



Ontario Caregiver Coalition (OCC) March 2022 Newsletter

News from OCC

Note to readers: After you read the first two articles in this newsletter, please visit the link below and complete the short survey to let us know how you would be willing to help us and strengthen our OCC work by becoming engaged in our upcoming activities. Thank you!

<https://www.surveymonkey.com/r/HQ87RR7>

Family Caregiver Day – April 5, 2022 – submitted by Daniel Nowoselski, Chair, OCC Awareness & Communications Committee

The first Tuesday of April is National Caregiver Day – **Family Caregiver Day** in Ontario - a day when we recognize the work that family caregivers do and raise awareness and advocate to address the challenges we face. OCC usually has engaged in a campaign in and around this day to emphasize caregiver issues, and we think it is critical with the upcoming Ontario election to make sure the challenges facing caregivers are front and centre.

As we discussed at the General Members' Meeting, this year, on behalf of the OCC, the Communications and Awareness Committee proposed a theme of "When Caregiving Happens to You" – to get people who see our content to think about what it would mean for their day-to-day life, their financial circumstance, their families, and their futures should they need to step into a caregiving role. The hope would be that this message would help people who are, who have been, and/or who could reasonably foresee themselves becoming a caregiver see themselves in our work and support our call to action of asking all parties to make caregiving a priority in this election.

There are many ways you can be involved – sharing our messages on social media, sending an email to your local candidates or the provincial political parties, or volunteering to tell your story in the event we can secure some media attention on the day. We plan to share

the content around the campaign in our next newsletter, in advance of Family Caregiver Day. If you want to be involved, please fill out the caregiver survey included in this email or send a message to Daniel Nowoselski at daniel.nowoselski@cancer.ca.

Advocating for Change During the Upcoming Provincial Election Campaign –

submitted by Lauren Bates, Chair, OCC Research & Advocacy Committee

Ontario's provincial election, which will be held on June 2, 2022, offers an important opportunity to bring the experiences and concerns of caregivers into the public eye, and to advocate for changes to public policy that will provide caregivers with the supports that they need and deserve.

Our caregiver members have consistently identified three top priorities for policy-makers:

Priority 1 - Recognition of the essential contributions of caregivers: While we all know how vital caregivers are to the functioning of our health and social systems, the fabric of our communities and the wellbeing of our loved ones, caregivers – and caregiving – are rarely part of in policy discussions. When the public and politicians debate our health and social care systems and how they can be strengthened in the wake of the pandemic, we want to see the role and needs of caregivers recognized and addressed.

Priority 2- Improving home care supports, including through enhancements to Direct Funding Programs: Ontario's home care system has been seriously under-resourced for years. Further strained by the pandemic, it is now completely inadequate to the needs of caregivers who are trying to support the wishes of their loved ones to remain in the community. The OCC will be advocating for significant investment to create a responsive, flexible and effective home care system that meets the needs of caregivers and their loved ones. Building on the advocacy of the OCC over the past year, this should include enhancements to Direct Funding programs, such as Family Managed Homecare, Managed Attendant Services, the Passport Program, and Special Services at Home. These programs can provide flexibility and choice for families.

Priority 3 – Addressing financial distress among caregivers: Our caregiver members consistently tell us that improved financial supports are a top priority for them. Because the intensive demands of caregiving can make it difficult to balance work and family responsibilities, and because there can be significant out-of-pocket costs associated with caregiving, many caregivers experience significant financial hardship. Ontario caregivers have the highest unmet needs of any province with one in three caregivers reporting they need additional support; financial support is the most common unmet need. Manitoba and Quebec provide refundable tax credits for caregivers, while Nova Scotia has had a Caregiver Allowance

in place for a number of years. Ontario has no such program for caregivers. OCC will be advocating for direct financial supports to caregivers to address this gap.

The OCC's Research and Advocacy Committee has begun reaching out to organizational members to see how we can work together during this election cycle. We are also hard at work developing tools that will empower caregivers to be heard by parties and candidates. This includes plain language information about party platforms, as well as materials to support caregivers to write to their MPPs, raising questions at candidate's debates, and engage candidates in discussion on the doorstep. At the centre of all that we do, will be the stories and experiences of our caregiver members.

We would love to hear from you. Share with us:

- Your caregiving stories and experiences, that show why change is needed, and what supports could make a difference to you
- How you are engaging in this election – whether it is talking to your neighbours and friends about caregiver issues, highlighting caregiver issues in your social media feeds, attending a candidate's debate, or something else.
- Your thoughts on how OCC can help to put caregiver issues at the centre of the conversation over the next few months.

To keep abreast of our election activities, follow us on Twitter or Facebook, check out our website, or keep an eye on this space for updates.

Social Work Week – March 7 – 13, 2022



On behalf of the Ontario Association of Social Workers (OASW), a valued Organization Member of OCC, we encourage everyone to express their appreciation this week to all social workers in Ontario who offer so much support to caregivers throughout the year. *Thank you for your caring and compassion!*

Opportunities to Participate in Research Project

Young Caregiver Study – submitted by Giselle Franco, Ryerson University

Principal Investigator: Dr. Alexandra Fiocco, afiocco@ryerson.ca



ARE YOU
A
YOUNG
CARE
GIVER?

CONTACT US!

afiocco@ryerson.ca
Subject: Young Caregiver Study

Approved by the Ryerson Research
Ethics Board: REB#2020-297

Ryerson
University

Study: Understanding vulnerability and resilience among young informal caregivers of persons with neurodegenerative disease

We are recruiting 100 caregivers and 50 non-caregiver controls for this 60-minute (max) online study.

Youth/Young Caregivers must:

- Identify as a young caregiver of person(s) with neurodegenerative disease such as dementia (e.g. Alzheimer's disease), Parkinson's disease, multiple sclerosis (MS), Amyotrophic Lateral Sclerosis (ALS)) or a neurological disorder (e.g., stroke, brain tumor)

Non-Caregivers must:

- Not be in a caregiver role, even for a young sibling.

All participants must:

- Be aged between 16 and 25 years old
- Have no hearing and/or vision impairment that is not corrected
- Have access high speed internet connection to ensure that you can complete the study

All participants will receive a 10\$ incentive and will be entered into a draw to win a \$100 gift card of their choosing.

If interested, or would like more information about this study, please contact us!

PAT-MS Study – University of Ottawa

Are you a caregiver for a close friend or family member with multiple sclerosis?

Researchers at the University of Ottawa are seeking volunteers to take part in a study on the effects of an online physical activity program for people with multiple sclerosis (MS) and their support partners.

Who can participate in the study?

- Care-partners (family members or close friends) who are 18 years of age or older and regularly support someone living with MS may be eligible to participate.
- People living with MS who are 18 years of age or older, relapse-free in the past 30-days, and experience some MS difficulty (e.g., walking, cognitive challenges, sensory problems, etc.) may be eligible to participate.
- All prospective participants must not currently be exercising on a regular basis.

If you are interested and choose to participate, you and your study partner would randomly be placed into one of two groups: an immediate intervention group or a wait-list group.

Here is a short video about the PAT-MS study:

<https://www.powtoon.com/s/enjaQUdSMRT/1/m/s>

Please click here to see the PAT-MS study flyer which contains detailed information about the study.



PAT-MS Study Flyer

For more information about other eligibility criteria and participation, please contact the research coordinator in the Clinical Exercise Physiology Lab (CEPL), University of Ottawa.

Email: cepl@uottawa.ca

Phone: 613-562-5800 x 3274

Website: <https://clinicaexercisephyslab.weebly.com/>

Resources of Interest to Caregivers:

The Ontario Caregiver Organization (OCO) is here to improve the lives of caregivers –
submitted by Maria-Helena Pacelli, OCO

The Ontario Caregiver Organization (OCO) exists to improve the lives of an estimated 3.3 million caregivers across the province. One of the main points of entry and navigation points is OCO's [24/7 Caregiver Helpline](#). The Helpline a one-stop resource for information and referrals connecting caregivers to the support they need in their communities. This might include respite, a support group or programs for the person you care for.

We offer two ways to access the helpline:

1) Call **1-833-416-2273 (CARE)** to speak to a helpline Community Resource Specialist, 24/7 by phone.

2) Use the online live chat feature, found at ontariocaregiver.ca. The chat is available Monday to Friday 7am-9pm EST

In addition to referring providers and caregivers to community programs, resources and organizations that offer the services they may need, the Community Resource Specialists can also refer to OCO's many free programs and services, which include:

- [Peer Support](#): OCO's 1:1 Peer Support Programs connects caregivers with a trained Peer Mentor.
- [Helpful Webinars](#): OCO offers live and recorded webinars for caregivers and providers on a variety of topics that may support caregivers, such as caregiver well-being, advance care planning, caregiver skill development as well as financial and legal tips.
- [Group and 1:1 Counseling](#): The SCALE Program offers a flexible yet structure program that includes topical webinars alongside individual and group counseling options. Many caregivers find it so helpful that they take the program multiple times.
- [E-Learning and Educational Resources](#): OCO's e-Learning platform provides free online learning for caregivers to learn more about the caregiving role, as well as courses designed for providers and also for employers.
- [Toolkits for Caregivers](#): Initially developed in response to COVID-19, OCO's tip sheets and toolkits quickly became a very useful tool for caregivers. There are special toolkits for working caregivers and those new to caregiving as well as helpful information on a variety of topics related to caregiving.
- youngcaregiversconnect.ca: This new website dedicated to young caregivers aged 15-25 provides tailored information for young caregivers as well as a unique, free and confidential forum space where young caregivers can ask questions and talk to one another safely and anonymously about their experience.
- [Podcasts](#): OCO understands that caregivers are busy. That's why we've also developed our "Time to Talk" podcasts on topics including caregiver mental health, nutrition and sleep, as well as conversations with subject matter experts and caregivers themselves that can be listened to casually while making a meal or doing tasks at home.
- [And more...](#)

[Save the Date for Upcoming OCO webinars](#)

- [March 10: Caregiving and Chronic Liver Disease: Challenges, Insights and Support](#)
- [March 23: The Role of Pharmacies & Pharmacists in Supporting Caregivers in the Community](#)
- [April 7: Dancing with Dementia: Fostering Inclusion and Challenging Stigma](#)
- [April 21: Prendre d'abord soin de soi \(French webinar\)](#)

For more information on upcoming webinars and other events for caregivers, visit [OCO's Events Calendar](#).

To stay in touch and receive updates from OCO you can sign up for Connect our e-newsletter for caregivers at www.ontariocaregiver.ca/subscribe.

IFA Global Cafe— submitted by Jane Teasdale, Mosaic Home Care Services & Community Resource Centres

I wanted to provide this information from the IFA Global Café presentation that I thought was very interesting for the OCC to hear. It is about time banks, helping others out in the community, volunteering time. This model is widely used in the UK. You are able to listen to the recording through the IFA.

[IFA Global Café | International Federation on Ageing](#)

<https://static1.squarespace.com/static/5c2fa7b03917eed9b5a436d8/t/60f19e0b9f13d96b48e1d861/1626447381041/Titanium+Ring+-+July+16%2C+2021.pdf>

Deadline to submit articles for our next newsletter is March 31, 2022.

You can visit our OCC website for the most recent updates -
<https://www.ontariocaregivercoalition.ca/>

Please consider signing our petition when you visit!

Thank you to the following OCC Organization Members for their support of our newsletter:

AdvantAge Ontario; Baycrest; Bellwoods Centre for Community Living; Canadian Cancer Society; Circle of Care; Evergreen Hospice; Mosaic Home Care; MS Society; Ontario Association of Social Workers; SRT MedStaff; Wesway; Woodgreen.



Disclaimer: This newsletter is for information purposes only.