CAHPS® Hospice Survey

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

[NAME OF HOSPICE]

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

If you want to know more about this survey, please call [TOLL FREE NUMBER]. All calls to that number are free.

OMB#0938-1257
Expires December 31, 2020

CAHPS® Hospice Survey

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.
- Use a dark colored pen to fill out the survey.
- Place an X directly inside the square indicating a response, like in the sample below.

  ☐ Yes
  ☒ No

- 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?

1 ☐ My spouse or partner
2 ☐ My parent
3 ☐ My mother-in-law or father-in-law
4 ☐ My grandparent
5 ☐ My aunt or uncle
6 ☐ My sister or brother
7 ☐ My child
8 ☐ My friend
9 ☐ Other (please print):

_____

2. For this survey, the phrase "family member" refers to the person listed on the survey cover letter. In what locations did your family member receive care from this hospice? Please choose one or more.

1 ☐ Home
2 ☐ Assisted living facility
3 ☐ Nursing home
4 ☐ Hospital
5 ☐ Hospice facility/hospice house
6 ☐ 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?

1☐ Never ➔ **If Never, go to Question 41**
2☐ Sometimes
3☐ Usually
4☐ 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 named on the survey cover.

4. For this survey, the <u>hospice team</u> 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 your family member's care?

1☐ Yes
2☐ No ➔ **If No, go to Question 6**

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

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

6. 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?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

7. 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?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

8. While your family member was in hospice care, how often did the hospice team explain things in a way that was easy to understand?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

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

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

10. 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?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

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

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

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

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

13. 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?

1☐ Yes
2☐ No ➔ **If No, go to Question 15**

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

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

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

1☐ Yes
2☐ No ➔ **If No, go to Question 17**

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

1☐ Yes, definitely
2☐ Yes, somewhat
3☐ No

17. While your family member was in hospice care, did he or she receive any pain <u>medicine</u>?

1☐ Yes
2☐ No ➔ **If No, go to Question 21**

18. 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?

1☐ Yes, definitely
2☐ Yes, somewhat
3☐ No

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

- [1] ☐ Yes, definitely
- [2] ☐ Yes, somewhat
- [3] ☐ No

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

- [1] ☐ Yes, definitely
- [2] ☐ Yes, somewhat
- [3] ☐ No
- [4] ☐ I did not need to give pain medicine to my family member

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

- [1] ☐ Yes
- [2] ☐ No ➔ **If No, go to Question 24**

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

- [1] ☐ Never
- [2] ☐ Sometimes
- [3] ☐ Usually
- [4] ☐ Always

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

- [1] ☐ Yes, definitely
- [2] ☐ Yes, somewhat
- [3] ☐ No
- [4] ☐ I did not need to help my family member with trouble breathing

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

- [1] ☐ Yes
- [2] ☐ No ➔ **If No, go to Question 26**

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

- [1] ☐ Never
- [2] ☐ Sometimes
- [3] ☐ Usually
- [4] ☐ Always

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

- [1] ☐ Yes
- [2] ☐ No ➔ **If No, go to Question 28**

27. How often did your family member get the help he or she needed <u>from the hospice team</u> for feelings of anxiety or sadness?

- [1] ☐ Never
- [2] ☐ Sometimes
- [3] ☐ Usually
- [4] ☐ Always

28. While your family member was in hospice care, did he or she ever become restless or agitated?

- [1] ☐ Yes
- [2] ☐ No ➔ **If No, go to Question 30**

29. Did the hospice team give you the training you needed about what to do if your family member became restless or agitated?

- [1] ☐ Yes, definitely
- [2] ☐ Yes, somewhat
- [3] ☐ No

30. 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 the training you needed about how to safely move your family member?

- [1] ☐ Yes, definitely
- [2] ☐ Yes, somewhat
- [3] ☐ No
- [4] ☐ I did not need to move my family member

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

- [1] ☐ Yes, definitely
- [2] ☐ Yes, somewhat
- [3] ☐ No

HOSPICE CARE RECEIVED IN A NURSING HOME

32. Some people receive hospice care while they are living in a nursing home. Did your family member receive care from this hospice while he or she was living in a nursing home?

- [1] ☐ Yes
- [2] ☐ No ➔ **If No, go to Question 35**

33. 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?

- [1] ☐ Never
- [2] ☐ Sometimes
- [3] ☐ Usually
- [4] ☐ Always

34. 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?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

YOUR OWN EXPERIENCE WITH HOSPICE

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

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ 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?

1☐ Too little
2☐ Right amount
3☐ Too much

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

1☐ Too little
2☐ Right amount
3☐ Too much

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

1☐ Too little
2☐ Right amount
3☐ 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☐ 0 Worst hospice care possible
- 1☐ 1
- 2☐ 2
- 3☐ 3
- 4☐ 4
- 5☐ 5
- 6☐ 6
- 7☐ 7
- 8☐ 8
- 9☐ 9
- 10☐ 10 Best hospice care possible

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

- 1☐ Definitely no
- 2☐ Probably no
- 3☐ Probably yes
- 4☐ Definitely yes

ABOUT YOUR FAMILY MEMBER

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

- 1☐ 8th grade or less
- 2☐ Some high school but did not graduate
- 3☐ High school graduate or GED
- 4☐ Some college or 2-year degree
- 5☐ 4-year college graduate
- 6☐ More than 4-year college degree
- 7☐ Don't know

42. Was <u>your family member</u> of Hispanic, Latino, or Spanish origin or descent?

- 1☐ No, not Spanish/Hispanic/Latino
- 2☐ Yes, Puerto Rican
- 3☐ Yes, Mexican, Mexican American, Chicano/a
- 4☐ Yes, Cuban
- 5☐ Yes, Other Spanish/Hispanic/ Latino

43. What was <u>your family member's</u> race? Please choose one or more.

- 1☐ White
- 2☐ Black or African American
- 3☐ Asian
- 4☐ Native Hawaiian or other Pacific Islander
- 5☐ American Indian or Alaska Native

ABOUT YOU

44. What is your age?

- [1] ☐ 18 to 24
- [2] ☐ 25 to 34
- [3] ☐ 35 to 44
- [4] ☐ 45 to 54
- [5] ☐ 55 to 64
- [6] ☐ 65 to 74
- [7] ☐ 75 to 84
- [8] ☐ 85 or older

45. Are you male or female?

- [1] ☐ Male
- [2] ☐ Female

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

- [1] ☐ 8th grade or less
- [2] ☐ Some high school but did not graduate
- [3] ☐ High school graduate or GED
- [4] ☐ Some college or 2-year degree
- [5] ☐ 4-year college graduate
- [6] ☐ More than 4-year college degree

47. What language do you <u>mainly</u> speak at home?

- [1] ☐ English
- [2] ☐ Spanish
- [3] ☐ Chinese
- [4] ☐ Russian
- [5] ☐ Portuguese
- [6] ☐ Vietnamese
- [7] ☐ Polish
- [8] ☐ Korean
- [9] ☐ Some other language (please print):

_____

THANK YOU

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

[NAME OF SURVEY VENDOR]

[RETURN ADDRESS OF SURVEY VENDOR]

Sample Follow-up Cover Letter for the CAHPS Hospice Survey

[HOSPICE OR VENDOR LETTERHEAD]

[SAMPLED CAREGIVER NAME]
[ADDRESS]
[CITY, STATE ZIP]

Dear [SAMPLED CAREGIVER NAME]:

Our records show that you were recently a caregiver for [DECEDENT NAME] at [NAME OF HOSPICE]. Approximately three weeks ago, we sent you a survey regarding the care you and your family member or friend received from this hospice. If you have already returned the survey to us, please accept our thanks and disregard this letter. However, if you have not done so already, we would greatly appreciate it if you would take the time to complete this important questionnaire.

We hope that you will take this opportunity to help us learn about the quality of care your family member or friend received. The results from this survey will be used to help ensure that all Americans get the highest quality hospice care.

Questions [NOTE THE QUESTION NUMBERS] in the enclosed survey are part of a national initiative sponsored by the United States Department of Health and Human Services (HHS) to measure the quality of care in hospices. The Centers for Medicare & Medicaid Services (CMS) pays for most of the hospice care in the U.S. It is CMS' responsibility to ensure that hospice patients and their family members and friends get high quality care. One of the ways they can fulfill this responsibility is to find out directly from you about the hospice care your family member or friend received. Your participation is voluntary and will not affect any health care or benefits you receive.

Please take a few minutes and complete the enclosed survey. After you have completed the survey, please return it in the pre-paid envelope. Your answers may be shared with the hospice for purposes of quality improvement. [OPTIONAL: You may notice a number on the survey. This number is used to let us know if you returned your survey so we don't have to send you reminders.]

If you have any questions about the enclosed survey, please call the toll-free number 1-800-xxx-xxxx. Thank you for helping to improve hospice care for all consumers.

Sincerely,
[HOSPICE ADMINISTRATOR]
[HOSPICE NAME]

OMB Paperwork Reduction Act Language

The OMB Paperwork Reduction Act language must appear in the mailing, either on the cover letter or on the front or back of the questionnaire. In addition, the OMB control number must appear on the front page of the questionnaire. The following is the language that must be used:

English Version

"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 0938-1257 (Expires December 31, 2020). The time required to complete this information collection is estimated to average 11 minutes for questions 1 – 40, the "About Your Family Member" questions and the "About You" questions on the survey, including the time to review instructions, search existing data resources, gather the data needed, and complete and review the information collection. If you have any comments concerning the accuracy of the time estimate(s) or suggestions for improving this form, please write to: Centers for Medicare & Medicaid Services, 7500 Security Boulevard, C1-25-05, Baltimore, MD 21244-1850."