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Family Presence in Older Adult Care A Statement Regarding Family Caregivers^{1,2,3} and the Provision of Essential Care

In response to the declaration of a pandemic due to the COVID-19 virus, in March 2020 visitor restrictions were implemented across Canadian health care organizations. Early decisions about visitor restrictions were informed by emerging evidence, experience, provincial policy, the availability of personal protective equipment (PPE) and other resources. Within health care organizations, human resources were directed to immediate patient care priorities. The presence of Family Caregivers to assist with the care of older adult in these early, fluctuating and uncertain days was not an initial focus for most health services.

As of June 2020, provinces have begun to move ahead cautiously with relaxing restrictions^{4,5}. With the benefit of hindsight, reflection and new evidence, there is an opportunity to rethink the role and importance of family presence in the provision of essential care, even during a pandemic. This document has been prepared to support the restoration of family presence, to aid the fulfilment of commitments to patient and family centred care across health organizations and to enable the integration of Family Caregivers across the health care system moving forward.

Caught up in the early restrictions was a large number of Family Caregivers who provide regular physical and psychosocial care and support to older adults in acute care, retirement homes and long term care (LTC) homes. In 2018, approximately 3.6M Canadians reported providing care for their parents or parents-in-law and another 1M, usually older Canadians, supported a spouse or partner⁶. Parmar et al. noted that “in 2012, 28% of Canadians (8 million people aged 15 and over) were Family Caregivers. At least 80% of Canadian Seniors care is provided by Family Caregivers. They delivered 1.5 billion hours of care, equivalent to work of 1.2 million full-time employees...Janet Fast estimates \$66.5 billion as replacement value for Family Caregiver’s

¹ For the purposes of this document, we have adapted the Alberta Health’s definition of family caregiver which means any person (including relatives and/or friends etc.) who takes on a generally unpaid caring role providing emotional, physical or practical support in response to an illness, disability or age-related need.

² <https://onlinelibrary.wiley.com/doi/full/10.1111/jgs.15988>

³ [https://www.jamda.com/article/S1525-8610\(20\)30430-8/pdf](https://www.jamda.com/article/S1525-8610(20)30430-8/pdf)

⁴ https://files.ontario.ca/mltc-resuming-visits-long-term-care-homes-en-2020-06-11-v3.pdf?_ga=2.25559357.1622894720.1592250385-1895005198.1585922985

⁵ https://files.ontario.ca/msaa-reopening-retirement-homes-en-2020-06-12.pdf?_ga=2.25559357.1622894720.1592250385-1895005198.1585922985

⁶ <https://www150.statcan.gc.ca/n1/daily-quotidien/200108/dq200108a-eng.htm>

care”(2019, p. 4)⁷. The Change Foundation and Ontario Caregiver Organization have identified that Family Caregivers provide between 11 and 30 hours of essential care a week⁸.

The importance of family presence has previously been endorsed by many health care organizations⁹ and there is growing recognition of the critical role of Family Caregivers and family presence in older adult care^{10,11,12}.

Family presence includes among other things, in-person presence for care, regular scheduled clinical updates, engagement in clinical or shared decision making, and more recently, support for outside and virtual visits and participation in co-planning for the pandemic response. There is, however, inconsistency in the application of family presence policy in practice across organizations.

Specialists in geriatric care across Canada are concerned about the ongoing systematic exclusion of Family Caregivers from the health care team providing essential care for older adults. We believe that, for many older adults, the risks associated with ongoing and prolonged visitor restrictions have started to outweigh the risks associated with potential COVID-19 infection. We recognize and support the efforts underway across the health system to support Family Caregivers and balance individual need and the greater societal good. This balance must consider an array of ethical principles such as dignity and respect, information sharing, participation and collaboration as well as medical interventions, individual preference, quality of life and contextual factors¹³.

Considerations:

- A Family Caregiver who provides care that is essential to maintaining the care recipient’s mental and physical health is not a visitor.
- For older adults who cannot independently communicate their hunger, thirst, pain, anxiety or other critical health information, the presence of Family Caregivers can be life-saving¹⁴.
- For some older adults, particularly those living in congregate settings whose cognitive function may not permit them to understand infection prevention and control (IPAC) considerations, the presence of an appropriately trained Family Caregiver may facilitate adherence to IPAC procedures.

⁷ <https://seniorsnetworkcovenant.ca/wp-content/uploads/2020-06-02-Competency-Framework.pdf> p. 4.

⁸ https://ontariocaregiver.ca/wp-content/uploads/2019/12/Spotlight-on-ontarios-caregivers-2019_EN.pdf p. 4

⁹ https://www.cfhi-fcass.ca/docs/default-source/itr/tools-and-resources/better_together_executive-summary_en.pdf?sfvrsn=aee3cdcc_2

¹⁰ https://ontariocaregiver.ca/wp-content/uploads/2019/12/Spotlight-on-ontarios-caregivers-2019_EN.pdf

¹¹ <https://www150.statcan.gc.ca/n1/daily-quotidien/200108/dq200108a-eng.htm>

¹² Schulz R, Beach SR, Czaja SJ, Martire LM, Monin JK. Family caregiving for older adults. Annual Review of Psychology, 2020:635-59.

¹³ Toronto Central Community Care Access Centre. (2008). Community ethics toolkit: Ethical decision-making in the community health and support sector.

¹⁴ [https://www.jamda.com/article/S1525-8610\(20\)30354-6/pdf](https://www.jamda.com/article/S1525-8610(20)30354-6/pdf)

- The impact of lengthy restrictions in health care settings, including the ongoing absence of regular Family Caregivers, can be life changing for a vulnerable person and places them at risk of adverse events¹⁵. This is particularly true of people living with dementia and other complex health problems – and some will not return to their former level of function and engagement when visitor restrictions are loosened.
- Family Caregivers regularly provide feeding, grooming and washing, toileting, exercise, social and emotional support, memory support, and mobilization in LTC and other settings. This care was and is in short supply in many settings, including long term care (LTC), supportive living and retirement homes, during the COVID-19 pandemic due to staff illness and increased resident/patient care demands.
- Family Caregivers are attuned to changes in behaviour and condition in the person in their care that can signal delirium, infection, or acute physical and mental illness. They enable early detection which in turn facilitates early intervention, reducing overall impact of illness.
- In LTC, Family Caregivers also facilitate resident centred activities, such as resident councils and peer to peer support.
- Not being able to see and help the older adult they usually provide care to increases anxiety and stress for Family Caregivers. Other outcomes of COVID-19 protocols include loneliness and social isolation for Family Caregivers and those they care for, which may contribute to premature mortality and chronic conditions such as heart disease, diabetes, depression and dementia^{16,17}.
- Dying alone is the greatest fear of many older adults^{18,19}. Of the 8474 deaths related to COVID-19 reported in Canada (June 25, 2020), approximately 97% occurred in individuals over the age of 60²⁰. Many of these individuals will have died without the comfort of family presence. Dying in this way has caused suffering for many, including patients, families and the health professionals who have witnessed this.
- In LTC, time is precious. Many people entering LTC are in their final months and years of life and length of stay in LTC is decreasing in many Canadian jurisdictions²¹. Inclusion of family caregivers during this period of an older adult's life should be prioritized.

¹⁵ <https://nyshealthfoundation.org/wp-content/uploads/2019/11/Sick-Scared-Separated-From-Loved-Ones-Nov-2019.pdf>

¹⁶ Holt-Lunstad J, Smith TB, Baker M, Harris T, Stephenson D. Loneliness and social isolation as risk factors for mortality: a meta-analytic review. *Perspect Psychol Sci.* 2015;10(2):227-237. doi:10.1177/1745691614568352

¹⁷ Perissinotto C, Holt-Lunstad J, Periyakoil VS, Covinsky K. A Practical Approach to Assessing and Mitigating Loneliness and Isolation in Older Adults. *Journal of the American Geriatrics Society* 2019;67(4):657-62 doi: 10.1111/jgs.15746

¹⁸ <https://www.ctvnews.ca/health/coronavirus/agonies-and-anguish-patients-fear-dying-alone-from-covid-19-isolation-rules-1.4872323>

¹⁹ <https://www.nytimes.com/2020/04/07/nyregion/dying-alone-coronavirus.html>

²⁰ <https://health-infobase.canada.ca/covid-19/epidemiological-summary-covid-19-cases.html#a8>, retrieved June 19, 2020

²¹ Hoben et al. (2019). Nursing home length of stay in 3 Canadian health regions: Temporal trends, jurisdictional differences, and associated factors. *Journal of Post Acute and Long Term Care Medicine (JAMDA)*, 20, 1121-1128. <https://pubmed.ncbi.nlm.nih.gov/30879948/>

- Family presence is not a replacement for staffing in congregate and other settings. Specifically, the implementation of promising practices²² in LTC, including adjustments to staffing models, should occur regardless of the participation of Family Caregivers.

The role of Family Caregivers has been recognized by federal and provincial governments^{23,24,25}, and health care organizations across the continuum. The importance of this role has not decreased due to the pandemic.

One third of Family Caregivers already carry out technical aspects of care such as changing bandages, monitoring or administering medications, while 18% carry out medical procedures such as changing gastric tubes, and giving injections²⁶. Pre-COVID-19, Family Caregivers assisted with about 30% of the care in LTC^{27,28}. Family Caregivers have the capacity to learn and carry out IPAC procedures and are highly motivated to do so meticulously.

To inform the ongoing role of Family Caregivers, there are excellent models for collaboration between formal health care services and volunteers²⁹ and well-developed core competencies enabling health care providers to work effectively with caregivers³⁰. It is necessary to build on the success of these and other prior initiatives in a manner that reintegrates Family Caregivers into the care team and safely keeps them involved in the support of older adults going forward.

Strategies to support the full return and ongoing role of Family Caregivers may include:

1. Designation of Family Caregiver(s)³¹ for every older person living with complex health concerns. This is a person or persons who will participate regularly in their care, especially during times when regular health services may be limited. Designation may include visual identification (e.g. Caregiver ID³²) and training as important steps in establishing or strengthening a relationship that can yield better care outcomes. The name and contribution of Family Caregiver(s) (e.g. aspects of caregiving to be provided) should be noted in the care plan.

²² Baines, D., & Armstrong, P. (2018). [Promising Practices in Long Term Care: Can Work Organization Treat both Residents and Providers with Dignity and Respect?](https://openjournals.library.sydney.edu.au/index.php/SWPS/article/view/11736) *Social Work and Policy Studies: Social Justice, Practice and Theory*,1(1); special issue on Critical Engagements with Ageing and Care. <https://openjournals.library.sydney.edu.au/index.php/SWPS/article/view/11736>

²³ <https://ontariocaregiver.ca/about-oco/mission/>

²⁴ <https://caregiversns.org/who-we-are/our-funders/>

²⁵ <https://www.quebec.ca/en/health/health-issues/a-z/2019-coronavirus/caregivers-during-the-covid-19-pandemic/#c58521>

²⁶ https://ontariocaregiver.ca/wp-content/uploads/2019/12/Spotlight-on-ontarios-caregivers-2019_EN.pdf p. 10

²⁷ Ansah JP, Koh V, Qureshi MA, Matchar DB. Modeling to inform long-term care policy and planning for an aging society. *Understanding Complex Systems*, 2017:183-224.

²⁸ Beach PR, White BE. Applying the evidence to help caregivers torn in two. *Nursing* 2015;**45**(6):30-37 doi: 10.1097/01.NURSE.0000464983.54444.80.

²⁹ <https://www.hospitalelderlifeprogram.org/about/goals-of-help/>

³⁰ <https://seniorsnetworkcovenant.ca/wp-content/uploads/2020-06-02-Competency-Framework.pdf>

³¹ <https://www.nsmgs.ca/Uploads/ContentDocuments/Visiting%20Restrictions%20Discussion%20Final.pdf> p. 10

³² <https://changeofoundation.ca/caregiver-id/>

2. Recognition of Family Caregivers as members of the core health team in all health organizations³³. This should include the participation of Family Caregivers in organizational pandemic preparation, rehearsal and response as well as their inclusion in ongoing and emergent care planning activities.
3. Inclusion of Family Caregivers in current and future organizational pandemic planning³⁴. This includes, immediate and ongoing:
 - a. Training related to Infection Prevention and Control (IPAC)
 - b. Training related to Personal Protective Equipment (PPE) use
 - c. Inclusion in censuses for PPE procurement and inventory
 - d. Advance care planning discussions, given the potential of high mortality related to COVID-19 among the older adult population.
4. Prioritization by governments and health services to provide necessary resources (e.g. financial and human), supplies (e.g. PPE) and education that are needed to safely support Family Caregivers to return to their caring roles.
5. With respect to the above, a return to and ongoing full inclusion of Family Caregivers in care activities at the earliest possible opportunity.
6. Prioritizing family participation and recognition in the anticipated review and transformation of LTC and other health services to ensure a focus on the needs of older adults.

The positive effects of family and friend caregivers has been well documented^{35, 36, 37,38}. The prolonged absence of Family Caregivers during the COVID-19 pandemic has been devastating to residents of congregate settings and older adult patients and deeply felt by organizations and health care professionals. Without their contribution, care in some congregate settings has not kept pace with demand. Family Caregivers are not simply visitors, they are carers. Older adults need them to be supported to return now.

Prepared by members of the Long-Term Care Interest Group of the [Provincial Geriatrics Leadership Office](#), of the [Regional Geriatric Programs of Ontario](#), and the [Canadian Geriatrics Society](#)

Contact: Kelly Kay, Executive Director, Provincial Geriatrics Leadership Office (ON), kkay@rgpo.ca

³³ Tupper, S. et al. (2020). Long-term care family presence during the COVID-19 pandemic: call to action for policy, practice, and research. Manuscript in preparation.

³⁴ <https://www.thestar.com/opinion/contributors/2020/03/31/family-caregivers-will-be-key-during-the-covid-19-pandemic.html>

³⁵ Cho, E. Lee, N-J., Kim, E-Y., Strumpf, N. (2011). The Impact of Informal Caregivers on Depressive Symptoms Among Older Adults Receiving Formal Home Health Care. *Geriatric Nursing*, 32(1), 18-28.

³⁶ Boltz, M., Resnick, B., Chippendale, T., Galvin, J. (2014) Testing a Family-Centered Intervention to Promote Functional and Cognitive Recovery in Hospitalized Older Adults. *Journal of the American Geriatrics Society*, 62(12), 2390-2406

³⁷ <http://www.hpcintegration.ca/media/37049/TWF-valuing-caregivers-report-final.pdf>

³⁸ <https://www.ncoa.org/news/press-releases/connections-with-community/>