



OCC May 2018 Newsletter

Happy Spring!

Second Annual Family Caregiver Day Celebrated by OCC Members Across the Province on April 3, 2018!

Many thanks to **Nicole Nunes**, (VHA Home HealthCare) and Chair of the OCC Awareness & Communications Committee for taking the lead on this and working diligently, along with **Michelle Lewis** (Powerhouse Project) and **Vinusiya Paranandan** (SEIU Healthcare), members of the Committee, to refresh our Family Caregiver Day toolkit for all OCC members to use. This year, an effort was made to expand awareness of the day and of caregivers by promoting our messages using social media. Below are some of the events and activities organized and attended by OCC members in several areas of the province.

Event Hosted in London by the Caregiver Exchange - submitted by *Paul Cavanagh*, Caregiver Exchange

*Our event was held at the Cherryhill Branch of the London Public Library. **Looking After a Family Member With a Health Condition** featured a live-streamed panel discussion with three experienced family caregivers and a preview of new features on caregiverexchange.ca. Opening remarks were provided by Dr. Gord Schacter, family physician, London-Middlesex clinical lead, who has also been a family caregiver.*

Here is the link to the recording of the panel discussion –

http://www.caregiverexchange.ca/Spotlight/387/3_experienced_caregivers_provide_their_insights_on_what_really_helps



Another Successful Family Caregiver Day Held at Toronto City Hall – submitted by Einat Danieli, ENRICHES Collaborative, Mount Sinai Health System

Many thanks to Einat Danieli, ENRICHES Collaborative, Sinai Health System, for spearheading the planning (along with a great team!) of the second Family Caregiver Day event at Toronto City Hall. She has shared photos and videos of the event which can be found by clicking on the following links:

Checkout our caregiver photos and videos on our Facebook page: <https://www.facebook.com/Toronto-Caregiver-Day-Event-795991170594819/>

And YouTube channel:

<https://www.youtube.com/watch?v=d5ZSfKehC1s&index=7&list=PLLM3up5xFnot8PFh8rHyjLj2mIAnn2JL>

OCC Caregiver Advisory Council Member Attends Private Screening of New Documentary: submitted by Jim LaPlante

I attended the private screening of The Caregivers' Club film yesterday. The event was well-attended at KPMG offices. No statement was made about those attending, but I can assume from the people that I met and comments that were made at the completion of the screening that the majority were caregivers.

I had a chance to spend some time with Cynthia Banks, the director, prior to and after the screening which helped me understand her commitment to supporting caregivers (The Caregivers' Club Family Relief Fund) in physically and financially challenging situations so they can hire private help at their convenience. Summary information about her in The Caregivers' Club website includes an important quote, "I started this documentary because I was angry with the healthcare system, but I turned my attention to the true heroes, the at-home caregivers."

The responses to the film were overwhelmingly emotional (this can be attested to by the boxes of Kleenex that were accessed by many of the participants). On a personal note, after fifteen years of caregiving with my wife for our four parents, the film touched on the challenges that we faced, many not unlike the challenges faced by the families in the film. The film captures the commitment of these families, at times because of changing necessities, but always with a commitment based on love, compassion and support. It focused on the human-side of dementia with respect to the changing behaviours of the dementia patient and the changing reactions of the loved ones' caregivers. It is a film of transition from these two perspectives. It is a film that recognizes the reality that 'dementia is dementia', a journey of constantly learning, adapting, coping, hoping, all part of a caregiver's commitment to a loved one.

I am glad I had a chance to see the film.

Please note that I had a chance to take pictures (I was told participants signed a waiver), including one with Cynthia Banks. See below.



The Change Foundation Hosts Lunenfeld-Tanenbaum Research Institute Meeting on Caregiver Engagement and Co-Design

On April 16th and 17th, several OCC members joined colleagues and caregivers from across Canada to explore together multiple perspectives on how to maximize caregiver engagement and make the experience of caregivers participating in improving the health system more meaningful and valuable.

The meeting provided an opportunity for caregivers, health care providers and researchers to openly share their thoughts about the challenges faced in ensuring caregiver needs are identified *reliably*. There was a clear consensus that caregivers who take the time to give input need to know that some positive **action** will be a result.

Dana MacMillan, (Wesway in Thunder Bay, an OCC member), gave a particularly well-received presentation. (This was despite having her flight delayed by the unfortunate ice storm that occurred that weekend!) **Joycelyn Adams**, OCC Chair of the Caregiver Advisory Council, **Odette Levac**, caregiver member and Joanne Bertrand, OCC Coordinator, also attended.

AdvantAge Ontario Hosts "Advancing Senior Care in Ontario" Election Forum

On April 23, 2018, OCC was invited to be a co-host of this event and **Denyse Lynch**, (see photo below) an OCC caregiver member, presented the opening remarks and introduced the guest panelists. **Vida Vaitonis**, OCC member, also attended and her report of the event follows:



“On April 23 at the University of Toronto’s OISE building, the OCC among other provincial associations and organizations was invited to attend an Election Forum with a panel of representatives from the four parties running in the upcoming provincial election on June 7th. Moderated by Andre Picard, the health columnist at the Globe & Mail and one of Canada’s top public policy writers, the session focused on Seniors’ health policy issues.

Representing the four parties were Hon. Dipika Damerla, Minister of Seniors Affairs for the Liberals, Bill Walker, Critic for Seniors and LTC for the PCs, Teresa Armstrong, Critic for Seniors Affairs and Home and LTC for the NDP and Valerie Powell, Candidate and Seniors Affairs Critic for the Green Party.

After each party representative presented their party’s Seniors platform for the election that is also on each of their websites, a series of questions were asked as follows:

- 1) How do we make Seniors’ housing more affordable and accessible with the Social Housing wait list being four years long?
- 2) How do we address the inequity for home care services with only 6% of the \$50B in the health budget going to home care?
- 3) With the CCACs having been folded into the LHINs, have the concerns been resolved to get more funds to front-line service?
- 4) Will the new agency set up to train PSWs work?
- 5) How do we help the Caregivers?

Many of the responses included new money and strategies or re-organizing and redirecting monies to address the assessed needs of the aging population.

In response to the question on how to help the Caregivers, ideas on tax relief, proper training of staff and funding to support a Dementia Strategy for caregivers and to prevent burnout were put forward by the candidates.” **Vida Vaitonis**

Congratulations to Lisa Levin and her team at AdvantAge Ontario for a well-planned event!

Note from OCC Research & Advocacy Committee: This committee recently met and in the coming days will be preparing and sending out to all OCC members a **mini-toolkit** that can be used by members in your local communities to promote messages about key OCC priorities related to caregiver needs prior to the June 7th election. You may find some ideas to help convey our messages when you meet candidates at the door or at town halls. This information will also be posted on the OCC website.

New Palliative Care Standards Announced

On behalf of Dr. Ahmed Jakda, Provincial Clinical Co-Lead, Ontario Palliative Care Network

Dear Colleagues;

We are pleased to announce that the **Palliative Care Quality Standard** has been released by Health Quality Ontario and the Ontario Palliative Care Network. The standard, with accompanying patient guide and recommendations for adoption, can be used by health care professionals and decision-makers to help improve care throughout the province.

This quality standard focuses on palliative care for adults with progressive life-limiting illness, and for their families, and their caregivers. It addresses palliative care provided in all settings, including primary care, home and community care, hospice, long-term care, and acute care.

The Palliative Care Quality Standard is available on Health Quality Ontario’s website here:

[Palliative Care – Care for Adults with Progressive, Life-Limiting Illness](#)

To support the launch of this quality standard, a communications toolkit is available on the OPCN SharePoint site here:

https://share.cancercare.on.ca/Sites/OPCN/Resources/Palliative_Care_Quality_Standard

Our partners and key stakeholders are encouraged to use the information contained in the toolkit to share information about the quality standard among your stakeholders.

Please feel free to contact us at info@ontariopalliativecarenetwork.on.ca if you have questions.

In Other News

I thought you might be interested in this article about self-care that I posted on our site. Please feel free to share. *Submitted by **Paul Cavanagh**, Caregiver Exchange*

http://www.caregiverexchange.ca/Spotlight/382/How_to_bounce_back_from_a_meltdown_moment

New study shows sleep problems among women and even more so for those who are caregivers.

<http://www.cbc.ca/news/health/caregivers-sleep-1.4469921?cmp=rss> - forwarded by Rosanne Meandro, Alzheimer Society of Ontario

From The New York Times: Easing the Burden on Caregivers A new program in Hawaii will provide stipends of up to \$70 a day to people caring for an elderly family member at home.

<https://www.nytimes.com/2017/12/15/well/family/easing-the-burden-on-caregivers.html> - Submitted by **Nellie Lanteigne**, OCC caregiver member

I am on the planning committee for the 11th International Short-Break (respite) conference that will be held in Reykjavik, Iceland in October 2018. This conference showcases innovative respite and caregivers support initiatives world-wide. Canada has had a strong presence in years past and I'd like to ensure that I'm reaching out to those who may have an interest in either submitting an abstract or attending the conference. Information about ISBA (International Short Break Association) can be found here: www.isba.me and the upcoming conference information can be found here: <http://mailchi.mp/8b60fd80b6e9/isba-reykjavik-october-2018-call-for-papers?e=3fe4410c41> – Submitted by **Dana MacMillan**, Wesway

Date and time of Next OCC General Members' Meeting:

Tuesday, June 26, 2018 – 1:30 p.m. to 3:30 p.m. – VHA Home HealthCare, 30 Soudan Avenue, Toronto (and via teleconference)

Agenda to follow in early June.

Disclaimer: *This newsletter is for information purposes only.*