

The Quality of Life's End

COMMUNITY SURVEY

The *Quality of Life's End* is a community project designed to meet the needs of people who are dying and their families. We want to help our loved ones meet end of life experiences in a positive and meaningful way. Please help us achieve this goal by answering the following questions:

1. Are you?

- Female
- Male

2. Are you?

- American Indian/Native American
- Asian/Hmong
- Black/African American
- Hispanic/Latino
- White/Caucasian
- Other

(_____)

3. Current Marital Status (check one):

- Married/Committed Relationship
- Separated
- Never married
- Divorced
- Widowed

4a. How many persons live in your

household including yourself?

_____ # persons in household, including you

4b. Who are they?

_____ # Spouse/Partner
_____ # Children
_____ # Other Family Members
_____ # Persons not related to you

5. What is your age?

6. Highest grade in school completed? (for example if you completed high school, mark 12. Mark 13 for one year of college or technical school, 14 for two years, & so on)

_____ highest grade completed

7. How long have you lived in this community:

- Less than 1 year
- _____ # Years (if 1 year or longer)

- _____ # hours per month
- Other: _____

8. What type of work do you do?

- professional
- technical
- service / sales / clerical
- agricultural
- other: _____

10. Do you identify yourself with an organized religion or have a spiritual orientation?

- No
- Yes (please describe below): _____

9. Regarding work, do you currently?

- Work for pay: _____ # hours per week
- Volunteer:

11. How often do you attend religious services?

- Never
- Rarely
- Occasionally
- Regularly

- through current employer
- self pay
- Medicare
- Medicaid
- HMO/PPO
- other government/military subsidy

12. Yearly Household Gross Income (before taxes):

- less than \$15,000 yearly
- \$15,001 - \$30,000 yearly
- \$30,001 - \$45,000 yearly
- \$45,001 - \$60,000 yearly
- \$60,001 - \$75,000 yearly
- more than \$75,000 yearly

14. About how much of your health care expenses are currently paid by your health insurance?

- None
- 1% to 25%
- 26% to 50%
- 51% to 75%
- 76% to 100%
- Don't Know

13. What kind of health insurance do you have? check ALL that apply

- none

15. How many times in the past year have you received services at the emergency room?

16. How many overnight stays have you had in a hospital over the past year?

_____ # overnight stays

17. Do you have a signed Living Will or Durable Power of Attorney (DPOA) for Health Care?

- Yes, Living Will
- Yes, Durable POA for Health Care
- Yes, Both
- No
- Don't know

18. While you were growing up, how often were death & dying talked about in your family?

- Never
- Rarely
- Occasionally
- Fairly often

19. Please list persons who have died whose death had a significant impact on you:

EXAMPLES: spouse/partner; lover; child; grandparent; sister or brother; close friend.

Relationship to You?

How long ago?

Please circle yrs or months

circle yrs or mnths

_____ yrs OR
 _____ mnths

_____ yrs OR
 _____ mnths
 -
 _____ yrs OR
 _____ mnths
 -
 _____ yrs OR
 _____ mnths
 -
 _____ yrs OR
 _____ mnths
 -
 _____ yrs OR
 _____ mnths

20. How familiar are you with hospice services? (check only ONE)

- I have never heard of hospice services
- I have heard a little bit about hospice
- I have a good understanding of hospice services, but no direct experience
- I know someone who has used hospice
- I am/have been a hospice volunteer
- I have direct experience with hospice services provided to my family or a close friend

Circle your level of discomfort

comfortable > > > > UNcomfortable

How uncomfortable would you be to:

- 21. talk about death? 1 2 3 4 5 6 7
- 22. see a dead body (e.g., at a funeral or wake)? 1 2 3 4 5 6 7
- 23. write your own will if you thought your death would occur soon? 1 2 3 4 5 6 7
- 24. think about life after death? 1 2 3 4 5 6 7

Circle your level of worry or fear

none at all > > > > > > extreme

How afraid are you of:

- 25. dying painfully? 1 2 3 4 5 6 7
- 26. getting cancer? 1 2 3 4 5 6 7
- 27. having a heart attack? 1 2 3 4 5 6 7
- 28. time passing so quickly? 1 2 3 4 5 6 7
- 29. the subject of death? 1 2 3 4 5 6 7

Circle how likely you would be

to

not at all > > > > > > extremely likely

How likely are you to:

- 30. avoid attending funerals or memorial services? 1 2 3 4 5 6 7

31. read books that deal with the subject of death and dying? 1 2 3 4 5 6 7
32. watch television programs or movies that deal with the subject of death and dying? 1 2 3 4 5 6 7
33. avoid medical checkups because you are afraid the doctor will find "something serious?" 1 2 3 4 5 6 7
34. speak freely to loved ones about death and dying? 1 2 3 4 5 6 7
35. visit or telephone a friend or relative who has recently lost a loved one in order to see how they are doing? 1 2 3 4 5 6 7
36. preplan your own funeral? 1 2 3 4 5 6 7

How strongly do you agree or disagree with the following statements? Circle a number on the right.

Circle *how strongly you agree*
strongly disagree > > > strongly agree

- 37. Old people should get out of the way to make room for young people. 1 2 3 4 5 6 7
- 38. I want to live in a world without death. 1 2 3 4 5 6 7
- 39. There is a special value in getting old. 1 2 3 4 5 6 7
- 40. Dying is an important stage of life. 1 2 3 4 5 6 7
- 41. If someone had the power to tell me when my death would be, I would want to know. 1 2 3 4 5 6 7
- 42. Caring for people who are dying is good for those giving care. 1 2 3 4 5 6 7
- 43. I don't know where people get the courage to face death. 1 2 3 4 5 6 7
- 44. I often wonder why people have to die. 1 2 3 4 5 6 7

Circle *your level of worry or fear*
none at all > > > > > > extreme

- 45. In thinking about dying, are you worried that your money won't last? 1 2 3 4 5 6 7
- 46. In thinking about dying, are you worried that your family's money will be used up? 1 2 3 4 5 6 7
- 47. In thinking about dying, are you worried about being a burden to your family or friends? 1 2 3 4 5 6 7
- 48. If you were terminally ill, do you think you might want assistance with suicide? 1 2 3 4 5 6 7

49. If you were terminally ill, where do you think you would want to die? (*choose only ONE*)

- at home
- in a hospital
- in a nursing home
- in a residential hospice
- other (please describe): _____

Why? _____

50. If you were dying, do you think you would want hospice support? (*choose only ONE*)

- Yes
- No, because: _____
- Not sure
- Don't know what hospice is

51. If you could choose the way in which you die (e.g., sudden death, suicide, lengthy illness), what would your choice be?

52. When you imagine yourself dying, are there any customs, activities, or forms of spiritual support that you think might help you deal with your own dying process?

53. How important would each of these be in helping you deal with your own dying?

	<i>not important</i>	➤	➤	➤	➤	➤	➤	<i>very important</i>
a) Family members visiting you	1	2	3	4	5	6	7	
b) Being able to stay in your home	1	2	3	4	5	6	7	
c) Honest answers from your doctor	1	2	3	4	5	6	7	
d) Religious/spiritual persons visiting you	1	2	3	4	5	6	7	
e) Attending services at your place of worship	1	2	3	4	5	6	7	
f) Knowing medicine was available to you	1	2	3	4	5	6	7	
g) Planning your own funeral	1	2	3	4	5	6	7	
h) Being able to complete your will	1	2	3	4	5	6	7	
i) Fulfilling personal goal(s)/pleasure(s)	1	2	3	4	5	6	7	
j) Reviewing your life history with your family	1	2	3	4	5	6	7	
k) Having health care professionals visit you at your home	1	2	3	4	5	6	7	
l) Participating in an Indian sweat lodge ceremony	1	2	3	4	5	6	7	
m) Getting your finances in order	1	2	3	4	5	6	7	
n) Outside help so your family won't have to work too hard	1	2	3	4	5	6	7	
o) other: _____	1	2	3	4	5	6	7	
p) other: _____	1	2	3	4	5	6	7	

54. If you have experienced the death of a loved one, were there any customs, activities, or spiritual support that seemed to help you with their dying process or death? *Please describe.*

55. When you think of a loved one dying, what would make for a “good death”?

56. In the dying process, what do you think is important:

	<i>not important</i>	➤	➤	➤	➤	➤	➤	<i>very important</i>
a) Physical comfort	1	2	3	4	5	6	7	
b) Freedom from pain	1	2	3	4	5	6	7	
c) Having things settled with the family	1	2	3	4	5	6	7	
d) Spiritual well-being	1	2	3	4	5	6	7	
e) Not being a burden to loved ones	1	2	3	4	5	6	7	
f) Knowing how to say goodbye	1	2	3	4	5	6	7	
g) Sense of my own worth	1	2	3	4	5	6	7	
h) other:	1	2	3	4	5	6	7	

57. When you are nearing life’s end, you will need support from people in your life. Place a checkmark ✓ in the boxes below to indicate the people you expect to support you.

Type of Support	spouse / partner	children	family / relatives	neighbors	friends	work associate	health providers	faith community
a) Will listen when I just want to talk.								
b) Provide transportation								
c) Help with chores.								
d) Do fun things with								

me.								
e) Work with agencies to provide my needs.								
f) Know about my illness.								
g) Know what I want when I die.								
h) Help care for other family members.								
i) Encourage me when I'm down.								
j) Understand what I'm going through.								

The *Missoula Demonstration Project* will also be conducting a companion study on issues related to pain. Completing the questions on this page will assist us in formulating a research strategy for the follow-up study.

Please circle how strongly you agree with each of the following statements (by circling the appropriate number on the right).

Circle how strongly you agree
strongly disagree > > strongly agree

- | | | | | | | | |
|---|---|---|---|---|---|---|---|
| 58. I am afraid my doctor may not believe or treat my pain. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 59. I feel that appearing ill is embarrassing. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 60. Cancer pain can be effectively relieved. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 61. Pain medicines should only be taken when pain is severe. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 62. Most people taking pain medicines will become addicted to the medicines over time. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 63. It is important to take the lowest amount of medicine possible to save larger doses for later when the pain is worse. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 64. There are other effective remedies for pain besides medicine (such as massage, heat, relaxation). | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 65. People are often given too much pain medicine. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 66. Pain medicine cannot really control pain. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 67. People get addicted to pain medicine easily. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 68. Good patients avoid talking about pain. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 69. It is easier to put up with pain than with the side effects that come from pain medicine. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 70. Complaints of pain could distract a physician from treating my underlying illness. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 71. Pain medicine should be "saved" in case the pain gets worse. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 72. The experience of pain is a sign that the illness has gotten worse. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 73. If you are living in daily pain, what have you found to be helpful? _____ | | | | | | | |

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Thank you for participating in this survey. Your input is greatly appreciated!!

Remember to fill out and return the postcard included if you want your name to be placed in the drawing to be held at the end of the survey collection process. Five winners will receive a bonus of \$100 each. Your survey responses will remain anonymous. We will separate your name card from the survey upon receipt.

Thank you again for your participation in this survey. Your input is greatly appreciated!