



# FAMILY EVALUATION OF HOSPICE CARE

Please answer these questions based on your experience and the patient's experience while under the care of hospice.

## SURVEY INSTRUCTIONS

Please answer each question by choosing the answer that best describes your experience and the patient's experience while under the care of hospice.

- Answer all the questions that apply to you by checking the box to the left of your answer or writing in the information in the space provided.
  
- 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

No → If No, Go to Question A2

❖ SECTION A ❖

A1) For about how many days or months did the patient receive hospice services?

- days  
\_\_\_\_\_  months

A2) As far as you know, did any member of the hospice team speak to the patient or to a family member about the patient's wishes for medical treatment as he/she was dying?

- Yes  
 No

A3) At any time while the patient was under the care of hospice, did the doctor or another hospice team member do anything with respect to end-of-life care that was inconsistent with the patient's previously stated wishes?

- Yes  
 No

❖ SECTION B ❖

B1) While under the care of hospice, did the patient have pain or take medicine for pain?

- Yes  
 No → **If No, Go to Question B5**

B2) How much medicine did the patient receive for his/her pain?

- Less than was wanted  
 Just the right amount  
 More than patient wanted

Please continue to the next column. 

B3) Did you or your family receive any information from the hospice team about the medicines that were used to manage the patient's pain?

- Yes  
 No  
 Don't Know

B4) Did you want more information than you got about the medicines used to manage the patient's pain?

- Yes  
 No

B5) While under the care of hospice, did the patient have trouble breathing?

- Yes  
 No → **If No, Go to Question B9**

B6) How much help in dealing with his/her breathing did the patient receive while under the care of hospice?

- Less than was wanted  
 Right amount  
 More than patient wanted

B7) Did you or your family receive any information from the hospice team about what was being done to manage the patient's trouble with breathing?

- Yes  
 No  
 Don't Know  
 No treatments used for breathing → **Go to Question B9**

Please continue to the next page. 

B8) Did you want more information than you got about what was being done for the patient's trouble with breathing?

- Yes
- No

B9) While the patient was under the care of hospice, did he/she have any feelings of anxiety or sadness?

- Yes
- No → **If No, Go to Question C1**

B10) How much help in dealing with these feelings did the patient receive?

- Less than was wanted
- Right amount
- More help or attention to these feelings than patient wanted

❖ **SECTION C** ❖

C1) How often were the patient's personal care needs - such as bathing, dressing, and changing bedding - taken care of as well as they should have been by the hospice team?

- Always
- Usually
- Sometimes
- Never
- Hospice team was not needed or wanted for personal care

C2) How often did the hospice team treat the patient with respect?

- Always
- Usually
- Sometimes
- Never

**Please continue to the next column.** 

❖ **SECTION D** ❖

D1) While the patient was under the care of hospice, did you participate in taking care of him/her?

- Yes
- No → **If No, Go to Question D5**

D2) Did you have enough instruction to do what was needed?

- Yes
- No

D3) How confident did you feel about doing what you needed to do in taking care of the patient?

- Very confident
- Fairly confident
- Not confident

D4) How confident were you that you knew as much as you needed to about the medicines being used to manage the patient's pain, shortness of breath, or other symptoms?

- Very confident
- Fairly confident
- Not confident

D5) How often did the hospice team keep you or other family members informed about the patient's condition?

- Always
- Usually
- Sometimes
- Never

**Please continue to the next page.** 

D6) Did you or your family receive any information from the hospice team about what to expect while the patient was dying?

- Yes
- No

D7) Would you have wanted more information about what to expect while the patient was dying?

- Yes
- No

D8) How confident were you that you knew what to expect while the patient was dying?

- Very confident
- Fairly confident
- Not confident

D9) How confident were you that you knew what to do at the time of death?

- Very confident
- Fairly confident
- Not confident

❖ SECTION E ❖

E1) Did any member of the hospice team talk with you about your religious or spiritual beliefs?

- Yes
- No

E2) Did you have as much contact of that kind as you wanted?

- Yes
- No

E3) How much emotional support did the hospice team provide to you prior to the patient's death?

- Less than was wanted
- Right amount
- More attention than was wanted

E4) How much emotional support did the hospice team provide to you after the patient's death?

- Less than was wanted
- Right amount
- More attention than was wanted

E5) While under the care of hospice, did the patient have a need for special medical equipment, such as a hospital bed, a wheel chair, or oxygen?

- Yes
- No → **If No, Go to Question E8**

E6) Did the patient receive all equipment needed?

- Yes
- No → **If No, Go to Question E8**

E7) How much of a problem, if any, was it to get the needed medical equipment?

- A big problem
- A small problem
- No problem

Please continue to the next column. 

Please continue to the next page. 

E8) How often did the patient have to wait too long for the pharmacy to deliver his/her medications?

- Always
- Usually
- Sometimes
- Never
- Don't Know
- Pharmacy did not deliver patient's medications

❖ SECTION F ❖

F1) How often did someone from the hospice team give confusing or contradictory information about the patient's medical treatment?

- Always
- Usually
- Sometimes
- Never

F2) While under the care of hospice, was there always one nurse who was identified as being in charge of the patient's overall care?

- Yes
- No

F3) Was there any problem with hospice doctors or nurses not knowing enough about the patient's medical history to provide the best possible care?

- Yes
- No

Please continue to the next column. 

Now, we would like you to rate some aspects of the care that the patient received while under the care of hospice.

For questions F4 through F8, please use a scale from 0 to 10, where 0 means the worst care possible and 10 means the best care possible. Circle the number below each question that matches your response.

F4) How well did the hospice team do at providing end-of-life medical care that respected the patient's wishes?

0 1 2 3 4 5 6 7 8 9 10  
Worst care Best care

F5) How well did the hospice team communicate with the patient and his/her family about the illness and the likely outcomes of care?

0 1 2 3 4 5 6 7 8 9 10  
Worst care Best care

F6) How well did the hospice team make sure that the patient's symptoms were controlled to a degree that was acceptable to him/her?

0 1 2 3 4 5 6 7 8 9 10  
Worst care Best care

F7) How well did the hospice team make sure that the patient died on his/her own terms?

0 1 2 3 4 5 6 7 8 9 10  
Worst care Best care

Please continue to the next page. 

F8) How well did the hospice team do at providing emotional support for you and the patient's family and friends?

0 1 2 3 4 5 6 7 8 9 10  
Worst care Best care

❖ SECTION G ❖

G1) Overall, how would you rate the care the patient received while under the care of hospice?

- Excellent
- Very good
- Good
- Fair
- Poor

G2) How would you rate the way the hospice team responded to your needs in the evenings and weekends?

- Excellent
- Very good
- Good
- Fair
- Poor
- Never contacted evening or weekend services

G2a) Overall, how would you rate the hospice team members who provided care?

- Excellent
- Very Good
- Good
- Fair
- Poor

G2b) Did the hospice team explain the plan of care to you in a way that you could understand?

- Yes
- No
- Hospice team did not explain plan of care to me

Please continue to the next column. 

G2c) How often did you agree with changes in the plan of care?

- Always
- Usually
- Sometimes
- Never
- No changes were made to plan of care

G2d) Did the hospice team's explanation of the Patient's Bill of Rights help you to understand your loved one's rights?

- Yes
- No
- Hospice team did not explain Patient's Bill of Rights to me

G3) Based on the care the patient received, would you recommend hospice services to others?

- Yes
- No

G3a) In your opinion, was the patient referred to hospice too early, at the right time, or too late during the course of his/her final illness?

- Too early → Go to Question G3b
- At the right time → Go to Question G3b
- Too late → Please explain

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G3b) While under the care of hospice, was the patient in a nursing home?

- Yes → Go to Question G3c
- No → Go to Question H1

Please continue to the next page. 

G3c) After hospice became involved, would you say the quality of end-of-life care the patient received:

- Improved
- Stayed the same
- Decreased

❖ SECTION H ❖

**Please give us the following information about your loved one:**

H1) How old was the patient when he/she died?

\_\_\_\_\_ years old

H2) Was the patient male or female?

- Male
- Female

H3) Please choose the one disease group that best describes the primary illness that caused the patient to be referred to hospice. *Please choose only one.*

- Cancers - all types
- Heart & circulatory diseases
- Lung & breathing diseases
- Kidney diseases
- Liver diseases
- Strokes
- Dementia & Alzheimer's disease
- AIDS & other infectious diseases
- Frailty and decline due to old age
- Another disease

\_\_\_\_\_ (Please write in)

H4) What is the highest grade or level of school that the patient completed?

- 8<sup>th</sup> grade or less
- Some high school but did not graduate
- High school graduate or GED
- 1-3 years of college
- 4-year college graduate
- More than a 4-year college degree

H5) Was the patient of Hispanic or Spanish family background?

- Yes
- No

H6) Which of the following best describes the patient's race?

- American Indian or Alaskan Native
- Asian or Pacific Islander
- Black or African-American
- White
- Another race or multiracial

\_\_\_\_\_

(Please write in)

❖ SECTION I ❖

**Please give us the following information about yourself:**

I1) What is your relationship to the patient?

- Spouse
- Partner
- Child
- Parent
- Sibling
- Other Relative
- Friend
- Other

\_\_\_\_\_

(Please write in)

I2) How old were you on your last birthday?

\_\_\_\_\_ years old

I3) Are you male or female?

- Male
- Female

