

## **Hospice Experience Survey – Nursing Home Version (65 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 15 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.**

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

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10. 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

11. Personal care needs include bathing, dressing, eating meals and changing bedding. While your family member was in hospice care, how often did your family member get as much help with personal care as he or she needed?

- Never
- Sometimes
- Usually
- Always

12. While your family member was in hospice care, were your family member's personal care needs ever not taken care of because the nursing home staff expected the hospice team to take care of those needs?

- Yes
- No

13. 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

14. 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

15. 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

16. 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

17. 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

18. 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

19. 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

20. 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

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

- Never
- Sometimes
- Usually
- Always

22. 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

23. 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

24. 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

25. 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 28.**

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

- Never
- Sometimes
- Usually
- Always

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

- Never
- Sometimes
- Usually
- Always

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

- Yes

**No ➔ If No, please go to Question 30.**

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

Yes, definitely

Yes, somewhat

No

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

Yes

No → **If No, please go to Question 33.**

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

Yes, definitely

Yes, somewhat

No

32. 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

33. 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.**

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

Never

Sometimes

Usually

Always

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

- Never
- Sometimes
- Usually
- Always

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 any member of the hospice team discuss your family member's religious or spiritual beliefs?

Yes

No → If No, please go to Question 43.

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

Never

Sometimes

Usually

Always

43. 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 45.

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

Yes, definitely

Yes, somewhat

No

### **YOUR OWN EXPERIENCE WITH HOSPICE**

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

Never

Sometimes

Usually

Always

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

- Never
- Sometimes
- Usually
- Always

47. 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 50.**

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

- Never
- Sometimes
- Usually
- Always

49. 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

50. 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

51. 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.

52. 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

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

Definitely no

Probably no

Probably yes

Definitely yes

54. 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

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

8<sup>th</sup> 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

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

Yes

**No → If No, please go to Question 58.**

57. Which group best describes your family member?

## Mexican, Mexican American, Chicano

## Puerto Rican

## Cuban

### Another Hispanic, Latino/a, or Spanish Origin

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58. 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**

59. 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

60. Are you male or female?

Male

Female

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

8<sup>th</sup> 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

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

Yes

**No ➔ If No, please go to Question 64.**

63. Which group best describes you?

Mexican, Mexican American, Chicano/a

Puerto Rican

Cuban

Another Hispanic, Latino/a, or Spanish Origin

64. 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

65. 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.**