

# ONTARIO BUDGET 2025 Submission to the Government of Ontario

**February 3, 2025** 



# **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. Since 2009, the OCC has been dedicated to improving the lives of caregivers through advocacy, education, and connection.

Throughout this submission, we will be referring to unpaid caregivers simply as caregivers. For those in professional roles who provide support to individuals, we will be referring to them as care providers.

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For more information about the OCC and our work, please see our website at <a href="https://www.ontariocaregivercoalition.ca">www.ontariocaregivercoalition.ca</a>, or follow us on social media.









### **KEY RECOMMENDATIONS**

- 1) Create an Ontario Caregiver Support Benefit, alleviating financial distress among caregivers and reducing admissions to our long-term care system.
- Create a comprehensive respite strategy to guide the development of the system, with additional funding support to existing programs to provide immediate relief.
- 3) In alignment with Ontario's mental health strategy, allocate additional funding to existing mental health services for caregivers allowing for increased capacity and access

There is growing awareness of the crucial role unpaid caregivers play in our health and social systems. Family, friends, and neighbors provide essential emotional, physical, and advocacy support to individuals with acute or chronic illness, disability, or frailty. In Canada, an estimated 75% of care is provided by unpaid caregivers, contributing approximately \$26–\$72 billion per year in unpaid work. Our health, long-term care, and social services sectors heavily rely on unpaid caregivers and could not function without them.

In 2024, the Ontario Caregiver Coalition (OCC) conducted a comprehensive survey to explore the experiences and needs of caregivers across Ontario. The survey, which ran from January 31 to March 12, 2024, received 612 responses from caregivers. The findings highlighted the significant burdens caregivers bear and underscored the urgent need for targeted support and policy interventions to improve their well-being and sustain their vital role in the healthcare system. Caregivers know they are essential but often feel invisible. Little policy attention has been paid to sustaining caregivers in their vital role. Few supports target caregivers directly, and those that exist often differ from region to region, target only specific needs or types of caregiving, or are institution-specific. This leaves caregivers navigating a fragmented system.

Caregiving also affects an individual's ability to juggle their responsibilities with their employment commitments. Survey respondents reported passing up opportunities for career advancement, giving up learning opportunities, downshifting to part-time, casual, or freelance work, scaling back their small businesses, or leaving the workforce altogether.

Caregivers reported feeling overwhelmed by their responsibilities and abandoned. Caregiving can be incredibly taxing—physically, mentally, emotionally, financially, and socially. It affects their employment, finances, relationships, and their own physical and mental health.

Research indicates that caregivers experience high levels of stress, depression, and physical health decline due to the intense demands of caregiving. Caregivers bear substantial out-of-pocket expenses, averaging several thousand dollars annually, for medical supplies, home

modifications, and additional care services. This is not sustainable.

Building a better Ontario for caregivers is possible and would benefit us all. Health and long-term care systems rely heavily on unpaid caregivers while providing little support in return. When community care fails under strain, the impact on the health system can be significant. Supporting Ontario's unpaid caregivers aligns with Ontario Health' Home First Operational Directive, which envisions every effort being made to ensure adequate resources are in place to support patients to remain at home whenever possible, and to ultimately return home upon discharge from all bedded levels of care (i.e., acute, rehab, complex continuing care, mental health).

By addressing the key areas outlined in this submission, the government can significantly improve the lives of caregivers and, by extension, the well-being of those they care for. We look forward to working with the government to create a supportive and inclusive environment for all caregivers in Ontario.

## **CURRENT FINANCIAL HARDSHIPS**

Like many in the province, it's no surprise to hear that caregivers are struggling with the rising costs of living. Caregivers often incur high costs for medical supplies, home modifications, travel, and private services not covered by public funding. When combined with reduced income from decreased workforce participation, we often experience significant financial distress. The 2024 Survey revealed that nearly half of unpaid caregivers experience financial hardships, with many dipping into savings or taking out loans to cover caregiving costs.

Financial strain not only impacts the quality of care caregivers are able to provide, such as deferring necessary therapies, but adds strain to our overburdened health and long-term care systems. As individuals finances break down, we must turn to the health and long-term care system, contributing to premature or avoidable admissions and increased costs.

Current financial supports for caregivers are limited and complex. Tax credits and self-directed funding programs provide some relief but are often insufficient and difficult to access. The vast majority of caregivers receive no financial support from government.

#### **BUILDING ON WHAT WORKS**

This year, the Government of Prince Edward Island launched the At Home Caregiver Benefit.

A new benefit supporting those with a high likelihood of admittance into long-term care, the province is recognizing the immense value unpaid caregivers provide and investing in sustaining their efforts.

With a maximum monthly benefit amount of \$1,500, the program will alleviate the financial strain of caregiving and allow the care recipient to stay in their home and community for as long as possible.

With this benefit, PEI joins many other Canadian provinces that are providing or committing to provide direct financial supports to

# **Proposed Ontario Caregiver Support Benefit**

Enhancing financial support for caregivers is essential to improving their quality of life, and

sustaining the care we provide. The OCC proposes the introduction of the Ontario Caregiver Support Benefit, a monthly direct financial support that will alleviate financial hardships and reduce strain on the healthcare system. An initial <u>cost-benefit analysis</u> shows such a benefit could replace up to 7.8% of Ontario's long-term care beds, resulting in substantial savings for the province.

<u>Targeted Support:</u> Initially directed at caregivers already recognized as in need, such as those receiving or waitlisted for existing programs like Passport or Special Services at Home.

**Meaningful Financial Assistance:** Providing \$1,000 per month to eligible caregivers to cover caregiving-related expenses.

<u>Accessible Processes:</u> Simplified application and eligibility processes to ensure that all caregivers who need financial support can benefit.

## THE IMPORTANCE OF RESPITE SERVICES

Caring for a loved one in need is a difficult, emotionally exhausting endeavour and the stress and strain it puts on individuals can lead to burnout, physical health decline, and mental health issues. In fact, caregivers who struggle to take breaks are twice as likely to cope with mental health struggles as those able to access respite care.

#### **CURRENT CHALLENGES**

Caregivers often face significant barriers in accessing respite care. These include:

**Limited Availability**: Many caregivers are waitlisted or receive minimal access to respite services due to limited resources.

**High Costs**: Caregivers frequently pay out-ofpocket for respite services, which can be prohibitively expensive.

Complex Application Processes: Navigating the fragmented and confusing system to access respite care can be overwhelming for caregivers. Respite care is essential for caregivers to maintain their well-being and continue providing high-quality care. It offers temporary relief from caregiving responsibilities, allowing caregivers to rest, recharge, and attend to their own health and personal needs. However, many caregivers struggle to access adequate respite services due to limited availability, high costs, and complex application processes.

Without adequate respite care both caregivers and the ones they support suffer. When individuals are unable to access respite support, it can lead to increased calls to 911, emergency room visits, hospital admissions, and early or preventable admission into our long-term care facilities.

# **Recognize the Essential Nature of Respite Services**

<u>Provide Immediate Relief:</u> Allocate additional dedicated funding to respite services to provide immediate relief to caregivers in need.

<u>Fix a Fractured System:</u> Commit to the development of a comprehensive and coordinated respite system for Ontario. A first step is the creation of a comprehensive respite strategy to guide the

development of the system, created in collaboration and consultation with caregivers and communities, and engaging all relevant Ministries. It must promote inter-Ministerial collaboration to ensure uninterrupted access to respite services that adhere to the principles of accessibility, inclusion, choice and flexibility, and quality in the design and delivery of respite services. And finally, it needs to build capacity for evidence generation and data collection to understand needs, outcomes, and best practices for respite services.

## STRENGTHENING CAREGIVER MENTAL HEALTH

#### **ONTARIO CAREGIVERS IN CRISIS**

According to the Ontario Caregiver Organization's 2024 Spotlight Report:

- Almost one-third of caregivers feel unable to cope with their caregiving role
- 72% say they are so burnt out, they don't know how they will continue
- 80% are so exhausted they are having difficulty getting things done
- 75% are concerned that they will not be able to handle the demands of their role in the future.

The need for mental health supports among caregivers is critical. Caregivers often experience high levels of stress, anxiety, and depression due to the demanding nature of their roles. We can often feel overwhelmed and isolated, as their duties can limit social interactions and personal time. The emotional strain of watching a loved one struggle with illness or disability, combined with financial pressures and lack of support, can exacerbate these feelings. Without adequate mental health resources and respite, caregivers are at risk of burnout, which can further compromise their well-being and the quality of care they provide.

Many caregivers who need mental health supports struggle to access them due to financial constraints, limited availability, and long wait times. There is a lack of

mental health services that address the specific needs and experiences of caregivers. While there are excellent examples of such services, they serve only specific groups, or small numbers of caregivers. Evaluations of mental health services for caregivers, such as those offered by the Ontario Caregiver Organization, shows that such services can be highly effective in reducing caregiver distress and strengthening their confidence and capacity to maintain their extremely demanding roles.

# Increase Funding for Caregiver-Focused Mental Health Services

We know that supporting mental health is an important concern for the government of Ontario, but much remains to do be done. We believe there is no need to reinvent the wheel, there are programs that can be built upon - but there is a desperate need to increase access. While it is important to increase awareness of mental health services and ensure they are easily accessible to caregivers, regardless of their location or financial situation, the impact is limited if caregivers simply find themselves waitlisted. Allocating additional funding to expand capacity and increase access to mental health services targeted to unpaid caregivers will help to sustain care in the community for as long as possible.