



Ontario Caregiver Coalition

September 2023 Newsletter

At the OCC

Please welcome our new Board members!

At our September 21st Annual General Meeting, the OCC welcomed a new slate of Board Directors for the upcoming year.

Several directors returned for another year of service, including **Lauren Bates, Rose-Marie Fraser-Haswell, Patti Lennox, Dana MacMillan, Daniel Nowoselski** and **Liana Sikharulidze**.

We are very pleased to welcome as new Board members **Kyle Fitzgerald** and **Keena Naik**. Keena Naik comes to the OCC with a long history of leadership at Bayshore Home Health as well as lived experience as a caregiver. Kyle Fitzgerald is a long-time member of the OCC, and has served in the past on the R&A and Partnership Committees. He is Director of Government Relations and Public Policy at ASO.

We also said goodbye to two long-serving Directors. **Cheryl Perera** was a member of OCC from the very beginning and served on many committees, as well as serving as our Chair. She is a strong strategic thinker, a great facilitator of connections and discussion, and brought a wealth of system and personal expertise to the OCC. **Sam Schwisberg** chaired our Membership and Governance Committee, as well as serving as Vice-Chair and Chair. In particular, he served a central role in enabling the OCC's incorporation as a not-for-profit. We thank them for their dedicated and invaluable service over many years.

Our Executive Committee is:

Chair: Lauren Bates

Co-Chair: Liana Sikharulidze

Vice-Chair: Daniel Nowoselski

Board Secretary: Dana MacMillan

Treasurer: Keena Naik

Launching the OCC's New Strategic Plan

The OCC was also pleased to launch our new three-year Strategic Plan, which will guide us in making decisions and allocating resources in the years ahead. The Strategic Plan was the result of very thoughtful discussions among our Membership, as well as dedicated work by our Board. A special thanks is due to Liana Sikharulidze for her leadership in development of the plan.

The Strategic Plan identified four key goals for us in the coming years, as well as immediate priorities for achieving those goals. The Board will now be working towards operationalizing these goals and priorities.



Planning for the year ahead

As we move into a new campaign year, all of our Committees are hard at work undertaking new initiatives and building on our existing strengths.

Our work as a Coalition is driven by these Committees, and we depend on their dedication and skills. All of our Committees would welcome new members and offer interesting opportunities to contribute and connect. If you would like to connect with or join a Committee, or explore which Committee might be the best fit for you, please email us at ontariocaregivercoalitionocc@gmail.com.

Research and Advocacy Committee

Chair: Lauren Bates

The Research and Advocacy Committee undertakes projects and campaigns to advance the OCC's advocacy goals. This includes supporting or engaging in work to develop the evidence base for change, government relations activities, and community and stakeholder outreach. This year, the R&A Committee will be building on last year's work on caregiver financial distress. It will also be undertaking a caregiver survey to help us to better understand what policy and programs solutions will best address caregiver needs.

Partnership Committee

Chair: Kyle Fitzgerald

The Partnership Committee develops and leads partnerships and collaboration opportunities both within the OCC and with external friends. This year, the Partnership Committee will be developing an engagement strategy. It will reach out to the OCC's organizational members to engage and look for areas of shared concern where the OCC can support collaboration. The Committee will also be identifying and reaching out to organizations whose interests may align with ours.

Communications and Awareness Committee

Chair: Daniel Nowoselski

The Communications and Awareness Committee leads public awareness campaigns, such as our annual Caregiver Day campaign, supports the OCC's advocacy work, and manages our social media accounts. The Communications and Awareness Committee would particularly benefit from volunteers with skills in social media and visual communication.

Caregiver Advisory Council/Collective

Co-Chairs: Malene Stewart and Cindy Diogo

The Caregiver Collective is rebuilding after a hiatus, and is looking to hear from and connect with our caregiver members. The Collective aims to foster a strong sense of community for our caregiver members, providing support and empowerment to caregivers from all walks of life and serving as a connection point for the OCC. The collective will meet as a group 3-4 times a year with opportunities outside of these times to speak to the media, local politicians and to participate in exciting projects the collective is engaged in.

Membership and Governance Committee

Chair: Patti Lennox

The Membership and Governance Committee undertakes the foundational work to ensure that the OCC is well managed, accountable, stable and resilient. The Membership and Governance Committee will be busy this year reviewing and developing policies and processes for the OCCm with a particular focus this year on financial oversight and transition planning.

Opportunities to Contribute to Caregiver Focused Research

VRx@Home Study

Researchers at the Toronto Rehabilitation Institute at UHN are conducting a study to better understand how better to support communication between persons living with dementia and their caregivers, recognizing that as symptoms of dementia progress, communications between the individual and their caregivers may be significantly affected. The aim is to improve quality of life for persons living with dementia and their caregivers. The study compares two different types of interventions, one of which is an innovative virtual reality based support.

The researchers are recruiting caregivers and care recipients who are able to provide 2 – 3 hours per week, over a period of five weeks. The study takes place in participant's homes. Participants will receive an honorarium of \$300.00.

For more information, please see the recruitment poster on our [website](#), or contact the research team by phone at (416) 597-3422 x7887 or by e-mail raheleh.saryazdi@uhn.ca.

Of Interest

New Research on Indigenous Caregivers

A new study funded by the Azrieli Foundation and Northern Alberta Academic Family Medicine Fund sheds light on the under-examined experiences of Indigenous caregivers and their needs. The study used participatory action research methods, and included family caregivers, health

and community providers, and healthcare and community leaders from two First Nations communities in Alberta. The study participants developed recommendations for better supporting Indigenous family caregivers and their care providers.

In considering the needs of family caregivers, participants recommended that policies and programs specifically include family caregivers as well as consider family caregivers' needs to support their caregiving and family caregivers' own wellbeing. Participants pointed out that while care and caregivers are valued in the Cree culture, the caregiver's role and work is taken for granted, and caregivers may not be seen as people with support needs of their own. Specifically, family caregivers need: (1) recognition of their role and work; (2) enhanced navigation and timely access to services, (3) improved home care support and respite, and (4) culturally safe care.

Participants also recommended that all care providers be provided with comprehensive, on-reserve education in Indigenous culture. Canadians often assume that Indigenous culture is the same for all Indigenous people when in fact there are many nations, pointing out that First Nations communities are multicultural. Education must take adequate time to provide a more complete understanding of Indigenous history, generational trauma, and the specific culture of each community.

The complete study can be found here: <https://www.mdpi.com/2079-9721/11/2/65>.

Statistics Canada Study on Caregivers Receiving the Canada Caregiver Credit

Statistics Canada this summer released a study of caregivers who receive the Canada Caregiver Credit, using data from nation-wide individual tax returns.

The CCC is a non-refundable federal tax credit in 2017 that provides limited financial relief to caregivers who support a low-income spouse or common-law partner or low-income dependants with a physical or mental impairment. A person claiming the CCC must provide evidence that the dependant's ability to perform basic activities of daily living is significantly limited and that the dependant requires the assistance of a caregiver to maintain everyday living.

The data shows that 2.5% of all Canadian families claimed that CCC in the years between 2017 and 2019, with the most common claims relating to care for an "infirm adult" (most commonly a parent) rather than care for a spouse or child. About 0.7% of families made a CCC claim with respect to a child (being a person under 18 years of age). Immigrant families had different claim patterns than others, with a greater likelihood of making claims with respect to parents, rather than spouses or children.

The full study provides a wealth of insights and data, and can be found [here](#).

PEI Commits to Caregiver Benefit

A core goal of the OCC's advocacy in recent years has been the creation of a meaningful caregiver allowance to address caregiver financial distress. Caregiving can impose a heavy financial burden, whether through direct costs for items such as transportation, special diets, medical supplies or supplemental care, or through foregone earnings due to caregiver responsibilities. There is very little financial support available to Ontario caregivers. Both the federal caregiver tax credit and the Compassionate Care Benefit under Employment Insurance are limited both in eligibility and amount.

We have been advocating for an Ontario Caregiver Support Benefit that provides streamlined eligibility, meaningful supports and monthly payments. For more information about the OCC's policy proposal, developed in partnership with the Public Good Initiative, see [here](#).

Ontario is behind the curve in developing a benefit or tax credit aimed specifically at supporting caregivers. Manitoba, Quebec and Nova Scotia have all developed programs that the OCC has learned from in developing our own proposal.

Now, we are heartened to see that Prince Edward Island has joined this group of forward-thinking jurisdictions that understand the importance of supporting caregivers. Following its recent election, the government of Prince Edward Island has [committed](#) to developing a primary caregiver grant of up to \$1,500 a month to support families who choose to keep their loved ones at home longer instead of entering care. We look forward to seeing the implementation of this promise, and learning from it to the benefit of Ontario caregivers.



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.

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