Supplementary File 1: Analysis Working Document

Number of participants who provided data = 119

# How To Read This Document

This is a working document that contains the sequential analytical steps used to code and theme the qualitative data gathered through the Family Caregiving in Long-Term Care Survey.

To follow the sequence of analytical steps, you must start with the final major heading in the document (Step 1: Raw Data), and then work your way to the front of the document.

The analysis consisted of the following steps:

Step 1: Import the raw data into a word file. Print this raw data to allow for pen-and-paper coding.

Step 2: Create data tables for the data. Add a column for the codes, and then code the data using the results from the pen-and-paper coding exercise.

Step 3: Sort the two tables into clusters of similar codes. This was done by adding a new column, and then adding numbers to this column identifying the cluster to which a code was assigned.

Step 4: Sort and theme the code clusters by resorting the tables so that all clusters are brought together. Then perform a more granular sort on each of the numeric code clusters, adding a letter character (A, B, C, etc.) to the numeric identifier to indicate nuances of meaning within the cluster. Then create a header cell for each numeric cluster, and place within this header cell a descriptor for the cluster, a count of codes within the cluster, and a descriptor of each subgrouping of codes that indicates a nuance of meaning. (Note: a quality assurance step was conducted before step four was completed, by which a second analysis reviewed the word done to this point and made suggestions for changes and improvements. Several changes were made as a result of this quality step.)

Step 5: Create theme names and descriptions. This was done by using the overall cluster descriptor as the basis for a a topic sentence for an opening paragraph on the cluster, and then using the subgrouping descriptor as the topic sentence for a paragraph about each nuance of meaning that makes up the cluster. In addition, quotations were extracted from the data to illustrate the overall theme and the more nuanced meanings.

Step 6: Perform some comparisons on the themes. This was done by creating tables showing the number of instances of the coded data for each theme, the theme name, and the theme description. The tables were sorted to compare the data in terms of the number of occurrences of data elements associated with different themes.

Step 7: Create a general commentary on the themes. This was done by reviewing the work produced by step five, and noting interesting features about the patterns evident through the theming. At the conclusion of this step, the working document was shared with one other investigator, with a view to preparing the work to share with the full investigator team.

# The word cloud

The following is a word could generated with NVIVO on the raw data considered here:



# Step 7: Create a general commentary on the themes

The following two subsection contains the theme narrative for the data, along with some additional commentary.

Note that the theme narrative provides commentary on all themes in descending order of themes strongly grounded in the data (i.e. the first descriptive paragraph describes the theme associated with the most codes, the second paragraph describes the theme associated with the second-most codes, etc.”. This is not meant to imply that more numerous codes are necessarily the most important.

### Theme Narrative

The analysis allowed us to identify 13 themes:

* Serious problems and deficiencies are caused by this LTC home’s culture, management, staff, policies, and practices (numeric code 4, associated with 72 data elements)
* Families are (or should be) a full part of the care team in long-term care homes (code 1, 32 data elements)
* Some long-term care homes and their staff and volunteers were described in extremely positive terms (code 11, 27 data elements)
* LTC staff behavior is characterized by neglect and incompetence, and family members are treated with resentment or indifference (code 2, associated with 26 data elements)
* Long-term care’s deficiencies cause suffering among family and necessitate extra efforts and expenditures (code 6, 16 data elements)
* The LTC home and staff try hard, but there are problems, including a lack of interaction (code 10, 15 data elements)
* The deficiencies and shortcomings of long-term care are systemic and can be found throughout the entire sector (code 5, 13 data elements)
* The rules imposed in long-term care homes during the pandemic have contributed to sharp declines in health and wellbeing (code 12, 13 data elements)
* There is insufficient staffing in long-term care homes (code 3, 12 data elements)
* The situation in long-term care homes could be improved through staff training and improved communications (code 7, 8 data elements)
* Despite the current difficulties, family members must cooperate with managers and staff in long-term care homes (code 14, 6 data elements)
* Family Councils are (or could be) a useful resource to support families and residents (code 8, 3 data elements)
* The long-term care sector needs national standards and a better deal for frontline workers (code 9, 3 data elements)

The following paragraphs describe the meaning associated with these themes. The themes are described in the same order as the above list, with a separate paragraph describing each theme.

The culture, policies, practices, management and staff of LTC homes, in other words the LTC home as a whole, gives rise to numerous negative or even horrific experiences for both residents and family members. We were told of a general malaise and/or numerous problematic situations arising in homes, of endemic poor care and neglect, and of needless suffering. In some cases it seemed that LTC homes had prioritized items such as staff contentment, diminishing or suppressing complaints, financial success, or procedural convenience, over and above resident care and wellbeing. Not surprisingly, we heard numerous specific stories of bad experiences related to specific residents and homes.

Many participants asserted that family members are (or should be) full members of the care team in long-term care homes, so they may be able to provide the care needed by residents. Some suggested that without the presence of family, the level of care is likely to decline to unacceptably low levels.

In describing their negative experiences with long-term care, many participants singled out the poor behavior of LTC frontline staff and spoke of unacceptable levels of incompetence and neglect. Participants said that staff often seemed to resent them, that communication was frequently poor, and that staff workload may have contributed to this unfortunate situation.

Some participants said that their residents lived in good long-term care homes with staff that are (for the most part) wonderful and caring. We were told of positive and respectful workplaces, with amazing staff and volunteers.

The shortcomings and problems in the long-term care sector have produced worry and suffering, and have led some families to pay for additional care in order to ensure the health and safety of their residents.

Some participants acknowledged how difficult the frontline staff job is, and acknowledged the efforts made by many of these staff, but nonetheless indicated that the quality of care and life for residents is unacceptably poor. Some specifically mentioned the lack of social interaction and loneliness that characterizes life in a long-term care home. Others emphasized that the problem primarily stems from the way frontline staff work is organized and managed.

Several participants suggested that years of government neglect has produced a failed LTC sector in Ontario. Some of those who offered sector-wide comments called for an end to for-profit long-term care. Some participants noted that the neglect, abuse, and other shortcomings of LTC homes results in families stepping in to provide additional support for their resident, and this increasing role of families tends to shore up the systemic deficiencies of long-term care.

Several participants reported that during the pandemic the health and wellbeing of their resident declined, and sometimes declined rapidly and badly. Other participants described how difficult it was to follow the overly restrictive rules imposted by the LTC home during the pandemic. Some participants have found the pandemic rules to be unfair and possibly even inhumane, reducing a long-term care resident to the status of a prisoner.

Insufficient staffing in long-term care homes make it difficult or even impossible for the homes to provide an adequate level of care for residents. This situation also puts additional pressure on existing staff, and as well as creating problems for residents and family members.

Some participants considered ways of improving the deficiencies evident in long-term care, and offered comments and suggestions related to the need to provide more training for staff, and to create more extensive two-way exchanges of information between homes and families.

Family Councils are a useful resource that can support all residents in a facility, including those whose families do not live nearby, and should be run in a manner that makes it possible for all family members to participate and have a voice.

Some called for improvement focused on the entire long-term care sector, and called for government action to create national standards for care. There was also a desire for greater accountability, and for improvements in the pay scales for frontline workers.

A few participants said that family members should be civil and cooperate when in long-term care homes, and suggested that some responsibility for the difficulties experienced in the sector may stem from family members.

### Additional Commentary

An overall tendency evident in the data is that participants will often describe general or specific experiences, and then will explain the meaning or significance of those experiences.

The themes display a tension between positive and negative comments about the Ontario long-term care homes, with more critical or negative comments than positive.

Some negative comments focus on the LTC home as a whole (its culture, management, staff, policies, and practices). Others focus on staff behavior that is said to be neglectful, incompetent, resentful, or indifferent. Still others suggest that the deficiencies are characteristic of the sector as a whole and should be viewed as systemic problems.

These comments that focus on problems and that then attempt to ascribe responsibility move from the personal to the impersonal. Some comments appear to commit the fundamental attribution error, ascribing blame to the traits of specific staff members. Others look for situational factors that could be giving rise to the negative experiences, and end up noting deficiencies embedded in a home’s way of operating or in the government’s handling of the overall long-term care sector.

The fourth-strongest theme includes acknowledgements of the good fortune experienced by family and residents when the resident is placed in a LTC home that is described as wonderful or amazing. If we compare the number of instances of positive and negative comments, however, one could argue that the coding reveals 165 negative and only 20 positive assertions. We must be cautious with these numeric comparisons, though, because in a few instances the same data element is associated with more than one code, and thus we may be double-counting some elements.

The importance of family, and the role of family in providing care to residents, is clear throughout the data. The second-strongest theme numerically is the assertion that families should be an integral part of the care team. Even many negative comments include statements confirming the vital caregiving role played by family.

Participants sometimes suggest ways of improving the deficiencies of long-term care. The suggestions include integrating families more fully with the long-term care care team, increasing the numbers of frontline staff, provide more staff training, improving the two-way communication between homes and families, making better use of Family Councils to support families and residents, providing better compensation for frontline staff, and creating national standards for long-term care.

# Step 6: Some comparisons on the themes

**Most numerous themes from all of the data:**

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| **# \*** | **Theme Name** |
| 72 | (Code 4): Serious problems and deficiencies are caused by this LTC home’s culture, management, staff, policies, and practices |
| 32 | (Code1): Families are (or should be) a full part of the care team in long-term care homes |
| 27 | (Code 11): Some long-term care homes and their staff and volunteers were described in extremely positive terms |
| 26 | (Code 2): LTC staff behavior is characterized by neglect and incompetence, and family members are treated with resentment or indifference |

\*Number of times the code appears in the data.

# Step 5: Create theme names and descriptions

In this step the first analyst created theme names and descriptions for all of the clusters. The following procedure was used. First, the analyst copied the two cluster tables from step 4 into this area of the document. Then the analyst merged all of the data cells (in the right-most column” for the first subcluster of codes for the first cluster (the 1A codes, in other words). Then the analyst read through the code names and data for the cluster. At this point the analyst began to write a description of the meaning of this subcluster of codes, drawing on wording from the code names and the data, and incorporating quotations to ensure that the description remained close to the data. This procedure was continued with each subcluster of codes (1B, 1C, etc.). When all of the subclusters were complete, the analyst wrote a brief paragraph as the overall theme description, in some cases simply drawing on the topic sentences for each subcluster description. Finally, after reviewing the results of this work, the analyst gave a name to the theme.

This procedure was applied to each numeric cluster in data.

## Data Clusters with Names and Descriptions

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| Theme Name (Code1): Families are (or should be) a full part of the care team in long-term care homesThere are 32 instances of codes associated with the number 1.Many participants asserted that family members are (or should be) full members of the care team in long-term care homes, so they may be able to provide the care needed by residents. Some suggested that without the presence of family, the level of care is likely to decline to unacceptably low levels. Presence of family has provided company and fended off loneliness, and has allowed family to provide support in a variety of ways.1A was associated with codes that involved simple assertions about families being on the care teamMany of our research participants stated in a clear and emphatic manner that families are an essential part of the care team that provides care to a resident. Just as LTC staff have a particular role in the delivery of care, so too do family members. Staff and family must work together as an integrated and supportive team to ensure that residents receive the appropriate level of care. Some residents with special needs or circumstances (including health conditions and language barriers) will particularly benefit when family members are fully involved in the care process. The involvement of family members can compensate for inconsistencies in care delivery that occasionally arise in the LTC setting, and can also relieve staff of some of the care burden. Family involvement was said to be *essential* and *critical*. It help the resident to feel known and loved, and it also serves to remind staff that people are present who are dedicated to the idea that all reasonable steps must be taken to ensure the safety and wellbeing of the resident. 1B was associated with codes asserting the importance of the care provided by family membersThe importance of family participation stems in part from the likelihood that family will ensure that all aspects of health and psycho-social care are properly attended to. This is in part a necessity because of the ongoing understaffing problem in LTC homes, and also because as a resident ages their needs are likely to increase, and family members are more likely to notice and respond to this changing situation. Some participants felt that residents require assistance from family members on a daily basis, to ensure that the resident is able to enage in activities, interact with other people, and enjoy time out of doors. Family members must also advocate for their resident, help with health concerns, and participate in numerous other activities involving such things as finances, hair salons and barber shops, physiotherapy appointments, family celebrations, outings to restaurants, and so on. Participants emphasized the importance of continuing to participate in the life of the family, and some lamented the restrictions imposed by the pandemic. Others noted that it is evident that visits from family members can allow the resident to feel informed, connected, and happier.1C was associated with codes linking family care or participation with resident wellbeing or healthSeveral participants emphasized the extent to which family members contribute to resident wellbeing and happiness. Participants mentioned the positive effects of spending time together in conversation, or playing a game, performing a chore, or decorating a room. They also emphasized the importance of the activities provided by the LTC homes, particularly for residents living with dementia (and some suggested that people with demential should be brought to these activities rather than simply invited and allowed to decline), and expressed the concern that without these activities the residents are left inert and inactive like “a body filling a space.” Interacting with family also gives a resident a sense of having some control over life, and of staving off the danger of loneliness. As one participant observed, “I hate to think what my mothers life would be like if she did not have family visiting and advocating for her.”1D was associated with codes asserting the importance of family presence for monitoring care and wellbeingParticipants also emphasized that family presence is necessary to ensure that the LTC leaders and staff provide the necessary care. We heard of the need to be constantly vigilant and watchfaul, to play the role of the advocate, and to cope with the stress that this constant monitoring puts on the family. One participant mentioned feeling “as though you must watch literally everything they do,” and another described having “to stand over a nurse or a director of care to get them to attend to it.” Another said that after discussing the need for some aspect of care to be adjusted for her resident and would then go to the LTC home to ensure that the work had been done, and added that “it turned out to always be necessary.” |
| Theme Name (Code 2): LTC staff behavior is characterized by neglect and incompetence, and family members are treated with resentment or indifferenceThere are 26 “2” codes.In describing their negative experiences with long-term care, many participants singled out the poor behavior of LTC frontline staff and spoke of unacceptable levels of incompetence and neglect. Participants said that staff often seemed to resent them, that communication was frequently poor, and that staff workload may have contributed to this unfortunate situation.2A deal with staff neglect, incompetence, and poor behaviorParticipants made numerous comments relating to staff neglect, incompetence, and poor behavior. Staff were said to be “always rushing to get [residents] to bed so they don’t have to work anymore,” and to be “very task oriented” and “negative in their communication with residents.” Some went so far as to say that the care received by residents was “not humane,” and pointed out that this deficiency existed before the onset of the pandemic. Participants described hearing stories from their residents about “an uncaring, rushed and cold hearted rude, rough staff member.” These problems were said to be compounded by the LTC home reliance on temporary replacement staff who would be called in to help cope with shortages, and who were said to “not know how to care for a resident.” However, although some said that most regular full time staff do a good job, others said that even full-time staff were lacking in the skills and competencies needed to work with the frail elderly. We heard that LTC staff must be held accountable for providing quality care to LTC residents.These problems have worsened during the pandemic, with participants noting that the level of care and/or staff attentiveness has declined. One participant lamented that “an ‘air’ of complacency/lassitude is quite prevalent among staff.”2B deal with staff resentment toward and lack of appreciation of familyParticipants also emphasized that some staff actively seem to rebuff families as they attempt to make useful contributions to care, and seem threatened by family members. Staff sometimes act as though questions are suggestions are forms of criticism, and adopt an “us and them” attitude toward family rather than seeing family as members of the care team. One participant said that even when PSWs provided help, they did so “with a ‘you’re bothering me’ negative attitude” even when family members showed appreciation and made efforts to not ask for too much. Some lamented a lack of empathy on the part of LTC staff, and told stories of churlish or resentful behavior. As one participant said, “sometimes I come in and my mom’s underbriefs are wet and all bunched up and uncomfortable, and I have to ask for them to clean her up and change her. Some staff will try to convince me that my mom is OK the way she is and when I insist and they do as I ask, they do it with resentment even though after it has been done, my mom is clearly more comfortable. I have asked that they change my mom regularly mid morning and mid afternoon and it is not done unless I am there and ask for it to be done.” Another told us of feeling “like we were intruding or bothering staff if we called to ask questions on the phone or stopped to ask them something in the hallways.” Even when a family member covered off PSW duties with her resident, thus freeing up the PSW to attend to other duties, no appreciation is shown, and the effect has been that staff make no effort to get to know this family member’s resident.2C deal with poor communication between staff and familyUnhelpful staff behavior includes poor, and sometimes even dishonest, communication. Participants report not being told about changes in care, or about changes requested by family not being added to the care routine. One participant said that “Staff would cover things up, make excuses,” and others complained about not being told about medication changes. As one participant explained, “More communication from staff would be of benefit to me. I know there is a lot to do and only so much time but being more aware of changes in my family member’s behaviour would help me do a better job of helping to meet their needs.”2D deal with staff needing help from family but lacking the time to engage and understandWe were also told that staff sometimes were too busy to communicate with families or to form a bond with the resident. One participant said, “My experience was that my involvement was sometimes viewed as unwelcome, and it was often a struggle to engage fruitfully with staff. Partly that was because staff were too overburdened to engage in a constructive manner.” Another said that staff seemed to think that she ought to keep them informed, but they had no reciprocal obligation.  |
| Theme Name (Code 3): Insufficient staffing in long-term care homes There are 12 instances of code 3.Insufficient staffing in long-term care homes make it difficult or even impossible for the homes to provide an adequate level of care for residents. This situation also puts additional pressure on existing staff, and as well as creating problems for residents and family members.3A call for LTC homes to have sufficient staff to do the necessary job.Several participants stated that it is important for there to be enough staff in LTC homes. At the moment, too many homes are inadequately staffed, and family members worry that this will result in neglect, and also in unfamiliar temporary staff providing care (which could be especially difficult for residents with dementia). This was also mentioned as a reason why family must make extra efforts to be onsite as often as possible, to make sure that their resident is receiving appropriate care. We were told that staff shortages meant that staff were unable to interact with residents, and sometimes seemed to forget to feed residents. Others said that staffing shortages meant that existing full-time staff were overworked and tended to burn out, which served to aggravate the existing problems. As one participant commented, “Unfortunately our LTC homes in Ontario are not provided with adequate staffing, so the staff members can only provide the very basic care for the residents. That is why the presence of the caregiver is essential to the overall well being of the resident.” Another, expressing frustration about these shortages, said that the result is “NO CARE.”3B identify staffing issues such as overwork and turnover.Other participants focused more on the problems caused by staff shortages, turnover, and overwork. We were told that “PSWs do not have time to sit and talk with residents - they are always on the run.” We also learned that turnover makes it more difficult for PSWs to get to know the residents they care for, and makes it more likely that a resident will receive some modicum of attention and then be left neglected while staff move on to other tasks. |
| Theme Name (Code 4): Serious problems and deficiencies are caused by this LTC home’s culture, management, staff, policies, and practicesThere are 72 “4” codes.The culture, policies, practices, management and staff of LTC homes, in other words the LTC home as a whole, gives rise to numerous negative or even horrific experience for both residents and family members. We were told of a general malaise and or numerous problematic situations arising in homes, of endemic poor care and neglect, and of needless suffering. In some cases it seemed that LTC homes had prioritized items such as staff contentment, diminishing or suppressing complaints, financial success, or procedural convenience, over and above resident care and wellbeing. LTC homes sometimes ignore suggestions from residents and family, and do not hold enough care conferences during the year. Not surprisingly, we heard numerous specific stories of bad experiences related to specific residents and homes.4A – This LTC home treats families and residents poorlyMany participants described concerns and problems that emanated from the long-term care home as a whole, including its policies, practices, management and staff. One resident recited a litany of issues that were present both before and during the pandemic, including “insufficient staff, lack of training, lack of supervision, PSW’s were poorly paid, had no benefits, making it necessary for them to work in more than one home …LTC processes, systems were broken or non existent …internal and external communications with staff & families.” We were told that family are excluded from care plans and from activities in the home, and that facilities can be “dangerously disorganized” and that the participant had witnessed residents dying needlessly “from inadequate wound care.” One participant, reflecting on her decision to place her husband in a home, said “I was forced to abandon my husband to these people! These have been the darkest days of my life and I doubt that I will ever recover completely.” We were told of a lack of trust and respect, of families feeling like they are being spied on, and of a need to appear compliant and to cater favour with “the bosses.” Many disturbing terms were used: brutal, threats, inept, ageism, horrible, mistrust, and distress. Some homes respond only to complaints, and engage in little or no communication with family. One respondent said that the problems are related to “the way the whole system is designed, including the physical structure itself.” Some participants said that they no longer try to engage fruitfully with the home, because they have been rebuffed too many times. The overall tone of these comments is that family simply must function as advocates, and their advocacy is usually unwelcome and is often ignored.4B – This home has some specific and serious problemsSeveral respondents wanted to catalogue a variety of specific problems, errors, and shortcomings that they had encountered in their resident’s home. We were told of complicated and error-prone admissions processes, and the lack of wifi, digital devices, and videoconferencing capability. Several participants pointed our problems related to food quality, nutrition, and diet, and insufficient fluids. We were told about poorly organized and attended care conferences, about delayed and inadequate palliative care, and about unworkable and undignified bathroom arrangements. These situations caused considerable distress among our respondents, leading one person to write: “Where is the quality of life when there are no choices but to place your most precious loved one? We live in a bountiful farm community, that these fragile elderly loved ones have no access to once they are placed!”4C – Residents without family are sufferingSeveral participants indicated that during their visits to the LTC home to provide care to their resident, they became concerned for the wellbeing of residents who seemed to receive few visitors. Some indicated that residents who were living without family caregivers who could provide support and advocacy were at a clear disadvantage, and perhaps even experienced neglect or even suffered. Some said that they would assist these residents because it was so obvious that they needed help. One person commented, “I worry about the people who do not have family to keep watch for their loved ones…” And another lamented, “But what about other people on my mother’s floor? Some only had a visitor once a week if that! There just wasn’t enough staff to talk to residents or communicate with residents or feed residents. Also, my sister and I helped other residents at times with feeding and with getting staff to assist them.” Later this respondent added, “Frankly, if my mother hadn’t had us visiting (visiting? We worked like dogs!), she would have acted out and had to be medicated because she was so disabled or she would have shut down and had a much worse time of it than she did.” Another participant said that she saw neglected residents who did not have family advocates seem to “shrivel away” and die over a number of months.4D – Poor care and neglect are characteristic of this homeAs if these accounts were not sufficiently disturbing, other participants told us that poor care and serious neglect seemed to be a basic characteristic of the long-term care home. One participant spoke of witnessing “substandard medical services provided to the residents in our LTC facility, care that would be deemed unacceptable in any other health care setting.” We heard of “unnecessary suffering” and needless trips to the hospital emergency room, and of residents not being given a meal or being served with food that the resident was not able to eat. One participant said, “Everyone I know who has a loved one in that establishment wants assisted suicide rather than being moved there in case of dementia. That is how bad our system is.” Another said they “could write a horror story about seniors’ residences” and then related stories of soiled diapers lying on the floor, of faecies on a bedroom floor, and of clothing and other personal items vanishing from resident rooms. We were told of untended bedsores, of unacceptable and sudden weight gain, and of “appalling” care. One person said their mother was administered suppositories that caused severe diarrhea that became life threatening, and that this occurred more than once. We also heard of wrong-headed policies such as a refusal to post an allergy alert by a resident’s bedside because of privacy issues. Participants spoke of a shameful need to closely monitor care, and of “horrific experiences” during end-of-life care. Residents in LTC homes are compared to prisoners, and one participant said that assisted suicide should be an option for people living with Alzheimer’s disease.4F – This home is acting on the wrong prioritiesParticipants described behaviour, policies, and decisions that suggested that some LTC homes are not prioritizing the needs, care and wellbeing of their residents, but instead are motivated by other priorities. We were told of a home whose management is very sympathetic to the demands of the staff union, such that the needs of staff are top of mind and resident are relegated to the status of “innocent, helpless bystanders.” Some family members have faced threats of legal proceedings from homes, and have noticed that rules and policies focus on limiting legal liability rather than maximizing resident wellbeing. Others have noticed that residents with less money are given less attention and care. Several participants indicated that for-profit homes important services may be withheld. One participant said that during the pandemic they and their resident were summoned “…into a small room to discuss arrears and lecture, yes lecture, a 78 year old man with dementia on how to live within his means.” Another participant said that “…Administrators are invisible and not accessible and yet they have power to make policies that are designed as a one-size-fits-all approach.”4E – I can tell disturbing stories of neglect and incompetence at this homeNot surprisingly, we heard numerous stories of neglect and competence related to specific family members and residents. These are merely a few examples:* Mom called me a few times at 6:30 at night to say she had not been given dinner so I drove over with food. I found if I called in a request in response to a phone call from my mom (she needs to be changed/she hasn’t had dinner) the nurse did not ensure the request was met. I always followed up my phone call with a drive over and it turned out to always be necessary.
* An ongoing issue throughout the home was residents not being changed when a change was needed. I saw feces leaking from a resident that asked for a change for over an hour. I asked the PSW for help, another caregiver made the same request. It was ignored.
* I saw my mom Mar 14/20 and she was missing her dentures and the staff found them under her be 8 weeks later – during a pandemic what are the cleaning staff doing – 8 weeks under her bed – no she has been without her glasses for 7 weeks now and no one care where her glasses are – WHAT KIND OF CARE ARE WE PAYING FOR – I am disgusted with the level of indifference to the care of the residents
* I am shocked at the lack of infection control and cleanliness in the facility – it always smells like poop
* with the arrival of the pandemic the situation in LTC has been horrific and they still are horrific 14 months later nothing has changed and the care is non existent – we should all be ashamed of what is happening in LTC
* my mom is not the same person she was 14 months ago and I blame the LTC system for it’s complete failure to protect and care for our most vulnerable citizens. SHAME ON ALL OF YOU
* The Administrators and Unit Managers were not empathetic and in some cases they created a ‘toxic environment’ for their employees, residents and caregivers.
 |
| Theme Name (Code 5): The deficiencies and shortcomings of long-term care are systemic and can be found throughout the entire sectorCode 5 has 13 instances Several participants suggested that years of government neglect has produced a failed LTC sector in Ontario. Some of those who offered sector-wide comments called for an end to for-profit long-term care. Some participants noted that the neglect, abuse, and other shortcomings of LTC homes results in families stepping in to provide additional support for their resident, and this increasing role of families tends to shore up the systemic deficiencies of long-term care.5A – The current LTC sector is a failureSeveral participants suggested that years of government neglect has produced a failed LTC sector in Ontario. One participant reported having “… seen how the various governments over decades did not act on the many commission reports, submitted long before Covid-19. Our loved ones were abused, neglected and the presence, involvement of families enabled the LTC sector to be maintained. I and many others chose caring for our loved ones over working, saving and planning for our own retirements and elder care. I advocated endlessly to no avail and listened to promises never kept.” This view was shared by several others, to talked about ongoing advocacy, broken promises, and a growing sense of distrust in the long-term care system. As one participant noted, “The system is deeply flawed and under funded. Caring for people should not be done in this big institutional way. It didn’t work for schooling Indigenous children…Care to seniors should be provided at home for as long as possible with home care services. The few people who require institutional care should be cared for in small facilities where there is adequate staff paid wages that fit the work they do.” Others agreed that the system should be realigned so the elderly can remain in their homes, with funding redirected to support this. 5B – For-profit LTC is especially poor and should be endedSome of those who offered sector-wide comments called for an end to for-profit long-term care. One participant asserted that care is better in not-for-profit homes, and asserted “Privately run for profit LTC needs to end.” When profit and financial gain enter the picture, priorities become skewed and profits take precedence of resident wellbeing.5C – The efforts of family caregivers can shore up the failure and this is wrongSome participants noted that the neglect, abuse, and other shortcomings of LTC homes results in families stepping in to provide additional support for their resident, and this increasing role of families tends to shore up the systemic deficiencies of long-term care. One person commented, “Our loved ones were abused, neglected and the presence, involvement of families enabled the LTC sector to be maintained.” Another talked about the under-funding of LTC facilities and the chronic staff shortages, and acknowledged that “We need to fill the gap....or the system falls apart.” |
| Theme Name (Code 6): Long-term care’s deficiencies cause suffering among family and necessitate extra efforts and expendituresCode 6 has 16 instancesThe shortcomings and problems in the long-term care sector have produced worry and suffering, and have led some families to pay for additional care in order to ensure the health and safety of their residents.6A – Families suffer because of the way the LTC sector operates, especially during the pandemicParticipants told us how difficult it can be to make the decision to more a parent into long-term care, and of the emotional, physical, and financial suffering that can ensue. However, it often turns out that long-term care is no solution at all. As one participant said, “I advocated endlessly to no avail and listened to promises never kept. Covid-19 clearly showed the ugly side of government, Families have realized their loved ones are most important to them. The hurt is still profound.” Another participant told a story about experiences in a home, and commented “Add Covid to that and I was forced to abandon my husband to these people! These have been the darkest days of my life and I doubt that I will ever recover completely.” Participants refered to long-term care as being akin to “human storage” that offers “zero quality of life.” Pandemic restrictions have made the situation even more difficult. Another participant said that it was positive to be able to enter into the long-term care home as an essential caregiver during the pandemic, but having to act as the only person allowed to take on that role has created strains and exacerbated stresses. Another told us that “…it is incredibly stressful and exhausting, to feel as though I must watch literally everything related to the care of my LO, due to a lack of trust in the way the whole system is designed. Of course, that feeling has increased dramatically during the pandemic. Treatment of family was poor and communication with management strained.” Another added, “During the pandemic, the limiting of family visitors and those deemed ‘essential’ has caused a great deal of stress and strife within the family.”6B – I provide and also pay for additional care to make up the shortfall in careIn addition to the stress and suffering that people have experienced, some participants indicate that they regularly pay out of pocket to provide additional care for their resident. This is done because without it, their resident will receive care that is “inept” or at an unacceptable caliber. Participants indicate that they are more aware of their resident’s health, prognosis, and favoured psycho-social behaviors. One participant indicated that between family and two privately hired PSWs, they provide a minimum of four hours additional daily care for their resident. This was done to ensure that the resident would “not suffer from isolation, neglect, lack of being outdoors, participation in activities, being changed when needed, being fed a warm meal, making sure baths were given and hair clean, we always brushed her teeth, PSW had no time to provide oral care.” Another participant indicated that they “provide the majority of daily care, all personal and legal matters, all feeding, laundry, arrange outside medical services to attend (Footcare, massage), entertainment and social ops, decisions re her care (med changes, dietary, etc), administer all meds and topical applications.” |
| Theme Name (Code 7): The situation in long-term care homes could be improved through staff training and improved communicationsThere are 8 instances of this code.Some participants considered ways of improving the deficiencies evident in long-term care, and offered comments and suggestions related to the need to provide more training for staff, and to create more extensive two-way exchanges of information between homes and families.7A – Staff need training to see the value of family caregivers, and to gain competence in providing careSome participants suggested that the major deficiency in long-term care homes has to do with staff competencies, and believe that the solution is to provide additional training for staff. As one person said, “I feel more training of staff is required as to how all these pieces come together and provide value in the level of care given to our loved ones.” Some suggested that additional training is especially needed in relation to caring for residents with dementia. Another participant spoke of their high level of involvement in the resident’s care, and of observing staff (including doctors and nurses) display biases concerning mental illness, and concluded that “staff lack insight into behaviours that indicate a problem (e.g. pain which can cause agression)” and that they mistakenly “focus on managing the behaviour as opposed to understanding the cause or trigger.” One participant pointedly asserted “I think more training is needed for staff --- I would urge trainers to clearly communicate and reinforce regularly the need to respect residents and be professional and attentive at all times.” This training should include helping staff to understand what it means to maintain the dignity of residents.7B – This LTC home needs to do more to communicate with familiesSome participants felt that the situation in LTC homes could be improved if the homes would show more trust in family members and establish more open two-way communication channels that would give both LTC staff and family members the chance to share concerns and initiative cooperative efforts. This communication should include all family members, and not be restricted just to the family member who has power of attorney, and could include general information that would allow family to understand the circumstances and care routines of their family member. Communication could also include day-to-day matters such as activities, menus, and upcoming meetings. One participant noted that the annual care plan discussion takes only fifteen minutes, and could be made more extensive and dynamic. |
| Theme Name (Code 8): Family Councils are (or could be) a useful resource to support families and residentsThere are 3 instances of this code.Family Councils are a useful resource that can support all residents in a facility, including those whose families do not live nearby, and should be run in a manner that makes it possible for all family members to participate and have a voice.8A – Family Councils are (or could be) a useful resource to support familiesThough not a dominant theme in the data, three participants offered strong statements about the importance or potential importance of Family Councils in long-term care homes. One stated that Family Councils must be mandated in all homes, saying “These provide a critical link and safety mechanism for resident care, especially where some residents don't have family nearby, or family is absent from care.” A second agreed with this characterization of the councils, saying “The Family Council has also been a strong support for care-givers, providing information and an opportunity to talk to family members of other residents and share information and experiences.” Another said that “The family council meetings are a place to discuss items of common interest”, and indicated that these meetings are not accessible to all family because of how they are scheduled, and expressed a wish that the home “priorize opportunities for family member input and advocacy.” |
| Theme name (Code 9): The long-term care sector needs national standards and a better deal for frontline workersThere are 3 instances of this code.Some calls for improvement focused on the entire long-term care sector, and called for government action to create national standards for care. There was also a desire for greater accountability, and for improvements in the pay scales for frontline workers.9A – The LTC sector must be improvedThe participant data includes some concise comments about the need to improve the long-term care sector. After describing some negative experiences, one participants called for programs that allow elderly people to remain at home for as long as possible, and for national standards and compliance processes: “This is not an isolated case as we have seen. There needs to be enforceable national standards in LTC. There need to be enforceable penalties for noncompliance. There needs to be adequate and affordable home support so elders can remain at home longer.” A second participant also called for the need for a national standard of care for all residents, including those who cannot advocate for themselves: “There ought to be a standard across the board and every resident ought to get the same good care whether a family member is with them or not.” A third, lamenting the situation that developed at the start of the pandemic, called for governments to take action, with a particular focus on frontline staffing and an end to for-profit homes: “I feel we need both the Federal & Provincial Governments to make Long Term Care reform a priority starting with PSWS getting the recognition they so rightly deserve starting with their wages so it will attract dedicated people to take proper care of our most vulnerable. Proper care means legislating more time to care for them and taking the for profit out of equation,” |
| Theme Name (Code 10): The LTC home and staff try hard, but there are problems, including a lack of interactionCode 10 has 15 instances.Some participants acknowledged how difficult the frontline staff job is, and acknowledged the efforts made by many of these staff, but nonetheless indicated that the quality of care and life for residents is unacceptably poor. Some specifically mentioned the lack of social interaction and loneliness that characterizes life in a long-term care home. Others emphasized that the problem primarily stems from the way frontline staff work is organized and managed.10A – The home and most staff try hard, but there are still problemsSeveral participants made positive or somewhat positive comments about the home and staff, and then went on to describe their negative experiences of assessments of the home. The following comments sum up the overall sense of this data: “I found the staff and facility provided reasonable care within the system as it is structured.” Another commented: “I witnessed how difficult care workers’ jobs were every time I visited, which helped me understand why they had little to no time for quality person-centred care.” One person said their mother was well cared for but experienced loneliness, and wondered if it could not be possible for staff to create the conditions for more interactions among residents. Another said that staff did a good job when they were present, but the problem was that staff were rarely present, and family needed to make up this shortfall. Variations on this “good, but…” construct took a variety of forms. Some indicated that staff were both good and poor: “Some staff are excellent and some do not seem to care and appear not to be really interested in providing compassionate care.” Others put the onus on family, saying that staff are doing their best and families should be cooperative and supportive. Another person stated their goal to ensure that their wife received excellent care, and that this was available from only some staff. This long quotation offers a poignant summation: “Some staff had excellent work ethic, they truly cared about the wellbeing and comfort of the resident and would do anything and everything to provide exemplary care. They would get to know the resident’s personal history, likes & dislikes, emotional & physical needs, medical issues (physical pain, emotional pain), family relationships, look at photos, sit and talk, answer the call bell as soon as possible, give gentle kind compassionate care when bathing, dressing, transporting, toileting etc. BUT, there were far too many other staff who worked only for a pay cheque, did minimal amount of work necessary to just get the job done and with no emotional support, personal involvement or extra time towards the resident. i.e. rush to get the resident toileted, washed & dressed in the morning to be in the dining room for breakfast (taking all of 10 minutes); rushed to do same tasks at nighttime for bed so the staff member could take a break (thus leaving resident uncomfortable in bed or in pain), rush the residents to eat their meals so staff could take his/her break; ignore call bells thinking it wasn’t important (“oh that person always rings bell for nothing”) thus leaving resident to soil their brief and be left sitting in personal waste matter mbarrassed and crying from shame), not listening or giving resident who has trouble speaking, time to try and speak when there is a problem, (causing frustration for resident and crying).”10B – One persistent problem is that residents lack social interactionSome participants drew particular attention to the lack of social interaction experienced by residents. Residents spend a great deal of time alone, and the busy frontline staff simply cannot provide the level and quantity of interaction that is offered by family. This was often said with a sense of rueful understanding for the workload of staff. However, the disappointment is clear: “I arrive for visits and find him in the middle of the day in his room, door closed, lights off, curtains closed, radio playing, screaming, face and ears extremely hot and red. I don’t know how long he has been left this way, without interaction.”10C – Staff behavior stems from the nature of the workThough there is clear disappointment concerning the sense of isolation and lack of interaction experienced by residents, these family members were loathe to put the blame on frontline staff. Staff are concerned firstly with delivering basic care, and they “barely have enough time to do the necessary care.” One participant described repeatedly witnessing the difficult work carried out by staff, adding that this “helped me understand why they had little to no time for quality person-centred care.” Participants also said “I don’t blame the staff” and “It’s not an easy job. They are overworked and underpaid!” |
| Theme Name (Code 11): Some long-term care homes and their staff and volunteers were described in extremely positive termsCode 11 has 27 instances.Some participants said that their residents lived in good long-term care homes with staff that are (for the most part) wonderful and caring. We were told of positive and respectful workplaces, with amazing staff and volunteers. Some participants talked about homes that provide excellent care and that treat residents with respect, warmth, and inclusivity. They also direct specific praise at the home’s staff.11A – This is a really good LTC homeSome participants stated that their resident is in a good long-term care home with wonderful staff. One participant said “I know my dad is liked and looked after and he is safe. The staff have been wonderful and especially during this covid time they have been kept us abreast of everything. We are very thankful and blessed.” Others commented that care in their home was above average, that the level of care is a comfort to them, and that staff work hard and do a good job. Another added, “All of my efforts to make my sister as happy as possible are rewarded with the realization that she is in a good home where we work as a team for her.”11B – The staff in this LTC home are wonderfulSome participants emphasized that managers and staff (or at least permanent, full-time staff) are friendly, compassionate, and competent. Staff were said to be proactive in seeking or sharing information, and care conferences were open and effective. One participant described having almost daily interactions with staff, and said their problems mostly had to do with other family members. Staff, including RNs, RPSn and PSWs, were described as wonderful, awesome, genuinely caring, and willing to share information. One person lamented that their parent is confused and is “closed to staff members,” while this family member trusts the staff’s abilities. We were told: “The LTC staff have been unstinting in their provision of care and support for, not just my spouse, all residents of the Home.”11C – The managers and staff at this LTC home do a good jobOther participants focused mostly on the competence and professionalism of administrators and staff, and on being treated like a member of the team. This has resulted in “positive, respectful, working relationships.” Another participant described the long-term care home as a “fantastic facility” with staff that are for the most part “very caring and compassionate.” Another described the long-term care home as “amazing” with wonderful staff, concluding “I am so happy to know he is loved and cared for and he really likes it there.”11D – The volunteers at this LTC home are wonderfulOne participant particularly extolled the work of volunteers and program managers.11E – We have several family members who visit our residentOne participant said that it was important and helpful to have several family visiting the resident. |
| Theme Name (Code 12): The rules imposed in long-term care homes during the pandemic have contributed to sharp declines in health and wellbeingCode 12 has 13 instances.Several participants reported that during the pandemic the health and wellbeing of their resident declined, and sometimes declined rapidly and badly. Other participants described how difficult it was to follow the overly restrictive rules imposted by the LTC home during the pandemic. Some participants have found the pandemic rules to be unfair and possibly even inhumane, reducing a long-term care resident to the status of a prisoner.12A – During the pandemic this LTC home could not cope and my resident’s health declinedSeveral participants reported that during the pandemic the health and wellbeing of their resident declined, and sometimes declined rapidly and badly. People mentioned isolation, confinement, and meaningful life interactions, along with the absence of normal interactions, family visits, and social activities, and an overall loss of capacity and independence. One participant described the altered condition of their father: “He went from being able to walk, converse, feed himself, pee, wash his hands, try to dress himself to losing 40 lbs, being confined to a wheelchair, unable to feed himself a diet that now consists of puréed food, unable to communicate, screaming most of the time.” Another participant described the dreadful effects of an injury: “She suffered a fall during the first 3 months of the pandemic, at her Retirement Home and because of the fear of attending a hospital / medical appointment did not receive the care she required in a timely manner. It was discovered a few months later, that the fall resulted in an L1 lumbar fracture which required hospitalization in July 2020, and subsequent LTC placement in August 2020, due to her health conditions and the injury resulted in her being wheelchair-bound.” Another described the rapid decline of their mother in the midst of “horrific” deprivation and treatment in a long-term care home. 12B – LTC rules during the pandemic have been difficult to follow and been needlessly restrictiveOther participants described how difficult it was to follow the overly restrictive rules imposted by the LTC home during the pandemic. One participant said that their father, who lives in a retirement home, was no longer permitted to visit his wife in an LTC home because he was unable to cope with the numerous procedures, rules, and technologies. Participants have found the pandemic experience to be unstable and a whirlwind that could include hospital visits, retirement homes, rehabilitation, respite care, as well as long-term care. Restricting essential caregivers to a single person has sometimes done little to help the situation, especially for residents whose families have difficulty in visiting the home. 12C – LTC rules during the pandemic have been unfair and possibly inhumaneSome participants have found the pandemic rules to be unfair and possibly even inhumane, reducing a long-term care resident to the status of a prisoner. One resident was quoted as saying, “I know what it is like to be captured. There are a lot of rules and because I am captured I have to listen.” A participant complained, “In my opinion, my mother has been denied her rights to see her spouse, visit with her 2 other children and grandchildren.” Another said, “In essence, she is a prisoner within her LTC home.” Another commended on the restrictions of the pandemic, saying “She has been a prisoner since.”  |
| Theme Name (Code 14): Despite the current difficulties, family members must cooperate with managers and staff in long-term care homesCode 14 has 6 instances.A few participants said that family members should be civil and cooperate when in long-term care homes, and suggested that some responsibility for the difficulties experienced in the sector may stem from family members. One participant expressed frustration at playing the DCP role but not having the ability to act as “power of attorney” for the resident.14A – Families should be civil and cooperative as they interact with managers and staff in LTCSome participants acknowledged the difficulties experienced during the pandemic, but added that family members must avoid negative clashes with the home and should try to create productive and cooperative relationships. One person said “I had family members who were creating negative and destructive relationships with all the staff, causing major conflict with all of their visits in LTC and in which police had to be involved.” Another added that “Families are important, however, families should not have the right to be abusive to staff and I do believe that the LTC homes should have the right to put measures in place for the public who are confrontational and who show destructive behaviours towards staff in the workplace as this affects their work.” The suggestion was made that the negative impression people have of long-term care may be partly due to media reports and information circulating on social media. |

# Step 4: Sorting and Theming the Data Clusters

In this step the data tables were sorted to bring together all data associated with the same number.

Before proceeding further, a quality assurance step was carried out. A second analyst reviewed all of the work done to this point in detail, considering whether any codes were improperly assigned, or other discrepancies or errors were evident. This analyst brought concerns (noted in 8 comments, and mostly having to do with other ways in which a piece of data might be coded) to the attention of the first analyst. The second analyst also identified some additional codes that could be added to the initial coding table. The two analysts met to discuss the comments, and reached agreement on how each should be handled. The first analyst then incorporated the changes into the tables in this section of the working document.

After this quality step was complete, the first analyst then continued with the sorting and theming task.

The first analyst then performed a more granular sort on each of the numeric code clusters. The analyst reviewed, for example, all codes associated with the number 1, and added a letter (A through D) to further sort the codes into more granular sets of meaning. In the case of these “1” codes, 1A was associated with codes that involved simple assertions about families being on the care team; 1B was associated with codes asserting the importance of the care provided by family members; 1C was associated with codes linking family care or participation with resident wellbeing or health; and 1D was associated with codes asserting the importance of family presence for monitoring care and wellbeing. The first analyst created a cell at the start of each numeric cluster, and used this to create a working title for the cluster, a count of the number of coded data segments in the cluster, and a brief description of each granular subcode.

The same more granular sorting (which served to distinguish slight differentiations in the meaning of numeric clusters) was performed for each cluster of numeric codes. This was done to ensure that these differentiations in meaning would be evident to the analyst before the code name and narrative were created.

As part of this step, the analyst considered whether numbers associated with fewer than 10 codes should be integrated or combined with the codes associated with another number. The single code 13 was added to code 10 as a result of this, and the single code 15 was added to code 14. The single code 16 was determined to be an outlier and was eliminated from the subsequent steps.

## Sorted and Themed Data

|  | **Code** | **Corresponding Data** |
| --- | --- | --- |
| Code 1 is about the importance of family for the care provided in LTCThere are 32 instances of codes associated with the number 1.1A was associated with codes that involved simple assertions about families being on the care team1B was associated with codes asserting the importance of the care provided by family members1C was associated with codes linking family care or participation with resident wellbeing or health1D was associated with codes asserting the importance of family presence for monitoring care and wellbeing |
| 1A | Families should be part of the care team | Families are an essential component in a resident's level of care - we are part of the team and we have a role to play.  |
| 1A | Families should be part of the care team | However each person within the home and the family need to work together holistically to provide the level of care our loved one needs.  |
| 1A | Families should be part of the care team | We have so much to offer. While the home was very short of staff I volunteered to take a course to learn how to transfer my husband safely in the sit to stand lift.  |
| 1A | Family should be part of the care team | I think it is extremely important to have family members involved in the care of their loved one as the care provided by the LTC staff is very inconsistent. |
| 1A | Families should be part of the care team | My Mom is legally blind and profoundly deaf so it was extremely important that I be a part of her care team.  |
| 1A | Families should be part of the care team | With appropriate training, family members/care partners are in a unique position to assist in LTC, taking some of the burden off staff.  |
| 1A | Families should be part of the care team | Family members want to be a part of the "care team" and to be fully involved in every level of care. |
| 1A | Families should be part of the care team | It’s essential! |
| 1A | Families should be part of the care team | Critical. Being able to be part of my mom's life is critical to her care. The more involvement, the better off she is. Its not just that she knows she loved, but that staff understand that there will be somebody there often to make sure everything is being done in their power to ensure she is safe and well.  |
| 1A | Presence of family is very important | The presence of the family caregiver is very important, especially when the resident cannot look after herself, cannot make decisions, or is not capable of initiating actions. Also when language barriers exist, the caregiver role is very important.  |
| 1A | Presence of family is very important for residents | It is important to be able to provide company and support for the residents. This includes: technology support to allow for 'family visits', providing a familiar face and a hug from home, picking up odds and ends that a resident needs, hooking up telephones and doing other small tasks to make the resident feel comfortable and at home. |
| 1A | Presence of family has been a lifeline for many residents | While you are looking for this "going forward" during COVID it has been the lifeline for many within LTC to have someone come and visit -- it has been very lonely.  |
| 1A | Presence of family is very important for my resident’s wellbeing | I feel it is so important for family to be well involved with their loved one and the LTC home. I need to make sure my mom is well looked after and I know the care she is getting. My mom could not say sentences to me but when I came into her room she would become more animated, vocal, and smiling and laughing. It made my day!  |
| 1B | Family member participation is extremely important | Family member participation is extremely important to ensure residents are kept safe and provided quality care. With the understaffing problem, family members are required to be sure their loved ones are eating regularly, walking, and personal care needs are met. |
| 1B | Presence of family is essential in LTC | Quoique je reconnais les efforts et l'expertise des membres du personnel, les soins disponibles n'étaient pas suffisants pour assurer la qualité de vie des résidants à besoins élevés. Lorsque ma mère est entrée en SLD, il n'était pas nécessaire pour moi d'y être chaque jour mais, à mesure que sa condition se détériorait, il devenait évident qu'il nous fallait quelqu'un sur les lieux pour assurer son bien-être. Entre autres, elle aurait perdu sa mobilité, sa capacité de se nourrir convenablement, sa continence, sa capacité de communiquer avec le personnel si nous n'avions pas été là pour en prendre soin. Il fallait constamment répéter pour que les soins prévus dans son plan de soins soient prodigués, surtout lorsqu'il y avait du personnel à temps partiel ou remplaçant. Pendant les repas, j'ai observé combien facile il était pour le personnel d'oublier de donner le repas à un résident, d'offrir un repas avec une texture inappropriée, de retirer une assiette avant que le résident ait la chance de dire qu'il n'avait pas fini. Un résident qui a la capacité de communiquer avec des mots peut se protéger contre ce genre d'oubli, mais celui qui est aphasique doit avoir un interprète. Lorsque le foyer a fermé ses portes aux visiteurs il y a maintenant plus d'un an, j'ai amené ma mère avec moi pour habiter avec ma famille afin d'assurer qu'elle ait tous les soins dont elle a besoin. (While I recognize the efforts and expertise of staff members, the care available was not sufficient to ensure the quality of life of high-need residents. When my mother entered LTC, it was not necessary for me to be there every day but, as her condition deteriorated, it became clear that we needed someone there to take care of her. -to be. Among other things, she would have lost her mobility, her ability to eat properly, her continence, her ability to communicate with staff if we had not been there to take care of her.  |
| 1B | Family caregivers provide vital help | The involvement of caregivers is vital. …Providing hands on care can be so meaningful, a rewarding way to visit and help for staff. |
| 1B | Family caregivers provide vital assistance | Daily family assistance is crucial in long-term care. Residents are only allowed outside with a family member. Many residents never go outside. Residents are much more likely to go on resident arranged outings if a family member can sign them up and help out. |
| 1B | My family is very involved in our resident’s care | My brother is the primary care giver, he lives close by our loved one. He schedules and attends all medical appt's, visits and interacts with her frequently and is the contact person for staff. My role is much more reduced than his as I live further away and am snowbird in the winter. We are dedicated to her well being. |
| 1B | Family support and care is essential for LTC residents | Having been closely involved in my mother’s care & well-being in the past eight years or so while she has been living in LTCH, I KNOW how important it is to have a family member (i.e. me, her daughter) in this role. I honestly don’t know how elderly residents without family nearby manage! I continually advocate for her, provide emotional & physical support, regularly liaise with the staff & the Doctor and nurses, as required regarding her care and medical needs. I handle all her financial affairs, arrange appts with hairdresser, footcare nurse, physiotherapist etc. All these things have been made more difficult to do since March 2020. Also, I used to take her out to run errands or have a meal at a restaurant or bring her over to my house for dinner or a bbq & family celebrations/impt religious holidays (Easter, Christmas, Thanksgiving) -these occasions often attended by her other kids & grandkids who live out of town. This may not be considered “hands-on care” but it’s extremely impt for me and my mom that she remain connected with her family. Since the pandemic, we are restricted to phone calls & sometimes I do FaceTime/virtual calls so she can ‘see’ these loved ones but it has been really difficult. |
| 1B | Family support and care is essential for LTC residents | Pour moi, je vois la différence chez mon parent lorsque je la visite. Elle est plus alerte, souriante et participante lorsque je vais la visiter régulièrement.(For me, I see the difference in my parent when I visit them. She is more alert, smiling and participating when I visit her regularly.) |
| 1B | Family caregivers play a vital role | Family members are very important for the residents in LTC.  |
| 1B | Presence of family helps the resident and the family | I think it’s very important to have family members involved, for both the family and the resident in LTC. I’m very fortunate to come from a close family who is happy to share the visiting with our mother.  |
| 1B | Presence of family is vital for my resident’s health | Mes visites régulières à ma mère lui permettent de savoir ce qui se passe à l'extérieur de la résidence (famille élargie, actualité, pandémie, température etc.). Quand ces visites ont été arrêtées au début de la pandémie, elle dépérissait et était déprimée. Elle a besoin de se sentir aimée et soutenue.(My regular visits to my mother allow her to know what is going on outside the residence (extended family, news, pandemic, temperature etc.). When these visits were stopped at the onset of the pandemic, she was wasting away and depressed. She needs to feel loved and supported.) |
| 1C | Presence of family is important for resident happiness | In the 4 years that my mom has been at this care facility I feel my involvement has been extremely important to her happiness and to my peace of mind. |
| 1C | Family make important contributions to resident wellbeing | I find that it's these moments of playing a game, chatting, tidying up, sorting through and even setting up a Christmas tree or decorations, giving a little tlc - these personal touches are needed and necessary for the wellbeing of the resident. Thank goodness for the activities and the programs- dementia residents should be encouraged to do those things and not asked if they want to. They are in a LTC facility because they cannot make their own decisions. If playing a game means they have other people around then that is so important. Residents should be brought in to the activity environment even if they don't participate. They will still have that energy from those around them. It is the little things that allow the caregivers (family) of the resident to have that peace of mind that their loved one is more than just a body filling a space. |
| 1C | Presence of family is important for our resident’s wellbeing | Extremely important as it makes my mother still feel somewhat in control of her life. She depends on each member of her family for certain stimulants. Loneliness is terrible and the months we could only communicate on the phone or facetime took a toll |
| 1C | Family involvement and advocacy is vital to my resident’s wellbeing | I hate to think what my mothers life would be like if she did not have family visiting and advocating for her. |
| 1D | It is vital that family be present to monitor the resident’s situation | It's incredibly stressful to feel as though you must watch literally everything they do. |
| 1D | It is vital that family be present to monitor the resident’s situation | I had to stand over a nurse or a director of care to get them to attend to it. |
| 1D | It was important that we advocate on behalf of our resident | We found it very important to advocate on her behalf, whether it was to restrict a specific staff member from attending to her (too rough), to request testing for a uti, to ask for measures to control the temperature in her room (often 27C), and the temperature in the bathing room (too cold), to request medication for panic attacks, etc. |
| 1D | Family need to be present to make sure LTC delivers the needed care | I always followed up my phone call with a drive over and it turned out to always be necessary. |
| 1D | Family need to be present to make sure LTC delivers the needed care | On every visit I would change mom's brief after lunch. |
| Code 2 is about concerns related to LTC staffThere are 26 “2” codes.2A deal with staff neglect, incompetence, and poor behavior2B deal with staff resentment toward and lack of appreciation of family2C deal with poor communication between staff and family2D deal with staff needing help from family but lacking the time to engage and understand |
| 2A | Concerns about staff behavior | Definitely want to know what staff are and aren't doing cause they are always rushing to get them to bed so they don't have to work anymore |
| 2A | Staff behavior produces poor results | Staff are very task oriented. They are very negative in their communication with residents. Quick to tell them what can't be done. Rushed for time. Poor communication between staff. |
| 2A | PSWs were not humane in my LTC home | At my mom’s LTC the PSWs were a very powerful group and it negatively affected my mom’s care. The care she received was not humane - and this was before the pandemic. |
| 2A | All staff should be required to provide good care | There should be NO exception to the treatment or level of care. I and my daughters would countlessly receive calls from my wife early morning or late evening or anytime if none of us could be with her, crying over an uncaring, rushed and cold hearted rude, rough staff member. |
| 2A | Temporary and some full-time staff are not competent | Reliance on agency staff results in people who do not know how to care for a resident. Even full-time staff are not well trained on how to hoyer someone using a broda. How to place them in the sling. How the chair must be positioned and where to place the wheels of the hoyer so that the resident can be placed right at the back of the base of the seat so their back is fully supported. |
| 2A | Temporary staff do not do a good job | the regular staff that have gotten to know him are exemplary however there are too many 'agency staff' or transient staff that just come in to do a job and don't make the time to either know him and/or me and end up doing a below par job |
| 2A | Staff in this home need to be held accountable | staff need to be held more accountable which will then improve quality of care given. |
| 2A | Staff in this LTC home do not know how to care for someone with dementia | I was the full time caregiver for my mom while she was in Long Term card and working full time. The staff do not know how to care for anyone with Dementia … |
| 2A | Some staff are not competent  | While most of the staff are competent, some are not and really not interested in their job, but they have a job!  |
| 2A | Staff in this home have become complacent and neglectful | I visit my mother twice a day: at lunch for a couple of hours to assist with feeding (my mother is not capable of feeding herself) and dinner, to assist in feeding and bathing, putting her to bed, etc. Since September, 2020, when we caregivers were permitted back into the residence to care to our loved ones, I have noticed a significant decline in the level of care/involvement by staff with regards to residents. Despite the increased assistance provided to the general complement of daily staff during the Covid pandemic, an "air" of complacency/lassitude is quite prevalent among staff. I would be pleased to discuss my "views" with interviewers. |
| 2B | Some staff are threatened by the presence of family | Families are an essential component in a resident's level of care - we are part of the team and we have a role to play. Depending on the staff, sometimes this is not shared by everyone and they feel they are there to take care of our loved one. They feel threatened or take questions/concerns raised personally.  |
| 2B | Family / staff tensions and divisions are unfortunate | It would be nice if there wasn't an us and them mentality just one family! |
| 2B | PSWs were negative toward us | What support we needed from the PSWs was frequently provided with a “you’re bothering me” negative attitude, despite the fact that we were kind, appreciative and asked for very little support. |
| 2B | Some staff neglect my resident and resent my advocacy | They don’t appear to have the empathy required to put themselves in the shoes of the one they are caring for and my experience is they will avoid taking the time to really do a good and thorough job. ie. sometimes I come in and my mom’s underbriefs are wet and all bunched up and uncomfortable, and I have to ask for them to clean her up and change her. Some staff will try to convince me that my mom is OK the way she is and when I insist and they do as I ask, they do it with resentment even though after it has been done, my mom is clearly more comfortable. I have asked that they change my mom regularly mid morning and mid afternoon and it is not done unless I am there and ask for it to be done. |
| 2B | Some staff neglect my resident and resent my advocacy | …when I do speak up politely, many staff resent being asked to do their job and that comes out in how the staff treats me now. When I speak up for my mom, they treat me as if I am a pain in their side, and I am very polite and friendly because I do not want them to take anything out on my mom when I am not there. That is a constant concern of mine. |
| 2B | Staff resented our advocacy | We also were often made to feel like we were intruding or bothering staff if we called to ask questions on the phone or stopped to ask them something in the hallways. |
| 2B | Staff do not appreciate the role of family | I do not feel that the staff of the facility show or express appreciation of the care I provide(d) i.e. coverage of all PSW duties for 5-6 hours every day; thereby freeing up staff to provide more adequate care to other residents. In almost 4 years, I have provided direct care since Day 1, there has been no recognition of this assistance. Indeed, sometimes, I think it may be a mistake on my part, because staff on the relevant shifts do not get to know my husband, and really make little attempt to do so. |
| 2C | Sometimes staff do not share important information | Parfois, le personnel oublie que ce qui est naturel pour eux est nouveau pour les membres de la famille. Par ex., j’aurais eu besoin d’être informé des changements graduels des soins, par ex., que ma mère avait besoin d’une tasse pour enfants plutôt que de la voir du jour au lendemain utiliser cette tasse pour enfants. (Sometimes staff forget that what is natural for them is new to family members. For example, I would have needed to be informed of gradual changes in care, e.g., that my mother needed a children's cup rather than seeing her overnight use that children's cup.) |
| 2C | Staff communication and follow up are poor | Communication is very poor, between staff and to me. A decision or request from one day often does not get carried through by tomorrow's staff. |
| 2C | Staff would not be honest with us | Staff would cover things up, make excuses. |
| 2C | Staff would not tell us about changes to the care plan | We were often left out of the loop if changes were made to my wifes medicines or health care. |
| 2C | What staff say is not consistent with what I see | They say they never run short but I see it . |
| 2C | Staff need to communicate more with family so we are aware of changes | More communication from staff would be of benefit to me. I know there is a lot to do and only so much time but being more aware of changes in my family member's behaviour would help me do a better job of helping to meet their needs. In these 'Covid' times perhaps more use of Zoom or similar would be appropriate. |
| 2D | Staff don’t have time to understand my resident | I was extremely involved in my mom’s care so I didn’t need to have her behaviour explained to me. I sometimes had trouble getting staff to understand her behaviour though. Mostly it was because they were so rushed and were not allocated sufficient time to care for residents |
| 2D | Staff may be too busy to engage with families | My experience was that my involvement was sometimes viewed as unwelcome, and it was often a struggle to engage fruitfully with staff. Partly that was because staff were too overburdened to engage in a constructive manner.  |
| 2D | Staff need my information but don’t help me | Because my mom lived with us for 10y ears as she declined, I felt I was informing the staff more than they were helping me. She was admitted when my husband became ill as a crisis placement. |
| Code 3 is about the need for adequate staffing in LTCThere are 12 instances of code 3.3A call for LTC homes to have sufficient staff to do the necessary job.3B identify staffing issues such as overwork and turnover. |
| 3A | LTC needs to be well staffed | I think its important for there to be enough staff in the home, I think it's important for loved ones to feel a connection to the staff, familiarity is especially important for those with dementia, so same staff and someone they can relate to is important. |
| 3A | LTC needs to be well staffed | There is not enough staff to provide proper care and i worry my mother is being neglected. That is why I am there daily plus to monitor how she is being treated. |
| 3A | LTC home needs to be well staffed | Facility was always understaffed and I felt like I needed to do the evening care or settle for poor care. |
| 3A | LTC homes need to be well staffed | There just wasn't enough staff to talk to residents or communicate with residents or feed residents. … All LTCs need more staff and more positive staff involvement.  |
| 3A | LTC needs to be well staffed | The facility was understaffed and the staff over worked. The staff did not really have the time to spend quality time with the residents.  |
| 3A | LTC needs to be well staffed | ....not enough staff to provide proper care...2 psw's to put 22 ppl to bed....not good! |
| 3A | LTC needs to be well staffed | my mom has not had a very good experience in LTC - the staff are so over worked and burnt out (even before the pandemic) that there is NO CARE - |
| 3A | LTC needs to be well staffed | Also there was ( and still is) not enough PSWs who do the actual care for the Residents which leaves caregivers sometimes much to help with the caring. |
| 3A | LTC homes need to be adequately staffed | Unfortunately our LTC homes in Ontario are not provided with adequate staffing, so the staff members can only provide the very basic care for the residents. That is why the presence of the caregiver is essential to the overall well being of the resident. |
| 3B | PSWs are always on the run | The PSWs do not have time to sit and talk with residents - they are always on the run. |
| 3B | Frequent staff turnover causes problems | Frequent Staff turn-over, difficult to get to know, or PSW to know or familiarize themselves with resident and vis a vis.  |
| 3B | Staff are overworked and this causes problems | Staff rush to provide care, lack of attention how resident is left, ie. half dressed, disheveled, slouching in wheelchair.  |
| Code 4 is about deficiencies at the level of the specific LTC homeThere are 72 “4” codes.4A – This LTC home treats families and residents poorly4B – This home has some specific and serious problems4C – Residents without family are suffering4D – Poor care and neglect are characteristic of this home4E – I can tell disturbing stories of neglect and incompetence at this home4F – This home is acting on the wrong priorities |
| 4A | LTC homes are full of challenges | This home in 2008 -2104, experienced the same challenges as were uncovered during Covid-19 - insufficient staff, lack of training, lack of supervision, PSW's were poorly paid, had no benefits, making it necessary for them to work in more than one home and were over-worked. LTC processes, systems were broken or non existent as were their internal and external communications with staff & families. |
| 4A | LTC homes must consider the needs of residents and families | As a family caregiver, I have never been part of mom’s care plan, included in activities. When a family caregiver is welcomed so is a resident. Keeping family members happy and taking care of their needs to best help their family members is key. Having kitchens as the heart of the home so family members can warm up home cooked meals complete with proper equipment creates a friendly and welcoming atmosphere. Also, providing a place for caregivers to have a meal before they head home is also important especially if family members help with meal times. |
| 4A | This LTC home is unhelpful and full of challenges | This facility was unhelpful, dangerously disorganized extremely short staffed (why I was so involved in his care). I watched as 2 residents succumbed to painful early deaths from inadequate wound care in my husband’s 15 person ward alone. There were so many others! I learned quickly not to trust a word management said. Numerous reports to licensing concluded “unfounded" even with photos. Ultimately a public administrator was assigned to the facility - but she’s got now and there is yet another GM. I feel terrible for everyone still living there. Add Covid to that and I was forced to abandon my husband to these people! These have been the darkest days of my life and I doubt that I will ever recover completely. It took 12 months but I finally got a call that a bed in a new facility was available.  |
| 4A | There is tension and conflict between families and bosses/staff | Inconsistencies between how staff are interpreting the COVID ‘rules’ and weak staff communication skills result in conflict between family members and staff. Trust and respect are eroding, family members are feeling “watched” and fear that, if they are caught doing something wrong, they will be barred from entry. Much of the family's experience depends on their ability to be diplomatic, agreeable, invisible, compliant, easy to get along with and liked by the bosses. |
| 4A | This LTC home and staff were inept and bullying | The home 10years ago was totally brutal to my mother and I because of her dementia and related behaviours that wete often aggressive during care. They would call me at work and "bully' and threaten and put my mom on antipsychotic meds. I learned quickly they wete inept in caring for residents with dementia and decided to care for her myself twice daily plus I hired private PSWs to come in twice daily after I left. Due to new administration and increased knowledge things fod slowly improve over last 3years..I never completely trusted Some staff and continued this csre until 2weeks ago when mom passed away with me by her side. |
| 4A | I saw ageism at this LTC home | LTCH and staff need to undergo many changes and stop AGEISM attitudes. |
| 4A | This LTC home does not value family and treats us poorly | Adminisration does not seem to be involved with families unless there is a complaint. Often that complaint is handed down to a lower ranking member. Families do not seem to be important, are forgotten and even mistrusted. …I was chastised for using the lift while we sat for what seemed like an eternity to get someone to help. I was point blank asked "Do you have a funeral home picked out for your husband" soon after Covid started. No preamble or anything. Families are not encouraged nor do they have many rights within the home. One family member said that they did not put their mother up for adoption when she entered the home. We are definitely undervalued or not valued at all. |
| 4A | The LTC home administration is unresponsive and secretive | …the biggest issue is with our current administration, where we must result to submitting a complaint to MoLTC for information about the home. The current administration is secretive, non transparent and the current ED is not the right fit for the home. |
| 4A | The LTC home communicates poorly and is poorly managed | Really no level of communication between the facility and the outside world no newsletter no posted activities it's just horrible run around with heads cut off too many bosses no directions yikes maybe being stuck in their rooms isolated has keep se form of organization and healthy observation |
| 4A | My home makes it difficult for family to be involved in care | In my experiences with providing care for my family member, the staff (and really the way the whole system is designed, including the physical structure itself) does not always facilitate or make it comfortable or convenient for family caregivers to provide the level of involvement and care that we really want to do. My vision of a truly welcoming LTC home doesn't exist in the community in which I live, and sadly, in most communities that I am familiar with. The facility hasn't upgraded at all to accommodate space and electrical outlets for technology such as cell phones and laptops and even TV's. (in semi-private rooms)  |
| 4A | This LTC home does not communicate with me | I visit my Nephew 2 or 3 times every week. The care place never calls me about any thing about my nephew. |
| 4A | Family involvement is sometimes not welcomed | My experience was that my involvement was sometimes viewed as unwelcome, and it was often a struggle to engage fruitfully with staff. Partly that was because staff were too overburdened to engage in a constructive manner.  |
| 4A | The LTC home excludes us and resents our advocacy | It is extremely distressing to feel like a "visitor" to my mother's home and to lose all control of decision making and personal care of our mother. We have felt like we were causing problems or imposing on staff whenever we asked questions or tried to offer input. |
| 4A | My advocacy and suggestions are ignored | I find there are several areas that require attention in standard operating protocols and have discussed with administrator and staff to no avail. I now d what is best for my daughter and do not bother with staff whenever possible. |
| 4A | Staff in this LTC home resent my advocacy | …they do not like anyone like me who works in the field interfering with what they did not provide.  |
| 4A | I am treated like an outsider, but I should be part of the team | There should be more questions about decision making and how the institution staff and doctors work closely together and have access to infomation, but as the substitute decision maker, I am treated as an outsider. So I am expected to make decision on treatment based on anecdotal information, not documented. I have to go through nurse, or care coordinator - to get access to doctor - no direct access. Care conferences are not focused on actual care. And (this one is a gripe) but an obgyn should not be a primary physician for a geriatric patient. |
| 4A | The LTC home does not always welcome my advocacy | I have been her advocate but it is not always welcomed |
| 4A | This LTC home does not listen to family and blames resource shortages | Staff/management are happy to have care partners/family come in and assist with staff-designated care items (feeding, physio, cleaning/organizing room) yet do not take the feedback/input from resident and family member regarding service and care plan seriously. Have made many complaints and input regarding physio regime etc based on personal health history and goals yet they are mostly ignored and we are told the residence lacks staff and resources to provide what we would like. Always comes down to the [name of home] residence not having enough and we are just supposed to deal with it. |
| 4B | Errors occurred during admissions | Gap from my experience was the admission process. Too many documents to fill out on admission day; errors were made.  |
| 4B | LTC home needs better digital technology  | My concern is making video conferencing easier and more accessible, which means better wifi and more digital devices in homes. |
| 4B | Nutrition and diet are not properly seen to in this LTC home | Food quality not the greatest. Many residents are constipated due to poor balance of diet. Residents were often given laxatives rather than address nutritional needs. |
| 4B | This LTC home does not provide adequate dietary and nutritional care | Lack of fluids is another issue. The home provides the minimum amount of water/juice in tiny 120 ml or 170 ml cups. Often mom was extremely thirsty. I would provide juice for mom which was labelled and kept in the tiny resident fridge. Occasionally I would notice some residents were missing their cups at lunchtime and I would ask the kitchen staff for cups of juice/water for the resident. |
| 4B | This LTC home does not provide adequate dietary and nutritional care | The home changed the food service provider (to save money I guess) resulting in ongoing issues like no bananas, no yogurt, powdered apple juice being used. Soft foods like these are often the only thing many residents can/will eat. One day there was no sugar for residents coffee/tea/cereal. Our seniors deserve much better! |
| 4B | Care conferences in this home are inadequate | However, when it comes to a care conference, it is arranged by phone, and only the director of programs and services attended. (That just happened recently)  |
| 4B | I complain about the palliative care my resident received | Ma seule plainte lors du décès de ma mère est la difficulté que moi et ma famille ont eu pour soins palliatifs. Cela a pris une semaine avant que le foyer la déclare palliative bien qu’elle l’était depuis un peu plus qu’une semaine. Par le temps que ce processus fut complété ma mère n’à vécu que des heures. Donc elle est restée dans sa chambre avec sa colocataire et seules 2 des 6 enfants ont pu être présents.(My only complaint about my mother's death was the difficulty I and my family had with palliative care. It took a week before the home declared her palliative although she had been palliative for just over a week. By the time this process was completed my mother lived only hours. So she stayed in her room with her roommate and only 2 of the 6 children were able to be present.) |
| 4B | Poor facilities can lead to a loss of dignity | My father had physical disabilities, had a hard time getting around. He was bariatric but they didn't have a suitable bathroom setup for him, i.e. rails around toilet, raised seat, narrow doorway his wheelchair couldn't go through, inaccesseible sink. He couldn't enter the bathroom in his w/c but could with his walker, however, he shared a bathroom and they couldn't place equipment in without it being too crowded and unsuitable for other person. So, he would get up with his walker, walk into the bathroom, but not have a place to sit for bm or at sink to wash hands. I would help him , stand beside him in bathroom hand him items like tootbrush etc and have w/c ready at the bathroom doorway for him to sit down on in case he started to weaken. With an accessible set up I coud have helped more effectively and my father would have had some dignity and independence in self care. |
| 4B | This LTC home does not provide adequate dietary and nutritional care | I am appauled that all residents not just for my mother that they are only entitled to 7$ a day in food, this includes breakfast lunch and dinner plus snacks. I never hear fresh fruit or vegetables, my mother is a brittle diabetic and the amount of sugary foods is disgusting,and not good for her overall health and well being. I hear fish nuggets, french fries, hot dogs, puddings pies dough nuts cakes powdered orange juice it's heart wrenching,her sugars range from 2.5- mid to high 20s!!! I am concerned and worried have spoke with so many people in management it's crazy and the cycle continues. Where is the quality of life when their are no choices but to place your most precious loved one? We live in a bountiful farm community that these fragile elderly loved ones have no access to wounce they are placed! |
| 4B | This home does not hold enough care conferences | [name of home] schedules one resident Care Conference a year. This is far too infrequent. I have attended care conferences both in person, and on the phone. I would suggest Zoom 'in-person' care conferences every 2 months, or as needed, would be most valuable. |
| 4C | Residents without supportive family may be neglected or suffering | I worry about the people who do not have family to keep watch for their loved ones or on the rare days when we cannot have someone with my mom, I am wondering if she is being cared for well. I am constantly concerned when there is no one there advocating for my mom, that she is receiving compassionate care. |
| 4C | I also support other residents whose family are not present | Also felt that I was advocating and monitoring for other residents. Several times it was me who discovered and reported a fall or a resident in need. Only contact residents had with psw was for a few minutes to either dress / undress or toilet. No social contact or occasional checks by psw's. they had no time for that. |
| 4C | Residents without family or with few visits are having difficulties | But what about other people on my mother's floor? Some only had a visitor once a week if that! There just wasn't enough staff to talk to residents or communicate with residents or feed residents. Also, my sister and I helped other residents at times with feeding and with getting staff to assist them. You don't mention what help we may have provided to residents other than my mother. We also brought our Shiba Inu (a Japanese canine breed) up with us. Some of the residents really delighted in seeing him. Another woman saw her husband a lot and also helped entertain other residents. The sitters would sometimes help with other residents as well. Frankly, if my mother hadn't had us visiting (visiting? we worked like dogs!) , she would have acted out and had to be medicated because she was so disabled or she would have shut down and had a much worse time of it than she did.  |
| 4C | I sometimes help other residents (not just family) because they need help | I also assisted with other residents in dining room, distressed times where I have a good relationship with resident, personal shopping for them if required. |
| 4C | Residents without family caregivers or advocacy suffer | We all saw care recipients who did not have families to advocate and we observed less attention, and less care at the dinner table - food was placed before them but they hadn't touched their food, andin no time shrivelled away to learn they passed in 6 months time.  |
| 4D | Health care in my LTC home is unacceptable | I witnessed substandard medical services provided to the residents in our LTC facility, care that would be deemed unacceptable in any other health care setting. It was a constant struggle to communicate with the medical team and their lack of involvement led (and still leads) to unnecessary suffering and trips to ER that could have been avoided if residents were properly monitored. |
| 4D | Family need to be present to make sure LTC delivers the needed care | (Translated from French)(…Constant rehearsal was required to ensure the care provided for in his care plan was provided, especially when there were part-time or replacement staff. During meals, I observed how easy it was for the staff to forget to give the meal to a resident, to offer a meal with an inappropriate texture, to remove a plate before the resident had a chance to say that it was 'he hadn't finished. A resident who has the ability to communicate with words can protect himself from this kind of forgetfulness, but one who is aphasic must have an interpreter. When the home closed its doors to visitors over a year ago, I brought my mother with me to live with my family to ensure she had all the care she needed.) |
| 4D | I provide care because that is the only way I know it is done | I worry about foot care, basic hygiene care hence why I do it after dinner so I know it’s done ! |
| 4D | People in this LTC home are in despair | Everyone I know who has a loved one in that establishment wants assisted suicide rather than being moved there in case of dementia. That is how bad our system is. People walking around with dirty diapers... staff not knowing what a patient's routine is... I could go on. |
| 4D | The signs of neglect in this LTC home are horrible and frustrating | I could write a horor story about seniors' residences. Three times, I have arrived for my visit to find discarded soiled diapers (not my loved one's) on the floor in her room. I have found faecies on her bedroom floor or bathroom floor, in her closet... Her clothes disappear. Her winter boots disappeared and were lost for the whole winter. I had to buy a new pair. He photo album has vanished, never to be found... One staff member gives me one instruction, another gives me a different one... anyway, you can sense my frustration, I am sure. |
| 4D | Quality of care in this LTC home is appalling | I had to fight for every medical procedure for my mother. My mother had stage 3 bedsores and I was not even informed about this until I commented on the smell in her room. My mother also put on 25 lbs once she was in a wheelchair with her stomach bloated and I had to fight to get her an ultrasound so as much as these questions ask what was important to me they all were but the care in this private long term residence was so below any kind of standards it was appalling |
| 4D | Care is neglectful in this LTC home | Often a concern about medical care was brought forward and not followed up on. I had to stand over a nurse or a director of care to get them to attend to it. Eg. My mother nearly died from anal suppositories. It caused extreme diarrhea. This happened 3 times.  |
| 4D | I have to advocate and check up on their work | I had to stand over the assistant director of care to see she posted an allergy alert on my mother’s care plan and I pushed to have a sign posted over the head of her bed. They didn’t want the sign up. They said it contradicted privacy issues. I said my mother’s life is more important than your damn concerns for privacy. It got put up. Changing of wound bandages was sometimes not done. They would deny that the bandage hadn’t been changed. Urine samples for a bladder infection were handled improperly.  |
| 4D | Family must advocate, complain, and check up on LTC staff work | A family member must advocate to get care for a resident. You can’t lay a complaint to the Ministry all the time. You have to stand over staff to see it gets done. A shame! |
| 4D | Care in this LTC home is horrible | The care of our mom during her last days was a horrific experience. |
| 4D | This LTC home offers poor health care | Medical expertise was lacking in many critical areas. |
| 4D | I must monitor care every day to ensure adequate care | My parent was in LTCH for 10 years....I learned very quickly that I had to monitor my parent daily and hire private PSWs to ensure they were cared for in the way that they deserved. Things did improve somewhat over the 10 years they were there...but not to the caliber they would have expected |
| 4D | Family advocacy was vital to ensure that our resident received decent care | My father ,my siblings and myself were involved with mom's care. We communicated regularly and solicited feedback about moms daily living, changes, and times where care could have been better. Mom was a quiet person and with a very low voice because of her Parkinson's I am not sure she would have seen the kind of care if we did not advocate.  |
| 4D | My mother went into severe decline after entering LTC | As a working single mother, I was not able to provide the required care for my mother; therefore had to put her in a home. Brought her up to a '1' on the waiting list as I was told it could take up to 3 months. Within 1 week we got a call and HAD to accept, otherwise, she would go to the bottom of the list. My mom suffers from Alzheimer; even though she was confused and lost, there was still some of her left in her souol. Within one month in the home - she was no longer herself. She has been a prisoner since.  |
| 4D | Assisted suicide is preferable to living in LTC | We have watched her deteriate over the years and if she could take her own life, she would. You MUST convince the government to allow assisted suicide even if the person is not of sound mind. Living with Alzheimer is not living, it's slowly rotting away. I would not even let my dog live through that. |
| 4D | Psycho-social needs are not being met | I would say in general that physical needs are well met. Its daily companionship, conversation and warmth that is lacking. The only interaction with psws is to attend to physical needs - very task oriented and hurried. |
| 4E | Stories of neglect and incometence | I arrived late one Saturday morning at 10:30 to find mom still in bed, not dressed, not fed, not changed. Full-time staff didn't show for their shift and only 1 agency person was there and it takes 2 people to use the hoyer. Mom called me a few times at 6:30 at night to say she had not been given dinner so I drove over with food. I found if I called in a request in response to a phone call from my mom (she needs to be changed/she hasn't had dinner) the nurse did not ensure the request was met. I always followed up my phone call with a drive over and it turned out to always be necessary. |
| 4E | Stories of neglect and incometence | On every visit I would change mom's brief after lunch. Sometimes there were no soaker pads under mom and no clean ones on the floor. What does this mean? It's impossible to turn someone on their side to change them without a soaker pad to pull on. Pulling on the resident directly results in injuries and pain to them. |
| 4E | Stories of neglect and incometence | I had to provide zincofax or sudocrem for mom because it was the only way to ensure it would be available when needed. Initially the nurse took the cream to keep at the nursing station resulting in it not being used by the PSW's as they didn't have time to go looking for it. I had to battle for it to be left on her side table. |
| 4E | Stories of neglect and incometence | An ongoing issue throughout the home was residents not being changed when a change was needed. I saw feces leaking from a resident that asked for a change for over an hour. I asked the PSW for help, another caregiver made the same request. It was ignored. Another resident removed his brief full of feces and feces was smeared all over the room, down the hall. If they had met the request when needed a massive cleanup would have been avoided. I spoke to management about these 2 incidents. Nothing changed. Staff do the minimum and if it is close to end of shift every request gets left for the next team to deal with. |
| 4E | Stories of neglect and incometence | the residents are in very cheaply made DIAPERS NOT BRIEFS - even though they have dementia they know they are in diapers and no one seems to care about their dignity - the activities are very poor quality and I feel none of the staff are trained in dementia care - they know nothing -  |
| 4E | Stories of neglect and incometence | I saw my mom Mar 14/20 and she was missing her dentures and the staff found them under her be 8 weeks later - during a pandemic what are the cleaning staff doing - 8 weeks under her bed - no she has been without her glasses for 7 weeks now and no one care where her glasses are - WHAT KIND OF CARE ARE WE PAYING FOR - I am disgusted with the level of indifference to the care of the residents - the well paid activities staff know nothing about activitives for geriatric patients -  |
| 4E | Stories of neglect and incometence | I worked in mental health for decades and I am shocked at the lack of infection control and cleanliness in the facility - it always smells like poop - I would give anything to have my mom back home here with me -  |
| 4E | Stories of neglect and incometence | when we visited the LTC home before my mom arrived and I was sold a bill of goods - everything they said sounded great until my mom was there and everything I was told was a real stretch of the truth -  |
| 4E | Stories of neglect and incometence | with the arrival of the pandemic the situation in LTC has been horrific and they still are horrific 14 months later nothing has changed and the care is non existent - we should all be ashamed of what is happening in LTC - extendicare organization gives 171 million dollars to shareholders and takes 121 million dollars from the government to pay for pandemic costs - HOW IS THAT RIGHT!!!!!!  |
| 4E | Stories of neglect and incometence | my mom is not the same person she was 14 months ago and I blame the LTC system for it's complete failure to protect and care for our most vulnerable citizens. SHAME ON ALL OF YOU |
| 4E | Stories of neglect and incompetence | I would sometimes receive calls from the nurses regarding my mothers physical health such as suggestions regarding medications and pain management. As to her mental and emotional health there did not appear to be any care plan specific to her. |
| 4E | Stories of neglect and incompetence | No effort was made to seat my mother with other residents who were mentally competent and could carry on a conversation with her at meal times. Therefore her only meaningful conversations would be with staff or family. |
| 4E | Stories of neglect and incompetence | We found it very important to advocate on her behalf, whether it was to restrict a specific staff member from attending to her (too rough), to request testing for a uti, to ask for measures to control the temperature in her room (often 27C), and the temperature in the bathing room (too cold), to request medication for panic attacks, etc. The PSWs do not have time to sit and talk with residents - they are always on the run. It often takes too long for a call bell to be answered and all too often the call bell would not be left within the residents reach. |
| 4E | Stories of neglect and incompetence | As you can read by my tone, I am not your typical easily intimidated caregiver. I cut my caregiver teeth at [name of home]. The Administrators and Unit Managers were not empathetic and in some cases they created a 'toxic environment' for their employees, residents and caregivers. When my spouse was transferred to [name of new home] it was a beautiful yet short lived experience. To this day, when care has not been provided as I would like at my husbands current LTC, I simply remember the time at [name of first home] and I use that as my benchmark for poor care. I have 16 years of experience as my husband's designated caregiver he was 48 and I was 46 years old. I have a story to tell and I have the journals to support that. I sincerely hope this survey is taken seriously and should also provide more qualitative questions versus quantitative. Maybe you will undertake that as a next step. Its a hope that the information gathered will spearhead real change in LTC. |
| 4F | Care is union minded, not resident centered | Staff are very union minded and not resident centered. The home is run by admin who are very sympathetic to the union demands of staff. Residents pay the price of having staff who are not committed and admin who do not create and sustain a culture of resident cantered LTC. The demands of the unions are running LTCs. Staff are kings, residents are innocent, helpless bystanders. Anytime suggestions or complaints are made, admin and staff stick together to support the facility’s reputation. |
| 4F | The LTC home threatened legal action due to my advocacy | As a family member who advocates for their loved one, I was given a letter by [name of home], stating that my behavior was disruptive to the running of the facility. I had to employ a lawyer to respond to the allegations. |
| 4F | This home is unfair to residents with less money | If you are a resident on the lower income scale, it is a struggle to pay for services and necessary equipment that the care home does not provide. If you withhold some funds to pay for any of these services or items, they are breathing down your neck. Even if the services are medically necessary. In For Profit LTC, they come first.  |
| 4F | This home protects itself from litigation | As well, I noticed some of their rules and policies are designed to protect themselves from litigation and have nothing to do with the well-being of the resident.  |
| 4F | This home does not advocate for its residents, and provides insufficient support | They do nothing to advocate on behalf of the resident. Even the social worker is sub-contracted out and works only 2 days of the week. In the 2 years, my LO has been in LTC, he has been in 3 different rooms. They do not do any work ahead of time to determine if the other resident is going to be a good match. If the bed is vacant, that is all that is considered. Even when they are aware of, and have knowledge of issues with a potential roommate for your loved one. It's incredibly stressful to feel as though you must watch literally everything they do. In the second room, the maintenance staff told my LO on the first night, to move back to the room he came from. Because, even they, the cleaning staff, knew it would not be a good fit for him. |
| 4F | This home cares too much about money and is condescending to some residents | During Covid, they will call you (the POA/Caregiver) and the resident, in person into a small room to discuss arrears and lecture, yes lecture, a 78 year old man with dementia on how to live within his means. |
| 4F | Managers at this LTC home resent complaints  | Management frowned on having issues brought to their attention, threatened with Trespassing law. Management from home office participated in meetings, answer always that they are within Ministry guidelines?  |
| 4F | The LTC unions are a barrier to better care | …staff … all have to belong to the Union which makes complaints sometimes never resolved.  |
| 4F | Administrators at this LTC home create roadblocks and value uniformity | However, the 'Administrators' are putting up roadblocks and in some cases 'gag orders' to withhold information. These Administrators are invisible and not accessible and yet they have power to make policies that are designed as a one-size-fits-all approach. The age groups range from 19 to 100 years old and yet everyone is being treated to quote the [name of home]'s Administrator in 2005 "Now that you are in the sunset years of your life" is evidence that Resident's and the Caregivers should comply by their policies without question. |
| Code 5 is about deficiencies in the entire LTC sectorCode 5 has 13 instances 5A – The current LTC sector is a failure5B – For-profit LTC is especially poor and should be ended5C – The efforts of family caregivers can shore up the failure and this is wrong |
| 5A | Government neglect has produced a failed LTC sector | I, along with many families have … seen how the various governments over decades did not act on the many commission reports, submitted long before Covid-19. Our loved ones were abused, neglected and the presence, involvement of families enabled the LTC sector to be maintained. I and many others chose caring for our loved ones over working, saving and planning for our own retirements and elder care. I advocated endlessly to no avail and listened to promises never kept. |
| 5A | Government neglect has produced a failed LTC sector | I advocated endlessly to no avail and listened to promises never kept. Covid-19 clearly showed the ugly side of government, Families have realized their loved ones are most important to them. |
| 5A | I don’t trust the LTC system | I certainly developed mistrust in the long-term care system and its values, not necessarily mistrust in the care workers themselves. |
| 5A | The LTC sector is flawed and underfunded | The system is deeply flawed and under funded. Caring for people should not be done in this big institutional way. It didn’t work for schooling Indigenous children, or people with developmental delays or the mentally way. LTC is not a hospital. Care to seniors should be provided at home for as long as possible with home care services. The few people who require institutional care should be cared for in small facilities where there is adequate staff paid wages that fit the work they do. LTC needs to not be the orphan of health care funding. |
| 5A | LTC is a failed system and money should be redirected so people can live in their homes in the community | Mom was in an LTC for 5 months and died due to neglect. LTC staff had absolutely no dementia training whatsoever despite being the largest LTC in Canada. Pathetic. Government needs to provide support so people can stay home. LTCs are no place for people with dementia and complex medical needs. The subsidy the government pays to LTCs should be made available so people can stay home and hire help or pay family members to stay home and care for them. Mom would be alive today if I could have kept her home. |
| 5A | The LTC sector is shameful | …we should all be ashamed of what is happening in LTC - extendicare organization gives 171 million dollars to shareholders and takes 121 million dollars from the government to pay for pandemic costs - HOW IS THAT RIGHT!!!!!! |
| 5B | For-profit LTC is wrong | We have to end Profit LTC! No one should be redirecting money to a company away from human services and care. |
| 5B | Care is better in not for profit LTC homes | My wife is in a NFP home and the care is difference when staff are paid and treated well. When they know that management cares for them and the residents. When they know that money is not being taken was from the care in the home for someone else to profit from. |
| 5B | For-profit LTC must end | Privately run for profit LTC needs to end. |
| 5B | For profit LTC focuses mostly on profit | I strongly feel it's about profit, not the well being the residents deserve. |
| 5C | Presence of family can shore up a failing LTC sector and this is wrong | Our loved ones were abused, neglected and the presence, involvement of families enabled the LTC sector to be maintained. I and many others chose caring for our loved ones over working, saving and planning for our own retirements and elder care. |
| 5C | Presence of family shores up for the deficiencies of the LTC sector  | I always felt like I needed to make daily visit to monitor care. If not, quality of care was not good. Inconsistency of staff on afternoon shift made it difficult for my loved one as new psw's did not know care routines which did not help the residents moods. … Facility was always understaffed and I felt like I needed to do the evening care or settle for poor care. |
| 5C | Family caregivers shore up a failing system | The good care givers deeply understand that LTC facilities are under funded - under staffed - require 24/7 365 care and are doing their best...but sometimes its not enough - they have 100's of folk to care for. We need to fill the gap....or the system falls apart. |
| Code 6 is about family members suffering and having to make up for the shortcomings of LTCCode 6 has 16 instances6A – Families suffer because of the way the LTC sector operates, especially during the pandemic6B – I provide and also pay for additional care to make up the shortfall in care |
| 6A | Families suffer because of the poor LTC sector | I left a much enjoyed & lucrative career due to decades of government's neglect of this LTC sector and inability of the LTC home to provide quality care. I dearly loved and wanted to care for my parent in my home until his death. He moved from another province to ON so I could do this. When he needed more assistance, Community Care was unable to meet his requirements. LTC became our only option. It was heart breaking to be separated. I, along with many families have suffered tremendously -physically, emotionally & financially. |
| 6A | Families suffer because of the poor LTC sector | I advocated endlessly to no avail and listened to promises never kept. Covid-19 clearly showed the ugly side of government, Families have realized their loved ones are most important to them. The hurt is still profound. |
| 6A | Families have suffered | I feel terrible for everyone still living there [*previous home where husband lived*]. Add Covid to that and I was forced to abandon my husband to these people! These have been the darkest days of my life and I doubt that I will ever recover completely.  |
| 6A | I am suffering because of the poor LTC sector  | At this point long term care is just human storage. There is zero quality of life. All activities remain off limits, a year later, and residents are still confined to their rooms. I hate it. |
| 6A | The pandemic LTC restrictions have been very difficult for family | I have found LTC restrictions very difficult.  |
| 6A | Family have suffered because of LTC pandemic rules | As the only Essential Caregiver, I am grateful that I can enter the home and provide emotional support, care and physical supports including the assistance of feeding, however, the strain of being the "only one" without an opportunity for respite has exacerbated stresses… |
| 6A | Family suffer because of the actions of this home | To conclude my feedback, I must say, it is incredibly stressful and exhausting, to feel as though I must watch literally everything related to the care of my LO, due to a lack of trust in the way the whole system is designed. Of course, that feeling has increased dramatically during the pandemic. |
| 6A | This LTC home treats families poorly | Treatment of family was poor and communication with management strained. |
| 6A | Families have suffered due to Covid rules | During the pandemic, the limiting of family visitors and those deemed “essential” has caused a great deal of stress and strife within the family |
| 6B | I find it necessary to pay for and/or provide extra care to support my resident | I learned quickly they wete inept in caring for residents with dementia and decided to care for her myself twice daily plus I hired private PSWs to come in twice daily after I left. |
| 6B | I pay for and provide extra care for my resident | We hired an private caregiver (RNA) to support my mom during her waking hours. If she was not available, I provided care (I am a former RN). |
| 6B | I find it necessary to pay for and/or provide extra care to support my resident | I learned very quickly that I had to …hire private PSWs to ensure they were cared for in the way that they deserved. Things did improve somewhat over the 10 years they were there...but not to the caliber they would have expected |
| 6B | I find it necessary to pay for and/or provide extra care to support my resident | I am a retired RN and have sought out and procured services and care for my resident.I am much more aware of the residents’ specific medical condition, prognosis, and psychosocial behaviours than the majority of the staff. |
| 6B | We pay for extra care for our resident | My sister also hired a sitter 2 or 3 times a week for an hour for my mother during week days. Because my mother was an Overseas WW2 vet she paid only $1,000 a month for her LTC so she could afford the sitter and pay us gas money for coming up from Kingston weekly.  |
| 6B | We pay for additional care and this makes the difference | My sister and I and 2 Private PSW's provided daily care of 4 + hrs so Mom did not suffer from isolation, neglect, lack of being outdoors, participation in activities, being changed when needed, being fed a warm meal, making sure baths were given and hair clean, we always brushed her teeth, PSW had no time to provide oral care. 3PSW for 33 residents, at least 25 of whom in wheelchairs requiring 2 PSW for care.  |
| 6B | I provide most of the daily care | I provide the majority of daily care, all personal and legal matters, all feeding, laundry, arrange outside medical services to attend (Footcare, massage), entertainment and social ops, decisions re her care (med changes, dietary, etc), administer all meds and topical applications, In many ways staff have deferred to me given my presence there and at times over look her care. |
| Code 7 is about the need for more training and better communicationThere are 8 instances of this code.7A – Staff need training to see the value of family caregivers, and to gain competence in providing care7B – This LTC home needs to do more to communicate with families |
| 7A | Staff need training to see the value of presence of family | I feel more training of staff is required as to how all these pieces come together and provide value in the level of care given to our loved ones. |
| 7A | Staff need training | The staff who deal with my mother's care need much more training about dementia. |
| 7A | Staff are not properly prepared or trained to care for some residents | I am more involved in my parent's care (predates LTC) than most. I spend hours researching, monitoring, advocating and working to find a balance to address the needs of the institution (schedules, rules, etc) - making the best decisions for my parent in her interest - managing biases about mental illness from doctors and nurses - and sadly watch someone screams of pain being unheeded by personnel who attribute that to dementia or mental illness. But I feel staff lack insight into behaviours that indicate a problem (eg pain which can cause agression) and staff focus on managing the behaviour as opposed to understanding the cause or trigger.  |
| 7A | Staff need to be trained to treat residents with dignity | I think more training is needed for staff --- I would urge trainers to clearly communicate and reinforce regularly the need to respect residents and be professional and attentive at all times. It should include assessment and monitoring of staff's approach/attitude towards residents and their understanding of what 'maintaining resdients' dignity' means -- this is an area I find quite lacking at the [name of home] in Ottawa. |
| 7A | Staff need dementia training | le personnel (préposé) ne semble pas comprendre la démence et les approches à prendre auprès ma mère...parfois je dois éduquer le personnel...(the staff (attendant) don't seem to understand dementia and how to approach my mother ... sometimes I have to educate the staff ...) |
| 7B | LTC homes should improve trust and communication with family | LTC homes should trust family members as they are important stakeholders and should establish open channels of communication where all parties can cooperate and express concerns. |
| 7B | The LTC home needs to provide more information to family | I feel like more information should be shared with all family members concerning their loved one and not just shared with the power of attorney for care. This information does not need to be intimate details but general information to help with the understanding and care of their loved one. |
| 7B | This LTC home could improve its communication with family | A mon avis le personnel administatif devrait communiquer plus souvent avec les familles au sujet des activités, des menus, avoir des rencontres familles/résidents.Je trouve que la rencontre annuelle multidisciplinaire afin de discuter du plan de soins et qui prend environ 15 minutes pourrait être plus dynamique. (In my opinion, administrative staff should communicate more often with families about activities, menus, and having family / resident meetings.I find that the annual multidisciplinary meeting to discuss the care plan and which takes about 15 minutes could be more dynamic.) |
| Code 8 is about the usefulness or potential of Family CouncilsThere are 3 instances of this code.8A – Family Councils are (or could be) a useful resource to support families |
| 8A | Family Councils must be mandated to they can raise issues | It is vital for Family Councils to be \*mandated\* at all LTC homes. These provide a critical link and safety mechanism for resident care, especially where some residents don't have family nearby, or family is absent from care. Often other FC members can raise issues even when it's not about their respective resident. |
| 8A | Family councils should be operated so more families can participate | It has been difficult to be involved in Family Council meetings as they occur at 2:00 in the afternoon 1 x per month. I work full-time in health care and do not have the flexibility to join in. I would really like to see the facility priorize opportunities for family member input and advocacy. The family council meetings are a place to discuss items of common interest. Not being able to participate means relying on newsletters. |
| 8A | Family Council is a strong support for family | The Family Council has also been a strong support for care-givers, providing information and an opportunity to talk to family members of other residents and share information and experiences |
| Code 9 is about the need to improve the LTC sectorThere are 3 instances of this code.9A – The LTC sector must be improved |
| 9A | The LTC sector must be improved | This is not an isolated case as we have seen. There needs to be enforceable national standards in LTC. There need to be enforceable penalties for noncompliance. There needs to be adequate and affordable home support so elders can remain at home longer.  |
| 9A | The LTC sector needs to be improved | I don’t think we should have to be concerned about the care our loved ones are getting in LTC. There ought to be a standard across the board and every resident ought to get the same good care whether a family member is with them or nor. That does not appear to be the case. Many of the residents cannot speak their needs and it shouldn’t be up to family to ensure that those needs are met. Each resident should get the same level of excellent care regardless of whether they have family advocating for them or not. That does not appear to be the case in my opinion. |
| 9A | The LTC sector must be improved | There is no comparison how family members can interact now versus before COVID with their love ones and I feel it will have long term effects on both the love one and family members. I feel we need both the Federal & Provincial Governments to make Long Term Care reform a priority starting with PSWS getting the recognition they so rightly deserve starting with their wages so it will attract dedicated people to take proper care of our most vulnerable. Proper care means legislating more time to care for them and taking the for profit out of equation, |
| Code 10 is about how the LTC home and staff try hard, but there are problems, including a lack of interactionCode 10 has 15 instances.10A – The home and most staff try hard, but there are still problems10B – One persistent problem is that residents lack social interaction10C – Staff behavior stems from the nature of the work |
| 10 | Care for my resident is good, but… | My mother went into LTC during Covid so hard to assess everything accurately but she is well taken care of, though lonely. I think it would be nice to perhaps have smaller groups of like-minded residents interact - groups cannot always offer inclusivity to all. Skill set levels & age can be so broad - those with trouble hearing or speaking might not feel comfortable participating - it can be quite boring for someone who was previously quite ‘with it’ but suffered a physical set back (ie stroke..).It can feel quite ‘institutional’ and not as homey as perhaps it could be. |
| 10 B | PSWs have no time to socially interact with residents | No social contact or occasional checks by psw's. they had no time for that |
| 10A | Care for my resident is good, but… | I feel that the care we have had for dad has been wonderful. Filling in the gaps when staff cannot is a concern. There seems to be much time that is alone time and the staff as wonderful as they are cannot provide the one to one social interactions and extra time that we as family members can provide at times during a week. |
| 10A | The LTC home and its staff do their best | I found the staff and facility provided reasonable care within the system as it is structured. |
| 10A | Some staff are good and some are not | Some staff are excellent and some do not seem to care and appear not to be really interested in providing compassionate care. |
| 10A | Staff are doing their best | Families should learn to work cooperatively with the LTC homes and be ready to be supportive of staff as they are trying their best. |
| 10A | Some staff are good and some are not | It was extremely important to me that my wife receive 24hr a day 7 days a week exceptional care. However I could never trust ALL the staff to provide the same level of care that each was trained and hired to give. i.e. Some staff had excellent work ethic, they truly cared about the wellbeing and comfort of the resident and would do anything and everything to provide exemplary care. They would get to know the resident's personal history, likes & dislikes, emotional & physical needs, medical issues (physical pain, emotional pain), family relationships, look at photos, sit and talk, answer the call bell as soon as possible, give gentle kind compassionate care when bathing, dressing, transporting, toileting etc. BUT, there were far too many other staff who worked only for a pay cheque, did minimal amount of work necessary to just get the job done and with no emotional support, personal involvement or extra time towards the resident. i.e. rush to get the resident toileted, washed & dressed in the morning to be in the dining room for breakfast (taking all of 10 minutes); rushed to do same tasks at nighttime for bed so the staff member could take a break (thus leaving resident uncomfortable in bed or in pain), rush the residents to eat their meals so staff could take his/her break; ignore call bells thinking it wasn't important ("oh that person always rings bell for nothing") thus leaving resident to soil their brief and be left sitting in personal waste matter embarassed and crying from shame), not listening or giving resident who has trouble speaking, time to try and speak when there is a problem, (causing frustration for resident and crying). Many many things that would upset my wife because she had come to expect that ALL staff would treat her the as well as and as compassionately, gently, kindly and with great care as the GOOD staff were treating her. |
| 10A | Staff in this home do their best | The staff did the best they could with the staff they had....not enough staff to provide proper care...2 psw's to put 22 ppl to bed....not good! |
| 10A | Front-line LTC workers have difficult jobs, and that explains their behaviour | I witnessed how difficult care workers' jobs were every time I visited, which helped me understand why they had little to no time for quality person-centred care. |
| 10B | I wish my resident had more chances to interact with others | There seems to be much time that is alone time and the staff as wonderful as they are cannot provide the one to one social interactions and extra time that we as family members can provide at times during a week. |
| 10B | I wish my resident was not so frequently ignored and had more chances to interact with others | At the same time, I wished that my grandfather had more opportunities to socialize and laugh with staff and fellow residents. |
| 10B | I wish my resident had more chances to interact with others | I arrive for visits and find him in the middle of the day in his room, door closed, lights off, curtains closed, radio playing, screaming, face and ears extremely hot and red. I don’t know how long he has been left this way, without interaction. |
| 10C | Staff are not to blame | I don't blame the staff. They do ask for a history of the patient but with a ratio of too many patients, how are they to spend time with them? They barely have enough time to do the necessary care. |
| 10C | PSWs are overworked and underpaid | Its not an easy job. They are overworked and underpaid! |
| 10C | Front-line LTC workers have difficult jobs, and that explains their behaviour | I witnessed how difficult care workers' jobs were every time I visited, which helped me understand why they had little to no time for quality person-centred care. |
| Code 11 is about how this LTC home and its staff and volunteers do a good jobCode 11 has 27 instances.11A – This is a really good LTC home11B – The staff in this LTC home are wonderful11C – The managers and staff at this LTC home do a good job11D – The volunteers at this LTC home are wonderful11E – We have several family members who visit our resident |
| 11A | My resident is safe in this LTC home | I know my dad is liked and looked after and he is safe. The staff have been wonderful and especially during this covid time they have been kept us abreast of everything. We are very thankful and blessed. |
| 11A | My resident’s home is above average | The LTC Home my mom is in is above average in my opinion (having friends who also have had family in LTC). |
| 11A | The quality of care in this LTC home is good | I would just like to say that the level of care and the safety of my parent at the facility has given me great comfort and ease of mind. |
| 11A | This LTC home does a good job | I am very happy were my mom is. They only thing is I hope the people that work there get good pay. Because they work hard. |
| 11A | Things have gone reasonably well for my resident | Ma mère était relativement autonome dans son appartement. Je faisais ses courses, j'allais à ses rendez-vous (médecin, dentiste, coiffeur), je lui faisais livrer des repas et ses médicaments. Elle recevait des soins des pieds à la maison (infirmière) et des préposées du RLISS lui rendaient visite. Je la sortais luncher une fois par semaine. D'autres membres de ma famille (cousins, cousines) lui rendaient visite. Ma mère parlait à ses soeurs tous les jours. Maman est entrée à la résidence en octobre 2019. J'allais la visiter et luncher avec elle plusieurs fois par semaine. Une cousine l'amenait visiter une de ses soeurs aux deux semaines. Parents et amis l'ont visité. Ça, c'était avant la pandémie... J'ai laissé plusieurs questions sans réponses puisque ma mère est toujours vivante et qu'elle ne souffre pas de démence. Récemment, on l'a diagnostiquée comme souffrant de perte de mémoire modérée. Il lui est difficile de trouver le mot juste. Aussi, lorsqu'elle est moins médicamentée (elle souffre beaucoup), j'ai encore de belles conversations avec elle.(My mother was relatively independent in her apartment. I did her shopping, I went to her appointments (doctor, dentist, hairdresser), I delivered her meals and her medicines. She received foot care at home (nurse) and was visited by LHIN workers. I took her out to lunch once a week. Other members of my family (cousins, cousins) visited him. My mother spoke to her sisters every day. Mom entered the residence in October 2019. I would visit her and have lunch with her several times a week. A cousin took her to visit one of her sisters every two weeks. Relatives and friends visited it. That was before the pandemic ... I left several questions unanswered since my mother is still alive and does not suffer from dementia. Recently she was diagnosed with moderate memory loss. It is difficult for him to find the right word. Also, when she is less medicated (she is in a lot of pain), I still have great conversations with her.) |
| 11A | This LTC home welcomes family and we work as a team | La question #61 est mal posée. Je ne comprenais pas. Je ne suis pas son POA, alors mes renseignements et les décisions viennent de sa fille qui vient rarement et qui habite à l'extérieur. Tous mes efforts pour rendre ma soeur aussi heureuse que possible sont récompensés par la réalisation qu'elle est dans un bon foyer où on travaille en équipe pour elle. Pas toujours facile mais ça vaut la peine. Merci de tenter de rendre la vie de ces gens plus heureuse. (Question # 61 is incorrectly asked. I did not understand. I'm not his POA, so my information and decisions come from his daughter who rarely comes and lives outside. All of my efforts to make my sister as happy as possible are rewarded with the realization that she is in a good home where we work as a team for her. Not always easy but worth it. Thank you for trying to make these people's lives happier.) |
| 11A | This LTC home was well managed | My two friends were in a well managed L T C Home which I am most grateful. |
| 11A | This LTC home is inclusive and helpful | [name of home] is very inclusive of family. Our loved one (my mother) lives in LTC due to her lack of mobility, not her cognition or ability to communicate. She is our messenger for a lot of happenings. She uses the phone on her own and is able to communicate to the staff. We are fortunate she can still do that - it's very helpful for her care. |
| 11A | Care at this LTC home makes me happy | I am very happy with the level of care at [name of home].  |
| 11A | This home provides excellent care | [name of home] is providing excellent care. Everyone seems like they are doing their best. |
| 11A | This LTC home treats families and residents with respect | Involving the family as knowledgeable team members is important. [name of home] taff treat patients and families with warmth and respect. |
| 11A | This home helps my resident by letting her interact more with others | The home provides her with more interactions with people than I could give her when she lived with me. |
| 11B | Most staff are friendly and compassionate  | Majority of frontline staff (minus the numerous Agency staff) are very friendly, compassionate toward our loved one… |
| 11B | The staff in my LTC home are wonderful | The LTC had wonderful staff who would call if they noticed a change or had a question. They also held care conferences with her doctor which was a great opportunity to give and receive feedback on care concerns. |
| 11B | LTC staff support me and I support them. | I supported the LTC staff and they supported me, and we had to communicate almost daily and always weekly in attempting to manage this behaviour from my other family members. I had to have lawyers involved to support me as POA. The administrators continued to provide ongoing support for both of my parents. |
| 11B | Staff are wonderful | The wonderful staff RNs, RPNs and PSWs can only do so much. |
| 11B | Staff in this LTC home are awesome | The staff are awesome, they genuinely show that they care and are willing to share info with me about my parent. |
| 11B | I trust the staff in this LTC home | Staff have always answered my questions and/or followed up if I found my family member confused during a visit. She opens up to me, but is quite closed to staff members which is not helpful to them. However, I do trust in their professional abilities. |
| 11B | Staff in this LTC home are excellent | The LTCH staff have been unstinting in their provision of care and support for, not just my spouse, all residents of the Home. |
| 11B | Frontline staff in this LTC home do a good job | When I see 'Staff' I think of those who are providing direct care and yes they are doing a good job. |
| 11B | Staff are supportive at this LTC home | The staff has always been very supportive and have been particularly careful during the pandemic. We have not had a single case of Covid-19 at [name of home]. |
| 11B | Staff at this LTC home are caring and efficient | All the staff are kind caring and efficient in all facets of duties and responsibilities. I am so happy they were accepted at people care |
| 11C | Staff, managers, and health care providers in my home do a good job and treat me like a member of the team | I have to commend the staff, doctor, DOC, ADOC and administrators in their role with my parent's care. They were always professional and kind. As the POA, I always worked in cooperation with them keeping the lines of communication open at all times. I am of the belief that we are a team and we must work together in the care of the residents and this is what creates positive, respectful, working relationships. |
| 11C | This LTC home and most staff are fantastic | The [name of home] has been a fantastic facility for my mother. The majority of the staff are very caring and compassionate. |
| 11C | This LTC home and staff are wonderful | The LTC home where my brother resides is an amazing place. They have wonderful staff who connect to residents like family. I am so happy to know he is loved and cared for and he really likes it there. |
| 11D | Volunteers in this LTC home are wonderful | The volunteers were wonderful and would sometimes pop in to say hello. The program managers would do a great job of arranging entertainment such as bingo and music. Our mother would usually rely on one of her family members to get take her. |
| 11E | Our family has several members who visit our resident | My mother had 3 daughters and 1 son. Only my youngest sister lived in Ottawa. She had POA of care and finance. She arranged for her step-daughter to take charge if my mother died since she lived in Gatineau. Fortunately, my mother died while my sister was in Ottawa. My sister visited my mother at least every 2nd day and fed her a meal then. Otherwise, the staff fed her her meals except when I and my husband were there once a week. …My other sister and brother visited sporadically. |
| Code 12 is about the negative impact of LTC rules during the pandemicCode 12 has 13 instances.12A – During the pandemic this LTC home could not cope and my resident’s health declined12B – LTC rules during the pandemic have been difficult to follow and been needlessly restrictive12C – LTC rules during the pandemic have been unfair and possibly inhumane |
| 12A | During Covid this home could not provide adequate care | The home [name of home] where my mom is in has the ability to provide basic care prior to Covid. After Covid not a passing mark for taking care of my mom and other residents. |
| 12A | During Covid my resident declined badly | My father moved from [name of retirement home] in a retirement home to Long Term Care just 9 days before the lockdown due to Covid 19. I don’t know how different it might have been compared to this past year. I do know that the continued isolation and confinement has accelerated my father’s decline in the extreme. He went from being able to walk, converse, feed himself, pee, wash his hands, try to dress himself to losing 40 lbs, being confined to a wheelchair, unable to feed himself a diet that now consists of puréed food, unable to communicate, screaming most of the time. I have seen my dad nearly every day for the past five months since I am the only caregiver allowed in the home. Prior to that my husband was able to alternate with me. The only way I can bring family in to see him is through FaceTime. We are confined to his room except since the weather is improving I am able to wheel him out into the fenced in gardens. |
| 12A | My family member declined rapidly during the pandemic | During the lockdown and subsequent isolation which began in March 2020 for Retirement Home and LTC residents, the isolation, absence of family visits, social activities, and meaningful life interactions took a huge toll and I believe was the root cause of the quick advance of her dementia and mobility issues. She suffered a fall during the first 3 months of the pandemic, at her Retirement Home and because of the fear of attending a hospital / medical appointment did not receive the care she required in a timely manner. It was discovered a few months later, that the fall resulted in an L1 lumbar fracture which required hospitalization in July 2020, and subsequent LTC placement in August 2020, due to her health conditions and the injury resulted in her being wheelchair-bound.  |
| 12A | My family member declined rapidly during the pandemic | I have noticed my mother decline rapidly, due to the continued isolation, loneliness, lack of mental stimulation, lack of socialization lack of access to her religious services, lack of foot care and hair care (basic grooming is denied), and denial of visits of her spouse.  |
| 12A | Conditions during Covid have been horrible | During COVID situation HORRIFIC, residents confined to 8 X 8 room 24/7, many not fed or provided fluids between meals, no social interaction, left soiled, crying in pain, all of this personally observed, and MORE. |
| 12A | Covid restrictions have impaired my resident’s health | Prior to the Covid pandemic, I was free to take my spouse for drives and even picnic in the local park. The restrictions brought about by Covid have brought these pleasures to an end. As a result, my spouse's health has deteriorated significantly and I visit her daily to help with emotional support.  |
| 12B | Pandemic rules means that my father cannot visit my mother in LTC | My father, who resides at a retirement home requires assistance to enter the LTC home due to his disabilities, and when Ontario went into grey colour status in Mid-November 2020, he was denied access to his wife as he could not enter on his own and navigate the sanitization/elevator codes, etc. on his own.  |
| 12B | Pandemic rules have exacerbated the strains on residents and family | As the only Essential Caregiver…the strain of being the "only one" without an opportunity for respite has exacerbated stresses… |
| 12B | LTC during the pandemic has been a whirlwind of different events | The last two years have been a whirlwind of hospital stays, independent living, retirement residence, LTC, rehab and respite care. Your survey presumes a degree of stability which was not the case. |
| 12B | LTC needs to open to more family members | Please start thinking about how to reopen LTC homes to family members other than the designated essential care givers. My mother has only had one 15 minute visit in the last 13 months and my sister who is POA cannot go there. |
| 12C | LTC implementation of pandemic rules have infringed on the rights of elderly residents | Further, our Local Health Unit, in Mid-November 2020 [name of LHU] limited LTC residents in our area to only "one" Essential Caregiver (even though the Ontario Provincial Guidelines authorize 2 Essential Caregivers per resident). In my opinion, my mother has been denied her rights to see her spouse, visit with her 2 other children and grandchildren. |
| 12C | Residents are treated like prisoners | …[*pandemic rules have*] denied meaningful relationships for my mother with her spouse and other 2 children and grandchildren. In essence, she is a prisoner within her LTC home. As my mother said to me "I know what it is like to be captured. There are a lot of rules and because I am captured I have to listen". While my mother has dementia, she is very aware, of her circumstances, and the absence of meaningful family interactions has advanced her dementia far quicker than it would have if she had been allowed visits and social interactions.  |
| 12C | Being an LTC resident is like being a prisoner | She has been a prisoner since.  |
| Code 14 is about the responsibility of family to cooperate with staff and managers in LTCCode 14 has 6 instances.14A – Families should be civil and cooperative as they interact with managers and staff in LTC14B – I want to be given more responsibility and involvement with my resident |
| 14A | I have relatives who cause trouble at the LTC home | I had family members who were creating negative and destructive relationships with all the staff, causing major conflict with all of their visits in LTC and in which police had to be involved. One of my family members was put on restrictive visits due to the confrontational manner that he displayed. This ongoing conflict that family members caused put a lot of strain on the LTC staff and me, as POA. Staff, at times, felt uncomfortable in providing care as a result due to other family interference as they were anti-LTC. |
| 14A | Families can be abusive and confrontional with LTC staff | Families are important, however, families should not have the right to be abusive to staff and I do believe that the LTC homes should have the right to put measures in place for the public who are confrontational and who show destructive behaviours towards staff in the workplace as this affects their work. The media, and social media, sadly, perpetuates a lot of negativity about LTC and the care they provide to residents. |
| 14A | Families should work cooperatively with LTC homes | Families should learn to work cooperatively with the LTC homes and be ready to be supportive of staff as they are trying their best. And, if there are issues there are ways to communicate effectively to resolve the issues. Families should be ready to provide assistance if needed.  |
| 14B | I lack rights because I am not POA | I would love to have more of a role in the decision making. As it stands I am DCP but if something happened in her care ex. Her dying I wouldn’t get that call to be with her. I have no rights as I don’t have power of attorney. I am good enough to be her care giver at this time but not other than that. Her son is my husband and is also DCP but is in the same position as I am. Out in the cold so to speak. Hurtful. |

# Step 3: Clustering of the Coded Data

This section shows the results of an initial categorizing step. The analyst went through the data and assigned a number to each segment of coded data. The numbers were meant to identify codes that had some affinity with each other. For example, codes associated with the number “1” were statements about the importance of presence of family for the care of residents. Codes associated with the number “2” were statements critical of the attitudes and behaviour of frontline staff in LTC homes. Codes associated with the number “3” were statements about staffing shortages. Codes associated with the number “4” were statements critical of the LTC home as a whole (including the administration of management of the home).

Through this analytical step, all coded data were associated with a number between 1 and 15. The next analytical step involved the sorting and theming of the data clusters.

## Initial Clustering of the Coded Data

|  | **Code** | **Corresponding Data** |
| --- | --- | --- |
| 1 | Families should be part of the care team | Families are an essential component in a resident's level of care - we are part of the team and we have a role to play.  |
| 2 | Some staff are threatened by the presence of family | Families are an essential component in a resident's level of care - we are part of the team and we have a role to play. Depending on the staff, sometimes this is not shared by everyone and they feel they are there to take care of our loved one. They feel threatened or take questions/concerns raised personally.  |
| 1 | Families should be part of the care team | However each person within the home and the family need to work together holistically to provide the level of care our loved one needs.  |
| 7 | Staff need training to see the value of presence of family | I feel more training of staff is required as to how all these pieces come together and provide value in the level of care given to our loved ones. |
| 3 | LTC needs to be well staffed | I think its important for there to be enough staff in the home, I think it's important for loved ones to feel a connection to the staff, familiarity is especially important for those with dementia, so same staff and someone they can relate to is important. |
| 2 | Family / staff tensions and divisions are unfortunate | It would be nice if there wasn't an us and them mentality just one family! |
| 4 | LTC homes are full of challenges | This home in 2008 -2104, experienced the same challenges as were uncovered during Covid-19 - insufficient staff, lack of training, lack of supervision, PSW's were poorly paid, had no benefits, making it necessary for them to work in more than one home and were over-worked. LTC processes, systems were broken or non existent as were their internal and external communications with staff & families. |
| 5 | Government neglect has produced a failed LTC sector | I, along with many families have … seen how the various governments over decades did not act on the many commission reports, submitted long before Covid-19. Our loved ones were abused, neglected and the presence, involvement of families enabled the LTC sector to be maintained. I and many others chose caring for our loved ones over working, saving and planning for our own retirements and elder care. I advocated endlessly to no avail and listened to promises never kept. |
| 6 | Families suffer because of the poor LTC sector | I left a much enjoyed & lucrative career due to decades of government's neglect of this LTC sector and inability of the LTC home to provide quality care. I dearly loved and wanted to care for my parent in my home until his death. He moved from another province to ON so I could do this. When he needed more assistance, Community Care was unable to meet his requirements. LTC became our only option. It was heart breaking to be separated. I, along with many families have suffered tremendously -physically, emotionally & financially. |
| 5 | Presence of family can shore up a failing LTC sector and this is wrong | Our loved ones were abused, neglected and the presence, involvement of families enabled the LTC sector to be maintained. I and many others chose caring for our loved ones over working, saving and planning for our own retirements and elder care. |
| 6 | Families suffer because of the poor LTC sector | I advocated endlessly to no avail and listened to promises never kept. Covid-19 clearly showed the ugly side of government, Families have realized their loved ones are most important to them. The hurt is still profound. |
| 5 | Government neglect has produced a failed LTC sector | I advocated endlessly to no avail and listened to promises never kept. Covid-19 clearly showed the ugly side of government, Families have realized their loved ones are most important to them. |
| 2 | Concerns about staff behavior | Definitely want to know what staff are and aren't doing cause they are always rushing to get them to bed so they don't have to work anymore |
| 4 | LTC homes must consider the needs of residents and families | As a family caregiver, I have never been part of mom’s care plan, included in activities. When a family caregiver is welcomed so is a resident. Keeping family members happy and taking care of their needs to best help their family members is key. Having kitchens as the heart of the home so family members can warm up home cooked meals complete with proper equipment creates a friendly and welcoming atmosphere. Also, providing a place for caregivers to have a meal before they head home is also important especially if family members help with meal times. |
| 8 | Family Councils must be mandated to they can raise issues | It is vital for Family Councils to be \*mandated\* at all LTC homes. These provide a critical link and safety mechanism for resident care, especially where some residents don't have family nearby, or family is absent from care. Often other FC members can raise issues even when it's not about their respective resident. |
| 4 | This LTC home is unhelpful and full of challenges | This facility was unhelpful, dangerously disorganized extremely short staffed (why I was so involved in his care). I watched as 2 residents succumbed to painful early deaths from inadequate wound care in my husband’s 15 person ward alone. There were so many others! I learned quickly not to trust a word management said. Numerous reports to licensing concluded “unfounded" even with photos. Ultimately a public administrator was assigned to the facility - but she’s got now and there is yet another GM. I feel terrible for everyone still living there. Add Covid to that and I was forced to abandon my husband to these people! These have been the darkest days of my life and I doubt that I will ever recover completely. It took 12 months but I finally got a call that a bed in a new facility was available.  |
| 6 | Families have suffered | I feel terrible for everyone still living there [*previous home where husband lived*]. Add Covid to that and I was forced to abandon my husband to these people! These have been the darkest days of my life and I doubt that I will ever recover completely.  |
| 9 | The LTC sector must be improved | This is not an isolated case as we have seen. There needs to be enforceable national standards in LTC. There need to be enforceable penalties for noncompliance. There needs to be adequate and affordable home support so elders can remain at home longer.  |
| 2 | Staff behavior produces poor results | Staff are very task oriented. They are very negative in their communication with residents. Quick to tell them what can't be done. Rushed for time. Poor communication between staff. |
| 5 | I find it necessary to pay for and/or provide extra care to support my resident | I am a retired RN and have sought out and procured services and care for my resident.I am much more aware of the residents’ specific medical condition, prognosis, and psychosocial behaviours than the majority of the staff. |
| 2 | Sometimes staff do not share important information | Parfois, le personnel oublie que ce qui est naturel pour eux est nouveau pour les membres de la famille. Par ex., j’aurais eu besoin d’être informé des changements graduels des soins, par ex., que ma mère avait besoin d’une tasse pour enfants plutôt que de la voir du jour au lendemain utiliser cette tasse pour enfants. (Sometimes staff forget that what is natural for them is new to family members. For example, I would have needed to be informed of gradual changes in care, e.g., that my mother needed a children's cup rather than seeing her overnight use that children's cup.) |
| 1 | Presence of family is important for resident happiness | In the 4 years that my mom has been at this care facility I feel my involvement has been extremely important to her happiness and to my peace of mind. |
| 7 | Staff need training | The staff who deal with my mother's care need much more training about dementia. |
| 4 | There is tension and conflict between families and bosses/staff | Inconsistencies between how staff are interpreting the COVID ‘rules’ and weak staff communication skills result in conflict between family members and staff. Trust and respect are eroding, family members are feeling “watched” and fear that, if they are caught doing something wrong, they will be barred from entry. Much of the family's experience depends on their ability to be diplomatic, agreeable, invisible, compliant, easy to get along with and liked by the bosses. |
| 3 | LTC needs to be well staffed | There is not enough staff to provide proper care and i worry my mother is being neglected. That is why I am there daily plus to monitor how she is being treated. |
| 4 | This LTC home and staff were inept and bullying | The home 10years ago was totally brutal to my mother and I because of her dementia and related behaviours that wete often aggressive during care. They would call me at work and "bully' and threaten and put my mom on antipsychotic meds. I learned quickly they wete inept in caring for residents with dementia and decided to care for her myself twice daily plus I hired private PSWs to come in twice daily after I left. Due to new administration and increased knowledge things fod slowly improve over last 3years..I never completely trusted Some staff and continued this csre until 2weeks ago when mom passed away with me by her side. |
| 6 | I find it necessary to pay for and/or provide extra care to support my resident | I learned quickly they wete inept in caring for residents with dementia and decided to care for her myself twice daily plus I hired private PSWs to come in twice daily after I left. |
| 4 | I saw ageism at this LTC home | LTCH and staff need to undergo many changes and stop AGEISM attitudes. |
| 10 | Care for my resident is good, but… | I feel that the care we have had for dad has been wonderful. Filling in the gaps when staff cannot is a concern. There seems to be much time that is alone time and the staff as wonderful as they are cannot provide the one to one social interactions and extra time that we as family members can provide at times during a week. |
| 10 | I wish my resident had more chances to interact with others | There seems to be much time that is alone time and the staff as wonderful as they are cannot provide the one to one social interactions and extra time that we as family members can provide at times during a week. |
| 1 | Family make important contributions to resident wellbeing | I find that it's these moments of playing a game, chatting, tidying up, sorting through and even setting up a Christmas tree or decorations, giving a little tlc - these personal touches are needed and necessary for the wellbeing of the resident. Thank goodness for the activities and the programs- dementia residents should be encouraged to do those things and not asked if they want to. They are in a LTC facility because they cannot make their own decisions. If playing a game means they have other people around then that is so important. Residents should be brought in to the activity environment even if they don't participate. They will still have that energy from those around them. It is the little things that allow the caregivers (family) of the resident to have that peace of mind that their loved one is more than just a body filling a space. |
| 11 | My resident is safe in this LTC home | I know my dad is liked and looked after and he is safe. The staff have been wonderful and especially during this covid time they have been kept us abreast of everything. We are very thankful and blessed. |
| 4 | Errors occurred during admissions | Gap from my experience was the admission process. Too many documents to fill out on admission day; errors were made.  |
| 4 | LTC home needs better digital technology  | My concern is making video conferencing easier and more accessible, which means better wifi and more digital devices in homes. |
| 5 | For-profit LTC is wrong | We have to end Profit LTC! No one should be redirecting money to a company away from human services and care. |
| 5 | Care is better in not for profit LTC homes | My wife is in a NFP home and the care is difference when staff are paid and treated well. When they know that management cares for them and the residents. When they know that money is not being taken was from the care in the home for someone else to profit from. |
| 2 | PSWs were not humane in my LTC home | At my mom’s LTC the PSWs were a very powerful group and it negatively affected my mom’s care. The care she received was not humane - and this was before the pandemic. |
| 6 | I pay for and provide extra care for my resident | We hired an private caregiver (RNA) to support my mom during her waking hours. If she was not available, I provided care (I am a former RN). |
| 2 | PSWs were negative toward us | What support we needed from the PSWs was frequently provided with a “you’re bothering me” negative attitude, despite the fact that we were kind, appreciative and asked for very little support. |
| 1 | Families should be part of the care team | We have so much to offer. While the home was very short of staff I volunteered to take a course to learn how to transfer my husband safely in the sit to stand lift.  |
| 4 | This LTC home does not value family and treats us poorly | Adminisration does not seem to be involved with families unless there is a complaint. Often that complaint is handed down to a lower ranking member. Families do not seem to be important, are forgotten and even mistrusted. …I was chastised for using the lift while we sat for what seemed like an eternity to get someone to help. I was point blank asked "Do you have a funeral home picked out for your husband" soon after Covid started. No preamble or anything. Families are not encouraged nor do they have many rights within the home. One family member said that they did not put their mother up for adoption when she entered the home. We are definitely undervalued or not valued at all. |
| 2 | Staff communication and follow up are poor | Communication is very poor, between staff and to me. A decision or request from one day often does not get carried through by tomorrow's staff. |
| 11 | Most staff are friendly and compassionate  | Majority of frontline staff (minus the numerous Agency staff) are very friendly, compassionate toward our loved one… |
| 4 | The LTC home administration is unresponsive and secretive | …the biggest issue is with our current administration, where we must result to submitting a complaint to MoLTC for information about the home. The current administration is secretive, non transparent and the current ED is not the right fit for the home. |
| 12 | During Covid this home could not provide adequate care | The home [name of home] where my mom is in has the ability to provide basic care prior to Covid. After Covid not a passing mark for taking care of my mom and other residents. |
| 13 | Front-line LTC workers have difficult jobs, and that explains their behaviour | I witnessed how difficult care workers' jobs were every time I visited, which helped me understand why they had little to no time for quality person-centred care. |
| 6 | I wish my resident had more chances to interact with others | At the same time, I wished that my grandfather had more opportunities to socialize and laugh with staff and fellow residents. |
| 5 | I don’t trust the LTC system | I certainly developed mistrust in the long-term care system and its values, not necessarily mistrust in the care workers themselves. |
| 10 | The LTC home and its staff do their best | I found the staff and facility provided reasonable care within the system as it is structured. |
| 5 | The LTC sector is flawed and underfunded | The system is deeply flawed and under funded. Caring for people should not be done in this big institutional way. It didn’t work for schooling Indigenous children, or people with developmental delays or the mentally way. LTC is not a hospital. Care to seniors should be provided at home for as long as possible with home care services. The few people who require institutional care should be cared for in small facilities where there is adequate staff paid wages that fit the work they do. LTC needs to not be the orphan of health care funding. |
| 5 | For-profit LTC must end | Privately run for profit LTC needs to end. |
| 1 | Family should be part of the care team | I think it is extremely important to have family members involved in the care of their loved one as the care provided by the LTC staff is very inconsistent. |
| 10 | Some staff are good and some are not | Some staff are excellent and some do not seem to care and appear not to be really interested in providing compassionate care. |
| 2 | Some staff neglect my resident and resent my advocacy | They don’t appear to have the empathy required to put themselves in the shoes of the one they are caring for and my experience is they will avoid taking the time to really do a good and thorough job. ie. sometimes I come in and my mom’s underbriefs are wet and all bunched up and uncomfortable, and I have to ask for them to clean her up and change her. Some staff will try to convince me that my mom is OK the way she is and when I insist and they do as I ask, they do it with resentment even though after it has been done, my mom is clearly more comfortable. I have asked that they change my mom regularly mid morning and mid afternoon and it is not done unless I am there and ask for it to be done. |
| 4 | Residents without supportive family may be neglected or suffering | I worry about the people who do not have family to keep watch for their loved ones or on the rare days when we cannot have someone with my mom, I am wondering if she is being cared for well. I am constantly concerned when there is no one there advocating for my mom, that she is receiving compassionate care. |
| 9 | The LTC sector needs to be improved | I don’t think we should have to be concerned about the care our loved ones are getting in LTC. There ought to be a standard across the board and every resident ought to get the same good care whether a family member is with them or nor. That does not appear to be the case. Many of the residents cannot speak their needs and it shouldn’t be up to family to ensure that those needs are met. Each resident should get the same level of excellent care regardless of whether they have family advocating for them or not. That does not appear to be the case in my opinion. |
| 2 | Some staff neglect my resident and resent my advocacy | …when I do speak up politely, many staff resent being asked to do their job and that comes out in how the staff treats me now. When I speak up for my mom, they treat me as if I am a pain in their side, and I am very polite and friendly because I do not want them to take anything out on my mom when I am not there. That is a constant concern of mine. |
| 11 | My resident’s home is above average | The LTC Home my mom is in is above average in my opinion (having friends who also have had family in LTC). |
| 7 | LTC homes should improve trust and communication with family | LTC homes should trust family members as they are important stakeholders and should establish open channels of communication where all parties can cooperate and express concerns. |
| 1 | Family member participation is extremely important | Family member participation is extremely important to ensure residents are kept safe and provided quality care. With the understaffing problem, family members are required to be sure their loved ones are eating regularly, walking, and personal care needs are met. |
| 5 | Presence of family shores up for the deficiencies of the LTC sector  | I always felt like I needed to make daily visit to monitor care. If not, quality of care was not good. Inconsistency of staff on afternoon shift made it difficult for my loved one as new psw's did not know care routines which did not help the residents moods. … Facility was always understaffed and I felt like I needed to do the evening care or settle for poor care. |
| 4 | I also support other residents whose family are not present | Also felt that I was advocating and monitoring for other residents. Several times it was me who discovered and reported a fall or a resident in need. Only contact residents had with psw was for a few minutes to either dress / undress or toilet. No social contact or occasional checks by psw's. they had no time for that. |
| 3 | LTC home needs to be well staffed | Facility was always understaffed and I felt like I needed to do the evening care or settle for poor care. |
| 4 | Nutrition and diet are not properly seen to in this LTC home | Food quality not the greatest. Many residents are constipated due to poor balance of diet. Residents were often given laxatives rather than address nutritional needs. |
| 4 | Care is union minded, not resident centered | Staff are very union minded and not resident centered. The home is run by admin who are very sympathetic to the union demands of staff. Residents pay the price of having staff who are not committed and admin who do not create and sustain a culture of resident cantered LTC. The demands of the unions are running LTCs. Staff are kings, residents are innocent, helpless bystanders. Anytime suggestions or complaints are made, admin and staff stick together to support the facility’s reputation. |
| 12 | During Covid my resident declined badly | My father moved from [name of retirement home] in a retirement home to Long Term Care just 9 days before the lockdown due to Covid 19. I don’t know how different it might have been compared to this past year. I do know that the continued isolation and confinement has accelerated my father’s decline in the extreme. He went from being able to walk, converse, feed himself, pee, wash his hands, try to dress himself to losing 40 lbs, being confined to a wheelchair, unable to feed himself a diet that now consists of puréed food, unable to communicate, screaming most of the time. I have seen my dad nearly every day for the past five months since I am the only caregiver allowed in the home. Prior to that my husband was able to alternate with me. The only way I can bring family in to see him is through FaceTime. We are confined to his room except since the weather is improving I am able to wheel him out into the fenced in gardens. |
| 10 | I wish my resident had more chances to interact with others | I arrive for visits and find him in the middle of the day in his room, door closed, lights off, curtains closed, radio playing, screaming, face and ears extremely hot and red. I don’t know how long he has been left this way, without interaction. |
| 6 | I am suffering because of the poor LTC sector  | At this point long term care is just human storage. There is zero quality of life. All activities remain off limits, a year later, and residents are still confined to their rooms. I hate it. |
| 1 | Families should be part of the care team | My Mom is legally blind and profoundly deaf so it was extremely important that I be a part of her care team.  |
| 11 | The staff in my LTC home are wonderful | The LTC had wonderful staff who would call if they noticed a change or had a question. They also held care conferences with her doctor which was a great opportunity to give and receive feedback on care concerns. |
| 12 | My family member declined rapidly during the pandemic | During the lockdown and subsequent isolation which began in March 2020 for Retirement Home and LTC residents, the isolation, absence of family visits, social activities, and meaningful life interactions took a huge toll and I believe was the root cause of the quick advance of her dementia and mobility issues. She suffered a fall during the first 3 months of the pandemic, at her Retirement Home and because of the fear of attending a hospital / medical appointment did not receive the care she required in a timely manner. It was discovered a few months later, that the fall resulted in an L1 lumbar fracture which required hospitalization in July 2020, and subsequent LTC placement in August 2020, due to her health conditions and the injury resulted in her being wheelchair-bound.  |
| 6 | The pandemic LTC restrictions have been very difficult for family | I have found LTC restrictions very difficult.  |
| 12 | My family member declined rapidly during the pandemic | I have noticed my mother decline rapidly, due to the continued isolation, loneliness, lack of mental stimulation, lack of socialization lack of access to her religious services, lack of foot care and hair care (basic grooming is denied), and denial of visits of her spouse.  |
| 12 | Pandemic rules means that my father cannot visit my mother in LTC | My father, who resides at a retirement home requires assistance to enter the LTC home due to his disabilities, and when Ontario went into grey colour status in Mid-November 2020, he was denied access to his wife as he could not enter on his own and navigate the sanitization/elevator codes, etc. on his own.  |
| 12 | LTC implementation of pandemic rules have infringed on the rights of elderly residents | Further, our Local Health Unit, in Mid-November 2020 [name of LHU] limited LTC residents in our area to only "one" Essential Caregiver (even though the Ontario Provincial Guidelines authorize 2 Essential Caregivers per resident). In my opinion, my mother has been denied her rights to see her spouse, visit with her 2 other children and grandchildren. |
| 6 | Family have suffered because of LTC pandemic rules | As the only Essential Caregiver, I am grateful that I can enter the home and provide emotional support, care and physical supports including the assistance of feeding, however, the strain of being the "only one" without an opportunity for respite has exacerbated stresses… |
| 12 | Residents are treated like prisoners | …[*pandemic rules have*] denied meaningful relationships for my mother with her spouse and other 2 children and grandchildren. In essence, she is a prisoner within her LTC home. As my mother said to me "I know what it is like to be captured. There are a lot of rules and because I am captured I have to listen". While my mother has dementia, she is very aware, of her circumstances, and the absence of meaningful family interactions has advanced her dementia far quicker than it would have if she had been allowed visits and social interactions.  |
| 4 | The LTC home threatened legal action due to my advocacy | As a family member who advocates for their loved one, I was given a letter by [name of home], stating that my behavior was disruptive to the running of the facility. I had to employ a lawyer to respond to the allegations. |
| 2 | Staff don’t have time to understand my resident | I was extremely involved in my mom’s care so I didn’t need to have her behaviour explained to me. I sometimes had trouble getting staff to understand her behaviour though. Mostly it was because they were so rushed and were not allocated sufficient time to care for residents |
| 4 | The LTC home communicates poorly and is poorly managed | Really no level of communication between the facility and the outside world no newsletter no posted activities it's just horrible run around with heads cut off too many bosses no directions yikes maybe being stuck in their rooms isolated has keep se form of organization and healthy observation |
| 4 | My home makes it difficult for family to be involved in care | In my experiences with providing care for my family member, the staff (and really the way the whole system is designed, including the physical structure itself) does not always facilitate or make it comfortable or convenient for family caregivers to provide the level of involvement and care that we really want to do. My vision of a truly welcoming LTC home doesn't exist in the community in which I live, and sadly, in most communities that I am familiar with. The facility hasn't upgraded at all to accommodate space and electrical outlets for technology such as cell phones and laptops and even TV's. (in semi-private rooms)  |
| 4 | This home is unfair to residents with less money | If you are a resident on the lower income scale, it is a struggle to pay for services and necessary equipment that the care home does not provide. If you withhold some funds to pay for any of these services or items, they are breathing down your neck. Even if the services are medically necessary. In For Profit LTC, they come first.  |
| 4 | This home protects itself from litigation | As well, I noticed some of their rules and policies are designed to protect themselves from litigation and have nothing to do with the well-being of the resident.  |
| 4 | This home does not advocate for its residents, and provides insufficient support | They do nothing to advocate on behalf of the resident. Even the social worker is sub-contracted out and works only 2 days of the week. In the 2 years, my LO has been in LTC, he has been in 3 different rooms. They do not do any work ahead of time to determine if the other resident is going to be a good match. If the bed is vacant, that is all that is considered. Even when they are aware of, and have knowledge of issues with a potential roommate for your loved one. It's incredibly stressful to feel as though you must watch literally everything they do. In the second room, the maintenance staff told my LO on the first night, to move back to the room he came from. Because, even they, the cleaning staff, knew it would not be a good fit for him. |
| 4 | This home cares too much about money and is condescending to some residents | During Covid, they will call you (the POA/Caregiver) and the resident, in person into a small room to discuss arrears and lecture, yes lecture, a 78 year old man with dementia on how to live within his means. |
| 4 | Care conferences in this home are inadequate | However, when it comes to a care conference, it is arranged by phone, and only the director of programs and services attended. (That just happened recently)  |
| 6 | Family suffer because of the actions of this home | To conclude my feedback, I must say, it is incredibly stressful and exhausting, to feel as though I must watch literally everything related to the care of my LO, due to a lack of trust in the way the whole system is designed. Of course, that feeling has increased dramatically during the pandemic. |
| 5 | LTC is a failed system and money should be redirected so people can live in their homes in the community | Mom was in an LTC for 5 months and died due to neglect. LTC staff had absolutely no dementia training whatsoever despite being the largest LTC in Canada. Pathetic. Government needs to provide support so people can stay home. LTCs are no place for people with dementia and complex medical needs. The subsidy the government pays to LTCs should be made available so people can stay home and hire help or pay family members to stay home and care for them. Mom would be alive today if I could have kept her home. |
| 4 | This LTC home does not communicate with me | I visit my Nephew 2 or 3 times every week. The care place never calls me about any thing about my nephew. |
| 11 | Staff, managers, and health care providers in my home do a good job and treat me like a member of the team | I have to commend the staff, doctor, DOC, ADOC and administrators in their role with my parent's care. They were always professional and kind. As the POA, I always worked in cooperation with them keeping the lines of communication open at all times. I am of the belief that we are a team and we must work together in the care of the residents and this is what creates positive, respectful, working relationships. |
| 14 | I have relatives who cause trouble at the LTC home | I had family members who were creating negative and destructive relationships with all the staff, causing major conflict with all of their visits in LTC and in which police had to be involved. One of my family members was put on restrictive visits due to the confrontational manner that he displayed. This ongoing conflict that family members caused put a lot of strain on the LTC staff and me, as POA. Staff, at times, felt uncomfortable in providing care as a result due to other family interference as they were anti-LTC. |
| 11 | LTC staff support me and I support them. | I supported the LTC staff and they supported me, and we had to communicate almost daily and always weekly in attempting to manage this behaviour from my other family members. I had to have lawyers involved to support me as POA. The administrators continued to provide ongoing support for both of my parents. |
| 14 | Families can be abusive and confrontional with LTC staff | Families are important, however, families should not have the right to be abusive to staff and I do believe that the LTC homes should have the right to put measures in place for the public who are confrontational and who show destructive behaviours towards staff in the workplace as this affects their work. The media, and social media, sadly, perpetuates a lot of negativity about LTC and the care they provide to residents. |
| 10 | Staff are doing their best | Families should learn to work cooperatively with the LTC homes and be ready to be supportive of staff as they are trying their best. |
| 15 | Families should work cooperatively with LTC homes | Families should learn to work cooperatively with the LTC homes and be ready to be supportive of staff as they are trying their best. And, if there are issues there are ways to communicate effectively to resolve the issues. Families should be ready to provide assistance if needed.  |
| 3 | LTC homes need to be well staffed | There just wasn't enough staff to talk to residents or communicate with residents or feed residents. … All LTCs need more staff and more positive staff involvement.  |
| 11 | Our family has several members who visit our resident | My mother had 3 daughters and 1 son. Only my youngest sister lived in Ottawa. She had POA of care and finance. She arranged for her step-daughter to take charge if my mother died since she lived in Gatineau. Fortunately, my mother died while my sister was in Ottawa. My sister visited my mother at least every 2nd day and fed her a meal then. Otherwise, the staff fed her her meals except when I and my husband were there once a week. …My other sister and brother visited sporadically. |
| 6 | We pay for extra care for our resident | My sister also hired a sitter 2 or 3 times a week for an hour for my mother during week days. Because my mother was an Overseas WW2 vet she paid only $1,000 a month for her LTC so she could afford the sitter and pay us gas money for coming up from Kingston weekly.  |
| 4 | Residents without family or with few visits are having difficulties | But what about other people on my mother's floor? Some only had a visitor once a week if that! There just wasn't enough staff to talk to residents or communicate with residents or feed residents. Also, my sister and I helped other residents at times with feeding and with getting staff to assist them. You don't mention what help we may have provided to residents other than my mother. We also brought our Shiba Inu (a Japanese canine breed) up with us. Some of the residents really delighted in seeing him. Another woman saw her husband a lot and also helped entertain other residents. The sitters would sometimes help with other residents as well. Frankly, if my mother hadn't had us visiting (visiting? we worked like dogs!) , she would have acted out and had to be medicated because she was so disabled or she would have shut down and had a much worse time of it than she did.  |
| 12 | LTC during the pandemic has been a whirlwind of different events | The last two years have been a whirlwind of hospital stays, independent living, retirement residence, LTC, rehab and respite care. Your survey presumes a degree of stability which was not the case. |
| 4 | I complain about the palliative care my resident received | Ma seule plainte lors du décès de ma mère est la difficulté que moi et ma famille ont eu pour soins palliatifs. Cela a pris une semaine avant que le foyer la déclare palliative bien qu’elle l’était depuis un peu plus qu’une semaine. Par le temps que ce processus fut complété ma mère n’à vécu que des heures. Donc elle est restée dans sa chambre avec sa colocataire et seules 2 des 6 enfants ont pu être présents.(My only complaint about my mother's death was the difficulty I and my family had with palliative care. It took a week before the home declared her palliative although she had been palliative for just over a week. By the time this process was completed my mother lived only hours. So she stayed in her room with her roommate and only 2 of the 6 children were able to be present.) |
| 1 | Families should be part of the care team | With appropriate training, family members/care partners are in a unique position to assist in LTC, taking some of the burden off staff.  |
| 4 | Family involvement is sometimes not welcomed | My experience was that my involvement was sometimes viewed as unwelcome, and it was often a struggle to engage fruitfully with staff. Partly that was because staff were too overburdened to engage in a constructive manner.  |
| 2 | Staff may be too busy to engage with families | My experience was that my involvement was sometimes viewed as unwelcome, and it was often a struggle to engage fruitfully with staff. Partly that was because staff were too overburdened to engage in a constructive manner.  |
| 4 | Health care in my LTC home is unacceptable | I witnessed substandard medical services provided to the residents in our LTC facility, care that would be deemed unacceptable in any other health care setting. It was a constant struggle to communicate with the medical team and their lack of involvement led (and still leads) to unnecessary suffering and trips to ER that could have been avoided if residents were properly monitored. |
| 1 | Presence of family is essential in LTC | Quoique je reconnais les efforts et l'expertise des membres du personnel, les soins disponibles n'étaient pas suffisants pour assurer la qualité de vie des résidants à besoins élevés. Lorsque ma mère est entrée en SLD, il n'était pas nécessaire pour moi d'y être chaque jour mais, à mesure que sa condition se détériorait, il devenait évident qu'il nous fallait quelqu'un sur les lieux pour assurer son bien-être. Entre autres, elle aurait perdu sa mobilité, sa capacité de se nourrir convenablement, sa continence, sa capacité de communiquer avec le personnel si nous n'avions pas été là pour en prendre soin. Il fallait constamment répéter pour que les soins prévus dans son plan de soins soient prodigués, surtout lorsqu'il y avait du personnel à temps partiel ou remplaçant. Pendant les repas, j'ai observé combien facile il était pour le personnel d'oublier de donner le repas à un résident, d'offrir un repas avec une texture inappropriée, de retirer une assiette avant que le résident ait la chance de dire qu'il n'avait pas fini. Un résident qui a la capacité de communiquer avec des mots peut se protéger contre ce genre d'oubli, mais celui qui est aphasique doit avoir un interprète. Lorsque le foyer a fermé ses portes aux visiteurs il y a maintenant plus d'un an, j'ai amené ma mère avec moi pour habiter avec ma famille afin d'assurer qu'elle ait tous les soins dont elle a besoin. (While I recognize the efforts and expertise of staff members, the care available was not sufficient to ensure the quality of life of high-need residents. When my mother entered LTC, it was not necessary for me to be there every day but, as her condition deteriorated, it became clear that we needed someone there to take care of her. -to be. Among other things, she would have lost her mobility, her ability to eat properly, her continence, her ability to communicate with staff if we had not been there to take care of her.  |
| 4 | Family need to be present to make sure LTC delivers the needed care | (Translated from French)(…Constant rehearsal was required to ensure the care provided for in his care plan was provided, especially when there were part-time or replacement staff. During meals, I observed how easy it was for the staff to forget to give the meal to a resident, to offer a meal with an inappropriate texture, to remove a plate before the resident had a chance to say that it was 'he hadn't finished. A resident who has the ability to communicate with words can protect himself from this kind of forgetfulness, but one who is aphasic must have an interpreter. When the home closed its doors to visitors over a year ago, I brought my mother with me to live with my family to ensure she had all the care she needed.) |
| 12 | LTC needs to open to more family members | Please start thinking about how to reopen LTC homes to family members other than the designated essential care givers. My mother has only had one 15 minute visit in the last 13 months and my sister who is POA cannot go there. |
| 10 | Some staff are good and some are not | It was extremely important to me that my wife receive 24hr a day 7 days a week exceptional care. However I could never trust ALL the staff to provide the same level of care that each was trained and hired to give. i.e. Some staff had excellent work ethic, they truly cared about the wellbeing and comfort of the resident and would do anything and everything to provide exemplary care. They would get to know the resident's personal history, likes & dislikes, emotional & physical needs, medical issues (physical pain, emotional pain), family relationships, look at photos, sit and talk, answer the call bell as soon as possible, give gentle kind compassionate care when bathing, dressing, transporting, toileting etc. BUT, there were far too many other staff who worked only for a pay cheque, did minimal amount of work necessary to just get the job done and with no emotional support, personal involvement or extra time towards the resident. i.e. rush to get the resident toileted, washed & dressed in the morning to be in the dining room for breakfast (taking all of 10 minutes); rushed to do same tasks at nighttime for bed so the staff member could take a break (thus leaving resident uncomfortable in bed or in pain), rush the residents to eat their meals so staff could take his/her break; ignore call bells thinking it wasn't important ("oh that person always rings bell for nothing") thus leaving resident to soil their brief and be left sitting in personal waste matter embarassed and crying from shame), not listening or giving resident who has trouble speaking, time to try and speak when there is a problem, (causing frustration for resident and crying). Many many things that would upset my wife because she had come to expect that ALL staff would treat her the as well as and as compassionately, gently, kindly and with great care as the GOOD staff were treating her. |
| 2 | All staff should be required to provide good care | There should be NO exception to the treatment or level of care. I and my daughters would countlessly receive calls from my wife early morning or late evening or anytime if none of us could be with her, crying over an uncaring, rushed and cold hearted rude, rough staff member. |
| 2 | Staff would not be honest with us | Staff would cover things up, make excuses. |
| 2 | Staff resented our advocacy | We also were often made to feel like we were intruding or bothering staff if we called to ask questions on the phone or stopped to ask them something in the hallways. |
| 2 | Staff would not tell us about changes to the care plan | We were often left out of the loop if changes were made to my wifes medicines or health care. |
| 2 | What staff say is not consistent with what I see | They say they never run short but I see it . |
| 4 | I provide care because that is the only way I know it is done | I worry about foot care, basic hygiene care hence why I do it after dinner so I know it’s done ! |
| 11 | Staff are wonderful | The wonderful staff RNs, RPNs and PSWs can only do so much. |
| 1 | Family caregivers provide vital help | The involvement of caregivers is vital. …Providing hands on care can be so meaningful, a rewarding way to visit and help for staff. |
| 8 | Family councils should be operated so more families can participate | It has been difficult to be involved in Family Council meetings as they occur at 2:00 in the afternoon 1 x per month. I work full-time in health care and do not have the flexibility to join in. I would really like to see the facility priorize opportunities for family member input and advocacy. The family council meetings are a place to discuss items of common interest. Not being able to participate means relying on newsletters. |
| 4 | Poor facilities can lead to a loss of dignity | My father had physical disabilities, had a hard time getting around. He was bariatric but they didn't have a suitable bathroom setup for him, i.e. rails around toilet, raised seat, narrow doorway his wheelchair couldn't go through, inaccesseible sink. He couldn't enter the bathroom in his w/c but could with his walker, however, he shared a bathroom and they couldn't place equipment in without it being too crowded and unsuitable for other person. So, he would get up with his walker, walk into the bathroom, but not have a place to sit for bm or at sink to wash hands. I would help him , stand beside him in bathroom hand him items like tootbrush etc and have w/c ready at the bathroom doorway for him to sit down on in case he started to weaken. With an accessible set up I coud have helped more effectively and my father would have had some dignity and independence in self care. |
| 1 | Families should be part of the care team | Family members want to be a part of the "care team" and to be fully involved in every level of care. |
| 4 | The LTC home excludes us and resents our advocacy | It is extremely distressing to feel like a "visitor" to my mother's home and to lose all control of decision making and personal care of our mother. We have felt like we were causing problems or imposing on staff whenever we asked questions or tried to offer input. |
| 1 | Presence of family is important for our resident’s wellbeing | Extremely important as it makes my mother still feel somewhat in control of her life. She depends on each member of her family for certain stimulants. Loneliness is terrible and the months we could only communicate on the phone or facetime took a toll |
| 4 | People in this LTC home are in despair | Everyone I know who has a loved one in that establishment wants assisted suicide rather than being moved there in case of dementia. That is how bad our system is. People walking around with dirty diapers... staff not knowing what a patient's routine is... I could go on. |
| 10 | Staff are not to blame | I don't blame the staff. They do ask for a history of the patient but with a ratio of too many patients, how are they to spend time with them? They barely have enough time to do the necessary care. |
| 4 | The signs of neglect in this LTC home are horrible and frustrating | I could write a horor story about seniors' residences. Three times, I have arrived for my visit to find discarded soiled diapers (not my loved one's) on the floor in her room. I have found faecies on her bedroom floor or bathroom floor, in her closet... Her clothes disappear. Her winter boots disappeared and were lost for the whole winter. I had to buy a new pair. He photo album has vanished, never to be found... One staff member gives me one instruction, another gives me a different one... anyway, you can sense my frustration, I am sure. |
| 4 | Quality of care in this LTC home is appalling | I had to fight for every medical procedure for my mother. My mother had stage 3 bedsores and I was not even informed about this until I commented on the smell in her room. My mother also put on 25 lbs once she was in a wheelchair with her stomach bloated and I had to fight to get her an ultrasound so as much as these questions ask what was important to me they all were but the care in this private long term residence was so below any kind of standards it was appalling |
| 11 | The quality of care in this LTC home is good | I would just like to say that the level of care and the safety of my parent at the facility has given me great comfort and ease of mind. |
| 11 | Staff in this LTC home are awesome | The staff are awesome, they genuinely show that they care and are willing to share info with me about my parent. |
| 4 | Care is neglectful in this LTC home | Often a concern about medical care was brought forward and not followed up on. I had to stand over a nurse or a director of care to get them to attend to it. Eg. My mother nearly died from anal suppositories. It caused extreme diarrhea. This happened 3 times.  |
| 4 | I have to advocate and check up on their work | I had to stand over the assistant director of care to see she posted an allergy alert on my mother’s care plan and I pushed to have a sign posted over the head of her bed. They didn’t want the sign up. They said it contradicted privacy issues. I said my mother’s life is more important than your damn concerns for privacy. It got put up. Changing of wound bandages was sometimes not done. They would deny that the bandage hadn’t been changed. Urine samples for a bladder infection were handled improperly.  |
| 4 | Family must advocate, complain, and check up on LTC staff work | A family member must advocate to get care for a resident. You can’t lay a complaint to the Ministry all the time. You have to stand over staff to see it gets done. A shame! |
| 4 | This LTC home does not provide adequate dietary and nutritional care | I am appauled that all residents not just for my mother that they are only entitled to 7$ a day in food, this includes breakfast lunch and dinner plus snacks. I never hear fresh fruit or vegetables, my mother is a brittle diabetic and the amount of sugary foods is disgusting,and not good for her overall health and well being. I hear fish nuggets, french fries, hot dogs, puddings pies dough nuts cakes powdered orange juice it's heart wrenching,her sugars range from 2.5- mid to high 20s!!! I am concerned and worried have spoke with so many people in management it's crazy and the cycle continues. Where is the quality of life when their are no choices but to place your most precious loved one? We live in a bountiful farm community that these fragile elderly loved ones have no access to wounce they are placed! |
| 5 | For profit LTC focuses mostly on profit | I strongly feel it's about profit, not the well being the residents deserve. |
| 3 | Frequent staff turnover causes problems | Frequent Staff turn-over, difficult to get to know, or PSW to know or familiarize themselves with resident and vis a vis.  |
| 3 | Staff are overworked and this causes problems | Staff rush to provide care, lack of attention how resident is left, ie. half dressed, disheveled, slouching in wheelchair.  |
| 6 | We pay for additional care and this makes the difference | My sister and I and 2 Private PSW's provided daily care of 4 + hrs so Mom did not suffer from isolation, neglect, lack of being outdoors, participation in activities, being changed when needed, being fed a warm meal, making sure baths were given and hair clean, we always brushed her teeth, PSW had no time to provide oral care. 3PSW for 33 residents, at least 25 of whom in wheelchairs requiring 2 PSW for care.  |
| 4 | Managers at this LTC home resent complaints  | Management frowned on having issues brought to their attention, threatened with Trespassing law. Management from home office participated in meetings, answer always that they are within Ministry guidelines?  |
| 12 | Conditions during Covid have been horrible | During COVID situation HORRIFIC, residents confined to 8 X 8 room 24/7, many not fed or provided fluids between meals, no social interaction, left soiled, crying in pain, all of this personally observed, and MORE. |
| 1 | Family caregivers provide vital assistance | Daily family assistance is crucial in long-term care. Residents are only allowed outside with a family member. Many residents never go outside. Residents are much more likely to go on resident arranged outings if a family member can sign them up and help out. |
| 2 | Temporary and some full-time staff are not competent | Reliance on agency staff results in people who do not know how to care for a resident. Even full-time staff are not well trained on how to hoyer someone using a broda. How to place them in the sling. How the chair must be positioned and where to place the wheels of the hoyer so that the resident can be placed right at the back of the base of the seat so their back is fully supported. |
| 4 | Stories of neglect and incometence | I arrived late one Saturday morning at 10:30 to find mom still in bed, not dressed, not fed, not changed. Full-time staff didn't show for their shift and only 1 agency person was there and it takes 2 people to use the hoyer. Mom called me a few times at 6:30 at night to say she had not been given dinner so I drove over with food. I found if I called in a request in response to a phone call from my mom (she needs to be changed/she hasn't had dinner) the nurse did not ensure the request was met. I always followed up my phone call with a drive over and it turned out to always be necessary. |
| 4 | Stories of neglect and incometence | On every visit I would change mom's brief after lunch. Sometimes there were no soaker pads under mom and no clean ones on the floor. What does this mean? It's impossible to turn someone on their side to change them without a soaker pad to pull on. Pulling on the resident directly results in injuries and pain to them. |
| 4 | Stories of neglect and incometence | I had to provide zincofax or sudocrem for mom because it was the only way to ensure it would be available when needed. Initially the nurse took the cream to keep at the nursing station resulting in it not being used by the PSW's as they didn't have time to go looking for it. I had to battle for it to be left on her side table. |
| 4 | Stories of neglect and incometence | Lack of fluids is another issue. The home provides the minimum amount of water/juice in tiny 120 ml or 170 ml cups. Often mom was extremely thirsty. I would provide juice for mom which was labelled and kept in the tiny resident fridge. Occasionally I would notice some residents were missing their cups at lunchtime and I would ask the kitchen staff for cups of juice/water for the resident. |
| 4 | Stories of neglect and incometence | The home changed the food service provider (to save money I guess) resulting in ongoing issues like no bananas, no yogurt, powdered apple juice being used. Soft foods like these are often the only thing many residents can/will eat. One day there was no sugar for residents coffee/tea/cereal. Our seniors deserve much better! |
| 4 | Stories of neglect and incometence | An ongoing issue throughout the home was residents not being changed when a change was needed. I saw feces leaking from a resident that asked for a change for over an hour. I asked the PSW for help, another caregiver made the same request. It was ignored. Another resident removed his brief full of feces and feces was smeared all over the room, down the hall. If they had met the request when needed a massive cleanup would have been avoided. I spoke to management about these 2 incidents. Nothing changed. Staff do the minimum and if it is close to end of shift every request gets left for the next team to deal with. |
| 2 | Temporary staff do not do a good job | the regular staff that have gotten to know him are exemplary however there are too many 'agency staff' or transient staff that just come in to do a job and don't make the time to either know him and/or me and end up doing a below par job |
| 2 | Staff need to communicate more with family so we are aware of changes | More communication from staff would be of benefit to me. I know there is a lot to do and only so much time but being more aware of changes in my family member's behaviour would help me do a better job of helping to meet their needs. In these 'Covid' times perhaps more use of Zoom or similar would be appropriate. |
| 6 | I provide most of the daily care | I provide the majority of daily care, all personal and legal matters, all feeding, laundry, arrange outside medical services to attend (Footcare, massage), entertainment and social ops, decisions re her care (med changes, dietary, etc), administer all meds and topical applications, In many ways staff have deferred to me given my presence there and at times over look her care. |
| 4 | I sometimes help other residents (not just family) because they need help | I also assisted with other residents in dining room, distressed times where I have a good relationship with resident, personal shopping for them if required. |
| 4 | My advocacy and suggestions are ignored | I find there are several areas that require attention in standard operating protocols and have discussed with administrator and staff to no avail. I now d what is best for my daughter and do not bother with staff whenever possible. |
| 9 | The LTC sector must be improved | There is no comparison how family members can interact now versus before COVID with their love ones and I feel it will have long term effects on both the love one and family members. I feel we need both the Federal & Provincial Governments to make Long Term Care reform a priority starting with PSWS getting the recognition they so rightly deserve starting with their wages so it will attract dedicated people to take proper care of our most vulnerable. Proper care means legislating more time to care for them and taking the for profit out of equation, |
| 2 | Staff do not appreciate the role of family | I do not feel that the staff of the facility show or express appreciation of the care I provide(d) i.e. coverage of all PSW duties for 5-6 hours every day; thereby freeing up staff to provide more adequate care to other residents. In almost 4 years, I have provided direct care since Day 1, there has been no recognition of this assistance. Indeed, sometimes, I think it may be a mistake on my part, because staff on the relevant shifts do not get to know my husband, and really make little attempt to do so. |
| 1 | Families should be part of the care team | It’s essential! |
| 4 | Care in this LTC home is horrible | The care of our mom during her last days was a horrific experience. |
| 4 | This LTC home offers poor health care | Medical expertise was lacking in many critical areas. |
| 6 | This LTC home treats families poorly | Treatment of family was poor and communication with management strained. |
| 3 | LTC needs to be well staffed | The facility was understaffed and the staff over worked. The staff did not really have the time to spend quality time with the residents.  |
| 8 | Family Council is a strong support for family | The Family Council has also been a strong support for care-givers, providing information and an opportunity to talk to family members of other residents and share information and experiences |
| 6 | Families have suffered due to Covid rules | During the pandemic, the limiting of family visitors and those deemed “essential” has caused a great deal of stress and strife within the family |
| 11 | This LTC home does a good job | I am very happy were my mom is. They only thing is I hope the people that work there get good pay. Because they work hard. |
| 1 | Families should be part of the care team | Critical. Being able to be part of my mom's life is critical to her care. The more involvement, the better off she is. Its not just that she knows she loved, but that staff understand that there will be somebody there often to make sure everything is being done in their power to ensure she is safe and well.  |
| 5 | Family caregivers shore up a failing system | The good care givers deeply understand that LTC facilities are under funded - under staffed - require 24/7 365 care and are doing their best...but sometimes its not enough - they have 100's of folk to care for. We need to fill the gap....or the system falls apart. |
| 11 | This LTC home and most staff are fantastic | The [name of home] has been a fantastic facility for my mother. The majority of the staff are very caring and compassionate. |
| 11 | This LTC home and staff are wonderful | The LTC home where my brother resides is an amazing place. They have wonderful staff who connect to residents like family. I am so happy to know he is loved and cared for and he really likes it there. |
| 1 | My family is very involved in our resident’s care | My brother is the primary care giver, he lives close by our loved one. He schedules and attends all medical appt's, visits and interacts with her frequently and is the contact person for staff. My role is much more reduced than his as I live further away and am snowbird in the winter. We are dedicated to her well being. |
| 10 | Staff in this home do their best | The staff did the best they could with the staff they had....not enough staff to provide proper care...2 psw's to put 22 ppl to bed....not good! |
| 3 | LTC needs to be well staffed | ....not enough staff to provide proper care...2 psw's to put 22 ppl to bed....not good! |
| 2 | Staff in this home need to be held accountable | staff need to be held more accountable which will then improve quality of care given. |
| 10 | Care for my resident is good, but… | My mother went into LTC during Covid so hard to assess everything accurately but she is well taken care of, though lonely. I think it would be nice to perhaps have smaller groups of like-minded residents interact - groups cannot always offer inclusivity to all. Skill set levels & age can be so broad - those with trouble hearing or speaking might not feel comfortable participating - it can be quite boring for someone who was previously quite ‘with it’ but suffered a physical set back (ie stroke..).It can feel quite ‘institutional’ and not as homey as perhaps it could be. |
| 11 | I trust the staff in this LTC home | Staff have always answered my questions and/or followed up if I found my family member confused during a visit. She opens up to me, but is quite closed to staff members which is not helpful to them. However, I do trust in their professional abilities. |
| 2 | Staff in this LTC home do not know how to care for someone with dementia | I was the full time caregiver for my mom while she was in Long Term card and working full time. The staff do not know how to care for anyone with Dementia … |
| 4 | Staff in this LTC home resent my advocacy | …they do not like anyone like me who works in the field interfering with what they did not provide.  |
| 3 | LTC needs to be well staffed | my mom has not had a very good experience in LTC - the staff are so over worked and burnt out (even before the pandemic) that there is NO CARE - |
| 4 | Stories of neglect and incometence | the residents are in very cheaply made DIAPERS NOT BRIEFS - even though they have dementia they know they are in diapers and no one seems to care about their dignity - the activities are very poor quality and I feel none of the staff are trained in dementia care - they know nothing -  |
| 4 | Stories of neglect and incometence | I saw my mom Mar 14/20 and she was missing her dentures and the staff found them under her be 8 weeks later - during a pandemic what are the cleaning staff doing - 8 weeks under her bed - no she has been without her glasses for 7 weeks now and no one care where her glasses are - WHAT KIND OF CARE ARE WE PAYING FOR - I am disgusted with the level of indifference to the care of the residents - the well paid activities staff know nothing about activitives for geriatric patients -  |
| 4 | Stories of neglect and incometence | I worked in mental health for decades and I am shocked at the lack of infection control and cleanliness in the facility - it always smells like poop - I would give anything to have my mom back home here with me -  |
| 4 | Stories of neglect and incometence | when we visited the LTC home before my mom arrived and I was sold a bill of goods - everything they said sounded great until my mom was there and everything I was told was a real stretch of the truth -  |
| 4 | Stories of neglect and incometence | with the arrival of the pandemic the situation in LTC has been horrific and they still are horrific 14 months later nothing has changed and the care is non existent - we should all be ashamed of what is happening in LTC - extendicare organization gives 171 million dollars to shareholders and takes 121 million dollars from the government to pay for pandemic costs - HOW IS THAT RIGHT!!!!!!  |
| 4 | Stories of neglect and incometence | my mom is not the same person she was 14 months ago and I blame the LTC system for it's complete failure to protect and care for our most vulnerable citizens. SHAME ON ALL OF YOU |
| 1 | Family support and care is essential for LTC residents | Having been closely involved in my mother’s care & well-being in the past eight years or so while she has been living in LTCH, I KNOW how important it is to have a family member (i.e. me, her daughter) in this role. I honestly don’t know how elderly residents without family nearby manage! I continually advocate for her, provide emotional & physical support, regularly liaise with the staff & the Doctor and nurses, as required regarding her care and medical needs. I handle all her financial affairs, arrange appts with hairdresser, footcare nurse, physiotherapist etc. All these things have been made more difficult to do since March 2020. Also, I used to take her out to run errands or have a meal at a restaurant or bring her over to my house for dinner or a bbq & family celebrations/impt religious holidays (Easter, Christmas, Thanksgiving) -these occasions often attended by her other kids & grandkids who live out of town. This may not be considered “hands-on care” but it’s extremely impt for me and my mom that she remain connected with her family. Since the pandemic, we are restricted to phone calls & sometimes I do FaceTime/virtual calls so she can ‘see’ these loved ones but it has been really difficult. |
| 11 | Things have gone reasonably well for my resident | Ma mère était relativement autonome dans son appartement. Je faisais ses courses, j'allais à ses rendez-vous (médecin, dentiste, coiffeur), je lui faisais livrer des repas et ses médicaments. Elle recevait des soins des pieds à la maison (infirmière) et des préposées du RLISS lui rendaient visite. Je la sortais luncher une fois par semaine. D'autres membres de ma famille (cousins, cousines) lui rendaient visite. Ma mère parlait à ses soeurs tous les jours. Maman est entrée à la résidence en octobre 2019. J'allais la visiter et luncher avec elle plusieurs fois par semaine. Une cousine l'amenait visiter une de ses soeurs aux deux semaines. Parents et amis l'ont visité. Ça, c'était avant la pandémie... J'ai laissé plusieurs questions sans réponses puisque ma mère est toujours vivante et qu'elle ne souffre pas de démence. Récemment, on l'a diagnostiquée comme souffrant de perte de mémoire modérée. Il lui est difficile de trouver le mot juste. Aussi, lorsqu'elle est moins médicamentée (elle souffre beaucoup), j'ai encore de belles conversations avec elle.(My mother was relatively independent in her apartment. I did her shopping, I went to her appointments (doctor, dentist, hairdresser), I delivered her meals and her medicines. She received foot care at home (nurse) and was visited by LHIN workers. I took her out to lunch once a week. Other members of my family (cousins, cousins) visited him. My mother spoke to her sisters every day. Mom entered the residence in October 2019. I would visit her and have lunch with her several times a week. A cousin took her to visit one of her sisters every two weeks. Relatives and friends visited it. That was before the pandemic ... I left several questions unanswered since my mother is still alive and does not suffer from dementia. Recently she was diagnosed with moderate memory loss. It is difficult for him to find the right word. Also, when she is less medicated (she is in a lot of pain), I still have great conversations with her.) |
| 7 | Staff are not properly prepared or trained to care for some residents | I am more involved in my parent's care (predates LTC) than most. I spend hours researching, monitoring, advocating and working to find a balance to address the needs of the institution (schedules, rules, etc) - making the best decisions for my parent in her interest - managing biases about mental illness from doctors and nurses - and sadly watch someone screams of pain being unheeded by personnel who attribute that to dementia or mental illness. But I feel staff lack insight into behaviours that indicate a problem (eg pain which can cause agression) and staff focus on managing the behaviour as opposed to understanding the cause or trigger.  |
| 4 | I am treated like an outsider, but I should be part of the team | There should be more questions about decision making and how the institution staff and doctors work closely together and have access to infomation, but as the substitute decision maker, I am treated as an outsider. So I am expected to make decision on treatment based on anecdotal information, not documented. I have to go through nurse, or care coordinator - to get access to doctor - no direct access. Care conferences are not focused on actual care. And (this one is a gripe) but an obgyn should not be a primary physician for a geriatric patient. |
| 1 | Family support and care is essential for LTC residents | Pour moi, je vois la différence chez mon parent lorsque je la visite. Elle est plus alerte, souriante et participante lorsque je vais la visiter régulièrement.(For me, I see the difference in my parent when I visit them. She is more alert, smiling and participating when I visit her regularly.) |
| 7 | Staff need to be trained to treat residents with dignity | I think more training is needed for staff --- I would urge trainers to clearly communicate and reinforce regularly the need to respect residents and be professional and attentive at all times. It should include assessment and monitoring of staff's approach/attitude towards residents and their understanding of what 'maintaining resdients' dignity' means -- this is an area I find quite lacking at the [name of home] in Ottawa. |
| 11 | This LTC home welcomes family and we work as a team | La question #61 est mal posée. Je ne comprenais pas. Je ne suis pas son POA, alors mes renseignements et les décisions viennent de sa fille qui vient rarement et qui habite à l'extérieur. Tous mes efforts pour rendre ma soeur aussi heureuse que possible sont récompensés par la réalisation qu'elle est dans un bon foyer où on travaille en équipe pour elle. Pas toujours facile mais ça vaut la peine. Merci de tenter de rendre la vie de ces gens plus heureuse. (Question # 61 is incorrectly asked. I did not understand. I'm not his POA, so my information and decisions come from his daughter who rarely comes and lives outside. All of my efforts to make my sister as happy as possible are rewarded with the realization that she is in a good home where we work as a team for her. Not always easy but worth it. Thank you for trying to make these people's lives happier.) |
| 4 | The LTC home does not always welcome my advocacy | I have been her advocate but it is not always welcomed |
| 2 | Staff need my information but don’t help me | Because my mom lived with us for 10y ears as she declined, I felt I was informing the staff more than they were helping me. She was admitted when my husband became ill as a crisis placement. |
| 11 | Staff in this LTC home are excellent | The LTCH staff have been unstinting in their provision of care and support for, not just my spouse, all residents of the Home. |
| 12 | Covid restrictions have impaired my resident’s health | Prior to the Covid pandemic, I was free to take my spouse for drives and even picnic in the local park. The restrictions brought about by Covid have brought these pleasures to an end. As a result, my spouse's health has deteriorated significantly and I visit her daily to help with emotional support.  |
| 4 | I must monitor care every day to ensure adequate care | My parent was in LTCH for 10 years....I learned very quickly that I had to monitor my parent daily and hire private PSWs to ensure they were cared for in the way that they deserved. Things did improve somewhat over the 10 years they were there...but not to the caliber they would have expected |
| 4 | I find it necessary to pay for and/or provide extra care to support my resident | I learned very quickly that I had to …hire private PSWs to ensure they were cared for in the way that they deserved. Things did improve somewhat over the 10 years they were there...but not to the caliber they would have expected |
| 4 | Family advocacy was vital to ensure that our resident received decent care | My father ,my siblings and myself were involved with mom's care. We communicated regularly and solicited feedback about moms daily living, changes, and times where care could have been better. Mom was a quiet person and with a very low voice because of her Parkinson's I am not sure she would have seen the kind of care if we did not advocate.  |
| 4 | Residents without family caregivers or advocacy suffer | We all saw care recipients who did not have families to advocate and we observed less attention, and less care at the dinner table - food was placed before them but they hadn't touched their food, andin no time shrivelled away to learn they passed in 6 months time.  |
| 7 | The LTC home needs to provide more information to family | I feel like more information should be shared with all family members concerning their loved one and not just shared with the power of attorney for care. This information does not need to be intimate details but general information to help with the understanding and care of their loved one. |
| 2 | Some staff are not competent  | While most of the staff are competent, some are not and really not interested in their job, but they have a job!  |
| 1 | Family caregivers play a vital role | Family members are very important for the residents in LTC.  |
| 4 | The LTC unions are a barrier to better care | …staff … all have to belong to the Union which makes complaints sometimes never resolved.  |
| 3 | LTC needs to be well staffed | Also there was ( and still is) not enough PSWs who do the actual care for the Residents which leaves caregivers sometimes much to help with the caring. |
| 4 | My mother went into severe decline after entering LTC | As a working single mother, I was not able to provide the required care for my mother; therefore had to put her in a home. Brought her up to a '1' on the waiting list as I was told it could take up to 3 months. Within 1 week we got a call and HAD to accept, otherwise, she would go to the bottom of the list. My mom suffers from Alzheimer; even though she was confused and lost, there was still some of her left in her souol. Within one month in the home - she was no longer herself. She has been a prisoner since.  |
| 12 | Being an LTC resident is like being a prisoner | She has been a prisoner since.  |
| 4 | Assisted suicide is preferable to living in LTC | We have watched her deteriate over the years and if she could take her own life, she would. You MUST convince the government to allow assisted suicide even if the person is not of sound mind. Living with Alzheimer is not living, it's slowly rotting away. I would not even let my dog live through that. |
| 11 | This LTC home was well managed | My two friends were in a well managed L T C Home which I am most grateful. |
| 7 | Staff need dementia training | le personnel (préposé) ne semble pas comprendre la démence et les approches à prendre auprès ma mère...parfois je dois éduquer le personnel...(the staff (attendant) don't seem to understand dementia and how to approach my mother ... sometimes I have to educate the staff ...) |
| 1 | Presence of family helps the resident and the family | I think it’s very important to have family members involved, for both the family and the resident in LTC. I’m very fortunate to come from a close family who is happy to share the visiting with our mother.  |
| 2 | Staff in this home have become complacent and neglectful | I visit my mother twice a day: at lunch for a couple of hours to assist with feeding (my mother is not capable of feeding herself) and dinner, to assist in feeding and bathing, putting her to bed, etc. Since September, 2020, when we caregivers were permitted back into the residence to care to our loved ones, I have noticed a significant decline in the level of care/involvement by staff with regards to residents. Despite the increased assistance provided to the general complement of daily staff during the Covid pandemic, an "air" of complacency/lassitude is quite prevalent among staff. I would be pleased to discuss my "views" with interviewers. |
| 4 | Stories of neglect and incompetence | I would sometimes receive calls from the nurses regarding my mothers physical health such as suggestions regarding medications and pain management. As to her mental and emotional health there did not appear to be any care plan specific to her. |
| 4 | Stories of neglect and incompetence | No effort was made to seat my mother with other residents who were mentally competent and could carry on a conversation with her at meal times. Therefore her only meaningful conversations would be with staff or family. |
| 4 | Stories of neglect and incompetence | We found it very important to advocate on her behalf, whether it was to restrict a specific staff member from attending to her (too rough), to request testing for a uti, to ask for measures to control the temperature in her room (often 27C), and the temperature in the bathing room (too cold), to request medication for panic attacks, etc. The PSWs do not have time to sit and talk with residents - they are always on the run. It often takes too long for a call bell to be answered and all too often the call bell would not be left within the residents reach. |
| 3 | PSWs are always on the run | The PSWs do not have time to sit and talk with residents - they are always on the run. |
| 1 | It was important that we advocate on behalf of our resident | We found it very important to advocate on her behalf, whether it was to restrict a specific staff member from attending to her (too rough), to request testing for a uti, to ask for measures to control the temperature in her room (often 27C), and the temperature in the bathing room (too cold), to request medication for panic attacks, etc. |
| 11 | Volunteers in this LTC home are wonderful | The volunteers were wonderful and would sometimes pop in to say hello. The program managers would do a great job of arranging entertainment such as bingo and music. Our mother would usually rely on one of her family members to get take her. |
| 4 | Psycho-social needs are not being met | I would say in general that physical needs are well met. Its daily companionship, conversation and warmth that is lacking. The only interaction with psws is to attend to physical needs - very task oriented and hurried. |
| 10 | PSWs are overworked and underpaid | Its not an easy job. They are overworked and underpaid! |
| 1 | Family involvement and advocacy is vital to my resident’s wellbeing | I hate to think what my mothers life would be like if she did not have family visiting and advocating for her. |
| 7 | This LTC home could improve its communication with family | A mon avis le personnel administatif devrait communiquer plus souvent avec les familles au sujet des activités, des menus, avoir des rencontres familles/résidents.Je trouve que la rencontre annuelle multidisciplinaire afin de discuter du plan de soins et qui prend environ 15 minutes pourrait être plus dynamique. (In my opinion, administrative staff should communicate more often with families about activities, menus, and having family / resident meetings.I find that the annual multidisciplinary meeting to discuss the care plan and which takes about 15 minutes could be more dynamic.) |
| 1 | Presence of family is vital for my resident’s health | Mes visites régulières à ma mère lui permettent de savoir ce qui se passe à l'extérieur de la résidence (famille élargie, actualité, pandémie, température etc.). Quand ces visites ont été arrêtées au début de la pandémie, elle dépérissait et était déprimée. Elle a besoin de se sentir aimée et soutenue.(My regular visits to my mother allow her to know what is going on outside the residence (extended family, news, pandemic, temperature etc.). When these visits were stopped at the onset of the pandemic, she was wasting away and depressed. She needs to feel loved and supported.) |
| 11 | Frontline staff in this LTC home do a good job | When I see 'Staff' I think of those who are providing direct care and yes they are doing a good job. |
| 4 | Administrators at this LTC home create roadblocks and value uniformity | However, the 'Administrators' are putting up roadblocks and in some cases 'gag orders' to withhold information. These Administrators are invisible and not accessible and yet they have power to make policies that are designed as a one-size-fits-all approach. The age groups range from 19 to 100 years old and yet everyone is being treated to quote the [name of home]'s Administrator in 2005 "Now that you are in the sunset years of your life" is evidence that Resident's and the Caregivers should comply by their policies without question. |
| 4 | Stories of neglect and incompetence | As you can read by my tone, I am not your typical easily intimidated caregiver. I cut my caregiver teeth at [name of home]. The Administrators and Unit Managers were not empathetic and in some cases they created a 'toxic environment' for their employees, residents and caregivers. When my spouse was transferred to [name of new home] it was a beautiful yet short lived experience. To this day, when care has not been provided as I would like at my husbands current LTC, I simply remember the time at [name of first home] and I use that as my benchmark for poor care. I have 16 years of experience as my husband's designated caregiver he was 48 and I was 46 years old. I have a story to tell and I have the journals to support that. I sincerely hope this survey is taken seriously and should also provide more qualitative questions versus quantitative. Maybe you will undertake that as a next step. Its a hope that the information gathered will spearhead real change in LTC. |
| 1 | Presence of family is very important | The presence of the family caregiver is very important, especially when the resident cannot look after herself, cannot make decisions, or is not capable of initiating actions. Also when language barriers exist, the caregiver role is very important.  |
| 3 | LTC homes need to be adequately staffed | Unfortunately our LTC homes in Ontario are not provided with adequate staffing, so the staff members can only provide the very basic care for the residents. That is why the presence of the caregiver is essential to the overall well being of the resident. |
| 11 | This LTC home is inclusive and helpful | [name of home] is very inclusive of family. Our loved one (my mother) lives in LTC due to her lack of mobility, not her cognition or ability to communicate. She is our messenger for a lot of happenings. She uses the phone on her own and is able to communicate to the staff. We are fortunate she can still do that - it's very helpful for her care. |
| 11 | Care at this LTC home makes me happy | I am very happy with the level of care at [name of home].  |
| 11 | Staff are supportive at this LTC home | The staff has always been very supportive and have been particularly careful during the pandemic. We have not had a single case of Covid-19 at [name of home]. |
| 1 | Presence of family is very important for residents | It is important to be able to provide company and support for the residents. This includes: technology support to allow for 'family visits', providing a familiar face and a hug from home, picking up odds and ends that a resident needs, hooking up telephones and doing other small tasks to make the resident feel comfortable and at home. |
| 16 | My resident is still quite independent | Hands on care not important as she can look after herself except for bathroom |
| 11 | This home provides excellent care | [name of home] is providing excellent care. Everyone seems like they are doing their best. |
| 14 | I lack rights because I am not POA | I would love to have more of a role in the decision making. As it stands I am DCP but if something happened in her care ex. Her dying I wouldn’t get that call to be with her. I have no rights as I don’t have power of attorney. I am good enough to be her care giver at this time but not other than that. Her son is my husband and is also DCP but is in the same position as I am. Out in the cold so to speak. Hurtful. |
| 11 | Staff at this LTC home are caring and efficient | All the staff are kind caring and efficient in all facets of duties and responsibilities. I am so happy they were accepted at people care |
| 1 | Presence of family has been a lifeline for many residents | While you are looking for this "going forward" during COVID it has been the lifeline for many within LTC to have someone come and visit -- it has been very lonely.  |
| 4 | This LTC home does not listen to family and blames resource shortages | Staff/management are happy to have care partners/family come in and assist with staff-designated care items (feeding, physio, cleaning/organizing room) yet do not take the feedback/input from resident and family member regarding service and care plan seriously. Have made many complaints and input regarding physio regime etc based on personal health history and goals yet they are mostly ignored and we are told the residence lacks staff and resources to provide what we would like. Always comes down to the [name of home] residence not having enough and we are just supposed to deal with it. |
| 4 | This home does not hold enough care conferences | [name of home] schedules one resident Care Conference a year. This is far too infrequent. I have attended care conferences both in person, and on the phone. I would suggest Zoom 'in-person' care conferences every 2 months, or as needed, would be most valuable. |
| 11 | This LTC home treats families and residents with respect | Involving the family as knowledgeable team members is important. [name of home] taff treat patients and families with warmth and respect. |
| 1 | Presence of family is very important for my resident’s wellbeing | I feel it is so important for family to be well involved with their loved one and the LTC home. I need to make sure my mom is well looked after and I know the care she is getting. My mom could not say sentences to me but when I came into her room she would become more animated, vocal, and smiling and laughing. It made my day!  |
| 11 | This home helps my resident by letting her interact more with others | The home provides her with more interactions with people than I could give her when she lived with me. |

# Step 2: Coding of the Raw Data

The following table shows the results of the coding of the raw data. The coding was done with pen and paper, and after the full data set had been coded the analyst returned to this Word document and constructed the two tables.

Later, during a quality check, a second analyst made suggestions for some changes to the coding. These suggestions were incorporated into the sorted tables above.

## Coding the Raw Data

| **Code** | **Corresponding Data** |
| --- | --- |
| Families should be part of the care team | Families are an essential component in a resident's level of care - we are part of the team and we have a role to play.  |
| Some staff are threatened by the presence of family | Families are an essential component in a resident's level of care - we are part of the team and we have a role to play. Depending on the staff, sometimes this is not shared by everyone and they feel they are there to take care of our loved one. They feel threatened or take questions/concerns raised personally.  |
| Families should be part of the care team | However each person within the home and the family need to work together holistically to provide the level of care our loved one needs.  |
| Staff need training to see the value of presence of family | I feel more training of staff is required as to how all these pieces come together and provide value in the level of care given to our loved ones. |
| LTC needs to be well staffed | I think its important for there to be enough staff in the home, I think it's important for loved ones to feel a connection to the staff, familiarity is especially important for those with dementia, so same staff and someone they can relate to is important. |
| Family / staff tensions and divisions are unfortunate | It would be nice if there wasn't an us and them mentality just one family! |
| LTC homes are full of challenges | This home in 2008 -2104, experienced the same challenges as were uncovered during Covid-19 - insufficient staff, lack of training, lack of supervision, PSW's were poorly paid, had no benefits, making it necessary for them to work in more than one home and were over-worked. LTC processes, systems were broken or non existent as were their internal and external communications with staff & families. |
| Government neglect has produced a failed LTC sector | I, along with many families have … seen how the various governments over decades did not act on the many commission reports, submitted long before Covid-19. Our loved ones were abused, neglected and the presence, involvement of families enabled the LTC sector to be maintained. I and many others chose caring for our loved ones over working, saving and planning for our own retirements and elder care. I advocated endlessly to no avail and listened to promises never kept. |
| Families suffer because of the poor LTC sector | I left a much enjoyed & lucrative career due to decades of government's neglect of this LTC sector and inability of the LTC home to provide quality care. I dearly loved and wanted to care for my parent in my home until his death. He moved from another province to ON so I could do this. When he needed more assistance, Community Care was unable to meet his requirements. LTC became our only option. It was heart breaking to be separated. I, along with many families have suffered tremendously -physically, emotionally & financially. |
| Presence of family can shore up a failing LTC sector and this is wrong | Our loved ones were abused, neglected and the presence, involvement of families enabled the LTC sector to be maintained. I and many others chose caring for our loved ones over working, saving and planning for our own retirements and elder care. |
| Families suffer because of the poor LTC sector | I advocated endlessly to no avail and listened to promises never kept. Covid-19 clearly showed the ugly side of government, Families have realized their loved ones are most important to them. The hurt is still profound. |
| Government neglect has produced a failed LTC sector | I advocated endlessly to no avail and listened to promises never kept. Covid-19 clearly showed the ugly side of government, Families have realized their loved ones are most important to them. |
| Concerns about staff behavior | Definitely want to know what staff are and aren't doing cause they are always rushing to get them to bed so they don't have to work anymore |
| LTC homes must consider the needs of residents and families | As a family caregiver, I have never been part of mom’s care plan, included in activities. When a family caregiver is welcomed so is a resident. Keeping family members happy and taking care of their needs to best help their family members is key. Having kitchens as the heart of the home so family members can warm up home cooked meals complete with proper equipment creates a friendly and welcoming atmosphere. Also, providing a place for caregivers to have a meal before they head home is also important especially if family members help with meal times. |
| Family Councils must be mandated to they can raise issues | It is vital for Family Councils to be \*mandated\* at all LTC homes. These provide a critical link and safety mechanism for resident care, especially where some residents don't have family nearby, or family is absent from care. Often other FC members can raise issues even when it's not about their respective resident. |
| This LTC home is unhelpful and full of challenges | This facility was unhelpful, dangerously disorganized extremely short staffed (why I was so involved in his care). I watched as 2 residents succumbed to painful early deaths from inadequate wound care in my husband’s 15 person ward alone. There were so many others! I learned quickly not to trust a word management said. Numerous reports to licensing concluded “unfounded" even with photos. Ultimately a public administrator was assigned to the facility - but she’s got now and there is yet another GM. I feel terrible for everyone still living there. Add Covid to that and I was forced to abandon my husband to these people! These have been the darkest days of my life and I doubt that I will ever recover completely. It took 12 months but I finally got a call that a bed in a new facility was available.  |
| Families have suffered | I feel terrible for everyone still living there [*previous home where husband lived*]. Add Covid to that and I was forced to abandon my husband to these people! These have been the darkest days of my life and I doubt that I will ever recover completely.  |
| The LTC sector must be improved | This is not an isolated case as we have seen. There needs to be enforceable national standards in LTC. There need to be enforceable penalties for noncompliance. There needs to be adequate and affordable home support so elders can remain at home longer.  |
| Staff behavior produces poor results | Staff are very task oriented. They are very negative in their communication with residents. Quick to tell them what can't be done. Rushed for time. Poor communication between staff. |
| I find it necessary to pay for and/or provide extra care to support my resident | I am a retired RN and have sought out and procured services and care for my resident.I am much more aware of the residents’ specific medical condition, prognosis, and psychosocial behaviours than the majority of the staff. |
| Sometimes staff do not share important information | Parfois, le personnel oublie que ce qui est naturel pour eux est nouveau pour les membres de la famille. Par ex., j’aurais eu besoin d’être informé des changements graduels des soins, par ex., que ma mère avait besoin d’une tasse pour enfants plutôt que de la voir du jour au lendemain utiliser cette tasse pour enfants. (Sometimes staff forget that what is natural for them is new to family members. For example, I would have needed to be informed of gradual changes in care, e.g., that my mother needed a children's cup rather than seeing her overnight use that children's cup.) |
| Presence of family is important for resident happiness | In the 4 years that my mom has been at this care facility I feel my involvement has been extremely important to her happiness and to my peace of mind. |
| Staff need training | The staff who deal with my mother's care need much more training about dementia. |
| There is tension and conflict between families and bosses/staff | Inconsistencies between how staff are interpreting the COVID ‘rules’ and weak staff communication skills result in conflict between family members and staff. Trust and respect are eroding, family members are feeling “watched” and fear that, if they are caught doing something wrong, they will be barred from entry. Much of the family's experience depends on their ability to be diplomatic, agreeable, invisible, compliant, easy to get along with and liked by the bosses. |
| LTC needs to be well staffed | There is not enough staff to provide proper care and i worry my mother is being neglected. That is why I am there daily plus to monitor how she is being treated. |
| This LTC home and staff were inept and bullying | The home 10years ago was totally brutal to my mother and I because of her dementia and related behaviours that wete often aggressive during care. They would call me at work and "bully' and threaten and put my mom on antipsychotic meds. I learned quickly they wete inept in caring for residents with dementia and decided to care for her myself twice daily plus I hired private PSWs to come in twice daily after I left. Due to new administration and increased knowledge things fod slowly improve over last 3years..I never completely trusted Some staff and continued this csre until 2weeks ago when mom passed away with me by her side. |
| I find it necessary to pay for and/or provide extra care to support my resident | I learned quickly they wete inept in caring for residents with dementia and decided to care for her myself twice daily plus I hired private PSWs to come in twice daily after I left. |
| I saw ageism at this LTC home | LTCH and staff need to undergo many changes and stop AGEISM attitudes. |
| Care for my resident is good, but… | I feel that the care we have had for dad has been wonderful. Filling in the gaps when staff cannot is a concern. There seems to be much time that is alone time and the staff as wonderful as they are cannot provide the one to one social interactions and extra time that we as family members can provide at times during a week. |
| I wish my resident had more chances to interact with others | There seems to be much time that is alone time and the staff as wonderful as they are cannot provide the one to one social interactions and extra time that we as family members can provide at times during a week. |
| Family make important contributions to resident wellbeing | I find that it's these moments of playing a game, chatting, tidying up, sorting through and even setting up a Christmas tree or decorations, giving a little tlc - these personal touches are needed and necessary for the wellbeing of the resident. Thank goodness for the activities and the programs- dementia residents should be encouraged to do those things and not asked if they want to. They are in a LTC facility because they cannot make their own decisions. If playing a game means they have other people around then that is so important. Residents should be brought in to the activity environment even if they don't participate. They will still have that energy from those around them. It is the little things that allow the caregivers (family) of the resident to have that peace of mind that their loved one is more than just a body filling a space. |
| My resident is safe in this LTC home | I know my dad is liked and looked after and he is safe. The staff have been wonderful and especially during this covid time they have been kept us abreast of everything. We are very thankful and blessed. |
| Errors occurred during admissions | Gap from my experience was the admission process. Too many documents to fill out on admission day; errors were made.  |
| LTC home needs better digital technology  | My concern is making video conferencing easier and more accessible, which means better wifi and more digital devices in homes. |
| For-profit LTC is wrong | We have to end Profit LTC! No one should be redirecting money to a company away from human services and care. |
| Care is better in not for profit LTC homes | My wife is in a NFP home and the care is difference when staff are paid and treated well. When they know that management cares for them and the residents. When they know that money is not being taken was from the care in the home for someone else to profit from. |
| PSWs were not humane in my LTC home | At my mom’s LTC the PSWs were a very powerful group and it negatively affected my mom’s care. The care she received was not humane - and this was before the pandemic. |
| I pay for and provide extra care for my resident | We hired an private caregiver (RNA) to support my mom during her waking hours. If she was not available, I provided care (I am a former RN). |
| PSWs were negative toward us | What support we needed from the PSWs was frequently provided with a “you’re bothering me” negative attitude, despite the fact that we were kind, appreciative and asked for very little support. |
| Families should be part of the care team | We have so much to offer. While the home was very short of staff I volunteered to take a course to learn how to transfer my husband safely in the sit to stand lift.  |
| This LTC home does not value family and treats us poorly | Adminisration does not seem to be involved with families unless there is a complaint. Often that complaint is handed down to a lower ranking member. Families do not seem to be important, are forgotten and even mistrusted. …I was chastised for using the lift while we sat for what seemed like an eternity to get someone to help. I was point blank asked "Do you have a funeral home picked out for your husband" soon after Covid started. No preamble or anything. Families are not encouraged nor do they have many rights within the home. One family member said that they did not put their mother up for adoption when she entered the home. We are definitely undervalued or not valued at all. |
| Staff communication and follow up are poor | Communication is very poor, between staff and to me. A decision or request from one day often does not get carried through by tomorrow's staff. |
| Most staff are friendly and compassionate  | Majority of frontline staff (minus the numerous Agency staff) are very friendly, compassionate toward our loved one… |
| The LTC home administration is unresponsive and secretive | …the biggest issue is with our current administration, where we must result to submitting a complaint to MoLTC for information about the home. The current administration is secretive, non transparent and the current ED is not the right fit for the home. |
| During Covid this home could not provide adequate care | The home [name of home] where my mom is in has the ability to provide basic care prior to Covid. After Covid not a passing mark for taking care of my mom and other residents. |
| Front-line LTC workers have difficult jobs, and that explains their behaviour | I witnessed how difficult care workers' jobs were every time I visited, which helped me understand why they had little to no time for quality person-centred care. |
| I wish my resident had more chances to interact with others | At the same time, I wished that my grandfather had more opportunities to socialize and laugh with staff and fellow residents. |
| I don’t trust the LTC system | I certainly developed mistrust in the long-term care system and its values, not necessarily mistrust in the care workers themselves. |
| The LTC home and its staff do their best | I found the staff and facility provided reasonable care within the system as it is structured. |
| The LTC sector is flawed and underfunded | The system is deeply flawed and under funded. Caring for people should not be done in this big institutional way. It didn’t work for schooling Indigenous children, or people with developmental delays or the mentally way. LTC is not a hospital. Care to seniors should be provided at home for as long as possible with home care services. The few people who require institutional care should be cared for in small facilities where there is adequate staff paid wages that fit the work they do. LTC needs to not be the orphan of health care funding. |
| For-profit LTC must end | Privately run for profit LTC needs to end. |
| Family should be part of the care team | I think it is extremely important to have family members involved in the care of their loved one as the care provided by the LTC staff is very inconsistent. |
| Some staff are good and some are not | Some staff are excellent and some do not seem to care and appear not to be really interested in providing compassionate care. |
| Some staff neglect my resident and resent my advocacy | They don’t appear to have the empathy required to put themselves in the shoes of the one they are caring for and my experience is they will avoid taking the time to really do a good and thorough job. ie. sometimes I come in and my mom’s underbriefs are wet and all bunched up and uncomfortable, and I have to ask for them to clean her up and change her. Some staff will try to convince me that my mom is OK the way she is and when I insist and they do as I ask, they do it with resentment even though after it has been done, my mom is clearly more comfortable. I have asked that they change my mom regularly mid morning and mid afternoon and it is not done unless I am there and ask for it to be done. |
| Residents without supportive family may be neglected or suffering | I worry about the people who do not have family to keep watch for their loved ones or on the rare days when we cannot have someone with my mom, I am wondering if she is being cared for well. I am constantly concerned when there is no one there advocating for my mom, that she is receiving compassionate care. |
| The LTC sector needs to be improved | I don’t think we should have to be concerned about the care our loved ones are getting in LTC. There ought to be a standard across the board and every resident ought to get the same good care whether a family member is with them or nor. That does not appear to be the case. Many of the residents cannot speak their needs and it shouldn’t be up to family to ensure that those needs are met. Each resident should get the same level of excellent care regardless of whether they have family advocating for them or not. That does not appear to be the case in my opinion. |
| Some staff neglect my resident and resent my advocacy | …when I do speak up politely, many staff resent being asked to do their job and that comes out in how the staff treats me now. When I speak up for my mom, they treat me as if I am a pain in their side, and I am very polite and friendly because I do not want them to take anything out on my mom when I am not there. That is a constant concern of mine. |
| My resident’s home is above average | The LTC Home my mom is in is above average in my opinion (having friends who also have had family in LTC). |
| LTC homes should improve trust and communication with family | LTC homes should trust family members as they are important stakeholders and should establish open channels of communication where all parties can cooperate and express concerns. |
| Family member participation is extremely important | Family member participation is extremely important to ensure residents are kept safe and provided quality care. With the understaffing problem, family members are required to be sure their loved ones are eating regularly, walking, and personal care needs are met. |
| Presence of family shores up for the deficiencies of the LTC sector  | I always felt like I needed to make daily visit to monitor care. If not, quality of care was not good. Inconsistency of staff on afternoon shift made it difficult for my loved one as new psw's did not know care routines which did not help the residents moods. … Facility was always understaffed and I felt like I needed to do the evening care or settle for poor care. |
| I also support other residents whose family are not present | Also felt that I was advocating and monitoring for other residents. Several times it was me who discovered and reported a fall or a resident in need. Only contact residents had with psw was for a few minutes to either dress / undress or toilet. No social contact or occasional checks by psw's. they had no time for that. |
| LTC home needs to be well staffed | Facility was always understaffed and I felt like I needed to do the evening care or settle for poor care. |
| Nutrition and diet are not properly seen to in this LTC home | Food quality not the greatest. Many residents are constipated due to poor balance of diet. Residents were often given laxatives rather than address nutritional needs. |
| Care is union minded, not resident centered | Staff are very union minded and not resident centered. The home is run by admin who are very sympathetic to the union demands of staff. Residents pay the price of having staff who are not committed and admin who do not create and sustain a culture of resident cantered LTC. The demands of the unions are running LTCs. Staff are kings, residents are innocent, helpless bystanders. Anytime suggestions or complaints are made, admin and staff stick together to support the facility’s reputation. |
| During Covid my resident declined badly | My father moved from [name of retirement home] in a retirement home to Long Term Care just 9 days before the lockdown due to Covid 19. I don’t know how different it might have been compared to this past year. I do know that the continued isolation and confinement has accelerated my father’s decline in the extreme. He went from being able to walk, converse, feed himself, pee, wash his hands, try to dress himself to losing 40 lbs, being confined to a wheelchair, unable to feed himself a diet that now consists of puréed food, unable to communicate, screaming most of the time. I have seen my dad nearly every day for the past five months since I am the only caregiver allowed in the home. Prior to that my husband was able to alternate with me. The only way I can bring family in to see him is through FaceTime. We are confined to his room except since the weather is improving I am able to wheel him out into the fenced in gardens. |
| I wish my resident had more chances to interact with others | I arrive for visits and find him in the middle of the day in his room, door closed, lights off, curtains closed, radio playing, screaming, face and ears extremely hot and red. I don’t know how long he has been left this way, without interaction. |
| I am suffering because of the poor LTC sector  | At this point long term care is just human storage. There is zero quality of life. All activities remain off limits, a year later, and residents are still confined to their rooms. I hate it. |
| Families should be part of the care team | My Mom is legally blind and profoundly deaf so it was extremely important that I be a part of her care team.  |
| The staff in my LTC home are wonderful | The LTC had wonderful staff who would call if they noticed a change or had a question. They also held care conferences with her doctor which was a great opportunity to give and receive feedback on care concerns. |
| My family member declined rapidly during the pandemic | During the lockdown and subsequent isolation which began in March 2020 for Retirement Home and LTC residents, the isolation, absence of family visits, social activities, and meaningful life interactions took a huge toll and I believe was the root cause of the quick advance of her dementia and mobility issues. She suffered a fall during the first 3 months of the pandemic, at her Retirement Home and because of the fear of attending a hospital / medical appointment did not receive the care she required in a timely manner. It was discovered a few months later, that the fall resulted in an L1 lumbar fracture which required hospitalization in July 2020, and subsequent LTC placement in August 2020, due to her health conditions and the injury resulted in her being wheelchair-bound.  |
| The pandemic LTC restrictions have been very difficult for family | I have found LTC restrictions very difficult.  |
| My family member declined rapidly during the pandemic | I have noticed my mother decline rapidly, due to the continued isolation, loneliness, lack of mental stimulation, lack of socialization lack of access to her religious services, lack of foot care and hair care (basic grooming is denied), and denial of visits of her spouse.  |
| Pandemic rules means that my father cannot visit my mother in LTC | My father, who resides at a retirement home requires assistance to enter the LTC home due to his disabilities, and when Ontario went into grey colour status in Mid-November 2020, he was denied access to his wife as he could not enter on his own and navigate the sanitization/elevator codes, etc. on his own.  |
| LTC implementation of pandemic rules have infringed on the rights of elderly residents | Further, our Local Health Unit, in Mid-November 2020 [name of LHU] limited LTC residents in our area to only "one" Essential Caregiver (even though the Ontario Provincial Guidelines authorize 2 Essential Caregivers per resident). In my opinion, my mother has been denied her rights to see her spouse, visit with her 2 other children and grandchildren. |
| Family have suffered because of LTC pandemic rules | As the only Essential Caregiver, I am grateful that I can enter the home and provide emotional support, care and physical supports including the assistance of feeding, however, the strain of being the "only one" without an opportunity for respite has exacerbated stresses… |
| Residents are treated like prisoners | …[*pandemic rules have*] denied meaningful relationships for my mother with her spouse and other 2 children and grandchildren. In essence, she is a prisoner within her LTC home. As my mother said to me "I know what it is like to be captured. There are a lot of rules and because I am captured I have to listen". While my mother has dementia, she is very aware, of her circumstances, and the absence of meaningful family interactions has advanced her dementia far quicker than it would have if she had been allowed visits and social interactions.  |
| The LTC home threatened legal action due to my advocacy | As a family member who advocates for their loved one, I was given a letter by [name of home], stating that my behavior was disruptive to the running of the facility. I had to employ a lawyer to respond to the allegations. |
| Staff don’t have time to understand my resident | I was extremely involved in my mom’s care so I didn’t need to have her behaviour explained to me. I sometimes had trouble getting staff to understand her behaviour though. Mostly it was because they were so rushed and were not allocated sufficient time to care for residents |
| The LTC home communicates poorly and is poorly managed | Really no level of communication between the facility and the outside world no newsletter no posted activities it's just horrible run around with heads cut off too many bosses no directions yikes maybe being stuck in their rooms isolated has keep se form of organization and healthy observation |
| My home makes it difficult for family to be involved in care | In my experiences with providing care for my family member, the staff (and really the way the whole system is designed, including the physical structure itself) does not always facilitate or make it comfortable or convenient for family caregivers to provide the level of involvement and care that we really want to do. My vision of a truly welcoming LTC home doesn't exist in the community in which I live, and sadly, in most communities that I am familiar with. The facility hasn't upgraded at all to accommodate space and electrical outlets for technology such as cell phones and laptops and even TV's. (in semi-private rooms)  |
| This home is unfair to residents with less money | If you are a resident on the lower income scale, it is a struggle to pay for services and necessary equipment that the care home does not provide. If you withhold some funds to pay for any of these services or items, they are breathing down your neck. Even if the services are medically necessary. In For Profit LTC, they come first.  |
| This home protects itself from litigation | As well, I noticed some of their rules and policies are designed to protect themselves from litigation and have nothing to do with the well-being of the resident.  |
| This home does not advocate for its residents, and provides insufficient support | They do nothing to advocate on behalf of the resident. Even the social worker is sub-contracted out and works only 2 days of the week. In the 2 years, my LO has been in LTC, he has been in 3 different rooms. They do not do any work ahead of time to determine if the other resident is going to be a good match. If the bed is vacant, that is all that is considered. Even when they are aware of, and have knowledge of issues with a potential roommate for your loved one. It's incredibly stressful to feel as though you must watch literally everything they do. In the second room, the maintenance staff told my LO on the first night, to move back to the room he came from. Because, even they, the cleaning staff, knew it would not be a good fit for him. |
| This home cares too much about money and is condescending to some residents | During Covid, they will call you (the POA/Caregiver) and the resident, in person into a small room to discuss arrears and lecture, yes lecture, a 78 year old man with dementia on how to live within his means. |
| Care conferences in this home are inadequate | However, when it comes to a care conference, it is arranged by phone, and only the director of programs and services attended. (That just happened recently)  |
| Family suffer because of the actions of this home | To conclude my feedback, I must say, it is incredibly stressful and exhausting, to feel as though I must watch literally everything related to the care of my LO, due to a lack of trust in the way the whole system is designed. Of course, that feeling has increased dramatically during the pandemic. |
| LTC is a failed system and money should be redirected so people can live in their homes in the community | Mom was in an LTC for 5 months and died due to neglect. LTC staff had absolutely no dementia training whatsoever despite being the largest LTC in Canada. Pathetic. Government needs to provide support so people can stay home. LTCs are no place for people with dementia and complex medical needs. The subsidy the government pays to LTCs should be made available so people can stay home and hire help or pay family members to stay home and care for them. Mom would be alive today if I could have kept her home. |
| This LTC home does not communicate with me | I visit my Nephew 2 or 3 times every week. The care place never calls me about any thing about my nephew. |
| Staff, managers, and health care providers in my home do a good job and treat me like a member of the team | I have to commend the staff, doctor, DOC, ADOC and administrators in their role with my parent's care. They were always professional and kind. As the POA, I always worked in cooperation with them keeping the lines of communication open at all times. I am of the belief that we are a team and we must work together in the care of the residents and this is what creates positive, respectful, working relationships. |
| I have relatives who cause trouble at the LTC home | I had family members who were creating negative and destructive relationships with all the staff, causing major conflict with all of their visits in LTC and in which police had to be involved. One of my family members was put on restrictive visits due to the confrontational manner that he displayed. This ongoing conflict that family members caused put a lot of strain on the LTC staff and me, as POA. Staff, at times, felt uncomfortable in providing care as a result due to other family interference as they were anti-LTC. |
| LTC staff support me and I support them. | I supported the LTC staff and they supported me, and we had to communicate almost daily and always weekly in attempting to manage this behaviour from my other family members. I had to have lawyers involved to support me as POA. The administrators continued to provide ongoing support for both of my parents. |
| Families can be abusive and confrontional with LTC staff | Families are important, however, families should not have the right to be abusive to staff and I do believe that the LTC homes should have the right to put measures in place for the public who are confrontational and who show destructive behaviours towards staff in the workplace as this affects their work. The media, and social media, sadly, perpetuates a lot of negativity about LTC and the care they provide to residents. |
| Staff are doing their best | Families should learn to work cooperatively with the LTC homes and be ready to be supportive of staff as they are trying their best. |
| Families should work cooperatively with LTC homes | Families should learn to work cooperatively with the LTC homes and be ready to be supportive of staff as they are trying their best. And, if there are issues there are ways to communicate effectively to resolve the issues. Families should be ready to provide assistance if needed.  |
| LTC homes need to be well staffed | There just wasn't enough staff to talk to residents or communicate with residents or feed residents. … All LTCs need more staff and more positive staff involvement.  |
| Our family has several members who visit our resident | My mother had 3 daughters and 1 son. Only my youngest sister lived in Ottawa. She had POA of care and finance. She arranged for her step-daughter to take charge if my mother died since she lived in Gatineau. Fortunately, my mother died while my sister was in Ottawa. My sister visited my mother at least every 2nd day and fed her a meal then. Otherwise, the staff fed her her meals except when I and my husband were there once a week. …My other sister and brother visited sporadically. |
| We pay for extra care for our resident | My sister also hired a sitter 2 or 3 times a week for an hour for my mother during week days. Because my mother was an Overseas WW2 vet she paid only $1,000 a month for her LTC so she could afford the sitter and pay us gas money for coming up from Kingston weekly.  |
| Residents without family or with few visits are having difficulties | But what about other people on my mother's floor? Some only had a visitor once a week if that! There just wasn't enough staff to talk to residents or communicate with residents or feed residents. Also, my sister and I helped other residents at times with feeding and with getting staff to assist them. You don't mention what help we may have provided to residents other than my mother. We also brought our Shiba Inu (a Japanese canine breed) up with us. Some of the residents really delighted in seeing him. Another woman saw her husband a lot and also helped entertain other residents. The sitters would sometimes help with other residents as well. Frankly, if my mother hadn't had us visiting (visiting? we worked like dogs!) , she would have acted out and had to be medicated because she was so disabled or she would have shut down and had a much worse time of it than she did.  |
| LTC during the pandemic has been a whirlwind of different events | The last two years have been a whirlwind of hospital stays, independent living, retirement residence, LTC, rehab and respite care. Your survey presumes a degree of stability which was not the case. |
| I complain about the palliative care my resident received | Ma seule plainte lors du décès de ma mère est la difficulté que moi et ma famille ont eu pour soins palliatifs. Cela a pris une semaine avant que le foyer la déclare palliative bien qu’elle l’était depuis un peu plus qu’une semaine. Par le temps que ce processus fut complété ma mère n’à vécu que des heures. Donc elle est restée dans sa chambre avec sa colocataire et seules 2 des 6 enfants ont pu être présents.(My only complaint about my mother's death was the difficulty I and my family had with palliative care. It took a week before the home declared her palliative although she had been palliative for just over a week. By the time this process was completed my mother lived only hours. So she stayed in her room with her roommate and only 2 of the 6 children were able to be present.) |
| Families should be part of the care team | With appropriate training, family members/care partners are in a unique position to assist in LTC, taking some of the burden off staff.  |
| Family involvement is sometimes not welcomed | My experience was that my involvement was sometimes viewed as unwelcome, and it was often a struggle to engage fruitfully with staff. Partly that was because staff were too overburdened to engage in a constructive manner.  |
| Staff may be too busy to engage with families | My experience was that my involvement was sometimes viewed as unwelcome, and it was often a struggle to engage fruitfully with staff. Partly that was because staff were too overburdened to engage in a constructive manner.  |
| Health care in my LTC home is unacceptable | I witnessed substandard medical services provided to the residents in our LTC facility, care that would be deemed unacceptable in any other health care setting. It was a constant struggle to communicate with the medical team and their lack of involvement led (and still leads) to unnecessary suffering and trips to ER that could have been avoided if residents were properly monitored. |
| Presence of family is essential in LTC | Quoique je reconnais les efforts et l'expertise des membres du personnel, les soins disponibles n'étaient pas suffisants pour assurer la qualité de vie des résidants à besoins élevés. Lorsque ma mère est entrée en SLD, il n'était pas nécessaire pour moi d'y être chaque jour mais, à mesure que sa condition se détériorait, il devenait évident qu'il nous fallait quelqu'un sur les lieux pour assurer son bien-être. Entre autres, elle aurait perdu sa mobilité, sa capacité de se nourrir convenablement, sa continence, sa capacité de communiquer avec le personnel si nous n'avions pas été là pour en prendre soin. Il fallait constamment répéter pour que les soins prévus dans son plan de soins soient prodigués, surtout lorsqu'il y avait du personnel à temps partiel ou remplaçant. Pendant les repas, j'ai observé combien facile il était pour le personnel d'oublier de donner le repas à un résident, d'offrir un repas avec une texture inappropriée, de retirer une assiette avant que le résident ait la chance de dire qu'il n'avait pas fini. Un résident qui a la capacité de communiquer avec des mots peut se protéger contre ce genre d'oubli, mais celui qui est aphasique doit avoir un interprète. Lorsque le foyer a fermé ses portes aux visiteurs il y a maintenant plus d'un an, j'ai amené ma mère avec moi pour habiter avec ma famille afin d'assurer qu'elle ait tous les soins dont elle a besoin. (While I recognize the efforts and expertise of staff members, the care available was not sufficient to ensure the quality of life of high-need residents. When my mother entered LTC, it was not necessary for me to be there every day but, as her condition deteriorated, it became clear that we needed someone there to take care of her. -to be. Among other things, she would have lost her mobility, her ability to eat properly, her continence, her ability to communicate with staff if we had not been there to take care of her.  |
| Family need to be present to make sure LTC delivers the needed care | (Translated from French)(…Constant rehearsal was required to ensure the care provided for in his care plan was provided, especially when there were part-time or replacement staff. During meals, I observed how easy it was for the staff to forget to give the meal to a resident, to offer a meal with an inappropriate texture, to remove a plate before the resident had a chance to say that it was 'he hadn't finished. A resident who has the ability to communicate with words can protect himself from this kind of forgetfulness, but one who is aphasic must have an interpreter. When the home closed its doors to visitors over a year ago, I brought my mother with me to live with my family to ensure she had all the care she needed.) |
| LTC needs to open to more family members | Please start thinking about how to reopen LTC homes to family members other than the designated essential care givers. My mother has only had one 15 minute visit in the last 13 months and my sister who is POA cannot go there. |
| Some staff are good and some are not | It was extremely important to me that my wife receive 24hr a day 7 days a week exceptional care. However I could never trust ALL the staff to provide the same level of care that each was trained and hired to give. i.e. Some staff had excellent work ethic, they truly cared about the wellbeing and comfort of the resident and would do anything and everything to provide exemplary care. They would get to know the resident's personal history, likes & dislikes, emotional & physical needs, medical issues (physical pain, emotional pain), family relationships, look at photos, sit and talk, answer the call bell as soon as possible, give gentle kind compassionate care when bathing, dressing, transporting, toileting etc. BUT, there were far too many other staff who worked only for a pay cheque, did minimal amount of work necessary to just get the job done and with no emotional support, personal involvement or extra time towards the resident. i.e. rush to get the resident toileted, washed & dressed in the morning to be in the dining room for breakfast (taking all of 10 minutes); rushed to do same tasks at nighttime for bed so the staff member could take a break (thus leaving resident uncomfortable in bed or in pain), rush the residents to eat their meals so staff could take his/her break; ignore call bells thinking it wasn't important ("oh that person always rings bell for nothing") thus leaving resident to soil their brief and be left sitting in personal waste matter embarassed and crying from shame), not listening or giving resident who has trouble speaking, time to try and speak when there is a problem, (causing frustration for resident and crying). Many many things that would upset my wife because she had come to expect that ALL staff would treat her the as well as and as compassionately, gently, kindly and with great care as the GOOD staff were treating her. |
| All staff should be required to provide good care | There should be NO exception to the treatment or level of care. I and my daughters would countlessly receive calls from my wife early morning or late evening or anytime if none of us could be with her, crying over an uncaring, rushed and cold hearted rude, rough staff member. |
| Staff would not be honest with us | Staff would cover things up, make excuses. |
| Staff resented our advocacy | We also were often made to feel like we were intruding or bothering staff if we called to ask questions on the phone or stopped to ask them something in the hallways. |
| Staff would not tell us about changes to the care plan | We were often left out of the loop if changes were made to my wifes medicines or health care. |
| What staff say is not consistent with what I see | They say they never run short but I see it . |
| I provide care because that is the only way I know it is done | I worry about foot care, basic hygiene care hence why I do it after dinner so I know it’s done ! |
| Staff are wonderful | The wonderful staff RNs, RPNs and PSWs can only do so much. |
| Family caregivers provide vital help | The involvement of caregivers is vital. …Providing hands on care can be so meaningful, a rewarding way to visit and help for staff. |
| Family councils should be operated so more families can participate | It has been difficult to be involved in Family Council meetings as they occur at 2:00 in the afternoon 1 x per month. I work full-time in health care and do not have the flexibility to join in. I would really like to see the facility priorize opportunities for family member input and advocacy. The family council meetings are a place to discuss items of common interest. Not being able to participate means relying on newsletters. |
| Facilities can lead to a loss of dignity | My father had physical disabilities, had a hard time getting around. He was bariatric but they didn't have a suitable bathroom setup for him, i.e. rails around toilet, raised seat, narrow doorway his wheelchair couldn't go through, inaccesseible sink. He couldn't enter the bathroom in his w/c but could with his walker, however, he shared a bathroom and they couldn't place equipment in without it being too crowded and unsuitable for other person. So, he would get up with his walker, walk into the bathroom, but not have a place to sit for bm or at sink to wash hands. I would help him , stand beside him in bathroom hand him items like tootbrush etc and have w/c ready at the bathroom doorway for him to sit down on in case he started to weaken. With an accessible set up I coud have helped more effectively and my father would have had some dignity and independence in self care. |
| Families should be part of the care team | Family members want to be a part of the "care team" and to be fully involved in every level of care. |
| The LTC home excludes us and resents our advocacy | It is extremely distressing to feel like a "visitor" to my mother's home and to lose all control of decision making and personal care of our mother. We have felt like we were causing problems or imposing on staff whenever we asked questions or tried to offer input. |
| Presence of family is important for our resident’s wellbeing | Extremely important as it makes my mother still feel somewhat in control of her life. She depends on each member of her family for certain stimulants. Loneliness is terrible and the months we could only communicate on the phone or facetime took a toll |
| People in this LTC home are in despair | Everyone I know who has a loved one in that establishment wants assisted suicide rather than being moved there in case of dementia. That is how bad our system is. People walking around with dirty diapers... staff not knowing what a patient's routine is... I could go on. |
| Staff are not to blame | I don't blame the staff. They do ask for a history of the patient but with a ratio of too many patients, how are they to spend time with them? They barely have enough time to do the necessary care. |
| The signs of neglect in this LTC home are horrible and frustrating | I could write a horor story about seniors' residences. Three times, I have arrived for my visit to find discarded soiled diapers (not my loved one's) on the floor in her room. I have found faecies on her bedroom floor or bathroom floor, in her closet... Her clothes disappear. Her winter boots disappeared and were lost for the whole winter. I had to buy a new pair. He photo album has vanished, never to be found... One staff member gives me one instruction, another gives me a different one... anyway, you can sense my frustration, I am sure. |
| Quality of care in this LTC home is appalling | I had to fight for every medical procedure for my mother. My mother had stage 3 bedsores and I was not even informed about this until I commented on the smell in her room. My mother also put on 25 lbs once she was in a wheelchair with her stomach bloated and I had to fight to get her an ultrasound so as much as these questions ask what was important to me they all were but the care in this private long term residence was so below any kind of standards it was appalling |
| The quality of care in this LTC home is good | I would just like to say that the level of care and the safety of my parent at the facility has given me great comfort and ease of mind. |
| Staff in this LTC home are awesome | The staff are awesome, they genuinely show that they care and are willing to share info with me about my parent. |
| Care is neglectful in this LTC home | Often a concern about medical care was brought forward and not followed up on. I had to stand over a nurse or a director of care to get them to attend to it. Eg. My mother nearly died from anal suppositories. It caused extreme diarrhea. This happened 3 times.  |
| I have to advocate and check up on their work | I had to stand over the assistant director of care to see she posted an allergy alert on my mother’s care plan and I pushed to have a sign posted over the head of her bed. They didn’t want the sign up. They said it contradicted privacy issues. I said my mother’s life is more important than your damn concerns for privacy. It got put up. Changing of wound bandages was sometimes not done. They would deny that the bandage hadn’t been changed. Urine samples for a bladder infection were handled improperly.  |
| Family must advocate, complain, and check up on LTC staff work | A family member must advocate to get care for a resident. You can’t lay a complaint to the Ministry all the time. You have to stand over staff to see it gets done. A shame! |
| This LTC home does not provide adequate dietary and nutritional care | I am appauled that all residents not just for my mother that they are only entitled to 7$ a day in food, this includes breakfast lunch and dinner plus snacks. I never hear fresh fruit or vegetables, my mother is a brittle diabetic and the amount of sugary foods is disgusting,and not good for her overall health and well being. I hear fish nuggets, french fries, hot dogs, puddings pies dough nuts cakes powdered orange juice it's heart wrenching,her sugars range from 2.5- mid to high 20s!!! I am concerned and worried have spoke with so many people in management it's crazy and the cycle continues. Where is the quality of life when their are no choices but to place your most precious loved one? We live in a bountiful farm community that these fragile elderly loved ones have no access to wounce they are placed! |
| For profit LTC focuses mostly on profit | I strongly feel it's about profit, not the well being the residents deserve. |
| Frequent staff turnover causes problems | Frequent Staff turn-over, difficult to get to know, or PSW to know or familiarize themselves with resident and vis a vis.  |
| Staff are overworked and this causes problems | Staff rush to provide care, lack of attention how resident is left, ie. half dressed, disheveled, slouching in wheelchair.  |
| We pay for additional care and this makes the difference | My sister and I and 2 Private PSW's provided daily care of 4 + hrs so Mom did not suffer from isolation, neglect, lack of being outdoors, participation in activities, being changed when needed, being fed a warm meal, making sure baths were given and hair clean, we always brushed her teeth, PSW had no time to provide oral care. 3PSW for 33 residents, at least 25 of whom in wheelchairs requiring 2 PSW for care.  |
| Managers at this LTC home resent complaints  | Management frowned on having issues brought to their attention, threatened with Trespassing law. Management from home office participated in meetings, answer always that they are within Ministry guidelines?  |
| Conditions during Covid have been horrible | During COVID situation HORRIFIC, residents confined to 8 X 8 room 24/7, many not fed or provided fluids between meals, no social interaction, left soiled, crying in pain, all of this personally observed, and MORE. |
| Family caregivers provide vital assistance | Daily family assistance is crucial in long-term care. Residents are only allowed outside with a family member. Many residents never go outside. Residents are much more likely to go on resident arranged outings if a family member can sign them up and help out. |
| Temporary and some full-time staff are not competent | Reliance on agency staff results in people who do not know how to care for a resident. Even full-time staff are not well trained on how to hoyer someone using a broda. How to place them in the sling. How the chair must be positioned and where to place the wheels of the hoyer so that the resident can be placed right at the back of the base of the seat so their back is fully supported. |
| Stories of neglect and incometence | I arrived late one Saturday morning at 10:30 to find mom still in bed, not dressed, not fed, not changed. Full-time staff didn't show for their shift and only 1 agency person was there and it takes 2 people to use the hoyer. Mom called me a few times at 6:30 at night to say she had not been given dinner so I drove over with food. I found if I called in a request in response to a phone call from my mom (she needs to be changed/she hasn't had dinner) the nurse did not ensure the request was met. I always followed up my phone call with a drive over and it turned out to always be necessary. |
| Stories of neglect and incometence | On every visit I would change mom's brief after lunch. Sometimes there were no soaker pads under mom and no clean ones on the floor. What does this mean? It's impossible to turn someone on their side to change them without a soaker pad to pull on. Pulling on the resident directly results in injuries and pain to them. |
| Stories of neglect and incometence | I had to provide zincofax or sudocrem for mom because it was the only way to ensure it would be available when needed. Initially the nurse took the cream to keep at the nursing station resulting in it not being used by the PSW's as they didn't have time to go looking for it. I had to battle for it to be left on her side table. |
| Stories of neglect and incometence | Lack of fluids is another issue. The home provides the minimum amount of water/juice in tiny 120 ml or 170 ml cups. Often mom was extremely thirsty. I would provide juice for mom which was labelled and kept in the tiny resident fridge. Occasionally I would notice some residents were missing their cups at lunchtime and I would ask the kitchen staff for cups of juice/water for the resident. |
| Stories of neglect and incometence | The home changed the food service provider (to save money I guess) resulting in ongoing issues like no bananas, no yogurt, powdered apple juice being used. Soft foods like these are often the only thing many residents can/will eat. One day there was no sugar for residents coffee/tea/cereal. Our seniors deserve much better! |
| Stories of neglect and incometence | An ongoing issue throughout the home was residents not being changed when a change was needed. I saw feces leaking from a resident that asked for a change for over an hour. I asked the PSW for help, another caregiver made the same request. It was ignored. Another resident removed his brief full of feces and feces was smeared all over the room, down the hall. If they had met the request when needed a massive cleanup would have been avoided. I spoke to management about these 2 incidents. Nothing changed. Staff do the minimum and if it is close to end of shift every request gets left for the next team to deal with. |
| Temporary staff do not do a good job | the regular staff that have gotten to know him are exemplary however there are too many 'agency staff' or transient staff that just come in to do a job and don't make the time to either know him and/or me and end up doing a below par job |
| Staff need to communicate more with family so we are aware of changes | More communication from staff would be of benefit to me. I know there is a lot to do and only so much time but being more aware of changes in my family member's behaviour would help me do a better job of helping to meet their needs. In these 'Covid' times perhaps more use of Zoom or similar would be appropriate. |
| I provide most of the daily care | I provide the majority of daily care, all personal and legal matters, all feeding, laundry, arrange outside medical services to attend (Footcare, massage), entertainment and social ops, decisions re her care (med changes, dietary, etc), administer all meds and topical applications, In many ways staff have deferred to me given my presence there and at times over look her care. |
| I sometimes help other residents (not just family) because they need help | I also assisted with other residents in dining room, distressed times where I have a good relationship with resident, personal shopping for them if required. |
| My advocacy and suggestions are ignored | I find there are several areas that require attention in standard operating protocols and have discussed with administrator and staff to no avail. I now d what is best for my daughter and do not bother with staff whenever possible. |
| The LTC sector must be improved | There is no comparison how family members can interact now versus before COVID with their love ones and I feel it will have long term effects on both the love one and family members. I feel we need both the Federal & Provincial Governments to make Long Term Care reform a priority starting with PSWS getting the recognition they so rightly deserve starting with their wages so it will attract dedicated people to take proper care of our most vulnerable. Proper care means legislating more time to care for them and taking the for profit out of equation, |
| Staff do not appreciate the role of family | I do not feel that the staff of the facility show or express appreciation of the care I provide(d) i.e. coverage of all PSW duties for 5-6 hours every day; thereby freeing up staff to provide more adequate care to other residents. In almost 4 years, I have provided direct care since Day 1, there has been no recognition of this assistance. Indeed, sometimes, I think it may be a mistake on my part, because staff on the relevant shifts do not get to know my husband, and really make little attempt to do so. |
| Families should be part of the care team | It’s essential! |
| Care in this LTC home is horrible | The care of our mom during her last days was a horrific experience. |
| This LTC home offers poor health care | Medical expertise was lacking in many critical areas. |
| This LTC home treats families poorly | Treatment of family was poor and communication with management strained. |
| LTC needs to be well staffed | The facility was understaffed and the staff over worked. The staff did not really have the time to spend quality time with the residents.  |
| Family Council is a strong support for family | The Family Council has also been a strong support for care-givers, providing information and an opportunity to talk to family members of other residents and share information and experiences |
| Families have suffered due to Covid rules | During the pandemic, the limiting of family visitors and those deemed “essential” has caused a great deal of stress and strife within the family |
| This LTC home does a good job | I am very happy were my mom is. They only thing is I hope the people that work there get good pay. Because they work hard. |
| Families should be part of the care team | Critical. Being able to be part of my mom's life is critical to her care. The more involvement, the better off she is. Its not just that she knows she loved, but that staff understand that there will be somebody there often to make sure everything is being done in their power to ensure she is safe and well.  |
| Family caregivers shore up a failing system | The good care givers deeply understand that LTC facilities are under funded - under staffed - require 24/7 365 care and are doing their best...but sometimes its not enough - they have 100's of folk to care for. We need to fill the gap....or the system falls apart. |
| This LTC home and most staff are fantastic | The [name of home] has been a fantastic facility for my mother. The majority of the staff are very caring and compassionate. |
| This LTC home and staff are wonderful | The LTC home where my brother resides is an amazing place. They have wonderful staff who connect to residents like family. I am so happy to know he is loved and cared for and he really likes it there. |
| My family is very involved in our resident’s care | My brother is the primary care giver, he lives close by our loved one. He schedules and attends all medical appt's, visits and interacts with her frequently and is the contact person for staff. My role is much more reduced than his as I live further away and am snowbird in the winter. We are dedicated to her well being. |
| Staff in this home do their best | The staff did the best they could with the staff they had....not enough staff to provide proper care...2 psw's to put 22 ppl to bed....not good! |
| LTC needs to be well staffed | ....not enough staff to provide proper care...2 psw's to put 22 ppl to bed....not good! |
| Staff in this home need to be held accountable | staff need to be held more accountable which will then improve quality of care given. |
| Care for my resident is good, but… | My mother went into LTC during Covid so hard to assess everything accurately but she is well taken care of, though lonely. I think it would be nice to perhaps have smaller groups of like-minded residents interact - groups cannot always offer inclusivity to all. Skill set levels & age can be so broad - those with trouble hearing or speaking might not feel comfortable participating - it can be quite boring for someone who was previously quite ‘with it’ but suffered a physical set back (ie stroke..).It can feel quite ‘institutional’ and not as homey as perhaps it could be. |
| I trust the staff in this LTC home | Staff have always answered my questions and/or followed up if I found my family member confused during a visit. She opens up to me, but is quite closed to staff members which is not helpful to them. However, I do trust in their professional abilities. |
| Staff in this LTC home do not know how to care for someone with dementia | I was the full time caregiver for my mom while she was in Long Term card and working full time. The staff do not know how to care for anyone with Dementia … |
| Staff in this LTC home resent my advocacy | …they do not like anyone like me who works in the field interfering with what they did not provide.  |
| LTC needs to be well staffed | my mom has not had a very good experience in LTC - the staff are so over worked and burnt out (even before the pandemic) that there is NO CARE - |
| Stories of neglect and incometence | the residents are in very cheaply made DIAPERS NOT BRIEFS - even though they have dementia they know they are in diapers and no one seems to care about their dignity - the activities are very poor quality and I feel none of the staff are trained in dementia care - they know nothing -  |
| Stories of neglect and incometence | I saw my mom Mar 14/20 and she was missing her dentures and the staff found them under her be 8 weeks later - during a pandemic what are the cleaning staff doing - 8 weeks under her bed - no she has been without her glasses for 7 weeks now and no one care where her glasses are - WHAT KIND OF CARE ARE WE PAYING FOR - I am disgusted with the level of indifference to the care of the residents - the well paid activities staff know nothing about activitives for geriatric patients -  |
| Stories of neglect and incometence | I worked in mental health for decades and I am shocked at the lack of infection control and cleanliness in the facility - it always smells like poop - I would give anything to have my mom back home here with me -  |
| Stories of neglect and incometence | when we visited the LTC home before my mom arrived and I was sold a bill of goods - everything they said sounded great until my mom was there and everything I was told was a real stretch of the truth -  |
| Stories of neglect and incometence | with the arrival of the pandemic the situation in LTC has been horrific and they still are horrific 14 months later nothing has changed and the care is non existent - we should all be ashamed of what is happening in LTC - extendicare organization gives 171 million dollars to shareholders and takes 121 million dollars from the government to pay for pandemic costs - HOW IS THAT RIGHT!!!!!!  |
| Stories of neglect and incometence | my mom is not the same person she was 14 months ago and I blame the LTC system for it's complete failure to protect and care for our most vulnerable citizens. SHAME ON ALL OF YOU |
| Family support and care is essential for LTC residents | Having been closely involved in my mother’s care & well-being in the past eight years or so while she has been living in LTCH, I KNOW how important it is to have a family member (i.e. me, her daughter) in this role. I honestly don’t know how elderly residents without family nearby manage! I continually advocate for her, provide emotional & physical support, regularly liaise with the staff & the Doctor and nurses, as required regarding her care and medical needs. I handle all her financial affairs, arrange appts with hairdresser, footcare nurse, physiotherapist etc. All these things have been made more difficult to do since March 2020. Also, I used to take her out to run errands or have a meal at a restaurant or bring her over to my house for dinner or a bbq & family celebrations/impt religious holidays (Easter, Christmas, Thanksgiving) -these occasions often attended by her other kids & grandkids who live out of town. This may not be considered “hands-on care” but it’s extremely impt for me and my mom that she remain connected with her family. Since the pandemic, we are restricted to phone calls & sometimes I do FaceTime/virtual calls so she can ‘see’ these loved ones but it has been really difficult. |
| Things have gone reasonably well for my resident | Ma mère était relativement autonome dans son appartement. Je faisais ses courses, j'allais à ses rendez-vous (médecin, dentiste, coiffeur), je lui faisais livrer des repas et ses médicaments. Elle recevait des soins des pieds à la maison (infirmière) et des préposées du RLISS lui rendaient visite. Je la sortais luncher une fois par semaine. D'autres membres de ma famille (cousins, cousines) lui rendaient visite. Ma mère parlait à ses soeurs tous les jours. Maman est entrée à la résidence en octobre 2019. J'allais la visiter et luncher avec elle plusieurs fois par semaine. Une cousine l'amenait visiter une de ses soeurs aux deux semaines. Parents et amis l'ont visité. Ça, c'était avant la pandémie... J'ai laissé plusieurs questions sans réponses puisque ma mère est toujours vivante et qu'elle ne souffre pas de démence. Récemment, on l'a diagnostiquée comme souffrant de perte de mémoire modérée. Il lui est difficile de trouver le mot juste. Aussi, lorsqu'elle est moins médicamentée (elle souffre beaucoup), j'ai encore de belles conversations avec elle.(My mother was relatively independent in her apartment. I did her shopping, I went to her appointments (doctor, dentist, hairdresser), I delivered her meals and her medicines. She received foot care at home (nurse) and was visited by LHIN workers. I took her out to lunch once a week. Other members of my family (cousins, cousins) visited him. My mother spoke to her sisters every day. Mom entered the residence in October 2019. I would visit her and have lunch with her several times a week. A cousin took her to visit one of her sisters every two weeks. Relatives and friends visited it. That was before the pandemic ... I left several questions unanswered since my mother is still alive and does not suffer from dementia. Recently she was diagnosed with moderate memory loss. It is difficult for him to find the right word. Also, when she is less medicated (she is in a lot of pain), I still have great conversations with her.) |
| Staff are not properly prepared or trained to care for some residents | I am more involved in my parent's care (predates LTC) than most. I spend hours researching, monitoring, advocating and working to find a balance to address the needs of the institution (schedules, rules, etc) - making the best decisions for my parent in her interest - managing biases about mental illness from doctors and nurses - and sadly watch someone screams of pain being unheeded by personnel who attribute that to dementia or mental illness. But I feel staff lack insight into behaviours that indicate a problem (eg pain which can cause agression) and staff focus on managing the behaviour as opposed to understanding the cause or trigger.  |
| I am treated like an outsider, but I should be part of the team | There should be more questions about decision making and how the institution staff and doctors work closely together and have access to infomation, but as the substitute decision maker, I am treated as an outsider. So I am expected to make decision on treatment based on anecdotal information, not documented. I have to go through nurse, or care coordinator - to get access to doctor - no direct access. Care conferences are not focused on actual care. And (this one is a gripe) but an obgyn should not be a primary physician for a geriatric patient. |
| Family support and care is essential for LTC residents | Pour moi, je vois la différence chez mon parent lorsque je la visite. Elle est plus alerte, souriante et participante lorsque je vais la visiter régulièrement.(For me, I see the difference in my parent when I visit them. She is more alert, smiling and participating when I visit her regularly.) |
| Staff need to be trained to treat residents with dignity | I think more training is needed for staff --- I would urge trainers to clearly communicate and reinforce regularly the need to respect residents and be professional and attentive at all times. It should include assessment and monitoring of staff's approach/attitude towards residents and their understanding of what 'maintaining resdients' dignity' means -- this is an area I find quite lacking at the [name of home] in Ottawa. |
| This LTC home welcomes family and we work as a team | La question #61 est mal posée. Je ne comprenais pas. Je ne suis pas son POA, alors mes renseignements et les décisions viennent de sa fille qui vient rarement et qui habite à l'extérieur. Tous mes efforts pour rendre ma soeur aussi heureuse que possible sont récompensés par la réalisation qu'elle est dans un bon foyer où on travaille en équipe pour elle. Pas toujours facile mais ça vaut la peine. Merci de tenter de rendre la vie de ces gens plus heureuse. (Question # 61 is incorrectly asked. I did not understand. I'm not his POA, so my information and decisions come from his daughter who rarely comes and lives outside. All of my efforts to make my sister as happy as possible are rewarded with the realization that she is in a good home where we work as a team for her. Not always easy but worth it. Thank you for trying to make these people's lives happier.) |
| The LTC home does not always welcome my advocacy | I have been her advocate but it is not always welcomed |
| Staff need my information but don’t help me | Because my mom lived with us for 10y ears as she declined, I felt I was informing the staff more than they were helping me. She was admitted when my husband became ill as a crisis placement. |
| Staff in this LTC home are excellent | The LTCH staff have been unstinting in their provision of care and support for, not just my spouse, all residents of the Home. |
| Covid restrictions have impaired my resident’s health | Prior to the Covid pandemic, I was free to take my spouse for drives and even picnic in the local park. The restrictions brought about by Covid have brought these pleasures to an end. As a result, my spouse's health has deteriorated significantly and I visit her daily to help with emotional support.  |
| I must monitor care every day to ensure adequate care | My parent was in LTCH for 10 years....I learned very quickly that I had to monitor my parent daily and hire private PSWs to ensure they were cared for in the way that they deserved. Things did improve somewhat over the 10 years they were there...but not to the caliber they would have expected |
| I find it necessary to pay for and/or provide extra care to support my resident | I learned very quickly that I had to …hire private PSWs to ensure they were cared for in the way that they deserved. Things did improve somewhat over the 10 years they were there...but not to the caliber they would have expected |
| Family advocacy was vital to ensure that our resident received decent care | My father ,my siblings and myself were involved with mom's care. We communicated regularly and solicited feedback about moms daily living, changes, and times where care could have been better. Mom was a quiet person and with a very low voice because of her Parkinson's I am not sure she would have seen the kind of care if we did not advocate.  |
| Residents without family caregivers or advocacy suffer | We all saw care recipients who did not have families to advocate and we observed less attention, and less care at the dinner table - food was placed before them but they hadn't touched their food, andin no time shrivelled away to learn they passed in 6 months time.  |
| The LTC home needs to provide more information to family | I feel like more information should be shared with all family members concerning their loved one and not just shared with the power of attorney for care. This information does not need to be intimate details but general information to help with the understanding and care of their loved one. |
| Some staff are not competent  | While most of the staff are competent, some are not and really not interested in their job, but they have a job!  |
| Family caregivers play a vital role | Family members are very important for the residents in LTC.  |
| The LTC unions are a barrier to better care | …staff … all have to belong to the Union which makes complaints sometimes never resolved.  |
| LTC needs to be well staffed | Also there was ( and still is) not enough PSWs who do the actual care for the Residents which leaves caregivers sometimes much to help with the caring. |
| My mother went into severe decline after entering LTC | As a working single mother, I was not able to provide the required care for my mother; therefore had to put her in a home. Brought her up to a '1' on the waiting list as I was told it could take up to 3 months. Within 1 week we got a call and HAD to accept, otherwise, she would go to the bottom of the list. My mom suffers from Alzheimer; even though she was confused and lost, there was still some of her left in her souol. Within one month in the home - she was no longer herself. She has been a prisoner since.  |
| Being an LTC resident is like being a prisoner | She has been a prisoner since.  |
| Assisted suicide is preferable to living in LTC | We have watched her deteriate over the years and if she could take her own life, she would. You MUST convince the government to allow assisted suicide even if the person is not of sound mind. Living with Alzheimer is not living, it's slowly rotting away. I would not even let my dog live through that. |
| This LTC home was well managed | My two friends were in a well managed L T C Home which I am most grateful. |
| Staff need dementia training | le personnel (préposé) ne semble pas comprendre la démence et les approches à prendre auprès ma mère...parfois je dois éduquer le personnel...(the staff (attendant) don't seem to understand dementia and how to approach my mother ... sometimes I have to educate the staff ...) |
| Presence of family helps the resident and the family | I think it’s very important to have family members involved, for both the family and the resident in LTC. I’m very fortunate to come from a close family who is happy to share the visiting with our mother.  |
| Staff in this home have become complacent and neglectful | I visit my mother twice a day: at lunch for a couple of hours to assist with feeding (my mother is not capable of feeding herself) and dinner, to assist in feeding and bathing, putting her to bed, etc. Since September, 2020, when we caregivers were permitted back into the residence to care to our loved ones, I have noticed a significant decline in the level of care/involvement by staff with regards to residents. Despite the increased assistance provided to the general complement of daily staff during the Covid pandemic, an "air" of complacency/lassitude is quite prevalent among staff. I would be pleased to discuss my "views" with interviewers. |
| Stories of neglect and incompetence | I would sometimes receive calls from the nurses regarding my mothers physical health such as suggestions regarding medications and pain management. As to her mental and emotional health there did not appear to be any care plan specific to her. |
| Stories of neglect and incompetence | No effort was made to seat my mother with other residents who were mentally competent and could carry on a conversation with her at meal times. Therefore her only meaningful conversations would be with staff or family. |
| Stories of neglect and incompetence | We found it very important to advocate on her behalf, whether it was to restrict a specific staff member from attending to her (too rough), to request testing for a uti, to ask for measures to control the temperature in her room (often 27C), and the temperature in the bathing room (too cold), to request medication for panic attacks, etc. The PSWs do not have time to sit and talk with residents - they are always on the run. It often takes too long for a call bell to be answered and all too often the call bell would not be left within the residents reach. |
| Volunteers in this LTC home are wonderful | The volunteers were wonderful and would sometimes pop in to say hello. The program managers would do a great job of arranging entertainment such as bingo and music. Our mother would usually rely on one of her family members to get take her. |
| Psycho-social needs are not being met | I would say in general that physical needs are well met. Its daily companionship, conversation and warmth that is lacking. The only interaction with psws is to attend to physical needs - very task oriented and hurried. |
| PSWs are overworked and underpaid | Its not an easy job. They are overworked and underpaid! |
| Family involvement and advocacy is vital to my resident’s wellbeing | I hate to think what my mothers life would be like if she did not have family visiting and advocating for her. |
| This LTC home could improve its communication with family | A mon avis le personnel administatif devrait communiquer plus souvent avec les familles au sujet des activités, des menus, avoir des rencontres familles/résidents.Je trouve que la rencontre annuelle multidisciplinaire afin de discuter du plan de soins et qui prend environ 15 minutes pourrait être plus dynamique. (In my opinion, administrative staff should communicate more often with families about activities, menus, and having family / resident meetings.I find that the annual multidisciplinary meeting to discuss the care plan and which takes about 15 minutes could be more dynamic.) |
| Presence of family is vital for my resident’s health | Mes visites régulières à ma mère lui permettent de savoir ce qui se passe à l'extérieur de la résidence (famille élargie, actualité, pandémie, température etc.). Quand ces visites ont été arrêtées au début de la pandémie, elle dépérissait et était déprimée. Elle a besoin de se sentir aimée et soutenue.(My regular visits to my mother allow her to know what is going on outside the residence (extended family, news, pandemic, temperature etc.). When these visits were stopped at the onset of the pandemic, she was wasting away and depressed. She needs to feel loved and supported.) |
| Frontline staff in this LTC home do a good job | When I see 'Staff' I think of those who are providing direct care and yes they are doing a good job. |
| Administrators at this LTC home create roadblocks and value uniformity | However, the 'Administrators' are putting up roadblocks and in some cases 'gag orders' to withhold information. These Administrators are invisible and not accessible and yet they have power to make policies that are designed as a one-size-fits-all approach. The age groups range from 19 to 100 years old and yet everyone is being treated to quote the [name of home]'s Administrator in 2005 "Now that you are in the sunset years of your life" is evidence that Resident's and the Caregivers should comply by their policies without question. |
| Stories of neglect and incompetence | As you can read by my tone, I am not your typical easily intimidated caregiver. I cut my caregiver teeth at [name of home]. The Administrators and Unit Managers were not empathetic and in some cases they created a 'toxic environment' for their employees, residents and caregivers. When my spouse was transferred to [name of new home] it was a beautiful yet short lived experience. To this day, when care has not been provided as I would like at my husbands current LTC, I simply remember the time at [name of first home] and I use that as my benchmark for poor care. I have 16 years of experience as my husband's designated caregiver he was 48 and I was 46 years old. I have a story to tell and I have the journals to support that. I sincerely hope this survey is taken seriously and should also provide more qualitative questions versus quantitative. Maybe you will undertake that as a next step. Its a hope that the information gathered will spearhead real change in LTC. |
| Presence of family is very important | The presence of the family caregiver is very important, especially when the resident cannot look after herself, cannot make decisions, or is not capable of initiating actions. Also when language barriers exist, the caregiver role is very important.  |
| The LTC sector needs to be improved | Unfortunately our LTC homes in Ontario are not provided with adequate staffing, so the staff members can only provide the very basic care for the residents. That is why the presence of the caregiver is essential to the overall well being of the resident. |
| This LTC home is inclusive and helpful | [name of home] is very inclusive of family. Our loved one (my mother) lives in LTC due to her lack of mobility, not her cognition or ability to communicate. She is our messenger for a lot of happenings. She uses the phone on her own and is able to communicate to the staff. We are fortunate she can still do that - it's very helpful for her care. |
| Care at this LTC home makes me happy | I am very happy with the level of care at [name of home].  |
| Staff are supportive at this LTC home | The staff has always been very supportive and have been particularly careful during the pandemic. We have not had a single case of Covid-19 at [name of home]. |
| Presence of family is very important for residents | It is important to be able to provide company and support for the residents. This includes: technology support to allow for 'family visits', providing a familiar face and a hug from home, picking up odds and ends that a resident needs, hooking up telephones and doing other small tasks to make the resident feel comfortable and at home. |
| My resident is still quite independent | Hands on care not important as she can look after herself except for bathroom |
| This home provides excellent care | [name of home] is providing excellent care. Everyone seems like they are doing their best. |
| I lack rights because I am not POA | I would love to have more of a role in the decision making. As it stands I am DCP but if something happened in her care ex. Her dying I wouldn’t get that call to be with her. I have no rights as I don’t have power of attorney. I am good enough to be her care giver at this time but not other than that. Her son is my husband and is also DCP but is in the same position as I am. Out in the cold so to speak. Hurtful. |
| Staff at this LTC home are caring and efficient | All the staff are kind caring and efficient in all facets of duties and responsibilities. I am so happy they were accepted at people care |
| Presence of family has been a lifeline for many residents | While you are looking for this "going forward" during COVID it has been the lifeline for many within LTC to have someone come and visit -- it has been very lonely.  |
| This LTC home does not listen to family and blames resource shortages | Staff/management are happy to have care partners/family come in and assist with staff-designated care items (feeding, physio, cleaning/organizing room) yet do not take the feedback/input from resident and family member regarding service and care plan seriously. Have made many complaints and input regarding physio regime etc based on personal health history and goals yet they are mostly ignored and we are told the residence lacks staff and resources to provide what we would like. Always comes down to the [name of home] residence not having enough and we are just supposed to deal with it. |
| This home does not hold enough care conferences | [name of home] schedules one resident Care Conference a year. This is far too infrequent. I have attended care conferences both in person, and on the phone. I would suggest Zoom 'in-person' care conferences every 2 months, or as needed, would be most valuable. |
| This LTC home treats families and residents with respect | Involving the family as knowledgeable team members is important. [name of home] taff treat patients and families with warmth and respect. |
| Presence of family is very important for my resident’s wellbeing | I feel it is so important for family to be well involved with their loved one and the LTC home. I need to make sure my mom is well looked after and I know the care she is getting. My mom could not say sentences to me but when I came into her room she would become more animated, vocal, and smiling and laughing. It made my day!  |
| This home helps my resident by letting her interact more with others | The home provides her with more interactions with people than I could give her when she lived with me. |

# Step 1: Raw Data

This data represents the way in which survey respondents answered the open-ended question that reads: …we are interested in hearing more about your experience. You are welcome to use the space below to share your interpretations, feedback and reflections on the level of involvement and importance of family members (or other care partners) in providing hands-on care for residents in long-term care homes.

Each paragraph represents the response of a single individual. Line breaks are used to show how participants formatted their response; paragraph breaks indicate the end of one participant’s response.

French translations were done using an online French-to-English translator.

## Uncoded Raw Data

Families are an essential component in a resident's level of care - we are part of the team and we have a role to play. Depending on the staff, sometimes this is not shared by everyone and they feel they are there to take care of our loved one. They feel threatened or take questions/concerns raised personally. However each person within the home and the family need to work together holistically to provide the level of care our loved one needs. I feel more training of staff is required as to how all these pieces come together and provide value in the level of care given to our loved ones.

I think its important for there to be enough staff in the home, I think it's important for loved ones to feel a connection to the staff, familiarity is especially important for those with dementia, so same staff and someone they can relate to is important. It would be nice if there wasn't an us and them mentality just one family!

This home in 2008 -2104, experienced the same challenges as were uncovered during Covid-19 - insufficient staff, lack of training, lack of supervision, PSW's were poorly paid, had no benefits, making it necessary for them to work in more than one home and were over-worked. LTC processes, systems were broken or non existent as were their internal and external communications with staff & families.
I left a much enjoyed & lucrative career due to decades of government's neglect of this LTC sector and inability of the LTC home to provide quality care. I dearly loved and wanted to care for my parent in my home until his death. He moved from another province to ON so I could do this. When he needed more assistance, Community Care was unable to meet his requirements. LTC became our only option. It was heart breaking to be separated. I, along with many families have suffered tremendously -physically, emotionally & financially. We've seen how the various governments over decades did not act on the many commission reports, submitted long before Covid-19. Our loved ones were abused, neglected and the presence, involvement of families enabled the LTC sector to be maintained. I and many others chose caring for our loved ones over working, saving and planning for our own retirements and elder care. I advocated endlessly to no avail and listened to promises never kept. Covid-19 clearly showed the ugly side of government, Families have realized their loved ones are most important to them. The hurt is still profound.

Definitely want to know what staff are and aren't doing cause they are always rushing to get them to bed so they don't have to work anymore

As a family caregiver, I have never been part of mom’s care plan, included in activities. When a family caregiver is welcomed so is a resident. Keeping family members happy and taking care of their needs to best help their family members is key. Having kitchens as the heart of the home so family members can warm up home cooked meals complete with proper equipment creates a friendly and welcoming atmosphere. Also, providing a place for caregivers to have a meal before they head home is also important especially if family members help with meal times.

It is vital for Family Councils to be \*mandated\* at all LTC homes. These provide a critical link and safety mechanism for resident care, especially where some residents don't have family nearby, or family is absent from care. Often other FC members can raise issues even when it's not about their respective resident.

I’m not sure if I answered these questions correctly but tried. This facility was unhelpful, dangerously disorganized extremely short staffed (why I was so involved in his care). I watched as 2 residents succumbed to painful early deaths from inadequate wound care in my husband’s 15 person ward alone. There were so many others! I learned quickly not to trust a word management said. Numerous reports to licensing concluded “unfounded" even with photos. Ultimately a public administrator was assigned to the facility - but she’s got now and there is yet another GM. I feel terrible for everyone still living there. Add Covid to that and I was forced to abandon my husband to these people! These have been the darkest days of my life and I doubt that I will ever recover completely. It took 12 months but I finally got a call that a bed in a new facility was available. Things are better in his new home but I hated the idea of moving him during a lockdown. It will be a long time before I trust again. This is not an isolated case as we have seen. There needs to be enforceable national standards in LTC. There need to be enforceable penalties for noncompliance. There needs to be adequate and affordable home support so elders can remain at home longer.

Staff are very task oriented. They are very negative in their communication with residents. Quick to tell them what can't be done. Rushed for time. Poor communication between staff.

I am a retired RN and have sought out and procured services and care for my resident.
I am much more aware of the residents’ specific medical condition, prognosis, and psychosocial behaviours than the majority of the staff.

Parfois, le personnel oublie que ce qui est naturel pour eux est nouveau pour les membres de la famille. Par ex., j’aurais eu besoin d’être informé des changements graduels des soins, par ex., que ma mère avait besoin d’une tasse pour enfants plutôt que de la voir du jour au lendemain utiliser cette tasse pour enfants.
(Sometimes staff forget that what is natural for them is new to family members. For example, I would have needed to be informed of gradual changes in care, e.g., that my mother needed a children's cup rather than seeing her overnight use that children's cup.)

In the 4 years that my mom has been at this care facility I feel my involvement has been extremely important to her happiness and to my peace of mind. The staff who deal with my mother's care need much more training about dementia.

Inconsistencies between how staff are interpreting the COVID ‘rules’ and weak staff communication skills result in conflict between family members and staff. Trust and respect are eroding, family members are feeling “watched” and fear that, if they are caught doing something wrong, they will be barred from entry. Much of the family's experience depends on their ability to be diplomatic, agreeable, invisible, compliant, easy to get along with and liked by the bosses.

There is not enough staff to provide proper care and i worry my mother is being neglected. That is why I am there daily plus to monitor how she is being treated.

The home 10years ago was totally brutal to my mother and I because of her dementia and related behaviours that wete often aggressive during care. They would call me at work and "bully' and threaten and put my mom on antipsychotic meds. I learned quickly they wete inept in caring for residents with dementia and decided to care for her myself twice daily plus I hired private PSWs to come in twice daily after I left. Due to new administration and increased knowledge things fod slowly improve over last 3years..I never completely trusted Some staff and continued this csre until 2weeks ago when mom passed away with me by her side. LTCH and staff need to undergo many changes and stop AGEISM attitudes.

I feel that the care we have had for dad has been wonderful. Filling in the gaps when staff cannot is a concern. There seems to be much time that is alone time and the staff as wonderful as they are cannot provide the one to one social interactions and extra time that we as family members can provide at times during a week. I find that it's these moments of playing a game, chatting, tidying up, sorting through and even setting up a Christmas tree or decorations, giving a little tlc - these personal touches are needed and necessary for the wellbeing of the resident. Thank goodness for the activities and the programs- dementia residents should be encouraged to do those things and not asked if they want to. They are in a LTC facility because they cannot make their own decisions. If playing a game means they have other people around then that is so important. Residents should be brought in to the activity environment even if they don't participate. They will still have that energy from those around them. It is the little things that allow the caregivers (family) of the resident to have that peace of mind that their loved one is more than just a body filling a space. I know my dad is liked and looked after and he is safe. The staff have been wonderful and especially during this covid time they have been kept us abreast of everything. We are very thankful and blessed.

Gap from my experience was the admission process. Too many documents to fill out on admission day; errors were made.

This survey appears to repeat itself. I have not answered the questions I feel don't apply, as my dad only entered the facility 6 weeks before lockdown. My concern is making video conferencing easier and more accessible, which means better wifi and more digital devices in homes.

We have to end Profit LTC! No one should be redirecting money to a company away from human services and care. My wife is in a NFP home and the care is difference when staff are paid and treated well. When they know that management cares for them and the residents. When they know that money is not being taken was from the care in the home for someone else to profit from.

At my mom’s LTC the PSWs were a very powerful group and it negatively affected my mom’s care. The care she received was not humane - and this was before the pandemic. We hired an private caregiver (RNA) to support my mom during her waking hours. If she was not available, I provided care (I am a former RN). What support we needed from the PSWs was frequently provided with a “you’re bothering me” negative attitude, despite the fact that we were kind, appreciative and asked for very little support.

Adminisration does not seem to be involved with families unless there is a complaint. Often that complaint is handed down to a lower ranking member. Families do not seem to be important, are forgotten and even mistrusted. We have so much to offer. While the home was very short of staff I volunteered to take a course to learn how to transfer my husband safely in the sit to stand lift. My request was refused and I was chastised for using the lift while we sat for what seemed like an eternity to get someone to help. I was point blank asked "Do you have a funeral home picked out for your husband" soon after Covid started. No preamble or anything. Families are not encouraged nor do they have many rights within the home. One family member said that they did not put their mother up for adoption when she entered the home. We are definitely undervalued or not valued at all.

Communication is very poor, between staff and to me. A decision or request from one day often does not get carried through by tomorrow's staff.

Majority of frontline staff (minus the numerous Agency staff) are very friendly, compassionate toward our loved one, the biggest issue is with our current administration, where we must result to submitting a complaint to MoLTC for information about the home. The current administration is secretive, non transparent and the current ED is not the right fit for the home.

The home [name of home] where my mom is in has the ability to provide basic care prior to Covid. After Covid not a passing mark for taking care of my mom and other residents.

I witnessed how difficult care workers' jobs were every time I visited, which helped me understand why they had little to no time for quality person-centred care. At the same time, I wished that my grandfather had more opportunities to socialize and laugh with staff and fellow residents. I certainly developed mistrust in the long-term care system and its values, not necessarily mistrust in the care workers themselves.

I found the staff and facility provided reasonable care within the system as it is structured. The system is deeply flawed and under funded. Caring for people should not be done in this big institutional way. It didn’t work for schooling Indigenous children, or people with developmental delays or the mentally way. LTC is not a hospital. Care to seniors should be provided at home for as long as possible with home care services. The few people who require institutional care should be cared for in small facilities where there is adequate staff paid wages that fit the work they do. LTC needs to not be the orphan of health care funding. Privately run for profit LTC needs to end.

The LTC Home my mom is in is above average in my opinion (having friends who also have had family in LTC). I think it is extremely important to have family members involved in the care of their loved one as the care provided by the LTC staff is very inconsistent. Some staff are excellent and some do not seem to care and appear not to be really interested in providing compassionate care. They don’t appear to have the empathy required to put themselves in the shoes of the one they are caring for and my experience is they will avoid taking the time to really do a good and thorough job. ie. sometimes I come in and my mom’s underbriefs are wet and all bunched up and uncomfortable, and I have to ask for them to clean her up and change her. Some staff will try to convince me that my mom is OK the way she is and when I insist and they do as I ask, they do it with resentment even though after it has been done, my mom is clearly more comfortable. I have asked that they change my mom regularly mid morning and mid afternoon and it is not done unless I am there and ask for it to be done. I worry about the people who do not have family to keep watch for their loved ones or on the rare days when we cannot have someone with my mom, I am wondering if she is being cared for well. I am constantly concerned when there is no one there advocating for my mom, that she is receiving compassionate care. I don’t think we should have to be concerned about the care our loved ones are getting in LTC. There ought to be a standard across the board and every resident ought to get the same good care whether a family member is with them or nor. That does not appear to be the case. Many of the residents cannot speak their needs and it shouldn’t be up to family to ensure that those needs are met. Each resident should get the same level of excellent care regardless of whether they have family advocating for them or not. That does not appear to be the case in my opinion. And when I do speak up politely, many staff resent being asked to do their job and that comes out in how the staff treats me now. When I speak up for my mom, they treat me as if I am a pain in their side, and I am very polite and friendly because I do not want them to take anything out on my mom when I am not there. That is a constant concern of mine.

LTC homes should trust family members as they are important stakeholders and should establish open channels of communication where all parties can cooperate and express concerns.

Family member participation is extremely important to ensure residents are kept safe and provided quality care. With the understaffing problem, family members are required to be sure their loved ones are eating regularly, walking, and personal care needs are met.

I always felt like I needed to make daily visit to monitor care. If not, quality of care was not good. Inconsistency of staff on afternoon shift made it difficult for my loved one as new psw's did not know care routines which did not help the residents moods. Also felt that I was advocating and monitoring for other residents. Several times it was me who discovered and reported a fall or a resident in need. Only contact residents had with psw was for a few minutes to either dress / undress or toilet. No social contact or occasional checks by psw's. they had no time for that. Facility was always understaffed and I felt like I needed to do the evening care or settle for poor care. Food quality not the greatest. Many residents are constipated due to poor balance of diet. Residents were often given laxatives rather than address nutritional needs.

Staff are very union minded and not resident centered. The home is run by admin who are very sympathetic to the union demands of staff. Residents pay the price of having staff who are not committed and admin who do not create and sustain a culture of resident cantered LTC. The demands of the unions are running LTCs. Staff are kings, residents are innocent, helpless bystanders. Anytime suggestions or complaints are made, admin and staff stick together to support the facility’s reputation. .

My father moved from [name of retirement home] in a retirement home to Long Term Care just 9 days before the lockdown due to Covid 19. I don’t know how different it might have been compared to this past year. I do know that the continued isolation and confinement has accelerated my father’s decline in the extreme. He went from being able to walk, converse, feed himself, pee, wash his hands, try to dress himself to losing 40 lbs, being confined to a wheelchair, unable to feed himself a diet that now consists of puréed food, unable to communicate, screaming most of the time. I have seen my dad nearly every day for the past five months since I am the only caregiver allowed in the home. Prior to that my husband was able to alternate with me. The only way I can bring family in to see him is through FaceTime. We are confined to his room except since the weather is improving I am able to wheel him out into the fenced in gardens. I arrive for visits and find him in the middle of the day in his room, door closed, lights off, curtains closed, radio playing, screaming, face and ears extremely hot and red. I don’t know how long he has been left this way, without interaction. At this point long term care is just human storage. There is zero quality of life. All activities remain off limits, a year later, and residents are still confined to their rooms. I hate it.

My Mom is legally blind and profoundly deaf so it was extremely important that I be a part of her care team. The LTC had wonderful staff who would call if they noticed a change or had a question. They also held care conferences with her doctor which was a great opportunity to give and receive feedback on care concerns.

My mother was admitted to LTC in August 2020. Prior to that time, she lived at a Retirement Home. She was living at the retirement home at the beginning of the pandemic. During the lockdown and subsequent isolation which began in March 2020 for Retirement Home and LTC residents, the isolation, absence of family visits, social activities, and meaningful life interactions took a huge toll and I believe was the root cause of the quick advance of her dementia and mobility issues. She suffered a fall during the first 3 months of the pandemic, at her Retirement Home and because of the fear of attending a hospital / medical appointment did not receive the care she required in a timely manner. It was discovered a few months later, that the fall resulted in an L1 lumbar fracture which required hospitalization in July 2020, and subsequent LTC placement in August 2020, due to her health conditions and the injury resulted in her being wheelchair-bound. I have found LTC restrictions very difficult. I have noticed my mother decline rapidly, due to the continued isolation, loneliness, lack of mental stimulation, lack of socialization lack of access to her religious services, lack of foot care and hair care (basic grooming is denied), and denial of visits of her spouse. My father, who resides at a retirement home requires assistance to enter the LTC home due to his disabilities, and when Ontario went into grey colour status in Mid-November 2020, he was denied access to his wife as he could not enter on his own and navigate the sanitization/elevator codes, etc. on his own. Further, our Local Health Unit, in Mid-November 2020 [name of LHU] limited LTC residents in our area to only "one" Essential Caregiver (even though the Ontario Provincial Guidelines authorize 2 Essential Caregivers per resident). In my opinion, my mother has been denied her rights to see her spouse, visit with her 2 other children and grandchildren. As the only Essential Caregiver, I am grateful that I can enter the home and provide emotional support, care and physical supports including the assistance of feeding, however, the strain of being the "only one" without an opportunity for respite has exacerbated stresses, and denied meaningful relationships for my mother with her spouse and other 2 children and grandchildren. In essence, she is a prisoner within her LTC home. As my mother said to me "I know what it is like to be captured. There are a lot of rules and because I am captured I have to listen". While my mother has dementia, she is very aware, of her circumstances, and the absence of meaningful family interactions has advanced her dementia far quicker than it would have if she had been allowed visits and social interactions.

As a family member who advocates for their loved one, I was given a letter by [name of home], stating that my behavior was disruptive to the running of the facility. I had to employ a lawyer to respond to the allegations.

I was extremely involved in my mom’s care so I didn’t need to have her behaviour explained to me. I sometimes had trouble getting staff to understand her behaviour though. Mostly it was because they were so rushed and were not allocated sufficient time to care for residents

Really no level of communication between the facility and the outside world no newsletter no posted activities it's just horrible run around with heads cut off too many bosses no directions yikes maybe being stuck in their rooms isolated has keep se form of organization and healthy observation

In my experiences with providing care for my family member, the staff (and really the way the whole system is designed, including the physical structure itself) does not always facilitate or make it comfortable or convenient for family caregivers to provide the level of involvement and care that we really want to do. My vision of a truly welcoming LTC home doesn't exist in the community in which I live, and sadly, in most communities that I am familiar with. The facility hasn't upgraded at all to accommodate space and electrical outlets for technology such as cell phones and laptops and even TV's. (in semi-private rooms) If you are a resident on the lower income scale, it is a struggle to pay for services and necessary equipment that the care home does not provide. If you withhold some funds to pay for any of these services or items, they are breathing down your neck. Even if the services are medically necessary. In For Profit LTC, they come first. As well, I noticed some of their rules and policies are designed to protect themselves from litigation and have nothing to do with the well-being of the resident. They do nothing to advocate on behalf of the resident. Even the social worker is sub-contracted out and works only 2 days of the week. In the 2 years, my LO has been in LTC, he has been in 3 different rooms. They do not do any work ahead of time to determine if the other resident is going to be a good match. If the bed is vacant, that is all that is considered. Even when they are aware of, and have knowledge of issues with a potential roommate for your loved one. It's incredibly stressful to feel as though you must watch literally everything they do. In the second room, the maintenance staff told my LO on the first night, to move back to the room he came from. Because, even they, the cleaning staff, knew it would not be a good fit for him. During Covid, they will call you (the POA/Caregiver) and the resident, in person into a small room to discuss arrears and lecture, yes lecture, a 78 year old man with dementia on how to live within his means. However, when it comes to a care conference, it is arranged by phone, and only the director of programs and services attended. (That just happened recently) To conclude my feedback, I must say, it is incredibly stressful and exhausting, to feel as though I must watch literally everything related to the care of my LO, due to a lack of trust in the way the whole system is designed. Of course, that feeling has increased dramatically during the pandemic. Thank you for giving me the opportunity to provide this feedback.

Mom was in an LTC for 5 months and died due to neglect. LTC staff had absolutely no dementia training whatsoever despite being the largest LTC in Canada. Pathetic. Government needs to provide support so people can stay home. LTCs are no place for people with dementia and complex medical needs. The subsidy the government pays to LTCs should be made available so people can stay home and hire help or pay family members to stay home and care for them. Mom would be alive today if I could have kept her home.

I visit my Nephew 2 or 3 times every week. The care place never calls me about any thing about my nephew.

I have to commend the staff, doctor, DOC, ADOC and administrators in their role with my parent's care. They were always professional and kind. As the POA, I always worked in cooperation with them keeping the lines of communication open at all times. I am of the belief that we are a team and we must work together in the care of the residents and this is what creates positive, respectful, working relationships.
I had family members who were creating negative and destructive relationships with all the staff, causing major conflict with all of their visits in LTC and in which police had to be involved. One of my family members was put on restrictive visits due to the confrontational manner that he displayed. This ongoing conflict that family members caused put a lot of strain on the LTC staff and me, as POA. Staff, at times, felt uncomfortable in providing care as a result due to other family interference as they were anti-LTC.
I supported the LTC staff and they supported me, and we had to communicate almost daily and always weekly in attempting to manage this behaviour from my other family members. I had to have lawyers involved to support me as POA. The administrators continued to provide ongoing support for both of my parents.
Families are important, however, families should not have the right to be abusive to staff and I do believe that the LTC homes should have the right to put measures in place for the public who are confrontational and who show destructive behaviours towards staff in the workplace as this affects their work. The media, and social media, sadly, perpetuates a lot of negativity about LTC and the care they provide to residents.
Families should learn to work cooperatively with the LTC homes and be ready to be supportive of staff as they are trying their best. And, if there are issues there are ways to communicate effectively to resolve the issues. Families should be ready to provide assistance if needed.
On a personal note, as a principal of a school, I always appreciated the support of families and as partners it was part of their duty to support their child and provide hands on support also.
Thank you for the survey.

My mother had 3 daughters and 1 son. Only my youngest sister lived in Ottawa. She had POA of care and finance. She arranged for her step-daughter to take charge if my mother died since she lived in Gatineau. Fortunately, my mother died while my sister was in Ottawa. My sister visited my mother at least every 2nd day and fed her a meal then. Otherwise, the staff fed her her meals except when I and my husband were there once a week. My sister also hired a sitter 2 or 3 times a week for an hour for my mother during week days. Because my mother was an Overseas WW2 vet she paid only $1,000 a month for her LTC so she could afford the sitter and pay us gas money for coming up from Kingston weekly. My other sister and brother visited sporadically. But what about other people on my mother's floor? Some only had a visitor once a week if that! There just wasn't enough staff to talk to residents or communicate with residents or feed residents. Also, my sister and I helped other residents at times with feeding and with getting staff to assist them. You don't mention what help we may have provided to residents other than my mother. We also brought our Shiba Inu (a Japanese canine breed) up with us. Some of the residents really delighted in seeing him. Another woman saw her husband a lot and also helped entertain other residents. The sitters would sometimes help with other residents as well. Frankly, if my mother hadn't had us visiting (visiting? we worked like dogs!) , she would have acted out and had to be medicated because she was so disabled or she would have shut down and had a much worse time of it than she did. All LTCs need more staff and more positive staff involvement.

The last two years have been a whirlwind of hospital stays, independent living, retirement residence, LTC, rehab and respite care. Your survey presumes a degree of stability which was not the case.

Ma seule plainte lors du décès de ma mère est la difficulté que moi et ma famille ont eu pour soins palliatifs. Cela a pris une semaine avant que le foyer la déclare palliative bien qu’elle l’était depuis un peu plus qu’une semaine. Par le temps que ce processus fut complété ma mère n’à vécu que des heures. Donc elle est restée dans sa chambre avec sa colocataire et seules 2 des 6 enfants ont pu être présents.
(My only complaint about my mother's death was the difficulty I and my family had with palliative care. It took a week before the home declared her palliative although she had been palliative for just over a week. By the time this process was completed my mother lived only hours. So she stayed in her room with her roommate and only 2 of the 6 children were able to be present.)

With appropriate training, family members/care partners are in a unique position to assist in LTC, taking some of the burden off staff. My experience was that my involvement was sometimes viewed as unwelcome, and it was often a struggle to engage fruitfully with staff. Partly that was because staff were too overburdened to engage in a constructive manner.
I witnessed substandard medical services provided to the residents in our LTC facility, care that would be deemed unacceptable in any other health care setting. It was a constant struggle to communicate with the medical team and their lack of involvement led (and still leads) to unnecessary suffering and trips to ER that could have been avoided if residents were properly monitored.

Quoique je reconnais les efforts et l'expertise des membres du personnel, les soins disponibles n'étaient pas suffisants pour assurer la qualité de vie des résidants à besoins élevés. Lorsque ma mère est entrée en SLD, il n'était pas nécessaire pour moi d'y être chaque jour mais, à mesure que sa condition se détériorait, il devenait évident qu'il nous fallait quelqu'un sur les lieux pour assurer son bien-être. Entre autres, elle aurait perdu sa mobilité, sa capacité de se nourrir convenablement, sa continence, sa capacité de communiquer avec le personnel si nous n'avions pas été là pour en prendre soin. Il fallait constamment répéter pour que les soins prévus dans son plan de soins soient prodigués, surtout lorsqu'il y avait du personnel à temps partiel ou remplaçant. Pendant les repas, j'ai observé combien facile il était pour le personnel d'oublier de donner le repas à un résident, d'offrir un repas avec une texture inappropriée, de retirer une assiette avant que le résident ait la chance de dire qu'il n'avait pas fini. Un résident qui a la capacité de communiquer avec des mots peut se protéger contre ce genre d'oubli, mais celui qui est aphasique doit avoir un interprète. Lorsque le foyer a fermé ses portes aux visiteurs il y a maintenant plus d'un an, j'ai amené ma mère avec moi pour habiter avec ma famille afin d'assurer qu'elle ait tous les soins dont elle a besoin.
(While I recognize the efforts and expertise of staff members, the care available was not sufficient to ensure the quality of life of high-need residents. When my mother entered LTC, it was not necessary for me to be there every day but, as her condition deteriorated, it became clear that we needed someone there to take care of her. -to be. Among other things, she would have lost her mobility, her ability to eat properly, her continence, her ability to communicate with staff if we had not been there to take care of her. Constant rehearsal was required to ensure the care provided for in his care plan was provided, especially when there were part-time or replacement staff. During meals, I observed how easy it was for the staff to forget to give the meal to a resident, to offer a meal with an inappropriate texture, to remove a plate before the resident had a chance to say that it was 'he hadn't finished. A resident who has the ability to communicate with words can protect himself from this kind of forgetfulness, but one who is aphasic must have an interpreter. When the home closed its doors to visitors over a year ago, I brought my mother with me to live with my family to ensure she had all the care she needed.)

Please start thinking about how to reopen LTC homes to family members other than the designated essential care givers. My mother has only had one 15 minute visit in the last 13 months and my sister who is POA cannot go there.

It was extremely important to me that my wife receive 24hr a day 7 days a week exceptional care. However I could never trust ALL the staff to provide the same level of care that each was trained and hired to give. i.e. Some staff had excellent work ethic, they truly cared about the wellbeing and comfort of the resident and would do anything and everything to provide exemplary care. They would get to know the resident's personal history, likes & dislikes, emotional & physical needs, medical issues (physical pain, emotional pain), family relationships, look at photos, sit and talk, answer the call bell as soon as possible, give gentle kind compassionate care when bathing, dressing, transporting, toileting etc. BUT, there were far too many other staff who worked only for a pay cheque, did minimal amount of work necessary to just get the job done and with no emotional support, personal involvement or extra time towards the resident. i.e. rush to get the resident toileted, washed & dressed in the morning to be in the dining room for breakfast (taking all of 10 minutes); rushed to do same tasks at nighttime for bed so the staff member could take a break (thus leaving resident uncomfortable in bed or in pain), rush the residents to eat their meals so staff could take his/her break; ignore call bells thinking it wasn't important ("oh that person always rings bell for nothing") thus leaving resident to soil their brief and be left sitting in personal waste matter embarassed and crying from shame), not listening or giving resident who has trouble speaking, time to try and speak when there is a problem, (causing frustration for resident and crying). Many many things that would upset my wife because she had come to expect that ALL staff would treat her the as well as and as compassionately, gently, kindly and with great care as the GOOD staff were treating her. There should be NO exception to the treatment or level of care. I and my daughters would countlessly receive calls from my wife early morning or late evening or anytime if none of us could be with her, crying over an uncaring, rushed and cold hearted rude, rough staff member. Staff would cover things up, make excuses. We also were often made to feel like we were intruding or bothering staff if we called to ask questions on the phone or stopped to ask them something in the hallways. We were often left out of the loop if changes were made to my wifes medicines or health care.

They say they never run short but I see it .
I worry about foot care, basic hygiene care hence why I do it after dinner so I know it’s done !

The involvement of caregivers is vital. The wonderful staff RNs, RPNs and PSWs can only do so much. Providing hands on care can be so meaningful, a rewarding way to visit and help for staff.
It has been difficult to be involved in Family Council meetings as they occur at 2:00 in the afternoon 1 x per month. I work full-time in health care and do not have the flexibility to join in. I would really like to see the facility priorize opportunities for family member input and advocacy. The family council meetings are a place to discuss items of common interest. Not being able to participate means relying on newsletters.

My father had physical disabilities, had a hard time getting around. He was bariatric but they didn't have a suitable bathroom setup for him, i.e. rails around toilet, raised seat, narrow doorway his wheelchair couldn't go through, inaccesseible sink. He couldn't enter the bathroom in his w/c but could with his walker, however, he shared a bathroom and they couldn't place equipment in without it being too crowded and unsuitable for other person. So, he would get up with his walker, walk into the bathroom, but not have a place to sit for bm or at sink to wash hands. I would help him , stand beside him in bathroom hand him items like tootbrush etc and have w/c ready at the bathroom doorway for him to sit down on in case he started to weaken. With an accessible set up I coud have helped more effectively and my father would have had some dignity and independence in self care.

Family members want to be a part of the "care team" and to be fully involved in every level of care. It is extremely distressing to feel like a "visitor" to my mother's home and to lose all control of decision making and personal care of our mother. We have felt like we were causing problems or imposing on staff whenever we asked questions or tried to offer input.

Extremely important as it makes my mother still feel somewhat in control of her life. She depends on each member of her family for certain stimulants. Loneliness is terrible and the months we could only communicate on the phone or facetime took a toll

Questions 60 onward are difficult to understand. For example, 79: I feel comfortable phoning staff members... I don't feel comfortable because they don't answer (too busy so I understand) and they don't return calls... of course it would be very important to me but I don't feel comfortable so I don't understand how I am supposed to answer. It's a strangely worded survey. Thank you for the effort anyway. Everyone I know who has a loved one in that establishment wants assisted suicide rather than being moved there in case of dementia. That is how bad our system is. People walking around with dirty diapers... staff not knowing what a patient's routine is... I could go on. I don't blame the staff. They do ask for a history of the patient but with a ratio of too many patients, how are they to spend time with them? They barely have enough time to do the necessary care. I could write a horor story about seniors' residences. Three times, I have arrived for my visit to find discarded soiled diapers (not my loved one's) on the floor in her room. I have found faecies on her bedroom floor or bathroom floor, in her closet... Her clothes disappear. Her winter boots disappeared and were lost for the whole winter. I had to buy a new pair. He photo album has vanished, never to be found... One staff member gives me one instruction, another gives me a different one... anyway, you can sense my frustration, I am sure.

I had to fight for every medical procedure for my mother. My mother had stage 3 bedsores and I was not even informed about this until I commented on the smell in her room. My mother also put on 25 lbs once she was in a wheelchair with her stomach bloated and I had to fight to get her an ultrasound so as much as these questions ask what was important to me they all were but the care in this private long term residence was so below any kind of standards it was appalling

I would just like to say that the level of care and the safety of my parent at the facility has given me great comfort and ease of mind.
The staff are awesome, they genuinely show that they care and are willing to share info with me about my parent.
Overall awesome job folks!
Thank You

Often a concern about medical care was brought forward and not followed up on. I had to stand over a nurse or a director of care to get them to attend to it. Eg. My mother nearly died from anal suppositories. It caused extreme diarrhea. This happened 3 times. I had to stand over the assistant director of care to see she posted an allergy alert on my mother’s care plan and I pushed to have a sign posted over the head of her bed. They didn’t want the sign up. They said it contradicted privacy issues. I said my mother’s life is more important than your damn concerns for privacy. It got put up. Changing of wound bandages was sometimes not done. They would deny that the bandage hadn’t been changed. Urine samples for a bladder infection were handled improperly. A family member must advocate to get care for a resident. You can’t lay a complaint to the Ministry all the time. You have to stand over staff to see it gets done. A shame!

I am appauled that all residents not just for my mother that they are only entitled to 7$ a day in food, this includes breakfast lunch and dinner plus snacks. I never hear fresh fruit or vegetables, my mother is a brittle diabetic and the amount of sugary foods is disgusting,and not good for her overall health and well being. I hear fish nuggets, french fries, hot dogs, puddings pies dough nuts cakes powdered orange juice it's heart wrenching,her sugars range from 2.5- mid to high 20s!!! I am concerned and worried have spoke with so many people in management it's crazy and the cycle continues. Where is the quality of life when their are no choices but to place your most precious loved one? We live in a bountiful farm community that these fragile elderly loved ones have no access to wounce they are placed! I strongly feel it's about profit, not the well being the residents deserve.

Frequent Staff turn-over, difficult to get to know, or PSW to know or familiarize themselves with resident and vis a vis. Staff rush to provide care, lack of attention how resident is left, ie. half dressed, disheveled, slouching in wheelchair. Mom was admitted in March 2016 and passed on Dec. 19, 2020. My sister and I and 2 Private PSW's provided daily care of 4 + hrs so Mom did not suffer from isolation, neglect, lack of being outdoors, participation in activities, being changed when needed, being fed a warm meal, making sure baths were given and hair clean, we always brushed her teeth, PSW had no time to provide oral care. 3PSW for 33 residents, at least 25 of whom in wheelchairs requiring 2 PSW for care. Management frowned on having issues brought to their attention, threatened with Trespassing law. Management from home office participated in meetings, answer always that they are within Ministry guidelines? Above preCOVID, During COVID situation HORRIFIC, residents confined to 8 X 8 room 24/7, many not fed or provided fluids between meals, no social interaction, left soiled, crying in pain, all of this personally observed, and MORE.

Daily family assistance is crucial in long-term care. Residents are only allowed outside with a family member. Many residents never go outside. Residents are much more likely to go on resident arranged outings if a family member can sign them up and help out.
Reliance on agency staff results in people who do not know how to care for a resident. Even full-time staff are not well trained on how to hoyer someone using a broda. How to place them in the sling. How the chair must be positioned and where to place the wheels of the hoyer so that the resident can be placed right at the back of the base of the seat so their back is fully supported.
I arrived late one Saturday morning at 10:30 to find mom still in bed, not dressed, not fed, not changed. Full-time staff didn't show for their shift and only 1 agency person was there and it takes 2 people to use the hoyer. Mom called me a few times at 6:30 at night to say she had not been given dinner so I drove over with food. I found if I called in a request in response to a phone call from my mom (she needs to be changed/she hasn't had dinner) the nurse did not ensure the request was met. I always followed up my phone call with a drive over and it turned out to always be necessary.
On every visit I would change mom's brief after lunch. Sometimes there were no soaker pads under mom and no clean ones on the floor. What does this mean? It's impossible to turn someone on their side to change them without a soaker pad to pull on. Pulling on the resident directly results in injuries and pain to them.
I had to provide zincofax or sudocrem for mom because it was the only way to ensure it would be available when needed. Initially the nurse took the cream to keep at the nursing station resulting in it not being used by the PSW's as they didn't have time to go looking for it. I had to battle for it to be left on her side table.
Lack of fluids is another issue. The home provides the minimum amount of water/juice in tiny 120 ml or 170 ml cups. Often mom was extremely thirsty. I would provide juice for mom which was labelled and kept in the tiny resident fridge. Occasionally I would notice some residents were missing their cups at lunchtime and I would ask the kitchen staff for cups of juice/water for the resident.
The home changed the food service provider (to save money I guess) resulting in ongoing issues like no bananas, no yogurt, powdered apple juice being used. Soft foods like these are often the only thing many residents can/will eat. One day there was no sugar for residents coffee/tea/cereal. Our seniors deserve much better!
An ongoing issue throughout the home was residents not being changed when a change was needed. I saw feces leaking from a resident that asked for a change for over an hour. I asked the PSW for help, another caregiver made the same request. It was ignored. Another resident removed his brief full of feces and feces was smeared all over the room, down the hall. If they had met the request when needed a massive cleanup would have been avoided. I spoke to management about these 2 incidents. Nothing changed. Staff do the minimum and if it is close to end of shift every request gets left for the next team to deal with.

the regular staff that have gotten to know him are exemplary however there are too many 'agency staff' or transient staff that just come in to do a job and don't make the time to either know him and/or me and end up doing a below par job

question 60 onwards are difficult to answer...what does "unimportant to me" or "extremely important to me" when the question is rather ambiguous. Unimportant to me...would mean I don't care...and extremely important means it is extremely important to me. On these questions, the issues are extremely important to me, but the home doesn't do them..so they would get a 1...which is "unimportant to me"...when it is the reverse. So, the home fails on all those counts...but...I can't put a 1 or a 4 due to my confusion.

More communication from staff would be of benefit to me. I know there is a lot to do and only so much time but being more aware of changes in my family member's behaviour would help me do a better job of helping to meet their needs. In these 'Covid' times perhaps more use of Zoom or similar would be appropriate.

I provide the majority of daily care, all personal and legal matters, all feeding, laundry, arrange outside medical services to attend (Footcare, massage), entertainment and social ops, decisions re her care (med changes, dietary, etc), administer all meds and topical applications, In many ways staff have deferred to me given my presence there and at times over look her care. I also assisted with other residents in dining room, distressed times where I have a good relationship with resident, personal shopping for them if required. I find there are several areas that require attention in standard operating protocols and have discussed with administrator and staff to no avail. I now d what is best for my daughter and do not bother with staff whenever possible.

There is no comparison how family members can interact now versus before COVID with their love ones and I feel it will have long term effects on both the love one and family members. I feel we need both the Federal & Provincial Governments to make Long Term Care reform a priority starting with PSWS getting the recognition they so rightly deserve starting with their wages so it will attract dedicated people to take proper care of our most vulnerable. Proper care means legislating more time to care for them and taking the for profit out of equation,

I am confused about the interpretation of this last section. I answered from the perspective of this statement reflects what I wanted to happen, not necessarily what did happen.
In terms of this section, I do not feel that the staff of the facility show or express appreciation of the care I provide(d) i.e. coverage of all PSW duties for 5-6 hours every day; thereby freeing up staff to provide more adequate care to other residents. In almost 4 years, I have provided direct care since Day 1, there has been no recognition of this assistance. Indeed, sometimes, I think it may be a mistake on my part, because staff on the relevant shifts do not get to know my husband, and really make little attempt to do so.

It’s essential!

The care of our mom during her last days was a horrific experience. Medical expertise was lacking in many critical areas. Treatment of family was poor and communication with management strained.

The facility was understaffed and the staff over worked. The staff did not really have the time to spend quality time with the residents.

The Family Council has also been a strong support for care-givers, providing information and an opportunity to talk to family members of other residents and share information and experiences

During the pandemic, the limiting of family visitors and those deemed “essential” has caused a great deal of stress and strife within the family

I am very happy were my mom is. They only thing is I hope the people that work there get good pay. Because they work hard.

Critical. Being able to be part of my mom's life is critical to her care. The more involvement, the better off she is. Its not just that she knows she loved, but that staff understand that there will be somebody there often to make sure everything is being done in their power to ensure she is safe and well. The good care givers deeply understand that LTC facilities are under funded - under staffed - require 24/7 365 care and are doing their best...but sometimes its not enough - they have 100's of folk to care for. We need to fill the gap....or the system falls apart.

The [name of home] has been a fantastic facility for my mother. The majority of the staff are very caring and compassionate.

The LTC home where my brother resides is an amazing place. They have wonderful staff who connect to residents like family. I am so happy to know he is loved and cared for and he really likes it there.

My brother is the primary care giver, he lives close by our loved one. He schedules and attends all medical appt's, visits and interacts with her frequently and is the contact person for staff. My role is much more reduced than his as I live further away and am snowbird in the winter. We are dedicated to her well being.
I am confused by the word 'support' in questions regarding religious gatherings or activities. Neither my brother or physically go to religious gatherings with her but we do 'support' her desire/need for that activity.

The staff did the best they could with the staff they had....not enough staff to provide proper care...2 psw's to put 22 ppl to bed....not good!

staff need to be held more accountable which will then improve quality of care given.

My mother went into LTC during Covid so hard to assess everything accurately but she is well taken care of, though lonely. I think it would be nice to perhaps have smaller groups of like-minded residents interact - groups cannot always offer inclusivity to all. Skill set levels & age can be so broad - those with trouble hearing or speaking might not feel comfortable participating - it can be quite boring for someone who was previously quite ‘with it’ but suffered a physical set back (ie stroke..).
It can feel quite ‘institutional’ and not as homey as perhaps it could be. Thanks!

Staff have always answered my questions and/or followed up if I found my family member confused during a visit. She opens up to me, but is quite closed to staff members which is not helpful to them. However, I do trust in their professional abilities.

I was the full time caregiver for my mom while she was in Long Term card and working full time. The staff do not know how to care for anyone with Dementia and they do not like anyone like me who works in the field interfering with what they did not provide. My mom came home with me every weekend for 3 years while in LTC until Covid.

The questions I have not answered is becasue they were NA. I have been actively involved as a volunteer in this LTC home since my mother was a resident 24 years ago. Now my husband is a resident.

my mom has not had a very good experience in LTC - the staff are so over worked and burnt out (even before the pandemic) that there is NO CARE - the residents are in very cheaply made DIAPERS NOT BRIEFS - even though they have dementia they know they are in diapers and no one seems to care about their dignity - the activities are very poor quality and I feel none of the staff are trained in dementia care - they know nothing - I saw my mom Mar 14/20 and she was missing her dentures and the staff found them under her be 8 weeks later - during a pandemic what are the cleaning staff doing - 8 weeks under her bed - no she has been without her glasses for 7 weeks now and no one care where her glasses are - WHAT KIND OF CARE ARE WE PAYING FOR - I am disgusted with the level of indifference to the care of the residents - the well paid activities staff know nothing about activitives for geriatric patients - I worked in mental health for decades and I am shocked at the lack of infection control and cleanliness in the facility - it always smells like poop - I would give anything to have my mom back home here with me - when we visited the LTC home before my mom arrived and I was sold a bill of goods - everything they said sounded great until my mom was there and everything I was told was a real stretch of the truth - with the arrival of the pandemic the situation in LTC has been horrific and they still are horrific 14 months later nothing has changed and the care is non existent - we should all be ashamed of what is happening in LTC - extendicare organization gives 171 million dollars to shareholders and takes 121 million dollars from the government to pay for pandemic costs - HOW IS THAT RIGHT!!!!!! my mom is not the same person she was 14 months ago and I blame the LTC system for it's complete failure to protect and care for our most vulnerable citizens. SHAME ON ALL OF YOU

Having been closely involved in my mother’s care & well-being in the past eight years or so while she has been living in LTCH, I KNOW how important it is to have a family member (i.e. me, her daughter) in this role. I honestly don’t know how elderly residents without family nearby manage! I continually advocate for her, provide emotional & physical support, regularly liaise with the staff & the Doctor and nurses, as required regarding her care and medical needs. I handle all her financial affairs, arrange appts with hairdresser, footcare nurse, physiotherapist etc. All these things have been made more difficult to do since March 2020. Also, I used to take her out to run errands or have a meal at a restaurant or bring her over to my house for dinner or a bbq & family celebrations/impt religious holidays (Easter, Christmas, Thanksgiving) -these occasions often attended by her other kids & grandkids who live out of town. This may not be considered “hands-on care” but it’s extremely impt for me and my mom that she remain connected with her family. Since the pandemic, we are restricted to phone calls & sometimes I do FaceTime/virtual calls so she can ‘see’ these loved ones but it has been really difficult.

Ma mère était relativement autonome dans son appartement. Je faisais ses courses, j'allais à ses rendez-vous (médecin, dentiste, coiffeur), je lui faisais livrer des repas et ses médicaments. Elle recevait des soins des pieds à la maison (infirmière) et des préposées du RLISS lui rendaient visite. Je la sortais luncher une fois par semaine. D'autres membres de ma famille (cousins, cousines) lui rendaient visite. Ma mère parlait à ses soeurs tous les jours. Maman est entrée à la résidence en octobre 2019. J'allais la visiter et luncher avec elle plusieurs fois par semaine. Une cousine l'amenait visiter une de ses soeurs aux deux semaines. Parents et amis l'ont visité. Ça, c'était avant la pandémie... J'ai laissé plusieurs questions sans réponses puisque ma mère est toujours vivante et qu'elle ne souffre pas de démence. Récemment, on l'a diagnostiquée comme souffrant de perte de mémoire modérée. Il lui est difficile de trouver le mot juste. Aussi, lorsqu'elle est moins médicamentée (elle souffre beaucoup), j'ai encore de belles conversations avec elle.
(My mother was relatively independent in her apartment. I did her shopping, I went to her appointments (doctor, dentist, hairdresser), I delivered her meals and her medicines. She received foot care at home (nurse) and was visited by LHIN workers. I took her out to lunch once a week. Other members of my family (cousins, cousins) visited him. My mother spoke to her sisters every day. Mom entered the residence in October 2019. I would visit her and have lunch with her several times a week. A cousin took her to visit one of her sisters every two weeks. Relatives and friends visited it. That was before the pandemic ... I left several questions unanswered since my mother is still alive and does not suffer from dementia. Recently she was diagnosed with moderate memory loss. It is difficult for him to find the right word. Also, when she is less medicated (she is in a lot of pain), I still have great conversations with her.)

I am more involved in my parent's care (predates LTC) than most. I spend hours researching, monitoring, advocating and working to find a balance to address the needs of the institution (schedules, rules, etc) - making the best decisions for my parent in her interest - managing biases about mental illness from doctors and nurses - and sadly watch someone screams of pain being unheeded by personnel who attribute that to dementia or mental illness. But I feel staff lack insight into behaviours that indicate a problem (eg pain which can cause agression) and staff focus on managing the behaviour as opposed to understanding the cause or trigger. There should be more questions about decision making and how the institution staff and doctors work closely together and have access to infomation, but as the substitute decision maker, I am treated as an outsider. So I am expected to make decision on treatment based on anecdotal information, not documented. I have to go through nurse, or care coordinator - to get access to doctor - no direct access. Care conferences are not focused on actual care. And (this one is a gripe) but an obgyn should not be a primary physician for a geriatric patient.

Pour moi, je vois la différence chez mon parent lorsque je la visite. Elle est plus alerte, souriante et participante lorsque je vais la visiter régulièrement.
(For me, I see the difference in my parent when I visit them. She is more alert, smiling and participating when I visit her regularly.)

I think more training is needed for staff --- I would urge trainers to clearly communicate and reinforce regularly the need to respect residents and be professional and attentive at all times. It should include assessment and monitoring of staff's approach/attitude towards residents and their understanding of what 'maintaining resdients' dignity' means -- this is an area I find quite lacking at the [name of home] in Ottawa.

La question #61 est mal posée. Je ne comprenais pas.
Je ne suis pas son POA, alors mes renseignements et les décisions viennent de sa fille qui vient rarement et qui habite à l'extérieur. Tous mes efforts pour rendre ma soeur aussi heureuse que possible sont récompensés par la réalisation qu'elle est dans un bon foyer où on travaille en équipe pour elle. Pas toujours facile mais ça vaut la peine. Merci de tenter de rendre la vie de ces gens plus heureuse.
(Question # 61 is incorrectly asked. I did not understand. I'm not his POA, so my information and decisions come from his daughter who rarely comes and lives outside. All of my efforts to make my sister as happy as possible are rewarded with the realization that she is in a good home where we work as a team for her. Not always easy but worth it. Thank you for trying to make these people's lives happier.)

I have been her advocate but it is not always welcomed

Because my mom lived with us for 10y ears as she declined, I felt I was informing the staff more than they were helping me. She was admitted when my husband became ill as a crisis placement.

Prior to the Covid pandemic, I was free to take my spouse for drives and even picnic in the local park. The restrictions brought about by Covid have brought these pleasures to an end. As a result, my spouse's health has deteriorated significantly and I visit her daily to help with emotional support. The LTCH staff have been unstinting in their provision of care and support for, not just my spouse, all residents of the Home.

My parent was in LTCH for 10 years....I learned very quickly that I had to monitor my parent daily and hire private PSWs to ensure they were cared for in the way that they deserved. Things did improve somewhat over the 10 years they were there...but not to the caliber they would have expected

My father ,my siblings and myself were involved with mom's care. We communicated regularly and solicited feedback about moms daily living, changes, and times where care could have been better. Mom was a quiet person and with a very low voice because of her Parkinson's I am not sure she would have seen the kind of care if we did not advocate. We all saw care recipients who did not have families to advocate and we observed less attention, and less care at the dinner table - food was placed before them but they hadn't touched their food, andin no time shrivelled away to learn they passed in 6 months time.

I feel like more information should be shared with all family members concerning their loved one and not just shared with the power of attorney for care. This information does not need to be intimate details but general information to help with the understanding and care of their loved one.

Family members are very important for the residents in LTC. While most of the staff are competent, some are not and really not interested in their job, but they have a job! and all have to belong to the Union which makes complaints sometimes never resolved. Also there was ( and still is) not enough PSWs who do the actual care for the Residents which leaves caregivers sometimes much to help with the caring.

Ma mère est entrée à la fin 2019 à la résidence et la pandémie est survenue en mars 2020. Mes réponses sont le reflet de quelques mois seulement à la résidence. Avant son entrée à la résidence, c'est moi qui s'occupait de tous ses rendez-vous (dentiste, médecins, coiffeuse), je faisais ses courses, j'organisais les soins avec le RLISS, etc. J'espère avoir bien saisi toutes les questions.
(My mother entered the residence at the end of 2019 and the pandemic occurred in March 2020. My answers reflect only a few months at the residence. Before entering the residence, I took care of all his appointments (dentist, doctors, hairdresser), I did his shopping, I organized care with the LHIN, etc. I hope I understood all the questions correctly.)

As a working single mother, I was not able to provide the required care for my mother; therefore had to put her in a home. Brought her up to a '1' on the waiting list as I was told it could take up to 3 months. Within 1 week we got a call and HAD to accept, otherwise, she would go to the bottom of the list. My mom suffers from Alzheimer; even though she was confused and lost, there was still some of her left in her souol. Within one month in the home - she was no longer herself. She has been a prisoner since. We have watched her deteriate over the years and if she could take her own life, she would. You MUST convince the government to allow assisted suicide even if the person is not of sound mind. Living with Alzheimer is not living, it's slowly rotting away. I would not even let my dog live through that.

My two friends were in a well managed L T C Home which I am most grateful.

le personnel (préposé) ne semble pas comprendre la démence et les approches à prendre auprès ma mère...parfois je dois éduquer le personnel...
(the staff (attendant) don't seem to understand dementia and how to approach my mother ... sometimes I have to educate the staff ...)

I think it’s very important to have family members involved, for both the family and the resident in LTC. I’m very fortunate to come from a close family who is happy to share the visiting with our mother.

I visit my mother twice a day: at lunch for a couple of hours to assist with feeding (my mother is not capable of feeding herself) and dinner, to assist in feeding and bathing, putting her to bed, etc. Since September, 2020, when we caregivers were permitted back into the residence to care to our loved ones, I have noticed a significant decline in the level of care/involvement by staff with regards to residents. Despite the increased assistance provided to the general complement of daily staff during the Covid pandemic, an "air" of complacency/lassitude is quite prevalent among staff. I would be pleased to discuss my "views" with interviewers.

I would sometimes receive calls from the nurses regarding my mothers physical health such as suggestions regarding medications and pain management. As to her mental and emotional health there did not appear to be any care plan specific to her. No effort was made to seat my mother with other residents who were mentally competent and could carry on a conversation with her at meal times. Therefore her only meaningful conversations would be with staff or family.
We found it very important to advocate on her behalf, whether it was to restrict a specific staff member from attending to her (too rough), to request testing for a uti, to ask for measures to control the temperature in her room (often 27C), and the temperature in the bathing room (too cold), to request medication for panic attacks, etc. The PSWs do not have time to sit and talk with residents - they are always on the run. It often takes too long for a call bell to be answered and all too often the call bell would not be left within the residents reach.
The volunteers were wonderful and would sometimes pop in to say hello. The program managers would do a great job of arranging entertainment such as bingo and music. Our mother would usually rely on one of her family members to get take her.
I would say in general that physical needs are well met. Its daily companionship, conversation and warmth that is lacking. The only interaction with psws is to attend to physical needs - very task oriented and hurried. Its not an easy job. They are overworked and underpaid! I hate to think what my mothers life would be like if she did not have family visiting and advocating for her.

A mon avis le personnel administatif devrait communiquer plus souvent avec les familles au sujet des activités, des menus, avoir des rencontres familles/résidents.
Je trouve que la rencontre annuelle multidisciplinaire afin de discuter du plan de soins et qui prend environ 15 minutes pourrait être plus dynamique.
(In my opinion, administrative staff should communicate more often with families about activities, menus, and having family / resident meetings.
I find that the annual multidisciplinary meeting to discuss the care plan and which takes about 15 minutes could be more dynamic.)

Mes visites régulières à ma mère lui permettent de savoir ce qui se passe à l'extérieur de la résidence (famille élargie, actualité, pandémie, température etc.). Quand ces visites ont été arrêtées au début de la pandémie, elle dépérissait et était déprimée. Elle a besoin de se sentir aimée et soutenue.
(My regular visits to my mother allow her to know what is going on outside the residence (extended family, news, pandemic, temperature etc.). When these visits were stopped at the onset of the pandemic, she was wasting away and depressed. She needs to feel loved and supported.)

When I see 'Staff' I think of those who are providing direct care and yes they are doing a good job. However, the 'Administrators' are putting up roadblocks and in some cases 'gag orders' to withhold information. These Administrators are invisible and not accessible and yet they have power to make policies that are designed as a one-size-fits-all approach. The age groups range from 19 to 100 years old and yet everyone is being treated to quote the [name of home]'s Administrator in 2005 "Now that you are in the sunset years of your life" is evidence that Resident's and the Caregivers should comply by their policies without question. As you can read by my tone, I am not your typical easily intimidated caregiver. I cut my caregiver teeth at [name of home]. The Administrators and Unit Managers were not empathetic and in some cases they created a 'toxic environment' for their employees, residents and caregivers. When my spouse was transferred to [name of new home] it was a beautiful yet short lived experience. To this day, when care has not been provided as I would like at my husbands current LTC, I simply remember the time at [name of first home] and I use that as my benchmark for poor care. I have 16 years of experience as my husband's designated caregiver he was 48 and I was 46 years old. I have a story to tell and I have the journals to support that. I sincerely hope this survey is taken seriously and should also provide more qualitative questions versus quantitative. Maybe you will undertake that as a next step. Its a hope that the information gathered will spearhead real change in LTC.

The presence of the family caregiver is very important, especially when the resident cannot look after herself, cannot make decisions, or is not capable of initiating actions. Also when language barriers exist, the caregiver role is very important. Unfortunately our LTC homes in Ontario are not provided with adequate staffing, so the staff members can only provide the very basic care for the residents. That is why the presence of the caregiver is essential to the overall well being of the resident.

[name of home] is very inclusive of family. Our loved one (my mother) lives in LTC due to her lack of mobility, not her cognition or ability to communicate. She is our messenger for a lot of happenings. She uses the phone on her own and is able to communicate to the staff. We are fortunate she can still do that - it's very helpful for her care.

I am very happy with the level of care at [name of home]. The staff has always been very supportive and have been particularly careful during the pandemic. We have not had a single case of Covid-19 at [name of home].

It is important to be able to provide company and support for the residents. This includes: technology support to allow for 'family visits', providing a familiar face and a hug from home, picking up odds and ends that a resident needs, hooking up telephones and doing other small tasks to make the resident feel comfortable and at home.

Hands on care not important as she can look after herself except for bathroom

[name of home] is providing excellent care. Everyone seems like they are doing their best.

Same as before. I would love to have more of a role in the decision making. As it stands I am DCP but if something happened in her care ex. Her dying I wouldn’t get that call to be with her. I have no rights as I don’t have power of attorney. I am good enough to be her care giver at this time but not other than that. Her son is my husband and is also DCP but is in the same position as I am. Out in the cold so to speak. Hurtful.

Question 43 est incompréhensible. Certaines questions ne donnent pas l'option S/O.
(Question 43 is incomprehensible. Some questions do not give the N / A option.)

All the staff are kind caring and efficient in all facets of duties and responsibilities. I am so happy they were accepted at people care

While you are looking for this "going forward" during COVID it has been the lifeline for many within LTC to have someone come and visit -- it has been very lonely.

Staff/management are happy to have care partners/family come in and assist with staff-designated care items (feeding, physio, cleaning/organizing room) yet do not take the feedback/input from resident and family member regarding service and care plan seriously. Have made many complaints and input regarding physio regime etc based on personal health history and goals yet they are mostly ignored and we are told the residence lacks staff and resources to provide what we would like. Always comes down to the SLR residence not having enough and we are just supposed to deal with it.

[name of home] schedules one resident Care Conference a year. This is far too infrequent. I have attended care conferences both in person, and on the phone. I would suggest Zoom 'in-person' care conferences every 2 months, or as needed, would be most valuable.

Involving the family as knowledgeable team members is important. [name of home] taff treat patients and families with warmth and respect.

I feel it is so important for family to be well involved with their loved one and the LTC home. I need to make sure my mom is well looked after and I know the care she is getting. My mom could not say sentences to me but when I came into her room she would become more animated, vocal, and smiling and laughing. It made my day! The home provides her with more interactions with people than I could give her when she lived with me.