



Welcome to the questionnaire for close family from the Swedish Register of Palliative Care, a national quality register.

The purpose of the questionnaire is to improve end-of-life care. We are grateful to you for taking the time to answer the questions; your experiences and comments are valuable.

By completing the questionnaire you give your consent to allow us to use it for research. Neither you nor your loved one will be identifiable; your personal data will not be disclosed.

Many thanks in advance!

1. First and last name of your loved one:

Ward/team where your loved one died:

1b. Personal identity number/reserve number _____

If the answer is RESERVE NUMBER, also answer 1c and 1d.

1c. Sex

- Man
- Woman
- Unknown

1d. Age _____

Before your loved one arrived at the place where s/he died:

2. Did you feel that your loved one received the care s/he needed before coming to the ward/care team where s/he died?

- Yes, completely
- Yes, partly
- No, not completely
- No, not at all
- Don't know
- Not applicable

3. Did you receive the support you needed from the healthcare system before your loved one came to the ward/care team where s/he died?

- Yes, completely
- Yes, partly
- No, not completely
- No, not at all
- I did not feel I needed any support
- Don't know
- Not applicable

The last days of life:

4. Did you feel that your loved one understood that s/he was dying?

- Yes, completely
- Yes, occasionally/partly
- Yes, but too late
- No
- No, but my loved one did not want to have more information than s/he received
- No, as a close relative I did not want the healthcare system to inform my loved one
- Don't know

5. Did you receive counselling from a doctor who told you or helped you understand that your loved one was dying?

- Yes, it was a good counselling session
- Yes, but it was not a good counselling session
- No
- No, but from a different care provider
- No, but I did not want more information than I received
- Don't know

6. Did you receive information from a care provider about the possibility of using the cash benefit for care of closely related persons?

- Yes
- No
- Not applicable

7. Did you know where to turn to receive emergency assistance (including at night or on a weekend or holiday) for your loved one during the last week of life?

- Yes
- No

8. Did you know how to get in touch with the doctor who was responsible for your loved one?

- Yes
- No

9. Did you feel that your loved one received the care s/he needed at the ward/care team where s/he died?

- Yes, completely
- Yes, partly
- No, not completely
- No, not at all
- Don't know

10. Did you receive the support you needed from the healthcare system before the death of your loved one at the ward/care team where your loved one died?

- Yes, completely
- Yes, partly
- No, not completely
- No, not at all
- I did not feel I needed any support
- Don't know

11. Please feel free to leave further comment:

12. How long before the death of your loved one did s/he lose the ability to express his/her wishes and participate in decisions about the care s/he would receive?

- Hour(s)
- Day(s)
- Week(s)
- Month(s)
- Unable to make decisions for several months or more
- Retained ability until end of life
- Don't know

Did your loved one experience any of the following symptoms (13–15) at any time during the last week of life?

13a. Pain

- Yes
- No
- Don't know

13b. If the answer is YES:

The pain was relieved

- Completely
- Partly
- Not at all
- Don't know

14a. Anxiety

- Yes
- No
- Don't know

14b. If the answer is YES:

The anxiety was relieved

- Completely
- Partly
- Not at all
- Don't know

15a. Confusion

- Yes
- No
- Don't know

15b. If the answer is YES:

The confusion was relieved

- Completely
- Partly
- Not at all
- Don't know

16. Was anyone present at the moment of death?

- Yes, I or another close relative
- Yes, close relative and staff
- Yes, someone from the staff
- No
- Don't know

16b. Please feel free to leave further comment about the situation:

After the death:

17. Were you offered counselling with healthcare staff a period of time after the death?

- Yes, I received/will receive counselling
- Yes, but I refused
- No
- Don't know

18. Do you have any suggestions for improving end-of-life care for people in a similar situation to your loved one?

19. Do you have any suggestions for improving support for you as a close relative?

20. Filled in by:

- Husband/wife/partner
- Child
- Sibling
- Other relative
- Friend
- Custodian
- Parent

21. Would you like to provide any feedback to the department/care team where your loved one died? (The Register will forward this feedback to those concerned in a way that you and your loved one remain anonymous):

Thank you for your participation!