

**HOW EPILEPSY AFFECTS MY LIFE**  
**A Questionnaire For Young People Who Have Epilepsy**

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

Name: \_\_\_\_\_

Age: \_\_\_ \_\_

**INSTRUCTIONS**

The QOLIE-AD-48 is a survey of health-related quality of life for adolescents (11-18 years of age) with 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 48 questions (in two parts) about your health and daily activities. Answer every question by circling the appropriate number (1, 2, 3...). The first part asks about your general health. The second part asks about the effects of your epilepsy and antiepileptic medications. **Please answer every question** by circling the appropriate number (1, 2, 3, 4, 5). If you are not sure about how to answer a question, please give the **best answer you can**. You may write notes in the margin to explain your feelings. Even if some questions look similar, answer every question.

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-AD-48 with your doctor. Completing the QOLIE-AD-48 before and after treatment changes may help you and your doctor understand how the changes have affected your life.

**PART 1: GENERAL HEALTH**

1. In general, would you say your health is: *(Circle one number)*

Excellent	Very Good	Good	Fair	Poor
5	4	3	2	1

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

Much better now	Somewhat better now	About the same now	Somewhat worse now	Much worse now
5	4	3	2	1

The following questions are about activities you might do during a TYPICAL DAY. We want you to answer how much **your health** limits you in these activities. *(Circle one number on each line)*

Very often    Often    Some-times    Not often    Never

In the past 4 weeks, how often has your health limited: \_\_\_\_\_

3. Heavy activities, such as running, participating in very active sports (such as gymnastics, roller-blading, skiing)?

1	2	3	4	5
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	Very often	Often	Some-times	Not often	Never
4. Moderate activities (such as walking to school, bicycle riding)?	1	2	3	4	5

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	Very often	Often	Some-times	Not often	Never
5. Light activities (such as carrying packages or a school bag full of books)?	1	2	3	4	5

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6. Other daily activities (such as taking a bath/shower alone, going to and from school alone)?	1	2	3	4	5
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The following questions are about your regular daily activities, such as chores at home, baby-sitting, attending school, being with friends and family, doing homework, or taking part in after-school activities and lessons. We want to know if you had any of the following difficulties with your regular activities as a result of any **physical problems (such as illness) or emotional problems (such as feeling sad or nervous)?**

	Very often	Often	Some-times	Not often	Never
In the past 4 weeks, how often have physical or emotional problems caused you to:					

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7. Do fewer things than you would have liked to do?	1	2	3	4	5
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8. Limit the <b>kind</b> of schoolwork, chores, sports, or other activities you did?	1	2	3	4	5
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9. Have <b>difficulty</b> performing the schoolwork, chores, sports, or other activities you did (for example, it took extra effort) ?	1	2	3	4	5
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	Very often	Often	Some-times	Not often	Never
In the past 4 weeks, how often:					

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10. Did you skip school for no reason?	1	2	3	4	5
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11. Were you in trouble <u>in</u> school (with teachers or other staff)?	1	2	3	4	5
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12. Were you in trouble <u>out</u> of school (with police, security guards, bus driver, etc)?	1	2	3	4	5
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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.

*(Circle one number on each line)*

All of the time	Most of the time	Some of the time	A little of the time	None of the time
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In the past 4 weeks, how often have you:

- 
- |   |   |   |   |   |   |
|---|---|---|---|---|---|
| 13. Had trouble concentrating on an activity? | 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|---|
- 
- |   |   |   |   |   |   |
|---|---|---|---|---|---|
| 14. Had trouble concentrating on reading? | 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|---|
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The following questions are about mental activities and language problems that may interfere with your normal schoolwork or living activities. *(Circle one number on each line)*

All of the time	Most of the time	Some of the time	A little of the time	None of the time
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In the past 4 weeks, how often have you:

- 
- |                              |   |   |   |   |   |
|------------------------------|---|---|---|---|---|
| 15. Had difficulty thinking? | 1 | 2 | 3 | 4 | 5 |
|------------------------------|---|---|---|---|---|
- 
- |   |   |   |   |   |   |
|---|---|---|---|---|---|
| 16. Had difficulty figuring out and solving problems (such as making plans, making decisions, learning new things)? | 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|---|
- 
- |   |   |   |   |   |   |
|---|---|---|---|---|---|
| 17. Had a problem with complicated projects that require organization or planning like computer games or difficult homework)? | 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|---|
- 
- |   |   |   |   |   |   |
|---|---|---|---|---|---|
| 18. Had trouble remembering things you read hours or days before? | 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|---|
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- |   |   |   |   |   |   |
|---|---|---|---|---|---|
| 19. Had trouble finding the correct word? | 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|---|
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- |  |   |   |   |   |   |
|--|---|---|---|---|---|
| 20. Had trouble understanding your teachers? | 1 | 2 | 3 | 4 | 5 |
|--|---|---|---|---|---|
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- |  |   |   |   |   |   |
|--|---|---|---|---|---|
| 21. Had trouble understanding what you read? | 1 | 2 | 3 | 4 | 5 |
|--|---|---|---|---|---|
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The following questions ask about the support you get from others (including family and friends). *(Circle one number on each line)*

Very Often	Often	Some- times	Not often	Never
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In the past 4 weeks, how often did you:

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- |   |   |   |   |   |   |
|---|---|---|---|---|---|
| 22. Have someone available to help you if you needed and wanted help? | 5 | 4 | 3 | 2 | 1 |
|---|---|---|---|---|---|
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	Very Often	Often	Some-times	Not often	Never
23. Have someone you could confide in or talk to about things that were troubling you?	5	4	3	2	1

24. Have someone you could talk to when you were confused and needed to sort things out?	5	4	3	2	1
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25. Have someone who accepted you as you were, both your good points and bad points?	5	4	3	2	1
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## PART 2: EFFECTS OF EPILEPSY AND ANTIEPILEPSY MEDICATIONS

The following questions ask about how your epilepsy or medications (antiepileptic drugs) have affected your life in the past 4 weeks. *(Circle one number on each line)*

	Very Often	Often	Some-times	Not often	Never
In the past 4 weeks, how often did you:					

26. Feel that <b>epilepsy or medications</b> limited your social activities (such as hanging out with friends, doing extra-curricular activities) compared with social activities of others your age?	1	2	3	4	5
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27. Feel alone and isolated from others because of your epilepsy/seizures ?	1	2	3	4	5
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28. Miss classes because of seizures or medications?	1	2	3	4	5
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29. Use epilepsy or medication side effects as an excuse to avoid doing something you didn't really want to do?	1	2	3	4	5
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30. Feel embarrassed or "different" because you had to take medications?	1	2	3	4	5
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	Very Often	Often	Some-times	Not often	Never
In the past 4 weeks, how often did you:					

31. Feel that epilepsy or medications limited your school performance?	1	2	3	4	5
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32. Feel you had limitations because of your seizures?	1	2	3	4	5
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33. Feel that epilepsy or medications limited your independence?	1	2	3	4	5
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	Very Often	Often	Some-times	Not often	Never
134. Feel that epilepsy or medications limited your social life or dating?	1	2	3	4	5

35. Feel that epilepsy or medications limited your participation in sports or physical activities?	1	2	3	4	5
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The following question asks about possible side effects from antiepileptic drugs.  
In the past 4 weeks, how did you feel:

	Very Bad	Bad	OK	Good	Very good
36. About how you looked (side effects such as weight gain, acne/pimples, hair change, etc.)?	1	2	3	4	5

In the past 4 weeks, how much were you bothered by:

	A Lot	Some	Not much	A little	Not at all
37. Limits set by parents/family because of your epilepsy or medications?	1	2	3	4	5

Next are some statements people with epilepsy sometimes make about themselves.

For each statement, circle the answer that comes closest to the way **you** have felt about **yourself** in the **past 4 weeks**.

	Strongly agree	Agree	Disagree	Strongly disagree
38. I consider myself to be less than perfect because I have epilepsy.	1	2	3	4

39. If I applied for a job, and someone else also applied who didn't have epilepsy, the employer should hire the other person.	1	2	3	4
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40. I can understand why someone wouldn't want to date me because I have epilepsy.	1	2	3	4
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41. I don't blame people for being afraid of me because I have epilepsy.	1	2	3	4
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42. I don't blame people for taking my opinions less seriously than they would if I didn't have epilepsy.	1	2	3	4
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43. I feel that my epilepsy makes me mentally unstable.	1	2	3	4
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The following questions ask about your attitudes toward epilepsy. Circle one number for how often in the **past 4 weeks** you have had these attitudes.

	Very bad	A little bad	Not sure	A little good	Very good
44. How good or bad has it been that you have epilepsy?	1	2	3	4	5

	Very Unfair	A little unfair	Not sure	A little fair	Very fair
45. How fair has it been that you have epilepsy?	1	2	3	4	5

	Very sad	A little sad	Not sure	A little happy	Very happy
46. How happy or sad has it been for you to have epilepsy?	1	2	3	4	5

	Very bad	A little bad	Not sure	A little good	Very good
47. How bad or good have you felt it is to have epilepsy?	1	2	3	4	5

	Very often	Often	Some-times	Not often	Never
48. How often do you feel that your epilepsy kept you from starting new things?	1	2	3	4	5

Optional Items:

In the past 4 weeks, how often did you:	Very often	Often	Some-times	Not often	Never
Worry about having another seizure?	1	2	3	4	5
Fear dying because of seizures?	1	2	3	4	5
Worry about hurting yourself during a seizure?	1	2	3	4	5

*This copy of the QOLIE-AD-48 is provided by the QOLIE Development Group. We wish you success in living your life with epilepsy!*