



Ontario Caregiver Coalition
The voice of caregivers in Ontario
www.ontariocaregivercoalition.ca
ontariocaregivercoalitionocc@gmail.com

Submission to the Government of Ontario for the 2026 Budget Consultation

From: Ontario Caregiver Coalition

Date: Wednesday, January 28, 2026

About the Ontario Caregiver Coalition

The Ontario Caregiver Coalition (OCC) is the voice of caregivers in Ontario. We advocate for the recognition and support of family, friends, and neighbours whose unpaid care is the hidden backbone of Ontario's health system. Our members include both individual 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 support.

Recommendations

1. Recognize and protect the contributions caregivers make to Ontario's economy by:
 - a. Introducing an Ontario Caregiver Support Benefit
 - b. Supporting caregivers in the workplace

2. Improve the critical supports that caregivers and their loved ones rely on to protect their well-being by:
 - a. Developing a provincial respite strategy
 - b. Increasing funding for mental health services tailored to the specific needs of caregivers
 - c. Continuing improving access to essential home and community care for all Ontarians



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Introduction

There is growing awareness of the crucial role unpaid caregivers play in our health and social systems. Family, friends, and neighbours provide essential day-to-day physical, emotional, 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 in unpaid work each year. Our health, long-term care, and social services sectors heavily rely on unpaid caregivers and could not function without them.

In 2024, the OCC conducted a comprehensive survey to explore the experiences and needs of caregivers across Ontario. The survey ran from January 31 to March 12, 2024 and received 612 responses. The findings highlighted the significant burdens caregivers bear and underscored the urgency of improving their well-being and sustaining their vital role through targeted supports and policy interventions.

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 someone's ability to juggle their responsibilities with their employment. Survey respondents reported passing up career advancement opportunities, giving up learning opportunities, downshifting to part-time, casual, or freelance work, scaling back their small businesses, or leaving the workforce altogether due to their caregiving responsibilities.

Caregivers reported feeling overwhelmed by their responsibilities and abandoned. 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.

To build a more competitive, resilient and self-reliant province, we must support caregivers. Health and long-term care systems rely heavily on unpaid caregivers while



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providing little support in return. When community care fails under strain, the impact on more costly parts of our health and community care systems can be significant.

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 ensure that Ontario is the best place in the world to live, work, and care for a family.



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Recommendation 1: Recognize and protect the contributions caregivers make to Ontario's economy

Current Financial Hardships

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, this often leads to significant financial distress. The 2024 Survey revealed that nearly half of unpaid caregivers experience financial hardships, with many dipping into savings, including those for retirement or taking out loans to cover caregiving costs.

Impact of Financial Distress

- **Quality of Care:** Financially strained caregivers may compromise on the quality of care, such as cutting back on special diets or deferring necessary therapies.
- **Caregiver Health and Well-being:** Financial stress affects caregivers' health, leading to burnout and poor mental health. Many caregivers struggle to afford their own health and wellness needs.
- **Health System Strain:** Financial pressures force caregivers to rely on the hospitals and long-term care, leading to premature or avoidable admissions to emergency rooms or long-term care residences when they do not want their loved ones to be there, and, as a result, higher healthcare costs.
- **Long-term Financial Insecurity:** Caregivers face long-term financial insecurity due to reduced savings and pension contributions, which can impact their future financial stability.

Current financial supports for caregivers are limited and complex. Tax credits and self-directed funding programs provide some relief but are often insufficient, non-refundable (so they exclude caregivers who have to leave their jobs or reduce their hours to care for their loved one), and are administratively difficult to access. The majority of caregivers receive no financial support.

Recommendation 1A. Introduce an Ontario Caregiver Support Benefit

Enhancing financial support for caregivers is essential to improving their quality of life and the care they provide. **The OCC proposes introducing [an Ontario Caregiver Support Benefit](#)**, a monthly direct financial support that will alleviate financial hardships, reduce strain on the healthcare system, and help ensure caregivers can



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continue their vital roles in supporting Ontario's health and long-term care systems.

Why We Recommend a Caregiver Benefit

Targeted Support: Eligibility could be initially directed at caregivers already recognized as needing help through existing assessments, 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.

Building on Best Practices

Similar allowances already exist in Nova Scotia, Newfoundland and Labrador, and Prince Edward Island.

The Government of New Brunswick has also committed to developing a similar program.

A similar recommendation is included in the Canadian Centre for Caregiving Excellence's recommendations for a National Caregiving Strategy

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

Reduces System Pressures & Costs: Based on the [best available research](#), we concluded this type of financial support could result in a 7.8% reduction in long-term care admissions

Recommendation 1B. Support Caregivers in the Workforce

Approximately two-thirds of caregivers in Ontario are part of the labour force, balancing paid employment alongside caregiving responsibilities. These caregivers need workplace policies and support that allow them to fulfill their care duties while remaining employed. However, caregiving needs are often poorly understood by employers, and many caregivers feel compelled to hide their challenges to protect their careers. While some policy supports do exist to support working caregivers (such as family caregiver leaves under the Employment Standards Act), these supports are fragmented, administratively complex, and difficult to access. The OCC's 2024 survey of 612 Ontario caregivers found that the vast majority are making significant adjustments to their work lives to manage caregiving responsibilities, a challenge made more difficult by gaps in community supports such as home and community care and developmental services. 30.3% of respondents to the OCC survey have not accessed any employment-related supports.



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Impact of Inadequate Workplace Supports

Without sufficient workplace support, caregivers frequently reduce their labour force participation by:

- Reducing hours of paid work
- Declining or foregoing career advancement opportunities
- Shifting into less demanding or non-standard work
- Leaving the workforce entirely

These outcomes have direct economic consequences not only for the individual, but for society. Reduced labour force participation lowers overall economic output and government revenues, while caregivers who leave paid work experience significant income loss and contribute less in taxes. Employers also lose experienced workers in which they have invested. At the same time, pressures on public programs may increase, including reliance on income supports and social benefits such as the Ontario Trillium Benefit, Employment Insurance, and other assistance programs.

Strengthening Supports for Working Caregivers

Without action, working caregivers will continue to experience stress and burnout, and many will be forced to leave the workforce altogether. Caregivers need the flexibility to take job-protected time away from work when needed, and supportive workplaces that recognize and respond to their unique needs as caregivers. There is an opportunity for Ontario to improve policy coherence and better support caregivers through flexible, accessible workplace standards that reflect the diversity of caregiving experiences.

Limitations with Current Supports Available to Working Caregivers

Gaps in Employment Protections:

Current ESA provisions focus on a confusing number of narrow, time-limited leaves that do not reflect the ongoing and unpredictable nature of caregiving responsibilities. While the *Occupational Health and Safety Act* and Human Rights Code may offer some protections, they are not explicit and caregivers may not have the capacity to pursue legal recourse

Workplace culture barriers: Even where supports exist, caregivers often avoid accessing them due to stigma, fear of negative career impacts, and perceptions that caregiving reduces commitment or capability.

Self employed caregivers:

Caregivers who are self-employed or business owners receive little policy attention and have limited access to employment-related protections or benefits.



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The Ontario Caregiver Coalition calls on the Ontario Government to:

- Harmonize existing caregiving-related leaves under the Employment Standards Act into a single, simplified Caregiver Leave that is flexible and inclusive
- Expand Family Responsibility Leave from three days to 10 days annually to support caregivers in meeting short-term caregiving demands
- Amend the Occupational Health and Safety Act to require workplaces to develop safety plans and programs that address the needs of working caregivers.



Recommendation 2: Improve the critical supports that caregivers and their loved ones rely on to protect their well-being

Recommendation 2A. Develop a Provincial Respite Strategy

Respite care is crucial 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.

Impact of Unmet Respite Needs

- **Caregiver Health and Well-being:** Caregivers who struggle to take breaks face twice the risk of mental health issues compared to those who can access respite. The intense demands of caregiving can lead to burnout, physical health decline, and emotional exhaustion.
- **Quality of Care:** Without adequate respite, caregivers may be unable to provide the best possible care, potentially compromising their loved one's well-being.
- **Health System Strain:** Unmet respite needs can lead to increased 911 calls, [emergency room visits](#), hospital admissions, and early or preventable admissions to long-term care facilities.

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-of-pocket 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.

Recognize the Essential Nature of Respite Services

Fix a Fractured System: Commit to developing a comprehensive, coordinated respite system for Ontario. This roadmap should be developed in collaboration with caregivers and communities, and should engage 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, flexibility, and quality in their



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design and delivery. And finally, it needs to build capacity for generating evidence and collecting data to understand needs, outcomes, and best practices for respite services.

Provide Immediate Relief: Allocate additional dedicated funding for respite services to support caregivers in need.

Recommendation 2B. Increase funding for mental health services tailored to the specific needs of caregivers

The need for mental health support among caregivers is critical. Caregivers often experience high levels of stress, anxiety, and depression due to the demanding nature of their roles. They may 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.

Impact of Poor Mental Health

- **High Levels of Stress and Burnout:** Caregivers frequently report feeling overwhelmed by their responsibilities. The constant demands of caregiving can lead to chronic stress and burnout, significantly impacting their mental health.
- **Lack of Access to Mental Health Services:** Many caregivers struggle to access mental health services due to financial constraints, limited availability, and long wait times. This lack of support exacerbates their mental health issues.
- **Isolation and Loneliness:** Caregivers often feel isolated and lonely, as their responsibilities can limit their social interactions and support networks. This isolation can contribute to feelings of depression and anxiety.

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.



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- **Financial Strain:** The financial burden of caregiving, including out-of-pocket expenses and lost income, adds to caregivers' stress and anxiety. Financial strain can also limit their ability to seek professional mental health support.

Increase Funding for Mental Health Services

We welcome the Government of Ontario's investment of \$303 million in mental health and addictions supports, and its interest in conducting more research on how best to support caregivers, as highlighted in the [Ministry of Health's Annual Plan](#). We strongly encourage the Government of Ontario to allocate additional funding to expand access to mental health services for caregivers, such as the ones offered through the Ontario Caregiver Organization or the Princess Margaret Cancer Centre's Caregiver Clinic. There is no need to reinvent the wheel, but there is a desperate need to increase access. Increasing awareness of mental health services and ensuring they are easily accessible to caregivers, regardless of their location or financial situation, is important, but not if they simply end up on a waitlist. Increased funding for counselling, support groups, and stress management programs specifically designed for caregivers, offered through various channels such as in-person, online, and telephone, is urgently needed.

Recommendation 2C. Continue improving access to essential home and community care for all Ontarians

Fundamentally, one of the most important steps we can take to improve caregivers' lives is to make it easier for them to access care for their loved ones. Survey respondents care for those living in a range of settings, including their own homes, retirement homes, and long-term care homes. However, for many families, avoiding institutional settings is a primary goal. The support needed to achieve this is often difficult to find. Survey respondents report that publicly funded home and community care services are overstretched, often providing limited support, while private services are out of reach financially. Developmental services involve long waitlists and complex processes. Long-term planning seems impossible, as families and systems must constantly respond to crises.

We welcome the commitments in the Ministry of Health's Annual Plan to reduce wait times for home and community care and the Ministry of Children, Community, and Social Services to improve access to developmental services. But given the current and



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future demands on home and community services, we echo the recommendations in Care Watch Ontario's [2025 Pre-Budget Submission](#), particularly to ensure that the Government of Ontario's investments are based on clear selection criteria and that providers are transparent and publicly accountable.

Ensuring access to high-quality home and community care services

- **Standards:** Establish, monitor, and enforce province-wide standards for home and community care, with consistent consequences and penalties for failing to meet those standards.
- **Indicators:** Report the results of consistent indicators and the performance of Ontario Health at Home regularly and publicly
- **Selection criteria:** In addition to overall structures, home and community services depend on individual providers and agencies. Make clear to Ontarians how and why those providers are chosen.
- **Reward good actors:** Specify that priority will be given to providers who demonstrate they can meet high and measurable standards for quality of care, and equitable staff compensation and benefit