

FAMILY EVALUATION OF PALLIATIVE CARE



Please answer these questions based on your experience and the patient's experience while he or she was receiving palliative care.



Your answers are completely confidential.

SURVEY INSTRUCTIONS

This survey asks about your experience and the patient's experience while he or she was receiving palliative care.

- **'Palliative care' is medical care provided by a doctor, nurse, or other health care provider that focuses on managing pain and other symptoms in people with advanced illnesses.**
- **Answer each question based on the time period just before the patient's death during which he or she was receiving palliative care.**
- **Please answer each question by choosing one answer from the list provided for that question. Choose the answer that best describes your experience and/or the patient's experience while he or she was receiving palliative care.**
- **Answer all the questions that apply to you by checking the box to the left of the answer you choose or by writing your response 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 palliative care?

- _____ days
 months

A2) As far as you know, did any member of the medical care 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 receiving palliative care, did the doctor or another member of the medical care team 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 receiving palliative care, 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 medical care 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 receiving palliative care, 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 receiving palliative care?

- Less than was wanted
 Right amount
 More than patient wanted

B7) Did you or your family receive any information from the medical care 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 receiving palliative care, 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 medical care team?

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

C2) While the patient was receiving palliative care, how often did the medical care team treat him/her with respect?

- Always
- Usually
- Sometimes
- Never

Please continue to the next column. 

❖ **SECTION D** ❖

D1) While the patient was receiving palliative care, 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 medical care 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 medical care 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 medical care 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

Please continue to the next column. 

E3) How much emotional support did the medical care 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 medical care team provide to you after the patient's death?

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

❖ SECTION F ❖

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

- Always
- Usually
- Sometimes
- Never

F2) While receiving palliative care, was there always one doctor who was identified as being in charge of the patient's overall care?

- Yes
- No

F3) Was there any problem with 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 page. 

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

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) While the patient was receiving palliative care, how well did the medical care team do at providing care that respected his/her wishes?

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

F5) While the patient was receiving palliative care, how well did the medical care 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) While the patient was receiving palliative care, how well did the medical care team make sure that his/her symptoms were controlled to a degree that was acceptable to the patient?

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

Please continue to the next column. 

F7) While the patient was receiving palliative care, how well did the medical care 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

F8) While the patient was receiving palliative care, how well did the medical care 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 palliative care the patient received?

- Excellent
- Very good
- Good
- Fair
- Poor

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

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

Please continue to the next page. 

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

Please continue to the next column.



I3) Are you male or female?

- Male
- Female

I4) 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
- 1-3 years of college
- 4-year college graduate
- More than a 4-year college degree

I5) Are you of Hispanic or Spanish family background?

- Yes
- No

I6) Which of the following best describes your race?

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

(Please write in)

Please continue to the next page.



