



Ontario Caregiver Coalition 2023 Pre-Budget Submission January 2023

About the OCC

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 caregivers from across Ontario and the organizations that support them.

We appreciate the opportunity to provide our recommendations for the 2023 Ontario budget and would be pleased to provide further information. We can be contacted at ontariocaregivercoalitionocc@gmail.com

Our Goal: Addressing Caregiver Financial Distress

"I think it's very troubling and surprising that caregivers are not given any financial assistance. Caregivers are not only helping the ones they care for but also helping the government save a world of healthcare costs by taking care of their loved one." (OCC Caregiver Member)

Our caregiver members have told us over and over again that their top policy priority is to address the financial impact of caregiving. Caregiving is expensive, with considerable out of pocket costs incurred by the caregiver for transportation; prescriptions and medical supplies; home renovations; and supplementary home care, respite services, or 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.

Caregiver financial distress is not only a problem for caregivers themselves. The stress and budgetary restrictions can affect the level of care they are able to provide for their loved ones. Where caregivers are unable to care for their loved ones, it substantially impacts the health and long-term care (LTC) systems: caregiver financial distress is a significant cause of collapse of community caregiving arrangements, leading to admission to acute or institutionalized care. This has significant government cost implications.

The OCC therefore urges government to address caregiver financial distress by:

1. **Providing direct financial supports to caregivers:** Make the current Ontario caregiver tax credit fully refundable to benefit all Ontario caregivers and provide the financial relief they desperately need.
2. **Strengthening our vital home and community care system** by implementing wage parity across all sectors of health care, thereby ensuring that caregivers can find the support they need at home so they can balance work and caregiving.
3. **Reducing the financial impact of geographically distant long-term care placements for patients who meet alternate level of care (ALC) designation:** Replace the current allowable geographical long-term care placements for individuals who meet the ALC designation with

individualized assessments that consider the caregiver's ability to travel and automatically cover the full cost of transferring ALC patients to LTC.

4. **Ensuring equitable access to Ontario's direct funding programs:** Ensure that substitute decision makers and family caregivers are eligible to manage applications and act as fund administrators for all direct funding programs. Expand base funding for the Passport Program to improve accessibility. Manage all direct funding programs on a reconciliation rather than a reimbursement model.

Understanding Caregiver Financial Distress

"There is a financial struggle in our particular situation. You know, we do dip into our savings and our investments and our lines of credits to pay these things, to get the support and care that not only they need, but that they deserve. So there is a great financial impact and with financial impact comes emotional impact because you are always thinking about money. You are always thinking about debt. You're always thinking about how to pay off that debt." (OCC Caregiver Member)

Ontario caregivers are the backbone of our health care system, providing an estimated \$28.5 billion per year worth of care. However, their value to the Ontario health care system comes at a personal cost. Caregiving is both expensive and time consuming. With limited access to supports and services, caregivers spend countless hours providing essential care that would otherwise be performed by professional care staff.

Approximately 75% of caregivers juggle work and caregiving. Of these, in a 12 month period:

- 30% were late for work or had to leave early
- 29% missed an average of 6 days work due to caregiving
- 1% had to leave their employment as a result of caregiving responsibilities

The Change Foundation, Profile of Caregivers

Caregiver financial distress occurs when the costs associated with caregiving place a significant financial burden on the caregiver, creating economic hardship and additional stress. Caregiver financial distress is much more common than is generally assumed.

9 % of Ontario caregivers (297,000 Ontarians) report financial hardship because of their caregiving responsibilities. Of these:

- 90% have modified their own spending & budgeting
- 77% have dipped into their saving to support their caregiving
- 33% have borrowed from family or friends
- 20% have taken a loan from a financial institution

The Change Foundation, Profile of Caregivers

Caregivers consistently report financial assistance as their most important *unmet* need, ranking this higher than more traditional policy priorities, such as navigational or mental health supports.

- Of the 30% of caregivers who indicate a desire for additional supports, 68% indicate a need for some type of government financial support, such as a tax credit or other government assistance (2018 General Social Survey).

- The OCC's 2020 Caregiver Survey identified financial distress as a top advocacy priority, with 51% of respondents needing additional financial supports for their caregiving.

Our Recommendations

1. Make Ontario's Caregiver Tax Credit Refundable

Make the Ontario Caregiver Credit refundable, thus ensuring that financial supports are received by those caregivers who need them most.

Unlike other provinces such as Manitoba, Quebec and Nova Scotia, Ontario offers limited direct financial relief for caregivers. The existing Ontario Caregiver Credit is a non-refundable tax credit for family caregivers, often providing little to no benefit for low-income earners who are arguably the ones most in need. A [Cost Benefit Analysis](#) conducted for the OCC demonstrates that in order to receive the maximum credit of \$7,348, Ontarians must be earning \$74,700. Meanwhile, 37% of caregivers have a personal income of under \$40,000 per year. Many do not even earn enough to pay taxes, resulting in the inability to access this important tax credit.

Providing direct financial supports to caregivers is highly cost effective. Research indicates that providing even modest direct financial supports to caregivers can delay or even avoid placing their loved one in costly long-term care. Our Cost Benefit Analysis suggests that modest financial supports, such as making the Ontario tax credit refundable, could replace up to 7.8% of Ontario long term care beds, with estimated savings of at minimum \$307 million to the Ontario government.

In making the Caregiver Tax Credit refundable, Ontario can build on the experiences of other provinces that provide direct financial supports to caregivers, including Nova Scotia's Caregiver Allowance, Manitoba's Primary Caregiver Tax Credit, and Quebec's Caregiver Strategy.

Ontario can also strengthen other credits that are available to caregivers, families, and older adults to further support the financial needs of Ontarians. For example, the Ontario Seniors Care at Home Tax Credit is a refundable tax credit that helps older Ontarians with medical expenses age at home. The OCC supports the recommendations of Home Care Ontario to strengthen the impact of this credit by:

- eliminating the requirement for a disability certificate in respect of claims for in-home attendant care; and
- either eliminating or increasing the income threshold.

2. Strengthen Our Vital Home and Community Care Sector by Addressing the Health Human Resources Crisis

Increase investment in home and community care, by implementing wage parity across health care staff to address the health human resources crisis in the sector.

Home and community care is vital to Ontario's health system, allowing individuals and families to receive and provide the essential care they need to remain at home, in their communities. Greater

investments in the home and community care system will sustain the important work that caregivers provide, ensuring that they have access to the reliable, responsive, and high-quality supports they need to continue to provide care at home for their loved ones.

It's no secret that Ontario is facing a health human resource crisis. Unfortunately, the home and community care sector is being hit the hardest, as they continue to lose care staff to hospital and long-term care sectors as workers seek out better compensation, benefits, and support for the same work.

"I wasn't able to work full time because some of our caregivers or the agencies weren't reliable. [...] So I never felt like I could commit to working really for a bit, and so that was hard financially." (OCC Caregiver Member)

As a result, unpaid caregivers are left to fill in the gaps. The pressures on caregivers are growing in part because they increasingly find themselves called upon to provide the kind of care traditionally provided by health professionals.

Pre-pandemic, 26% of caregivers were providing more than 10 hours of unpaid care per week. In 2021, this number increased to 34%, with 58% of Ontario's 3.3 million caregivers feeling burnt out and half reporting their mental health being worse than the previous year. The impact on caregiver's personal finances is also greater than prior to the pandemic, with 9% reporting financial hardship because of their caregiving responsibilities.

Ontario Caregiver Organization, Spotlight Reports 2020 and 2021

Growing staffing shortages in home and community care are leading to longer wait-lists to access these supports. If the current trajectory continues, we risk the cancellation of programs and services that caregivers desperately rely on. This will only exacerbate the problem of caregiver burn out and financial distress, leaving them with no choice but to turn to hospitals and long-term care homes for the care their loved one could have received at home with proper investment in home and community care.

We urge the government to recognize that the home and community care sector is the foundation of what will bring our healthcare system out of crisis. By supporting home and community care workers, the government will in turn be supporting Ontario's caregivers. We support our member organizations in asking for greater investment in home and community care by implementing wage parity across health care staff between sectors and developing a system wide health human resource plan to help keep Ontarians where they want to be — at home.

3. Reduce the Financial Impact of Bill 7 on Caregivers

Reduce the financial impact of Bill 7 on caregivers by ensuring that caregiver ability to travel is taken into account in placement decisions, and by automatically covering the costs of transfer to long-term care for ALC patients.

Bill 7 allows for ALC transfers to long-term care homes up to 70 km distant in urban and 150 km in northern or rural areas. For caregivers — many of whom provide the healthcare system with countless hours of unpaid care every day — these distances will impose significant additional

financial burdens. Some may rely on public transportation when visiting and caring for their loved one. Others may be limited for time because they are also juggling work responsibilities and care for other family members. Each person's situation is unique.

We urge the Ontario government to *replace arbitrary geographical limits with individualized assessments by placement coordinators, in which caregiver ability to bear the costs and time pressures of travel are taken into account.* The distances proposed in Bill 7 move people with complex care needs further from their homes, families, and support networks. The increased travel costs will hit hard for caregivers who are already experiencing financial distress and the cost of living crisis. They will have to spend more time away from work and home life for increased travel, and experience greater financial costs due to higher gas prices and the need for accommodation when a round-trip is too great to travel every day. We urge the government to replace these arbitrary distance criteria with individualized assessments by placement coordinators, where each person and their caregiver's ability to travel and bear costs will be carefully considered in choosing the long-term care home.

Automatically cover the costs of hospital transfers occurring under Bill 7. When ALC patients are transferred to a distant placement not of their choosing, hospital transfer fees are still charged. Given the greater distances, these transfer costs can be significant, especially where patients have complex needs that necessitate specialized transfer equipment. Families should not be left picking up the tab for a hospital transfer they never wanted in the first place. We ask the government to cover the cost of hospital transfers occurring under Bill 7 from the outset, as it is unreasonable that yet another substantial cost be downloaded onto already heavily burdened families.

3. Create equitable access to direct funding programs

Strengthen Direct Funding programs by enabling substitute decision-makers and family caregivers to make applications and act as fund administrators; moving all Direct Funding to a reconciliation rather than reimbursement model; and increasing funding to end waitlists.

Direct funding programs (such as the Passport Program, the CILT Direct Funding Program, Family Managed Home Care, and Special Services at Home) across Ontario are one of the few ways the government offers financial relief to people living with disabilities and their caregivers by putting money directly into their pocket to be managed in the way that best suits their needs. While not suitable for all families, these programs provide important enhancements and flexibility to existing home and community care supports. Unfortunately, the impact of Direct Funding programs is limited by arbitrary and inequitable requirements. The OCC recommends that the government strengthen its Direct Funding programs by:

Ensuring that all Direct Funding programs enable substitute decision-makers and family caregivers to manage applications and act as fund administrators. Currently a person who requires support in decision making due to cognitive impairment cannot apply for the Family Managed Home Care Program because eligibility requirements do not allow a substitute decision maker or caregiver to complete the application or manage funds on behalf of another person. This limits the impact of these programs for the growing population of persons with cognitive or intellectual impairments.

Ensure all Direct Funding programs use a reconciliation rather than a reimbursement funding model: Direct Funding programs managed by the Ministry of Children, Community and Social Services, such as the Passport and Special Services at Home programs, are currently based on a reimbursement model. This means that the family must first pay for services and supports while waiting for reimbursement. Oftentimes, they are left waiting up to eight weeks for reimbursement for the funds already spent. Many families, especially those with limited financial resources, do not have eight weeks to wait. Instead, they must choose between paying their bills, feeding their family, or getting the proper care their loved one needs. That is a choice no one should have to make. While there are options for families who cannot wait for reimbursement, such as engaging with a Transfer Payment Agency to provide direct support, these agencies may claim up to 10% of the client's funds that could otherwise be used for care purposes. Direct Funding programs managed by the Ministry of Health use the much more accessible reconciliation model. We recommend that all Direct Funding programs move to the reconciliation model to ensure accessibility for all families.

Increase base funding for these programs to reduce lengthy waitlists, such as those for the Passport program. Funding caps for Direct Funding programs such as Passport, have resulted in lengthy wait lists to access sufficient support. To clear the long waitlists, previous governments had given waitlisted individuals \$5000, which is far less than their needs and what the program offers. Band-aid solutions are neither sustainable nor equitable. We ask the government to increase investments for funding to these programs to promote greater accessibility and equity.

“Society is monetized. To receive no compensation for the 24/7 care I give can be daunting and depressing.... This is a lonely, isolated life of tremendous responsibility and sacrifice. It is done due to necessity and out of love. But there is a price paid by the unpaid.” (OCC Caregiver Member)