



January 2024 Newsletter

At the OCC

Please Support our 2024 Caregiver Survey!

We are excited to announce that the OCC has just launched its 2024 Caregiver Survey! To complete the survey, share the link, or find sample social media posts, visit <https://www.ontariocaregivercoalition.ca/caregiver-survey-2024>.

The results of this Survey will shape our advocacy priorities, and those of our partners and friends, in the upcoming years. It builds on the successes of our 2020 Survey, which collected hundreds of responses, and which has been crucial in helping us to inform decision-makers about what caregivers most urgently need.

We know caregivers in Ontario are struggling more than ever, and it's important we make our concerns heard. We want to get as many caregivers as possible participating in this survey, so our message is as strong as possible when we take it to elected officials.

Please help us to get this survey in front of as many caregivers as possible! We are asking you to complete this survey yourself if you are or have been a caregiver. We are also asking you to share it with your networks, and your caregiver friends and family.

The OCC would be happy to support you in this with any materials you may need. If you have questions, or if we can provide any assistance with sharing the Survey, please reach out to us through our general email.

We look forward to sharing the results with you at our June General Members Meeting, as well as in this space.

OCC's 2024 Pre-Budget Submission Highlights the Cost of Caregiving

The OCC has now released its 2024 pre-budget submission to the Ontario Provincial Government. You can find it [here](#).

Our submission highlighted an ongoing OCC priority: the financial impact of caregiving. Considerable out of pocket costs are incurred by caregivers for transportation, prescriptions, medical supplies, home renovations, and supplementary home care, respite services, and occupational and other therapies. Caregiving is also time-consuming, so that many caregivers must reduce their labour force participation, thereby cutting into their income and savings. As a result, many caregivers experience significant financial distress.

Our submission focused on three recommendations to address caregiver financial distress:

- 1. Implement an Ontario Caregiver Support Benefit:** The OCC continues to advocate for a direct monthly financial allowance to caregivers that is inclusive, accessible and meaningful. The OCSB would replace the current Ontario Amount for the Caregiver Tax Credit, which benefits very few caregivers because of its restrictive criteria, and has little impact on caregiver financial distress.
- 2. Increase investment in home and community care:** Caregivers rely on home, community and respite care to carrying out our essential roles. This sector is under increasing strain, with unpaid caregivers left to fill the gaps. The OCC recommends that the government implement wage parity across health care staff to address the health human resources crisis in the sector.
- 3. Strengthen Direct Funding programs:** Direct Funding programs, such as Passport, Special Services at Home, Family Managed Home Care and the CILT program are vital for many caregivers. However, programs run by the Ministry of Children, Community and Social Services run on a reimbursement model, requiring families to pay up front for expensive services. This is a barrier to access for many families. We recommend that these programs move to a reconciliation model, as is used for Direct Funding programs overseen by the Ministry of Health.

OCC Member Initiatives

Elevate Impact Hub: Ontario Community Support Association

The home and community sector continues to undergo rapid change. Researchers, providers and policy-makers rely on finding the best evidence to understand and guide this change.

The Elevate Impact Hub was launched one year ago to meet this need. Elevate is a not-for-profit under The Ontario Community Support Association that curates and presents new and exciting research in the field of home and community caregiving. Elevate also focuses on spreading the knowledge from their carefully selected research findings by facilitating coordination between research and service providers, as well as hosting webinars and peer-based learning opportunities.

For those looking to learn more about the latest developments in home and community care research, you can access the Elevate Impact Hub by clicking on the following link: <https://www.elevateimpacthub.ca/>

Opportunities to Contribute to Caregiver Focused Research

CAN Protect Study

CAN-PROTECT is a Canada-wide online study of brain aging that is recruiting a broad and diverse representation of Canadians over 40 years of age. There are brain training games, and annual assessments of cognition, function, behaviour, quality of life, diet, and lifestyle. The CAN-PROTECT platform will boost our understanding of brain aging and fast forward our research on dementia prevention and treatment.

Importantly, CAN-PROTECT is also exploring the experience of those who care or cared for persons with dementia. This sub-study is looking at multiple aspects of caregiving including patient factors, caregiver factors, and system factors, to help identify both risk and resilience. Family/friend caregivers and professional caregivers (i.e., nurses, physicians, and all allied health professionals) are welcome to participate as everyone's perspective is valuable. CAN-PROTECT is currently recruiting caregivers for this study.

CAN-PROTECT is also recruiting members of its Community Advisory Group. Members consist of study participants, partners, and caregivers willing to give feedback about this and future studies, to help CAN-PROTECT study be more inclusive, respectful, and better able to meet the needs of those involved. Participation in the CAG is online.

For more information on how to participate, please visit : www.can-protect.ca.

Of Interest

The Advancing Grief Literacy in Canada Project

The Canadian Grief Alliance (CGA) has recently received a groundbreaking \$1 million in funding from the Government of Canada for its *Advancing Grief Literacy in Canada* project.

The aim of the project is to better address the needs of the millions of grieving Canadians, by improving access to educational tools and learning opportunities for people who are grieving, as well as their families and friends. While grief awareness in Canada seems to be at an all-time high since the onset of the pandemic, grief literacy is incredibly low. As more and more Canadians grapple with the losses of their loved ones and other, less-recognized forms of grief, there are significant gaps in the access to resources they have to understand, talk about, and support others in grief.

The Canadian Grief Alliance (CGA), is a group of leading grief specialists and more than 150 national and provincial organizations that are encouraging the Government to adopt a proposal to address national gaps in grief services that are leaving hurting Canadians unsupported in their grief. The CGA began their public consultations on the project last month, December 2023, and will deliver an action plan with recommendations to the Government of Canada in 2025.

For those interested in learning more about the CGA and this project, you can access their press release here: https://www.canadiangriefalliance.ca/media/b3wmxmev/2023-11-15-cga-funding-announcement-nr_final_approved.pdf

Auditor General's Report: The Impact of the *More Beds, Better Care Act 2022*

When the *More Beds, Better Care Act* (sometimes referred to as Bill 7) was introduced in 2022, the OCC raised concerns about the potential impacts on caregivers (see our [Open Letter](#) to government).

The intent of the legislation was to hasten the flow of Alternative Level of Care patients from hospitals into long-term care. To this purpose, the legislation enabled Home and Community Care Support Services to determine eligibility for long-term care and to select homes within a defined geographic area without the consent of the patient (or their substitute decision-maker). Once a bed in the selected LTCH becomes available, they must either accept the offer or risk being charged \$400 per day to remain in hospital.

The OCC, along with many other organizations, was concerned that this legislation would separate families and friends from their loved ones, particularly given the wide geographic parameters for placement, as well as imposing extremely burdensome travel time and costs on caregivers attempting to provide essential supports to loved ones in a fragile and under-resourced LTC system. Concerns were also raised about the additional impact of this legislation on those waiting for ethno-culturally specific LTCH placements.

Now, approximately one year after the implementation of this controversial legislation, Ontario's Auditor-General has reported on its impact, as part of its value-for-money auditor of . The Auditor-General found that:

- 99 patients were placed in LTCHs without their consent. The number of patients charged the \$400 daily fee is unknown, as the Ministry is not collecting this information.
- While the government stated that the intent was to improve care outcomes for ALC patients by ensuring that they were in a more appropriate setting, the Ministry has not monitored the care outcomes of ALC patients after their admission to long-term care homes to determine if these patients are doing well after being discharged from hospitals.
- In general, ALC patients who are transferred into LTC tend to be more frail and living with more complex needs than other residents. LTCHs may need additional training or supports to provide an appropriate level of care for these residents.
- The government has not been transparent with the public regarding the available information related to the implementation of the *More Beds, Better Care Act*.

The Auditor General recommended increased transparency and data collection related to the legislation, as well as for the Ministry to work closely with LTC to ensure that ALC patients who are transferred into LTC receive the care they need. The full Auditor General's report on Long-Term Care can be accessed [here](#).



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.