’s known to be difficult to qualify. If we can modernize the DTC, it will reduce financial strain, improve access to other benefits, and help Canadians with MS achieve greater income security.”

-Barb, diagnosed in 2011, Manitoba

Barb sponsored a [Parliamentary e-petition](#), giving us a real chance to change the DTC system for Canadians living with MS. The e-petition calls on the federal government to modernize the DTC to better reflect the daily realities and fluctuating symptoms experienced by people living with MS. This petition brings the problems with the current DTC to the forefront for the government and forces a written response. When the DTC fails to recognize the lived reality of MS, people are shut out of crucial financial support they should qualify for. That must change.

MS Canada wants to reach 10,000 signatures to show how important DTC reform is for Canada’s MS community. If you’d like to help them reach this goal, please sign the [petition](#) by June 4th.

Please note that when you sign, there will be two steps required. After you click *Sign the petition* at the bottom of the page, you will be asked to enter your information and complete a brief verification. Then:

Step 1. Submit your signature on the petition website.

Step 2. Check your email and click confirm your support to finish the petition process.

Your signature *does not count* unless you complete the confirmation email sent by the House of Commons.

Thank you for helping amplify the voices of Canadians living with MS and episodic disabilities.

Opportunities to Participate in Caregiver-Focused Research

Participate in a Study on the Impact of Workplace Injuries on Family Members

The Thunder Bay & District Injured Workers Support Group has teamed up with Lakehead University and the EPID@Work Research Institute for a study on the impacts of workplace injuries on family members. Do you have a family member you’ve been caring for who was injured and off work for 3+ months? If yes, you are invited to participate in this research project.

Participants will attend a 2-hour focus group or complete an individual interview and receive a \$50 gift card. All information collected is confidential. Individual interviews can be arranged with a research member at your earliest convenience.

If interested, please [complete this survey](#). For more information, call Eugene at 807-622-8897.

Of Interest

Mental Illness Caregivers Association (MICA): Caregiver Future Planning Pilot Project.

This initiative addresses an important question for caregivers: What will happen to our loved ones when we are no longer able to support them? For many aging caregivers who provide support for loved ones, this question is top of mind.

MICA believes this issue can be solved through:

- A caregiver-focused approach funded by the provincial and/or federal government with the mandate resources and means to assist caregivers planning for when they are gone.
- A process that results in the establishment of an independent organization that will see to the development of a sustainable plan and support its implementation when the caregiver is gone.

MICA is asking for your support in spreading awareness. Please consider submitting a letter of support [here](#). Click [here](#) to learn more about the project.

The NIA Has Released its 2025 Ageing in Canada Survey Results

The National Institute on Ageing has released its Perspectives on Growing Older in Canada: The 2025 NIA Ageing in Canada Survey.

Now in its fourth year, this survey continues to be one of Canada's most comprehensive annual snapshots of the experiences, perspectives and expectations of Canadians aged 50 and older. Conducted by the NIA with support from Manulife and the Waltons Trust, this report reflects the successes and challenges of ageing in Canada. The annual survey examines 10 indicators of ageing well in Canada, including social well-being, financial security, health and independence and perspectives on ageing for Canadians 50 years and older across the country. The findings serve as a call to action for policymakers, organizations, and stakeholders to prioritize evidence-based strategies that address social isolation, financial insecurity, and barriers to health care access. By leveraging the insights from this survey, decision-makers can design and implement programs and services where older adults feel valued, included, supported and better prepared to age with confidence.

To read the full report, click [here](#), or click [here](#) for an executive summary.



If you have items that you would like to see included in future issues of this newsletter, please let us know. Sharing the accomplishments and activities of our members is part of our mandate. If you have received this newsletter in error, or no longer wish to receive it, please reply to this email to let us know, and we will remove you from our mailing list.