

UNIVERSITY OF WASHINGTON SCHOOL OF MEDICINE



**QUALITY OF DYING AND DEATH
QUESTIONNAIRE FOR FAMILY MEMBERS – VERSION 3.2A**

Please return your completed questionnaire in the enclosed envelope to:

[*Return Address*]

RNID _____

PID _____

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**A QUESTIONNAIRE FOR FAMILIES ABOUT
A LOVED ONE’S EXPERIENCES AT THE END OF LIFE**

This questionnaire is about experiences that you and your loved one had during his or her stay in the Intensive Care Unit (ICU). We are interested in your experiences because we want to improve the care received by patients and family members.

Some of these questions may be difficult to answer because you may not have had all these experiences. Other questions may be hard to answer because they remind you of a difficult emotional time. Please feel free to skip questions that you find too difficult to answer. This questionnaire will be kept entirely confidential. None of the healthcare providers who provided care to your loved one will see any of your answers.

From your perspective, we would like to know how often your loved one had the experiences described below. Please pick a number from 0 to 5 with “0” indicating “none of the time” and “5” indicating “all of the time”. Then, we would like you to rate this aspect of your loved one’s dying experience on a scale from 0 to 10, where “0” is a “terrible experience”, and “10” is an “almost perfect experience”.

Please make your best effort to choose a number, even if you are not completely certain of the answer. If you cannot pick a number, please circle “Don’t Know” so that we will know that this is a question you cannot answer. We want you to choose a number based on your experience, not what you think your loved one might have answered.

A stamped self-addressed envelope is attached. Please complete this questionnaire and send it back to us as soon as possible. If you have any questions or problems when filling out this questionnaire, please feel free to call us and we’ll do everything we can to assist you. There is also room for your comments at the end of the questionnaire. Once again, thank you for your help.

During the last several days that your loved one was in the ICU:

1a. How often did your loved one appear to have his/her pain under control?
(Circle one number)

- 0 None of the time
- 1 A little bit of the time
- 2 Some of the time
- 3 A good bit of the time
- 4 Most of the time
- 5 All of the time
- 6 Don't know >>>>>>>>> Go to Question 2a.

b. How would you rate this aspect of your loved one's dying experience?
(Circle one number)

Terrible	0	1	2	3	4	5	6	7	8	9	10	Almost Perfect
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2a. How often did your loved one appear to have control over what was going on around him/her? (Circle one number)

- 0 None of the time
- 1 A little bit of the time
- 2 Some of the time
- 3 A good bit of the time
- 4 Most of the time
- 5 All of the time
- 6 Don't know >>>>>>>>> Go to Question 3a.

b. How would you rate this aspect of your loved one's dying experience?
(Circle one number)

Terrible	0	1	2	3	4	5	6	7	8	9	10	Almost Perfect
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During the last several days that your loved one was in the ICU:

3a. How often was your loved one able to feed her/himself? *(Circle one number)*

- 0 None of the time
- 1 A little bit of the time
- 2 Some of the time
- 3 A good bit of the time
- 4 Most of the time
- 5 All of the time
- 6 Don't know >>>>>>>>> Go to Question 4a.

b. How would you rate this aspect of your loved one's dying experience?
(Circle one number)

Terrible	0	1	2	3	4	5	6	7	8	9	10	Almost Perfect
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4a. How often did your loved one appear to breathe comfortably?
(Circle one number)

- 0 None of the time
- 1 A little bit of the time
- 2 Some of the time
- 3 A good bit of the time
- 4 Most of the time
- 5 All of the time
- 6 Don't know >>>>>>>>> Go to Question 5a.

b. How would you rate this aspect of your loved one's dying experience?
(Circle one number)

Terrible	0	1	2	3	4	5	6	7	8	9	10	Almost Perfect
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During the last several days that your loved one was in the ICU:

5a. How often did your loved one appear to feel at peace with dying?
(Circle one number)

- 0 None of the time
- 1 A little bit of the time
- 2 Some of the time
- 3 A good bit of the time
- 4 Most of the time
- 5 All of the time
- 6 Don't know >>>>>>>>> Go to Question 6a.

b. How would you rate this aspect of your loved one's dying experience?
(Circle one number)

Terrible	0	1	2	3	4	5	6	7	8	9	10	Almost Perfect
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6a. How often did your loved one appear to be unafraid of dying? (Circle one number)

- 0 None of the time
- 1 A little bit of the time
- 2 Some of the time
- 3 A good bit of the time
- 4 Most of the time
- 5 All of the time
- 6 Don't know >>>>>>>>> Go to Question 7a.

b. How would you rate this aspect of your loved one's dying experience?
(Circle one number)

Terrible	0	1	2	3	4	5	6	7	8	9	10	Almost Perfect
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During the last several days that your loved one was in the ICU:

7a. How often did your loved one laugh and smile? *(Circle one number)*

- 0 None of the time
- 1 A little bit of the time
- 2 Some of the time
- 3 A good bit of the time
- 4 Most of the time
- 5 All of the time
- 6 Don't know >>>>>>>>> Go to Question 8a.

b. How would you rate this aspect of your loved one's dying experience?
(Circle one number)

Terrible	0	1	2	3	4	5	6	7	8	9	10	Almost Perfect
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8a. How often did your loved one appear to keep his/her dignity and self-respect?
(Circle one number)

- 0 None of the time
- 1 A little bit of the time
- 2 Some of the time
- 3 A good bit of the time
- 4 Most of the time
- 5 All of the time
- 6 Don't know >>>>>>>>> Go to Question 9a.

b. How would you rate this aspect of your loved one's dying experience?
(Circle one number)

Terrible	0	1	2	3	4	5	6	7	8	9	10	Almost Perfect
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During the last several days that your loved one was in the ICU:

9a. How often did your loved one spend time with his/her family or friends?
(Circle one number)

- 0 None of the time
- 1 A little bit of the time
- 2 Some of the time
- 3 A good bit of the time
- 4 Most of the time
- 5 All of the time
- 6 Don't know >>>>>>>>>> Go to Question 10a.

b. How would you rate this aspect of your loved one's dying experience?
(Circle one number)

Terrible	0	1	2	3	4	5	6	7	8	9	10	Almost Perfect
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10a. How often did your loved one spend time alone? (Circle one number)

- 0 None of the time
- 1 A little bit of the time
- 2 Some of the time
- 3 A good bit of the time
- 4 Most of the time
- 5 All of the time
- 6 Don't know >>>>>>>>>> Go to Question 11a.

b. How would you rate this aspect of your loved one's dying experience?
(Circle one number)

Terrible	0	1	2	3	4	5	6	7	8	9	10	Almost Perfect
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The following questions are answered with either a “Yes” or “No” based on whether your loved one did certain activities. Please rate the quality of that aspect of the dying experience. Again, we are asking you to focus on your loved one’s last several days.

During the last several days that your loved one was in the ICU:

11a. Was your loved one touched or hugged by his/her loved ones? (Circle one number)

- 1 Yes
- 2 No
- 3 Don't know >>>>>>>>> Go to Question 12a.

b. How would you rate this aspect of your loved one’s dying experience? (Circle one number)

Terrible	0	1	2	3	4	5	6	7	8	9	10	Almost Perfect
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12a. Were all of your loved one’s health care costs taken care of? (Circle one number)

- 1 Yes
- 2 No
- 3 Don't know >>>>>>>>> Go to Question 13a.

b. How would you rate this aspect of your loved one’s dying experience? (Circle one number)

Terrible	0	1	2	3	4	5	6	7	8	9	10	Almost Perfect
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REMEMBER: IF YOU HAVE ANY QUESTIONS, PLEASE CALL.

During the last several days that your loved one was in the ICU:

13a. Did your loved one say goodbye to loved ones? *(Circle one number)*

- 1 Yes
- 2 No
- 3 Don't know >>>>>>>>>> Go to Question 14a.

b. How would you rate this aspect of your loved one's dying experience?
(Circle one number)

Terrible	0	1	2	3	4	5	6	7	8	9	10	Almost Perfect
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14a. Did your loved one clear up any bad feelings with others? *(Circle one number)*

- 1 Yes
- 2 No
- 3 Don't know >>>>>>>>>> Go to Question 15a.

b. How would you rate this aspect of your loved one's dying experience?
(Circle one number)

Terrible	0	1	2	3	4	5	6	7	8	9	10	Almost Perfect
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15a. Did your loved one have one or more visits from a religious or spiritual advisor?
(Circle one number)

- 1 Yes
- 2 No
- 3 Don't know >>>>>>>>>> Go to Question 16a.

b. How would you rate this aspect of your loved one's dying experience?
(Circle one number)

Terrible	0	1	2	3	4	5	6	7	8	9	10	Almost Perfect
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During the last several days that your loved one was in the ICU:

16a. Did your loved one have a spiritual service or ceremony before his/her death?

(Circle one number)

- 1 Yes
- 2 No
- 3 Don't know >>>>>>>>> Go to Question 17a.

b. How would you rate this aspect of your loved one's dying experience?

(Circle one number)

Terrible	0	1	2	3	4	5	6	7	8	9	10	Almost Perfect
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17a. Did your loved one receive a mechanical ventilator (respirator) to breathe for him/her? *(Circle one number)*

- 1 Yes
- 2 No
- 3 Don't know >>>>>>>>> Go to Question 18a.

b. How would you rate this aspect of your loved one's dying experience?

(Circle one number)

Terrible	0	1	2	3	4	5	6	7	8	9	10	Almost Perfect
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18a. Did your loved one receive dialysis for his/her kidneys? *(Circle one number)*

- 1 Yes
- 2 No
- 3 Don't know >>>>>>>>> Go to Question 19a.

b. How would you rate this aspect of your loved one's dying experience?

(Circle one number)

Terrible	0	1	2	3	4	5	6	7	8	9	10	Almost Perfect
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Please answer either "Yes" or "No" if your loved one ever experienced the following. Then, rate the quality of this aspect of your loved one's dying experience.

19a. Did your loved one have his or her funeral arrangements in order prior to death?
(Circle one number)

- 1 Yes
- 2 No
- 3 Don't know >>>>>>>>> Go to Question 20a.

b. How would you rate this aspect of your loved one's dying experience?
(Circle one number)

Terrible	0	1	2	3	4	5	6	7	8	9	10	Almost Perfect
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20a. Did your loved one discuss his or her wishes for end of life care with his/her doctor -- for example, resuscitation or intensive care? (Circle one number)

- 1 Yes
- 2 No
- 3 Don't know >>>>>>>>> Go to Question 21a.

b. How would you rate this aspect of your loved one's dying experience?
(Circle one number)

Terrible	0	1	2	3	4	5	6	7	8	9	10	Almost Perfect
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21a. Was anyone present at the moment of your loved one's death? *(Circle one number)*

- 1 Yes
- 2 No
- 3 Don't know >>>>>>>>> *Go to Question 22a.*

b. How would you rate this aspect of your loved one's death? *(Circle one number)*

Terrible	0	1	2	3	4	5	6	7	8	9	10	Almost Perfect
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22a. In the moment before your loved one's death, was he/she: *(Circle one number)*

- 1 Awake
- 2 Asleep
- 3 In a coma or unconscious
- 4 Don't know >>>>>>>>> *Go to Question 23.*

b. How would you rate this aspect of your loved one's death? *(Circle one number)*

Terrible	0	1	2	3	4	5	6	7	8	9	10	Almost Perfect
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23. Overall, how would you rate the quality of your loved one's dying? *(Circle one number)*

Terrible	0	1	2	3	4	5	6	7	8	9	10	Almost Perfect
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24. **Rate the care your loved one received from all doctors and other health care providers (including nurses, caseworkers, and other health care professionals) during the last several days of his or her life while in the ICU. (Circle the number)**

Worst Healthcar e Possible	0	1	2	3	4	5	6	7	8	9	10	Best Healthcar e Possible
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25. **Rate the care your loved one received from his or her doctor during the last several days of his or her life while in the ICU. (Circle the number)**

Worst Healthcar e Possible	0	1	2	3	4	5	6	7	8	9	10	Best Healthcar e Possible
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REMEMBER: IF YOU HAVE ANY QUESTIONS, PLEASE CALL.

ABOUT YOU

In this section, we would like to ask a few questions about you and about your loved one.

1. **When were you born?** *(Please write the year)*

19 _____

2. **When was your loved one born?** *(Please write the year)*

19 _____

3. **What is your gender?** *(Circle one number)*

1 Male

2 Female

4. **What is your loved one's gender?** *(Circle one number)*

1 Male

2 Female

5. **Approximately how many days was your loved one in the hospital?**
(Please write the number of days)

_____ days

6. **Approximately how many days was your loved one in the intensive care unit (ICU)?** *(Please write the number of days)*

_____ days

7. **What is your ethnicity?** *(Circle one number)*

1 Hispanic

2 Non-Hispanic

8. What is your race? *(Circle all that apply)*

- 1 White
- 2 Black / African American
- 3 Asian
- 4 Pacific Islander
- 5 Native American or Alaskan Native
- 6 Other (please specify) _____

9. What is the highest level of schooling you have completed? *(Circle one number)*

- 1 8th grade or less
- 2 Some high school
- 3 High school diploma or GED
- 4 Some college or trade school
- 5 4-year college degree (e.g. BA, BS)
- 6 Graduate or professional school

10. How are you related to your loved one? *(Circle one number)*

- 1 I am his/her spouse or partner
- 2 I am his/her child
- 3 I am his/her sibling
- 4 I am his/her parent
- 5 I am another relative
- 6 I am his/her friend
- 7 Other (please specify) _____

11. Did you live with your loved one? *(Circle one number)*

- 1 Yes
- 2 No

12. **How long have you known your loved one?** *(Please fill in)*

_____ number of years OR _____ number of months

13. **Today's date is:** *(Please fill in today's date)*

____/____/20____
Month Day Year

14. **We would like to get feedback from you on how burdensome it was to complete this questionnaire. This information will help guide us in future research. Overall, how much of a burden on you was this questionnaire?** *(Circle one number)*

No burden at all	Moderate burden										Great burden
	0	1	2	3	4	5	6	7	8	9	

Thank you for taking the time to complete this survey. If you have any comments, please feel free to add them to the margins of the survey or to the space below, or call to talk with study staff. Thank you again for your help.