



Through the Looking Glass

The Impact of COVID-19 Isolation on Long-Term Care
Facility Residents — A Visitor's Perspective

*A Patient-Initiated Research Project in Newfoundland and Labrador's Eastern and Western Health Zones
(formerly Eastern Health and Western Health)*

Letter from The Patient and Public Partners



Isolation killed my mother; she died of a broken heart. The chance to never say goodbye to a loved one is very difficult. We have to live with the guilt of never being there for her in the last few months of life.

— Survey Respondent

Our survey echoed many of the key themes we heard from friends and family during the COVID-19 pandemic in Newfoundland and Labrador (NL) in the spring and summer of 2020. As Patient and Public Partners on NL SUPPORT's Patient and Public Advisory Council, we also heard concerns about the impact visitor restrictions were having on residents in long-term care facilities. These concerns led to the study outlined in this report. This study is a Patient Partner-Initiated Research Study, with two Patient Partners volunteering to be full members of the research team. The goal of this study was to determine the impact of COVID-19 restrictions on visitors and residents of long-term care facilities in Eastern and Western Health.

This study involved the development of a visitor survey and its promotion to community members. We would like to thank all those who took the time to complete our survey, as well as those who helped with its promotion. We appreciate that for many visitors it was difficult to answer the survey questions, as they sparked many deep emotions. We thank all those who responded for giving a voice not only to their own experiences but for speaking for their resident(s) in long-term care whom we could not include in this study.

While many themes emerged from the research outlined in this report, as Patient Partners the most important theme to us was loss. As seniors (and Patient Partners) we felt an overriding sense of loss—sometimes unbearable loss. Loss of time with loved ones, loss of day-to-day activities, loss of confidence in the residents' well-being, loss of daily communication, loss of trust in the system, and sometimes the unbearable loss of losing a loved one without the chance to say goodbye. Certainty was often replaced with worry and confusion as restrictions on visitation, masks, and distancing constantly changed.

Health authorities and long-term care facilities were doing their best to keep up with the evolving science and changes in patient care while waiting for a COVID-19 vaccine to become available. The focus was on safety, and this trumped other concerns, such as the impacts of isolation and loneliness on residents in long-term care. Some visitors felt that the benefits of visits from family and friends far outweighed the risk of contracting COVID-19, highlighting the important role that visits play in a resident's quality of life. This study provides insight into important lessons that society can take away and makes recommendations that we hope policy-makers will consider as we move forward in developing long-term care policies and pandemic preparedness plans. These recommendations are listed on page 31 of the report.

From our point of view, the recommendations boil down to one thing: put the residents and their families first. Consider their needs and build a better system to address them. Create change from the bottom up—keep what is working while building new procedures and policies that follow a resident-centred approach. One size does not fit all, as long-term care facilities manage residents with a wide variety of cognitive and physical impairments, such as dementia, hearing loss, and mobility issues. To do this, we will require a willingness to act from our leaders, as well as their understanding and compassion.

For seniors like us, the experience of long-term care residents during COVID-19 lockdowns sparked fear for our future, with concerns for our well-being and the quality of care we will receive. The question at the top of our minds is: where are we going to go when we can no longer take care of ourselves? With the well-publicized reports of the crisis and mortalities in long-term care facilities during COVID-19, seniors are reconsidering their options. They want control of their health care choices and the ability to make decisions regarding their care. Living in long-term care should not mean a relinquishing of control of one's life or one's willingness to live at risk.

This project has been a labour of love. We have devoted many volunteer hours to its completion over the past three years. As patient and public partners, we have had many rewarding challenges working for the first time with an experienced research team, and there is much we hope to share with patients eager to get involved in our health care system and policy-making at the ground level. Engagement of all Newfoundlanders and Labradorians in creating change is essential. We encourage those who are interested in getting involved in research as a patient partner to participate in groups such as the NL SUPPORT Patient and Public Advisory Council. We thank the research team for investing their time and energy into this project, NL SUPPORT's Patient and Public Advisory Council for its feedback, and NL SUPPORT for providing the funding to make this project possible. Together we can improve the quality of life for residents in long-term care and for our province's aging population.



Cris Carter is a patient and public partner and volunteer in the health care sector working to improve health care outcomes for seniors through various research and health care initiatives.



Rosemary Lester is a patient and public partner and advocate for the rights and protection of older persons. She successfully sought support for a number of initiatives designed to improve the lives of seniors in Newfoundland and Labrador.



Hopefully policymakers have learned, as we all have, from COVID. It's tough to find that middle ground but that is their job. Restrictions in future will need to find a better balance. Loneliness will kill as well.

— Survey Respondent



Letter from The Clinical Lead

March, 2024

Reading this report will leave you questioning what we could have done differently for the residents of long-term care facilities during the COVID-19 pandemic. Many of the quotes from visitors and family members of the residents are raw and emotional, showing the depth of feeling they experienced. Despite this, I am delighted that NL SUPPORT was able to support Patient and Public Partners in taking this project forward, as the experiences of visitors and family members of residents needed to be told. This work highlights important lessons learned, as well as the vital insights patient and public partners can provide to health care research and evaluation.

This project represents a further step in the work of the [NL SUPPORT Unit](#). While it has supported patient-oriented research in many forms since its inception in 2014, this project is the Unit's first patient-initiated research project, or research led by Patient and Public Partners. Everyone involved in this project has learned a great deal from this process, and are proud to present the research findings in this report.

This project was an ideal fit for patient-initiated research because the topic was identified by members of NL SUPPORT's Patient and Public Advisory Council as one of concern early in the COVID-19 pandemic and one of personal importance. Given the personal relevance of the topic and NL SUPPORT's Patient and Public Partners' enthusiasm, we felt this was an opportunity to support them in embarking on a patient-initiated research project.

A key component of patient-oriented research is selecting topics that are of importance to people directly affected by an issue. In listening to reports from visitors and families, it was clear that this topic was of great concern to many people in Newfoundland and Labrador who were looking to balance safety and quality of life for those living in long-term care facilities. The knowledge generated from this study adds further weight to the importance of conducting patient-oriented research.

The research team was encouraged by the willingness of the Regional Health Authorities (now referred to as NL Health Services) to participate in this work, despite the tremendous additional pressure placed on them

by the realities of the pandemic. This willingness demonstrates a desire to learn from the experiences of the pandemic to help better prepare for the future and provide the best care possible to residents of long-term care facilities. This desire for systems improvement also aligns with NL SUPPORT’s work on developing and supporting a learning health and social system in the province. A learning health and social system works to continuously improve by taking in information on system performance and using it to adapt and adjust service provision. As is apparent from the findings of this project, there is much to learn from this experience that can be used by the system to adapt and adjust for a better future. The research team is grateful to the directors in NL Health Services (formerly Eastern and Western Health) who encouraged this endeavor and the staff who facilitated this work within their facilities.

We thank the participants who took the time to complete the survey and contribute to this work. It is very clear from the responses that reflecting on their experiences was difficult for many respondents and the team is grateful for the time they took to share their experiences. These stories are incredibly impactful and allow the reader to understand the impact that provincial policies have on the lives of those in long-term care.

NL SUPPORT thanks its Patient Partners, Rosemary Lester and Cris Carter, for their tireless dedication to completing this project and ensuring the patient and caregiver voice is front and center in the information shared with decision-makers. After all, it is the patients’ and caregivers’ lives that are directly impacted by the policies decided upon by decision makers. The commitment of Rosemary and Cris to this work is a demonstration of the important role that patients play in all aspects of the health care system.

The world has now moved towards the “new normal” of living with COVID-19 and we are tasked with determining how best to apply learnings from the acute lockdown phase to the future. Readers of this report are encouraged to pay attention to the role of connection in the stories shared and remember that even in the midst of crisis, it is human connection that residents and visitors in long-term care facilities value. In the spirit of a learning health and social system, NL SUPPORT hopes that by sharing these research findings it can help residents and visitors shape system changes to come.

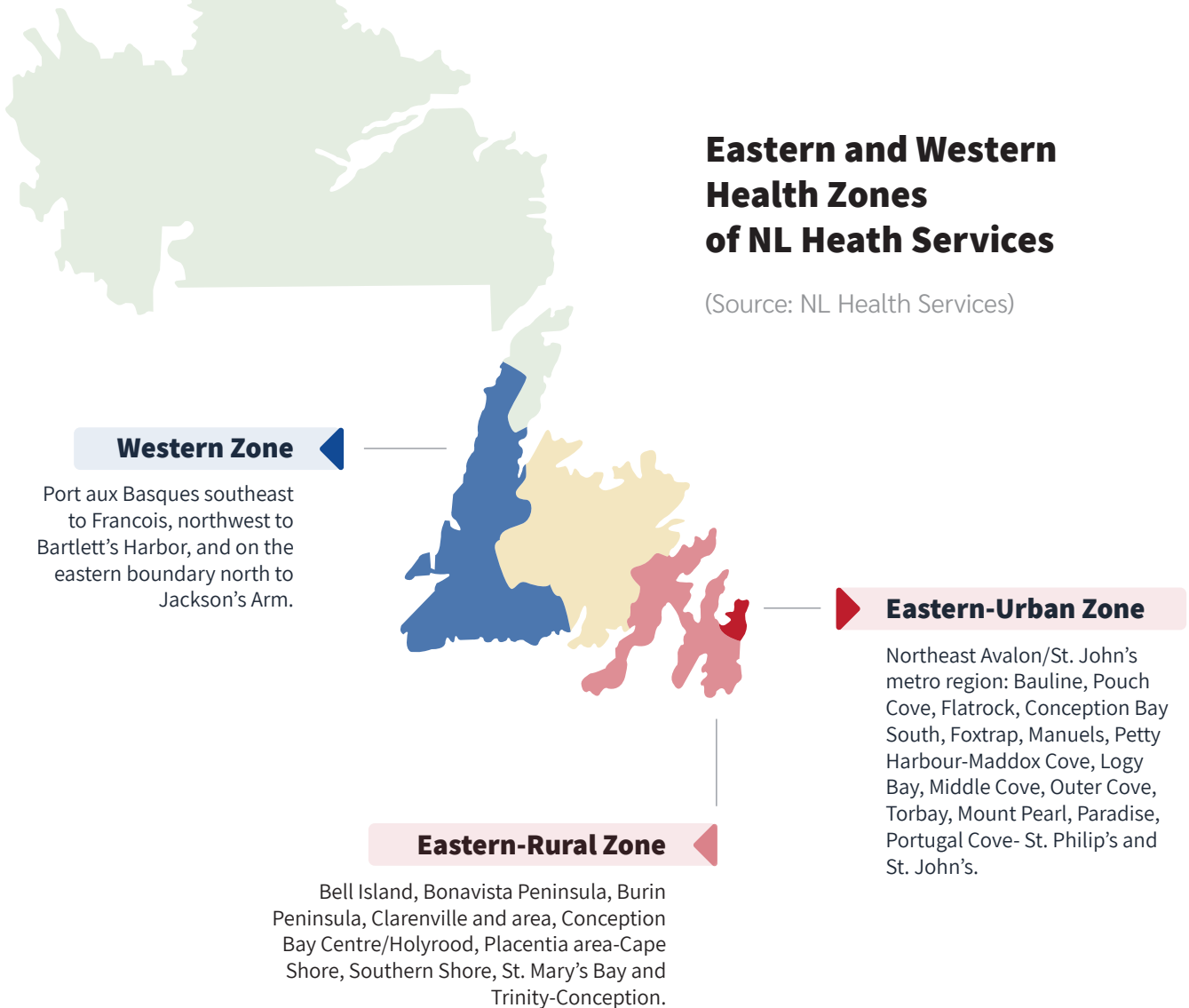


Dr. Brendan Barrett
NL SUPPORT Clinical Lead

Executive Summary

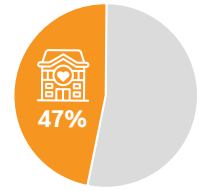
In long-term care facilities, visitors play a crucial role in the circle of care for residents. The COVID-19 pandemic unfortunately enforced tight restrictions and at times the complete removal of visitors which resulted in a significant increase in isolation for residents. Prolonged social isolation raised concern for residents' mental and physical health and overall well-being. In the fall of 2020, members of the Patient and Public Advisory Council of Newfoundland and Labrador's SPOR SUPPORT Unit (NL SUPPORT) expressed concerns regarding the impact of these restrictions on residents and their families. These concerns led to a research project investigating the effect of restrictions on the mental and physical well-being of residents and their visitors. This research project focused on the completion and analysis of a survey of visitors of long-term care facility residents during the COVID-19 pandemic. The survey was only completed by those who would have been visitors as many residents would have required unavailable assistance to provide their own perceptions.

A total of 184 respondents completed the survey. Survey respondents were from the Eastern and Western Health Zones of NL Health Services (formerly Eastern Health and Western Health).



Survey results showed:

47% of survey respondents reported that the resident they visited was residing in a long-term care facility prior to the start of the COVID-19 pandemic (March 2020)



These survey responses can be compared to data from the Resident Assessment Instrument – Minimum Data Set (RAI-MDS 2.0)* that is reported on all residents of long-term care in the province. Health care employees engaged in the residents' care complete the RAI-MDS 2.0 quarterly on all residents. It is included in this report to give a clinical interpretation that represents all residents of long-term care at the time and not just those represented by visitors in this survey. Comparing the **RAI-MDS 2.0 data points** from Mar 2020–Nov 2022 (the same period included in our survey) for all long-term care residents in Newfoundland and Labrador to before the pandemic (prior to March 2020), **we see some similarities and differences to the survey responses:**

Survey respondents reported that during COVID-19 pandemic restrictions:

20% of visitors reported that a resident **passed away**

60% of visitors reported that the **overall health of the resident they visited worsened**

62% of visitors reported that the resident's **cognitive function worsened**

5% of visitors reported that a resident **passed away in the first year** (Mar 2020–Apr 2021)

53% of visitors reported that the resident's **physical mobility worsened**

60% of visitors reported that the resident's **overall mood and well-being worsened**

69% of visitors reported the **quality of care** provided to residents was **very good**

41% of visitors reported **their own mental and emotional well-being worsened**

RAI-MDS 2.0 Data Points

During the COVID-19 pandemic restrictions:

21% of residents **passed away**#

28% of residents' **overall health** worsened, **53%** stayed the same, and **18%** improved

24% of residents' **cognitive function** worsened, **64%** stayed the same, and **11%** improved

24% of residents **passed away in the first year** (Mar 2020–Apr 2021)

25% of residents' **physical mobility** worsened, **65%** stayed the same, and **9%** improved

26% of residents' **mood and well-being** worsened, **55%** stayed the same, and **18%** improved

#Zero deaths due to COVID-19 were reported in the study period

*RAI-MDS 2.0 stands for Resident Assessment Instrument-Minimum Data Set. This is a data-reporting tool that is used in continuing care settings across the country. Data are regularly submitted to the Canadian Institute for Health Information (CIHI). According to CIHI submitted data are used to "plan and monitor care, understand populations, improve quality, and allocate resources".

Two major themes arose from respondents when given the opportunity to share their own thoughts and stories during the pandemic:

1. Restrictions had a negative impact on the mental health of residents. There were feelings of loneliness, isolation, confusion, and abandonment, particularly for residents with cognitive impairments such as dementia. Visitors identified the importance of social connection as a key focus area for decision-makers to consider when creating or amending policies that affect quality of life. Using social connection as a lens will ensure that polices will improve quality of life.
2. Negative feeling about provincial policies regarding restrictions in LTC facilities and the need to carefully weigh the harms and benefits of restrictions in place.

*Because we were not allowed in to see my mother, her condition worsened. She could not understand why we were not permitted to see her. Mentally this was too much for her. **3 months and no visit from her family at 95 years old was the cruellest punishment inflicted on her.***

— Survey Respondent



In careful review of the survey responses and of recent reports, the project team is making five major recommendations:

- 1** Always allow for at least one visitor in LTC facilities to support the quality of life of the resident. Permit alternative designated visitors to reduce the burden on the designated visitor.
- 2** Place priority on socialization and connection between residents. In addition, minimize the restriction on regular extracurricular, physical, social and routine activities.
- 3** Improve mechanisms of communication between facilities, staff, visitors and residents, specifically in relation to policies and decision-making processes regarding residents' physical and mental care.
- 4** Consider the different needs and circumstances of residents when developing policies and making decisions around restrictions (e.g. those with cognitive impairment, those in protective care units and those receiving palliative care).
- 5** Provide a method of communication available to residents that they know how to use or that they can be assisted to use with the support of staff, volunteers, and visitors.



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