

**Bill 37 An Act to Enact the Fixing Long-Term Care Act,
2021**

Brief to the Standing Committee

Submitted by:

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Introduction

Bill 37, An Act to enact the Fixing Long-Term Care Act, 2021 and amend or repeal various Acts, has included a new right of residents in long-term care (LTC) to be provided with care and services based on a palliative care philosophy. While I commend the Ministry of Long-Term Care for including this right, I also have significant concerns as there is no definition of palliative care and no elaboration of how it will be provided.

I am a Palliative Care Specialist who has worked in LTC facilities since 2014, in the Greater Toronto Area. During the first two waves of the pandemic, I led my hospital's response team into local LTC facilities. I serve in leadership roles at the local, provincial and national levels. I am a co-investigator on several research projects focussed on improving palliative care in LTC funded by the Canadian Institute of Health Information (CIHR) and also have provided input to the Health Standards Organization working on National Standards for LTC. I am often called upon to speak about issues related to the LTC crisis in the media and have presented at multiple provincial and national academic conferences on palliative care in LTC.

Background

LTC residents are an extremely vulnerable population that have been disproportionately affected by the COVID-19 pandemic in Ontario. The vast majority of residents are admitted to LTC with advanced life-limiting illnesses such as end-stage dementia, frailty, heart and lung disease, and cancer, with the median survival after admission to LTC being just 18 months (1). Yet as per the Canadian Institute of Health Information, just 6% of LTC residents have documentation of receiving palliative care in the last year of life (2). Approximately one in five residents are transferred to acute care hospitals for palliative care needs.

Central components of palliative care include management of symptoms such as pain, shortness of breath or agitation; as well as frequent discussions with residents and families, called *goals of care discussions*, to ensure that treatment decisions are being made in line with an understanding of the stage of an illness and the wishes of a resident.

Recommendations

For most residents, a palliative care approach should be considered upon admission to LTC, as the suffering associated with a life-limiting illness doesn't just start at the end-of-life. But many LTC facilities still think of palliative care exclusively as end-of-life care, only reserved for the last days or weeks. In addition, the palliative care approach is often mistaken for a plan of giving up on life-prolonging treatments. In fact, a palliative care approach can be integrated together with life-prolonging treatments. For example, a resident who is receiving antibiotics to prolong life can also receive medications such as opioids to relieve shortness of breath. It is essential that the act include language to support early, integrated palliative care to avoid these common misconceptions.

Through the COVID-19 crisis, what was undoubtedly devastating was the suffering of many LTC residents, where many died with untreated symptoms such as shortness of breath and agitation. However, even without the unique circumstances of the pandemic, symptoms like pain, shortness of breath, and agitation, which are common in many LTC residents, are not identified or treated well. It is my recommendation that the Act include language to ensure that

residents receive early identification and treatment of symptoms, including physical, psychological, social, and spiritual causes of suffering.

Furthermore, many residents and their substitute decision makers in LTC do not receive timely goals of care conversations. Goals of care conversations help residents and their substitute decision makers clarify what they value most and help their treating clinicians formulate a plan of care around residents' preferences and wishes. Residents' preferences and wishes vary from individual to individual and fluctuate depending on the circumstance; for example, a resident may choose to focus on some life-prolonging measures when they are mobile, and more on comfort if they are weaker and bedbound. Every resident should have a goals of care discussion with their physician or nurse practitioner upon admission to LTC, during an annual review, as well as times of transition (e.g. changes in functional status, acute medical events, hospital transfers, or when approaching end-of-life). I would recommend this be included as a right of residents in the Act.

Providing high-quality, evidence based palliative care in LTC requires staff who have skill as well as time. In my work in LTC, I often interact with well meaning and caring staff who have little to no training in palliative care. I hope that the

Minister of LTC will work to ensure that all staff in LTC have education and training in palliative care. Furthermore, I often see that staff do not have the time to provide palliative care. For example, in one LTC facility in which I work, there is one nurse for 25 residents in the day and 1 nurse for 50 residents at night; but a hospice just down the road has 1 nurse for 5 patients.

I support the Ministry's efforts to establish a Long-Term Care Quality Centre. It is essential that quality standards be established for palliative care, and included in the Act. Important metrics include monitoring of pain and other symptoms, frequency and quality of goals of care discussions, as well as hospital transfers and place of death.

References

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2. <https://www.cihi.ca/sites/default/files/document/access-palliative-care-2018-en-web.pdf>