

Appendix A

Hospice Experience of Care Survey

Please answer the questions in this survey about the care this patient received from this hospice:

[NAME OF HOSPICE LABEL GOES HERE]

All of the questions in the survey will ask about experience with this hospice.

SURVEY INSTRUCTIONS

- Please give this survey to the person in your household who knows the most about the hospice care received by the person listed on the survey cover letter.
- Answer all the questions by checking the box to the left of your answer.
- Some questions include an answer to choose if the question does not apply to you.
- You are sometimes told to skip over some questions in this survey. When this happens you will see an arrow with a note that tells you what question to answer next, like this:

Yes → **If Yes, go to Question 1.**

No

THE HOSPICE PATIENT

1. How are you related to the person listed on the survey cover letter?

My spouse or partner

My parent

My mother-in-law or father-in-law

My grandparent

My aunt or uncle

My sister or brother

My child

My friend

Other (please print): _____

2. For this survey, the phrase “family member” refers to the person listed on the survey cover. In what locations did your family member received care from this hospice?

Mark one or more

Home

Assisted living facility

Nursing home

Hospital

Hospice facility / hospice house

Other (please print): _____

YOUR ROLE

3. While your family member was in hospice care, how often did you take part in or oversee care for him or her?

Never → **If Never, please go to Question 41.**

Sometimes

Usually

Always

YOUR FAMILY MEMBER'S HOSPICE CARE

As you answer the rest of the questions in this survey, please think only about your family member's experience with the hospice listed on the survey cover. If your family member received care from this hospice more than one time, please think only about the last episode for which they received care.

4. For this survey, the hospice team includes all the nurses, doctors, social workers, chaplains and other people who provided hospice care to your family member. While your family member was in hospice care, did you need to contact the hospice team during evenings, weekends, or holidays for questions or help with his or her care?

Yes

No → **If No, please go to Question 6.**

5. How often did you get the help you needed from the hospice team during evenings, weekends, or holidays?

Never

Sometimes

Usually

Always

6. Did your family member receive care from this hospice while he or she was in a nursing home?

Yes

No → **If No, please go to Question 9.**

7. While your family member was in hospice care, how often did the nursing home staff and hospice team work well together to care for your family member?

Never

Sometimes

Usually

Always

8. While your family member was in hospice care, how often was the information you were given about your family member by the nursing home staff different from the information you were given by the hospice team?
- Never
 - Sometimes
 - Usually
 - Always
9. While your family member was in hospice care, how often did the hospice team tell you when they would arrive to care for your family member?
- Never
 - Sometimes
 - Usually
 - Always
10. While your family member was in hospice care, when you or your family member asked for help from the hospice team, how often did you get help as soon as you needed it?
- Never
 - Sometimes
 - Usually
 - Always
11. While your family member was in hospice care, how often did the hospice team explain things in a way that was easy to understand?
- Never
 - Sometimes
 - Usually
 - Always

12. While your family member was in hospice care, how often did the hospice team keep you informed about your family member's condition?

Never

Sometimes

Usually

Always

13. While your family member was in hospice care, how often did anyone from the hospice team give you confusing or contradictory information about your family member's condition or care?

Never

Sometimes

Usually

Always

14. While your family member was in hospice care, how often did the hospice team treat your family member with dignity and respect?

Never

Sometimes

Usually

Always

15. While your family member was in hospice care, how often did you feel that the hospice team really cared about your family member?

Never

Sometimes

Usually

Always

16. While your family member was in hospice care, did you talk with the hospice team about any problems with your family member's hospice care?

Yes

No → If No, please go to Question 18.

17. How often did the hospice team listen carefully to you when you talked with them about problems with your family member's hospice care?

Never

Sometimes

Usually

Always

18. While your family member was in hospice care, did he or she have any pain?

Yes

No → **If No, please go to Question 20.**

19. Did your family member get as much help with pain as he or she needed?

Yes, definitely

Yes, somewhat

No

20. While your family member was in hospice care, did he or she receive any pain medicine?

Yes

No → **If No, please go to Question 24.**

21. Side effects of pain medicine include things like sleepiness. Did any member of the hospice team discuss side effects of pain medicine with you or your family member?

Yes, definitely

Yes, somewhat

No

22. Did the hospice team give you enough training about what side effects to watch for from pain medicine?

Yes, definitely

Yes, somewhat

No

23. Did the hospice team give you enough training about if and when to give more pain medicine to your family member?

Yes, definitely

Yes, somewhat

No

I did not need to give pain medicine to my family member

24. While your family member was in hospice care, did your family member ever have trouble breathing or receive treatment for trouble breathing?

Yes

No → **If No, please go to Question 27.**

25. How often did your family member get the help he or she needed for trouble breathing?

Never

Sometimes

Usually

Always

26. Did the hospice team give you enough training about how to help your family member if he or she had trouble breathing?

Yes, definitely

Yes, somewhat

No

I did not need to help my family member with trouble breathing

27. While your family member was in hospice care, did your family member ever have trouble with constipation?

Yes

No → **If No, please go to Question 29.**

28. How often did your family member get the help he or she needed for trouble with constipation?
- Never
 - Sometimes
 - Usually
 - Always
29. While your family member was in hospice care, did he or she need help with feelings of anxiety or sadness?
- Yes
 - No → **If No, please go to Question 31.**
30. How often did your family member receive the help he or she needed from the hospice team for feelings of anxiety or sadness?
- Never
 - Sometimes
 - Usually
 - Always
31. While your family member was in hospice care, did he or she ever become restless or agitated?
- Yes
 - No → **If No, please go to Question 33.**
32. Did the hospice team give you enough training about what to do if your family member became restless or agitated?
- Yes, definitely
 - Yes, somewhat
 - No

33. Moving your family member includes things like helping him or her turn over in bed, or get in and out of bed or a wheelchair. Did the hospice team give you enough training about how to safely move your family member?

Yes, definitely

Yes, somewhat

No

I did not need to move my family member

34. Did the hospice team give you as much information as you wanted about what to expect while your family member was dying?

Yes, definitely

Yes, somewhat

No

YOUR OWN EXPERIENCE WITH HOSPICE

35. While your family member was in hospice care, how often did the hospice team listen carefully to you?

Never

Sometimes

Usually

Always

36. Support for religious or spiritual beliefs includes talking, praying, quiet time, or other ways of meeting your religious or spiritual needs. While your family member was in hospice care, how much support for your religious and spiritual beliefs did you get from the hospice team?

Too little

Right amount

Too much

37. While your family member was in hospice care, how much emotional support did you get from the hospice team?

Too little

Right amount

Too much

38. In the weeks after your family member died, how much emotional support did you get from the hospice team?

Too little

Right amount

Too much

OVERALL RATING OF HOSPICE CARE

39. Please answer the following questions about your family member's care from the hospice named on the survey cover. Do not include care from other hospices in your answers.

Using any number from 0 to 10, where 0 is the worst hospice care possible and 10 is the best hospice care possible, what number would you use to rate your family member's hospice care?

0 Worst hospice care possible

1

2

3

4

5

6

7

8

9

10 Best hospice care possible

40. Would you recommend this hospice to your friends and family?

Definitely no

Probably no

Probably yes

Definitely yes

ABOUT YOUR FAMILY MEMBER

41. What is the highest grade or level of school that your family member completed?

8th grade or less

Some high school but did not graduate

High school graduate or GED

Some college or 2-year degree

4-year college graduate

More than 4-year college degree

Don't know

42. Was your family member of Spanish, Hispanic or Latino origin or descent?

No, not Spanish/Hispanic/Latino

Yes, Puerto Rican

Yes, Mexican, Mexican American, Chicano

Yes, Cuban

Yes, other Spanish/Hispanic/Latino

43. What was your family member's race? Please mark one or more.

White

Black or African American

American Indian or Alaska Native

Asian Indian

Chinese

Filipino

Japanese

Korean

Vietnamese

Other Asian

Native Hawaiian

Guamanian or Chamorro

Samoan

Other Pacific Islander

ABOUT YOU

44. What is your age?

18 to 24

25 to 34

35 to 44

45 to 54

55 to 64

65 to 74

75 to 84

85 or older

45. Are you male or female?

Male

Female

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

8th grade or less

Some high school but did not graduate

High school graduate or GED

Some college or 2-year degree

4-year college graduate

More than 4-year college degree

Don't know

47. What language do you mainly speak at home?

English

Spanish

Chinese

Some other language:

Please print: _____

Thank you.

Please return the completed survey in the postage-paid envelope.