November 2024 Newsletter

At the OCC

Please join us at our upcoming General Members Meeting!

The OCC will be hosting our next General Members meeting on Thursday, December 12th, from 11.00 a.m. until 1.00 p.m. This will be another energizing meeting, including presentations from the Ontario Caregiver Organization regarding their approach to and learnings from their mental health support services for caregivers, and from Wesway about their innovative caregiver respite programs. The OCC will be sharing our recommendations on policy change in the areas of mental health supports and respite for caregivers, drawing on the results of our 2024 Caregiver Survey and our further research. We will also be hosting a discussion about Pre-Budget Submissions and preparing for the likely spring provincial election. We hope you will join the conversation!

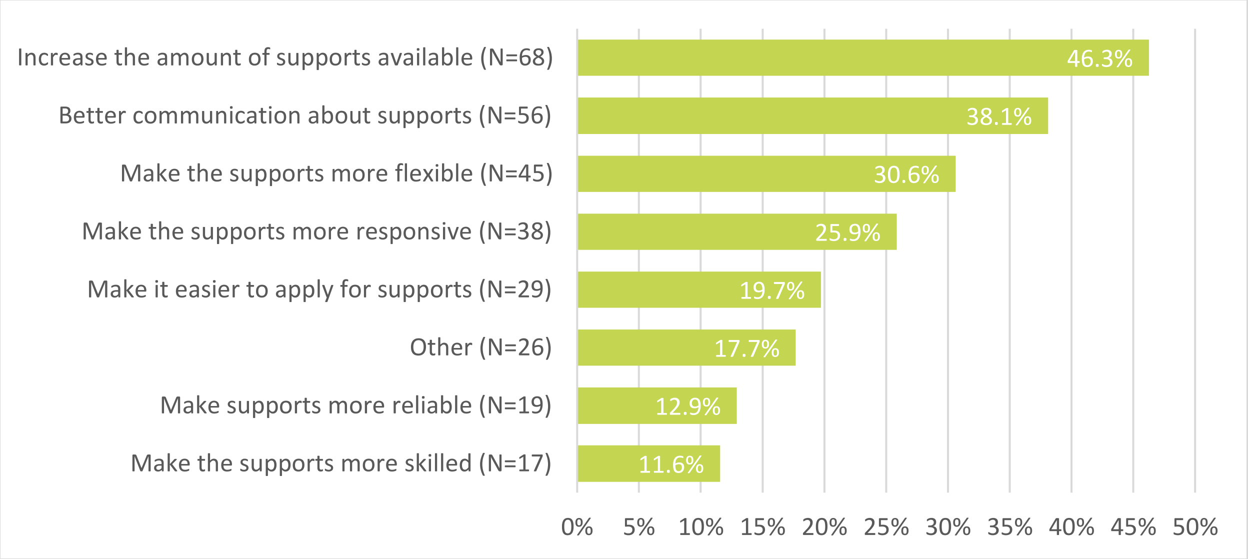
As with all of our Members Meeting, this meeting will be hosting virtually. Members and Friends should have received a calendar invitation with information for joining the meeting. If you have not received your invitation and wish to attend, please let us know.

Upcoming Policy Brief on Improving Caregiver Access to Respite Services

"I need actual physical help, not talk about how I should take time for me. I know that, but who will take care of my daughter?"

Respite services, which provide caregivers with temporary relief from their responsibilities of caregiving, are essential to maintaining the physical, mental and emotional health of those who are engaged in intensive caregiving. Yet relatively few caregivers have access to respite services. Our 2024 Caregiver Survey indicated that improved access to respite services was a top priority for survey respondents. Many were receiving no respite supports at all; others were receiving only informal supports from family and friends, or paying out of pocket for respite services.

Caregivers described a wide range of barriers to receipt of respite services, including a fragmented and reactive system that imposes significant navigational challenges on caregivers, limited options, lengthy waitlists, and unreliable or poor quality services.



The fourth in the OCC's series of Policy Briefs will focus on how to improve access to respite services for caregivers. h of caregivers, and will be launched early in 2025. Please keep an eye out for our launch email and be sure to share with your networks!

Can You Help Us to Prepare for the Upcoming Provincial Election?

It appears increasingly likely that there will be a provincial election early in 2025. Elections are a key opportunity for the OCC to share our priorities for policy changes that will better support caregivers, ensure that caregiver needs are part of the provincial conversation, and encourage the various political parties to commit to change.

To make the best use of this opportunity, we are looking for volunteers to help us build our election campaign. This includes individuals with skills in writing, messaging, social media, and campaign planning.

The OCC provides a flexible and supportive environment for volunteering. Whether you have a few hours per week, a couple of hours each month, or the capacity to complete a one-time project, we can find the right place for you. If you are interested in volunteering, please reach out to us at ontariocaregivercoalitionocc@gmail.com.

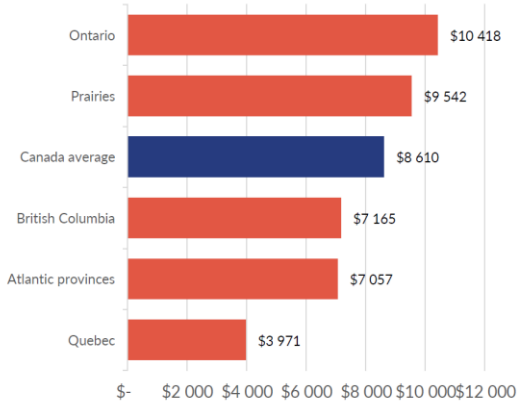
Member Initiatives

The Economic Impact of Parkinson’s in Canada Report

Parkinson Canada, the national organization representing people with Parkinson’s and their care partners, has released their Economic Burden of Parkinson’s in Canada Report which details the true financial impact of Parkinson’s in Canada. The report does a comprehensive analysis of the burden Parkinson’s places on people living with the disease, the healthcare system and care partners. Care partners provide critical support to people with Parkinson’s and the report highlights their contribution along with the significant financial challenges they face.

The report illustrates that caring for someone with Parkinson’s is a significant economic burden that affects care partners in several ways. This includes both the direct out of pocket costs for things like assisted living services and additional care help and the indirect costs associated with productivity losses due to caring for someone with Parkinson’s. The Economic Burden report is designed to both quantitatively describe these costs but also qualitatively outline what these costs mean for Parkinson’s care partners.

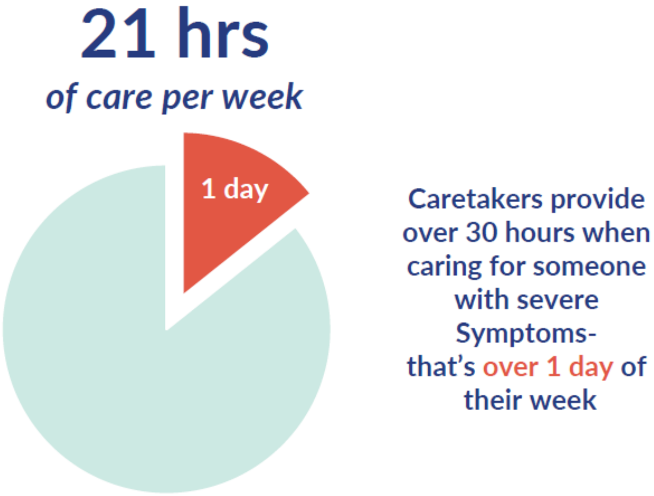
Figure 16: Out-of-pocket for care partners, by region
Average, as reported in the survey for 2023, n=190



Source: PwC-Léger Survey, PwC Analysis

The report found that care partners for people with Parkinson’s will shoulder a $990 million dollar burden in 2024. These costs are set to rise to $1.3B in a decade as our aging-population increases the amount of Parkinson’s in Canada. The report also demonstrates that the out-of-pocket costs placed on care partners is higher in Ontario than anywhere else in Canada (Figure 16); simultaneously, care partners in Ontario receive the least amount of financial support of any province.

Caring for someone with Parkinson's is also a significant physical and mental burden that often impacts care partners' careers and livelihoods leading to harsh indirect costs. The report describes the significant effect Parkinson's has on care partners' quality of life. For instance, over 80% of care partners reported reduced social interactions and life satisfaction, with 68% experiencing increased stress or anxiety. A reduction in care partners' quality of life not only adversely affects their ability to provide care but also to care for themselves.



The findings mentioned above are just scratching the surface of the burden that Parkinson's care partners must carry. For more information we encourage caregivers to view the full economic burden report and its associated shorter summary report. As the backbone of the healthcare system, all levels of government need to understand the plight of caregivers. Any efforts to share this report with key officials will help to create awareness of the Parkinson's price tag on caregivers while informing them of the need for better support systems and policies.

Ontario Caregiver Coalition Article: C-CART™ Empowers Caregivers Across Canada

The Canadian Caregiver Assessment and Resource Tool (C-CART™) is a free online tool created by Baycrest Koschitzky Centre for Innovations in Caregiving. It helps caregivers who may feel overwhelmed by challenges like finding the right services, financial support, and taking care of their mental health.

With just a short questionnaire, C-CART™ gives caregivers instant, personalized advice and connects them to useful resources like health information and local community programs. It's especially helpful for people in communities that might not have easy access to these kinds of supports.

C-CART™ is getting even better! New versions are being developed, including one for young caregivers who are balancing school with helping their families, and another for caregivers of people with dementia, who often face extra tough challenges.

By making it easier to find help and giving caregivers practical advice, C-CART™ is making life better for caregivers everywhere. Check it out at https://c-cart.baycrest.org/.

Opportunities to Participate in Caregiver Focused Research

Western University Seeks Caregiver Participants for COPD Study

Are you an unpaid caregiver for someone living with Chronic obstructive pulmonary disease (COPD)? The School of Health Studies of the University of Western Ontario is seeking caregiver participants for their study on understanding lived COPD experience, and the experience of carers for those living with it.

The study is investigating the impact of age, gender and financial wellbeing on the diagnosis journey and management of COPD, from the perspective of lived experience. The researchers plan to explore the range of needs that are currently unmet by the current healthcare system.

The findings may inform recommendations for more equitable and accessible COPD care. Caregivers participating will have the opportunity to share their concerns about COPD care and our current healthcare system, helping shape potential improvements.

Participants will only need to attend a single one hour interview, and interviewees will receive a gift card in compensation for their time. If interested in taking part, kindly click this link to sign up. For more information, please contact the principal investigator, Dr. Shannon Sibbald, via email.

Statistics Canada Seeks Caregiver Input for Life-Limiting Illness Study

Are you a caregiver for someone with a life-limiting illness? Statistics Canada is conducting a survey to better understand the lived experience of individuals with such illnesses and their caregivers, focusing on access to care and support services.

The study aims to understand how well current care meets physical, psychological and social needs. It also seeks to identify existing gaps and barriers to critical areas of care, and how those services can be improved. As a caregiver, this can be an opportunity for your voice to be heard by our federal government on difficulties you experience with the current accessibility of care.

Statistics Canada hopes that the survey findings may assist healthcare organizations and providers enhance the development, planning and delivery of higher-quality care for Canadians with life-limiting illnesses and their unpaid caregivers.

To participate, you can complete the online questionnaire by clicking on this link. For inquiries or questions about the study, contact the research team at the email address linked here.

Of Interest

New Brunswick Government Announces $250 Monthly Allowance for Unpaid Caregivers

In their new mandate, the government of New Brunswick has pledged to introduce a $250 monthly allowance for unpaid caregivers, recognizing their vital contributions to family health care.

New Brunswick held an election on October 21, 2024, where the incumbent Progressive Conservative party was defeated by the Liberals, winning a majority of seats in the legislature. On November 7, the new government published their mandate, highlighting the caregiver benefit as a component of their healthcare and home care strategy.

This announcement reflects growing momentum for caregiver support across Canada. For example, in October, the Saskatchewan Party pledged a caregiver tax credit and subsequently won a majority in their legislature. Caregiver support is becoming a key priority in policy platforms nationwide.

Financial supports are a consistent priority for policy reform among caregivers, as was reinforced by the OCC's recent Caregiver Survey.

Unlike many financial supports for caregivers, which are offered as non-refundable tax credits and often fail to support lower-income caregivers, New Brunswick's new allowance will be paid directly to recipients, approach which the OCC has supported in our own proposed Ontario Caregiver Support Benefit.

The mandate also includes broader commitments to home and community care, such as increased funding for personal support workers and retrofitting homes to improve safety and accessibility for seniors and individuals with disabilities. These measures aim to enhance healthcare access for all residents.

This announcement is an encouraging step forward, and we remain committed to advocating for the Ontario Caregiver Support Benefit. If you are interested in learning more about the mandate, please click here to read everything they've announced.

Health Canada Campaign Aims to Dispel Myths About Palliative Care

Palliative care may be an essential part of caring for someone living with a life-limiting illness, but conversations on the topic can be difficult to have. Health Canada is launching a campaign seeking to educate Canadians on palliative care, while dispelling myths that can make those conversations about it so difficult.

Palliative care is often thought of as exclusively an end-of-life treatment option, but it can begin at any point after diagnosis, even while receiving treatments intended to cure the serious illness. It can also be provided outside of a hospital, including at home, depending on the complexity of a person's symptoms.

Through correcting these myths, Health Canada is seeking to make conversations about a palliative approach to care between care recipients and their care providers easier to have. They are hoping to make it easier to talk about through other ways as well. For those receiving a diagnosis of a serious illness, they have released a guide on what to ask health and social service providers when facing a serious illness.

To learn more about the myths surrounding palliative care, and to hear the stories of those helped by palliative care, please visit this page. To learn more about the benefits of palliative care broadly, kindly view this link.

Celebrating the Legacy of Dr. Janet Evelyn Fast

The OCC would like to recognize the legacy of the recently deceased Dr. Janet Fast, a passionate and diligent advocate for improving the lives of caregivers in Canada. Her work focused on strengthening our understanding of family caregiving, debating the sustainability of unpaid caregiving, and documenting the economic value of that unpaid work within the Care Economy. Janet's passion for improving the lives of caregivers was felt by all those around her. She sought to bridge research, policy and practice to advance evidence-based solutions, and gave generously of her time, skills and knowledge to support change for caregivers, including assisting the OCC in the development of our proposed Ontario Caregiver Support Benefit.

If you have items that you would like to see included in future issues of this newsletter, please let us know. Sharing the accomplishments and activities of our members is part of our mandate. If you have received this newsletter in error, or no longer wish to receive it, please reply to this email to let us know, and we will remove you from our mailing list.