

Addressing the Costs of Caring: Responding to Caregiver Financial Distress

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It is common these days for policy-makers to acknowledge how vital family caregivers are not only to supporting their loved ones to lead good lives, but also to sustaining our overstretched health, long-term care and social services. All too often, however, caregivers receive little practical support beyond these words of thanks and empathy.

This is particularly true when it comes to the financial costs of caregiving. While some steps have been made in recent years to improve caregiver training and mental health supports, and to smooth system navigation, Ontario families are currently left to manage the costs of caring largely on their own. With the cost of living crisis and the ongoing shortfalls in home and community care, these costs continue to mount.

The recent Bill 7 (*More Beds, Better Care Act*) adds to these financial pressures. Bill 7 enables hospitals to identify long-term care placements for patients who have been identified as needing “alternative levels of care”: in Southern Ontario these placements may be up to 75 km away from the patient’s home community, and in Northern Ontario up to 150 km distant. Where families do not accede to the identified long-term care placement, a daily fee of \$400 may be levied, a clearly insupportable cost for the vast majority of families. Less publicized is that where families do accede to such a placement, they are responsible for the associated transportation costs, which may be considerable in light of the distances to be travelled and the frailty of the individuals involved.

This is therefore an opportune moment to redouble efforts to address caregiver financial distress.

What is caregiver financial distress?

“The end up cost I estimate would be in excess of \$1,000,000 that went to augment [my wife’s] care. The last year alone I spent over \$150,000 for the extra care that was necessary during her final year of life.” (OCC Member)

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. The OCC regularly hears from members who are in significant financial difficulties as a result of their caregiving responsibilities, including those who are sustaining their caregiving by taking out new mortgages or running up lines of credit. A 2021 OCC survey found that 45% of the caregivers who responded were experiencing financial hardship and 20% had taken out a loan or line of credit to help pay for caregiving expenses. Given that 29% of Ontarians – about 3.3 million of us – are unpaid family caregivers, caregiving may be a significant contributor to low-income and financial distress in this province.

What do we know about the extent of Caregiver Financial Distress?

- More than half of senior caregivers report needing financial assistance to support their caregiving responsibilities (2018 *General Social Survey on Caregiving and Care Receiving*)
- Among regular caregivers, financial difficulties related to caregiving are experienced by:
 - 28% of those who care for a child with special needs
 - 20% who care for a spouse
 - 7% of those who regularly helped their parents.
- Of those caring for a child with special needs, 10% had to borrow money from friends or family, and 12% had to take out a loan from a financial institution (2012 *General Social Survey on Caregiving*)

Caregivers consistently report financial assistance as their most important unmet need, ranking this higher than more commonly prioritized supports, such as navigational or mental health supports. In the 2018 *General Social Survey*, of the 30% of caregivers who indicated a desire for additional supports, 68% indicated a need for some type of government financial support, such as a tax credit or other government assistance.

Why do caregivers experience financial distress?

“I wasn't able to work full time because, you know, some of our caregivers or the agencies weren't reliable. And then my sister and I would be juggling taking turns. You know, if they weren't able to cover someone, or if the caregivers were late, who would stay with my parents to make sure that there's somebody there with them before going to work? So I never felt like I could commit to working really for a bit, and so that was hard financially.” (OCC Member)

The financial stressors of caregiving are a surprise to many caregivers. Those who are not yet caregivers can imagine the emotional and mental distress, the time pressures, perhaps even the navigational difficulties, but many caregivers report that they were unprepared for the financial impact. Financial pressures are the result of:

- *Extensive out of pocket costs:* Canadians assume that, with our public health system, the costs of caregiving will be minimal. However, the scanty levels of home and community care services leave many families paying for necessary additional supports from private providers, which can be a heavy cost. There may be costs for medications or associated health services, particularly for those with limited or no access to employer-sponsored health benefits. As well, many families end up with significant costs for travel, transportation and accommodation, whether for transporting loved ones to treatment, or for visiting loved ones who are placed in settings outside their home community.
- *Reduced workforce participation:* Caregiving can involve very significant time commitments that clash with employment commitments. For some caregivers, their responsibilities are equivalent to a full-time job: the *General Social Survey* reported that 31% of those caring for their spouse and 29% of those caring for their child with special needs had done so for 30 hours or more per week. Where a loved one's needs are intermittent and hard to schedule, workforce participation can be a challenge for caregivers even at much lower levels of time commitment. As a result, caregivers may reduce their labour force participation, or step out of the labour force entirely. This employment reduction has long-term as well as short-term financial impacts, as it reduces contributions to pensions and interrupts career trajectories.

What government supports are available for Ontario caregivers experiencing financial distress?

“This is where I get emotional, because [my parents] have worked really hard their entire life. They're honest, Canadian citizens who've contributed to their respective employers, who have contributed to the Canadian economy and in this time of dire need, there aren't any grants, subsidies, rebates and that kind of a thing... There are minimal, minimal supports and resources and tax credits available, but it does not outweigh what you pay out.” (OCC member)

Financial supports for caregivers are very limited, particularly in Ontario.

- *Compassionate Care Benefits* (Employment Insurance): The federal government provides “Compassionate Care Benefits” under the Employment Insurance Program, but these are available only to EI eligible employees who must be away from work temporarily to care for a family member who faces a significant risk of death within 26 weeks. Very few caregiving situations fall within these bounds.
- *Canadian Care Benefit* (federal tax credit): Through the tax system, the “Canadian Caregiver Benefit” provides a maximum benefit of \$6883 where an eligible relative is dependent on the taxpayer because of a mental or physical disability; however, this is a non-refundable tax credit¹, meaning that it has limited utility for caregivers already living in low-income.
- *Ontario Caregiver Amount* (Ontario tax credit): Ontario has a Caregiver Amount aligned with this federal tax credit; like its federal counterpart, it is non-refundable.

¹ The federal Liberals committed to making this refundable tax credit in the 2021 election campaign.

Why does caregiver financial distress matter?

“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. You're always thinking about that line of credit.” (OCC Member)

Addressing caregiver financial distress is the right thing to do. While caregivers act out of love and commitment, and often find their caregiving a rewarding experience, they should not find themselves living in poverty or severe financial stress as a result.

Beyond this, however, addressing financial distress is also the practical thing to do. Financial distress is a significant cause of collapse of care in the community. Where the financial costs of caregiving become unsustainable, families may have no choice but to turn to institutional alternatives. Caregiver exhaustion may also lead to unnecessary admission to acute care. A Cost Benefit Analysis developed for the OCC found that a modest direct financial support program for caregivers of about \$400 per month could replace 7.8% of Ontario’s long-term care beds. Each dollar provided in cash benefits to caregivers could replace up to \$2.69 spent subsidizing long-term care spaces. Such a transfer could immediately replace between \$479 and \$483 million in LTC beds. Gross savings could escalate over time to between \$679 and \$783 million, depending on rates of aging. This would represent a net saving of \$307 million when accounting for projected program expenses, escalating to between \$343 and \$390 million by 2040.

As well, financial stress has a direct impact on the health and wellbeing of caregivers. Many caregivers live with persistent worry about finances, and find themselves unable to afford the goods or activities needed to support their mental and physical health. As research on the social determinants of health has emphasized, living in low-income has significant impacts on health. Thus, caregiver financial distress may have additional long-term costs in health spending and lost wages.

It’s important to underline, that these consequences will fall more frequently and heavily on some groups than others. Women disproportionately take on the responsibility of caregiving, a contributor to their greater likelihood of living in low-income in older age. Newcomers and racialized caregivers often start their caregiving journey with lower incomes and fewer financial resources, so that the costs of caregiving can have especially heavy consequences.

What can be done to address caregiver financial distress?

“In the next 10 to 20 years, if there aren't supports available for the person who's ill as well as the caregiver, then I think we run into dangerous territory. From all parts - from the health care workers being overworked and under resourced and underfunded to, women leaving their jobs trying to be the caregiver - and in most cases it's women caregivers, women out of the workforce - immigration numbers up and down trying to fill these spots, turnover for employers because they're trying to fill

spots and people are leaving. So I think there's a big implication and a big effect to what we are going through.” (OCC Member)

There are a number of policy avenues to address caregiver financial distress

Provide caregivers with direct financial supports through refundable tax credits or caregiver allowances: Direct financial supports to caregivers are an effective policy option. Direct financial supports enable caregivers to meet the direct expenses of caregiving and better support their loved ones. They serve as a substitute for forfeited labour income, providing caregivers with the financial room to reduce work hours and provide care without sacrificing personal well-being. With direct support, caregivers can adjust their mix of working hours and additional services purchased to meet their circumstances, ensuring the best balance for both themselves and their loved ones. Successful models for this approach already exist in Nova Scotia, Manitoba, and Quebec. Ontario can learn from best practices in those jurisdictions to make implementation easier and more effective. As the Cost-Benefit Analysis developed for the OCC demonstrates, direct financial supports, by making care easier to sustain, can reduce dependence on expensive institutions and directly save the government money.

Examples of Direct Financial Supports for Caregivers

Nova Scotia: The Caregiver Benefit program provides an allowance of \$400 per month to caregivers who are in an ongoing care relationship with the person receiving care and who provide 20 or more hours of assistance per week. This is an income tested program.

Manitoba: The Primary Caregiver Tax Credit provides a refundable tax credit of up to \$1400 per year to a person providing unpaid care to a family member, friend or neighbor who has been assessed as requiring significant levels of assistance.

Quebec: As part of its ambitious and comprehensive Caregiver Strategy, Quebec provides a suite of tax credits, include a refundable tax credit of \$1560 for the cost of specialized respite services, a refundable tax credit of up to \$1266 for those caring for a person over the age of 70, and a separate refundable tax credit for those caring for persons living with a disability.

Strengthen supports and accommodations to enable caregivers to sustain both employment and caregiving. This can include improving and extending home care services, as well as strengthening the employment standards and human rights protections for employees who are juggling caregiving and employment. Current employment insurance supports for caregivers are so narrowly targeted as to exclude almost all caregivers.

In concert with improved home and community care supports, broaden access to direct funding programs that allow families to purchase the services they need most from the providers of their choice. Ontario’s direct funding programs including its Passport, Special Services at Home, Family Managed Care and Self Managed Attendant Services programs. Research finds that direct funding programs lead to greater care continuity, fewer unmet needs, innovative use of public resources, and higher overall user

satisfaction compared to traditional home care services. Caregivers emphasize the benefits of choice and flexibility in developing creative solutions to meet unique family needs, developing trusted and stable care-providing arrangements, and ensuring care is delivered in accordance with cultural and linguistic needs. While not appropriate for all families due to their greater administrative responsibilities, broadening access to these programs can ensure that those families who can benefit have the choice to do so.

What is the OCC doing about caregiver financial distress?

The OCC is working to ensure that caregivers have the financial and other supports that they need to be able continue in their vital role, and to have their own fundamental needs respected and met. We are:

- *Raising awareness and strengthening collaboration* among community organizations, researchers, service providers and advocates about this as-yet poorly understood issue, so that we can share resources and work together to make this a policy priority.
- *Building the policy evidence base*, to strengthen our ability to design and successfully implement effective policy solutions. This includes our Cost-Benefit Analysis for the provision of direct financial supports to caregivers, and a project we are undertaking in collaboration with the Public Good Initiative at the Munk School of Public Policy to evaluate various approaches to addressing caregiver financial distress. We will be building a dedicated space on our website for information and resources on caregiver financial distress, and will be reaching out to share those resources once our website hub is launched.
- *Connecting with policy-makers* to share evidence and ideas for change, both through the pre-budget process and by reaching out to members of the Social Policy Committee.

What can you do about caregiver financial distress?

The OCC is reaching out to ask that those who advocate for caregivers and for those they support take the following steps:

- *Raise awareness of caregiver financial distress among your networks.* Let others know that this is an issue of crucial importance to respecting and sustaining the vital work of caregiving, and thereby the wellbeing and dignity of those that they support.
- *Integrate caregiver financial distress into your own advocacy.* When you are reaching out to policy-makers, experts and advocates, let them know that this is an issue that is important to you.
- *Let us know how we can support your advocacy.* We are continuing to building evidence and tools to support policy change on caregiver financial distress. We invite you to use our tools, provide us with feedback on how they work, and let us know what else can help in making the case.

Together we can make a difference!