



NSAP Audit Tool 3

Family Evaluation of Palliative Care (FEPC)

This survey tool is designed to assist specialist palliative care services to undertake a self-assessment against the Standards for Providing Quality Palliative Care for all Australians. The results of the survey tool are one form of evidence that services can cite in the self-assessment component of the National Standards Assessment Program (NSAP). While use of this tool is highly recommended it is not compulsory, and services can use other tools, including existing audit tools in place of the FEPC where these tools may already be in use.

Audit tool 3 – helpful information

Purpose:

to gather retrospective data from family members or friends on the care that a patient received at the end of life, as well as data on the information and support provided to family members.

Sample size:

a final sample of between 20 and 30 interviews should be aimed for. (Services may need to select a larger number in the initial sample because some family members you choose will not be able to participate or will choose not to participate.)

Sample selection:

details on sample selection are available in section 4 of the NSAP Guide.

Disclaimer and Acknowledgements

This survey tool has been derived from the Family Evaluation of Hospice Care developed by Brown University/NHPCO as part of the Toolkit of Instruments to Measure End of Life Care. It has been adapted by Palliative Care Australia for Australian circumstances.

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Instructions for the Interviewer

- When conducting this interview, read only lowercase text aloud to the respondent.
- Words that are underlined should be emphasized when read aloud to the respondent (e.g., see Question 32). It is important to the meaning of the question that these words be read with emphasis.
- Throughout the survey, instructions for interviewers are provided in **BOLDED CAPITAL** letters. Words appearing in bolded capital letters are meant to guide the interviewer and should not be read aloud to the respondent.
- Instructions written in lowercase letters are meant to guide the respondent and, therefore, *should* be read aloud to the respondent.
- It is important to read questions in their entirety and exactly as written.
- Question numbers should *not* be read to the respondent.
- Many of the survey questions consist of two parts: i) a question about an aspect of end-of-life care, and ii) a question that provides the response categories and asks the respondent to choose one those categories (e.g., see Question 4) In such cases, read aloud to the respondent both parts of the question as written. It is important to read all of the answer choices before pausing for a response.
- Answer categories are written in CAPITAL letters. Answer categories should not be read aloud to the respondent unless they appear in lowercase letters as part of the question (e.g., see Question 4).
- For yes/no questions, the answer categories should not be read aloud. As a result, the answer categories for yes/no questions are not written into the question.
- The interviewer often will need to insert specific information into survey questions. For example, the patient's name often needs to be inserted into questions. The interviewer will know to substitute specific information when a word written in CAPITAL letters is enclosed in brackets [] within the question.
EXAMPLE: How much medicine did [PATIENT] receive for [HIS/HER] pain?
READ AS: How much medicine did Mrs. Jones receive for her pain?
- Read questions as they are written. The interviewer should not provide a definition or clarification to the respondent. If the respondent has trouble answering the question or chooses more than one answer category, explain that he or she should choose the one answer category that best describes the patient's or his/her experience. Then, re-read the question. Never re-phrase a question because doing so may introduce bias into the survey results.

- After a respondent chooses an answer category, clearly mark the box that corresponds to that answer. For write-in and open-ended answers, mark the corresponding box and record the information as stated by the respondent.
- Based on the answers to certain questions, it sometimes is logical to skip subsequent questions. For example, a respondent who reports that the patient did not have trouble with breathing should not then be asked about treatments for trouble with breathing. In such cases, you will see an arrow after an answer category with an instruction that tells you what question to go to next. If a respondent chooses one of these answer categories, mark the corresponding box and then move on to the question number indicated after that answer category.

EXAMPLE: Q7. While receiving palliative care, did [PATIENT] have trouble breathing?

YES

NO → **GO TO QUESTION 11**

ACTION: If the respondent chooses “NO”, mark the box corresponding to “NO” and then skip to question 11. The answer categories for questions 8, 9 and 10 will be left blank.

- Sometimes a respondent will say that he or she does not know the information needed to answer a question. If “DON’T KNOW” is listed as a response category for that question (e.g., see question 5), then mark the corresponding box and follow any instructions indicated after the “DON’T KNOW” category. If “DON’T KNOW” is not listed as one of the response categories for that question, then mark the box corresponding to “NO ANSWER” and follow any instructions indicated after the “NO ANSWER” category.
- For all questions asked of the respondent during the interview, record the respondent’s answer, even if that answer does not correspond with information from the medical record.
- Be sure to familiarise yourself with the survey questions before conducting interviews.
- If your facility requires informed consent, adapt or replace the supplied Informed Consent Statement and read it to the respondent before starting the survey.

INTRODUCTORY STATEMENT

BEGIN BY READING THIS INTRODUCTION TO RESPONDENT:

Hello, my name is [NAME] and I am calling on behalf of [NAME OF FACILITY]. Please accept our deepest sympathy for the loss of [PATIENT]. I'm calling today because [NAME OF FACILITY] is very interested in getting your feedback about your experience and [PATIENT'S] experience while [HE/SHE] was receiving care from them during the time just before [HIS/HER] death. I have a short survey that I'd like to go through with you. Your answers to these questions will help to ensure that [NAME OF FACILITY] is providing the highest quality of care for patients nearing the end of life. Is this a good time for me to ask you some questions?

- YES → IF YES, CONTINUE WITH THE EXPLANATORY TEXT AND SURVEY
- NO, BECAUSE IT IS NOT A CONVENIENT TIME OR IT IS TOO SOON TO TALK ABOUT PATIENT'S DEATH → ASK THE RESPONDENT WHEN WOULD BE A GOOD TIME FOR YOU TO CALL BACK; SET A DATE AND TIME FOR THE RETURN CALL
- NO BECAUSE [HE/SHE] DOES NOT WANT TO PARTICIPATE IN THE SURVEY
END THE INTERVIEW BY THANKING THE PERSON FOR HIS OR HER TIME

A. Can you tell me how you were related to [PATIENT]?

TICK ONE:

- SPOUSE
- PARTNER
- CHILD
- DAUGHTER-IN-LAW/SON-IN-LAW
- PARENT
- SIBLING
- OTHER RELATIVE
- FRIEND
- OTHER (SPECIFY: _____)

B. How would you describe your relationship to [PATIENT]?

-
- NO ANSWER

C. Are you over 18 years of age?

- YES → CONTINUE TO QUESTION D
- NO → END THE INTERVIEW BY THANKING THE PERSON FOR HIS OR HER TIME

D. Would you say you are one of the people who knows the most about how [PATIENT] was doing during (his/her) last few weeks of life?

- YES → GO TO INFORMED CONSENT STATEMENT
- NO → END THE INTERVIEW BY THANKING THE PERSON FOR HIS OR HER TIME

INFORMED CONSENT STATEMENT

IF NECESSARY MODIFY THIS INFORMED CONSENT STATEMENT BASED ON YOUR OWN INSTITUTION'S REQUIREMENTS.

To make sure you have all the information about the study, I am going to read you a few sentences.

Your participation in this interview is, of course, voluntary. If you decide not to participate, it will not affect you in any way.

Your answers will be kept completely confidential to the extent of the law. The information from this study will not be presented or published in any way that would allow the identification of any respondent. Your answers will be combined with the answers of other people for statistical analysis.

It is important that your answers be accurate. Take your time and be sure to ask me if you are not sure what a question means or what kind of answer is wanted. It is very important that you answer as honestly and as accurately as you can. If there is any question you would rather not to answer, just tell me and I will skip it.

Do you have any questions about who is doing the study or anything else pertaining to the study?

May we proceed with the interview?

- YES → CONTINUE THE INTERVIEW → GO TO QUESTION 1
- NO → **END THE INTERVIEW BY THANKING THE PERSON FOR HIS OR HER TIME**

This survey asks about your experience and [PATIENT'S] experience while [HE/SHE] was receiving palliative care from [NAME OF FACILITY]. 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. Please answer the questions based on the time period just before [PATIENT'S] death during which [HE/SHE] was receiving palliative care. Your answers are completely confidential.

Q1. To get started, for about how many days or months did [PATIENT] receive palliative care from [NAME OF FACILITY]?

- 2 DAYS OR LESS
- 3-7 DAYS
- 8-14 DAYS
- 15-29 DAYS
- 1-3 MONTHS
- 4-6 MONTHS
- 7-9 MONTHS
- 10-12 MONTHS
- LONGER THAN 1 YEAR
- NO ANSWER

Q2. At any time while [PATIENT] was receiving palliative care, did the doctor or another medical care team member do anything with respect to end-of-life care that was inconsistent with [PATIENT'S] previously stated wishes?

- YES
- NO
- NO ANSWER

Q3. While receiving palliative care, did [PATIENT] have pain or take medicine for pain?

- YES
- NO → **GO TO Q7**
- NO ANSWER → **GO TO Q7**

Q4. How much medicine did [PATIENT] receive for [HIS/HER] pain? Would you say less than was wanted, just the right amount, or more than [HE/SHE] wanted?

- LESS THAN WAS WANTED
- JUST THE RIGHT AMOUNT
- MORE THAN PATIENT WANTED
- NO ANSWER

Q5. Did you or your family receive any information from the palliative care team about the medicines that were used to manage [PATIENT'S] pain?

- YES
- NO
- DON'T KNOW
- NO ANSWER

Q6. Did you want more information than you got about the medicines used to manage [PATIENT'S] pain?

- YES
- NO
- NO ANSWER

Q7. While receiving palliative care, did [PATIENT] have trouble breathing?

- YES
- NO → GO TO Q11
- NO ANSWER → GO TO Q11

Q8. How much help in dealing with [HIS/HER] breathing did [PATIENT] get while receiving palliative care? Would you say less help than was wanted, the right amount, or more help than [PATIENT] wanted?

- LESS THAN WAS WANTED
- RIGHT AMOUNT
- MORE THAN PATIENT WANTED
- NO ANSWER

Q9. Did you or your family receive any information from the palliative care team about what was being done to manage [PATIENT'S] trouble with breathing?

- YES
- NO
- DON'T KNOW
- NO TREATMENTS USED FOR BREATHING → GO TO Q11
- NO ANSWER

Q10. Did you want more information than you got about what was being done for [PATIENT'S] trouble with breathing?

- YES
- NO
- NO ANSWER

Q11. While [PATIENT] was receiving palliative care, did [HE/SHE] have any feelings of anxiety or sadness?

- YES
- NO → GO TO Q13
- NO ANSWER → GO TO Q13

Q12. How much help in dealing with these feelings did [PATIENT] receive? Would you say less help than was wanted, the right amount, or more help or attention to these feelings than [HE/SHE] wanted?

- LESS THAN WAS WANTED
- RIGHT AMOUNT
- MORE HELP OR ATTENTION THAN PATIENT WANTED
- NO ANSWER

Q13. How often were [PATIENT]'s personal care needs - such as bathing, dressing, and changing bedding - taken care of as well as they should have been? Would you say always, usually, sometimes, never, or that support was not needed or wanted for personal care?

- ALWAYS
- USUALLY
- SOMETIMES
- NEVER
- SUPPORT NOT NEEDED/WANTED FOR PERSONAL CARE
- NO ANSWER

Q14. While [PATIENT] was receiving palliative care, how often did the palliative care team treat [HIM/HER] with respect? Would you say always, usually, sometimes, or never?

- ALWAYS
- USUALLY
- SOMETIMES
- NEVER
- NO ANSWER

Q15. While [PATIENT] was receiving palliative care, did you participate in taking care of [HIM/HER]?

- YES
- NO → **GO TO Q19**
- NO ANSWER → **GO TO Q19**

Q16. Did you have enough instruction to do what was needed?

- YES
- NO
- NO ANSWER

Q17. How confident did you feel about doing what you needed to do in taking care of [PATIENT]? Would you say very confident, fairly confident, or not confident?

- VERY CONFIDENT
- FAIRLY CONFIDENT
- NOT CONFIDENT
- NO ANSWER

Q18. How confident were you that you knew as much as you needed to about the medicines being used to manage [PATIENT'S] pain, shortness of breath, or other symptoms? Would you say very confident, fairly confident, or not confident?

- VERY CONFIDENT
- FAIRLY CONFIDENT
- NOT CONFIDENT
- NO ANSWER

Q19. How often did the palliative care team keep you or other family members informed about [PATIENT'S] condition? Would you say always, usually, sometimes or never?

- ALWAYS
- USUALLY
- SOMETIMES
- NEVER
- NO ANSWER

Q20. Did you or your family receive any information from the palliative care team about what to expect while [PATIENT] was dying?

- YES
- NO
- NO ANSWER

Q21. Would you have wanted more information about what to expect while [PATIENT] was dying?

- YES
- NO
- NO ANSWER

Q22. How confident were you that you knew what to expect while [PATIENT] was dying? Would you say very confident, fairly confident, or not confident?

- VERY CONFIDENT
- FAIRLY CONFIDENT
- NOT CONFIDENT
- NO ANSWER

Q23. How confident were you that you knew what to do at the time of death? Would you say very confident, fairly confident, or not confident?

- VERY CONFIDENT
- FAIRLY CONFIDENT
- NOT CONFIDENT
- NO ANSWER

Q24. Did any member of the palliative care team talk with you about your religious or spiritual beliefs?

- YES
- NO
- NO ANSWER

Q25. Did you have as much contact of that kind as you wanted?

- YES
- NO
- NO ANSWER

Q26. How much emotional support did the palliative care team provide to you prior to [PATIENT'S] death? Would you say less than was wanted, the right amount, or more attention than you wanted?

- LESS THAN WAS WANTED
- RIGHT AMOUNT
- MORE ATTENTION THAN WAS WANTED
- NO ANSWER

Q27. How much emotional support did the palliative care team provide to you after [PATIENT'S] death? Would you say less than was wanted, the right amount, or more attention than you wanted?

- LESS THAN WAS WANTED
- RIGHT AMOUNT
- MORE ATTENTION THAN WAS WANTED
- NO ANSWER

Q28. How often did someone from the palliative care team give confusing or contradictory information about [PATIENT'S] medical treatment? Would you say always, usually, sometimes, or never?

- ALWAYS
- USUALLY
- SOMETIMES
- NEVER
- NO ANSWER

Q29. While receiving palliative care, was there always one care coordinator who was identified as being in charge of [PATIENT'S] overall care?

- YES
- NO
- NO ANSWER

Q30. Was there any problem with doctors or nurses not knowing enough about [PATIENT'S] medical history to provide the best possible care?

- YES
- NO
- NO ANSWER

Now, we would like you to rate some aspects of the palliative care that [PATIENT] received. For the next several questions, please use a scale from 0 to 10, where 0 means the worst care possible and 10 means the best care possible.

PLEASE CIRCLE RATING PROVIDED BY PATIENT.

Q31. On a scale from 0 to 10, how well did the palliative care team do at providing care that respected [PATIENT'S] wishes?

0 1 2 3 4 5 6 7 8 9 10 NO ANSWER

Q32. On a scale from 0 to 10, how well did the palliative care team communicate with [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 NO ANSWER

Q33. On a scale from 0 to 10, how well did the palliative care team make sure that [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 NO ANSWER

Q34. On a scale from 0 to 10, how well did the palliative care team make sure that [PATIENT] died on [HIS/HER] own terms?

0 1 2 3 4 5 6 7 8 9 10 NO ANSWER

Q35. On a scale from 0 to 10, how well did the palliative care team do at providing emotional support for you and [PATIENT'S] family and friends?

0 1 2 3 4 5 6 7 8 9 10 NO ANSWER

Q36. Overall, how would you rate the palliative care [PATIENT] received? Would you say excellent, very good, good, fair, or poor?

- EXCELLENT
- VERY GOOD
- GOOD
- FAIR
- POOR
- NO ANSWER

Q37. How would you rate the way that health care services responded to your needs in the evenings and weekends? Would you say excellent, very good, good, fair, poor, or that you never contacted or observed the evening or weekend services?

- EXCELLENT
- VERY GOOD
- GOOD
- FAIR
- POOR
- NEVER CONTACTED EVENING OR WEEKEND SERVICES
- NO ANSWER

Q38. Based on the care [PATIENT] received, would you recommend palliative care to others?

- YES
- NO
- NO ANSWER

Q39. In your opinion, did [PATIENT] begin receiving palliative care too early, at the right time, or too late during the course of [HIS/HER] final illness?

- TOO EARLY
- AT THE RIGHT TIME
- TOO LATE
- NO ANSWER

Q40. Now I have a few background questions about [PATIENT]. How old was [PATIENT] when [HE/SHE] died?

- | | |
|---|--|
| <input type="checkbox"/> 100 YEARS OR OLDER | <input type="checkbox"/> 50-54 YEARS OLD |
| <input type="checkbox"/> 95-99 YEARS OLD | <input type="checkbox"/> 45-49 YEARS OLD |
| <input type="checkbox"/> 90-94 YEARS OLD | <input type="checkbox"/> 40-44 YEARS OLD |
| <input type="checkbox"/> 85-89 YEARS OLD | <input type="checkbox"/> 35-39 YEARS OLD |
| <input type="checkbox"/> 80-84 YEARS OLD | <input type="checkbox"/> 30-34 YEARS OLD |
| <input type="checkbox"/> 75-79 YEARS OLD | <input type="checkbox"/> 25-29 YEARS OLD |
| <input type="checkbox"/> 70-74 YEARS OLD | <input type="checkbox"/> 20-24 YEARS OLD |
| <input type="checkbox"/> 65-69 YEARS OLD | <input type="checkbox"/> 18-19 YEARS OLD |
| <input type="checkbox"/> 60-64 YEARS OLD | <input type="checkbox"/> NO ANSWER |
| <input type="checkbox"/> 55-59 YEARS OLD | |

Q41. Was [PATIENT] male or female?

- MALE
- FEMALE
- NO ANSWER

Q42. Please choose the one disease group that best describes the primary illness that caused [PATIENT'S] death? Please choose only one. Would you say cancers, heart and circulatory diseases, lung and breathing diseases, kidney diseases, liver diseases, strokes, dementia and Alzheimer's disease, AIDS and other infectious disease, frailty and decline due to old age, or another disease?

- | | |
|---|---|
| <input type="checkbox"/> CANCERS - ALL TYPES | <input type="checkbox"/> STROKES |
| <input type="checkbox"/> HEART & CIRCULATORY DISEASES | <input type="checkbox"/> AIDS & OTHER INFECTIOUS DISEASES |
| <input type="checkbox"/> LUNG & BREATHING DISEASES | <input type="checkbox"/> FRAILTY AND DECLINE DUE TO OLD AGE |
| <input type="checkbox"/> KIDNEY DISEASES | <input type="checkbox"/> ANOTHER DISEASE |
| <input type="checkbox"/> LIVER DISEASES | <input type="checkbox"/> NO ANSWER |
| <input type="checkbox"/> DEMENTIA & ALZHEIMER'S DISEASE | |

Q43. What was that disease?

- ANSWER _____
- NO ANSWER

That was all the questions about [PATIENT]. We just have a few more questions about you.

Q44. How old were you on your last birthday?

- | | |
|---|---|
| <input type="checkbox"/> 100 YEARS OR OLDER | <input type="checkbox"/> 50-54 YEARS OLD |
| <input type="checkbox"/> 95-99 YEARS OLD | <input type="checkbox"/> 45-49 YEARS OLD |
| <input type="checkbox"/> 90-94 YEARS OLD | <input type="checkbox"/> 40-44 YEARS OLD |
| <input type="checkbox"/> 85-89 YEARS OLD | <input type="checkbox"/> 35-39 YEARS OLD |
| <input type="checkbox"/> 80-84 YEARS OLD | <input type="checkbox"/> 30-34 YEARS OLD |
| <input type="checkbox"/> 75-79 YEARS OLD | <input type="checkbox"/> 25-29 YEARS OLD |
| <input type="checkbox"/> 70-74 YEARS OLD | <input type="checkbox"/> 20-24 YEARS OLD |
| <input type="checkbox"/> 65-69 YEARS OLD | <input type="checkbox"/> FROM 15-19 YEARS OLD |
| <input type="checkbox"/> 60-64 YEARS OLD | <input type="checkbox"/> NO ANSWER |
| <input type="checkbox"/> 55-59 YEARS OLD | |

Q45. Are you male or female?

- MALE
- FEMALE
- NO ANSWER

CONCLUDING STATEMENT:

Those are all of the questions I have for you. I really appreciate you taking the time to participate in this survey. I know that sometimes it can be difficult to talk about the experience of losing a loved one. Please know that your responses will be used to help ensure that [NAME OF FACILITY] provides the highest quality of care to all patients nearing the end of their lives and their family members. Thank you again.

CONCLUDE INTERVIEW