



# Asking you about your health

epilepsy

## **Instructions**

Please complete the questionnaire, making sure you reply to all the questions. This should take you about 20 minutes.

If you have difficulties completing the questionnaire, please ask someone else to help you. However, it is your answers that we are interested in.

## **Questions or help?**

If you have any questions or need any help please contact the research team on freephone 0800 9151 664 or via email at [YourHealth@dphpc.ox.ac.uk](mailto:YourHealth@dphpc.ox.ac.uk).

## **Need help with translation?**

Please ring 0800 9151 664

**Please return the questionnaire in the enclosed pre-paid envelope**

## QUALITY OF LIFE IN EPILEPSY

### QOLIE-31 (version 1.0)

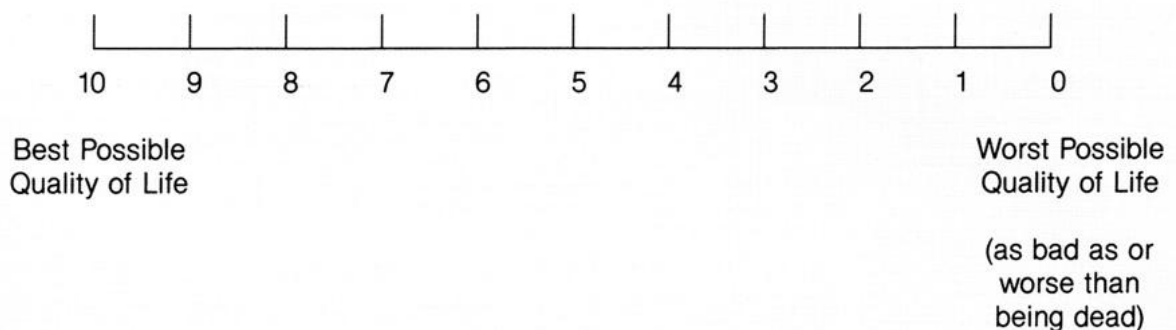
#### Instructions

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.

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

(Circle one number on the scale below)



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.

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 life?	1	2	3	4	5	6
3. Have you been very nervous?	1	2	3	4	5	6
4. Have you felt so down in the dumps that nothing could cheer you up?	1	2	3	4	5	6
5. Have you felt calm and peaceful?	1	2	3	4	5	6
6. Did you have a lot of energy?	1	2	3	4	5	6
7. Have you felt downhearted and depressed?	1	2	3	4	5	6
8. Did you feel worn out?	1	2	3	4	5	6
9. Have you been happy?	1	2	3	4	5	6
10. Did you feel tired?	1	2	3	4	5	6
11. Have you worried about having another seizure?	1	2	3	4	5	6
12. Did you have difficulty reasoning and solving problems (such as making plans, making decisions, learning new things)?	1	2	3	4	5	6
13. Has your health limited your social activities (such as visiting with friends or close relatives)?	1	2	3	4	5	6

(Circle one number)

	Very well: could hardly be better	Pretty good	Good & bad parts about equal	Pretty bad	Very bad: could hardly be worse
14. How has the <b>QUALITY OF YOUR LIFE</b> been during the <b>past 4 weeks</b> (that is, how have things been going for you)?	1	2	3	4	5

The following question is about **MEMORY**.

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

Circle one number for **how often** in the **past 4 weeks** you have had trouble *remembering* or **how often** this memory problem has 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
16. Trouble remembering things people tell you	1	2	3	4	5	6

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.

	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
17. Trouble concentrating on reading	1	2	3	4	5	6
18. Trouble concentrating on doing one thing at a time	1	2	3	4	5	6

(Circle one number on each line)

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
19.	Leisure time (such as hobbies, going out)	1	2	3	4	5
20.	Driving	1	2	3	4	5

The following questions relate to the way you **FEEL** about your **seizures**.

		Very fearful	Somewhat fearful	Not very fearful	Not fearful at all
21.	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
22.	Do you worry about hurting yourself during a seizure?	1	2	3

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

		Very worried	Somewhat worried	Not very worried	Not at all worried
24.	How worried are you that medications you are taking will be bad for you if taken for a long time?	1	2	3	4

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.

		Not at all bothersome			Extremely bothersome	
		1	2	3	4	5
25.	Seizures	1	2	3	4	5
26.	Memory difficulties	1	2	3	4	5
27.	Work limitations	1	2	3	4	5
28.	Social limitations	1	2	3	4	5
29.	Physical effects of antiepileptic medication	1	2	3	4	5
30.	Mental effects of antiepileptic medication	1	2	3	4	5

By placing a tick in one box in each group below, please indicate which statements best describe your own health state **today**.

31. **Mobility**

- I have no problems in walking about
- I have some problems in walking about
- I am confined to bed

32. **Self-Care**

- I have no problems with self-care
- I have some problems washing or dressing myself
- I am unable to wash or dress myself

33. **Usual Activities** (*e.g. work, study, housework, family or leisure activities*)

- I have no problems with performing my usual activities
- I have some problems with performing my usual activities
- I am unable to perform my usual activities

34. **Pain/Discomfort**

- I have no pain or discomfort
- I have moderate pain or discomfort
- I have extreme pain or discomfort

35. **Anxiety/Depression**

- I am not anxious or depressed
- I am moderately anxious or depressed
- I am extremely anxious or depressed

36. To help people say how good or bad a health state is, we have drawn a scale (rather like a thermometer) on which the best state you can imagine is marked 100 and the worst state you can imagine is marked 0.

We would like you to indicate on this scale how good or bad your own health is today, in your opinion. Please do this by drawing a line from the box below to whichever point on the scale indicates how good or bad your health state is today.

**Your own  
health state  
today**

Best  
imaginable  
health state

100

90

80

70

60

50

40

30

20

10

0

Worst  
imaginable  
health state



## About you

The following questions will help us see how health varies between different people.

37. **Are you male or female?**

- Male  
 Female

38. **How old are you?**

- |                                   |                                   |                                     |
|-----------------------------------|-----------------------------------|-------------------------------------|
| <input type="checkbox"/> Under 18 | <input type="checkbox"/> 35 to 44 | <input type="checkbox"/> 65 to 74   |
| <input type="checkbox"/> 18 to 24 | <input type="checkbox"/> 45 to 54 | <input type="checkbox"/> 75 to 84   |
| <input type="checkbox"/> 25 to 34 | <input type="checkbox"/> 55 to 64 | <input type="checkbox"/> 85 or over |

39. **Which of these best describes what you are doing at present? If more than one of these applies to you, please tick the main ONE only.**

- |   |   |
|---|---|
| <input type="checkbox"/> Full-time paid work (30 hours or more each week)     | <input type="checkbox"/> Permanently sick or disabled |
| <input type="checkbox"/> Part-time paid work (under 30 hours each week)       | <input type="checkbox"/> Fully retired from work      |
| <input type="checkbox"/> Full-time education at school, college or university | <input type="checkbox"/> Looking after the home       |
| <input type="checkbox"/> Unemployed   | <input type="checkbox"/> Doing something else         |

40. **Have you been told by a doctor that you have any of the following? Please tick all that apply.**

- |   |   |
|---|---|
| <input type="checkbox"/> Heart disease (for example angina, heart attack or heart failure)  | <input type="checkbox"/> Kidney disease   |
| <input type="checkbox"/> High blood pressure  | <input type="checkbox"/> Diseases of the nervous system (for example Parkinson's disease or multiple sclerosis) |
| <input type="checkbox"/> Problems caused by a stroke  | <input type="checkbox"/> Liver disease  |
| <input type="checkbox"/> Leg pain when walking due to poor circulation                      | <input type="checkbox"/> Cancer (within the last 5 years)   |
| <input type="checkbox"/> Lung disease (for example asthma, chronic bronchitis or emphysema) | <input type="checkbox"/> Depression   |
| <input type="checkbox"/> Diabetes   | <input type="checkbox"/> Arthritis  |

41. **How many years ago did you first receive a diagnosis for your epilepsy?**

\_\_\_\_ years \_\_\_\_ months

42. **What is your ethnic group?**

Choose one section from A to E below, then select the appropriate option to indicate your ethnic group.

**A. White**

- British
- Irish
- Any other White background, please write in: \_\_\_\_\_

**B. Mixed**

- White and Black Caribbean
- White and Black African
- White and Asian
- Any other Mixed background, please write in: \_\_\_\_\_

**C. Asian or Asian British**

- Indian
- Pakistani
- Bangladeshi
- Any other Asian background, please write in: \_\_\_\_\_

**D. Black or Black British**

- Caribbean
- African
- Any other Black background, please write in: \_\_\_\_\_

**E. Chinese or other ethnic group**

- Chinese
- Any other ethnic group, please write in: \_\_\_\_\_

43. **What is the first part of your postcode?** \_ \_ \_ \_

44. **Did you have any help with completing this questionnaire?**

- Yes
  - No
-

**If you have any other comments, please write them in the space below.**

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**Thank you for completing this questionnaire.**

**Please return it to the research team in the enclosed pre-paid envelope.**

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