



# March 2024 Newsletter

## At the OCC

### Caregiver Day 2024: Building the OCC, One Voice at a Time

Tuesday, April 2nd is Family Caregiver Day.

This year, we want to celebrate our current members – and bring new voices to our table. The theme we’ve chosen this year is “Building a Better Ontario for Caregivers, One Voice at a Time”. We want to showcase how involvement with the OCC has helped you on your journey, and how, by working together, we can create change for current and future caregivers – to inspire others to join us.

We have developed materials that highlight our current members, as well as why you should join the OCC. Materials will be found here as we add them:

[https://drive.google.com/drive/folders/1ChRmaqzdT21bQ3zSjERWk\\_X-i\\_G0rk7-?usp=drive\\_link](https://drive.google.com/drive/folders/1ChRmaqzdT21bQ3zSjERWk_X-i_G0rk7-?usp=drive_link)

*If you are a caregiver member:*

- If you have 5 minutes on Family Caregiver Day, please like, share, and/or retweet our materials on Facebook, Instagram, LinkedIn, and X.
- If you have 15 minutes, post why you are involved, using our materials. Remember to tag the OCC!
- If you have more time, why not reach out to a friend or family member who is also a caregiver and ask them to get involved?

*If you are a representative of an organizational member:*

- Please share the materials with your social media managers or communications team
- If they would like to discuss how we can feature them in our work, please feel free to put them in touch with us!

Thank you in advance for your support.

## Celebrating Volunteer Week

Canada's National Volunteer Week will be celebrated from April 14<sup>th</sup> to 20<sup>th</sup> 2024. National Volunteer Week is an opportunity to recognize and celebrate the importance of each and every volunteer's impact from coast to coast to coast.

As a volunteer-driven organization, the Ontario Caregiver Coalition is witness every day to the amazing contributions made by the talented volunteers who give of their limited time and unlimited skills to make a difference for caregivers across the province. The OCC's significant accomplishments in the fields of research, policy-development, awareness-raising, coalition-building and advocacy are due entirely to the tireless work of our Board, Committees, and members. OCC's members collaborate, innovate and support each other to make change.

The OCC will be celebrating Volunteer Week – meaning you! – this year. Please follow our social media during Volunteer Week, and help us to raise awareness about our shared efforts and accomplishments.

Thank you for your commitment to change!

## Thank You for Supporting the 2024 Caregiver Survey

Thank you to all who supported the 2024 Caregiver Survey by assisting with its development and design, disseminating it, or completing it. This was truly a collective endeavor, showcasing the capacity of the OCC to bring together many skills and perspectives to accomplish amazing things.

Because of you, we were able to surpass our starting goal, and received almost 450 responses from caregivers. With this strong response, we will be able to confidently guide the OCC's advocacy efforts over the next few years, help to inform the caregiving programs and initiatives of our Organization Members, and provide decision-makers with the information they need to design policies that will make a real difference to caregivers. We were pleased to see that we received responses from a wide range of caregivers, ensuring that we can advocate based on an understanding of the diverse needs of caregivers across the province.

Our Survey Subcommittee is just beginning analysis of the results, and we can already see that there is much valuable information in the data. We look forward to sharing the results of the Survey with our members at our June General Members Meeting, and will launch our public-facing report soon after.

## Thank you for supporting the 2024 Caregiver Survey!



### Survey Lead Team

- Lauren Bates (R & A Chair)
- Dr. Matthias Hoben (York University)
- Dr. Mary Chiu (Ontario Shores)
- Dr. Sharon Gabison (caregiver member)
- Rose-Marie Fraser (caregiver member)
- Lorena Araujo (Parkinson Canada)

### Survey Testing - Caregiver Collective

- Malene Stewart (Co-Chair of the Collective)
- Cindy Diogo (Co-Chair of the Collective)
- Frank Palmer (caregiver member)
- Stefanie Kociuba (caregiver member)
- Dawn Vernon (caregiver member)

### Communications Support

- Bhavini Patel (caregiver member)
- Devon Makse (OCC Coordinator)

### Survey Design Support

- Rebecca Cheff (R & A Committee)
- Patrick Boily (Ontario Community Support Association)
- Chris Cobus (Champlain Health)
- Marybeth Barrett and others (Wesway)
- Dan Corvino (MS Canada)
- Cindy Diogo (Caregiver member)
- Kyle Fitzgerald (ASO)

### Outreach – Partnership Committee

- Kyle Fitzgerald (ASO)
- Liana Sikharudlidze (Qualicare)
- Stephanie Chen (MyCareBase)
- Kayla Nicholls (IAMH)

**And everyone who completed or helped to disseminate the survey!**

## Member Initiatives

### Report Highlights Urgency of Investing in Ontario's Home Care System Now

*Sue VanderBent*

*CEO, Home Care Ontario*

As health sector leaders, we are all too aware of the aging population and what needs to be done to prepare our health system to support them, including building a home care system that meets the strong desire of seniors to stay and age at home. It is tempting, however, to think that preparing for this challenge is something that can be delayed or further postponed. But this work cannot be delayed. Home Care Ontario has been sounding the alarm to highlight these issues to government decision-makers, sector partners and patients. We must act now!

Home Care Ontario commissioned Dr. Arthur Sweetman and Dr. Boris Kralj at McMaster University's Centre for Health Economics & Policy Analysis (CHEPA) to help paint a clearer picture about the astounding growth in our seniors' population. The results of their research were sobering. This critical analysis identifies what needs to be done to build our home care workforce to support these seniors, and just as importantly their families and other caregivers. The research found that the proportion of those over the age of 65 will increase by 23 per cent or 650,000 people and those over the age of 75 will grow by 27 per cent or 350,000 people by 2029 respectively and that those increases are much faster than the general population growth.

The research also outlined the massive increase in home care staff that will be required to keep

pace with this demographic surge in Ontario's seniors' population. They specifically found that Ontario will need to hire an additional 6800 PSWs in the home care sector alone by 2028 just to maintain the level of current home care service provided across the province. The report also states that the need for additional staff is very likely similar for nursing, therapists, and all other health professionals working in the home care sector; and that we will require thousands more staff to increase the level of care seniors receive at home – where it has been repeatedly shown that seniors want to be.

Our Association has been sounding the alarm that we must act fast to grow our home care system and this research shows what is at stake. Our seniors' population is about to surge, and we need to make sure our health care system is ready. Continued investment is needed to massively expand the home care system to make sure the care is available where our seniors want it – at home - and we want to thank the Ontario Caregiver Coalition for its continued support of the home care sector and its continued calls for increased access to home care to support patients, caregivers, and their loved ones.

### National Caregiver Day Celebrations

There are many opportunities to mark National Caregiver Day next week, including several events by OCC members and friends. Below you'll see a short description of each event, where and when they'll be happening, and how you can attend.

[North York Seniors Centre:](#) North York Seniors Centre is hosting a free National Caregiver Day event from 2 - 4 PM at 21 Hendon Avenue in North York. It will feature a talk from Stephanie Muskat on "A Caregiver's Secret Key" and light refreshments for those in attendance. To register and learn more, please see their flyer [here](#).

[Ontario Shores \(April 4 Event\):](#) The Ontario Shores Centre for Mental Health Sciences is holding a National Caregiver Day Celebration on April 4 from 4:30-7 PM at 700 Gordon Street in Whitby. It will feature a caregiver resource fair, a townhall, a photography exhibit showcasing caregiver experiences and the premiere of the Ontario Shores in-house production, "The Caregivers". OCC Chair Lauren Bates will be part of a panel on the caregiver experience. Light refreshments will be served and there is free parking. To learn more, please read their flyer [here](#). To register, please click the link [here](#).

[Mississauga Halton Regional Learning Centre:](#) The Mississauga Halton Regional Learning Centre is holding a virtual Caregiver Appreciation event from 1 to 3 PM. The afternoon will include speakers set to inspire caregivers, covering topics including caregiver burnout, mindfulness and designing better policy solutions for the future. To learn more and to register to attend, you click [here](#).

[Canadian Centre for Caregiving Excellence:](#) The Canadian Centre for Caregiving Excellence is hosting a virtual webinar for National Caregiver Day from 1 to 2:30 PM. Attendees will hear from many speakers throughout the event, and the talks will focus on uplifting caregiver voices to build a caregiving national strategy for 2024. To learn more and to register, please click [here](#).

[Integrated Care Foundation:](#) The Integrated Care Foundation is hosting a virtual event for National Caregiver Day from 10 AM to 2 PM EST. There will be three webinars throughout the day:

- Valuing Family Caregivers and their Caregiving from 10 to 11 AM;
- Economic Benefits of Caregiving from 11:30 AM to 12:30 PM;
- Impact of Caregiving on Personal Growth and Relationships from 1 to 2 PM.

Please click [here](#) to register for the first webinar, click [here](#) to register for the second, and click [here](#) to register for the third.

## April is Parkinson's Awareness Month

April is Parkinson's Awareness Month in Canada, and April 11<sup>th</sup> will be World Parkinson's Day.

OCC Member Parkinson Canada will be marking the month with an event at Yonge and Dundas Square in Toronto on April 11<sup>th</sup>, and with the launch of a documentary and a new song by Martha Johnson of Martha and the Muffins. Parkinson Canada has prepared a social media toolkit to help raise awareness about Parkinson's. For more information, and to get involved, visit <https://www.parkinson.ca/parkinsons-awareness-month/>.

## Of Interest

### Opposition Health Critic Re-Introduces Family Caregiver Day Recognition Act

On March 27, 2024, Ontario NDP Health critic and MPP for Nickel Belt France Gélinas re-introduced an *Act proclaiming Family Caregiver Day*. This is the fourth time MPP Gélinas has introduced this piece of legislation. This bill would proclaim the first Tuesday of every April as Family Caregiver Day. While Family Caregiver Day has been recognized at the federal level, there has of yet been no such official recognition at the provincial level.

The Ontario Caregiver Coalition has long supported official recognition of Family Caregiver Day, as an important first step towards supporting the essential work of Ontario's unpaid caregivers.

The *Act proclaiming Family Caregiver Day* is a private member's bill. To support its passage through the House, please phone, write or email your local MPP to express your support.

## Disability Advocacy Committee Releases Report and Recommendations on the Disability Tax Credit

Earlier this month, the federal Disability Advisory Committee (DAC) released its fourth Annual Report, focusing on the crucial Disability Tax Credit. The DAC advises the Minister of National Revenue and the Canada Revenue Agency on how the CRA can improve the way it administers and interprets tax measures for Canadians with disabilities.

Individuals with severe disabilities experience many financial barriers and costs, leading to high rates of low income. The Disability Tax Credit is a critical support for these individuals. However, the multi-step process for accessing the Disability Tax Credit is complex, and full of potential barriers.

The report presents 26 recommendations aimed at enhancing the DTC program. These recommendations address issues of eligibility, accessibility, and outreach, and cover a wide range of areas, from reframing the definition of disability to tracking user feedback for the online DTC application, improving public education, making the DTC refundable, and enhancing healthcare provider support. The full report can be accessed [here](#).

## Seniors for Social Action Ontario Shares Results of FOI Request on Home Care Spending in Ontario

In 2024, Seniors for Social Action Ontario (SSAO) filed a Freedom of Information Request related to expenditures for home care funding. Having now received the results, SSAO is making them publicly available [here](#).

Information included in the FOI release includes:

- The provincial budget for each of the 14 Area Offices
- The number of clients served by each Area Office
- Expenditures for the Family Managed Home Care program
- The number of clients served by the Family Managed Home Care program
- The distribution of the \$1 B in funds announced by the Ministry on April 25, 2022
- Non-Crown sources of funding for Home and Community Care Services

The results provide some interesting insights into access to home and community care services across the province.

## Opportunities to Contribute to Caregiver Focused Research

### Queen's University Dementia Caregiver Medication Management Study

Queen's University is recruiting caregivers who can help with understanding the medication management experiences and needs of caregivers of people living with dementia. The goal of the study is to improve resources for caregivers of persons with dementia.

The study is currently seeking 20 caregivers of persons with dementia to take part in an 60 – 90 minute virtual interview. Those selected to participate will receive a \$20 Tim Horton's gift card after their interview is complete as a token of appreciation.

If you are interested in participating or finding about more, you can contact the research team at [19sci1@queensu.ca](mailto:19sci1@queensu.ca), or scan the QR code on the poster attached below.

## Do you provide support with managing medications for someone with dementia?



We are looking for past or current friend and/or family caregivers of people with dementia to participate in a research study investigating caregivers' experiences and needs of managing medications for someone with dementia

### Who can participate?

You may be eligible to participate if you:

1. Are an **unpaid friend or family caregiver for someone with dementia**
2. Have supported **in medication management** activities **weekly for at least 2 months**



### What will the study involve?

You will be asked to take part in a structured **60-90 minute virtual interview** over the course of 1 or 2 sessions. You will receive a **\$20 Tim Hortons gift card** in appreciation for your time.



### What happens next?

Please contact the research team using the QR code or via email at [19sci1@queensu.ca](mailto:19sci1@queensu.ca). If eligible, we will book an interview at a time most convenient for you.



V1.0 - This study has been reviewed for ethical compliance by the Queen's University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board.



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.