Ontario Caregiver Coalition

Coalition des aidantes et aidants naturels de l'Ontario

BUILDING A BETTER ONTARIO FOR CAREGIVERS

by Supporting Caregiver Respite

The 2024 Ontario Caregiver Coalition Survey of Caregivers:
Policy Brief #4

“I really don’t know what a break is. This is nonsense to think I could ever have a break. This is 24/7 365 care for 25 years non-stop until I fall over dead!”

January 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. For more information about the OCC and our work, please see our website at **www.ontariocaregivercoalition.ca**, or follow us on social media.

BUILDING A BETTER ONTARIO FOR CAREGIVERS: POLICY BRIEF SERIES

This Policy Brief, developed by the Ontario Caregiver Coalition (OCC) and informed by OCC's 2024 Ontario Caregiver Survey, is the fourth of a series of six Policy Briefs that will be presented to the Ontario Government in 2024 and 2025.

The OCC's 2024 Ontario Caregiver Survey sought to explore policy priorities among Ontario caregivers. The Survey was in the field from January 31, 2024, until March 12, 2024, and received 612 responses from Ontario caregivers. The policy recommendations presented in each Policy Brief are based on the views expressed in the Survey by caregivers.

The Ontario Caregiver Coalition would like to extend our thanks to all of the many members and friends who worked to design, distribute and complete our 2024 Ontario Caregiver Survey. Your passion for supporting unpaid caregivers and your commitment to change are inspiring, and make the impossible possible!

In particular, we would like to thank the following members of the Research and Advocacy Committee who devoted their time and skills to the development of this Policy Brief.

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GIVING CAREGIVERS A BREAK

> "I want time! If this was a job, I would quit immediately. There are no choices if you are a caregiver. Grin and bear it!."

Caregiving can be intensive, physically and mentally exhausting, and socially isolating. Caregivers may struggle with their own health and wellbeing, whether with sleep, nutrition, exercise, or accessing regular health screenings. Getting a break from caregiving responsibilities – referred to as "respite supports" in this policy brief – is essential in sustaining caregivers. Respite supports "provide caregivers temporary relief from their responsibilities of caregiving. The type of respite service, location, safety, duration, timing, frequency, and trust in provider must match with the changing family needs in order for caregivers to have an adequate break and receive the potential benefits of reduced stress and improved family quality of life."[1]

Currently, Ontario caregivers must navigate a fragmented, confusing and reactive system to access respite supports. Limited resources mean that many caregivers may be waitlisted or receive minimal access to a break. Caregivers who struggle to take breaks face twice the risk of mental health issues, compared to those who can access respite. Lack of access to respite for caregivers affects the quality of care they can provide and may ultimately add to strain on the health system in the form of additional calls to 911, emergency room visits, hospital admissions, and early or preventable admissions to long-term care.

The Ontario Caregiver Coalition calls on the Ontario government to recognize the essential nature of respite supports in sustaining caregiving by:

1. Building on the recent funding of respite supports for caregivers of persons with dementia, by providing immediate, ongoing, dedicated funding to respite services for all caregivers, thereby ensuring that all caregivers have access to the respite supports they need.
2. Taking concrete steps towards an effective, integrated and coordinated respite system for Ontario by committing to the development of a Roadmap to Respite Strategy that will:
    - be developed in collaboration and consultation with caregivers and communities;

All quotes in this Brief are from unpaid caregivers who completed the 2024 OCC Caregiver Survey

- engage all relevant Ministries, including Ministry of Children, Community and Social Services, Ministry of Health, Ministry of Long-term Care, and the Ministry for Seniors and Accessibility, among others;
- build capacity for evidence generation and data collection to develop understanding of needs, outcomes and best practices for respite services;
- promote inter-Ministerial collaboration to ensure uninterrupted access to respite across the life course and for families with complex needs; and
- promote the principles of accessibility, inclusion, choice and flexibility, and quality in the design of a respite system for Ontario and in the delivery of respite services

WHY IS ADDRESSING THE NEED FOR RESPITE A PRIORITY ISSUE FOR CAREGIVERS?

> “I need actual physical help, not talk about how I should take time for me. I know that but who will look after my daughter?”

LOOKING FOR A BREAK: EXAMPLES OF CAREGIVING WITHOUT RESPITE

Alia’s medically complex child, Raj, is now four years old. Because of the intensity and complexity of her son’s needs, Alia must get up multiple times per night to attend to him, for example to suction his airway to ensure his breathing is unimpeded, and to reposition him to avoid bedsores. As a result, she has only had three unbroken nights of sleep in four years. Despite her family’s efforts to provide breaks, Alia struggles to relax due to the fear of something going wrong. What she desperately needs is competent or skilled respite care, which she cannot access. Without this support, Alia is left exhausted, constantly on edge, and terrified of making a mistake that could jeopardize her son’s well-being.

John's wife of over 60 years, Louise, has advanced dementia. As part of her condition, Louise is constantly restless and on the move. John must always keep an eye on her to prevent her from wandering, injuries, or potential hazards like starting a fire while trying to cook. Their children live in another city, so John is reliant on home care services for brief moments of respite so that he can run errands or finish tasks around the house. What he would really like is a longer break, so that he could travel to spend time with his grandchildren – an opportunity that currently feels out of reach.

While experiences vary among caregivers, **caregiving can be extremely intense.** The list of responsibilities caregivers undertake is extensive, and for some, this role becomes the equivalent of a full-time job, in addition to other commitments, such as employment and childcare. Caregivers often provide care around the clock, struggling with interrupted or inadequate sleep. Caregivers describe the experience as always being "on" in case of an emergency.

The intensity of caregiving makes it difficult for caregivers to find time to take the break that they so desperately need to stay mentally, physically, and emotionally healthy. Similar to findings of our own survey, a recent survey by the Ontario Caregiver Organization found that 34% of caregivers provide more than 10 hours of care per week, 73% report their care-giving responsibilities have increased in the last 2 years, 32% are not coping well, 72% feel so burnt out that they are not sure how they will continue, and 75% are concerned they will not be able to handle all their caregiving duties, going forward.[2]

COMMON CAREGIVING RESPONSIBILITIES

- Emotional, cognitive, mental health support
- Housekeeping
- Meal preparation, help with eating
- House maintenance, outdoor work
- Buying groceries
- Assisting with self-care
- Ensuring safety
- Facilitating recreational activities
- Organizing access to care and medical services
- Scheduling, coordinating appointments
- Help with basic medical tasks
- Transportation
- Helping with finances
- Advocating for the person in need of care
- Substitute decision making

[†] This list only includes examples of common caregiving responsibilities, and does not attempt to provide a complete list.

Over one third of the caregivers who responded to the OCC Survey indicated that getting a break from caregiving was one of the top challenges they encountered. Many were not receiving any respite supports. Most of those who did receive supports were getting help from family or friends and/or using their own money to pay for these services. This suggests that caregivers who have no or limited support from family or friends and caregivers with low income may be even less able to take time off. Taking a break is particularly challenging when the person in need of care lives in the same home as the caregiver. Those caregivers are almost 2.7 times more likely to report challenges with taking a break than other caregivers.

Caregivers need support in order to get the break they need to sustain their roles. While caregivers can, and do, rely on family and friends for support, many caregivers need more regular, ongoing, and dependable respite in order to meet all of their responsibilities, including employment and support of other family members, while also caring for themselves. Yet, supports for taking a break are hard to find for caregivers.

30% OF CAREGIVERS WHO NEED A BREAK GET NO RESPITE SUPPORTS

45% OF CAREGIVERS RECEIVE RESPITE SUPPORT FROM FAMILY MEMBERS OR FRIENDS

27% OF CAREGIVERS USE THEIR OWN MONEY TO PAY FOR RESPITE SERVICES

WHAT ARE THE CONSEQUENCES OF UNMET RESPITE NEEDS?

> “Currently I’ve just been told I require open heart surgery or risk perishing. What do I do with my two special needs children ages 22 and 32. How could they remain in their home with a full time person who could do all I do daily?”

Intense caregiving is highly stressful, meaning that caregivers may need more opportunities for rest, exercise and socialization to effectively manage these stress levels.[3] However, the more time a caregiver spends on caregiving, the less time they have for family, self-care and social activities.[4] As a result, caregivers are at a high risk of distress and mental health issues.[3] Our Survey revealed **that those who are not receiving respite supports are at double the risk of other caregivers for mental health issues.** Getting a true break – whether to sleep, exercise, see friends and family, read a book, pursue a hobby, or any other activity that a caregiver finds restful – is essential to maintaining the mental, physical and emotional health of caregivers.

Beyond the impact on the health of caregivers themselves, **respite is essential to sustaining caregivers in their role.** The Ontario Caregiver Organization’s 2024 Spotlight Report highlights that 72% of caregivers feel so burnt out they are not sure how they will continue and 75% are concerned they will not be able to handle their caregiving duties going forward. These caregivers identified respite as key to helping them continue to cope.[2]

As our Policy Brief, Listening to Caregivers, revealed failure to provide necessary respite supports to caregivers can have impacts on our already strained health and social services. There is a strong connection between lack of support for caregivers and calls to 911, visits to emergency rooms, hospital admissions, and premature or avoidable admission to costly institutional settings. These consequences are the opposite of what Ontario’s Home First policy aims to achieve – i.e., keeping clients out of hospitals and long-term care homes, and ensuring that “all services and supports in the community are explored and exhausted before considering a LTC referral”.[5] Providing sufficient respite supports to caregivers is a prerequisite to achieving the provincial goals of Home First.

TO WHAT RESPITE SUPPORTS DO ONTARIO CAREGIVERS CURRENTLY HAVE ACCESS?

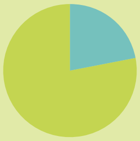
> “I am not aware of how I can get support for a break for more than the one hour at a time.”

While it is important for all caregivers to have the opportunity to take a meaningful break from their role, **what constitutes a break will vary.** The situations of caregivers differ depending on whether they are supporting spouses, children, adult children, or parents; whether they are caring for one or multiple individuals; whether they are living with the person they are caring for; whether they are living in rural or remote communities; whether they are in the workforce; the cultural and linguistic needs of the caregiver and care recipient; and much more.

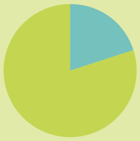
Caregivers seek different forms of respite to meet their diverse needs, including emergency respite programs; short-term stays in long-term care homes and other congregate settings; adult day programs; and in-home respite services, which may take a range of forms. Some caregivers need regular access to day programs for those they care for so that they can continue their employment. Others need regular, short breaks of a few hours at a time. Some require overnight respite so they can sleep. Others want a few days so they can visit family or friends. Some need respite providers with specialized skills to address the intensive or unique care needs of their loved ones. Some will need access to emergency respite when they themselves face a crisis.

CHALLENGES CAREGIVERS FACE WHEN ACCESSING RESPITE SUPPORTS

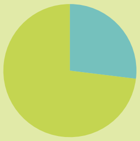
25% – Supports lack flexibility



22% – Care recipient not comfortable with care from anyone else



20% – Not aware of any supports



27% – Out-of-pocket payment is required

14% – Supports are unreliable

The current approach to delivery of respite services in Ontario is complex, fragmented, and confusing. Parents of children with developmental or physical disabilities may access respite services through the Special Services at Home program, while families of adults with developmental disabilities may seek respite supports through the Passport Program. The Ministry of Children, Community and Social Services funds these two programs as well as day programs through Development Services Ontario. The Ministry of Health, through Ontario Health at Home, funds Family Managed Home Care, a self-directed care program which can provide respite. The Ministry of Health, through Ontario Health, also partially funds a variety of Community Support Services that include respite, such as adult day programs and respite at home programs. These are delivered through non-profit agencies, which rely on donations and additional funding. Respite services may be directly delivered through agencies, or caregivers may be offered self-directed funding, which allows them to determine and purchase their own forms of respite. Caregivers who can afford it might access private respite services.

While the multiple respite pathways in Ontario partly reflect the diversity of caregiver needs, **they are a patchwork, rather than a coherent system, that leaves many caregivers behind and fails to address the needs of all caregivers.** The pathway depends on the care recipient and their diagnosis. Different authorities oversee delivery of the different pathways. The purpose, eligibility requirements, nature of the service, and costs vary widely. Access differs across the province, and in particular, those living in rural or remote communities may have few or no respite options. Application processes are often intensive.

Access to respite is often reactive and offered only when a crisis occurs. Caregivers must be aware of their options and advocate for themselves through multiple bureaucratic hurdles. Some respite services, such as those offered through the Passport program, require families to pay up-front for respite and then wait to be reimbursed, excluding families with modest financial means. Those providing care for multiple family members, an increasingly common situation, face intensive struggles to access respite. Families of persons receiving care across multiple life stages may need to navigate respite services repeatedly, as their person transitions between systems. In a system so fragmented, caregivers may require a high degree of patience, persistence, and navigational skills to access respite services. Already heavily burdened by navigational responsibilities on behalf of the person they are caring for, many caregivers do not have the capacity to pursue and access the respite services that do exist.

Moreover, **all publicly funded respite services struggle with limited resources**, resulting in chronic waitlisting, and limited services. Survey respondents pointed to lengthy waitlists or unaffordable out-of-pocket costs. When services are provided, high turnover among respite personnel may limit the effectiveness of the services provided. Caregivers describe having to orient new providers over and over, investing time to try to build the relationships of trust that are necessary for effective respite. Human resource challenges among respite providers may mean that services may be cancelled at the last minute, may be repeatedly late in arriving, or may be inflexible.

Essentially, while Ontario provides respite services, there is no respite system.

The Ontario government has recently announced additional funding focused on families of persons with dementia, including $20 million over three years for adult day programs and $20 million over three years for respite services.[6] While a welcome recognition of the importance of respite, more needs to be done to ensure that respite supports meet the principles of accessibility, inclusion, choice and flexibility, and quality (details below), and that all caregivers have access to respite, regardless of the diagnosis of their person or the type of respite that they require.

HOW CAN ONTARIO EFFECTIVELY ADDRESS CAREGIVER NEEDS FOR RESPITE?

> "Options are important. Caregiving is so varied that certain supports don't fit the caregiving situations."

AREAS FOR IMPROVEMENT

Addressing caregivers' respite needs will require a multi-faceted approach. The Survey revealed six crucial areas for improvement:

1. Almost half of the caregivers requested that **existing supports be available more frequently and for longer periods of time.** Rather than developing new supports, often it might be sufficient to increase a caregiver's access to supports that are already available and that caregivers experience as helpful.
2. More than one third of the caregivers also demanded **improved communication about existing respite supports.** Caregivers are often not aware of what supports they could have access to, or they are unclear about these services' nature, costs, and eligibility criteria.
3. **Existing supports must be more flexible.** Often the times at which services are available, locations in which the services are provided, or how services are delivered are not consistent with the caregiver's needs, resources, and abilities.
4. **Services must better align with the needs of the person receiving care.** For some care recipients, in-home respite may be more comfortable and accessible, while others may look for the social opportunities and change of environment offered by a day program. Some care recipients will need respite providers who have specialized skills to address their medical needs, while others may need providers who speak their language or are familiar with their culture. As we are all different, there can be no one-size fits all approach to respite: personalized approaches are best.
5. One in every five caregivers requested that **applying for respite services be simplified.** Caregiving is already highly stressful and complex applications for much needed services can be a severe access barrier.
6. Finally, caregivers were concerned about the **reliability and quality of services and demanded that those be improved.**

PRINCIPLES FOR EFFECTIVE RESPITE SERVICES

The OCC highlights four principles for effective respite services in Ontario:

Accessibility: all caregivers should be proactively and consistently offered the respite that they need to sustain their vital role and maintain their own health and wellbeing, and access barriers, such as out-of-pocket payments and complicated application processes, should be removed.

Inclusion: all caregivers who need respite should have access, especially caregivers from marginalized groups (including racialized, newcomer, Indigenous and, 2SLGBTQI+ caregivers), regardless of geographic location, cultural or linguistic barriers, financial constraints or other barriers.

Choice and Flexibility: Recognizing the diversity of contexts and needs among caregivers and those they care for, a range of respite options must be available within the respite system.

Quality: Respite services should offer peace of mind to the caregiver, as well as a positive experience to the care recipient.

Promising Respite Models in Ontario

There are examples of respite services which meet these principles. While excellent, these services reach limited numbers of individuals and serve either specific communities or regions. The following models could be scaled up and spread, to provide more flexible, effective, and innovative approaches to respite:

- Wesway, an organization based in Thunder Bay, provides respite services across Northern Ontario. Services are available to a range of caregivers, including those caring for persons across the lifespan with disabilities, chronic health conditions, or frailties associated with aging. To provide these comprehensive respite services, Wesway receives funding from multiple government and non-governmental sources. Wesway believes that respite supports benefit not only the caregiver but also the care recipient and the community as a whole. Its approach to respite is flexible and personalized, recognizing that no two families are the same. Wesway works in partnership with families to create personalized service plans built on individual strengths, needs, and preferences, as well as striving to reduce barriers to access. Wesway works in partnership with commu-nity organizations to build inclusive communities.

- Reena provides both day programs and weekend respite supports, as part of its mission to promote dignity, individuality, independence, personal growth, and community inclusion for persons with developmental disa-bilities within a framework of Jewish culture and values. Weekend respites stays are staffed at a low resi-dent-to-staff ratio, with users contributing a fee to support the program. All Reena programs focus on build-ing meaningful experiences and relationships for persons with developmental disabilities. Reena currently has the capacity to offer respite support to 68 individuals. Reena is a non-profit funded through government supports, user fees, and funds from various foundations.
- VHA Home Healthcare's Respite and Renew Program offers in-home respite for caregivers of seniors liv-ing with dementia in the GTA and Peel regions. Trained respite support staff engage the person with de-mentia in activities designed to spark joy and improve their mental and physical health. The program is lim-ited to 72 hours of service. It is targeted to low-income seniors. This program is funded through the United Way Greater Toronto's Allan Slaight Senior's Fund.

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