

PIN Visit: Screening ID Number:

Centre Name: B1,B2,F1,F2 d d m m y y y y

Initials: Date form started: / /

Modified ELDQoL Questionnaire - original courtesy of the Departments of
Primary Care and Neurosciences, University of Liverpool.

EPILEPSY AND LEARNING DISABILITIES

QUALITY OF LIFE (ELDQoL) QUESTIONNAIRE

ABOUT THESE QUESTIONS

1. These questions ask about how the participant has been in the last four weeks. We are interested in how much the participant's daily life and activities have been affected by his/her epilepsy and its treatment.
2. We are interested in **your views** about how things have been for the participant. Your opinions are very important to us, and we hope you will take time to complete the questionnaire. We do not think it will take more than 15-20 minutes for you to do so.
3. Some people with epilepsy have more than one type of seizure. If the participant experiences different types of seizures, please answer the questions as they apply to the **most severe** seizures, in your opinion, that he/she has.
4. Most of the questions can be answered simply by ringing a number next to the answer that applies to the participant. Sometimes you are asked to write in a number.
5. We want to know how things have been **in the last four weeks**. If you cannot remember, do not know, or are unable to answer a particular question, please write that in.
6. Your name and address do not appear anywhere in this booklet. The information you give us will be treated as strictly confidential.

A. Has the participant had a seizure in the last four weeks? (*Please circle*)
Yes No

First some questions about the seizures the participant has. Please answer about seizures in the last four weeks. If the participant has more than one type of seizure, please think about the most severe seizures he/she has, when answering the questions. Please be sure to answer every question.

1. How severe have the participant's seizures been in the last four weeks?

- | | | | |
|-----------------|-------|---|---|
| Very severe | | 1 | |
| Somewhat severe | | 2 | |
| Moderate | | 3 | |
| Mild | | 4 | |
| Can't say | | 5 | 4 |
-

2. In the last four weeks, do you think the participant was aware of his/her surroundings during seizures?

- | | | | |
|-----------------------------|-------|---|---|
| Yes, during all seizures | | 1 | |
| Yes, during most seizures | | 2 | |
| Yes, during some seizures | | 3 | |
| No, not during any seizures | | 4 | |
| Can't say | | 5 | 5 |
-

3. In the last four weeks, did the participant blank out/lose consciousness during any of his/her seizures? If yes, generally for how long?

- | | | | |
|---|-------|---|---|
| Yes, for less than 1 minute | | 1 | |
| Yes, for between 1-2 minutes | | 2 | |
| Yes, for between 2-5 minutes | | 3 | |
| Yes, for more than 5 minutes | | 4 | |
| No, did not blank out or lose consciousness in any seizures | | 5 | |
| Can't say | | 6 | 6 |
-

4.	In the last four weeks, when the participant had seizures, how often did he/she fall to the ground?			
		Always	1
		Usually	2
		Sometimes/rarely	3
		Never	4
	Does not apply - participant does not stand independently/participant wheelchair bound		5
		Can't say	6
				7

5.	In the last four weeks, was the participant ever confused, disorientated or non- responsive after seizures?			
		Yes, always	1
		Yes, often	2
		Yes, sometimes/rarely	3
		No, never	4
		Can't say	5
				8

6.	In the last four weeks, if the participant was confused, disorientated or non- responsive after seizures, how long did this usually last?			
		Usually lasted less than 1 minute	1
		Usually lasted for between 1-5 minutes	2
		Usually lasted for between 6 minutes - 1 hour	3
		Usually lasted for more than 1 hour	4
	Participant never seemed confused/disorientated/non-responsive		5
		Can't say	6
				9

7.	How often was the participant distressed after seizures in the last four weeks?			
		Always	1
		Usually.	2
		Sometimes/rarely	3
		Never	4
		Can't say	5
				10

8.	In the last four weeks, how often did the participant wet him/herself during seizures?			
		Always	1
		Usually	2
		Sometimes/rarely	3
		Never	4
	Can't say – participant has no control of bladder		5
				11

9. In the last four weeks, how often did the participant soil him/herself during seizures?

Always	1	
Usually	2	
Sometimes/rarely	3	
Never	4	
Can't say – participant has no control of bowels	5	12

10. In the last four weeks, did the participant suffer any injury to the mouth, cheek or tongue during a seizure?

Always	1	
Usually	2	
Sometimes/rarely	3	
Never	4	
Can't say	5	13

11. In the last four weeks, did the participant suffer any injury other than to the mouth, cheek or tongue during a seizure?

Always	1	
Usually	2	
Sometimes/rarely	3	
Never	4	
Can't say	5	14

12. How upset was the participant by the injury/injuries he/she suffered during seizures in the last four weeks?
- | | | | | |
|-------------------------------------|-------|---|--|----|
| Very upset | | 1 | | |
| Somewhat upset | | 2 | | |
| Not very upset | | 3 | | |
| Not at all upset | | 4 | | |
| Does not apply - no injuries | | 5 | | |
| Can't say | | 6 | | 15 |
-

13. In the last four weeks, when the participant recovered from his/her seizures, how often did he/she appear sleepy or subdued?
- | | | | | |
|------------------|-------|---|--|----|
| Always | | 1 | | |
| Usually | | 2 | | |
| Sometimes/rarely | | 3 | | |
| Never | | 4 | | |
| Can't say | | 5 | | 16 |
-

14. In the last four weeks, when the participant had seizures, how quickly could he/she usually return to what he/she was doing?
- | | | | | |
|-------------------------------|-------|---|--|----|
| In less than 1 minute | | 1 | | |
| In between 1-5 minutes | | 2 | | |
| In between 6 minutes - 1 hour | | 3 | | |
| In over 1 hour | | 4 | | |
| Can't say | | 5 | | 17 |

Now some more detailed questions about any injuries the participant experienced in the last four weeks, as a result of his/her seizures.

15. In the past four weeks, how many times did the participant injure him/herself during a seizure?
- | | | | | |
|--|-------|---|--|--|
| Not at all | | 0 | | <input type="button" value="Go to Q 17"/> |
| Number of times (<i>please write in</i>) | | | | <input type="button" value="Answer Q 16"/> |
- 18
-

16. Did he/she suffer any of the following injuries as a result of having a seizure in the last four weeks?
- a) An injury to his/her head which required assessment and/or treatment at hospital?
- | | | | | |
|-----|-------|---|--|----|
| Yes | | 1 | | |
| No | | 2 | | 19 |

b) An injury to his/her teeth or mouth which required dental or medical treatment?

Yes	1	
No	2	20

c) A fracture/broken bone?

Yes	1	
No	2	21

d) Bruising or friction burns to any part of the body?

Yes	1	
No	2	22

e) Cuts or grazes to any part of the body?

Yes	1	
No	2	23

f) Any other injury? (*please tell us what*):

Yes	1	
No	2	24

g) Please list other injuries:

1.....

2.....

Now a few questions about the drugs the participant takes for epilepsy

17. In the last four weeks, how well do you think the participant's seizures have been controlled by the drugs he/she is taking?

Very well controlled	1	
Fairly well controlled	2	
Not very well controlled	3	
Not controlled at all	4	
Can't say	5	

18. Below is a list of problems people sometimes have with the drugs they take for their epilepsy. During the last four weeks, has the participant had any of the problems listed **which you think may have been caused by the drugs** he/she takes for epilepsy?

For each of the things listed, if it has always been a problem in the last four weeks, ring 1; if it has often been a problem, ring 2; and so on. Please answer every item.

	Always a problem	Often a problem	Sometimes/ rarely a problem	Never a problem	Can't say	
A. Unsteadiness/dizziness.....	1.....	2.....	3.....	4.....	5.....	26
B. Tiredness.....	1.....	2.....	3.....	4.....	5.....	
C. Restlessness.....	1.....	2.....	3.....	4.....	5.....	
D. Hyperactivity.....	1.....	2.....	3.....	4.....	5.....	
E. Nervousness.....	1.....	2.....	3.....	4.....	5.....	
F. Headache.....	1.....	2.....	3.....	4.....	5.....	
G. Problems with skin, e.g. rash.....	1.....	2.....	3.....	4.....	5.....	
H. Disturbed vision.....	1.....	2.....	3.....	4.....	5.....	
I. Upset stomach/nausea.....	1.....	2.....	3.....	4.....	5.....	
J. Difficulty paying attention.....	1.....	2.....	3.....	4.....	5.....	
K. Trouble with mouth or gums.....	1.....	2.....	3.....	4.....	5.....	
L. Shaky hands/tremor.....	1.....	2.....	3.....	4.....	5.....	
M. Weight gain.....	1.....	2.....	3.....	4.....	5.....	
N. Weight loss.....	1.....	2.....	3.....	4.....	5.....	
O. Sleepiness/drowsiness.....	1.....	2.....	3.....	4.....	5.....	
P. Memory problems.....	1.....	2.....	3.....	4.....	5.....	
Q. Disturbed sleep.....	1.....	2.....	3.....	4.....	5.....	
R. Loss of appetite.....	1.....	2.....	3.....	4.....	5.....	
S. Behaviour problems (e.g. temper tantrums, irritability or agitation).....	1.....	2.....	3.....	4.....	5.....	44

18T. Any other problems (please list in the spaces below):

1.....	1.....	2.....	3.....	4.....	
2.....	1.....	2.....	3.....	4.....	46

Now some questions about how the participant has been generally. Please think about how the participant has been over the last four weeks, compared to how he/she is normally.

19. How aware has the participant been of his/her surroundings/things going on around him/her, in the last four weeks?

Very aware 1
Fairly aware 2

Not very aware	3	
Not at all aware	4	
Can't say	5	47

20. How often, in the last four weeks, did the participant have problems sleeping (either difficulty falling asleep, waking during the night, or waking early)?

Always a problem	1	
Often a problem	2	
Sometimes/rarely a problem	3	
Never a problem	4	
Can't say	5	48

21. How often was the participant's appetite a problem - either eating too much or too little?

Always a problem	1	
Often a problem	2	
Sometimes/rarely a problem	3	
Never a problem	4	
Can't say	5	49

22. In the last four weeks, how good overall has the participant's bladder control been?

Very good	1	
Good	2	
Poor	3	
Very poor	4	
Does not apply - does not have control of his/her bladder	5	
Can't say	6	50

23. In the last four weeks, how good overall has the participant's bowel control been?

Very good	1	
Good	2	
Poor	3	
Very poor	4	
Does not apply - does not have control of his/her bowels	5	
Can't say	6	51

24. In the last four weeks, how well has the participant been able to let you know what he/she wants?

Very well	1	
Fairly well	2	
Not very well	3	
Not at all well	4	
Can't say	5	52

25. In the last four weeks, how well has he/she been able to understand what you tell him/her?

Very well	1	
Fairly well	2	
Not very well	3	
Not at all well	4	
Can't say	5	53

26. In the last four weeks, how well has the participant been able to pay attention to his/her favourite activities?

Very well	1	
Fairly well	2	
Not very well	3	
Not at all well	4	
Can't say	5	54

27. How often in the last four weeks has the participant been prevented from taking part in his/her normal activities (e.g. seeing friends and relatives) by his/her seizures/epilepsy?

- Always 1
- Often 2
- Sometimes/rarely 3
- Never 4
- Can't say 5

Now some questions about the participant's mood in the last four weeks

28. Here is a list of words that carers have used to describe patient's moods. In the last four weeks, has the participant appeared:-

	Always	Often	Sometimes/ rarely	Never	Can't say	
A. Happy.....	1.....	2.....	3.....	4.....	5.....	56
B. Aggressive.....	1.....	2.....	3.....	4.....	5.....	
C. Calm.....	1.....	2.....	3.....	4.....	5.....	
D. Irritable.....	1.....	2.....	3.....	4.....	5.....	
E. Tearful.....	1.....	2.....	3.....	4.....	5.....	
F. Friendly.....	1.....	2.....	3.....	4.....	5.....	
G. Hyperactive.....	1.....	2.....	3.....	4.....	5.....	
H. Relaxed.....	1.....	2.....	3.....	4.....	5.....	
I. Sad.....	1.....	2.....	3.....	4.....	5.....	
J. Agitated.....	1.....	2.....	3.....	4.....	5.....	
K. Cheerful.....	1.....	2.....	3.....	4.....	5.....	
L. Restless.....	1.....	2.....	3.....	4.....	5.....	
M. Tantrum-prone.....	1.....	2.....	3.....	4.....	5.....	
N. Frustrated.....	1.....	2.....	3.....	4.....	5.....	
O. Withdrawn.....	1.....	2.....	3.....	4.....	5.....	
P. Cooperative/helpful.....	1.....	2.....	3.....	4.....	5.....	71