



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

October 2023 Newsletter

At the OCC

Upcoming Presentations

The OCC regularly presents on issues related to caregivers and caregiving. We are looking forward to two presentations in the month of November.

Advancement for Dementia Care Centre Showcase Event

On November 13th, OCC Chair Lauren Bates will be presenting on caregiving and policy change as part of a panel discussion at this annual showcase event.

The Advancement for Dementia Care Centre (ADCC) aims to improve the quality of life of those living with dementia by using innovation to develop new approaches to support their psychosocial needs and behavioural challenges. The ADCC aims to advance leading-edge innovation in dementia care by fostering new and existing partnerships, identifying innovators, and acting as a sustainable “living lab”, where cutting-edge technologies can be adapted, implemented in real clinical settings, and evaluated based on their practical application. You can find more information about ADCC and its activities [here](#).

The Regional Learning Centre - Nucleus Independent Living

On November 14th, OCC Chair Lauren Bates will be presenting on caregiver financial distress and pathways towards change for the Regional Learning Centre.

As part of their mandate to build community knowledge and practice through innovative and accessible education, the Regional Learning Centre offers **free** caregiver education to family caregivers and health care providers that support family caregivers in their work. Sessions are offered virtually or in-person at various locations in the Mississauga-Halton community. To view

and register for this or any other upcoming event, please visit the [Regional Learning Centre Family Caregiver Hub](#).

If you would like to host a presentation from the Ontario Caregiver Coalition, please reach out to use through our email: ontariocaregivercoalitionocc@gmail.com.

Declaration on Personal Health Data Rights in Canada

The OCC has agreed to endorse the *Declaration of Personal Health Data Rights*. The *Declaration* calls for improvements to Canada’s health data ecosystem that will ensure our health data are private, secure, and shared in such a way that everyone can access better services and achieve better outcomes; our healthcare systems can continually improve; and our understanding of health and interventions to improve health can continually grow and be implemented across the country.

The *Declaration of Personal Health Data Rights in Canada* aims to build consensus among patients, caregivers, citizens, and groups representing them; create awareness of health data related issues in Canada; spur conversations; and inform policies and decision-making. A future looking and living document, informed by its global context, the Declaration seeks to promote the equal importance of both privacy and sharing.

Work on the *Declaration* is being led by the Data Working Group, a small group of volunteers from diverse patient organizations and citizen groups, most with lived experience, who worked on drafting the Declaration. As a starting point, they asked, “who owns health data and what does this mean for patients’ access to that data?” The drafting process highlighted the confusion that exists around health data and the rights of patients and their families. The result is an aspirational document, aiming to remain relevant into the future as the digital healthcare landscape evolves.

You can find more information about the *Declaration* [here](#). As well, you may be interested in the 8th annual Patients Redefining the Future of Healthcare in Canada Summit. The Summit will include information on health data practices. You can find more information here:

<http://www.patientsredefininghealthcare.ca>

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/DTWGCQV](https://www.surveymonkey.com/r/DTWGCQV)

To sit on our "Caregiver Advisory Committee", please contact us at vrsimcarers@ontarioshores.ca

Building a Dementia Caregiver Virtual Reality Skills-Building Program with your input!

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.

We also invite you to consider joining our **Caregiver Advisory Committee**, and play a direct role in developing this innovation! Email us if you are interested: vrsimcarers@ontarioshores.ca

SCAN QR CODE TO ACCESS SURVEY

You may also access survey via link: <https://www.surveymonkey.com/r/DTWGCQV>

CONTACT US
For more information or a paper copy of survey please contact us at vrsimcarers@ontarioshores.ca

Of Interest

Canadian Caregiving Summit

From November 6 to 8, 2023, the Canadian Centre for Caregiving Excellence, an initiative of the Azrieli Foundation, will be hosting the Canadian Caregiving Summit, a hybrid event in Ottawa, Ontario and online. The event will feature discussions about the most pressing issues faced by caregivers and care providers from coast to coast to coast.

The three-day gathering will bring together lived experience experts, leaders, policy makers, and researchers across age, disability, and illness communities to work together to build the foundation of a national caregiving strategy.

To learn more or to register, please visit <https://canadiancaregivingsummit.ca/>

Seniors for Social Action Ontario Report: “Is Home Care Working in Ontario?”

Seniors for Social Action Ontario, a non-profit advocacy organization focused on enabling seniors to age in place in welcoming and inclusive communities, has released an extensive review of home care in Ontario. The report is based on surveys of seniors and caregivers, key informant interviews, and a policy review. The Ontario Caregiver Coalition provided substantive input to the Report.

The Report points to the challenges of a system that is struggling with a lack of adequate, timely funding, and in which convoluted and disempowering processes discourage those seeking supports. Repeated re-organizations and modernization initiatives have created confusion for users and additional pressures for those attempting to make the system work. The Report includes 17 recommendations for strengthening the system, including system improvements, complaints mechanisms, governance, philosophy and culture, and funding structures and levels. The Report can be viewed at <https://www.seniorsactionontario.com/policyandresearch>.



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.