

**Regional Long Term Care  
Family Experience  
July 2015 to February 2016**



**Western  
Health**

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# **Long Term Care Family Experience**

## **Background**

### **Survey Instrument**

The validated long term care family experience survey that was administered to family of long term care residents throughout the Western region was the Consumer Assessment of Healthcare Providers and Systems (CAHPS) Nursing Home Survey: Family Member Instrument (Appendix A) developed by Alberta Health Services in Canada. The survey was administered electronically through Google Forms.

### **Method**

Long term care facilities generated a list of email addresses of resident family members and emailed the survey link. Other facilities had students or a nurse on ease-back administer the survey over the telephone and entered the information directly into Google Docs.

### **Sample**

All resident family members were given the opportunity to complete the survey. Across the Western Health region, 165 participants completed the survey.

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

Privacy and confidentiality were achieved as the survey was completed anonymously and electronically through Google Docs. Any information that could potentially identify the family members was deleted. The data was stored on a password protected computer in the Western Memorial Health Clinic used by Information and Quality staff.

## **Data Analysis**

Survey data was entered directly into Google Docs and the information transferred to a data sheet which was then analyzed using Statistical Package for Social Sciences (SPSS). Descriptive statistics were calculated on regional and site specific data to obtain a general perspective of family or next of kin experiences with long term care services at Western Health. All comments were grouped based on common themes and included in this report as well as listed in Appendix B. The following report provides survey results for the entire Western Health region.

## Results

### Demographics

A total of 165 participants completed the survey. To gain a more thorough understanding of the demographics of the family or next of kin being surveyed and their loved ones living in long term care, respondents were asked several questions; relation to the resident, if the resident was discharged from the facility or had died, how long the resident lived there, and if they expected the family member to live in a long term care home permanently. When asked the relationship to the resident, 24.2% reported that the resident was their spouse or partner, 55.8% reported their parent, 3.0% reported their aunt or uncle, 11.5% reported their sibling, 3.6% reported their child, 0.6% reported their friend, 0.6% reported other and 0.6% did not report. Although efforts were taken to reduce the potential that a family member or next of kin received a survey after the resident had died, three respondents indicated that the resident had died. Just over 70.9% of respondents indicated that the resident lived in long term care for 12 months or longer, 9.7% reported 6 months to almost 12 months, 6.1% reported 3 months to almost 6 months, 7.9% reported 1 month to almost 3 months, 3.6% reported less the one month, and 1.8% did not report. Nearly 89% reported that they expected the resident to live in a long term care home permanently.

Respondents were asked about how many times they visited the resident in the past 6 months. Nearly 71% reported more than 20 times, 8.5% reported 11-20 times, 6.7% reported 6-10 times, 7.9% reported 2-5 times, 3.6% reported 0-1 times, and 2.4% did not report. Respondents were also asked to indicate whether they were the people who had the most experience with the residents' care and 87.9% reported yes, 8.5% reported no, 1.8% did not know, and 1.8% did not respond.

Other questions were asked about finances, power of attorney, and substitute decision maker (See Table 1). The majority of respondents had power of attorney and were the resident's substitute decision maker. They were also asked gender, education, and ethnic background. Nearly 32% of respondents were male, 66.7% female, and 1.8%

did not respond. Nearly 27% had completed grade school or some high school, 32.7% completed high school, 10.9% completed post-secondary technical school, 7.9% completed some university or college, 14.6% reported that they completed a college or university degree, 1.8% had a post graduate degree, and 6.1% did not report. Ninety point three percent of respondents were white/Caucasian, 6.7% were aboriginal, 0.6% indicated other, and 2.4% did not report.

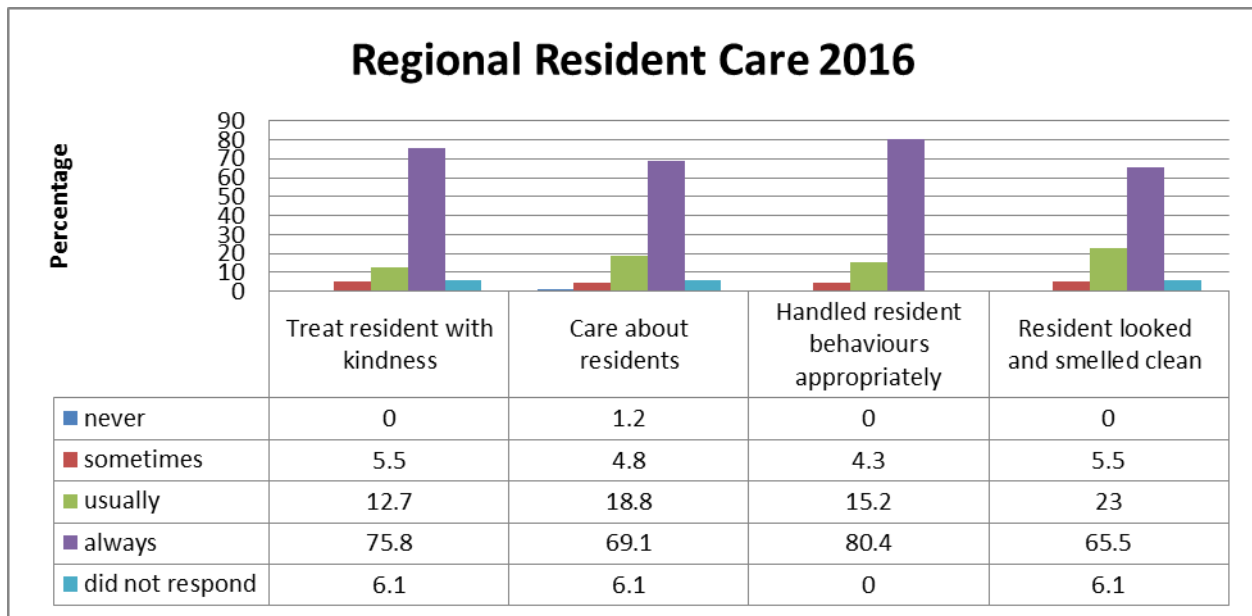
**Table 1. Respondent Information**

Question	Yes (%)	No (%)	Don't know (%)	Did not respond (%)
In the last 6 months, did you help your family with managing finances, such as paying bills or filling out insurance claims?	66.7	30.9	0.0	0.0
Do you have power of attorney for your family member?	61.8	33.3	3.0	1.8
Are you your family member's substitute decision maker (next of kin)?	89.1	7.3	1.8	1.8

**Resident Care**

Several questions were asked about nursing care in terms of the respondents' experiences over the past six months (See Figure 1). Of those who reported that they had tried to find a nurse, licensed practical nurse (LPN) or personal care attendant (PCA), 86.6% reported they could usually or always find one when they wanted one. Nearly 89% reported that they had always or usually seen the nursing staff treat the resident with kindness. Just over 87% reported that they usually or always felt that the nursing staff cared about the resident. Respondents were asked if in the last 6 months, they saw any resident behave in a way that made it hard for nurses or aides to provide care such as yelling, pushing, or hitting. Nearly 28% reported yes and of those, 95.7% reported that the nurses and aides always or usually handled this situation in a way that they felt was appropriate. When asked if they had ever seen any nursing staff be rude to their loved one or any other resident, 85.5% reported no, 8.5% reported yes, and 6.1% did not respond. Respondents were asked how often the resident looked and smelled clean in the last 6 months and 88.5% reported usually or always.

Figure 1. Resident Care



Respondents were asked questions about whether they helped residents with certain aspects of their care over the past six months and if this was because the staff either did not help or made the resident wait too long. When asked if they had helped the resident with eating, 40.0% reported yes. Of those who reported yes, 9.1% reported that it was because the nursing staff either did not help or made them wait too long. When asked if they helped the resident with drinking, nearly 39% reported yes and 7.9% reported that they helped because the nursing staff did not help or made the resident wait too long. Respondents were also asked if they helped the resident with toileting and 16.4% reported yes. Just over 14% reported that they helped the resident with toileting because the nursing staff did not help or made the resident wait too long. Respondents were also asked if they helped with the care of the resident when they visited and 61.2% reported yes, while 5.5% reported that they felt the long term care home staff expected them to help. Nearly 92.7% of respondents reported that the nursing staff always or usually treated them with courtesy and respect.

**Obtaining Information**

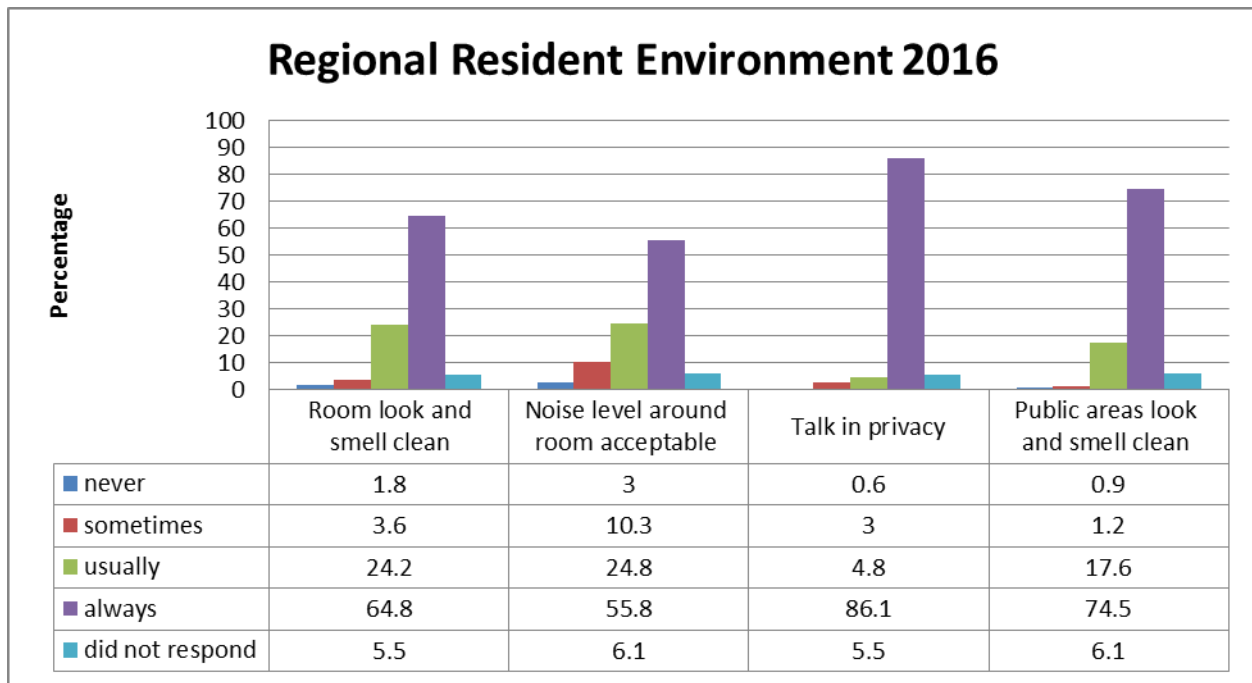
Questions about obtaining information were asked in relation to the last 6 months. Nearly 74% of respondents

reported that they wanted to get information about their family member from nursing staff and 86.9% reported they always or usually got the information as soon as they wanted. Nearly 91% reported that the nursing staff explained things in a way that was easy for them to understand and 92.1% reported that nursing staff did not ever try to discourage them from asking questions about their family member. Respondents were asked if they had asked the long term care home staff for information about payments or expenses and 20.0% reported yes. Of those asking for this information, 93.9% reported that they always or usually got all the information they wanted.

### **Environment**

Respondents were asked to report on various aspects of the environment based on the last 6 months (See Figure 2). When respondents were asked how often the residents' room looked and smelled clean, 89% report usually or always and 92.1% reported that the public areas looked and smelled clean. Nearly 80.6% reported that the noise level around the residents' room was acceptable to them. Privacy is also an important aspect of long term care. When respondents were asked how often they were able to find places to talk to the resident in private, 90.9% reported usually or always. Respondents were also asked if they had ever seen the nursing staff fail to protect any residents' privacy while the resident was dressing, showering, bathing, or in a public area and 92.1% reported no.

Figure 2. Environment



### **Residents' Personal Belongings**

Questions were asked related to personal belongings over the last 6 months. When asked how often residents' personal medical belongings (e.g., dentures, hearing aids, eye glasses) were damaged or lost, 60.6% reported never, 18.8% reported once, 13.9% reported two or more times, and 6.7% did not report. When asked how often the residents' clothes were damaged or lost, 52.8% reported never, 46.5% reported once or twice, and 0.7% did not indicate.

### **Communication**

Respondents were asked several questions about overall care in the long term care facility in the last 6 months. When respondents were asked if they were ever unhappy with the care the resident received, 11.5% reported yes, 82.4% reported no, and 6.1% did not report. Of those who reported having concerns, 89.5% reported that they spoke to long term care home staff about this concern and 47.3% were usually or always satisfied with the way the staff handled these problems, and 42.1% were sometimes or never satisfied. Of those who reported having



concerns over the last 6 months, 47.3% reported that they stopped themselves from talking to any long term care home staff about their concerns because they thought staff would take it out on the resident.

### **Care Conferences and Involvement in Care**

Nearly 81.2% of respondents reported being involved in decisions about the residents' care over the last 6 months and 80.0% reported being usually or always involved as much as they wanted to be. When respondents were asked about whether they have been part of a care conference, either in person or by telephone, over the last 12 months, 62.4% reported yes. Respondents were asked to report whether they had an opportunity to be a part of a care conference and 44.2% reported yes, 17.6% reported no, and 38.2% did not report.

### **Overall Care**

When respondents were asked to rate the care on a scale of 0 to 10, with 0 being the worst care possible and 10 being the best care possible, the average was 8.63, the median was 9.0 and the ratings ranged from 0 to 10.

Nearly 75% said they would definitely recommend the long term care home to someone needing long term care, 17.0% said probably yes, 1.8% said probably no, 1.2% said definitely no, and 5.5% did not report. Just over 52% of respondents indicated that there were usually or always enough nursing staff in the long term care home, 41.9% reported sometimes or never, and 6.1% did not report. Many comments indicated the respondents felt there was not enough staff or staff was over worked.

### **Other**

The survey did not include questions about activities, however, respondents frequently commented on activities. Family members reported that there should be more recreational opportunities for the residents.

## Opportunities for Improvement

Overall results indicate that Western Health's long term care services have many strengths including availability and kindness of nurses and their ability to handle difficult situations appropriately. Respondents also reported being satisfied with the overall care of their family member, including their treatment by staff. Other strengths include cleanliness of the physical environment, noise level, privacy, and sharing of information with next of kin/family.

Regionally, opportunities for improvement include:

- Explore ways to decrease the loss of or damage to residents' personal medical belongings (e.g., dentures, hearing aids, eye glasses) and clothing;
- Explore more effective problem solving strategies when issues arise;
- Explore opportunities to improve families' perceptions of their involvement in care through such means as care conferences;
- Explore opportunities to increase recreation activities for the residents; and
- Explore opportunities to address respondents concerns over short staffing or staff being over worked.

## **Appendix A**

### **CAHPS Nursing Home Survey: Family Member Instrument**

## THE RESIDENT

### 1. Relationship to the resident named in the cover letter?

- My Spouse/ Partner
- My Parent
- My Mother-in-law/ Father-in-law
- My Grandparent
- My Aunt/ Uncle
- My Sister/ Brother
- My Child
- My Friend
- Other (please print.)\_\_\_\_\_

### 2. For this survey, the phrase “family member” refers to the resident (person) named in the cover letter. Is your family member now living in the nursing home listed in the cover letter?

- Yes – If Yes, Go to Question 4
- No

### 3. Was your family member discharged from this facility or did he or she die?

- Discharged** – if you checked discharged, please stop completing this survey and return it in the postage paid envelope provided.
- Deceased** - If you family member is deceased; we understand that you may not want to fill out a survey at this time. If this is the case, please check the box indicating that your family member is deceased and return the survey in the enclosed envelope.

**If you would like to do the rest of the survey we would be very grateful for your feedback. Please answer the questions about your family member’s last six months at the nursing home. Thank you for your help.**

### 4. In total about how long has your family member lived in this nursing home?

- Less than 1 month
- 1 month to almost 3 months
- 3 months to almost 6 months
- 6 months to almost 12 months
- 12 months or longer

### 5. Do you expect your family member to live in this or any other nursing home permanently?

- Yes
- No
- Don’t Know

### 6. In the last 6 months. Has your family member ever shared a room with another person at this nursing home?

- Yes
- No

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

- Yes
- No

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

- Never
- Sometimes
- Usually
- Always

### 9. In the last 6 months, about how many times did you visit your family member in the nursing home?

- 0-1 time in last 6 months – Go to Question 53
- 2-5 times in the last 6 months
- 6-10 times in the last 6 months
- 11-20 times in the last 6 months
- More than 20 times in the last 6 months.

### 10. In the last 6 months, during any of your visits, did you try to find a nurse, licensed practical nurse or personal care attendant for any reason?

- Yes
- No – If no, Go to Question 12

11. In the last 6 months, how often were you able to find a nurse, licensed practical nurse or personal care attendant when you wanted one?
- Never
  - Sometimes
  - Usually
  - Always
12. In the last 6 months, how often did you see the nurses, licensed practical nurses or personal care attendants treat your family member with kindness?
- Never
  - Sometimes
  - Usually
  - Always
13. In the last 6 months, how often did you see the nurses, licensed practical nurses or personal care attendants treat your family member with kindness?
- Never
  - Sometimes
  - Usually
  - Always
14. In the last 6 months, how often did you feel that the nurses, licensed practical nurses or personal care attendants really cared about your family member?
- Never
  - Sometimes
  - Usually
  - Always
15. In the last 6 months, did you ever see any nurses, licensed practical nurses or personal care attendants be rude to your family member or any other resident?
- Yes
  - No
16. In the last 6 months, during any of your visits, did you help your family member with eating?
- Yes
  - No – If No, Go to Question 18
17. If you answered yes, was it because the nursing staff either didn't help or made him or her wait too long?
- Yes
  - No
18. In the last 6 months, during any of your visits, did you help your family member with drinking?
- Yes
  - No – If No, Go to Question 20
19. If yes, as it because the nursing staff either didn't help or made him or her wait too long?
- Yes
  - No
20. "Help toileting" mean helping someone get on and off the toilet, or helping change disposable briefs or pads.
- In the last 6 months, during any of your visits to the nursing home, did you help your family member with toileting?
- Yes
  - No – If No, Go to Question 22
21. If yes, was it because the nursing staff either didn't help or made him or her wait too long?
- Yes
  - No
22. In the last 6 months, how often did your family member look and smell clean?
- Never
  - Sometimes
  - Usually
  - Always
23. Sometimes residents make it hard for nursing staff to provide care by doing thing like yelling, pushing, or hitting. In the last 6 months, did you see any resident, including your family member; behave in a way that made it hard for nurses or aides to provide care?
- Yes
  - No – If no, Go to Question 25

24. In the last 6 months, how often did the nurses and aides handle this situation in a way that you felt was appropriate?

- Never
- Sometimes
- Usually
- Always

**YOUR EXPERIENCE WITH NURSING STAFF**

25. In the last 6 months, how often did the nursing staff treat you with courtesy and respect?

- Never
- Sometimes
- Usually
- Always

26. In the last 6 months, did you want to get information about your family member from nursing staff?

- Yes
- No – If No, Go to Question 28

27. If yes, how often did you get this information as soon as you wanted?

- Never
- Sometimes
- Usually
- Always

28. In the last 6 months, how often did the nursing staff explain things in a way that was easy for you to understand?

- Never
- Sometimes
- Usually
- Always

29. In the last 6 months, did nursing staff ever try to discourage you from asking questions about your family member?

- Yes
- No

**THE NURSING HOME**

30. In the last 6 months, how often did your family member's room look and smell clean?

- Never
- Sometimes
- Usually
- Always

31. In the last 6 months, how often was the noise level around your family member's room acceptable to you?

- Never
- Sometimes
- Usually
- Always

32. In the last 6 months, how often were you able to find places to talk to your family member in private?

- Never
- Sometimes
- Usually
- Always

33. In the last 6 months, how often did the public areas of the nursing home such as the main entrance, and dining rooms look and smell clean?

- Never
- Sometimes
- Usually
- Always

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

- Yes
- No

35. **Personal medical belongings are things like hearing aids, eye glasses, and dentures. In the last 6 months, how often were your family member's personal medical belongings damaged or lost?**

- Never
- Once
- Two or more times

36. **In the last 6 months, did your family member use the nursing home's laundry service for his or her clothes?**

- Yes
- No – If No, Go to Question 38

37. **If yes, how often were clothes damaged or lost?**

- Never
- Once or twice
- Three times or more

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

- Yes
- No – If No, Go to Question 42

39. **In the last 6 months, did you talk to any nursing home staff about this concern?**

- Yes
- No – If No, Go to Question 41

40. **In the last 6 months, how often were you satisfied with the way the nursing home staff handled these problems?**

- Never
- Sometimes
- Usually
- Always

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

- Yes
- No

## CARE OF YOUR FAMILY MEMBER

42. **In the last 6 months, have you been involved in decisions about your family member's care?**

- Yes
- No

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

- Never
- Sometimes
- Usually
- Always

44. **An interdisciplinary care conference is a meeting about care planning and health between a care team and resident and his or her family.**

**In the last 12 months, have you been part of an interdisciplinary care conference, either in person or by phone?**

- Yes – If Yes, Go to Question 46
- No

45. **Were you given the opportunity to be part of an interdisciplinary care conference in the last 12 months either in person or by phone?**

- Yes
- No

46. **Using any number from 0 to 10 where 0 is the worst care possible and 10 is the best care possible, what number would you use to rate the care at the nursing home?**

- 0 Worst care possible
- 1
- 2
- 3
- 4
- 5
- 6
- 7
- 8
- 9
- 10 Best care possible

47. If someone needed nursing home care, would you recommend this nursing home to them?

- Definitely No
- Probably No
- Probably Yes
- Definitely yes

48. In the last 6 months, how often did you feel that there was enough nursing staff in the nursing home?

- Never
- Sometimes
- Usually
- Always

### YOU AND YOUR ROLE

Please remember the questions in this survey are about your experiences. Do not include the experiences of other family members.

49. In the last 6 months, did you help with the care of your family member when you visited?

- Yes
- No

50. Do you feel that nursing home staff expect you to help with the care of your family member when you visit?

- Yes
- No

51. In the last 6 months, did you ask the nursing home for information about payments or expenses?

- Yes
- No – If No, Go to Question 53

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

- Never
- Sometimes
- Usually
- Always

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

- Yes
- No

54. Power of attorney is a legal document that allows you to make decisions about your family member's finances or property.

Do you have the power to attorney for your family member?

- Yes
- No
- Don't know

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

Are you your family member's substitute decision maker (next of kin)?

- Yes
- No
- Don't know

56. What is your age?

- 18 to 24
- 25 to 34
- 35 to 44
- 45 to 54
- 55 to 64
- 65 to 74



- 75 or older

**57. Are you male or female?**

- Male
- Female

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

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

**59. Would you say you are...**

- White/ Caucasian
- Aboriginal
- Other

If other, please specify \_\_\_\_\_

**60. What language do you mainly speak at home?**

- English
- French
- Other

If other, please specify \_\_\_\_\_

**61. Did someone help you complete this survey?**

- Yes
- No – Go to Question 64

**62. How did that person help you?**

- Read the questions to me
- Wrote down the answers I gave
- Answered the question for me
- Translated the questions into my language

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

- Yes
- No
- Don't know

**64. Do you have any suggestions how care and services at this nursing home could be improved? If so, please explain.**

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**Please return the completed survey in the postage-paid envelope.** Thank you for completing this survey. Your opinions are important to us.

Appendix B  
Family Comments

1. Bigger rooms, visiting places.
2. A secure outside area (eg. park, bench area) for residents to enjoy in safety.
3. Check to see if they need to be changed more often.
4. Get out a bit more.
5. I think they need to look at is for front-line staff should be more aware of basic information of their resident and should not send the family member to other workers for help (such as social workers). They should maintain one staff member on the floor and not just being the desk in the offices (such as in protective) and doing so would make family members feel more secure about their loved ones being watched and cared for. Regulations regarding visitors to the home should be made more readily available to visitors. When an incident occurs and the family member is called the notes regarding are too vague to articulate what happened with the resident. Also lack of communication about these events between nursing staff, such as nursing staff being unaware of an incident when it occurs and when it is brought up by a family member.
6. More nursing staff or personal care attendants to help ease the workload. More recreational activities for the residents (such as musical entertainment and conversation partners).
7. More physiotherapy for stroke victims and more therapy in general to promote residents' independence. Urine smell within the family member's room needs to be removed.
8. More staff.
9. My recommendation is that there should be more staff and that there should be more one on one time to interact with residents especially those with Alzheimer's disease and dementia.
10. Pets should be allowed (pet therapy), it helps residents.
11. Residents should have more recreational activities for them.
12. Would prefer that the men and women were separated on Protective Care. Feels there is potential for sexual misconduct with males and females who are incompetent and openly sharing the same space.
13. The one complaint I have is that they have stopped ironing my father's clothing. This is not acceptable since he has never gone without his clothes ironed. He wears dress shirts, dress, or cotton pants, and cardigans and it looks terrible to see it not ironed. I have complained on this matter and the answer is that it is standard- well I feel standards should always be raised, not downgraded. On my complaint, I wrote that "wrinkled faces, wrinkled minds, wrinkled clothes- who cares." I still feel this way and if I had time I would protest, maybe in front of the building with a sign but I am also caring for my mother so time is not mind.
14. I believe more staff is required. Many times residents are left without supervision while staff attend to the needs of other residents in their rooms. This can be dangerous for patients with Alzheimers.
15. I do not mind giving my name if needed.
16. I would like for the home to bring back the ironing of my husband's clothing as I find it very wrinkled now.
17. My father's personal care is very well done. Any issues we have are his, not of the personal staff.
18. We are happy with Dad's care.
19. Would like to have her husband to have regular physio as was promised.

20. Don't always smell nice; only one phone line for four people.
21. Could use 4 bathrooms instead of 2.
22. Full time recreational therapist (one, preferably 2). Heating system in bungalow 1 needs to be checked more staff (cleaning) dusting needs to be done.
23. Home needs a physical program- very big concern one bathroom for 5 people is not enough. Understaffed, residents need more one on one time for recreation.
24. Lost a lot of clothes.
25. More than one person working at night.
26. Not always clean, especially in winter lots of issues with clothes being lost.
27. The food is not up to par. Rooms are not cleaned often enough or thoroughly. Not enough personal hygiene. Heating can break down unnoticeably and makes residents really cold (no thermostats in rooms), been down to 19 degrees.
28. Understaffed at night. Need for social events.
29. More staff is needed. I cannot stress this enough. More communication with the next of kin other than the patients themselves as their memory is not the best at times.
30. During report at night the staff are usually confined to one room with no one on the unit with the residents.
31. I feel this facility is a great place for our loved ones. They are well taken care of there but the shortage of staff make it difficult for the staff to spend any quality time with the residents.
32. Lots of times my mom smells terrible from not cleaning herself properly, that's because the nursing home is under staffed. There have been times when I visit after supper I can't sit beside her. The residents only have one bath per week as far as I know and again, under staffed!
33. My mother is receiving excellent care but I do feel the staff is overworked.
34. Not enough care given to people who cannot help themselves.
35. She needs her bed cleaned and done more often. Every time we come she is on a mattress with no sheets and she should be checked on more often. Her room always smells terrible. The only complaint I would have regarding my parent is the lack of hairdressing services. The rec. therapy worker does hair care daily, ie. Styling the residents' hair. When she's off (on vacation or sick leave), no one is available to do the residents' hair. This may seem trivial, but it makes a huge difference when families and friends visit and the resident's hair is in a terrible state. It's so much nicer to see their hair combed and styled as they would have it at home.
36. There are not enough staff to cover nursing staff breaks, residents have to wait for staff to return to get any care during these times. Staff are over worked and tired and this is affecting the level of care they can provide.