

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

**Q1a** How often did your loved one appear to have his/her pain under control?

*Please circle one number*

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

**Q1b** How would you rate this aspect of your loved one's dying experience?

*Please circle one number*

|          |   |   |   |   |   |   |   |   |   |   |    |                |
|----------|---|---|---|---|---|---|---|---|---|---|----|----------------|
| Terrible | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | Almost perfect |
|----------|---|---|---|---|---|---|---|---|---|---|----|----------------|

**Q2a** How often did your loved one appear to have control over what was going on around him/her?

*Please circle one number*

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

**Q2b** How would you rate this aspect of your loved one's dying experience?

*Please circle one number*

|          |   |   |   |   |   |   |   |   |   |   |    |                |
|----------|---|---|---|---|---|---|---|---|---|---|----|----------------|
| Terrible | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | Almost perfect |
|----------|---|---|---|---|---|---|---|---|---|---|----|----------------|

## During the last several days that your loved one was in the ICU cont.

**Q3a** **How often was your loved one able to feed him/herself?**  
*Please circle one number*

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

**Q3b** **How would you rate this aspect of your loved one's dying experience?**  
*Please circle one number*

Terrible 0 1 2 3 4 5 6 7 8 9 10 Almost perfect

**Q4a** **How often did your loved one appear to breathe comfortably?**  
*Please circle one number*

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

**Q4b** **How would you rate this aspect of your loved one's dying experience?**  
*Please circle one number*

Terrible 0 1 2 3 4 5 6 7 8 9 10 Almost perfect

## During the last several days that your loved one was in the ICU cont.

**Q5a** **How often did your loved one appear to feel at peace with dying?**  
*Please circle one number*

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

**Q5b** **How would you rate this aspect of your loved one's dying experience?**  
*Please circle one number*

Terrible 0 1 2 3 4 5 6 7 8 9 10 Almost perfect

**Q6a** **How often did your loved one appear to be unafraid of dying?**  
*Please circle one number*

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

**Q6b** **How would you rate this aspect of your loved one's dying experience?**  
*Please circle one number*

Terrible 0 1 2 3 4 5 6 7 8 9 10 Almost perfect

## During the last several days that your loved one was in the ICU cont.

**Q7a** How often did your loved one laugh and smile?

*Please circle one number*

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

**Q7b** How would you rate this aspect of your loved one's dying experience?

*Please circle one number*

Terrible 0 1 2 3 4 5 6 7 8 9 10 Almost perfect

**Q8a** How often did your loved one appear to keep his/her dignity and self-respect?

*Please circle one number*

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

**Q8b** How would you rate this aspect of your loved one's dying experience?

*Please circle one number*

Terrible 0 1 2 3 4 5 6 7 8 9 10 Almost perfect

## During the last several days that your loved one was in the ICU cont.

**Q9a** How often did your loved one spend time with his/her family or friends?  
*Please circle one number*

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

**Q9b** How would you rate this aspect of your loved one's dying experience?  
*Please circle one number*

Terrible 0 1 2 3 4 5 6 7 8 9 10 Almost perfect

**Q10a** How often did your loved one spend time alone?  
*Please circle one number*

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

**Q10b** How would you rate this aspect of your loved one's dying experience?  
*Please circle one number*

Terrible 0 1 2 3 4 5 6 7 8 9 10 Almost perfect

## During the last several days that your loved one was in the ICU cont.

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.

**Q11a** Was your loved one touched or hugged by his/her loved ones?  
Please circle one number

- Yes 1
- No 2
- Don't know 3 → Go to question 12a

**Q11b** How would you rate this aspect of your loved one's dying experience?  
Please circle one number

Terrible 0 1 2 3 4 5 6 7 8 9 10 Almost perfect

**Q12a** Did your loved one say goodbye to loved ones?  
Please circle one number

- Yes 1
- No 2
- Don't know 3 → Go to question 13a

**Q12b** How would you rate this aspect of your loved one's dying experience?  
Please circle one number

Terrible 0 1 2 3 4 5 6 7 8 9 10 Almost perfect

**Q13a** Did your loved one clear up any bad feelings with others?  
Please circle one number

- Yes 1
- No 2
- Don't know 3 → Go to question 14a

**Q13b** How would you rate this aspect of your loved one's dying experience?  
Please circle one number

Terrible 0 1 2 3 4 5 6 7 8 9 10 Almost perfect

## During the last several days that your loved one was in the ICU cont.

**Q14a** Did your loved one have one or more visits from the hospital Chaplain or equivalent offering religious or spiritual support?

*Please circle one number*

- Yes 1
- No 2
- Don't know 3 → Go to question 15a

**Q14b** How would you rate this aspect of your loved one's dying experience?

*Please circle one number*

Terrible 0 1 2 3 4 5 6 7 8 9 10 Almost perfect

**Q15a** Did your loved one have a religious or spiritual service/ceremony before his/her death?

*Please circle one number*

- Yes 1
- No 2
- Don't know 3 → Go to question 16a

**Q15b** How would you rate this aspect of your loved one's dying experience?

*Please circle one number*

Terrible 0 1 2 3 4 5 6 7 8 9 10 Almost perfect

**Q16a** Did your loved one have a mechanical ventilator (respirator) breathe for him/her?

*Please circle one number*

- Yes 1
- No 2
- Don't know 3 → Go to question 17a

**Q16b** How would you rate this aspect of your loved one's dying experience?

*Please circle one number*

Terrible 0 1 2 3 4 5 6 7 8 9 10 Almost perfect

## During the last several days that your loved one was in the ICU cont.

**Q17a Did your loved one receive dialysis for his/her kidneys?**  
*Please circle one number*

- Yes 1
- No 2
- Don't know 3 → Go to question 18a

**Q17b How would you rate this aspect of your loved one's dying experience?**  
*Please circle one number*

Terrible 0 1 2 3 4 5 6 7 8 9 10 Almost perfect

*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.*

**Q18a Did your loved one have his/her funeral arrangements in order prior to death?**  
*Please circle one number*

- Yes 1
- No 2
- Don't know 3 → Go to question 19a

**Q18b How would you rate this aspect of your loved one's dying experience?**  
*Please circle one number*

Terrible 0 1 2 3 4 5 6 7 8 9 10 Almost perfect

**Q19a Did your loved one discuss his/her wishes for end of life care with his/her doctor - for example, resuscitation or intensive care?**  
*Please circle one number*

- Yes 1
- No 2
- Don't know 3 → Go to question 20a

**Q19b How would you rate this aspect of your loved one's dying experience?**  
*Please circle one number*

Terrible 0 1 2 3 4 5 6 7 8 9 10 Almost perfect



## During the last several days that your loved one was in the ICU cont.

**Q20a** Was anyone present at the moment of your loved one's death?

*Please circle one number*

- |            |   |                      |
|------------|---|----------------------|
| Yes        | 1 |                      |
| No         | 2 |                      |
| Don't know | 3 | → Go to question 21a |

**Q20b** How would you rate this aspect of your loved one's dying experience?

*Please circle one number*

|          |   |   |   |   |   |   |   |   |   |   |    |                |
|----------|---|---|---|---|---|---|---|---|---|---|----|----------------|
| Terrible | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | Almost perfect |
|----------|---|---|---|---|---|---|---|---|---|---|----|----------------|

**Q21a** In the moment before your loved one's death, was he/she:

*Please circle one number*

- |                          |   |                     |
|--------------------------|---|---------------------|
| Awake                    | 1 |                     |
| Asleep                   | 2 |                     |
| In a coma or unconscious | 3 |                     |
| Don't know               | 4 | → Go to question 22 |

**Q21b** How would you rate this aspect of your loved one's dying experience?

*Please circle one number*

|          |   |   |   |   |   |   |   |   |   |   |    |                |
|----------|---|---|---|---|---|---|---|---|---|---|----|----------------|
| Terrible | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | Almost perfect |
|----------|---|---|---|---|---|---|---|---|---|---|----|----------------|

## During the last several days that your loved one was in the ICU cont.

**Q22 Overall, how would you rate the quality of your loved one's dying?**  
*Please circle one number*

Terrible 0 1 2 3 4 5 6 7 8 9 10 Almost perfect

**Q23 Rate the care your loved one received from all doctors and other health care providers (including nurses and other health care professionals) during the last several days of his/her life while in the ICU.**  
*Please circle one number*

Worst healthcare possible 0 1 2 3 4 5 6 7 8 9 10 Best healthcare possible

**Q24 Rate the care your loved one received from his/her doctor during the last several days of his/her life while in the ICU.**  
*Please circle one number*

Worst healthcare possible 0 1 2 3 4 5 6 7 8 9 10 Best healthcare possible

*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.*

*Contact details are provided on the Information Sheet.*

*Thank you again for your help.*

Comments