

**Corner Brook Long Term Care &  
Protective Community Residences  
Family Experience Survey Results  
2021**



**Western  
Health**

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## **Background**

### **Long Term Care at Western Health**

Long Term Care (LTC) provides quality institutionally based programs and services within three LTC homes, four Protective Community Residences and four Rural Health Centers. LTC staff work collaboratively with other branches of Western Health in the planning, delivery, and monitoring of LTC programs and services. An interdisciplinary, collaborative model of care is important for delivery of quality LTC programming. Nursing, Social Work, Physiotherapy, Occupational Therapy, Behavior Management, Physicians, Pharmacy, Therapeutic Recreation, and Spiritual Care are all integral parts of the interdisciplinary team within LTC programs and services. In 2020/2021, LTC developed a new Regional LTC Quality Improvement Team composed of residents, family members, clinical staff, and support staff from various LTC sites in the region. As part of Western Health's commitment to quality improvement for residents and their families, it is important to measure resident and family experience. The Quality Improvement Team reviewed and provided input on modifications to the LTC Resident and Family Experience Surveys. The Team, and LTC sites, will use the survey results to guide quality improvement initiatives.

### **Impact of COVID-19 Pandemic**

The World Health Organization declared COVID-19 a global pandemic on March 11, 2021, the world faced profound economic and social impacts. Within Western Health, 2020/2021 was an exception year in many ways. The effects and implications of the pandemic affected all sites, services, and programs throughout the year. LTC residents, families and staff were impacted by many changes in staffing and safety protocols, resident and visitor screening practises, personal protective equipment, program delivery, and visitor restrictions.

### **Survey Instrument**

The validated Consumer Assessment of Healthcare Providers and Systems (CAHPS) Nursing Home Survey: Resident Instrument, developed by Alberta Health Services, was utilized as the basis for the survey administered to LTC residents throughout the Western region. Based on experiences using this survey within Western Health in 2010 and administering a modified version in 2013 and 2015/16, this survey tool was modified in collaboration with the Regional LTC Quality Improvement Team. Questions were modified to fit with current language and terminology for services and providers, to ask about additional services and providers, as well as to help assess the impact of the COVID-19 pandemic on resident experience. This modified tool (Appendix A) was used to evaluate resident experiences and administered electronically through the Get Feedback online survey platform.

## **Method**

Western Health promoted the LTC Family Experience Survey broadly on the organization's website and social media pages throughout the administration period of May 3 to June 25, 2021. The LTC facilities contacted residents' family members through mail or email to share a letter outlining the survey and provide the paper copy and/or electronic link. Each facility identified an individual who was available to administer the survey in-person or over the telephone. Posters were also displayed within the facility. Print copies of the surveys and return boxes were available at the visitor screening booth or LTC check-in areas. Completed print format surveys were transcribed into the Get Feedback platform by staff, students, and/or nurses on ease-back.

## **Sample**

All resident family members were given the opportunity to complete the survey. Across the Western Health region, 342 participants completed the survey. For Corner Brook Long Term Care (CBLTC) and the Protective Community Residences (PCRs), 177 family members completed the survey.

## **Privacy, Confidentiality, and Data Security**

Privacy and confidentiality were achieved as the residents names were not reported on the surveys. The electronic survey reports are stored in a password-protected account on the Get Feedback online platform. Any information that could potentially identify the family members or resident was deleted. All downloaded data was stored on a password protected computer in the Monaghan Hall office used by Quality staff.

## **Data Analysis**

Survey data was entered directly into Get Feedback by the respondent or transcribed into the platform from paper copies of the survey. Reports were developed and analyzed in this survey platform. Descriptive statistics were calculated to obtain a general perspective of family members' experiences with LTC services at Western Health. The not applicable and I don't know/I am unsure responses were removed from calculations to provide a more accurate representation of the measures. Comments were compiled based on common themes. Statistics were also filtered for each site or grouping of sites where the sample provided sufficient data to assist in quality improvement initiatives. Comparisons to the 2016 results must consider that the 2021 family members are not the same individuals whose loved ones were residing in LTC in 2016. As well results are combined for CBLTC and the PCRs. The following report provides survey results for CBLTC and the PCRs.

## Results

### Demographics

A total of 177 surveys were completed by family members of residents in CBLTC and the PCRs. This is a significant increase in sample size from the 102 family members CBLTC and the PCRs who participated in the 2016 survey. The majority of the respondents were from Corner Brook Long Term Care (89%).

Respondents were asked several questions to gain a more thorough understanding of the demographics of the family members being surveyed and their loved ones living in long term care, including relation to the resident, if the resident was discharged from the facility or had died, how long the resident lived there, and if they expected the family member to live in a long term care home permanently. When asked their relationship to the resident, 17% reported that the resident was their spouse or partner, 57% reported their parent, 3% reported their mother-in-law or father-in-law, 2% reported their grandparent, 1% reported their aunt or uncle, 13% reported their sibling, 2% reported their child, 2% reported their friend, and 2% reported other. In comparison, for CBLTC in 2016, 28.4% reported that the resident was their spouse or partner, 51.9% reported their parent, 2.5% reported their aunt or uncle, 13.6% reported their sibling, 2.5% reported their child, and 1.2% did not report. This shows some changes in family member composition, with a decrease in spouses/partners completing the survey and an increase in children, grandchildren and son-/daughter-in-laws completing the survey.

Although efforts were taken to reduce the potential that a family member or next of kin received a survey after the resident had died, two respondents indicated that the resident was deceased. Of these, one chose to discontinue the survey and one reported based on the residents last six months in the LTC home. The majority (66%) of the respondents indicated that the resident lived in LTC for twelve months or longer, 16% reported six months to almost twelve months, 11% reported three months to almost six months, 5% reported one month to almost three months, and 2% reported less one month. Of the respondents, 93% reported that they expected the resident to live in a LTC home permanently.

Respondents were also asked to indicate whether they were the individual who had the most experience with the resident's care and 74% reported yes, 20% reported no, and 6% did not know. Other questions were asked about finances, power of attorney, and substitute decision maker (See Table 1). The majority of the respondents (74%) were the resident's substitute decision maker and 58% of respondents reported that they had power of attorney.

**Table 1. Family Member Involvement and Role**

<b>Question</b>	<b>Yes (%)</b>	<b>No (%)</b>	<b>Don't know (%)</b>
In the last six months, did you help your family with managing finances, such as paying bills or filling out insurance claims?	53	47	N/A
Do you have power of attorney for your family member?	58	38	4
Are you your family member's substitute decision maker (next of kin)?	74	20	6

To gain a more thorough understanding of the demographics of the LTC families, respondents were asked about their age, gender identity, race or ethnicity, and educational background. Of the 169 respondents who reported their age, 1% were 85-94, 13% were 75-84, 34% were 65-74, and 33% were 55-64 and 15% were 45-54, and 4% were 44 or under. Of the respondents, 78% were female and 22% were male. The majority of the respondents (92%) identified as white/Caucasian and 8% identified as Indigenous/Aboriginal. Of the respondents, 12% had completed grade school or some high school, 17% completed high school, 20% completed post-secondary technical school, 12% completed some university or college, 24% reported that they completed a college diploma, 11% completed a university degree, and 4% had a postgraduate degree. When asked about support with survey completion, 15% of the respondents had assistance, with the most common assistance being 'read the questions to me' (96%) and 'recorded the answers I gave' (76%).

### **Visitation and Activities**

Family members were asked questions about virtual visits, designation as essential visitors, and in-person visits during the past six months.

Family members were asked if the visitor restrictions implemented during the previous six months had changed their in-person contact with their family member in LTC. Of the respondents, 24% reported a significant decrease, 40% reported some decrease, 29% reported no change, 5% reported some increase, and 2% reported a significant increase.

Family members were asked if, over the last six months, they were designated as an essential visitor or support person for their family member. Of the respondents, 71% reported yes and 29% reported no. Those designated as essential visitors or support persons were asked about how many times they visited the resident in the past six months.

Of the respondents, the majority (70%) reported more than 20 times, 18% reported 11-20 times, 5% reported 6-10 times, 5% reported 2-5 times, and 2% reported 0-1 times.

Family members were asked about frequency, purpose, and satisfaction with virtual visits, which were defined as talking on the phone or having video calls (Face Time, Google Duo, etc.). Of the respondents, 56% reporting having virtual visits and 44% reported they did not have virtual visits. Of those who had virtual visits, 12% reported daily visits, 21% reported several times per week, 43% reported weekly, 8% reported having visits several times per month, and 16% monthly or less. Of those who had virtual visits, 68% reported that they had virtual visits because they could not visit in-person due to restrictions, 30% had virtual visits to have additional contact with their family member between their in-person visits, and 13% of respondents reported that they had virtual visits because they live too far away for in-person visits. When asked if they had enough virtual visits to meet their family member's needs, 78% of respondents reported yes and 22% reported no.

Family members also provided comments on their experiences with visitor restrictions and virtual visits. Some family members provided positive comments, were pleased with their experience with in-person visits, and expressed gratitude for being deemed essential visitors. Others expressed frustration with the limited number of in-person visitors and the length and frequency of in-person visits. Family members expressed concerns that the limitations were hard on residents, especially those who did not understand the restrictions. Some family members also noted that the increased responsibility was hard on the designated visitor as well. Family members also expressed concerns that limited in-person visitation negatively impacted on their loved ones' health, specifically in relation to not being able to supplement meals and help with eating and drinking. A common recommendation was that all residents should have at least one designated essential visitor at all times.

The most common suggestion for change made by family members was to allow more visitors. Suggestions were made to increase the overall number of visitors per resident, allow family visits, as well as to change the visitor list more frequently. Several respondents specifically noted that family from out of town should be better accommodated. Family members also commonly expressed that visitors should be able to come and go throughout the day. Family members also suggested that they should have more access to spaces within the facility and should be able to take their time when ending visits and leaving.

Experience with virtual visits also varied. Some family members expressed their appreciation for the virtual visits. However, some family members experienced difficulty with organization of virtual visits and others explained that their loved one had difficulty with focusing or hearing during the visit.

While family members were not asked quantitative questions about the activities available to their loved ones, the need to enhance and increase frequency of activities was a common theme in the comments family members provided. Comments were closely split between two themes. The first was concern that residents were left alone or in their rooms, beds, or chairs too long and the second was concern that residents needed more activity and stimulation. Suggestions for improvement in activities included providing more of each exercise, individual attention and support, time outside, socialization, and small group activities. Several family members also commented that more recreation staff and extended hours for recreation were needed.

The survey results highlighted the importance of supporting visitors to be present as much as feasible and safe. The results of the survey also indicate opportunities for improvement in the variety and frequency of activities available to residents.

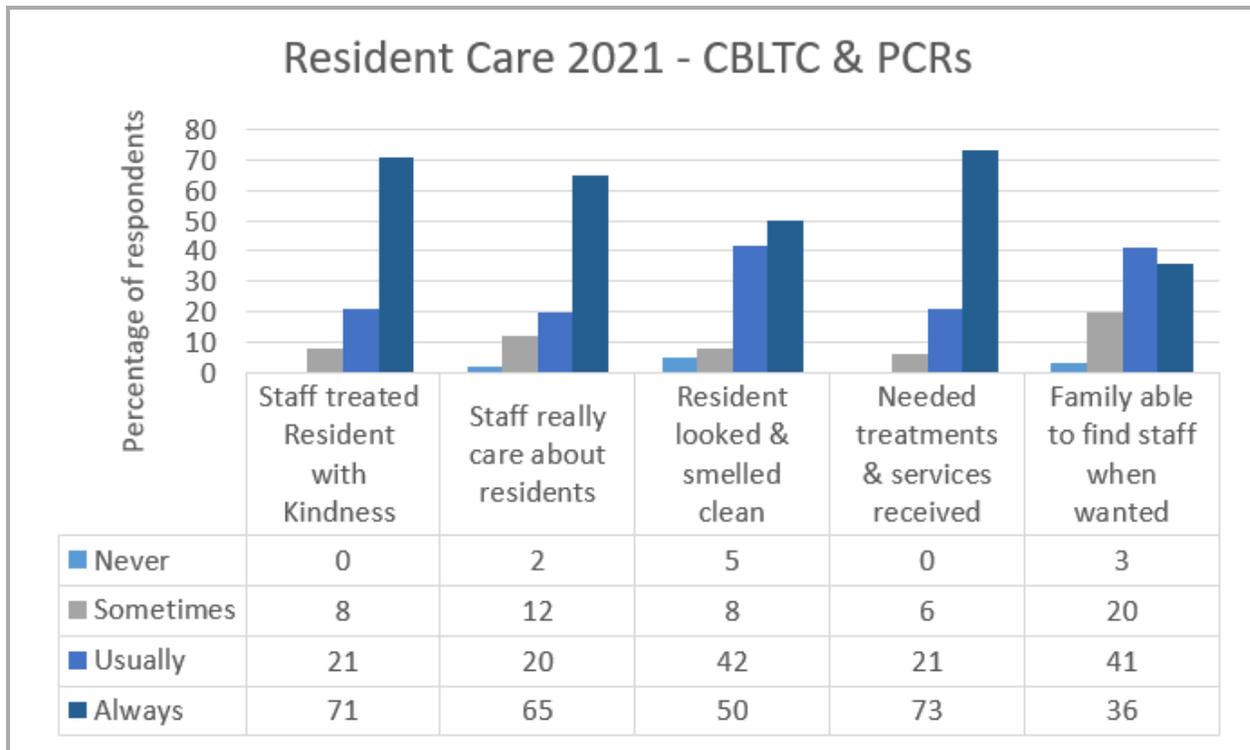
### **Resident Care**

Several questions were asked about health care in terms of the respondents' perspective and experiences over the past six months (See Figure 1). Respondents were asked how often they felt that there was enough nursing staff in the LTC home and, of the respondents, 26% reported always, 34% reported usually, 26% reported sometimes, and 14% reported never. When asked if their family member received all of the health care services and treatments they needed over the past six months, 94% of respondents reported usually or always. When asked if their satisfaction with their family member's access to programs and services had changed because of the pandemic, 76% of respondents reported no change, 18% reported decreased satisfaction, and 5% reported increase satisfaction. When asked if their satisfaction with their family member's access to the health care staff had changed because of the pandemic, 90% of respondents reported no change, 4% reported decreased satisfaction, and 5% reported increased satisfaction.

The majority of the respondents reported that they had always or usually seen the health care team treat the resident with kindness (92%) and that they always or usually felt that the health care staff really cared about the resident (85%). These are both comparable to the 2016 results for CBLTC, in which 94% reported nursing staff were kind and 90% reported nursing staff really cared.

Respondents were asked how often the resident looked and smelled clean in the last six months and 92% reported usually or always. This is a slight decrease from 95% reported in 2016 for CBLTC. Family members were also asked if they had ever seen the LTC home staff fail to protect any resident's privacy while the resident was dressing, showering, bathing, or in a public area and 97% of respondents reported no.

Figure 1. Resident Care



Respondents were asked about their satisfaction with the care provided to their family member by specific services or providers. Overall, the majority of respondents were usually or always satisfied with each of the services or providers. Results for those respondents whose family members availed of the services are outlined in Table 2.

Table 2. Family Member Satisfaction with Services/Providers (percent of respondents)

	Never (%)	Sometimes (%)	Usually (%)	Always (%)
Nursing staff	0	9	24	67
Doctor/Nurse Practitioner	1	8	22	69
Occupational Therapy	6	7	18	69
Physiotherapy	8	8	16	67
Recreation Therapy	7	12	13	68
Social Work	1	6	19	74
Spiritual Care	10	13	18	59

Respondents were also asked in their satisfaction with their family member’s overall care changed because of the pandemic. Of the respondents, 82% reported no change, 8% reported a decrease in satisfaction, and 9% reported an increase in satisfaction.

Respondents were asked if in the last six months, they saw any resident behave in a way that made it hard for LTC staff to provide care such as yelling, pushing, or hitting. Of the 60% who reported seeing this happen, 50% reported that the staff always or usually handled this situation in a way that they felt was appropriate. This was a decrease from 2016, when 97% of respondents from CBLTC reported that the nurses and aides always or usually handled this situation in a way that they felt was appropriate. When asked if they had ever seen any health care staff be rude to their loved one or any other resident, 87% reported never, 11% reported sometimes, and 2% reported always. This is comparable to 88% who reported no for CBLTC in 2016.

Respondents were asked if they helped with the care of the resident when they visited and 80% reported yes, while 16% reported that they felt the long term care home staff expected them to help. This is an increase from 2016 for CBLTC, when 54% reported yes and 5% reported that they felt staff expected them to help.

Family members were also asked questions about whether they helped residents with specific aspects of their care over the past six months and if this was because they chose to help or if it was because the staff either did not help or made the resident wait too long. When asked if they had helped the resident with eating, 33% reported that they did not help, 66% reported that they chose to help on their own, and 1% reported that they helped because staff did not help or made the resident wait too long. When asked if they had helped the resident with drinking, 34% reported that they did not help, 63% reported that they chose to help on their own, and 3% reported that they helped because staff did not help or made the resident wait too long. Respondents were also asked if they helped the resident with toileting and 74% reported that they did not help, 20% reported that they chose to help on their own, and 6% reported that they helped because staff did not help or made the resident wait too long. As shown in Table 3, in comparison to the 2016 results for CBLTC, there was an increase in family members helping with each aspect of care and also an overall decrease in family members reporting that they helped because staff did not or made the resident wait too long.

**Table 3. Help with Care (%)**

	Helped with care (general) (%)		Helped with eating (%)		Helped with drinking (%)		Helped with toileting (%)	
	2016	2021	2016	2021	2016	2021	2016	2021
Helped with care (total)	54	80	51	67	48	65	17	26
Helped because staff made resident wait too long	n/a	n/a	2	1	3	3	14	6

A common theme in family members' comments was that the LTC home was understaffed and staff were overworked. Some family members also noted that being understaffed caused or risked neglect, worsened care, or delays in care. Most comments focused on nursing care, with morning and evening hours specifically noted by some respondents. However, the need for additional staffing or extended hours in recreation and rehab/physiotherapy was also noted.

Family members provided comments regarding the overall care their family members received in LTC and their satisfaction with their family member's cleanliness. The majority of comments provided were that family members were very happy, pleased, or appreciative of the care provided and care was described as excellent. However, common themes were also presented for concerns. The most common theme in the concerns presented was that residents were left alone for long periods and need to be checked on and changed more frequently. Several comments specifically noted that the scheduling of bathroom checks and changes led to residents' discomfort and development of sores. The second most commonly noted concern was poor hygiene and personal care, including clothes and faces not being cleaned after meals, teeth not being brushed, hair being unkempt, and feet being cold and lacking socks. Family members also commonly raised concerns about slow responses to residents' buzzers and requests and care plans not being followed.

Family members also provided comments regarding their experience and satisfaction with the LTC staff. The main theme was that most family members are satisfied with the LTC staff. Common positive statements about staff included that staff were approachable, friendly, accommodating, caring, respectful, and compassionate. Negative comments were also provided, often prefaced with 'some staff' or 'at times'. Negative comments very varied and focused on some staff being less engaged, putting in less effort, and being rough with cares. The most common recommendation related to care was for staff to have more training, with comments about training for new and casual staff and training in dementia and dementia care. The other common recommendation was to improve safety measures regarding residents at risk for falls, including improving the alarm bell system and implementing other safety measures.

### **Resident Health and Wellness**

Respondents were asked about the health and wellness of their family member residing in the LTC home. The majority (76%) reported that their family member has serious memory problems because of Alzheimer's disease, dementia, stroke, accident, or something else. Family members were asked how often the resident was able to make decisions about his or her own daily life, such as when to get up, what clothes to wear, and which activities to do. The majority of the respondents (53%) were able to make decisions at least some of the

time. Overall, 47% reported never, 28% reported sometimes, 12% reported usually, and 13% reported always.

Family members were asked to indicate how they would rate their family member's overall mood or emotional wellbeing. Of the respondents, 8% reported excellent, 31% reported very good, 32% reported good, 23% reported fair, and 8% reported poor. Family members were also asked to indicate how their family member's mood had changed because of the pandemic. Of the respondents, 58% reported no change, 29% reported a little worse, 12% reported significantly worse, no one (0%) reported a little better, and 1% reported significantly better.

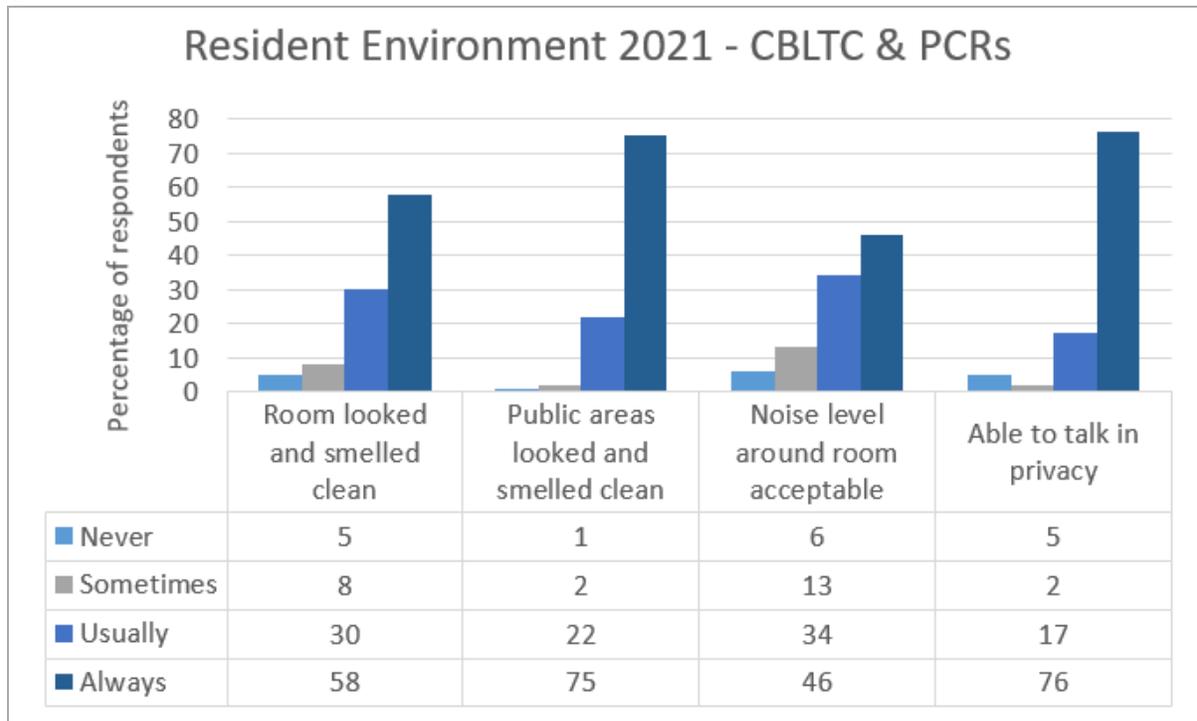
### **Environment**

Respondents were asked to report on various aspects of the environment based on the last six months (See Figure 2). When respondents were asked how often the residents' room looked and smelled clean, 88% report usually or always, while 97% reported that the public areas looked and smelled clean. Respondents were also asked if their satisfaction with the cleanliness of the facility changed because of the pandemic and 79% of respondents reported no change, 2% reported decreased satisfaction, and 18% reported increased satisfaction.

The majority of the respondents (80%) reported that the noise level around the residents' room was acceptable to them. Privacy is also an important aspect of long term care. When respondents were asked how often they were able to find places to talk to the resident in private, 93% reported usually or always. Respondents reported that the majority of their family members had a private room, with only 2% having shared a room with another person at the LTC home within the last six months.

While overall cleanliness was highly rated and some family members provided positive comments regarding the cleanliness of the facility, the most common theme in family members' comments about the environment was that more cleaning was needed. Specific areas noted varied and included rooms, bathrooms, floors, furniture, and mattresses, as well as the need to clean rooms and tables after meals. Some respondents also noted the smell of urine on items. The other common theme related to the environment was noted by family members was that other residents can be loud and disruptive, bothering their loved ones at times.

Figure 2. Environment



### Residents' Personal Belongings

Questions were asked related to personal belongings over the last six months. When asked how often residents' personal medical belongings (e.g., dentures, hearing aids, eye glasses) were clean and in good condition, 2% reported never, 17% reported sometimes, 36% reported usually, and 45% reported always. When asked how often residents' personal medical belongings were damaged or lost, 66% of respondents reported never, 28% reported sometimes, 3% reported usually, and 3% reported always. When asked how often clothes that were cleaned by LTC's laundry services were damaged or lost, of those who used the service, 43% reported never, 49% reported sometimes, 3% reported usually, and 4% reported always.

Family members also provided comments about their experiences with residents' personal belongings. The most common concern was personal items being lost. The other common concerns were items being misplaced or mixed-up with those of other residents and clothing being mislabelled.

### Residents' Meals

Family members were asked about their satisfaction with various aspects of the meals provided to their family member at the LTC home. The majority of the respondents were usually or always satisfied with the visual appeal (71%), taste (66%), temperature (69%), and mealtime experience (80%). When asked if their satisfaction with the meals provided

to their family member had changed because of the pandemic, 91% of respondents reported no change, 2% reported decreased satisfaction, and 5% reported increased satisfaction. When asked if their satisfaction with their family member's mealtime experience (how meals are served) had changed because of the pandemic, 88% of respondents reported no change, 6% reported decreased satisfaction, and 6% reported increased satisfaction.

Common themes in family members' comments about the meals provided in LTC were a lack of variety, the need for ore help with meals, and the need for more to drink or more frequent help with drinking. As noted above, family members also expressed concerns that limited in-person visitation negatively impacted on their loved ones' health, specifically in relation to not being able to supplement meals and help with eating and drinking.

### **Access, Communication, and Family Involvement**

Respondents were asked several questions about overall care and communication with the health care team in the last six months. Of those who reported that they had tried to find health care staff, 77% reported they could usually or always find one when they wanted one, which is a decrease from 86% in 2016 for CBLTC. When asked if their satisfaction with their access to the health care staff had changed because of the pandemic, 82% of respondents reported no change, 9% reported decreased satisfaction, and 8% reported increased satisfaction. The significant majority (93%) of the respondents reported that the health care team always or usually treated them with courtesy and respect.

Questions about obtaining information were asked in relation to the last six months. Of the respondents, 87% reported that they usually or always received the information they needed about their family member, a decrease from approximately 97% in 2016 for CBLTC. When asked if things were explained in a way that was easy for them to understand, 91% reported usually or always. When asked if they were discouraged from asking questions about their family member, 85% of respondents reported never, 11% reported sometimes, 1% reported usually, and 2% reported always. Respondents were asked if they got all of the information they wanted about payments or expenses. Of the 64% of respondents who asked for this information, 95% usually or always got all the information they wanted.

When respondents were asked if they were ever unhappy with the care the resident received, 27% of respondents reported yes and 73% reported no. Of those who reported having concerns, 89% reported that they spoke to long term care home staff about this concern and 37% were usually or always satisfied with the way the staff handled these problems, 56% were sometimes satisfied, and 7% were never satisfied. Only 14% of respondents reported that they stopped themselves from talking to any long term care home staff about their concerns because they thought staff would take it out on the

resident. This shows a significant increase in family members feeling open and safe to bring forward concerns, with 44% having reported stopping themselves from doing so in 2016.

Family members were asked about their involvement in care and experience with case conferences. Of the respondents, 92% reported being involved in decisions about the residents' care over the last six months, an increase from 89% in 2016 for CBLTC. Of those who were involved in decisions, 81% reported being usually or always involved as much as they wanted to be, a decrease from 85% in 2016 for CBLTC. Respondents were asked about whether they had been part of a care conference over the last 12 months, either in person by telephone or by videoconference. Of the respondents, 48% reported yes, 7% reported no because they chose not to attend, 32% reported no because they were not given the opportunity, and 13% reported that they did not know or were unsure.

Family members provided comments about communication with the health care staff. The majority of the comments were positive. Family members commonly noted that staff were helpful always willing to answer questions. However, not all families had this experience. The common theme in family members' concerns was that there was a lack of communication among staff, with a focus on change of shift, casuals, and care plans not being communicated. Other concerns were varied among individual family members; however, these can be combined into a general theme regarding concerns with communication and family members having to initiate communication in order to find out information.

## **Overall**

When asked to rate the LTC home, on average, respondents rated the home at 8.14 (range 0-10; 0 being the worst possible and 10 being the best possible). When family members were asked to rate the overall care their family member received at the LTC home, the respondents rated overall care at 8.46 (range 0-10; 0 being the worst possible and 10 being the best possible). This is a slight decrease from 8.6 in 2016. When asked if they would recommend this LTC home to someone needing long term care, 64% of the respondents reported definitely yes, 27% reported probably yes, 7% reported probably no, and 2% reported definitely no.

Respondents were also asked if they felt that the protocols and restriction put in place during the pandemic have worked to keep their family member safe from getting COVID-19. Of the respondents, 73% reported definitely yes, 22% reported probably yes, 2% reported probably no, and 3% reported definitely no.

Family members also provided some general comments about their experiences. Comments included general concerns with policies and procedures in LTC, as well some suggestions to provide direct payment or automated withdrawal options for payments.

### **Strengths and Opportunities for Improvement**

Overall results indicate that there are many strengths in the services provided by CBLTC and the PCRs, including availability, kindness, and compassion of the health care staff and the involvement of family members in decision making. Respondents also reported being satisfied with the service providers, the overall care of their family member, and their own treatment by staff. Other overall strengths include cleanliness of public areas, overall noise level, and privacy.

Also admirable is that BSG LTC responded to the pandemic without any significant negative impact on family members' experience and satisfaction. When asked about the impact of the pandemic on their satisfaction with various aspects of their experience and their family member' care, the significant majority of residents reported no change or improvement in their satisfaction with the resident's and their own access to health care staff, the residents' access to programs and treatment, overall care, among other factors.

The survey results identified the following areas for CBLTC and the PCRs to explore for opportunities for improvement:

- Variety and frequency of recreation activities, included extended hours;
- Quality and variety of meals, as well as availability of something to drink;
- Staffing levels;
- Responses to resident behaviours such as yelling, pushing or hitting;
- Frequency of resident checks and changes, as well as responsiveness to buzzers;
- Fall prevention protocols and devices/alarm systems;
- Effectiveness of problem solving strategies and communication with families when concerns arise;
- Communication among health care staff, with a focus on care plans;
- Protection against loss or damage of residents' clothing and personal medical belongings; and
- Staff training opportunities regarding long term care, dementia, and dementia care.

The survey results also suggest that LTC leadership support families to be present and much as feasible and safe, as well as consider advocating for the designation of an essential visitor for every resident at all times.

## **Appendix A**

### **Western Health Family Experience Survey 2021**

# Long Term Care Family Experience Survey

This survey is part of our efforts to understand how families view their experience of having a loved one in long term care. Any information that you decide to share will help us identify areas for improvement. Western Health will post a summary of the information from all families who respond on our website: [www.westernhealth.nl.ca](http://www.westernhealth.nl.ca). This report will be available in September 2021.

If you prefer to complete the survey electronically, it is available here: [www.westernhealth.nl.ca/survey](http://www.westernhealth.nl.ca/survey)

We hope that you will take the time to complete the survey. Your participation is greatly appreciated. Your participation in this survey is voluntary and will not affect your loved ones health care. We have prepared the survey to be anonymous and will not identify you as a participant. Please complete the survey by June 25, 2021.

If you have any questions about the survey, please call Tracey Wells-Stratton, Regional Manager Research and Evaluation at (709)784-6801, or email her at [traceywells@westernhealth.nl.ca](mailto:traceywells@westernhealth.nl.ca). Thank you for helping to improve long term care in the Western region.

1. For this survey, the phrase "family member" refers to the resident in long term care. At which Long Term Care (LTC) facility does your family member live?

*Mark only one oval.*

- Dr. Charles L. LeGrow Health Centre (Port Aux Basques)
- Calder Health Care Centre (Burgeo)
- Bay St. George Long Term Care Centre (Stephenville Crossing)
- Corner Brook Long Term Care (Corner Brook)
- Protective Community Residences (Corner Brook)
- Western Long Term Care (Corner Brook)
- Bonne Bay Health Centre (Bonne Bay)
- Rufus Guinchard Health Centre (Port Saunders)

2. Overall, how would you rate this LTC Home? 0 is the worst possible & 10 is the best possible

*Mark only one oval.*

	0	1	2	3	4	5	6	7	8	9	10	
Worst possible	<input type="radio"/>	Best possible										

3. Is your family member now living in long term care?

*Mark only one oval.*

Yes Skip to question 5

No

4. Was your family member discharged from this facility or is he/she deceased?

*Mark only one oval.*

Discharged - if you checked discharged, please stop completing this survey and submit.

Deceased - If your family member is deceased, we understand that you may not want to fill out a survey at this time. If this is the case, please check the box indicating that your family member is deceased and submit the survey.

Deceased - If your family member is deceased, we understand that you may not want to fill out a survey at this time. However, if you would like to do the rest of the survey, we would be grateful for your feedback. Please answer the questions based on your family member's last six months at the nursing home. Thank you for your help.

5. In total, about how long has your family member lived in this LTC home?

*Mark only one oval.*

Less than 1 month

1 month to almost 3 months

3 months to almost 6 months

6 months to almost 12 months

12 months or longer

6. Do you expect your family member to live in this or any other LTC home permanently?

*Mark only one oval.*

Yes

No

I don't know / I am not sure

7. In the last 6 months, has your family member ever shared a room with another person at this LTC home?

*Mark only one oval.*

- Yes  
 No

8. Does your family member have serious memory problems because of Alzheimer's disease, dementia, stroke, accident, or something else?

*Mark only one oval.*

- Yes  
 No

9. In the last 6 months, how often was your family member capable of making decisions about his or her own daily life, such as when to get up, what clothes to wear, and which activities to do?

*Mark only one oval.*

- Never  
 Sometimes  
 Usually  
 Always

10. How would you rate your family member's mood or emotional well-being?

*Mark only one oval.*

- Excellent  
 Very good  
 Good  
 Fair  
 Poor

11. How do you feel your family member's mood or emotional well-being has changed because of the pandemic?

*Mark only one oval.*

- Significantly worse
- A little worse
- No change
- A little better
- Significantly better

12. During the last 6 months, how often did you have 'virtual visits' with your family member: talk on the phone or through video calls (FaceTime, Google Duo, etc.)?

*Mark only one oval.*

- Daily
- Several times per week
- Weekly
- Several times per month
- Monthly or less
- Do not have virtual visits    *Skip to question 15*

13. Why did you have virtual visits?

*Check all that apply.*

- I live far too far away for in-person visits
- I could not visit in-person due to visitation restrictions
- To have additional contact with my family member between my in-person visits

14. Over the past 6 months, did you have enough virtual visits to meet your family member's needs?

*Mark only one oval.*

- Yes
- No

15. Did the visitor restrictions implemented during the last 6 months of the pandemic change your in-person contact with your family member?

*Mark only one oval.*

- Significant decrease  
 Some decrease  
 No change  
 Some increase  
 Significant increase

16. Do you have any additional comments you would like to share about your experience with visits at the LTC home or changes to visits during the pandemic? If so, please explain:

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17. Over the past 6 months, were you designated as an essential visitor or support person for your family member?

*Mark only one oval.*

- Yes  
 No *Skip to question 28*

18. If you were a designated visitor or support person, about how many times did you visit your family member in the LTC home in the last 6 months?

*Mark only one oval.*

- 0-1 times in the last 6 months *Skip to question 28*  
 2-5 times in the last 6 months  
 6-10 times in the last 6 months  
 11-20 times in the last 6 months  
 More than 20 times in the last 6 months

19. Please answer the following questions based on your experience in the last 6 months.

Mark only one oval per row.

	Never	Sometimes	Usually	Always	Not applicable
How often did you feel that there was enough nursing staff in the nursing home?	<input type="radio"/>				
If you tried to find for any reason, how often were you able to find a health care staff when you wanted one?	<input type="radio"/>				
How often did you see the health care team treat your family with kindness?	<input type="radio"/>				
How often did you feel that the health care team really cared about your family member?	<input type="radio"/>				
Did you see any of the health care staff be rude to your family member or any other resident?	<input type="radio"/>				

20. In the last 6 months, how often did your family member look and smell clean?

Mark only one oval.

- Never
- Sometimes
- Usually
- Always

21. In the last 6 months, did you ever see the nursing home staff fail to protect any resident's privacy while the resident was dressing, showering, bathing, or in a public area?

Mark only one oval.

- Yes
- No

22. Sometimes residents make it hard for LTC staff to provide care by doing things like yelling, pushing, or hitting. In the last 6 months, how often did you see the health care staff handle this situation in a way that you felt was appropriate?

Mark only one oval.

- Never  
 Sometimes  
 Usually  
 Always  
 Not applicable - situation did not occur

23. In the last 6 months, during any of your visits, did you help with the care of your family member when you visited?

Mark only one oval.

- Yes  
 No

24. Do you feel the LTC staff expect you to help with your family member's care when you visit?

Mark only one oval.

- Yes  
 No

25. In the last 6 months, did you help your family member with any of the following during your visits?

Mark only one oval per row.

	No	Yes - Chose to help on my own	Yes - Staff did not help or made him/her wait too long
Help with eating	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Help with drinking	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Help 'toileting' - helping someone get on and off the toilet or helping change disposable briefs or pads.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

THE LTC HOME

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26. In the last 6 months, how often did the following occur?

Mark only one oval per row.

	Never	Sometimes	Usually	Always	Not applicable
Family member's room looked and smelled clean	<input type="radio"/>				
Noise level around family member's room was acceptable	<input type="radio"/>				
Able to find places to talk to family member in private	<input type="radio"/>				
The public areas of the LTC home, such as the main entrance and dining areas, looked and smelled clean	<input type="radio"/>				
Personal medical belongs (hearing aides, eye glasses, dentures, etc.) were clean and in good condition	<input type="radio"/>				
Personal medical belongs were damaged or lost	<input type="radio"/>				
Clothes cleaned by LTC's laundry services were damaged or lost	<input type="radio"/>				

27. Do you have any additional comments you would like to share about your experience with cleanliness, noise level, or personal belongings the LTC home? If so, please explain:

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YOUR EXPERIENCE WITH LTC STAFF

28. In the past 6 months, how often did you experience the following with the LTC health care team:

*Mark only one oval per row.*

	Never	Sometimes	Usually	Always	Not applicable
You were treated with courtesy and respect	<input type="radio"/>				
You received the information you needed about your family member	<input type="radio"/>				
Things were explained to you in a way that was easy to understand	<input type="radio"/>				
You were discouraged from asking questions about your family member	<input type="radio"/>				

29. At any time in the last 6 months, were you ever unhappy with the care your family member received at the LTC home?

*Mark only one oval.*

- Yes  
 No *Skip to question 32*

30. Did you talk to any of the LTC staff about these concerns?

*Mark only one oval.*

- Yes  
 No *Skip to question 32*

31. How often were you satisfied with the way the LTC staff handled the concerns?

*Mark only one oval.*

- Never  
 Sometimes  
 Usually  
 Always

32. In the last 6 months, did you ever stop yourself from talking to any LTC staff about your concerns because you thought they would take it out on your family member?

*Mark only one oval.*

- Yes  
 No

#### CARE OF YOUR FAMILY MEMBER

33. In the last 6 months, how often were you involved as much as you wanted to be in the decisions about your family member's care?

*Mark only one oval.*

- Never  
 Sometimes  
 Usually  
 Always  
 Not applicable - not involved in care decisions

34. An interdisciplinary care conference is a meeting about care planning and health between a care team and resident and his/her family. In the last 12 months, have you been part of an interdisciplinary care conference, either in person, by phone, or by videoconference?

*Mark only one oval.*

- Yes  
 No - chose not to attend  
 No - not given the opportunity to attend  
 I don't know / I am not sure

35. In the last 6 months, how often did your family member receive all of the health care services and treatments they needed?

Mark only one oval.

- Never  
 Sometimes  
 Usually  
 Always  
 I don't know / I am not sure

36. Using any number from 0 to 10 where 0 is the worst care possible and 10 is the best care possible, what number would you use to rate the overall care your family member received at the LTC home?

Mark only one oval.

0	1	2	3	4	5	6	7	8	9	10	
Worst care possible	<input type="radio"/>	Best care possible									

37. In the past 6 months, how often were you satisfied with the care provided to your family member by the following services/providers?

Mark only one oval per row.

	Never	Sometimes	Usually	Always	Not applicable
Nursing Staff	<input type="radio"/>				
Nurse Practitioner / Doctor	<input type="radio"/>				
Occupational Therapy	<input type="radio"/>				
Physiotherapy	<input type="radio"/>				
Recreation Therapy	<input type="radio"/>				
Social Work	<input type="radio"/>				
Spiritual Care	<input type="radio"/>				

38. Over the past 6 months, how often were you satisfied with the following aspects of the meals provided to your family member at the LTC home?

Mark only one oval per row.

	Never	Sometimes	Usually	Always	Not present for meals
Visual appeal (how the food looked)	<input type="radio"/>				
Taste	<input type="radio"/>				
Temperature	<input type="radio"/>				
Mealtime experience (how meals are served)	<input type="radio"/>				

39. If someone needed long term care, would you recommend this LTC home to them?

Mark only one oval.

- Definitely no  
 Probably no  
 Probably yes  
 Definitely yes

40. How has your satisfaction with the following aspects of your family member's care changed because of the pandemic?

Mark only one oval per row.

	Decreased satisfaction	No change	Increased satisfaction	I don't know / I am not sure
Overall care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cleanliness of facility	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Meals - food provided	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Mealtime experience	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Your family member's access to health care staff	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Your family member's access to programs and treatments	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Your access to the health care staff	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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41. Do you agree that the protocols and restrictions put in place during the pandemic worked in keeping your family member safe from getting COVID-19?

*Mark only one oval.*

- Definitely no  
 Probably no  
 Probably yes  
 Definitely yes

42. Do you have any additional comments you would like to share about your experience with LTC staff and the care of your family member? If so, please explain:

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**YOU AND YOUR  
ROLE**

Please answer the questions in this section about your experiences. Please do not include the experiences of other family members.

43. In the last 6 months, how often did you get all the information you wanted about payments or expenses?

*Mark only one oval.*

- Never  
 Sometimes  
 Usually  
 Always  
 Not applicable - did not ask for information

44. In the last 6 months, did you help your family member with managing finances, such as paying bills or filling out insurance claims?

*Mark only one oval.*

- Yes  
 No

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45. Power of attorney is a legal document that allows you to make decisions about your family member's finances or property. Do you have the power of attorney for your family member?

*Mark only one oval.*

- Yes  
 No  
 I don't know / I am not sure

46. A substitute decision maker is a person who is at least 19 years of age who has accepted the responsibility for ensuring the prior health care wishes of a person, who is now incompetent, are communicated to and carried out by healthcare providers. If an individual had not appointed a substitute decision maker, legislation identifies a list of persons who may act in this capacity. Regardless of the relationship, a person can act as a substitute decision-maker only if they have had personal involvement with the incompetent person in the preceding twelve months. In the past, the substitute decision maker has been referred to as the next of kin. Are you your family member's substitute decision maker (next of kin)?

*Mark only one oval.*

- Yes  
 No  
 I don't know / I am not sure

47. What is your relationship to the resident?

*Mark only one oval.*

- My spouse/partner  
 My parent  
 My mother-in-law/father-in-law  
 My grandparent  
 My aunt/uncle  
 My sister/brother  
 My child  
 My friend  
 Other: \_\_\_\_\_

48. Considering all of the people who visit your family member in the LTC home, are you the person who has the most experience with his/her care?

*Mark only one oval.*

- Yes  
 No  
 I don't know / I am not sure

49. What is your age?

*Mark only one oval.*

- 18-24  
 25-34  
 35-44  
 45-54  
 55-64  
 65-74  
 75 or 84  
 85-94  
 95+

50. What is your gender?

*Mark only one oval.*

- Female  
 Non-binary  
 Male  
 Transgender  
 Prefer to self-describe:

51. What is the highest grade or level of school that you have completed?

*Mark only one oval.*

- Grade school or some high school
- Completed high school
- Post-secondary technical school
- Some university or college
- Completed college diploma
- Completed university degree
- Postgraduate degree (Master's or Ph.D)

52. What is your race/ethnicity?

*Mark only one oval.*

- White / Caucasian
- Indigenous / Aboriginal
- Multiracial / Multiethnic
- Other: \_\_\_\_\_

53. Did someone help you complete this survey?

*Mark only one oval.*

- Yes
- No

54. How did that person help you?

*Check all that apply.*

- Read the questions to me
- Recorded the answers I gave
- Answered the questions for me
- Translated the questions into my language

Other:  \_\_\_\_\_

55. Do you have any additional comments you would like to share about your your experience or your family member's care in this LTC home? If so, please explain:

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Thank You! Your opinions are very important to us.

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