

December, 2020

Family Council
Network 4
Advocacy
Committee

Newsletter



Committed to improving the lives of Ontario Residents in Long Term Care

Worrisome Persistent Trends for Caregivers in LTC

By Carol Dueck - Chair Advocacy FCN4

This edition of our newsletter is focused on the caregivers. After decades of lack of funding and attention for long term care (LTC) homes, now residents face isolation and despair as they are kept from their loved ones.

The [Ontario Time to Care Act \(2020\)](#) amends the [Long-Term Care Homes Act \(2007\)](#) so that a LTC home will have to provide its residents with at least four hours a day of nursing and personal support services, averaged across the residents. Yet, anticipated staffing corrections will take until 2025 to be enacted and many loved ones will continue to be denied access to the homes. So where does that leave our residents now?

As per [Directive 3 of the Ontario Long-Term Care Visitors and Admissions](#), each resident is allowed two essential caregivers that can continue to access the home during an outbreak. Despite this provincial directive, inconsistencies across homes is causing potential health concerns, delays and frustrations.

Action – in support of caregivers, we will continue to advocate with the Minister of Long Term Care, the LTC planning table and the LTC - COVID-19 Commission. Please share your concerns and ideas on caregivers with our network and your Member of Provincial Parliament.

We will also be monitoring the impact of [Bill 218 Supporting Ontario's Recovery and Municipal Elections Act \(2020\)](#) which makes it harder for families to hold LTC providers responsible for illness or death related to exposure to COVID-19. This includes supporting the Ontario Health Coalition's request of the Integrity Commissioner to investigate potential conflict of interest from Government members and their decision-making for this Bill.

Please share your experiences with these troublesome new processes. We value your input to ensure our advocacy actions align with your concerns. E-mail me your comments: carol.dueck@gmail.com.

How Are You Celebrating Christmas at Your Long Term Care Home?

By Carol Adamson

Needless to say, Christmas will not be the same this year for any of us, but will be particularly difficult for residents, families and staff in Long Term Care homes. There will be no bazaars, no shared Christmas carol sing a-longs, no communal festive turkey dinners, no Brownies, Boy Scouts and local choirs entertaining residents. Will Santa arrive on Christmas morning? Will residents and their families be able to decorate their rooms? Are decorations COVID safe?

How will we show staff that we appreciate them for their hard work throughout this very difficult year? Some homes do not allow family councils to give gift cards to staff. Some may not allow chocolates, cookies and other Christmas goodies to be delivered.

Share your creative ideas with us. Let's do our best to ensure that Christmas in long term care homes is a joyful time for all! Please e-mail your thoughts to our chair, Carol Dueck (carol.dueck@gmail.com) and we will post them on our website for all to see.



My Fight for 'Caregiver' Status

By Janet Volkes

The struggle to become a caregiver at a LTC as per Directive 3 of the Ontario Long-Term Care Visitors and Admissions is a real and frustrating one. It is understandable that setting up this new system under the pandemic is complicated. However, after eight months, we expect better for our vulnerable loved ones.

Delays in granting caregiver status, or constant and poorly communicated changes, are damaging to all sides – to the residents who face isolation and despair, to loved ones trapped on the outside, to over-worked staff who cannot fill the gap in personal attention.

For months spending time with my father has been reduced to waving from windows, outdoor supervised, timed-visits and chasing paper work to be granted indoor access. While I can access the latest government statements, it seems that residents, many of whom with dementia, are not fully aware of what was happening or why. Phone calls often had my dad in tears as he couldn't understand why we weren't visiting him.

The decline in residents' health is staggering – isolation is breaking them. After months stuck in his room, my father broke down after finally being let outside. These are care homes, not prisons. We can do better.

There are three classifications of visitors as defined under the Provincial Directives # 3 but some homes have chosen to add additional stipulations for being deemed a caregiver and when and how you might visit. I spent weeks getting my COVID testing, filling out paperwork and arguing about access to my father. Objecting to his home's constant and unnecessary roadblocks I fired off an e-mail outlining my rights and that I would indeed be visiting my father as an essential caregiver. But it was not to be, my father took seriously ill that Thursday and died the next day in the hospital. It breaks my heart that I was denied a meaningful last visit with my father due to bureaucracy.

McMaster Caregiver Study

By Cheryll Sullivan, Alzheimer Society

The Alzheimer Society of Hamilton is partnering with McMaster University for a research study in Ontario in an effort to better understand how best to support family caregivers who have their loved one with dementia in long term care.

This research is important because family caregivers frequently continue to be involved in the care of the person living with dementia when they are admitted into LTC and yet few supports are available to them through this time of transition and throughout the caring experience. The study will allow McMaster University to evaluate a new way of supporting family caregivers and help determine how it influences factors such as hope, quality of life, loss and grief, loneliness, social support, and the handling of adverse situations.

To participate in this study, you must be a family/friend caregiver (at least 18 years of age) of a person living with dementia (over the age of 65) who is currently residing in a LTC home. The participant must have an e-mail address and access to a computer. If you are interested in participating in the study or would like to know more, contact Cheryll at 905.529.7030 ext. 214; toll free 1.888.343.1017 or e-mail at cheryll.sullivan@alzda.ca.

Books For Sale

We have access to several books written by local writers that deal with issues related to Long Term Care, aging and seniors issues; caregiver topics; and healthy living. Check the website for details on the following titles: ***A Slice of Life*** (\$15); ***Voices of the City*** (\$12); ***Older Caregivers*** (\$12); ***Staying Healthy*** (\$10). Proceeds from the sale of these books are used to support the work of the FCN4 Advocacy Committee. To purchase any of these books, e-mail: Tom Carrothers at carphaltonchapter@gmail.com.

Building Bridges With Seneca College and Families Councils

By Carol Dueck



The FCN4 Advocacy Committee has engaged **Nodia Powell Bryan** from Seneca College's Gerontology Program. Our team is helping the college find virtual placements for students during the pandemic to further their skills for caring for residents. This remote education is new for Seneca and our team - one that is evolving as we learn!

As part of this placement, Nodia has been reaching out to family councils in our FCN4 region to help build and strengthen the network. This feedback will help ensure that our advocacy actions accurately reflect the needs you identify to target those with the authority and responsibility to make changes – local MPPs, the Long Term Care Commission and the LTC.

Caring for Residents During the Pandemic

By Nodia Powell Bryan

As the second wave of the COVID-19 virus hits, we continue to raise our voices for the basic needs of our residents - balanced diet, clean clothing and regular personal care. We should not, cannot, overlook the critical need for quality time with loved ones and social service workers (gerontologists). The gerontologist supports residents and their families through all aspects of the LTC experience from transition, to emotions such as guilt, anger and fear, and end of life care decisions. I joined this program, like many others to share my skills and time with residents and families. We provide counselling, emotional support, connections to community resources and psycho-social assessments.

Over the last 8 weeks, I have heard concerns that the therapeutic recreation programs in the LTC facilities are either reduced or becoming dormant. If we are serious about the health and wellbeing of our residents, then targeted advocacy efforts must engage authorities to ensure that the principles of the International Council on Active Aging are universally applied: "Active ageing promotes the vision of all individuals regardless of age, socioeconomic status for healthfully engaging in life within all seven dimensions of wellness: emotional, environmental, intellectual/cognitive, physical, professional/vocational, social and spiritual." These are rights, not privileges.

Promenade – “An Online Reminiscence Therapy Program - helping families connect”

Designed by Chris Benoit & Alexis Liddell.

Promenade is an app designed for family members and caregivers to use when visiting loved ones living with dementia or related illnesses. Created by Chris Benoit and Alexis Liddell, experts in the field of Gerontology and Therapeutic Recreation, **Promenade** is a tool that can help stimulate conversation, encourage reminiscence, and make personal visits more rewarding and engaging. In view of the proven positive effects of Reminiscence Therapy, **Promenade** uses photos and conversation-based questions in a way that makes it easier for someone with dementia to reminisce about past life events and pleasant memories.

Promenade presents groups of photographs based on user selected topics; however, it's much more than just an image search. Every topic is accompanied by a list of possible questions to stimulate and promote more active dialogues. Apps like these help prepare you for a visit and are a great tool to have with you to inspire sharing of old memories while you make new ones.

This app has been updated by Apple to use the latest Apple signing certificate. For more information:

<https://apps.apple.com/ca/app/promenade-revisit-a-life-of-memories-together/id782926783>.

Don't let COVID-19 Stop Your Family Council From Meeting

By Janet Volkes

Among the many, many events impacted by COVID-19 restrictions were in-person Family Council meetings. With COVID-19 disproportionately hitting long term care and the chronic shortage of staff in LTC homes, it is more important than ever that Family Councils meet and advocate for residents - one of the most vulnerable segments of our population.

There are a variety of ways that Family Councils have been meeting including outdoor, distance meetings and telephone meetings. But by far the most popular and rewarding is virtually. At our FCN4 conference on November 2nd, many of our members reported that they have increased participation by up to 50% since their meetings went virtual.

Holding a virtual meeting is a tad intimidating at first, but the rewards are well worth it. First step is contacting all of your family council member either with a blast e-mail or individual telephone calls to see if you have a Family Council member who is already comfortable with Skype, Zoom, Google Meets, MS Teams or another virtual platform. From there, decide which platform works for your group. Some have costs, but check with your LTC as they may already have an account and be willing to share it with your group.

Prior to our first virtual meeting, we found it very helpful to have a dry run with the Chair, recording secretary and the facilitator of the meeting, to become comfortable with the technology. Having a co-chair or facilitator allows the chair to conduct the meeting and the co-chair to manage the technical logistics of those participating – connecting people in and managing that mute button! We recommend first time users join the meeting 10 minutes early to test the connection.

Be sure to send out the agenda in advance and keep to your regular format for presentations, discussion and questions. There are features on virtual meeting platforms for muting everyone, raising your hand, conducting polls, etc. But, for your first meeting, don't feel pressured to use all these features. Simply conduct your meeting as you would in person and delight in connecting with everyone. You'll be surprised by the benefits of seeing and hearing from your members.

For additional assistance, Family Council of Ontario offers assistance in the form of their downloadable handbook "Digital Success Handbook" and periodically webinars on virtual meetings.

FCN-4 Advocacy Committee Website

<https://www.network4longtermcareadvocacy.com/>

Have you visited our website lately? If not then you would have missed seeing our logo; as well as the latest Breaking News including our submission to the Long Term Care Commission and our letters to Merrilee Fullerton, Minister of Long Term Care. If you did not get our first newsletter, go to our website and read it there. Check the website for everything you need to know about dealing with COVID in LTC and where to get help if you need it.

**TO LOVE SOMEONE LONG-TERM IS TO
ATTEND A THOUSAND FUNERALS OF THE
PEOPLE THEY USED TO BE.**

The people they're too exhausted to be any longer. The people they don't recognise inside themselves anymore. The people they grew out of, the people they never ended up growing into. We so badly want the people we love to get their spark back when it burns out; to become speedily found when they are lost.

But it is not our job to hold anyone accountable to the people they used to be. It is our job to travel with them between each version and to honour what emerges along the way.

Sometimes it will be an even more luminescent flame.

Sometimes it will be a flicker that disappears and temporarily floods the room with a perfect and necessary darkness.

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Newsletter Committee : Editor: Carly Volkes Design: Peter Gnish Proofing: Members of FCN4 Committee
Contact: Carol Dueck Chair FCN4 Advocacy Committee. carol.dueck@gmail.com