Study ID #_____ /_____ /_____

Measuring Quality of Care for People Living in Long-Term Care Homes

Family Caregiver Questionnaire
(Self-Administered)

Date of Completion: _____- _____- _____
DD   MM   YY

IF YOU HAVE ANY QUESTIONS WHILE COMPLETING THIS SURVEY OR REQUIRE ASSSISTANCE, please contact:

What is the CANHELP survey?

This is a satisfaction survey for family members of residents of long term care homes. The CANHELP survey gathers information about 22 aspects of care considered important in providing quality of care.

How do I complete the survey?

The survey asks your views about 22 aspects of long term care from two perspectives 1) the importance to you and 2) your satisfaction with care.

For each question you are asked to choose a number between 1 and 5 to indicate how important that care aspect is to you when considering the care of your relative. For example, if you choose option #1 "**Not at all important**", you will be indicating that this aspect of care is the least important of all care aspects when considering your relative's long term care. At the other end of the scale, your choice of option #5 "**Extremely Important**" will indicate that this aspect of the care is one of the most important aspects of the care your relative may receive in long term care.

Next, you will indicate how satisfied you are with that particular aspect of care. For example, if you choose option #1 "**Not at all Satisfied**", you will be indicating that this aspect of the care your relative received did not meet any of your expectations of high quality care. At the other end of the scale, your choice of option #5 "**Completely Satisfied**" will indicate that this aspect of the care your relative received met or exceeded your expectations of quality care. If you do not have enough experience with a particular aspect of care to rate satisfaction, please circle # 9 which means "**Do not know/ No basis to judge.**"

Will my survey responses remain anonymous?

Your responses will be completely anonymous. Surveys are mailed directly to _____ University. No identifying information about you or the resident will be collected. A study identification number will be used solely for tracking purposes, that is, to know who returned the survey and who did no

SECTION #1 IMPORTANCE					
Not at all Important	**Not very Important**	**Somewhat Important**	**Very Important**	**Extremely Important**	For each of the questions, please tell us first **HOW IMPORTANT** is that care issue(s), from your perspective of what represents good quality care provided to your relative. Place circle the appropriate number that best reflects your answer.
Importance: *Characteristics of the Long Term Care Home Staff*					
1	2	3	4	5	1. The <u>long term care staff</u> looking after your relative are compassionate and supportive <u>of him or her.</u>
1	2	3	4	5	2. The <u>long term care staff</u> looking after your relative are compassionate and supportive of <u>you.</u>
Importance: *Illness Management*					
1	2	3	4	5	3. The tests are done and the treatments are given for your relative's medical problems in the long term care home.
1	2	3	4	5	4. The physical symptoms (for example: pain, shortness of breath, nausea) your relative has are adequately assessed and controlled.
1	2	3	4	5	5. The emotional problems (for example: depression, anxiety) your relative has are adequately assessed and controlled.
1	2	3	4	5	6. Your relative receives help with personal care (for example: bathing, toileting, dressing, eating) when needed.
1	2	3	4	5	7. Your relative received good care when you were not able to be with him/her.

1	**2**	**3**	**4**	**5**	8. The health care workers worked together as a team to look after your relative.
1	**2**	**3**	**4**	**5**	9. You are able to manage the financial costs associated with your relative's long term care.
1	**2**	**3**	**4**	**5**	10. The environment or the surroundings in which your relative receives care is calm and restful.
1	**2**	**3**	**4**	**5**	11. The care and treatment your relative receives is consistent with his or her wishes.
				Importance: *Communication and Decision Making*	
1	**2**	**3**	**4**	**5**	12. The long term care staff explains things related to your relative's illness in a straightforward, <u>honest</u> manner.
1	**2**	**3**	**4**	**5**	13. You receive <u>consistent</u> information about your relative's condition from all the long term care staff looking after him or her.
1	**2**	**3**	**4**	**5**	14. The long term care staff <u>listen</u> to what you say.
1	**2**	**3**	**4**	**5**	15. You discuss options with the nursing staff about whether your relative would be transferred to hospital or cared for in the long term care home if he or she were to get worse.
				Importance: *Relationship with Doctors*	
1	**2**	**3**	**4**	**5**	16. The long term care home doctor(s) takes a personal interest in your relative.
1	**2**	**3**	**4**	**5**	17. The long term care home doctor(s) are available when you or your relative needs them (by phone or in person).
1	**2**	**3**	**4**	**5**	18. You have trust and confidence in the doctor(s) who look after your relative.
				Importance: *Your Involvement*	
1	**2**	**3**	**4**	**5**	19. You discuss options with the long term care Nurse about the use of life sustaining

					technologies (for example: CPR or cardiopulmonary resuscitation, breathing machines, dialysis).
1	2	3	4	5	20. You discuss options with the nursing staff about initiating palliative care or comfort care measures of your relative.
1	2	3	4	5	21. Your role in decision-making regarding your relative's medical care in the long term care home.
1	2	3	4	5	22. You discuss options with the long term care Nurse about your relative's end-of-life care wishes.

SECTION #2 SATISFACTION

Not at all Satisfied	Not very Satisfied	Somewhat Satisfied	Very Satisfied	Completely Satisfied	Don't Know / No basis to judge	Consider the care your relative received **during the past month** and tell us **HOW SATISFIED** you are right now with that aspect of care. Place circle the appropriate number that best reflects your answer.
Satisfaction: *Characteristics of the Long Term Care Home Staff*						
1	2	3	4	5	9	23. The <u>long term care staff</u> looking after your relative are compassionate and supportive <u>of him or her.</u>
1	2	3	4	5	9	24. The <u>long term care staff</u> looking after your relative are compassionate and supportive of <u>you.</u>
Satisfaction: *Illness Management*						
1	2	3	4	5	9	25. The tests are done and the treatments are given for your relative's medical problems in the long term care home.
1	2	3	4	5	9	26. The physical symptoms (for example: pain, shortness of breath, nausea) your relative has are adequately assessed and controlled.
1	2	3	4	5	9	27. The emotional problems (for example: depression, anxiety) your relative has are adequately assessed and controlled.
1	2	3	4	5	9	28. Your relative receives help with personal care (for example: bathing, toileting, dressing,

						eating) when needed.
1	2	3	4	5	9	29. Your relative received good care when you were not able to be with him/her.
1	2	3	4	5	9	30. The health care workers worked together as a team to look after your relative.
1	2	3	4	5	9	31. You are able to manage the financial costs associated with your relative's long term care.
1	2	3	4	5	9	32. The environment or the surroundings in which your relative receives care is calm and restful.
1	2	3	4	5	9	33. The care and treatment your relative receives is consistent with his or her wishes.
Satisfaction: *Communication and Decision Making*						
1	2	3	4	5	9	34. The long term care staff explains things related to your relative's illness in a straightforward, <u>honest</u> manner.
1	2	3	4	5	9	35. You receive <u>consistent</u> information about your relative's condition from all the long term care staff looking after him or her.
1	2	3	4	5	9	36. The long term care staff <u>listen</u> to what you say.
1	2	3	4	5	9	37. You discuss options with the nursing staff about whether your relative would be transferred to hospital or cared for in the long term care home if he or she were to get worse.
Satisfaction: *Relationship with Doctors*						
1	2	3	4	5	9	38. The long term care home doctor(s) takes a personal interest in your relative.
1	2	3	4	5	9	39. The long term care home doctor(s) are available when you or your relative needs them (by phone or in person).

1	**2**	**3**	**4**	**5**	**9**	40. You have trust and confidence in the doctor(s) who look after your relative.
					Satisfaction: *Your Involvement*	
1	**2**	**3**	**4**	**5**	**9**	41. You discuss options with the long term care Nurse about the use of life sustaining technologies (for example: CPR or cardiopulmonary resuscitation, breathing machines, dialysis).
1	**2**	**3**	**4**	**5**	**9**	42. You discuss options with the nursing staff about initiating palliative care or comfort care measures of your relative.
1	**2**	**3**	**4**	**5**	**9**	43. Your role in decision-making regarding your relative's medical care in the long term care home.
1	**2**	**3**	**4**	**5**	**9**	44. The discussions options with the long term care Nurse about your relative's end-of-life care wishes.

Study ID #_____ /_____/_____

Comments

45. Do you have any comments on things the long term care staff or the management did well?

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46. Please add any comments or suggestions that you feel may be helpful to the long term care staff looking after your relative that may help them improve the quality of care provided in the facility.

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Study ID #_____ /_____/_____

Family Demographics (Please provide answers about yourself)	**Resident Demographics** (Please provide answers about your relative)
Age: _____ years	**Age**: _____ years
Sex (√) one: ❑Male ❑Female	**Sex** (√) one: ❑Male ❑Female
Current Marital Status (√) one: ❑ Married or living as married ❑ Widowed ❑ Never married ❑ Divorced or separated; not remarried	**How many months has the resident been in the current LTC? (or date of admission):** _____.
Education – highest level achieved (√) one: ❑ Elementary school or less ❑ Some high school ❑ High school graduate ❑ Some college (including CEGEP)/ trade school ❑ College diploma (including DEC)/ trade school ❑ Some university ❑ University degree ❑ Post Graduate	**Last location of living prior to this LTC home** (√) one: ❑ Home (or other private dwelling) alone ❑ Home (or other private dwelling) with spouse or significant other ❑ Home (or other private dwelling) with children or other family ❑ Retirement Residence ❑ Long-Term Care or Nursing Home ❑ Rehabilitation Facility ❑ Hospital ❑ Other (specify): _____
Relationship to Resident (√) one**:** ❑ Spouse / Partner ❑ Parent ❑ Parent-in-law ❑ Daughter / Son ❑ Other (specify) : _____	**Location of resident prior to admission** (√)one: ❑Rural (Defined as population living in a community with 10,000 inhabitants or less). ❑Urban (Defined as population living in a community with 10,000 inhabitants or more).
Ethnicity: Are you Caucasian? ❑Yes ❑No (specify): _____	**Ethnicity:** Is the resident Caucasian? ❑Yes ❑No (specify): _____
Language: Besides English (or French if live in Quebec) do you speak another language on a daily basis? ❑ Yes (specify): _____ ❑ No	**Language:** Besides English (or French if live in Quebec) does the resident speak another language on a daily basis? ❑ Yes (specify): _____ ❑ No
How often do you visit the resident? (√) one**:** ❑ Daily ❑ Weekly ❑ Monthly ❑ Yearly ❑ Other (specify) : _____	

Thank you very much for completing this survey!

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