



BUILDING A BETTER ONTARIO FOR CAREGIVERS

**by Alleviating the Financial Hardships
of Caregiving**

**The 2024 Ontario Caregiver Coalition Survey of Caregivers:
Policy Brief #2**

“I truly feel if the government wants us to be a caregiver at home and to help alleviate pressure on institutions, there should be a lot more financial assistance and help in this area.”

September 2024



ABOUT THE ONTARIO CAREGIVER COALITION

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 both caregivers from across Ontario and organizations that support them. For more information about the OCC and our work, please see our website at www.ontariocaregivercoalition.ca, or follow us on social media.



BUILDING A BETTER ONTARIO FOR CAREGIVERS: POLICY BRIEF SERIES

This Policy Brief, developed by the Ontario Caregiver Coalition (OCC) and informed by OCC's 2024 Ontario Caregiver Survey, is the second of a series of six Policy Briefs that will be presented to the Ontario Government in 2024 and 2025.

The OCC's 2024 Ontario Caregiver Survey sought to explore policy priorities among Ontario caregivers. The Survey was in the field from January 31, 2024, until March 12, 2024, and received 612 responses from Ontario caregivers. The policy recommendations presented in each Policy Brief are based on the views expressed in the Survey by caregivers.

The Ontario Caregiver Coalition would like to extend our thanks to all of the many members and friends who worked to design, distribute and complete our 2024 Ontario Caregiver Survey. Your passion for supporting unpaid caregivers and your commitment to change are inspiring, and make the impossible possible!

In particular, we would like to thank the following members of the Research and Advocacy Committee who devoted their time and skills to the development of this Policy Brief.

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ALLEVIATING THE FINANCIAL HARDSHIPS OF CAREGIVING

“We are living below the poverty line, and food, fuel costs as well as loan interest is going up. The financial stress can be crushing.” *

The costs of unpaid caregiving are high in terms of both out-of-pocket expenses and lost opportunities for paid work. A growing proportion of caregivers are experiencing real financial hardships. Given the critical, yet undervalued role caregivers play in Ontario’s health and long-term care systems, these hardships are unacceptable. They can reduce the quality of care provided, impact caregiver health and wellbeing, and add to the pressures on Ontario’s health and long-term care systems. And yet, Ontario caregivers have access to very little in the way of financial supports, with most receiving no help at all.

The Ontario Caregiver Coalition calls on the Ontario government to implement the Ontario Caregiver Support Benefit, a monthly direct financial support to address the financial hardships associated with unpaid caregiving.

WHY IS FINANCIAL HARDSHIP A PRIORITY ISSUE FOR CAREGIVERS?

“I gave up my career to be a caregiver. My CPP is minimal, and I have no workplace pension.”

Studies have shown that **close to half of unpaid caregivers are experiencing significant financial hardships because of their role**, and that the extent of this problem is growing.¹ Caregivers are dipping into their savings and taking out loans and lines of credit to pay for their caregiving expenses.² Financial distress was a top priority in the OCC’s 2020 Caregiver Survey and remains so in our just completed 2024 Survey.

Out-of-pocket expenses for caregiving are high, and mounting. Caregivers are often very surprised to learn how little support is accessible through our health and social services systems. Highly rationed publicly-funded supports in the community leave families paying for expensive private services for everything from equipment and supplies, to allied health services such as physiotherapy or nutritional care, to home care and respite services. This is in addition to the costs of travel and transportation, special diets, and home modifications.

All quotes in this Brief are from unpaid caregivers who completed the 2024 OCC Caregiver Survey

At the same time, the demands of caregiving often reduce the ability to engage in paid work. In some cases, this can be because of the intensity of care required. In other cases, inconsistent or unreliable home care supports can make juggling work and care practically impossible.

However, there is very little support available to caregivers to address the significant financial hardships associated with their role.

WHAT IS THE IMPACT OF CAREGIVER FINANCIAL DISTRESS?

“Financial impacts go beyond paying for services. I am a young carer and it affects my whole career and income trajectory. Acknowledgement of this has been few and far between.”

The financial hardships associated with unpaid caregiving have unacknowledged but significant costs both for individuals and for society.

Caregiver financial distress affects quality of care.

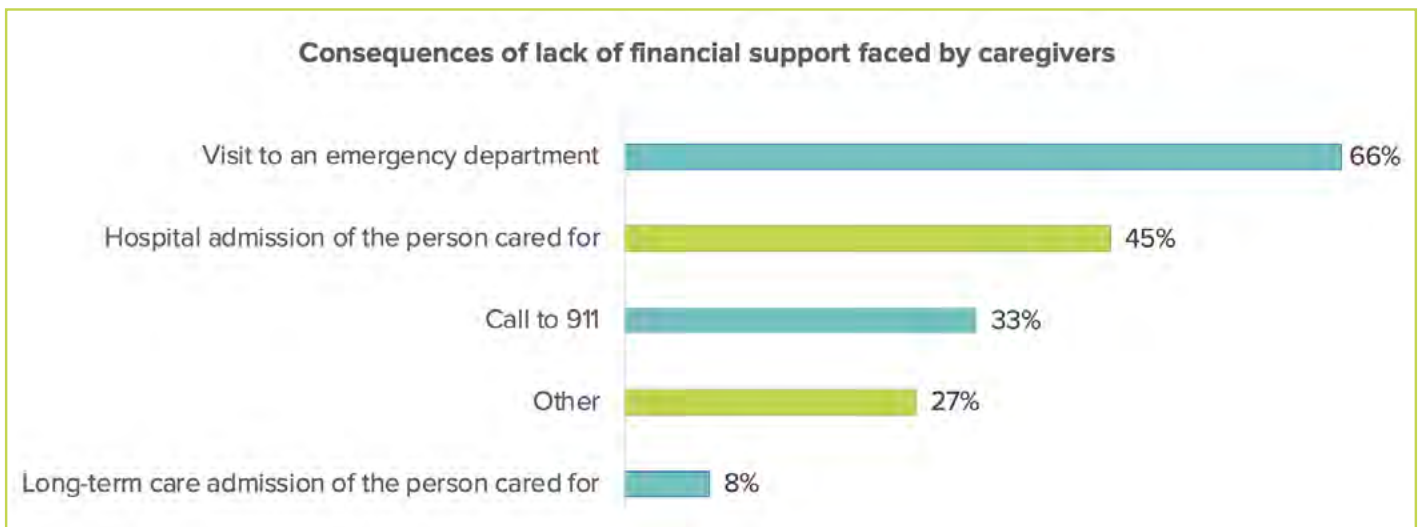
Cost-strapped caregivers may find themselves having to compromise the quality of care they can provide. Lacking the funds to pay for it, caregivers may ration care – for example, by cutting back on special diets or deferring physiotherapy for those they are caring for. They may also experience burnout as they attempt to take on additional tasks they cannot afford to pay for or lose access to the respite that they need to recharge.

Caregiver financial distress impacts caregiver health and wellbeing.

The out-of-pocket expenses and reduced income associated with caregiving can leave caregivers struggling to meet their own material needs, with serious consequences for their own health and wellbeing. Poverty in Ontario is associated with avoidable, costly health impacts: Ontarians with low-income face, for example, increased rates of food insecurity, which is associated with long-term physical and mental disabilities and increased health service use. They are also more likely to have multiple chronic health conditions, which has increased hospitalization risks and higher health care use.³ In our Survey, caregivers report an inability to pay for needed health and wellbeing supports for themselves such as counseling and getting a break (respite). It should not be surprising then that caregivers are at high risk for burnout and poor mental health.⁴

Caregiver financial distress contributes to strains on the health system.

While most families want to provide care in the community for as long as possible, acute financial pressures leave many caregivers with little choice but to turn to the health and long-term care systems for the help they so desperately need. For example, **16% of caregivers participating in our survey reported that the person they cared for needed to be admitted to a long-term care home because the caregivers did not receive the supports they needed.** Among our Survey respondents who identified financial supports as a top unmet need, two-thirds cited a visit to a hospital emergency room as one of the consequences of this unmet support, and 45% referenced a hospital admission. The resulting premature or avoidable hospital or long-term care admission contributes to the current high levels of strain on these systems. Financial support for caregivers would help to delay or reduce avoidable and premature long-term care admissions, and decrease repeated visits to acute care settings — a cost savings to the government of over \$307 million in long-term care home spending alone.⁵



Caregivers face long-term financial insecurity and low-income.

Caregiving contributes to both current and future financial insecurity. In our Survey, caregivers reported an inability to save or having to use their retirement savings to pay for out-of-pocket expenses for medical supplies, care services, and home modifications which can average thousands of dollars annually. Caregivers are often forced to reduce their paid work or exit the labour market entirely to provide care, which contributes to low income as well as reduced pension and CPP contributions.

TO WHAT SUPPORTS DO ONTARIO CAREGIVERS CURRENTLY HAVE ACCESS?

“I am a disabled senior in a wheelchair and I can not get help for him or myself. All I get given is a list with people I can hire for 40 dollars an hour which we can’t afford.”

Financial supports for Ontario caregivers are very limited. In fact, the vast majority of caregivers (78%) report receiving no financial supports whatsoever.

Compassionate Care Benefits: These benefits are provided through the federal government under the Employment Insurance Program. They are available only to EI eligible employees who must be away from work temporarily to care for a family member who either faces a significant risk of death within 26 weeks or is dealing with a critical illness or injury that puts their life at risk.⁶ **Very few caregiving situations fall within these bounds.**

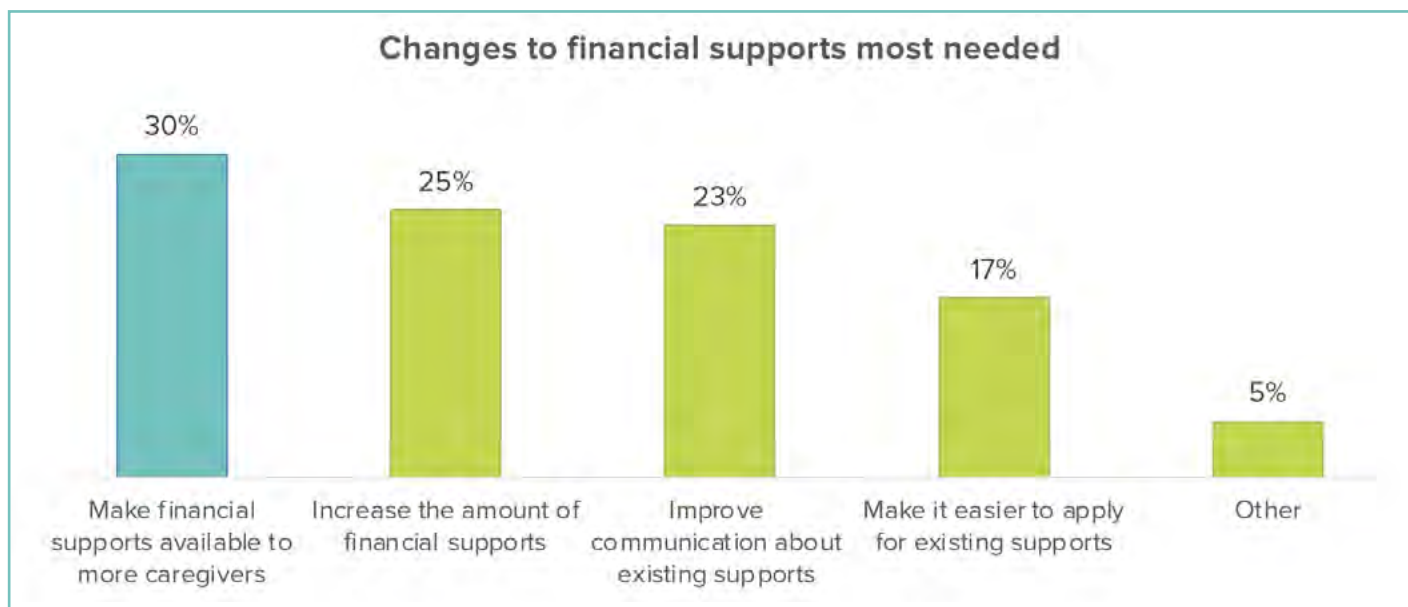
Tax Credits: There are several tax credits that may somewhat offset expenses related to care. However, the tax credit landscape is complex. The federal government provides several tax credits, including the Disability Tax Credit, the Canada Caregiver Credit, a Medical Expenses Tax Credit and a Home Accessibility Tax Credit. The Ontario government provides its own Caregiver Amount, the Ontario Medical Expenses Tax Credit, the Ontario Disability Tax Credit, the Healthy Homes Renovation Tax Credit and a newer Senior Care at Home Tax Credit. Some of these tax credits are directed to the care recipient but may have ancillary benefits for caregivers. Others, like the federal Disability Tax Credit, can be transferred from the care recipient to the caregiver in some circumstances. This landscape creates a complex patchwork of credits for caregivers to understand and access. **It should be noted that all these tax credits provide very limited amounts and most have stringent eligibility requirements.** Most are non-refundable, meaning that they have limited or no utility for those who owe little or nothing in the way of taxes.

Self-Directed Funding: Self-directed funding programs, such as Ontario’s Passport, Special Services at Home, Family Managed Care and Self Managed Attendant Services programs are not direct financial supports to caregivers. However, by placing money in the hands of families to purchase the supports they most need from the providers that they choose, these programs can offer families flexibility and choice, helping to reduce some financial pressures.

While the Canada Pension Plan provides some adjustments for those who temporarily reduce workforce commitment to care for a child, there is nothing that currently addresses retirement income shortfalls for long-term caregivers who reduce or end workforce participation.

The design of existing supports means that they reach only a tiny proportion of caregivers. When attempting to access financial supports, caregivers are faced with byzantine application processes, minimal communication about available supports, stringent eligibility requirements,

income testing that excludes many caregivers with sky-high caregiving expenses from receiving any supports, all to receive minimal amounts that do not cover basic needs.



HOW CAN ONTARIO EFFECTIVELY ADDRESS CAREGIVER FINANCIAL DISTRESS?

“Caregivers should be paid for so they can take care of themselves and keep taking care of their ‘person’. They are burnt-out and it reflects on the family overall health.”

Addressing caregiver financial distress will ultimately require a multi-pronged approach. Strengthening supports in the community will ease the out-of-pocket costs associated with unpaid caregiving. Improving opportunities for labour force participation among caregivers will reduce short and long-term effects on caregiver income.

Direct financial supports for caregivers are another key piece of the puzzle, enabling families to make effective and sustainable choices about how care is provided. Recognizing the intensive work of caregiving and the value that it provides to our health and social systems, is also a matter of fairness. Direct financial supports have demonstrated reduced or delayed resort to expensive institutional care, providing benefits to both care recipients and society.⁷ Other jurisdictions have pioneered approaches to caregiver financial supports from which we can learn to develop a made-in-Ontario approach that fits our needs and our systems.⁸

An effective direct financial support for caregivers will be designed to:

- ◆ Address the situations of the range of caregivers who need supports, such as young caregivers, those who are caring for children with complex medical conditions, those who are caring for persons with chronic or episodic conditions, and those caring for aging parents;
- ◆ Provide meaningful levels of financial support; and
- ◆ Have accessible processes and administrative requirements to ensure that all caregivers who need financial support can benefit.

OCC worked with the Munk School of Public Policy's Public Good Initiative to design a direct financial support program that would meet the needs of caregivers. The [Ontario Caregiver Support Benefit](#) would:

- ◆ Provide a monthly direct benefit to Ontario's unpaid caregivers,
- ◆ Initially be targeted to those who are already recognized as in need, such as those receiving or waitlisted for the Passport or Special Services at Home programs, respite programs, the Ontario Amount of the Caregiver Credit, or Family Managed Care, for example,
- ◆ Initially provide \$1000 per month to eligible caregivers.⁹

REFERENCES

1. Ontario Caregiver Organization. Spotlight Report 2021. In 2018, 22% of Ontario caregivers reported experiencing financial hardships. By 2020, this number had risen to 45%. Available from: <https://ontariocaregiver.ca/wp-content/uploads/2024/03/OCO-Spotlight-report-English-2021-NOV22-240PM.pdf>
2. Ontario Caregiver Organization. Spotlight Report 2021. Available from: <https://ontariocaregiver.ca/wp-content/uploads/2024/03/OCO-Spotlight-report-English-2021-NOV22-240PM.pdf>
3. Health Quality Ontario. Income and Health: Opportunities to achieve health equity in Ontario. Toronto: Queen's Printer for Ontario; 2016. Retrieved from: <https://www.hqontario.ca/Portals/0/documents/system-performance/health-equity-report-en.pdf>
4. Roth, D. L., Perkins, M., Wadley, V. G., Temple, E., & Haley, W. E. (2009). Family caregiving and emotional strain: Associations with psychological health in a national sample of community-dwelling middle-aged and older adults. *Quality of Life Research*, 18 , 679-688
5. La Prairie S., and O'Sullivan, M., (2022) Direct Financial Supports to Caregivers: A Cost-Benefit Analysis. Ontario Caregiver Coalition. Available from: https://www.ontariocaregivercoalition.ca/_files/ugd/3e14ad_6570ce52723e4e569abf4d284dc42f30.pdf
6. Government of Canada "EI Caregiving Benefits". Accessed January 30, 2023. <https://www.canada.ca/en/services/benefits/ei/caregiving.html>
7. La Prairie S., and O'Sullivan, M., (2022) Direct Financial Supports to Caregivers: A Cost-Benefit Analysis. Ontario Caregiver Coalition. Available from: https://www.ontariocaregivercoalition.ca/_files/ugd/3e14ad_6570ce52723e4e569abf4d284dc42f30.pdf
8. Imran A, McNamara G., Winger, C. (2023) Caregiver Program Review. Public Good Initiative and Ontario Caregiver Coalition. Available from: https://www.ontariocaregivercoalition.ca/_files/ugd/3e14ad_ae9c7650745446d78ba1e68debadc49b.pdf
9. Imran A, McNamara G., Winger, C. (2023) Caregiver Financial Distress: Recommendations for Change. Public Good Initiative and Ontario Caregiver Coalition. Available from: https://www.ontariocaregivercoalition.ca/_files/ugd/675ebd_765b027dc337474facfde338908dd0ec.pdf

See also Shane Ross, "P.E.I. government rolls out At Home Caregiver Benefit promised in 2023 platform", (July 15, 2024) CBC News. Available from: <https://www.cbc.ca/news/canada/prince-edward-island/pei-caregiver-benefit-1.7263923#:~:text=The%20At%20Home%20Caregiver%20Benefit,determine%20if%20they%20are%20eligible>