

QUALITY OF LIFE IN EPILEPSY
QOLIE-89 (Version 1.0)

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Patient Inventory

Today's Date ____/____/____

Patient's Name _____

Patient's ID# _____

Gender: Male Female

Birthdate ____/____/____

INSTRUCTIONS

This survey asks about your health and daily activities. **Answer every question** by circling the appropriate number (1, 2, 3, ...).

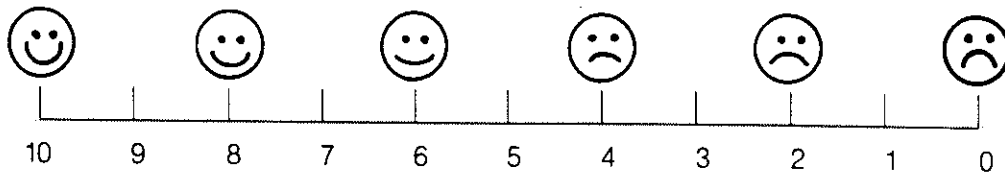
If you are unsure about how to answer a question, please give the best answer you can and write a comment or explanation in the margin.

Please feel free to ask someone to assist you if you need help reading or marking the form.

1. In general, would you say your health is: (Circle one number)
- | | |
|-----------|---|
| Excellent | 1 |
| Very good | 2 |
| Good | 3 |
| Fair | 4 |
| Poor | 5 |

2. Overall, how would you rate your quality of life?

(Circle one number on the scale below)



Best Possible
Quality of Life

Worst Possible
Quality of Life
(as bad as or worse
than being dead)

3. **Compared to 1 year ago**, how would you rate your health in general **now**?

(Circle one number)

Much better now than 1 year ago	1
Somewhat better now than 1 year ago	2
About the same as 1 year ago	3
Somewhat worse now than 1 year ago	4
Much worse now than 1 year ago	5

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4-13: The following questions are about activities you might do during a typical day. Does **your health** limit you in these activities? If so, **how much**?

(Circle 1, 2, or 3 on each line)

	Yes, limited a lot	Yes, limited a little	No, not limited at all
4. <i>Vigorous activities</i> , such as running, lifting heavy objects, participating in strenuous sports	1	2	3
5. <i>Moderate activities</i> , such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	1	2	3
6. Lifting or carrying groceries	1	2	3
7. Climbing <i>several</i> flights of stairs	1	2	3
8. Climbing <i>one</i> flight of stairs	1	2	3
9. Bending, kneeling, or stooping	1	2	3
10. Walking <i>more than one mile</i>	1	2	3
11. Walking <i>several blocks</i>	1	2	3
12. Walking <i>one block</i>	1	2	3
13. Bathing or dressing yourself	1	2	3

The following questions are about your regular daily activities, such as working at a job, keeping house, taking care of children, attending school, volunteer work, or taking part in community services.

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14-18: During the **past 4 weeks**, have you had any of the following difficulties with your regular daily activities or work **as a result of any physical problems**? (Please answer **YES** or **NO** for each question by circling 1 or 2 on each line)

	YES	NO
14. Cut down on the <i>amount of time</i> you spent on work or other activities	1	2
15. <i>Accomplished less</i> than you would like	1	2
16. Were limited in the <i>kind</i> of work or other activities you do	1	2
17. Had <i>difficulty</i> performing the work or other activities you do (for example, it took extra effort)	1	2
18. Did your work or other activities <i>less carefully</i> than usual	1	2

19-23: During the **past 4 weeks**, have you had any of the following difficulties with your regular daily activities or work **as a result of any emotional problems** (such as feeling depressed or anxious)? (Please answer **YES** or **NO** for each question by circling 1 or 2 on each line)

	YES	NO
19. Cut down on the <i>amount of time</i> you spent on work or other activities	1	2
20. <i>Accomplished less</i> than you would like	1	2
21. Were limited in the <i>kind</i> of work or other activities you do	1	2
22. Had <i>difficulty</i> performing the work or other activities you do (for example, it took extra effort)	1	2
23. Did work or other activities <i>less carefully</i> than usual	1	2

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24. How much **bodily pain** have you had during the **past 4 weeks**?

(Circle one number)

None	1
Very mild	2
Mild	3
Moderate	4
Severe	5
Very severe	6

25. During the **past 4 weeks**, how much did **bodily pain** interfere with your normal work (including both work outside the home and housework)?

(Circle one number)

Not at all	1
A little bit	2
Moderately	3
Quite a bit	4
Extremely	5

26. During the **past 4 weeks**, to what extent have your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?

(Circle one number)

Not at all	1
Slightly	2
Moderately	3
Quite a bit	4
Extremely	5

27–35: These questions are about how you **FEEL** and how things have been for you during the **past 4 weeks**. For each question, please indicate the one answer that comes closest to the way you have been feeling.

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How much of the time during the **past 4 weeks** . . .

(Circle one number on each line)

		All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
27.	Did you feel full of pep?	1	2	3	4	5	6
28.	Have you been a very nervous person?	1	2	3	4	5	6
29.	Have you felt so down in the dumps that nothing could cheer you up?	1	2	3	4	5	6
30.	Have you felt calm and peaceful?	1	2	3	4	5	6
31.	Did you have a lot of energy?	1	2	3	4	5	6
32.	Have you felt downhearted and blue?	1	2	3	4	5	6
33.	Did you feel worn out?	1	2	3	4	5	6
34.	Have you been a happy person?	1	2	3	4	5	6
35.	Did you feel tired?	1	2	3	4	5	6

36-43: How much of the time during the **past 4 weeks** . . .

(Circle one number on each line)

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	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
36. Has your epilepsy limited your social activities (such as visiting with friends or close relatives)?	1	2	3	4	5	6
37. Have you had difficulty concentrating and thinking?	1	2	3	4	5	6
38. Did you have trouble keeping your attention on an activity for long?	1	2	3	4	5	6
39. Were you discouraged by problems related to your health?	1	2	3	4	5	6
40. Have you worried about having another seizure?	1	2	3	4	5	6
41. Did you have difficulty reasoning and solving problems (such as making plans, making decisions, learning new things)?	1	2	3	4	5	6
42. Were you discouraged by your epilepsy-related problems?	1	2	3	4	5	6
43. Have your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc)?	1	2	3	4	5	6

44-48: Please choose the answer that best describes how **TRUE or FALSE** each of the following statements is for you. (Circle one number on each line)

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	Definitely true	Mostly true	Not sure	Mostly false	Definitely false
44. I seem to get sick (any kind of sickness) a little easier than other people	1	2	3	4	5
45. I am as healthy as anybody I know	1	2	3	4	5
46. I expect my health to get worse	1	2	3	4	5
47. My health is excellent	1	2	3	4	5
48. When there is an illness going around, I usually catch it	1	2	3	4	5

49. How has the **QUALITY OF YOUR LIFE** been during the **past 4 weeks** (that is, how have things been going for you)?

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(Circle
one
number)

Very well: could hardly be better	1
Pretty good	2
Good & bad parts about equal	3
Pretty bad	4
Very bad: could hardly be worse	5

The following question is about **MEMORY**. (Circle one number)

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	Yes, a great deal	Yes, somewhat	Only a little	No, not at all
50. In the past 4 weeks, have you had any trouble with your memory?	1	2	3	4

51–54: Circle one number for **how often** in the **past 4 weeks** you have had trouble *remembering* or **how often** these memory problems have interfered with your normal work or living.

	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
51. Names of people	1	2	3	4	5	6
52. Where you put things	1	2	3	4	5	6
53. Things people tell you	1	2	3	4	5	6
54. Things you read hours or days before	1	2	3	4	5	6

55–59: The following questions are about **LANGUAGE** problems you may have. Circle one number for **how often** you have trouble speaking or **how often** these problems have interfered with your normal work or living.

	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
55. Finding the correct word	1	2	3	4	5	6
56. Understanding what others are saying in conversation	1	2	3	4	5	6
57. Understanding directions	1	2	3	4	5	6
58. Understanding what you read	1	2	3	4	5	6
59. Writing	1	2	3	4	5	6

60–64: The following questions are about **CONCENTRATION** problems you may have. Circle one number for **how often** in the **past 4 weeks** you had trouble concentrating or **how often** these problems interfered with your normal work or living.

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	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
60. Concentrating on conversations	1	2	3	4	5	6
61. Concentrating on a task or job	1	2	3	4	5	6
62. Concentrating on reading	1	2	3	4	5	6
63. Concentrating on doing one thing at a time	1	2	3	4	5	6
64. How often do you feel you react slowly to things that are said or done?	1	2	3	4	5	6

65–68: The following questions are about problems you may have with certain **ACTIVITIES**. Circle one number for **how much** during the **past 4 weeks** your epilepsy or antiepileptic medication has caused trouble with . . .

	A great deal	A lot	Somewhat	Only a little	Not at all
65. Working	1	2	3	4	5
66. Friendships and relationships (romantic)	1	2	3	4	5
67. Leisure time (such as hobbies, going out)	1	2	3	4	5
68. Driving	1	2	3	4	5

69-73: The following questions relate to the way you **FEEL** about your **seizures**.
 (Circle one number on each line)

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	Very fearful	Somewhat fearful	Not very fearful	Not fearful at all
69. How fearful are you of having a seizure during the next month?	1	2	3	4

	Worry a lot	Occasionally worry	Don't worry at all
70. Do you worry about hurting yourself during a seizure?	1	2	3

	Very worried	Somewhat worried	Not very worried	Not worried at all
71. How worried are you about embarrassment or other social problems resulting from having a seizure during the next month?	1	2	3	4

	1	2	3	4
72. How worried are you that medications you are taking will be bad for you if taken for a long time?	1	2	3	4

	Very poorly	Not well	Fair	Well	Very well
73. How well do you do with complicated projects that require organization or planning?	1	2	3	4	5

74–80: For each of these **PROBLEMS**, circle one number for **how much they bother you** on a scale of 1 to 5, where 1 = Not at all bothersome, and 5 = Extremely bothersome.

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		Not at all bothersome			Extremely bothersome	
74.	Seizures	1	2	3	4	5
75.	Memory difficulties	1	2	3	4	5
76.	Driving limitations	1	2	3	4	5
77.	Work limitations	1	2	3	4	5
78.	Social limitations	1	2	3	4	5
79.	Physical effects of antiepileptic medication	1	2	3	4	5
80.	Mental effects of antiepileptic medication	1	2	3	4	5

81–83: In terms of **your satisfaction with your family and social life**, circle one number to indicate the following:

		Poor	Fair	Good	Very good	Excellent
81.	The amount of togetherness you have with your family and/or friends	1	2	3	4	5
82.	The support and understanding your family and/or friends give each other	1	2	3	4	5
83.	The amount you talk things over with your family and/or friends	1	2	3	4	5

84-88: In terms of **your satisfaction with your family and social life**, circle one number to indicate the following:

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	Very satisfied	Somewhat satisfied	Neither satisfied nor dissatisfied	Somewhat dissatisfied	Very dissatisfied	
84. Overall, how satisfied were you with your sexual relations during the past 4 weeks ?	1	2	3	4	5	
	Much more limited	Somewhat more limited	About the same	Somewhat less limited	Much less limited	
85. How limited are your social activities compared with others your age because of your epilepsy or epilepsy-related problems?	1	2	3	4	5	
	Yes, as much as I wanted	Yes, quite a bit	Yes, some	Yes, a little	No, not at all	
86. During the past 4 weeks , was someone available to help you if you needed and wanted help?	1	2	3	4	5	
	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
87. How much of the time during the past 4 weeks did you feel left out?	1	2	3	4	5	6
	Always	Very often	Fairly often	Sometimes	Almost never	Never
88. During the past 4 weeks , how often did you feel isolated from others?	1	2	3	4	5	6

89. How good or bad do you think your health is? On the thermometer scale below, the best imaginable state of health is 100 and the worst imaginable state is 0. Please indicate how you feel about your health by circling one number on the scale. **Please consider your epilepsy as part of your health when you answer this question.**

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