



Welcome to the Next-of-Kin Questionnaire.

The Swedish Register of Palliative Care has developed a questionnaire for people close to the deceased, with the aim of improving palliative care.

You receive this questionnaire from the healthcare staff who cared for your loved one during their final period of life, and by completing the questionnaire you consent to your answers also being used for research purposes.

Neither you nor your loved one can be identified, and no personal data will be disclosed.

If you are able to do so, we would be grateful if you would complete the questionnaire—your experiences and views are very valuable to us.

1. First and last name of your loved one:

Place where your loved one died:

1b. Personal identity number/temporary number _____

Enter the personal identity number in the format 19121212–1212.

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

1c. Sex

- Male
- Female
- Other

1d. Age _____

Before your loved one arrived at the place where they died:

2. Did you feel that your loved one received the care they needed before they came to the place where they died?

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



The “yes” and “no” response options are graded; choose the option that best matches your own view. If there was no other contact with healthcare before your loved one arrived at the place where they died, choose “Not applicable”.

3. Did you receive the support you needed from healthcare before your loved one came to the place where they 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 “yes” and “no” response options are graded; choose the option that best matches your own view. If there was no other contact with healthcare before your loved one arrived at the place where they died, choose “Not applicable”.

The last days of life:

4. Did you feel that your loved one had understood that they were dying?

- Yes, completely
- Yes, from time to time/partly
- Yes, but too late
- No
- No, but my loved one did not want more information than they received
- No, because as someone close to them I did not want the healthcare team to inform my loved one
- Don't know

The “yes” and “no” options are split into statements; choose the option that best matches how you perceived the situation. The option “Yes, but too late” should be understood as meaning that you feel the insight came too late and affected your loved one or the care negatively.

5. Did you have any conversation in which a physician told you, or helped you understand, that your loved one was dying?

- Yes, it was a good conversation
- Yes, but it was not a good conversation
- No
- No, but with other healthcare staff
- No, but I did not want more information than I received
- Don't know

The “yes” and “no” options are split into statements; choose the option that best matches how you experienced any conversation that took place. If you had a conversation that you



later (in retrospect) understood to be about your loved one dying, choose “Yes, but it was not a good conversation”.

6. Did you receive information from healthcare staff about the possibility of using so-called “närståendepenning” days (Swedish care benefit days for supporting a seriously ill loved one)?

- Yes
- No
- Not applicable

Even if you did not use “närståendepenning” but did receive information, answer “Yes”. Answer “Not applicable” if support through “närståendepenning” could not be offered—for example if you are not in paid employment, are retired, or are a student.

7. Did you know where to turn to get urgent help (including, for example, at night/weekends) for your loved one during the last week of life?

- Yes, but I did not need any help
- Yes, and I received help
- Yes, but I did not receive enough help
- No, I did not know

8. Were you able to get in contact with the physician who was responsible for your loved one?

- I did not need to make contact
- Yes, and it was easy to get in contact
- Yes, but it was difficult to get in contact
- No, I was not able to get in contact

9. Did you feel that your loved one received the care they needed at the place where they died?

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

The “yes” and “no” response options are graded; choose the option that best matches your own view.

10. Did you receive the support you needed from healthcare before the death, at the place 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

The "yes" and "no" response options are graded; choose the option that best matches your own view.

11. Please feel free to leave any additional comments:

Here you can, in your own words, leave comments about your experience and your loved one's experience of the care.

12. How long before the death did your loved one lose the ability to express their wishes and take part in decisions about what care they would receive?

Ability maintained until the end of life

Hour/hours

Day/days

Week/weeks

A month or more/never had decision-making capacity/did not have decision-making capacity from the time of admission

Don't know

Choose the option that best matches your view of your loved one's ability to take part in decisions and express their wishes—for example, to say yes or no to the care being offered.

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

The purpose of questions 13–15 is to understand how you perceived your loved one's symptoms.

13a. Pain

Yes

No

Don't know

Pain can present in many different ways, and in this question we are asking for your perception of whether pain occurred.

13b. If the answer is YES:

The pain was relieved

Completely

Partly, and my loved one felt it was enough

Partly, but my loved one was still distressed by it

Not at all

Don't know

14a. Unease/anxiety

Yes

- 
- No
 - Don't know

“Unease/anxiety” is a strong term and can present in many different ways, and in this question we are asking for your perception of whether anxiety occurred.

14b. If the answer is YES:

The unease/anxiety was relieved

- Completely
- Partly, and my loved one felt it was enough
- Partly, but my loved one was still distressed by it
- Not at all
- Don't know

15a. Shortness of breath (breathlessness)

- Yes
- No
- Don't know

In this question we are asking for your perception—whether you experienced that your loved one had shortness of breath.

15b. If the answer is YES:

The shortness of breath was relieved

- Completely
- Partly, and my loved one felt it was enough
- Partly, but my loved one was still distressed by it
- Not at all
- Don't know

16. Was anyone present in the room at the time of death?

- Yes, a relative or close friend (next of kin)
- Yes, a relative or close friend (next of kin) and staff
- Yes, staff only
- No
- Don't know

If your loved one died while the person who was present was asleep, please write this in the comment field below and choose the most suitable “Yes” option. If the person who was present temporarily left the room at the moment of death, please write this in the comment field below and choose “No”.

16b. Please feel free to leave any additional comments about the situation:

Here you can, in your own words, leave comments about your experience and your loved one's experience of the situation.



After the death:

17. Were you offered a conversation with the healthcare staff some time after the death?

- Yes, I have had the conversation/will have it
- Yes, but I declined
- No
- Don't know

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

Here you can, for example, mention something in your experience of the care that you wish more people had access to.

19. Do you have any suggestions for improving the support provided to you as someone close to the deceased?

Here you can, for example, mention support you appreciated and wish more people in your situation could have access to, or mention something you missed.

20. Completed by (more than one option is possible):

- Spouse/ partner
- Child
- Sibling
- Parent
- Other relative
- Friend
- Legal representative

21. Would you like to provide any feedback to the staff at the place where your loved one died?

(If you would like to make a personal greeting to the staff, you need to provide your name or your loved one's name, since the responses are otherwise anonymous.)

Thank you for your participation.