## **QUALITY OF LIFE IN EPILEPSY - PROBLEMS:**

QOLIE-31-P (Version 2)

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Today's Date\_\_\_\_/ \_\_\_/ \_\_\_/

Name \_\_\_\_\_ Age: \_\_\_ years

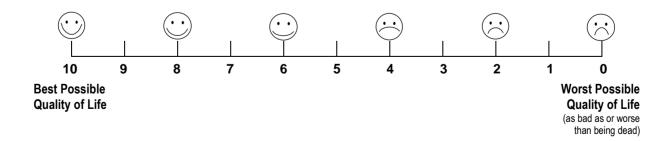
#### **INSTRUCTIONS**

The QOLIE-31-P is a survey of health-related quality of life for adults (18 years or older) with epilepsy. [Adolescents (ages 11-17 years) should complete the QOLIE-AD-48, designed for that age group.] This version differs from the original QOLIE-31 (version 1) in the addition of questions about how much distress you feel about problems and worries related to epilepsy. This questionnaire should be completed only by the person who has epilepsy (not a relative or friend) because no one else knows how YOU feel.

There are 38 questions 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 on the side of the page. These notes may be useful if you discuss the QOLIE-31-P with your doctor. Completing the QOLIE-31-P before and after treatment changes may help you and your doctor understand how the changes have affected your life.

This copy of the QOLIE-31-P is provided by <u>www.epilepsy.com</u>, your source for epilepsy information, and the QOLIE Development Group. We wish you success in living your life with epilepsy!

1. Overall, how would you rate your quality of life? (Circle one number on the scale below)



# Part A.

These questions are about how you have been FEELING during the past 4 weeks. For each question, please indicate the one answer that comes closest to the way you have been feeling.

## 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
2. Did you feel full of pep?	1	2	3	4	5	6
3. Did you have a lot of energy?	1	2	3	4	5	6
4. Did you feel worn out?	1	2	3	4	5	6
5. Did you feel tired?	1	2	3	4	5	6

Reviewing only questions in Part A, consider the overall impact of these issues on your life in the past 4 weeks.

	Not at all	Somewhat	Moderately	A lot	Very much
6. How much do the above problems and worries about energy distress you overall?	1	2	3	4	5

# Part B.

These questions are about how you have been FEELING during the past 4 weeks. For each question, please indicate the one answer that comes closest to the way you have been feeling.

# 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
7. Have you been a very nervous person?	1	2	3	4	5	6
Have you felt so down in the dumps that nothing could cheer you up?	1	2	3	4	5	6
9. Have you felt calm and peaceful?	1	2	3	4	5	6
10. Have you felt downhearted and blue?	1	2	3	4	5	6
11. Have you been a happy person?	1	2	3	4	5	6

Reviewing only questions in Part B, consider the overall impact of these issues on your life in the past 4 weeks.

	Not at all	Somewhat	Moderately	A lot	Very much
12. How much do the above problems and worries about emotions distress you overall?	1	2	3	4	5

## Part C.

The following questions are about how you FEEL and about problems you may have with daily ACTIVITIES during the past 4 weeks. For each question, please indicate the one answer that comes closest to the way you have been feeling.

The following question asks about how you FEEL and how things have been going for you.

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

(Circle one number)

	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
13. Has your health limited your social activities (such as visiting with friends or close relatives)?	1	2	3	4	5	6

The following questions ask about problems you may have with certain ACTIVITIES.

How much of the time during the past 4 weeks your epilepsy or antiepileptic medication has caused trouble with...

(Circle one number on each line)

	A great deal	A lot	Somewhat	Only a little	Not at all
14. Leisure activities (such as hobbies, going out)	1	2	3	4	5
15. Driving (or transportation)	1	2	3	4	5

	Not at all bothersome				Extremely bothersome
16. How much do your work limitations bother you?	1	2	3	4	5
17. How much do your social limitations bother you?	1	2	3	4	5

Reviewing only questions in Part C, consider the overall impact of these issues on your life in the past 4 weeks.

	Not at all	Somewhat	Moderately	A lot	Very much
How much do the above problems and worries about daily activities distress you overall?	1	2	3	4	5

# Part D.

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

These questions are about thinking, reading, concentrating and memory problems you may have had during the past 4 weeks. For each question, please indicate the one answer that comes closest to the way you have been feeling.

(Circle one number)	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
19. Did you have difficulty reasoning and solving problems (such as making plans, making decisions, learning new things)?	1	2	3	4	5	6
			Yes, a great deal	Yes, somewhat	Only A little	No, not at all
20. In the past 4 weeks, have you had any trouble with you	ur memor	y?	1	2	3	4
In the past 4 weeks, how often have you had						
(Circle one number on each line)	All of the	Most of the	A good bit of the	Some of the	A little	None of the

	of the time					
21. Trouble remembering things people tell you?	1	2	3	4	5	6
22. Trouble concentrating on reading?	1	2	3	4	5	6
23. Trouble concentrating on doing one thing at a time?	1	2	3	4	5	6

	Not at all bothersome				Extremely bothersome
24. How much do your memory difficulties bother you?	1	2	3	4	5

Reviewing only questions in Part D, consider the overall impact of these issues on your life in the past 4 weeks.

	Not at all	Somewhat	Moderately	A lot	Very much
How much do the above problems and worries about mental function distress you overall?	1	2	3	4	5

# Part E.

These questions are about problems you may have related to your epilepsy or antiepileptic medication.

## During the past 4 weeks...

(Circle one number on each line)

(Circle one number on each line)	Not at all bothersome				Extremely bothersome	
26. How much do physical effects of antiepileptic medication bother you?	1	2	3	4	5	
How much do mental effects of antiepileptic medication bother you?	1	2	3	4	5	
		Very worried	Somewhat worried	Not very worried	Not worried at all	
28. How worried are you that medications you are taking will be bad for you if taken for a long time?		1	2	3	4	

Reviewing only questions in Part E, consider the overall impact of these issues on your life in the past 4 weeks.

	Not at all	Somewhat	Moderately	A lot	Very much
29. How much do the above problems and worries about the effects of medication distress you overall?	1	2	3	4	5

# Part F.

These questions are about how you FEEL about your seizures during the past 4 weeks. For each question, please indicate the one answer that comes closest to the way you have been feeling.

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

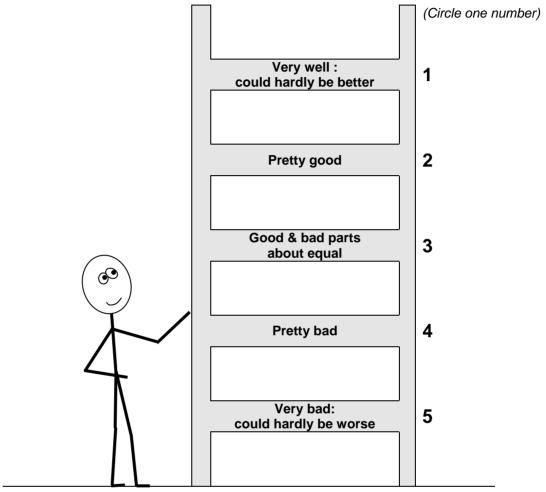
(Circle one number)	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
30. Have you worried about having another seizure?	1	2	3	4	5	6
			Very fearful	Somewhat fearful	Not very fearful	Not fearful at all
31. How fearful are you of having a seizure during the ne	ext month?		1	2	3	4
				Worry a lot	Occasionally worry	Don't worry at all
32. Do you worry about hurting yourself during a seizure	?			1	2	3
			Very worried	Somewhat worried	Not very worried	Not at all worried
33. How worried are you about embarrassment or other resulting from having a seizure during the next month		ems	1	2	3	4
		Not at all bothersome				Extremely bothersome
		1	2	3	4	5

	NOT at all	Somewhat	ivioderately	A IOI	very much
35. How much do the above problems and worries about seizures distress you overall?	1	2	3	4	5

# Part G.

The following question asks about how you FEEL about your overall quality of life. Please indicate the one answer that comes closest to the way you have been feeling.

36. 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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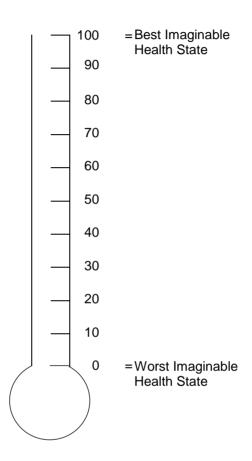
Reviewing only questions 1 and 36 in **Part G** (on page 1 and this page), consider the overall impact of your quality of life **in the past 4 weeks**.

	Not at all	Somewhat	Moderately	A lot	Very much
37. How much does the state of your <u>quality of life</u> distress you overall?	1	2	3	4	5

38. How good or bad do you think your HEALTH is?

On the scale below, the best imaginable state of health is 100 and the worst imaginable state is zero (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.



mc	most <b>IMPORTANT</b> to you <b>NOW.</b>						
39.			the following topics from '1' to '7', with '1' corresponding to the very most important topic and '7' to timportant one. Please use each number only once.				
L_		A.	Energy (tiredness)				
L		В.	Emotions (mood)				
L		C.	Daily activities (work, driving, social)				
L_	_	D.	Mental activity (thinking, concentrating, memory)				
L_		E.	Medication effects (physical, mental)				
L_		F.	Seizure worry (impact of seizures)				
L_		G.	Overall quality of life				

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Considering ALL the questions you have answered, please indicate the areas related to your epilepsy that are

Part I.