

LTC+ Acting on Pandemic Learning Together

Webinar Recap for August 10, 2020

TOPIC & KEY AREA(S)

Family Presence in Long-Term Care
Presence of Family

SPEAKER(S)

- Maggie Keresteci, Family Caregiver
- Debi Funk, Long-Term Care Resident
- Dr. Nathan Stall, Geriatrician, Sinai Health System
- Dr. Samir Sinha, Director of Geriatrics, Sinai Health System
- Kristin Grunert, Director, Patient and Family Centered Care, SHA

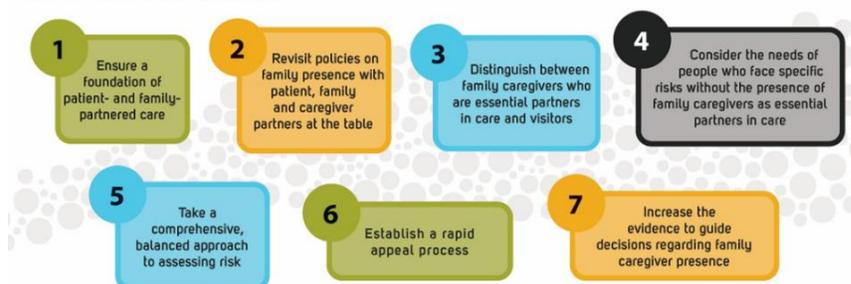
SESSION OBJECTIVE(S)

- Learn from the National Institute of Ageing / Sinai Health System on Family Presence in LTC during the pandemic.
- Generate discussion about challenges and solutions regarding Family Presence in LTC during the pandemic.
- Offer concrete strategies for homes to re-engage families and care partners as essential partners in care in LTC+.
- Share next steps to participate in the program LTC+: Acting on Pandemic Learning Together.

SUMMARY

1. The presence of family and caregiver is valuable, leading to better coordination of care, fewer medication errors, fewer falls, fewer 30-day readmissions, and better patient and family experience.
2. CFHI & CPSI have led work regarding the Re-Integration of Family Caregivers as Essential Partners in Care in a Time of COVID-19, of which, key steps include:

HOW TO MOVE AHEAD



3. Insights from a family caregiver yielded that we need to move forward in true partnership with patients and their caregivers as partners in care, especially in LTC. This could involve putting patients first by prioritizing care for the whole person, which includes their care partner, and embracing the

notion of allyship, co-design and shared decision-making with patients and their care partners as a concrete way of delivering better care to patients.

- CFHI & CPSI have led work regarding LTC preparedness and early experiences of COVID-19, as seen in the Reimagining Care for Older Adults Report. Notably, infrastructure and facility risks (i.e. for-profit status and older design standards), have contributed to the negative outcomes of COVID-19 in LTC.
- In the early policy and mitigation responses to COVID-19, the term ‘Iron Ring’ was popularized in Ontario to indicate the collective actions that the province would take to protect residents in LTC, which included restricting all ‘non-essential’ visits; eliminating family presence. This created a barrier between patients and their care partners and resulted in more isolated and lonely older adults in LTC, coined by Quebecois researchers as ‘Confinement Syndrome’ questioning whether the adverse impacts on morbidity and mortality of isolating older adults were worse than COVID-19 itself.

THE “CONFINEMENT SYNDROME”

- **Collateral damages:**
 - Dehydration and malnutrition
 - Physical and functional decline
 - Exacerbation of chronic medical conditions and mental health disorders
 - Cognitive decline and delirium
 - Worsening of responsive behaviors
 - Loneliness and social isolation
 - Psychological distress, depression and anxiety



- In late May, provinces and territories started offering some guidance on reopening Canadian LTC homes, however, that guidance was still too restrictive and providing families the accesses needed to patients. As such, the National Institute of Aging developed 6 guiding principles and planning assumptions about visitor policies and access, as well as for reopening LTC homes to family caregivers.

GUIDANCE ON REOPENING GUIDANCE ON REOPENING FOR FAMILY CAREGIVERS

Box 1: Guiding Principles and Planning Assumptions about Visitor Policies and Access

- Policies must differentiate between “family caregivers” and “general visitors”. Residents, substitute decision makers and their families should have the authority and autonomy to determine who is essential to support them in their care.
- Restricted access to visiting must balance the risks of COVID-19 infection with the risks of social isolation to resident health, wellbeing and quality of life.
- Visitor policies should prioritize equity over equality and be both flexible and compassionate. Whereas equality would mean giving all LTC residents the same access to visitors, equity means giving LTC residents the right amount of access they need to maintain their health and wellbeing.⁷
- Governments, public health authorities and LTC homes must provide regular, transparent, accessible and evidence-based communication and direction about visitor policies and access.
- Robust data related to re-opening LTC homes to family caregivers and general visitors should be collected and reported.
- A mechanism for feedback and a process for rapid appeals should be established.

1. Defining an “family caregiver”	<ul style="list-style-type: none"> Residents, substitute decision makers and their families must retain the authority and autonomy to determine who is essential to support them in their care and designate their own family caregivers.⁴ Governments, public health authorities and homes must not define who is a family caregiver, especially on the basis of either an individual’s caregiving involvement and role prior to the pandemic or by identifying those individuals providing services that would otherwise require a private duty caregiver.
2. Allowable number of designated family caregivers	<ul style="list-style-type: none"> A resident may designate at least two family caregivers. Similar to guidance from Alberta Health Services, a resident may identify a temporary replacement family caregiver if the primary designated family caregivers are unable to perform their roles for a period of time; the intent is not for designates to change regularly or multiple times but to enable a replacement, when required.¹⁶
3. Allowable number of family caregivers in the LTC home at one time	<ul style="list-style-type: none"> One family caregiver per resident should be allowed in the home at a time. Under extenuating circumstances (i.e., end-of-life), this allowable number should be flexible.
4. Allowable locations within the LTC home	<ul style="list-style-type: none"> As essential partners in care, family caregivers should have access to areas both outside and inside the home (similar to staff members) but must maintain physical distancing from other residents and staff. They should be provided with a caregiver identification and/or badge, and must abide by all IPAC and PPE requirements and procedures concerning staff members of the home.^{17,18} In order to promote relational continuity and meet the ongoing needs of residents, family caregivers should still have access to the home during a COVID-19 outbreak, as long as the following conditions are met: <ul style="list-style-type: none"> The family caregiver attests that they understand and appreciate they are entering a home under outbreak and that they are at increased risk of COVID-19 infection They must be trained in IPAC procedures and the proper use of PPE and abide by all outbreak-related policies that apply to staff members of the home.
6. Allowable frequency and length of time for family caregiver presence	<ul style="list-style-type: none"> No restrictions as long as it does not negatively impact the care of other residents or the ability of other family caregivers to provide care and support.
7. Screening and testing requirements	<ul style="list-style-type: none"> As partners in care, family caregivers should be subjected to the same COVID-19 screening requirements as LTC home staff. If asymptomatic COVID-19 testing is recommended, family caregivers should be provided with the same access to testing as staff members of the home.
8. IPAC and PPE requirements	<ul style="list-style-type: none"> As partners in care, family caregivers should receive an orientation and be educated and trained to follow the same IPAC and PPE requirements and procedures as staff members of the home, including remaining masked at all times.³ The Ottawa Hospital has designed a PPE training video specifically for family caregivers: www.ottawahospital.on.ca/files/2020/05/05/20200505-06 Family caregivers can only enter one LTC or congregate care setting within a 14-day period. Homes must maintain ample PPE supply to enable family caregivers’ participation in care. Failure of family caregivers to comply with these procedures could be grounds for loss of their rights to participate in care as family caregivers, which should be appealable.

7. In early May, the Saskatchewan Health Authority (SHA) created an expert panel to review and update compassionate care guidelines so that LTC residents, as well as a family presence support team to help stakeholders decipher the compassionate care guidelines and promote the reintegration of family support caregivers in LTC. A change to Public Health Order allowed LTC residents to designate two family caregivers for visitation. The SHA is now working to change the number of designated caregivers per resident, as well as their visitation frequency, in order to ensure family presence in the long-term throughout the pandemic. A testimonial from a LTC resident in Saskatchewan noted a great appreciation for LTC staff, however, highlighted the challenges of isolation, outdoor visitations, as well as choosing designated family caregivers.
8. The panel discussion demonstrated that fear, concerns over safety and liability, as well as a lack of evidence and guidance were major barriers for re-integrating family caregivers in LTC. Possible solutions to these and for supporting seniors' care operators in re-integrating family caregivers as essential partners in care for patients, included: giving credit to the role of caregivers in promoting the wellbeing of residents in LTC settings, educating and advocating for the presence of families, improving two-way communication between caregivers and operators, as well as other LTC staff, and fostering opportunities to work together to promote good quality and safe visits.

RESOURCES SHARED

Listed below are the resources mentioned during the webinar:

- [Reimagining Care for Older Adults Report](#)
- [BETTER TOGETHER: Re-Integration of Family Caregivers as Essential Partners in Care in a Time of COVID-19](#)
- [Reopening LTC Homes: Ideas from Families \[ENGLISH ONLY\]](#)
- [The NIA's 'Iron Ring' Guidance for Protecting Older Canadians in Long-Term Care and Congregate Living Settings \[ENGLISH ONLY\]](#)
- [SARS-CoV-2-Related Deaths in French Long-Term Care Facilities: The "Confinement Disease" Is Probably More Deleterious Than the Coronavirus Disease-2019 Itself \[ENGLISH ONLY\]](#)
- [Finding the Right Balance: Guidance Document to Support the Re-Opening of Canadian Long-Term Care Homes to Family Caregivers and Visitors during the COVID-19 Pandemic \[ENGLISH ONLY\]](#)
- [Personal Protective Equipment for Family Caregivers \[ENGLISH ONLY\]](#)
- [Allowing Visitors Back in the Nursing Home During the COVID-19 Crisis: A Dutch National Study Into First Experiences and Impact on Well-Being \[ENGLISH ONLY\]](#)

WEBINAR RECORDING

[Watch the full webinar here!](#)