

For the Bereaved Person
Assessing Your Experience

Physical Area

Please answer the following questions **based on your loved one's experience in the last 2 weeks of life**. Circle the number from 0 – 10 that best describes your loved one's experiences:

To what extent were the following a problem for your loved one:

1. Fatigue

No problem 0 1 2 3 4 5 6 7 8 9 10 Severe problem

2. Sleep changes

No problem 0 1 2 3 4 5 6 7 8 9 10 Severe problem

3. Problems with dry mouth, change in food tastes, drooling or appetite changes

No problem 0 1 2 3 4 5 6 7 8 9 10 Severe problem

4. Intestinal problems of constipation or diarrhea

No problem 0 1 2 3 4 5 6 7 8 9 10 Severe problem

5. Nausea

No problem 0 1 2 3 4 5 6 7 8 9 10 Severe problem

6. Shortness of breath or difficulty breathing

No problem 0 1 2 3 4 5 6 7 8 9 10 Severe problem

7. Aches or pain

No problem 0 1 2 3 4 5 6 7 8 9 10 Severe problem

8. Please rate your loved one's average pain level during those 2 weeks

No pain 0 1 2 3 4 5 6 7 8 9 10 Worst pain you can imagine

Emotional / Relationship Area

Please answer the following questions **based on your loved one's experience and / or your experience in the last 2 weeks of your loved one's life**. Circle the number from 0 – 10 that best describes the experiences. If not applicable, circle NA

9. How satisfying were those last 2 weeks of life for your loved one?

Not at all 0 1 2 3 4 5 6 7 8 9 10 Completely

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10. How much anxiety did your loved one have?

None at all 0 1 2 3 4 5 6 7 8 9 10 A great deal

11. How free were you and your loved one to express feelings such as sadness, grief, and anger?

Not at all 0 1 2 3 4 5 6 7 8 9 10 Completely

12. Did you have enough opportunity to talk with your loved one about his/her experiences, and approaching death?

Not at all 0 1 2 3 4 5 6 7 8 9 10 Completely

13. Did your loved one feel like a burden to your family?

Not at all 0 1 2 3 4 5 6 7 8 9 10 Completely

14. Did you have enough opportunity to talk with others about how your loved one's illness has affected you and how you are doing?

Not at all 0 1 2 3 4 5 6 7 8 9 10 Completely

15. Did you feel like your loved one's care was manageable?

Not at all 0 1 2 3 4 5 6 7 8 9 10 Completely

16. Were family and friends available and there for you and your loved one?

Not at all 0 1 2 3 4 5 6 7 8 9 10 A great deal

17. Did you have opportunities to talk openly about your experiences with family and friends?

Not at all 0 1 2 3 4 5 6 7 8 9 10 A great deal

18. Did family / friends give specific support without you asking?

Not at all 0 1 2 3 4 5 6 7 8 9 10 A great deal

19. Was the amount of support you received and connection to others sufficient to meet your needs?

Not at all 0 1 2 3 4 5 6 7 8 9 10 Completely

20. Did you feel the illness or treatment caused you to feel isolated from your loved one?

Not at all 0 1 2 3 4 5 6 7 8 9 10 A great deal

21. Did you know your loved one's treatment wishes and goals?

Not at all 0 1 2 3 4 5 6 7 8 9 10 Completely

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22. If you are still working, has your work place been supportive? (leave blank if not working)
NA Not at all 0 1 2 3 4 5 6 7 8 9 10 A great deal
23. How much financial burden has resulted from your loved one's illness or treatment?
None 0 1 2 3 4 5 6 7 8 9 10 Extreme
24. How much of a problem have you had receiving support to meet your financial needs?
No problem 0 1 2 3 4 5 6 7 8 9 10 Severe problem

Spiritual Area

Please answer the following questions based on your loved one's experience in the last 2 weeks of his or her life. Circle the number from 0 – 10 that best describes the experiences:

25. How important to your loved one was participation in spiritual or religious experiences (e.g. meditation, spiritual traditions or rituals, praying, or going to a place of worship)?
Not at all 0 1 2 3 4 5 6 7 8 9 10 Very important
26. To what extent did the last 2 weeks of your loved one's illness lead to positive changes in your loved one's remaining life?
Not at all 0 1 2 3 4 5 6 7 8 9 10 A great deal
27. Did your loved one express a purpose / mission for his/her life or a reason for being alive?
Not at all 0 1 2 3 4 5 6 7 8 9 10 A great deal
28. How hopeful did your loved one feel?
Not at all hopeful 0 1 2 3 4 5 6 7 8 9 10 Very hopeful
29. How much opportunity did your loved one have to reflect on his/her life?
None at all 0 1 2 3 4 5 6 7 8 9 10 A great deal
30. Did your loved one view time as precious and value each minute of life?
Not at all 0 1 2 3 4 5 6 7 8 9 10 A great deal
31. Did your loved one experience healing in spiritual, emotional, and / or relationship areas of life?
Not at all 0 1 2 3 4 5 6 7 8 9 10 A great deal

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Please share other comments about your experience

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Place of Care Environment (Health Care Experience)

Please answer the following questions **based on your loved one's experience and / or your experience in the last 2 weeks of your loved one's life**. Circle the number from 0 – 10 that best describes the experiences. For number 3, circle NA if not applicable.

1. **Your loved one's experience receiving effective and timely pain management**

No problem 0 1 2 3 4 5 6 7 8 9 10 Severe problem

2. **Your loved one's experience receiving effective and timely symptom relief, e.g. difficulty breathing, nausea, constipation**

No problem 0 1 2 3 4 5 6 7 8 9 10 Severe problem

3. **Adequate help for meeting your loved one's physical needs at home**

NA No problem 0 1 2 3 4 5 6 7 8 9 10 Severe problem

4. **Were you given enough information about your loved one's care and treatment choices to prepare you for his/her care and treatments?**

Not at all 0 1 2 3 4 5 6 7 8 9 10 Completely

5. **How difficult was it to find out information about your loved one's illness, care, and treatment choices?**

Not at all 0 1 2 3 4 5 6 7 8 9 10 A great deal

6. **If there was a conflict over your loved one's care, did you feel supported in having your care wishes honored?**

Not at all 0 1 2 3 4 5 6 7 8 9 10 A great deal

7. **Did you feel you had appropriate control over your loved one's care choices and health care experiences?**

Not at all 0 1 2 3 4 5 6 7 8 9 10 Completely

8. **Did you feel free to refuse care or treatments for your loved one?**

Not at all 0 1 2 3 4 5 6 7 8 9 10 Completely

9. **Were you given enough information about signs of approaching death to prepare you for your loved one's dying and death?**

Not at all 0 1 2 3 4 5 6 7 8 9 10 Completely

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- 10. Did you and other family members feel welcomed 24 hours a day wherever your loved one received care?**
Not at all 0 1 2 3 4 5 6 7 8 9 10 A great deal
- 11. Was your privacy and confidentiality respected?**
Not at all 0 1 2 3 4 5 6 7 8 9 10 A great deal
- 12. Were you given information about support groups for yourself and your loved one or put in touch with others who had similar experiences?**
Not at all 0 1 2 3 4 5 6 7 8 9 10 A great deal
- 13. Did you and do you now have access to and opportunity to talk with professional counselors?**
Not at all 0 1 2 3 4 5 6 7 8 9 10 A great deal
- 14. Were you given a choice to have chaplains or others pray with you and your loved one?**
Not at all 0 1 2 3 4 5 6 7 8 9 10 A great deal
- 15. Did the health care team ask about your loved one's advance care planning, e.g. Living Will, Advance Directives, or Durable Power of Attorney?**
Not at all 0 1 2 3 4 5 6 7 8 9 10 A great deal
- 16. Please rate your overall experience with the quality of your health services?**
Very inconsistent 0 1 2 3 4 5 6 7 8 9 10 Consistently high
- 17. Did those caring for your loved one have a good understanding of the illness, treatment, and care wishes?**
Not at all 0 1 2 3 4 5 6 7 8 9 10 A great deal
- 18. Did people consistently follow through with you and your loved one's care wishes?**
Not at all 0 1 2 3 4 5 6 7 8 9 10 A great deal
- 19. Did you get enough help obtaining and completing applications and financial forms, e.g. insurance, social security, disability?**
Not at all 0 1 2 3 4 5 6 7 8 9 10 A great deal
- 20. Did you get enough help finding needed resources and support, e.g. transportation or homemaker assistance?**
Not at all 0 1 2 3 4 5 6 7 8 9 10 A great deal

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**DOCTORS, NURSES, OTHER HEALTH CARE PROVIDERS /
COMMUNICATION**

21. Did you feel caring, respect, and genuine presence from your loved one's doctors?

Not at all 0 1 2 3 4 5 6 7 8 9 10 A great deal

22. Have you felt caring, respect, and genuine presence from your loved one's nurses and others?

Not at all 0 1 2 3 4 5 6 7 8 9 10 A great deal

23. Was your loved one's doctor's communication with you easy to understand and consistent?

Not at all 0 1 2 3 4 5 6 7 8 9 10 A great deal

24. Was the nurse's communication with you easy to understand and consistent?

Not at all 0 1 2 3 4 5 6 7 8 9 10 A great deal

25. Did you feel doctors were available for you and your loved one as you needed them?

Not at all 0 1 2 3 4 5 6 7 8 9 10 A great deal

26. Have you felt nurses and other professionals were available for you and your loved one as you needed?

Not at all 0 1 2 3 4 5 6 7 8 9 10 A great deal

27. Did you feel supported by your loved one's doctors if you looked for second opinions and other care choices?

Not at all 0 1 2 3 4 5 6 7 8 9 10 A great deal

28. If you had questions about "complementary therapies", did your loved one's doctors answer your questions to your satisfaction?

Not at all 0 1 2 3 4 5 6 7 8 9 10 A great deal

29. To what extent did communication with healthcare personnel assist your loved one to maintain hope?

Not at all 0 1 2 3 4 5 6 7 8 9 10 A great deal

30. Did your loved one's doctor(s) provide you the opportunity to discuss your loved one's approaching death and dying?

Not at all 0 1 2 3 4 5 6 7 8 9 10 A great deal

31. Did your nurses / others provide you the opportunity to discuss your loved one's possible death and dying?

Not at all 0 1 2 3 4 5 6 7 8 9 10 A great deal

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32. Since your loved one's death, how much opportunity have you had for follow-up contact with your loved one's doctors?

None at all 0 1 2 3 4 5 6 7 8 9 10 A great deal

33. Since your loved one's death, how much opportunity have you had for follow-up contact with your loved one's nurses and other health care providers?

None at all 0 1 2 3 4 5 6 7 8 9 10 A great deal

34. Did your loved one die in the care environment where you or your loved one wished?

Yes No

If yes, what services were most helpful in making that possible?

If not, why not? _____

Is there anything else we could have done for you or your loved one?

Please share other comments about your experience

Information About You

Please complete the following questions about you. This information will be kept strictly confidential.

Location Where Questionnaire Completed:

Home Hospital Long Term Care Doctor's Office
 Other (*please specify*) _____

Age _____

Gender: Male Female

Race/Ethnicity

White/Caucasian
 Black/African American
 Asian or Pacific Islander
 Hispanic
 Native American
 Other

Religion

Jewish
 Catholic
 Jehovah's Witness
 Christian Scientist
 Seventh Day Adventist
 Protestant
 Native American

Muslim
 Buddhist
 Bahia
 No religion
 Other (*specify*): _____

Insurance:

Private/Commercial insurance No insurance / self-payment
 Medicare Other insurance
 Medicaid

Health Maintenance Organization (HMO) yes no

Yearly household income before taxes:

less than \$25,000 \$50,001 - \$75,000 more than \$100,000
 \$25,001 - \$50,000 \$75,001 - \$100,000

Current Living Arrangements:

Living alone at home Assisted Living
 Home with family / friends Nursing Home
 Living with family / friends in their home

Health Services you received:

Home Health Church based ministries, e.g. Stephen Ministries
 Hospice Visiting Nurse
 Parish Nurse Other (*specify*): _____

Diagnosis or illness that was life – threatening for your loved one:

Place of your loved one's death home long term care hospital

Date of your loved one's death _____

Please call me about my loved one's care or this questionnaire yes no

Date questionnaires completed _____ I.D. number _____