Ontario Caregiver Coalition
Coalition des aidantes et aidants naturels de l'Ontario

BUILDING A BETTER ONTARIO FOR CAREGIVERS

by Providing Mental Health Supports

The 2024 Ontario Caregiver Coalition Survey of Caregivers:
Policy Brief #3

“A full-time caregiver living with the person they care for needs regular, reliable service which includes specific service for the caregiver such as emotional support in the form of counselling. Living with anticipatory grief and the stress of complex medical needs take an enormous toll.”

December 2024

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 second 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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PROVIDING MENTAL HEALTH SUPPORTS TO CAREGIVERS

> "Caregiver burnout is real. Through community care or through care coordinators, caregiver should be evaluated looking at their mental health and wellbeing. We are in a housing crisis and inflation economy. There are many external pressures." *

The impact of caregiving on caregiver mental and physical health was the top concern of respondents to the Ontario Caregiver Coalition's 2024 Caregiver Survey. The pressures of caregiving, together with the lack of effective supports for caregivers, can have a significant impact on the mental health of caregivers.

Caregivers need access to a range of affordable and accessible mental health supports, which may include crisis intervention, counselling, family counselling, facilitated peer supports, psychotherapy, bereavement supports, coaching, and other types of therapies provided by qualified professionals. While resources such as information and toolkits are also valuable, they cannot replace direct interventions for those who need them.

However, very few caregivers have meaningful access to mental health supports. They face a fragmented and confusing landscape of limited options and out-of-pocket costs. Various organizations are pioneering effective approaches to supporting the mental health of caregivers, which can be the foundation for broader services. Spreading access to mental health supports is a key element of any strategy to support and sustain caregivers in their essential role.

The Ontario Caregiver Coalition calls on the Ontario government to fund the delivery of a comprehensive approach to mental health supports for caregivers that:

- builds on the limited but promising models and practices that have been developed;
- includes facilitated peer support services and psychological interventions by qualified professionals; and
- is provided by those who understand the unique needs and experiences of caregivers.

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

WHY ARE MENTAL HEALTH SUPPORTS A PRIORITY ISSUE FOR CAREGIVERS?

> “Caregiving at such a young age is a huge loss of autonomy and career prospects. I have designed my life to support my sibling. Understanding caregiving from a life course perspective would be helpful in understanding the changing needs of caregivers over time and life stages.”

The unique mental health-related experiences and needs of caregivers are not well acknowledged. While caregiving can be a deeply meaningful experience, it can also have a significant impact on the mental health of caregivers. The intensive demands on the time of caregivers can limit their ability to attend to their own wellbeing.[1] The responsibilities associated with caregiving can be overwhelming, as caregivers take on personal care tasks, health procedures, and system navigation for which they are not trained. Caregivers commonly live with difficult feelings of hopelessness, anger, fear, shame, and loneliness. They must also cope with feelings of loss and grief, both for themselves and those they care for.[2,3] Caregivers report higher rates of depression, among other physical and mental health conditions, compared to non-caregivers.[4,5]

The pressures of caregiving are aggravated by the lack of supports for caregivers and their loved ones. Caregiving is inherently demanding. However, the financial pressures associated with high out-of-pocket costs; the stress of navigating a complex fragmented and under-resourced system; the shortage of adequate community health and social services; and the lack of any meaningful break from what can be a 24/7 job,[6] create a situation where the majority of caregivers have reached their breaking point and have no choice but to struggle on.[7]

The top challenge for caregivers is the impact of their role on their mental and physical health, according to 56% of survey respondents. Those caring for their spouse or partner are at more than double the risk for mental and physical health issues than other caregivers. Risks are also elevated for caregivers who are foreign-born, speak English as a second language, are Indigenous, or are racialized.

Supports for mental health are key to sustaining caregivers in their vital role, and thus to ensuring that older persons and persons with disabilities have the supports they need to live with dignity and security where they want to be – in community.

WHAT IS THE IMPACT OF THE LACK OF MENTAL HEALTH SUPPORTS FOR CAREGIVERS?

> "I felt overwhelmed, so tired, saddened, to be able to meal plan, groceries, even make a bed. I just needed to sleep. I worried so much about my children and coping but didn't know where to turn."

While many caregivers experience symptoms of depression and anxiety that reach clinical thresholds, many more ***show signs of poor mental health such as worry, disrupted sleep, social isolation, and physical manifestations of stress and anxiety.*** According to the Ontario Caregiver Organization (OCO), one-third of caregivers say they are not coping well, with the majority saying they feel depressed, unappreciated, resentful, lonely, and frustrated.[7] Year over year, the number of caregivers seeking crisis support from the OCO is growing. This includes caregivers experiencing suicidal thoughts or ideation due to their caregiving role and crisis circumstances at home such as frequent calls to police.

It is an indictment of our current system of supports for caregivers that so many caregivers are self-identifying as having experienced real negative effects on their mental and physical health as a result of their role. Caregiving is an expression of deeply held values and an acceptance of our most important shared responsibilities as humans. It is a source of meaning and connection. For many, it is a profound expression of love. ***While challenges come with the territory for caregiving, it should not make us ill or disabled.*** The fact that it is doing so indicates that something is deeply wrong.

The lack of supports for caregivers affects not only caregivers themselves, but also those that they are caring for. As one caregiver told us, "I could not give good caregiving at home as I was beyond exhausted and burned out. Desperate." Ultimately, caregiver burnout and distress affect the quality of care that they can provide. There may also be broader costs to the health system, if caregivers become too ill to continue effectively in their role. According to the OCO's 2024 Spotlight Report, almost one-third caregivers report feeling unable to cope with their caregiving role (32%, up from 28% in the previous year), and 72% now say they feel so burned out, they are not sure how they will continue. Three-quarters of caregivers are concerned that they will not be able to handle the demands of their caregiving role in the future and almost 80% feel so exhausted they are finding it difficult to get things done.[7]

Mental health supports, when well-designed and delivered, can be highly effective in addressing these challenges. For example, an evaluation of the OCO's Coaching program found: 92% of caregivers felt less hopeless and helpless in their caregiving role after completing the program; 87% felt less distressed or burnt out about caregiving; and 95% were better able to manage their own mental health and wellbeing while providing care. The evaluation of the OCO's SCALE program, which provides one-on-one counselling, group psycho-education and group counselling, showed similarly strong results.[8]

Taking a preventive approach to caregiver health by providing mental health supports when needed will benefit the caregiver, the care recipient, and the health system as a whole.

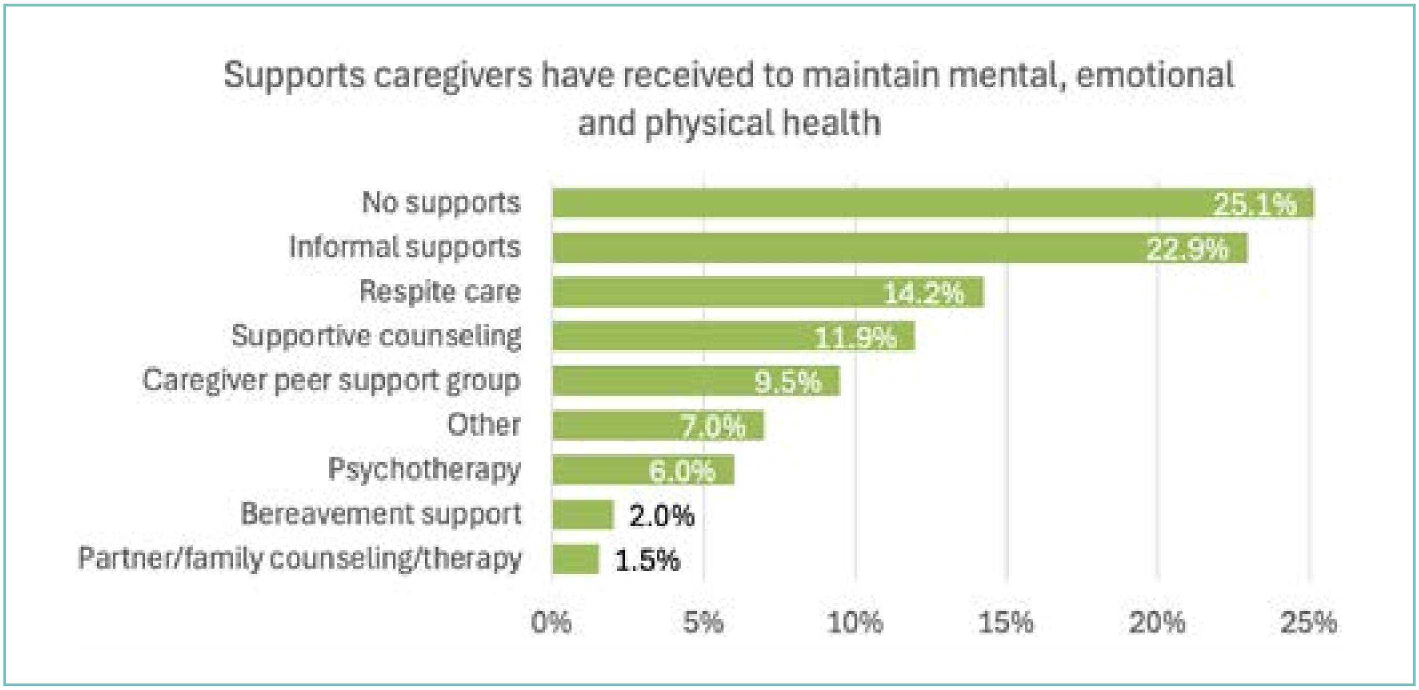
TO WHAT MENTAL HEALTH SUPPORTS DO ONTARIO CAREGIVERS CURRENTLY HAVE ACCESS?

> "I was fortunate – I had a car accident. Due to the accident, I required support of a psychiatrist – he continued to help me through my care giving and time of grief."

In Ontario, publicly available mental health supports include services provided by government-funded programs, non-profit organizations, and community health centers. These supports range from crisis intervention (e.g., Ontario's Mental Health Helpline, 9-8-8 Suicide Crisis Helpline) to counselling, psychotherapy, addiction services, and specialized programs for youth or seniors. Community-based services such as counseling, case management, and psychiatric services, as well as telehealth, texting and online services, may be provided by Canadian Mental Health Association in different Ontario locations. Hospital-based services are also available, including emergency mental health assessments and inpatient care.

These publicly-funded options are often limited or waitlisted. Some Ontarians seek mental health supports through their employer extended health benefits. About two-thirds of working adults have access to these benefits. However, the maximum median coverage – about $750 – is insufficient for virtually all mental health counselling beyond brief therapy.[9] Of course, caregivers who have left the workforce or who have moved to part-time or casual work in order to care for loved ones lose even this limited access to mental health supports.

Overall then, caregivers seeking mental health supports must navigate a patchwork of fragmented and limited services, facing lengthy waitlists or significant out-of-pocket costs. As a result, **the majority of caregivers reported receiving no formal mental health supports.** The most common source of supports include informal support, such as from family and friends. Notably, 14% of respondents highlighted respite care as a source of mental health supports.



Survey respondents identified a wide variety of barriers to accessing mental health supports, including long waitlists, navigational difficulties, and out-of-pocket costs. Approximately 30% of respondents cited the out-of-pocket costs associated with receiving supports as a barrier, while over half (51%) were either unaware of any available supports or had never been offered any. Approximately one-third indicated that they were too exhausted and overwhelmed to access supports. Others pointed to additional barriers including the lack of flexibility in the supports offered (20%), lack of suitable supports (15%), and waitlisting (10%).

"Sometimes supports are individual and I found the most help in therapy with a therapist I have developed a relationship with. However, I've had to pay out-of-pocket to access it."

"I had one counselling session from a palliative care service. I was told the counsellor would call me in a month. I never heard from anyone again...offered help was always after the fact."

"[Home and Community Care Support Services] closed the file when mom died, leaving myself and her teenage grandkids grieving, exhausted, and overwhelmed."

Recognizing the need, community agencies and health organizations have stepped in to try to address the gap. **The following programs all serve very limited numbers of caregivers, and have various restrictions in scope, whether in terms of the range of caregivers addressed, or the type and extent of services provided.** However, all provide examples of promising practices which could be scaled or spread.

- The Ontario Caregiver Organization (OCO) provides a range of mental health supports. Their free Learning Library provides e-learning modules on caregiver burnout, developing resilience, mental health and addiction, and more. Their Online Peer Support groups are facilitated by trained facilitators with lived experiences as caregivers. The OCO also provides access to one-on-one and group psycho-education and group counselling (e.g., the SCALE Program), although the sessions are limited to three and spots are limited.
- The Reitman Centre CARERS program is an evidence-based approach to supporting caregivers of persons living with dementia.[10] This structured group psychotherapy approach supports caregivers in mastering problem solving techniques and effective communications through simulation-based experiential learning. Mental health clinicians provide emotional support through the program.
- The Caregiver Clinic at the Princess Margaret Cancer Centre supports caregivers of persons with cancer through one-on-one counselling. The individual format can be expanded as needed to include the entire family unit. Caregivers may be referred through any health provider associated with Princess Margaret or may self-refer. The Clinic provides caregivers with an integrated, tailored psychosocial intervention. The Clinic also acts as an education resource for health professionals who are interested in developing knowledge and skills to address caregiver distress, as well as a “living lab” for advancing knowledge about caregiver needs. It is supported through the philanthropy of the Princess Margaret Foundation.

HOW CAN ONTARIO EFFECTIVELY SUPPORT THE MENTAL HEALTH OF CAREGIVERS?

> "Social supports and mental health resources are crucial to maintain caregiver wellness. Group supports especially, and services/programs must be affordable."

Strengthening the systems of support available to caregivers, including access to respite, financial supports, system navigation, and community services, will do much to reduce distress and burnout among caregivers. Investing upstream will reduce needs and costs downstream. Nevertheless, caregiving is inevitably associated with loss and stress – some caregivers will always need access to mental health supports.

Caregivers have emphasized the importance of supports that understand the caregiver experience and respond to their particular needs. In the words of one caregiver, "I've seen several therapists to help with my mental health but have a hard time finding someone that 'gets' the hardship that comes with constant caregiving, raising a young family and working full time." Providers who do not understand the caregiver experience can inadvertently cause active harm by directing caregivers to inappropriate courses of action. **It is important to offer supports that are specifically designed to address caregiver experiences and needs.** For example, the multiple time demands on caregivers suggest that flexibility is key to ensuring accessibility. The social isolation associated with caregiving points to the potential benefits of peer supports.

While there are commonalities across the caregiver experience, needs for support will vary depending on the type and stage of caregiving, as well as the specific needs of each caregiver. As one caregiver stated, "I am in the early stages of helping my partner manage two ongoing chronic conditions which will likely eventually require much more care and attention. Others, at a later stage of caregiving/more complex care situation, will clearly have greater/different needs." **A stepped approach to supports will be the most effective,** ensuring that resources are targeted to those that need them the most.[11]

The breadth of the need expressed by survey respondents indicates the benefit of **ensuring widespread access to preventive supports for all caregivers.** This can include self-assessments of caregiver wellbeing and information about how to gain access to mental health supports in the community. Caregivers who are experiencing challenges in their role will benefit from peer support (individual and group) services designed for caregivers – with the input of caregivers – that addresses social isolation, promotes health and connection, and builds the resilience of Ontarians with caregiving responsibilities. Finally, caregivers experiencing conditions which may threaten their wellbeing (e.g., depression and anxiety), or may impair their ability to continue with the provision of care should have access to psychological interventions by qualified health professionals with expertise in the caregiving experience. Supports should be responsive to the caregiver's family and cultural contexts.

Supports must be offered proactively to caregivers in need. Caregivers are often reluctant to raise their own needs, seeing those of their care recipients as more intensive and deserving of greater priority. They may also be reluctant to make any comments that might characterize their friend or family member as a burden or place them in a negative light. As well, the caregivers most in need of support are also those most likely to be incapacitated to take steps to seek help. Programs such as the Princess Margaret Caregiver Clinic, which educate health professionals to actively screen caregivers for distress and to refer them for supports, provide a practical example of an effective proactive approach.

As has been emphasized throughout these Policy Briefs, caregivers are struggling to fulfil their roles within a frustrating and maze-like system, replete with burdensome processes, narrow eligibility requirements, and navigational dead-ends. **It is essential that mental health supports are easy to find and simple to access.** Services can and should build on existing points of connection, proactively identify and assess caregivers for distress and burnout, and take inclusive approaches to eligibility. The top recommendations of caregivers for the design of mental health supports was to offer them proactively (72%), with increased flexibility (50%) and greater accessibility (36%).

As was noted above, good work is being done by community services to develop effective mental health supports for caregivers. **What is needed is not the invention of something new, but to spread and scale up existing evidence-based practices and effective models.**

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