

Understanding Caregiver Financial Distress

The most commonly reported unmet need for caregivers is financial supports.

While family, friends and neighbours who take on the responsibilities of unpaid care for a loved one expect to face many challenges, they are frequently surprised by the financial impact of caregiving, a challenge that receives little public attention or policy response.

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 savings to support their caregiving
- ◆ 33% have borrowed money from family or friends, and 20% have taken a loan from a financial institution

The Change Foundation, Spotlight on Caregiving 2020

Caregiving is expensive and time consuming

Caregiving is expensive. The strain on Ontario's home and community care system leaves families often paying high out-of-pocket expenses for private home care and respite services. They may also face significant costs for prescriptions and medical supplies. It may be necessary to renovate the home to enhance accessibility or to enable the caregiver and care recipient to live together. Travel to and from appointments or for visits can add up, especially with escalating gas prices.

Competing responsibilities may limit the ability to work. Where caregiving responsibilities are significant, they may be impossible to balance with work. Caregivers spend an average of 11 hours per week providing care; about one-quarter provide more than 10 hours per week. Even where fewer hours are required, unreliable home care supports may make it impossible to juggle work and caregiving.

Approximately 75% of caregivers juggle work and caregiving. Of these:

- ◆ 30% were late for work or had to leave early
- ◆ 29% missed an average of 6 days work due to caregiving needs
- ◆ 1% (33,000 caregivers) left their employment as a result of caregiving needs

The Change Foundation, Spotlight on Caregiving 2020

Ontario caregivers have access to only minimal financial supports

Ontario provides no direct financial assistance to caregivers. Some caregivers receive benefits through the federal Employment Insurance Compassionate Care program, but this is available only to EI eligible caregivers and where the care recipient is at significant risk of death within 26 weeks. The federal government also offers a Caregiver Tax Credit, but since it is non-refundable, it is of little to no benefit for caregivers with low income and only 8% of caregivers receive it.

Caregiver financial distress has serious consequences

Caregiver financial distress adds to the pressures on our health, long-term care, and social systems. Financial distress is a significant cause of collapse of community caregiving arrangements and resort to acute or institutionalized care. This adds to pressures on acute care, LTC and other public systems. An OCC Cost-Benefit Analysis found that a caregiver allowance of only \$400 per month could replace 7.8% of Ontario's LTC beds, for an immediate annual cost-saving of \$480 million.

Caregiver financial distress can affect the quality of life for care recipients. Caregiver financial distress may reduce the ability of families to provide care, whether this means scrimping on special diets, deferring physiotherapy, or reducing visits. Caregiver burnout can also reduce the quality of attention that caregivers can provide to their loved ones.

Caregiver financial distress can affect caregiver physical and mental health. Income is a social determinant of health, and prolonged financial insecurity or low income can have long-term effects on the physical, mental and emotional health of caregivers.

There are effective options for addressing caregiver financial distress

The Ontario Caregiver Coalition recommends that the province of Ontario:

- 1. Institute a Primary Caregiver Tax Credit*** that is refundable, broadly available to family, friends or neighbours who are providing significant levels of care, including care for those with disabilities, seniors, and those with acute illnesses.
- 2. Strengthen existing services to enable caregivers to balance work and care better,*** including by ensuring that home and community care services are accessible, reliable, adequate and of high quality.
- 3. Expand access to Direct Funding Programs*** by revising eligibility criteria, reducing waitlists, using reconciliation models of funding, and enhancing flexibility.

In designing a Primary Caregiver Tax Credit, 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.