

Measuring the Quality of Life of Seriously Ill Patients

I'd like you to think back over the last month. Please tell me the three physical symptoms or problems that have bothered you the most during that time. Some examples are pain, nausea, lack of energy, confusion, depression, anxiety, and shortness of breath.

Symptom #1 _____ Symptom #3 _____

Symptom #2 _____

- If no symptoms were elicited, then state the following:
So, just to be sure, over the last month, you have had no physical or emotional symptoms that bothered you.

If correct, skip to question #5.

Which of these symptoms or problems has bothered you the most this past week?

1. During the last week, how often have you experienced _____?

<i>Rarely</i> 1	<i>A few times</i> 2	<i>Fairly often</i> 3	<i>Very often</i> 4	<i>Most of the time</i> 5
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2. During the last week, on average, how severe has _____ been?

<i>Very mild</i> 1	<i>Mild</i> 2	<i>Moderate</i> 3	<i>Severe</i> 4	<i>Very severe</i> 5
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3. During the last week, how much has _____ interfered with your ability to enjoy your life?

<i>Not at all</i> 1	<i>A little bit</i> 2	<i>A moderate amount</i> 3	<i>Quite a bit</i> 4	<i>Completely</i> 5
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4. How worried are you about _____ occurring in the future?

<i>Not at all</i> 1	<i>A little bit</i> 2	<i>A moderate amount</i> 3	<i>Quite a bit</i> 4	<i>Completely</i> 5
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5. In general, how important are your PHYSICAL SYMPTOMS OR PROBLEMS to your overall quality of life?

<i>Not at all</i> 1	<i>A little bit</i> 2	<i>A moderate amount</i> 3	<i>Quite a bit</i> 4	<i>Completely</i> 5
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Below is a list of statements that other people with a serious illness have said may be important. Please tell me how true each statement is for you.

6. Although I cannot control certain aspects of my illness, I have a sense of control about my treatment decisions.

<i>Not at all</i>	<i>A little bit</i>	<i>A moderate amount</i>	<i>Quite a bit</i>	<i>Completely</i>
<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>	<i>5</i>

7. I participate as much as I want in the decisions about my care.

<i>Not at all</i>	<i>A little bit</i>	<i>A moderate amount</i>	<i>Quite a bit</i>	<i>Completely</i>
<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>	<i>5</i>

8. Beyond my illness, my doctor has a sense of who I am as a person.

<i>Not at all</i>	<i>A little bit</i>	<i>A moderate amount</i>	<i>Quite a bit</i>	<i>Completely</i>
<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>	<i>5</i>

9. In general, I know what to expect about the course of my illness.

<i>Not at all</i>	<i>A little bit</i>	<i>A moderate amount</i>	<i>Quite a bit</i>	<i>Completely</i>
<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>	<i>5</i>

10. As my illness progresses, I know where to go to get answers to my questions.

<i>Not at all</i>	<i>A little bit</i>	<i>A moderate amount</i>	<i>Quite a bit</i>	<i>Completely</i>
<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>	<i>5</i>

11. In general, how important is feeling like an ACTIVE PARTICIPANT in your HEALTH CARE to your overall quality of life?

<i>Not at all</i>	<i>A little bit</i>	<i>A moderate amount</i>	<i>Quite a bit</i>	<i>Completely</i>
<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>	<i>5</i>

12. I worry that my family is not prepared to cope with the future.

<i>Not at all</i> 1	<i>A little bit</i> 2	<i>A moderate amount</i> 3	<i>Quite a bit</i> 4	<i>Completely</i> 5
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13. I have regrets about the way I have lived my life.

<i>Not at all</i> 1	<i>A little bit</i> 2	<i>A moderate amount</i> 3	<i>Quite a bit</i> 4	<i>Completely</i> 5
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14. At times, I worry that I will be a burden to my family.

<i>Not at all</i> 1	<i>A little bit</i> 2	<i>A moderate amount</i> 3	<i>Quite a bit</i> 4	<i>Completely</i> 5
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15. Thoughts of dying frighten me.

<i>Not at all</i> 1	<i>A little bit</i> 2	<i>A moderate amount</i> 3	<i>Quite a bit</i> 4	<i>Completely</i> 5
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16. I worry about the financial strain caused by my illness.

<i>Not at all</i> 1	<i>A little bit</i> 2	<i>A moderate amount</i> 3	<i>Quite a bit</i> 4	<i>Completely</i> 5
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17. In general, how important are CONCERNS ABOUT THE FUTURE to your overall quality of life?

<i>Not at all</i> 1	<i>A little bit</i> 2	<i>A moderate amount</i> 3	<i>Quite a bit</i> 4	<i>Completely</i> 5
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18. I have been able to say important things to those close to me.

<i>Not at all</i> 1	<i>A little bit</i> 2	<i>A moderate amount</i> 3	<i>Quite a bit</i> 4	<i>Completely</i> 5
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19. I make a positive difference in the lives of others.

<i>Not at all</i> 1	<i>A little bit</i> 2	<i>A moderate amount</i> 3	<i>Quite a bit</i> 4	<i>Completely</i> 5
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20. I have been able to help others through time together, gifts, or wisdom.

<i>Not at all</i> 1	<i>A little bit</i> 2	<i>A moderate amount</i> 3	<i>Quite a bit</i> 4	<i>Completely</i> 5
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21. I have been able to share important things with my family.

<i>Not at all</i> 1	<i>A little bit</i> 2	<i>A moderate amount</i> 3	<i>Quite a bit</i> 4	<i>Completely</i> 5
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22. Despite my illness, I have a sense of meaning in my life.

<i>Not at all</i> 1	<i>A little bit</i> 2	<i>A moderate amount</i> 3	<i>Quite a bit</i> 4	<i>Completely</i> 5
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23. I feel at peace.

<i>Not at all</i> 1	<i>A little bit</i> 2	<i>A moderate amount</i> 3	<i>Quite a bit</i> 4	<i>Completely</i> 5
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24. There is someone in my life with whom I can share my deepest thoughts.

<i>Not at all</i> 1	<i>A little bit</i> 2	<i>A moderate amount</i> 3	<i>Quite a bit</i> 4	<i>Completely</i> 5
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25. In general, how important is the feeling that your LIFE IS COMPLETE to your overall quality of life?

<i>Not at all</i> 1	<i>A little bit</i> 2	<i>A moderate amount</i> 3	<i>Quite a bit</i> 4	<i>Completely</i> 5
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Now, I have one last question.

26. How would you rate your OVERALL QUALITY OF LIFE?

<i>Very Poor</i> 1	<i>Poor</i> 2	<i>Fair</i> 3	<i>Good</i> 4	<i>Excellent</i> 5
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References

Two phases of validation:

1. Factor structure

Steinhauser KE, Bosworth HB, Clipp EC, McNeilly M, Christakis NA, Tulsky JA. Initial assessment of a new measure of quality of life at the end of life (QUAL-E). *Journal of Palliative Medicine*. 2002, 5(6):829-42.

2. Construct divergent and convergent validity

Steinhauser KE, Clipp EC, Bosworth HB, McNeilly M, Christakis NA, Voils CI, Tulsky JA. Measuring quality of life at the end of life: Validation of the QUAL-E. *Palliative and Supportive Care*, 2004, Vol .2 (2):3-14.