Subjec	et # :
<u>Can</u> adian <u>H</u> ealth Care <u>E</u> va <u>l</u> uation <u>P</u> roje	ect
(CANHELP)	
Caregiver Questionnaire	
Date : DD	

CANHELP Caregiver Questionnaire 11 Nov 2014

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#### Instructions:

The following questionnaire includes items that are considered important in terms of quality of care for people with serious, life threatening illnesses.

Please think about the health care that your relative has received *during the past month* from doctors, nurses and other health care professionals. For each question you will be asked to choose a number between 1 and 5 to indicate how satisfied you are with that particular aspect of care -- the higher the number, the more satisfied you are. If you choose option #1 "Not at all Satisfied", for example, 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.

All answers are confidential and will not be shown to doctors or other health care professionals who are responsible for your relative's care. There are no right or wrong answers. **Completely honest answers are most helpful!** 

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Completely

5

# The following questions concern the care your relative received during the past month.

For each one, please indicate the degree to which you are satisfied.

1. <u>In general</u>, how satisfied are you with the quality of care your relative received *during* the past month?

Not At All Not Very Somewhat

1 2 3

2. In general, how satisfied are you with the way you were treated by the doctors and nurses looking after your relative *during the past month?* 

Not At All Not Very Somewhat Very Completely 1 2 3 4 5

Very

### Relationship with the Doctors

3. How satisfied are you that you knew the doctor(s) in charge of your relative's care during the past month?

Not At All Not Very Somewhat Very Completely 1 2 3 4 5

4. How satisfied are you that the doctor(s) took a personal interest in your relative during the past month?

Not At All Not Very Somewhat Very Completely 1 2 3 4 5

5. How satisfied are you that the doctor(s) were available when you or your relative needed them (by phone or in person) *during the past month*?

Not At All Not Very Somewhat Very Completely 1 2 3 4 5

6. How satisfied are you with the level of trust and confidence you had in the doctor(s) who looked after your relative *during the past month*?

Not At All Not Very Somewhat Very Completely
1 2 3 4 5

#### Characteristics of the Doctors and Nurses

7. How satisfied are you with the level of trust and confidence you had in the <u>nurses</u> who looked after your relative *during the past month*?

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8.	How satisfied are you during the past mon best possible care?				ed after your relative problems to give the
	Not At All 1	Not Very 2	Somewhat 3	Very 4	Completely 5
9.	How satisfied are you the past month were				ter your relative <i>during</i> or her?
	Not At All 1	Not Very 2	Somewhat 3	Very 4	Completely 5
10.	How satisfied are you the past month were				ter your relative during
	Not At All 1	Not Very 2	Somewhat 3	Very 4	Completely 5
11.	How satisfied are you during the past mon	•		•	e doctors and nurses sense of dignity?
	Not At All 1	Not Very 2	Somewhat 3	Very 4	Completely 5
II	llness Management				
12.	How satisfied are you				treatments that were ems?
	Not At All 1	Not Very 2	Somewhat 3	Very 4	Completely 5
13.	How satisfied are you		• • •	•	pain, shortness of e adequately controlled?
	Not At All 1	Not Very 2	Somewhat 3	Very 4	Completely 5
14.	How satisfied are vo	ou that emotion	nal problems (fo	or example:	depression, anxiety)

your relative had during the past month were adequately controlled?

the past month (for example: bathing, toileting, dressing, eating)?

Somewhat

3

Somewhat

How satisfied are you with the help your relative received with personal care during

Very

Very

4

Completely

5

Completely

Not Applicable No Help Needed

6

Not Very

2

Not Very

2

Not At All

1

Not At All

1

15.

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16.	How satisfied are you that, during the past month, your relative received good care
	when you were not able to be with him/ her?

Not At All Not Very Somewhat Very Completely
1 2 3 4 5

17. How satisfied are you with recent home care services your relative received?

Not At All Not Very Somewhat Very Completely Not Applicable.

No home care needed

1 2 3 4 5 6

18. How satisfied are you that health care workers worked together as a team to look after your relative *during the past month*?

Not At All Not Very Somewhat Very Completely 1 2 3 4 5

19. How satisfied are you that you were able to manage the financial costs associated with your relative's illness *during the past month*?

Not At All Not Very Somewhat Very Completely 1 2 3 4 5

20. How satisfied are you with the environment or the surroundings in which your relative was cared for *during the past month?* 

Not At All Not Very Somewhat Very Completely
1 2 3 4 5

21. How satisfied are you that the care and treatment your relative received *during the past month* was consistent with his or her wishes?

Not At All Not Very Somewhat Very Completely

## Communication and Decision Making

22. How satisfied are you that the doctor(s) explained things relating to your relative's illness in a straightforward, <u>honest</u> manner *during the past month*?

Not At All Not Very Somewhat Very Completely 1 2 3 4 5

23. How satisfied are you that the doctor(s) explained things relating to your relative's illness in a way you could <u>understand</u> during the past month?

24.	How satisfied are you that you received consistent information about your relative's
	condition from all the doctors and nurses looking after him or her during the past
	month?

Not At All Not Very Somewhat Very Completely 1 2 3 4 5

25. How satisfied are you that you received updates about your relative's condition, treatments, test results, etc. <u>in a timely manner during the past month?</u>

Not At All Not Very Somewhat Very Completely 1 2 3 4 5

26. How satisfied are you that the doctor(s) <u>listened</u> to what you had to say *during the past month*?

Not At All Not Very Somewhat Very Completely 1 2 3 4 5

27. How satisfied are you with discussions *during the past month* with the doctor(s) about where your relative would be cared for (in hospital, at home, or elsewhere) if he or she were to get worse?

Not At All Not Very Somewhat Very Completely

1 2 3 4 5

#### Your Involvement

28. How satisfied are you with the level of confidence you felt *during the past month* in your ability to help your relative manage his/ her illness?

Not At All Not Very Somewhat Very Completely 1 2 3 4 5

29. How satisfied are you with discussions *during the past month* with the doctor(s) about the use of life sustaining technologies (for example: CPR or cardiopulmonary resuscitation, breathing machines, dialysis)?

Not At All Not Very Somewhat Very Completely 1 2 3 4 5

30. How satisfied are you that, *during the past month*, you have come to understand what to expect at the end stage of your relative's illness (for example: in terms of symptoms and comfort measures)?

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31.	How satisfied are you with your role during the past month in decision-making
	regarding your relative's medical care?

Not At All Not Very Somewhat Very Completely 1 2 3 4 5

32. How satisfied are you with discussions with your relative *during the past month* about wishes for future care in the event he or she is unable to make those decisions?

Not At All Not Very Somewhat Very Completely 1 2 3 4 5

33. How satisfied are you that you were able *during the past month* to talk comfortably with your relative about his/ her illness, dying, and death?

Not At All Not Very Somewhat Very Completely 1 2 3 4 5

34. How satisfied are you that your relationship with your relative was strengthened *during the past month*?

Not At All Not Very Somewhat Very Completely
1 2 3 4 5

## Your Well Being

35. How satisfied are you with the level of confidence you felt *during the past month* in your relative's ability to manage his/her own illness?

Not At All Not Very Somewhat Very Completely 1 2 3 4 5

36. How satisfied are you that *during the past month* you had enough time and energy to take care of yourself?

Not At All Not Very Somewhat Very Completely 1 2 3 4 5

37. How satisfied are you that you had family or friends to support you when you felt lonely or isolated *during the past month*?

Not At All Not Very Somewhat Very Completely
1 2 3 4 5

38. How satisfied are you that you were able *during the past month* to contribute to others in a meaningful way?

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39. How satisfied are you that you and your relative did special things (for example: resolve conflicts, complete projects, participate in special family events, travel) you wanted to do during the past month?

Not At All Not Very Somewhat Very Completely

1 2 3 4 5

40. How satisfied are you that you were at peace during the past month?