

# EXECUTIVE SUMMARY

## CAREGIVERS OF LONG-TERM CARE RESIDENTS IN THE CONTEXT OF COVID-19: CURRENT KNOWLEDGE, INSPIRING PRACTICES AND RECOMMENDATIONS

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### CONTEXT

People living in long-term care (LTC) settings<sup>1</sup> were disproportionately affected during the first wave of the COVID-19 pandemic, representing 70% of deaths<sup>2</sup>. The LTC settings, already weakened due to a chronic lack of sufficient financial, material and human resources, were faced with significant additional challenges in their response to the pandemic. As a result of these challenges, both residents and their caregivers have also been deeply affected by the various measures implemented by LTC settings in response to the pandemic (e.g., visit restrictions, communication, collaboration, protective equipment).

Caregivers are essential for the well-being of residents. They provide up to 85% of the care for older adults in all living environments, and if they were remunerated for this care it would cost the Quebec government approximately ten billion dollars per year<sup>3</sup>. Their absence during the first wave likely contributed to the tragic outcomes in certain LTC settings, where the involvement of caregivers could have made a difference. Difficulties in access to these living environments and the varied responses of these settings raised many concerns among caregivers.

In response, the Centre for Research and Expertise in Social Gerontology (CREGÉS), by virtue of its expertise in the area of caregiving, produced this report to address these concerns.

# OBJECTIVES

1. To review the current knowledge on the challenges experienced by LTC settings and on the needs of caregivers of LTC residents in the context of a pandemic.
2. To identify inspiring practices that can be implemented to address those challenges and needs.
3. To propose recommendations to managers of LTC settings and decision-makers of the Quebec Health and Social Services Network (RSSS).

# METHODOLOGY

In order to meet these objectives, the team conducted a review of the scientific and grey literature that resulted in the analysis of a total of 180 documents. Several experts and caregivers were then consulted in order to provide their input on the report and develop recommendations. For more details, see Appendix 1 of the report.

# KEY FINDINGS

Despite varied responses to the pandemic, many LTC settings encountered common challenges related to:

- Communication and collaboration with caregivers
- Balancing the risks of infection against the risks of social isolation
- Access to personal protective equipment

The lack of access to the facilities combined with these challenges has exacerbated many of the pre-existing obstacles faced by caregivers of LTC residents, in addition to creating new ones during the pandemic. These needs are related to:

- Mental and emotional health support
- Communication and the involvement of caregivers in care planning
- Training
- Administrative support regarding the complaint process or various resources available to them
- Bereavement support

Finally, several inspiring practices are proposed in the report that can serve as useful inspiration for these settings to alleviate these challenges and meet the needs of caregivers.

# RECOMMENDATIONS

In an effort to help managers of LTC settings and decision-makers in the Health and Social Services Network improve the practices already in place and support them in prioritizing and selecting inspiring practices, the team consulted experts to develop recommendations.

Their implementation would make it possible to avert the negative consequences observed during the first wave in LTC settings. In addition, the adoption of these recommendations, detailed in the report, could also be beneficial in dealing with other health-related emergencies. Several recommendations may also be useful under regular circumstances and could have positive long-term impacts for caregivers of LTC residents.

1. Strengthen the recognition of caregivers as essential care partners by allowing designated caregivers access at all times to the LTC setting and by establishing a partnership between staff and caregivers
2. Designate a person responsible for communication with caregivers within the LTC setting
3. Establish partnerships with resources that support caregivers (e.g., CISSS/CIUSSS programs and services, community organizations)
4. Implement an integrated palliative care approach within the LTC setting
5. Establish a family/caregiver bereavement support follow-up plan and a plan of commemoration with rituals that respect the public health guidelines
6. Establish additional LTC setting review visits by the responsible CISSS/CIUSSS regarding actions to support caregivers
7. Facilitate direct social contact between the residents and their support network (including caregivers)
8. Create a Caregiver Steering Committee composed of caregivers and managers in each establishment (CISSS/CIUSSS)

This document is the executive summary of the report: "*Caregivers of Long-Term Care Residents in the Context of COVID-19: Current Knowledge, Inspiring Practices and Recommendations*" available online at [https://www.creges.ca/wp-content/uploads/2020/12/2020-12-16-Rapport-PPA-et-CHSLD\\_EN\\_FINAL.pdf](https://www.creges.ca/wp-content/uploads/2020/12/2020-12-16-Rapport-PPA-et-CHSLD_EN_FINAL.pdf).

For further details, we invite you to consult the full report in which you will find the following:

- current knowledge on the gaps in LTC settings and the needs of caregivers of LTC residents in the context of COVID-19
- inspiring practices in Canada and internationally
- detailed recommendations and available resources to support their implementation

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- 1 The term LTC settings refers to living and housing environments providing long-term care, whether public or private. This generic term was chosen to represent the diversity of this type of setting, designated by different terminologies worldwide (e.g., CHSLD in Quebec, EHPAD in France, Long-term care facilities/homes in English-speaking contexts), on which the findings are based.
- 2 According to data from the Institut national de la santé publique du Québec, as of June 1, 2020, 3,637 of the 5,206 deaths in the province occurred in a CHSLD, or nearly 70% (<https://www.inspq.qc.ca/covid-19/donnees>).
- 3 Based on 2007 data from Kempeneers and al. (2015) “Chiffre les solidarités familiales”, Interactions, 4, [https://centreinteractions.ca/wp-content/uploads/2020/03/carnets\\_synthese\\_4\\_final.pdf](https://centreinteractions.ca/wp-content/uploads/2020/03/carnets_synthese_4_final.pdf). This number is calculated based on the average number of hours of care provided to older adults by caregivers per week (10 hours), in all living environments, the average hourly wage of a home support worker (\$24.94) and the total number of caregivers over 45 years of age in Quebec (728,000) in 2007. The total cost would likely be higher today given wage increases and the expected increase in the number of caregivers.