

# DRAFT Hospice Survey

Survey content subject to pending rulemaking – August 2024

Please answer the survey questions about the care the patient listed on the survey cover letter received from this hospice:

[NAME OF HOSPICE]

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

If you want to know more about this survey, please call XXX-XXX-XXXX. All calls to this number are free.

OMB # XXXX-XXXX

Expires TBD

## Who Should Fill Out the Survey?

- ◆ The person in your household who knows the most about the hospice care received by the patient listed on the survey cover letter.

## How to Fill Out the Survey

- ◆ Please use a dark colored pen.
- ◆ Please put an X inside the square by your answer, like this:
  - Yes
  - No
- ◆ At times you will be asked to skip some questions. When this happens you will see an arrow with a note that tells you where to go next, like this:
  - Yes → **If Yes, Go to Question 1**
  - No

You may notice a number on the survey. This number is used to let us know if you returned your survey so we do not have to send you reminders.

---

## The Hospice Patient

---

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

In what locations did your family member receive care from this hospice? Please choose 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 them?

- Never → If Never, go to Question 32
- Sometimes
- Usually
- Always

---

## Your Family Member's Hospice Care

---

For the rest of the questions, please think only about your family member's experience with the hospice listed on the survey cover.

4. For this survey, the hospice team means all the nurses, doctors, social workers, chaplains and others who gave hospice care to your family member.

While your family member was in hospice care, did you need to contact anyone on the hospice team during evenings, weekends, or holidays for questions or help?

- Yes
- 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?

- Never
- Sometimes
- Usually
- Always

**6. How often did the hospice team let you know when they would arrive to care for your family member?**

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

**7. 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. 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. How often did the hospice team keep you informed about your family member's condition?**

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

**10. How often did the hospice team treat your family member with dignity and respect?**

- 1 Never
- 2 Sometimes
- 3 Usually

4 Always

**11. How often did you feel that the hospice team really cared about your family member?**

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

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

**12. Did the hospice team provide care that respected your family member's wishes?**

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

**13. Did the hospice team make an effort to listen to the things that mattered most to you or your family member?**

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

**14. 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 16

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

**16. While your family member was in hospice care, did they have any pain?**

- <sup>1</sup>  Yes  
<sup>2</sup>  No → If No, go to Question 18

**17. Did your family member get as much help with pain as they needed?**

- <sup>1</sup>  Yes, definitely  
<sup>2</sup>  Yes, somewhat  
<sup>3</sup>  No

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

- <sup>1</sup>  Yes  
<sup>2</sup>  No → If No, go to Question 20

**19. How often did your family member get the help they needed for trouble breathing?**

- <sup>1</sup>  Never  
<sup>2</sup>  Sometimes  
<sup>3</sup>  Usually  
<sup>4</sup>  Always

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

- <sup>1</sup>  Yes  
<sup>2</sup>  No → If No, go to Question 22

**21. How often did your family member get the help they needed for trouble with constipation?**

- <sup>1</sup>  Never  
<sup>2</sup>  Sometimes  
<sup>3</sup>  Usually  
<sup>4</sup>  Always

**22. While your family member was in hospice care, did they show any feelings of anxiety or sadness?**

- <sup>1</sup>  Yes  
<sup>2</sup>  No → If No, go to Question 24

**23. How often did your family member get the help they needed from the hospice team for feelings of anxiety or sadness?**

- <sup>1</sup>  Never  
<sup>2</sup>  Sometimes  
<sup>3</sup>  Usually  
<sup>4</sup>  Always

---

### **Your Own Experience with Hospice**

---

**24. Hospice teams may teach you how to care for family members who need pain medicine, have trouble breathing, are restless or agitated, or have other care needs.**

**Did the hospice team teach you how to care for your family member?**

- <sup>1</sup>  Yes, definitely  
<sup>2</sup>  Yes, somewhat  
<sup>3</sup>  No  
<sup>4</sup>  I did not need this teaching

25. 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

26. 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

27. Support for religious, spiritual, or cultural beliefs may include talking, praying, quiet time, or respecting traditions.

While your family member was in hospice care, how much support for your religious, spiritual, or cultural beliefs did you get from the hospice team?

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

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

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

29. In the weeks after 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

---

30. Please answer the following questions about 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

**31. 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**

---

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

- 1 8<sup>th</sup> 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

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

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

**34. What was your family member's race? Please choose one or more.**

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

**35. How often was your family member treated unfairly by the hospice team because of their race or ethnicity?**

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

---

**About You**

---

**36. 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

**37. Are you male or female?**

- 1 Male
- 2 Female

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

- 1  8<sup>th</sup> 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

**39. What language do you mainly 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.**

COMPANY  
Attn: NAME  
STREET  
CITY, STATE ZIP

*Questions 1-39 in this survey are works of the U.S. Government and are in the public domain and therefore are NOT subject to U.S. copyright laws.*



