



Monday, July 20, 2020

Re: Family Care Partner Visitation and Involvement Policies

Current family visitation and involvement policies in Canadian long-term care (LTC) homes and related settings are largely preventing essential family care partners (i.e., caregivers) from providing hands-on care and social support. While these restrictive policies were created with the intention of keeping LTC residents safe from the arrival of COVID-19 when evidence-based protocols to prevent its transmission were not available, policies that continue to block direct essential family care partner involvement are causing widespread harm, suffering and death.

Dementia Advocacy Canada has reviewed and will continue to review Canadian LTC home visitation and family care partner policies. This issue is highly relevant for Dementia Advocacy Canada since nearly all of our members live with dementia or are family care partners. Similarly, the majority of Canadians in LTC homes live with dementia or other cognitive conditions¹.

We urge that Alberta's model² of essential family care partner involvement in LTC homes be mandated immediately in all provinces and territories that are not using a similar safe, inclusive and humane model during the COVID-19 pandemic and all situations moving forward.

Dementia Advocacy Canada members and other individuals and groups we work with have experienced barriers with LTC home operators determining who they deem to be "essential". This is due to a misinterpretation of government policy or because the LTC home operator has been given unilateral decision-making authority by government.

Benefits of Alberta's family care partner involvement policy²:

- ➔ Reduces staff burden by resuming the direct involvement of 2-3 designated family care partners.
- ➔ Maintains residents' holistic needs with the safe indoor involvement of 2 family members and 3+ persons during end-of-life.
- ➔ Ensures balanced decisions about indoor involvement are collectively determined by the resident, designated family/support persons and LTC home operator.
- ➔ Bridges the divide when the resident no longer communicates or reverts to their first language.
- ➔ Reduces social isolation as up to 5 people can visit outdoors with a resident at the same time.

LTC homes with overly restrictive COVID-19 policies that inhibit essential family care partner involvement have led to an increasing number of LTC residents experiencing “confinement syndrome”^{3,4} due to their overwhelmingly isolated and immobile physical, mental and emotional state.

Confinement syndrome includes some or all of the following symptoms in LTC residents^{3,4}:

- Cognitive decline and delirium
- Dehydration and malnutrition
- Exacerbation of chronic medical conditions and mental health disorders
- Loneliness, social isolation and neglect
- Psychological distress, depression and anxiety
- Physical and functional decline
- Worsening personal expressions of distress/responsive behaviours

There is increasing national awareness of the suffering and trauma that people living with dementia in Canadian LTC homes and their family care partners are experiencing as a result of government policies that continue to inhibit meaningful contact.

André Picard, an award-winning Canadian health care journalist, stated the recent death of his father-in-law, who was an active and healthy LTC resident, was because of depression, isolation and loss of his life’s purpose and meaning^{5,6}. This could also possibly be attributed to other deaths of LTC residents where essential family care partners have been prohibited from providing direct care and support to their loved ones⁷.

Additionally, Dementia Advocacy Canada members support the National Institute on Ageing’s protocol for essential family care partners to stay directly involved indoors with their relative in LTC homes that have a COVID-19 outbreak⁸. This is done by the family care partner attesting they understand the risk of entering the home during a COVID-19 outbreak and agreeing to abide by the same policies and procedures at staff working in that LTC home⁸.

We applaud and appreciate the National Institute on Ageing’s continuous advocacy, comprehensive expertise and ongoing education on this vital matter and find their newly-released Canadian LTC essential family care partner access and involvement policy recommendations⁸ similar to Alberta’s mandated policy².

Currently, the aforementioned unilateral decisions by LTC homes and/or government violate the human and legal rights^{9,10,11} of people living with dementia in LTC and their essential family



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care partners, at least one of whom typically is the LTC resident's power of attorney or substitute decision maker.

Resuming essential family care partnerships for people living with dementia in Canadian LTC homes will rebuild the relationships, trust, quality care, and various forms of support that other Canadian and international groups have recently called for^{8,12,13,14,15}.

Contact us at admin@dementiacanada.com with any questions or to discuss this important matter further.

Sincerely,

Kim Brundrit, Len Carter, Matthew Dineen, Kate Ducak, Mary Huang, Roger Marple, Myrna Norman, Frank Palmer, Lisa Poole, Gail Sanders, Annette Scholes, Peter Sorby, Mary Beth Wighton

References:

¹ Canadian Association for Long-Term Care. (2020, January). *Crisis Point: Addressing the Needs of Seniors Living in Long-Term Care*. https://caltc.ca/wordpress/wp-content/uploads/2020/02/CALTC_budget_submission_2020.pdf

² Alberta Health. (2020, July 16). *Appendix A to Record of Decision – CMOH Order 29-2020: Guidance for safe visiting in licensed supportive living, long-term care and hospice settings*. <https://open.alberta.ca/dataset/f075e30e-7ba1-4520-abe1-fb6076889cd4/resource/6d280e9e-2f25-4929-b6ca-51188151523e/download/health-cmoh-record-of-decision-cmoh-29-2020.pdf>

³ Stall, N. (2020, June 25). *Lessons Learned in Providing Effective Care for Older Residents in Long Term Care Homes Affected by COVID-19*. Session from Sinai Health System/University Health Network COVID-19 Special Geriatrics Institute Education Day. <https://twitter.com/lpoole/status/1276205401227157504?s=20>

⁴ Diamantis, S., Noel, C., Tarteret, P., Vignier, N., & Gallien, S. (2020). Severe Acute Respiratory Syndrome 2 (SARS-CoV-2)-Related Deaths in French Long-Term Care Facilities: The “Confinement Disease” is probably more deleterious than the Coronavirus Disease-2019 (COVID-19) Itself, *Journal of the American Geriatrics Association* (in-press). <https://doi.org/10.1016/j.jamda.2020.04.023>

⁵ Picard, A. (2020, July 11). *Jérôme (Jerry) Lalonde: Dec 25, 1931 -- July 10, 2020. My father-in-law. Another victim of #COVID19. For journalists, the pandemic is a professional challenge; but it's a personal one too*. <https://twitter.com/picardonhealth/status/1281957461734371328?s=20>

⁶ CBC Radio, The Current. (2020, July 14). *The Current for July 14, 2020; with Nahlah Ayed featuring André Picard about the death of his father-in-law in long-term care (28:00-30:35)*. <https://www.cbc.ca/radio/thecurrent/the-current-for-july-14-2020-1.56478837>

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admin@dementiacanada.com | www.dementiacanada.com



- ⁷ Picard, A. for The Globe and Mail. (2020, June 5). *It's Time to Let Families Visit Long-Term Care Homes*. <https://www.theglobeandmail.com/canada/article-its-time-to-let-families-visit-long-term-care-homes/>
- ⁸ National Institute on Ageing. (2020, July 15). *Finding the Right Balance: An Evidence-Informed Guidance Document to Support the Re-Opening of Canadian Long-Term Care Homes to Family Caregivers and Visitors during the COVID-19 Pandemic*. <https://t.co/4EtEQEyoaD?amp=1>
- ⁹ Government of Canada. (1982). *Canadian Charter of Rights and Freedoms*. <https://laws-lois.justice.gc.ca/eng/const/page-15.html>
- ¹⁰ Justice Centre for Constitutional Freedoms. (2020, July). *COVID-19 News and Legal Activity*. <https://www.jccf.ca/in-the-news/covid-19/>
- ¹¹ United Nations. (2020, July). *Convention on the Rights of Persons with Disabilities (CRPD)*. <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>
- ¹² Canadian Foundation for Healthcare Improvement. (2020, July). *Better Together: Re-integration of family caregivers as essential partners in care in a time of COVID-19*. <https://www.cfhi-fcass.ca/docs/default-source/itr/tools-and-resources/bt-re-integration-of-family-caregivers-as-essential-partners-covid-19-e.pdf>
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