



*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:

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Ward/team where your loved one died:

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**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?

- 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:

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**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:**

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**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?

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

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**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):

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***Thank you for your participation!***