

Dear Sir or Madam,

We would kindly ask you to complete the form below. You will be asked to evaluate the care your child received from our hospice. Your evaluation is of great value for us to learn about your most important needs and to adjust our care system to them.

The questionnaire is anonymous. From the information you provide, neither you or your child's identity will be revealed.

The results will be analyzed and published by us in a scientific journal/magazine/paper, as well as presented in the form of lectures for medical doctors and nurses.

Each form is meant to be filled out by one person on their own without the assistance of any other people. Please put an X in the appropriate boxes .

Please complete and send us back the form, using the enclosed envelope, as soon as possible.

Thank you.

Dr

Nurse

QUESTIONNAIRE

Evaluation of the Hospice care

1. How did you learn about the hospice?

- from your doctor
- from parents of other ill children
- from friends
- from the press or TV
- other source (please state what)

2. Why did you decide to take the child home? (you may choose more than one answer)

- my child wanted to be at home
- we understood that further hospital care is not beneficial
- the conditions at the hospital ward were difficult
- we wanted the whole family to be together
- other reasons (please state)

3. Did you have any concerns about the hospice care? (you may choose more than one answer)

- my child would not receive medical treatment
- my child would die sooner
- my child would find out the truth about his/her illness
- strangers would be coming to visit
- we would not cope with home care
- the hospice would create a depressing atmosphere
- the neighbors would think negatively of us
- other (please explain)

4. How would you evaluate the preliminary conversation with the hospice staff? (you may choose more than one answer)

- the information about the hospice was given in a clear manner
- the information about the hospice was not clear
- I was too upset and I cannot remember that conversation
- I felt relieved
- my anxiety increased
- other reaction (please state)

5. How would you evaluate the material received from the hospice (leaflets, videos)? (you may choose more than one answer)

- it helped me understand the hospice care
- it was not clear
- it raised my anxiety
- it helped me with future co-operation with the hospice
- I did not need it
- other (please state)

6. What were your expectations about the hospice care? (you may choose more than one answer)

- my child would not suffer any more
- my child would feel safe
- our helplessness as caretakers would decrease
- we would receive medical assistance
- we would receive psychological support
- we would receive spiritual support
- we would receive financial support
- the hospice would help make formal arrangements after my child's death
- other expectations (please state)

7. How would you evaluate the frequency of home visits by hospice staff?

- visits were too frequent
- visits were not frequent enough
- frequency of visits was adequate

8. How would you evaluate the teaching about your child's care from the hospice doctors and nurses?

- adequate
- not adequate

Comment:

9. How would you evaluate financial costs during your child's home care?

- home care did not negatively affect our budget
- costs of home care exceeded our budget, adequate care was possible due to hospice financial support
- costs of home care exceeded our budget, adequate care was not possible in spite of hospice financial support

Comment:

10. What was most difficult for you during the home care of your child (please choose the **three** most important from the list or add your own choices and number according to importance: 1, 2 and 3).

- my own physical exhaustion
- my own emotional exhaustion
- spiritual crisis
- fear
- helplessness
- co-operation with the hospice
- co-operation with my spouse
- co-operation with other family members
- talking with my ill child
- talking with other children
- controlling pain and other symptoms
- my own inability to providing care
- making decisions (which ones?.....)
- other (please state)
-

11. Name the problems mentioned in question 10 which the hospice **was able** to help you with.

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.....

12. Name the problems mentioned in question 10 which the hospice **was not able** to help you with.

.....
.....

13. Did any decisions made by hospice doctors or recommendations by hospice staff were hard to agree with or did not meet your expectations?

- yes no

If yes, please state.....
.....

14. Did you speak honestly with your child about their approaching death?

- yes no

15. If you answered 'yes' to question 14, was this decision influenced by your contact with the hospice?

- yes no

16. If you have answered 'no' to question 14, please explain why.

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17. Did you feel prepared for your child's death?

- yes no

18. If you have answered 'yes' to question 16, please describe the role of the hospice.

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19. If you have answered 'no' to question 16, please explain why.

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.....

20. Which symptoms caused your child's suffering?

Please list.....
.....

21. How would you rate the treatment of symptoms listed in question 20 by doctors and nurses of the hospice?

- my child suffered very often because symptoms were not treated properly
 my child suffered most of the time, occasionally the treatment resulted in relief
 my child suffered rarely, occasionally symptoms increased, but were relieved when medications were provided
 my child never suffered because the symptoms were treated successfully

Comments:

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22. How would you describe the last hours of your child's life? (you may choose more than one answer)

- my child was peaceful
 my child did not suffer
 my child did suffer
 my child was unconscious
 my child was conscious
 my child was afraid
 my child did not want to die
 my child accepted his/her death
 other (please state)

23. Did you want a person from the hospice to be present at your child's death? (you may choose more than one answer)

- yes, a nurse
 yes, a doctor
 yes, a chaplain
 yes, an other person from the hospice (who?)
 no

24. How would you evaluate the presence of the hospice staff in the last moments of your child's life?

- it was helpful
 it made me feel uncomfortable
 I did not need it
 does not apply (if the hospice staff were not present)

Comments:

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25. How would you evaluate the assistance of the hospice staff with the formal arrangements following your child's death?

- positive
 negative

Comments:

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26. Did you take part in the meetings of the bereavement support group?

yes

If yes, please state how you benefited from these meetings:

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.....

no

If no, please state why:

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27. Were you satisfied with the hospice care your child received?

yes no

Please, rate giving a mark from **0** (very disappointed) to **10** (very satisfied)

Your mark:

28. How would you evaluate the assistance of the hospice doctors?

Please, evaluate giving a mark from **0** (very disappointed) to **10** (very satisfied)

Your mark:

29. How would you evaluate the assistance of the hospice nurses?

Please, evaluate giving a mark from **0** (very disappointed) to **10** (very satisfied)

Your mark:

30. How would you evaluate the assistance of the hospice social workers?

Please, evaluate giving a mark from **0** (very disappointed) to **10** (very satisfied)

Your mark:

31. How would you evaluate the assistance of the hospice chaplain?

Please, evaluate giving a mark from **0** (very disappointed) to **10** (very satisfied)

Your mark:

32. How would you evaluate the assistance of the hospice psychologist?

Please, evaluate giving a mark from **0** (very disappointed) to **10** (very satisfied)

Your mark:

33. How would you evaluate the assistance of the hospice counselor?

Please, evaluate giving a mark from **0** (very disappointed) to **10** (very satisfied)

Your mark:

34. How would you evaluate the assistance of the hospice volunteers?

Please, evaluate giving a mark from **0** (very disappointed) to **10** (very satisfied)

Your mark:

35. What would you change in our hospice care?

Comments:

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Date of completing this form:

Period of time under hospice care:

First and Last name of child:

Age of child:Sex of child:

Type of illness:

Personal data of the person completing this form:

Relationship: mother, father, grandmother, grandfather, other

Place of living: Warsaw, other town, village

Education: high school, vocational, college