



The Ontario Caregiver Coalition is the voice of Ontario's caregivers. We advocate for recognition and support for the family, friends, and neighbours whose unpaid care is the hidden backbone of Ontario's health system. Ontario and organizations

November 2023 Newsletter

At the OCC

Upcoming General Members Meeting

The OCC's next General Members Meeting will be held on Thursday December 14th, from 11.00 a.m. until 1.00 p.m. *via Zoom*.

The agenda is packed with informative presentations and opportunities to collaborate. The OCC will be leading discussions about plans for our annual Caregiver Day Campaign, our planned Caregiver Survey, and provincial budget submissions.

As well, we will hear from a variety of organizations and researchers about current programs and initiatives. This will include:

- Dr. Matthias Hoben, Helen Carswell Chair in Dementia Care at York University, will present on a major research project evaluation the impact of Adult Day Programs;
- Patrick Boily of the Ontario Community Support Association will present on Care Coordination, an area currently in a state of rapid evolution;
- Dr. Mary Chiu of Ontario Shores will present on Caregiver mental health research at Ontario Shores and the dementia caregiver virtual reality skills-building program
- Brittany Prokop, Toronto Dementia Research Alliance will present on research and informational opportunities for caregivers.

The depth and breadth of expertise in these presentations highlights a key strength of the OCC: the diverse knowledge and extensive skills sets of our members and friends. We hope that many of our members will be able to join us for this last General Members Meeting of 2023. If you have not received your calendar invite for this meeting, please send us a note at ontariocaregivercoalitionocc@gmail.com, and we will be sure to include you.

New Member Orientation Manual

With the leadership of our new Coordinator, Devon Makse, the OCC has completed a longstanding project: the development of an Orientation Manual for our members. As we continue to grow our membership and expand our work, our traditionally informal communications and orientation approaches began to fall short of what our membership needed to feel included and ready to engage.

The new Membership Manual ensures that we all have core information about the OCC and how we function, including:

- Our mission, vision and values
- A bit about our history
- Our organizational structure, including information about how committees and how to contact our Committee Chairs
- Our membership structure
- How we communicate, including our General Members Meetings and social media accounts

You should have received your Orientation Manual in mid-November via email. If we missed you, please email us and Devon will be pleased to send you a copy.

Our thanks to Devon for completing this important project so quickly after starting with us!

Caregiver Survey

As presented at the Annual General Meeting of the OCC in September, one of the OCC's key initiatives for this campaign year is a Caregiver Survey. Building on the learnings and successes of our 2020 Survey, which helped us understand caregiver priorities and shaped our advocacy agenda for the subsequent three years, the 2024 Survey will focus on identifying solutions for caregivers. The Survey will help the OCC, our members and our friends to understand the specific policy and program changes that will make a real difference for caregivers, so that we can shape the policy agenda around unpaid caregiving in Ontario in the coming years.

The Survey will be launched in January of 2024, with the intent to present results at our General Members Meeting in June of 2024. Stay tuned for more updates!

Upcoming Presentations

On January 18th, 2024, the OCC will be presenting at the Verity Women's Club in Toronto, as part of an evening for family caregivers that is being hosted by OCC Member, Mosaic Home Care Services. The event will include a light dinner, and panelists from a wide array of organizations, including the Alzheimer's Society of Toronto, the Blooming Caravan, the Dotsa Bitove Method, art therapist Robin Gertin, and many others. To find out more about this free event or to register, you can contact info@mosaichomecare.com or call 416.322.7002.

Opportunities to Contribute to Caregiver Focused Research

Ontario Shores Centre for Mental Health Sciences – VR-SIM Carers Initiative

Caregivers, the unsung heroes of dementia care, are taking centre stage in an innovative initiative to redefine aging-in-place for persons living with dementia. The VR-SIM Carers Initiative, generously funded by the National Research Council of Canada (NRC)'s Aging in Place Challenge program and the Canadian Institutes of Health Research (CIHR), is set to revolutionize dementia caregiver training through a multi-year research and development project.

This Collaborative Research and Development initiative is focused on co-designing a virtual reality (VR) simulation training environment tailored specifically for dementia caregivers. The project actively seeks end-user perspectives, addressing design and implementation challenges and opportunities. The outcome will be a virtual reality prototype that is not just innovative but clinically efficacious, scalable, and sustainable. This initiative will engage caregivers, older adults, and community partners in all phases of the development.

Within this training environment, caregivers will have the unique opportunity to immerse themselves in the world of caregiving. They can safely practice essential skills such as communication and behavioural management for persons with dementia.

There are multiple opportunities for caregivers to engage with this project. For more information, you can visit the dedicated project website, www.vrsimcarers.ca, which serves as a hub for knowledge mobilization and community-building, keeping knowledge users and dementia caregivers informed and actively engaged in co-creating the virtual reality training program. You may also inquire at vrsimcarers@ontarioshores.ca to learn more about our project!

Building a Virtual Reality Training Program for Dementia Caregivers, with your input!

Caregivers are key partners in supporting persons living with dementia with aging-in-place. Through a multi-year research & development initiative “Dementia Caregivers Skills-Training through Virtual Reality (VR) Simulation”, the VR-SIM Carers team aim to engage caregivers, aging adults and community partners in the design, development and testing of an innovative skills building program for dementia caregivers to safely immerse in a VR environment, to practice different skills that are instrumental in the caregiver role.

The first step is a 20-minute “Caregiver Survey”, which aims to understand what may be the most relevant and challenging relationships and caregiving scenarios that caregivers have to navigate through daily. We invite your input – please access and complete this survey [here: https://www.surveymonkey.com/r/DTWGQCQV](https://www.surveymonkey.com/r/DTWGQCQV)

To sit on our “Caregiver Advisory Committee”, please contact us at vrsmcarers@ontarioshores.ca

The collage features several images: two women in a virtual environment, a woman wearing a VR headset, a group of people in a meeting, and a woman sitting at a table. To the right is a flyer titled "Building a Dementia Caregiver Virtual Reality Skills-Building Program with your input!". The flyer includes the text: "Dementia Caregiver Survey. If you care for a family member or friend living with dementia, and 18 years and older, we need your input! Please consider completing an anonymous, 20 minute survey, and tell us which dementia caregiving scenarios resonate with you." It also includes a QR code and the link "https://www.surveymonkey.com/r/DTWGQCQV". At the bottom of the flyer, it says "CONTACT US For more information or a paper copy of survey please contact us at: vrsmcarers@ontarioshores.ca".

Of Interest

Canadian Caregiving Summit

The Canadian Centre for Caregiver Excellence (CCCE) hosted its first national Caregiver Summit, from November 6th to 8th, 2023. The summit was hosted in person in Ottawa, but was also available online.

The Summit brought together a wide array of expertise from across the country and around the world to consider the current state of caring in Canada, identify key priorities for change, and begin to plan the way forward. A core element of the Summit was the drive towards a National Caregiver Strategy which could clarify the path forward for caring in Canada, build coalitions, and mobilize change.

A Canadian Caregiver Strategy could build on the experience with the development the American [National Strategy to Support Caregivers](#), released late in 2022. The Strategy was nearly 500 recommendations that can be adopted at every level of government and across the public and private sectors to ensure that unpaid caregivers have the resources they need to maintain their own health, well-being, and financial security while providing crucial support for others. Importantly, the Strategy has a central focus on the physical, financial and emotional costs of caregiving. The overarching vision is to ensure that every single caregiver is recognized, assisted, included, supported, and engaged.

The OCC thanks the CCCE for ensuring that representatives of the OCC were able to attend and contribute to the Summit. We look forward to contributing to the efforts towards a National Caregiver Strategy for Canada.

CCCE Survey

The Canadian Centre for Caregiving Excellence (CCCE), an initiative of the Azrieli Foundation, has just released a preliminary summary of the results of a survey they conducted on the lived experience of current caregivers and paid care providers. Their findings shed light on the lives of the vastly underreported quarter of Canadians that are caregivers and care providers. The survey was conducted from July to September 2023, and saw over 3,100 respondents. This study can help with advocacy work, as it uses strong data to highlight key areas of struggle and what needs to be changed for caregivers.

Reform for caregiver support is popular among respondents, with 76% of care providers and 61% of caregivers stating that policy related to caregiving is important to how they vote. However, the results also show the lack of both information on how to access resources and tangible help that caregivers currently receive. 76% of survey respondents reported that over the preceding 12 months, they received no support services. 53% of caregivers answered that finding information about those services is difficult. While 9/10 caregivers would welcome an income tax credit, only 39% are aware of the existing Canada Caregiver Credit with an even smaller 9% having claimed it. This inaccessibility problem is very concerning, because nearly two thirds of caregivers reported experiencing financial hardship related to their caregiving.

The results of the survey indicate that there is an ongoing workforce crisis for care providers, with over a third of respondents reporting that they were considering leaving the field due to high stress and low wages.

Caregivers in Canada need more information on the resources available to them and more aid to begin with. The need to address these problems is only growing. The CCCE is anticipating that they will reveal their full data in Spring 2024, and we will provide an update when they do. If you are interested in learning more, you can access their summary of findings here: <https://canadiancaregiving.org/policy-and-research/survey-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.