

Hospice Experience Survey – Home Version (72 items)

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.

According to the Paperwork Reduction Act of 1995, no persons are required to respond to a collection of information unless it displays a valid OMB control number. The valid OMB control number for this information collection is **XXX-XXXX**. The time required to complete this information collection is estimated to average 16 minutes per response, including the time to review instructions, search existing data resources, gather the data needed, and complete and review the information collection. If you have comments concerning the accuracy of the time estimate(s) or suggestions for improving this form, please write to: CMS, 7500 Security Boulevard, Attn: PRA Reports Clearance Officer, Mail Stop C4-26-05, Baltimore, Maryland 21244-1850.

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.
- 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 letter. Did your family member receive care from the hospice listed on the survey cover letter?
Yes
No → **If No, please stop and return the survey in the envelope provided.**

Attachment A

3. What was the last location in which your family member received care from this hospice?

Home

Assisted living facility

Nursing home

Hospital

Hospice facility / hospice house

Other

YOUR ROLE

4. 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 stop and return the survey in the envelope provided.**

Sometimes

Usually

Always

5. Was your family member's hospice care your first experience with hospice services for a close friend or family member?

Yes

No

STARTING HOSPICE CARE

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. Please do not include hospice volunteers.

6. Did the hospice team explain the kinds of care and services they could give you and your family member?

Yes, definitely

Yes, somewhat

No

7. Did your family member begin getting hospice care too early, at the right time, or too late?

Too early

At the right time

Too late

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 this hospice in the last location in which he or she received hospice care.

8. 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 your family member’s care?

Yes

No → **If No, please go to Question 10.**

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

Never

Sometimes

Usually

Always

10. While your family member was in hospice care, how often did the hospice team keep you informed about when they would arrive to care for your family member?

Never

Sometimes

Usually

Always

Attachment A

11. 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

12. While your family member was in hospice care, did the hospice team give you and your family member enough privacy?

Yes, definitely

Yes, somewhat

No

13. While your family member was in hospice care, how often did you have a hard time speaking with or understanding members of the hospice team because you spoke different languages?

Never

Sometimes

Usually

Always

14. While your family member was in hospice care, did the hospice team seem informed and up-to-date about your family member's condition and care?

Yes, definitely

Yes, somewhat

No

Attachment A

15. 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

16. 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

17. 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

18. While your family member was in hospice care, how often did the hospice team respect your needs and preferences?

Never

Sometimes

Usually

Always

19. While your family member was in hospice care, how often did the hospice team spend enough time with your family member?

Never

Sometimes

Usually

Always

20. 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

21. 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

22. 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 25.**

23. 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

24. How often were problems with your family member's hospice care resolved as soon as you needed?

Never

Sometimes

Usually

Always

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

Yes

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

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

Yes, definitely

Yes, somewhat

No

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

Yes

No → **If No, please go to Question 32.**

28. Did you get the information you needed from the hospice team about your family member's pain medicine?

Yes, definitely

Yes, somewhat

No

29. 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

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

Yes, definitely

Yes, somewhat

No

31. 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

32. 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 36.**

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

Never

Sometimes

Usually

Always

34. How often did you get the information you needed from the hospice team about your family member's trouble breathing?

Never

Sometimes

Usually

Always

35. 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

36. 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 38.**

37. How often did your family member get the help he or she needed for trouble with constipation?

Never

Sometimes

Usually

Always

38. While your family member was in hospice care, did he or she show any feelings of anxiety or sadness?

Yes

No

39. Did your family member need help with feelings of anxiety or sadness?

Yes

No → **If No, please go to Question 41.**

40. 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

41. 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 43.**

42. 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

43. 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

44. While your family member was in hospice care, did any member of the hospice team discuss your family member's religious or spiritual beliefs?

Yes

No → **If No, please go to Question 46.**

45. How often did the hospice team treat your family member's religious or spiritual beliefs with respect?

Never

Sometimes

Usually

Always

46. 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 → **If No, please go to Question 48.**

47. Was the information provided in a way that was easy to understand?

Yes, definitely

Yes, somewhat

No

48. When your family member died, was the hospice team with you, or available as soon as you needed?

Yes, definitely

Yes, somewhat

No

Did not need the hospice team

SPECIAL MEDICAL EQUIPMENT

49. Special medical equipment includes things like hospital beds, wheelchairs, or oxygen. While your family member was in hospice care, did your family member need special medical equipment?

Yes

No → **If No, please go to Question 52.**

50. Did your family member get the equipment as soon as he or she needed it?

Yes

No

51. Was the equipment picked up in a timely manner when your family member no longer needed it?

Yes

No

YOUR OWN EXPERIENCE WITH HOSPICE

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

Never

Sometimes

Usually

Always

Attachment A

53. While your family member was in hospice care, how often did the hospice team spend enough time with you?

Never

Sometimes

Usually

Always

54. While your family member was in hospice care, were your religious or spiritual beliefs discussed with any member of the hospice team?

Yes

No → **If No, please go to Question 57.**

55. How often did the hospice team treat your religious or spiritual beliefs with respect?

Never

Sometimes

Usually

Always

56. 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

57. 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

58. 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

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

59. 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

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

Definitely no

Probably no

Probably yes

Definitely yes

61. In thinking about your experiences with hospice, was there anything that went especially well or that you wish had gone differently for you and your family member? Please tell us about those experiences.

ABOUT YOUR FAMILY MEMBER

62. 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

63. Was your family member of Hispanic, Latino/a or Spanish origin or descent?

- Yes
- No → **If No, please go to Question 65.**

64. Which group best describes your family member?

- Mexican, Mexican American, Chicano/a
- Puerto Rican
- Cuban
- Another Hispanic, Latino/and, or Spanish Origin

65. 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

66. 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

67. Are you male or female?

- Male
- Female

68. 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

69. Are you of Hispanic, Latino/a, or Spanish origin or descent?

Yes

No → If No, please go to Question 71.

70. Which group best describes you?

Mexican, Mexican American, Chicano

Puerto Rican

Cuban

Another Hispanic, Latino/a, or Spanish Origin

71. What is your 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

72. 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.