

Caregiver Financial Distress

Addressing the Costs of Caregiving

June 2023



What is the Ontario Caregiver Coalition?



We are
the voice of caregivers in Ontario

Our mission
is to improve the lives of caregivers by advocating
for fair access to needed supports

Our vision
an Ontario where caregivers feel valued, respected,
recognized and supported

Our members
span Ontario and include caregivers, health
charities, care providers and researchers



Who are Ontario's caregivers?

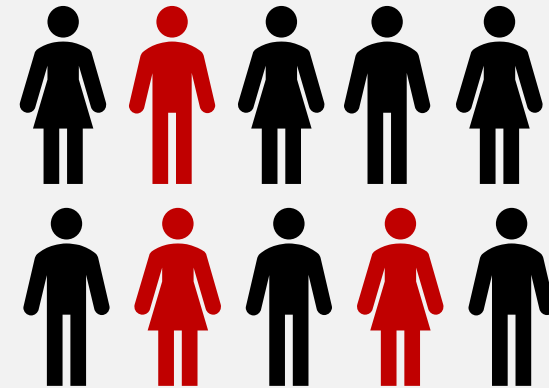
Ontario's caregivers are the family, friends and neighbours who provide personal, social, psychological and physical support, assistance and care, without pay, for loved ones in need of support due to frailty, illness, degenerative disease, physical/cognitive/mental disability, or end of life circumstances



Who are Ontario's caregivers?



- Age of Caregivers:
 - 17% 15- 24 years
 - 23% 45-54 years
 - 30% > 65 years
- 37% earn < \$40,000 per year
- 21% speak neither English nor French



3/10 Ontarians (~ 33 million)
~ 50% females, > 10 hr/week
Provide ~ 70% of Ontario's homecare
31% 'had no choice'

Financial distress: a core priority



Society is monetized. To receive no compensation for the 24/7 care I give can be daunting and depressing. Full-time unpaid caregivers should be given, at minimum, a basic income. 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."

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

"I feel there is no hope for the future and that we are abandoned by the government with almost no support financially."

"This is where I get emotional because my parents have worked hard their entire lives ... and in this time of dire need ... there are minimal, minimal supports available. "

"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. "

What is caregiver financial distress?



The most commonly reported unmet need for caregivers is financial supports. In Ontario in 2020:

- 45% of caregivers reported financial hardships due to their caregiving
- 20% took out a loan or line of credit to help pay for their caregiving expenses
- 74% have made alterations to their employment to manage their caregiving responsibilities

Spotlight Report 2021: Ontario Caregiver Organization

“Taking care of a severely ill mom that needs 24 hour care is hard, there are little resources I have found to help ... financially it is overwhelming at times and stressful. I wish there were resources and financial assistance to help.”

“There is a financial struggle in our particular situation. 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. There is a great financial impact.”

What causes caregiver financial distress ?



Out of pocket costs of caregiving: medical supplies, drugs, additional home care supports, travel and transportation, respite, home renovations, special diets

"The last year alone I spent over \$150,000 for the extra care that was necessary during [my wife's] final year of life."

Impact on labour force participation: ~ 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

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

The Change Foundation, Spotlight on Caregiving 2020

Long-term impacts of reduced labour force participation

- reduced career progress and lifetime earnings
- reduced contributions to government and employer pension plans
- reduced savings during peak earnings years compounds into old age

"When I started doing [caregiving] I was probably in my early 30s. At that point in my working life, I was working full-time, kind of building on your career and I feel like there was a bit of a sacrifice for my own personal career growth and financial gain because I ... chose to commit at that point to help"

Direct financial supports for Ontario caregivers



Tax Credits For Care Recipients

Federal

Disability Tax Credit
Medical Expense Tax Credit
Home Accessibility Credit

Ontario

Medical Expenses Tax Credit
Ontario Disability Tax Credit
Healthy Homes Renovation Tax Credit
Senior Care at Home Tax Credit

Tax Credits For Caregivers

Canada Caregiver Tax Credit Ontario Caregiver Amount

Nonrefundable
Caring for a spouse, common-law partner or dependent with a mental or physical impairment
Income tested
Minimal amounts

Employment Insurance

Compassionate Care Benefits

Available to caregivers

- Who are EI eligible employees
- Who are temporarily away from work

To care for a person who:

- is at significant risk of death within the next 26 weeks OR
- is dealing with a critical illness or injury that puts their life at risk

Existing direct financial supports are neither accessible nor adequate to meet caregiver need in Ontario



- Only 8% of caregivers report receiving the Caregiver Tax Credit
- Only 6% of caregivers report receiving assistance from a government program
- 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

(Stats Can, General Social Survey on Caregiving and Care, 2018)

Impacts of caregiver financial distress



Caregiver impact

- Income is a social determinant of health
- Prolonged financial insecurity or low income can have long-term effects on physical, mental and emotional health of caregivers

“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.”

Care recipient impact

- Caregiver financial distress, and resultant caregiver burnout can affect quality of care provided to loved ones
- Can reduce access to supports that would enhance health or quality of life

“Even the extra supports for physiotherapy or stuff like that, that my parents needed, like the LHIN only does it for so much. So just those extra supports like to really maintain a person's health, you know? It's a little extra cost that we don't [undertake].”

System impact

- Caregiver financial distress is a significant cause of collapse of community caregiving arrangements and resort to acute care or institutionalized care arrangements
- Increased pressures on acute care, LTC and other public systems with significant cost implications

“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 the health care workers being overworked and under resourced and underfunded to women leaving their jobs trying to be the caregiver [...], turnover for employers because they're trying to fill spots and people are leaving.”



Experience in other jurisdictions

- *Nova Scotia* provides an income-tested Caregiver allowance of \$400 per month to those providing care for 20+ hours weekly
- *Manitoba* provides a refundable Primary Caregiver Tax Credit of up to \$1400 per year
- *Quebec* provides a suite of tax credits for those caring for seniors, those caring for a person with a disability, and for specialized respite costs

Financial supports are cost-effective

A program modelled on the Nova Scotia allowance would *at minimum*:

- Replace 7.8% of Ontario's LTC beds
- Create an immediate annual cost-saving of \$480 M, rising over time

Additional savings could arise from reducing pressures on acute care and other types of institutional care provision

What is the OCC asking for?



Provide direct financial supports to caregivers

Build on the models in other provinces to directly address the financial needs of caregivers

Strengthen home and community care services

Ensure access to reliable, accessible, adequate and quality supports so caregivers can balance work and care

Reduce the financial impact of Bill 7 on caregivers

Individualize placement assessments to take into account impact on caregivers of travel time and transportation costs. Provide automatic coverage of costs of transportation from hospital to LTCH placements.

Enhance Direct Funding programs

Reduce the costs of services by improving access to Direct Funding programs such as Passport, Family Managed Care, SSAH and Attendant Services

What has the OCC been doing to make change?



Develop the Evidence Base

- Cost Benefit Analysis
- Caregiver Interviews
- PGI Partnership: Developing Policy Solutions

Knowledge Dissemination

- Creating KD materials
- Presentations
- Website hub:
<https://www.ontariocaregivercoalition.ca/caregiver-financial-distress>

Building Relationships with Decision-Makers

Asking the Standing Committee on Social Policy to undertake research

Expanding the coalition for change
Building connections between health, equity, income security and other areas

How can you be a part of change?



Join our coalition for change

*Our efforts are more powerful when we join together!
Email us at ontariocaregivercoalitionocc@gmail.com to
learn more*

Spread the word

*Use our tools and resources to raise awareness about
caregiver financial distress in your networks
[https://www.ontariocaregivercoalition.ca/caregiver-
financial-distress](https://www.ontariocaregivercoalition.ca/caregiver-financial-distress)*

Contact your MPP

*Help us to educate decision-makers and make this a
priority. Write to your MPP and let them know that this
is important to you*



Want to learn more or to get involved?



www.ontariocaregivercoalition.ca

ontariocaregivercoalitionocc@gmail.com



<https://www.facebook.com/OntCaregivers>



[@OntCaregivers](https://twitter.com/OntCaregivers)