
Long Term Care, Multiple Sclerosis, and COVID-19

Currently, there is a spotlight on long term care (LTC) in Canada as a result of the COVID-19 pandemic. During this unprecedented crisis in our country, and in particular in our LTC facilities, the perspective of younger adults with disabilities currently living there has largely been ignored. As journalist Andre Picard [noted in the Globe and Mail](#) *“During the COVID-19 pandemic, a lot has been written about the living conditions of elders in institutional care, but little attention has been focused on younger people with disabilities who also live in long-term care.”* We recognize the importance of the impact the pandemic in LTC has had on seniors but there is a need to ensure the response and recovery is inclusive of all Canadians living in long term care – including younger adults with disabilities. We need to ensure no one is left behind.

The Reality Prior to COVID-19 - *Being Young in an Old Folks Home, Grows Old Fast*

Long term care facilities are not designed for younger adults with disabilities currently living there. Although they have four walls and a roof – a physical structure (a house), it doesn’t feel like a home, they feel as though they don’t belong, they are not comfortable, it does not reflect their personality and they don’t have people around them that are like them.

Before the current crisis in LTC facilities, the situation for younger adults with disabilities in LTC was in need of change:

- Younger adults with disabilities are in the vast minority in our LTC facilities. For example, in British Columbia in 2018, Ministry of Health data show that of the 35,000 residents of LTC facilities, only 1865 were aged between 19 and 65. However, the picture is not complete, as there is a lack of data on the number of years these residents aged between 19-65 reside in these facilities. We know that many individuals living with MS are residents for decades.
- In Alberta, on May 5, 2016, more than 110 delegates attended A Place to Call Home: A Continuing Care Symposium for Younger Adults with Disabilities whose purpose was to understand the needs of adults with disabilities, 19 to 65 years of age, within the continuum of continuing care; to ensure individuals and their families have voices in the dialogue; to explore improvements in funding, care and the environment; to learn about innovations and technology and to develop a concrete action plan and “call to action”. [This call to action includes 5 priorities for action.](#)
- The physical and emotional characteristics of the younger residents differ markedly from most residents, who tends to be an average age of 85 and have some form of dementia. Younger residents tend to be cognitively intact and be more physically disabled, with complex care needs relating to fatigue, pain, and depression.
- There are many considerations for younger adults with disabilities in LTC that are not addressed. For example, care staff are not trained and do not have the time to respond to these needs, often leading to younger adults with disabilities not receiving the care they need. Other considerations include rehabilitation, programming, schedule, environment, and technology.
- *“Hence, placing young people with MS in LTC facilities contributes to advancing their physical decline by forcing them to adhere to structures and schedules that are directly opposed to the needs of their MS symptoms; and contributes to their mental and emotional decline by creating conditions that fail to adequately stimulate them mentally nor provide age appropriate social interactions, while also failing to address the high rate of depression in people with MS.”¹*

- ¹ (Hewitt, M, (forthcoming), “Reflections on advocating for Age Appropriate Care in BC”, Canadian Journal of Disability Studies).

What we have already heard from people with MS who live in LTC facilities

"When" COVID-19 started to spread across Canada, it was alarming to see how many outbreaks and deaths were occurring in LTC facilities in Ontario and Québec. The facility where I live, went into lockdown on March 9 and it became quickly apparent of just how serious this outbreak was. Our facility quickly became "militarized". Family, friends, companions, and the family dog were prohibited from visiting; all recreation and physical therapy activities stopped; and in-house amenities, such as hairdresser and a small tuck-shop still remain closed, to this day. My hair has not been cut since February! It was not until the beginning of June, that we were allowed 90 minutes of sunshine and fresh air a day. It wasn't until August that we were allowed out of front doors of the facility and given permission to leave the property. I became rather depressed when the economy started to reopen and most people were able to get out for a walk, shop for flowers, and prepare for summer projects. To further my demise, I became collateral damage of the pandemic, when I had to spend weeks in the hospital with lower back pain, because I was unable to see my chiropractor when they opened. I want people to know that we the younger people in LTC should not be forgotten as the pandemic recovery moves forward. We need to be included in these discussions and solutions." Katie Gerke

Debbie is 43 and she also lives in a residential care facility, on Vancouver Island. Debbie really wanted to stay living in her own home, but she was told there was not sufficient care hours available to support her in continue to live in the community. Now, in the care facility, she does not get the care that she requires either, as the care is patchy and inconsistent. Each day is the same. She eats, sleeps and watches her iPad and, bedtime for Debbie is 5:30pm. (Info Brief on Improved Home and Community Care, MS Society, BC and Yukon Division)

John is 29 years old and has lived for the past three years in a Kingston chronic care centre because of the disabilities caused by MS. He points out that although the institution is supposed to be his home, he can't even take a nap when he needs to: "Having MS, I am sometimes very fatigued in the middle of the day and wish to lie down for a nap. Recently... I was told by staff that if I lay down for a nap, I would have to stay in bed for the rest of the day." Finding My Place: Age-appropriate housing for younger adults with multiple sclerosis. Retrieved from <https://mssociety.ca/en/pdf/ont-LongTermCare-findingmyplace-apr06.pdf>

Deborah Cross said she is close with the staff at her care home and makes a point of getting to know people. But it's been difficult, she said, to befriend residents who are nearing the end of their lives. "I've watched friends that I've made pass away over and over again, and it's really distressing," she said. "I never wanted to get used to people dying, and it happens all the time. I can't help but be aware of it, because it's right there in front of me." Goffin, P., (2017), Thousands of under-65 adults with physical disabilities are being forced into Ontario nursing homes: Ministry data, The Star, retrieved from <https://www.thestar.com/news/gta/2017/07/09/thousands-of-under-65-adults-with-physical-disabilities-are-being-forced-into-ontario-nursing-homes-ministry-data.html>

The Path Forward – An Inclusive Approach

As our country moves forward with COVID-19 recovery and specific to long term care it will be imperative to include the perspectives of all those living in long term care including younger adults with disabilities. To exclude them and their lived experience will only exacerbate the situation. We have seen younger adults with disabilities living in LTC facilities being driven to extreme actions as was witnessed by the [recent protest by Jonathan Marchand](#), a 43 year old man with muscular dystrophy who spent five nights in a cage outside the Quebec Parliament to draw attention to his plight in a Quebec LTC facility.

There is a strong case which illustrates the need to improve the care of younger adults with disabilities in LTC and the time is now to include them and their current realities in the path forward with LTC COVID-19 recovery. While there are some areas of change that are common to all residents in LTC, there are unique and specific considerations for the younger LTC population that can only be addressed through inclusion of their perspectives in the COVID-19 recovery.

We ask the federal and provincial governments to include both younger adults with disabilities currently living in LTC as well as organizations that represent them in these ground-breaking discussions on the rebuilding of LTC in Canada. This will build a stronger Canada and will ensure no one is left behind.