

Patient ID:  
Assessment #:  
Date of assessment:  
Hospital recruited from:

## Epilepsy Project Questionnaire Pack

- Thank you for agreeing to answer the questions in this booklet. By answering these questions you will be helping us to understand how we can better support persons with epilepsy.
- The questions will ask you about your epilepsy, how it impacts on your life, the medication you take and what care you have received.
- There are many names to describe an epileptic attack, for example, “fit”, “turn”, “seizure”. You may have your own name for them. In the following questionnaire we use the terms “seizure” or “epileptic attack” to describe such an attack.
- The questions will often ask you about how your epilepsy was at a specific point in time. For example, some questions will ask about how your epilepsy has been during “during the past week”, whilst others will ask about how it was “during the last year”. Please be sure to read each question carefully and answer each question as it instructs.
- Most of the questions can be answered by simply circling a number or letter next to the answer which you feel applies.
- Should you have any problems or need help in completing the questions, please ask the member of the research team for assistance.
- Please be sure to answer all of the questions.

**First, we would like to ask you some questions about epileptic attacks. By epileptic attacks we mean any fits, seizures, convulsions, loss of consciousness or other attacks that you have experienced.**

**1 How long has it been since your last epileptic seizure?**

..... (If you do not know the number of days, but only the date, please write this here)

**2 How many seizures have you experienced during the past 4 weeks?**

..... (Please enter '0' if you have not experienced any in the last 4 weeks. If you cannot remember the number, please estimate based on the number you usually had during a single day or week)

**3 How many epileptic attacks have you had in the past year?**

**Circle  
one**

- |                           |   |
|---------------------------|---|
| (a) None                  | 0 |
| (b) Less than one a month | 1 |
| (d) One or more a month   | 2 |

**4 Exactly how many attacks have you had in the past year?**

**Circle  
one**

- |                 |    |
|-----------------|----|
| (a) None        | 0  |
| (b) One         | 1  |
| (c) Two         | 2  |
| (d) Three       | 3  |
| (e) Four        | 4  |
| (f) Five        | 5  |
| (g) Six         | 6  |
| (h) Seven       | 7  |
| (i) Eight       | 8  |
| (j) Nine        | 9  |
| (k) Ten or more | 10 |

**5 If you have experienced a seizure during the past 4 weeks, please answer the following questions based on the most severe seizure you have experienced in the past 4 weeks.**

• **I feel that my most severe seizures have been:**

**Circle  
one**

(a) Very Severe

0

(b) Severe

1

(c) Mild

2

(d) Very Mild

3

• **Most commonly when I blank out/ lose consciousness:**

**Circle  
one**

(a) I blank out for less than 1 minute

1

(b) I blank out for between 1 and 2 minutes

2

(c) I blank out for between 3 and 5 minutes

3

(d) I blank out for more than 5 minutes

4

(e) I never blank out/ lose consciousness

0

• **When I have my most severe seizures, I smack my lips, fidget,  
or behave in an unusual way:**

**Circle  
one**

(a) Always

0

(b) Usually

1

(c) Sometimes

2

(d) Never

3

• **After my most severe seizures:**

**Circle  
one**

(a) I feel very confused

0

(b) I feel fairly confused

1

(c) I feel slightly confused

2

(d) I do not feel confused at all

3

• **After my most severe seizures my confusion lasts for:**

**Circle  
one**

- (a) Less than 1 minute 1
- (b) Between 1 and 5 minutes 2
- (c) Between 6 minutes and 1 hour 3
- (d) 1 to 2 hours 4
- (e) More than 2 hours 5
- (f) I never feel confused 0

• **When I have my most severe seizures:** **Circle one**

- (a) I always fall to the ground 0
- (b) I usually fall to the ground 1
- (c) I sometimes fall to the ground 2
- (d) I never fall to the ground 3

• **After my most severe seizures:** **Circle one**

- (a) I always have a headache 0
- (b) I usually have a headache 1
- (c) I sometimes have a headache 2
- (d) I never have a headache 3

• **After my most severe seizures:** **Circle one**

- (a) I always feel sleepy 0
- (b) I usually feel sleepy 1
- (c) I sometimes feel sleepy 2
- (d) I never feel sleepy 3

• **After my most severe seizures:** **Circle one**

- |   |   |
|---|---|
| (a) I always find that I have wet myself    | 0 |
| (b) I usually find that I have wet myself   | 1 |
| (c) I sometimes find that I have wet myself | 2 |
| (d) I never find that I have wet myself     | 3 |

- **After my most severe seizures:** **Circle one**

- |   |   |
|---|---|
| (a) I always find that I have bitten my tongue    | 0 |
| (b) I usually find that I have bitten my tongue   | 1 |
| (c) I sometimes find that I have bitten my tongue | 2 |
| (d) I never find that I have bitten my tongue     | 3 |

- **After my most severe seizures:** **Circle one**

- |   |   |
|---|---|
| (a) I always find that I have injured myself (other than biting my tongue)    | 0 |
| (b) I usually find that I have injured myself (other than biting my tongue)   | 1 |
| (c) I sometimes find that I have injured myself (other than biting my tongue) | 2 |
| (d) I never find that I have injured myself (other than biting my tongue)     | 3 |

- **After my most severe seizures I can usually return to what I am doing in:** **Circle one**

- |                                  |   |
|----------------------------------|---|
| (a) Less than 1 minute           | 0 |
| (b) Between 1 and 5 minutes      | 1 |
| (c) Between 6 minutes and 1 hour | 2 |
| (d) 1 to 2 hours                 | 3 |
| (e) More than 2 hours            | 4 |

**Your answers to these next questions will help us to understand how your epilepsy affects your everyday life and how you are feeling, generally. For each of the questions, please ring**

the number next to the answer that applies to you.

**6 First, please can you tell us about the type of seizures you have. Circle one**

**Do you have:**

- |                                   |   |
|-----------------------------------|---|
| (a) MAJOR seizures only           | 1 |
| (b) MINOR seizures only           | 2 |
| (c) Both MAJOR and MINOR seizures | 3 |

**7 The statements below are about the MAJOR seizures you have. Circle one**  
**If you do not have major seizures, please go on to Question 8.**

**Please answer about the seizures you have had in the last four weeks.**

**• How often have your attacks occurred at a particular time of day or night? Circle one**

- |  |   |
|--|---|
| (a) Always                               | 1 |
| (b) Usually                              | 2 |
| (c) Sometimes                            | 3 |
| (d) Never – my attacks occur at any time | 4 |

**• When your attacks have happened, how often have you been able to tell when you will have them? Circle one**

- |               |   |
|---------------|---|
| (a) Always    | 1 |
| (b) Usually   | 2 |
| (c) Sometimes | 3 |
| (d) Never     | 4 |

**• How often have you been able to fight off your attacks? Circle one**

- |            |   |
|------------|---|
| (a) Always | 1 |
|------------|---|

- (b) Usually 2
- (c) Sometimes 3
- (d) Never 4

• **How often have you had an aura or warning with your attacks?** **Circle one**

- (a) Always 1
- (b) Usually 2
- (c) Sometimes 3
- (d) Never 4

• **In the last year, how much control have you had over your attacks?** **Circle one**

- (a) Very good control 1
- (b) Fairly good control 2
- (c) Little control 3
- (d) No control 4

• **When you have had attacks, how often have they occurred together in clusters?** **Circle one**

- (a) Always 1
- (b) Usually 2
- (c) Sometimes 3
- (d) Never 4

• **How often did your attacks occur when you were asleep?** **Circle one**

- (a) Always 1
- (b) Usually 2
- (c) Sometimes 3
- (d) Never 4

• **How many of the things you want to do have your attacks stopped you doing?** **Circle one**

- |                   |   |
|-------------------|---|
| (a) All of them   | 1 |
| (b) A lot of them | 2 |
| (c) A few of them | 3 |
| (d) None of them  | 4 |

**8 The statements below are about the MINOR seizures you have.**

**If you do not have minor seizures, please go on to Question 9.**

**Please answer about the seizures you have had in the last four weeks.**

- **How often have your attacks occurred at a particular time of day or night?** **Circle one**

- |  |   |
|--|---|
| (a) Always                               | 1 |
| (b) Usually                              | 2 |
| (c) Sometimes                            | 3 |
| (d) Never – my attacks occur at any time | 4 |

- **When your attacks have happened, how often have you been able to tell when you will have them?** **Circle one**

- |               |   |
|---------------|---|
| (a) Always    | 1 |
| (b) Usually   | 2 |
| (c) Sometimes | 3 |
| (d) Never     | 4 |

- **How often have you been able to fight off your attacks?** **Circle one**

- |               |   |
|---------------|---|
| (a) Always    | 1 |
| (b) Usually   | 2 |
| (c) Sometimes | 3 |
| (d) Never     | 4 |

- **How often have you had an aura or warning with your attacks?** **Circle one**

- |               |   |
|---------------|---|
| (a) Always    | 1 |
| (b) Usually   | 2 |
| (c) Sometimes | 3 |



(d) Never 4

• **In the last year, how much control have you had over your attacks?** **Circle one**

(a) Very good control 1

(b) Fairly good control 2

(c) Little control 3

(d) No control 4

• **When you have had attacks, how often have they occurred together in clusters?** **Circle one**

(a) Always 1

(b) Usually 2

(c) Sometimes 3

(d) Never 4

• **How often did your attacks occur when you were asleep?** **Circle one**

(a) Always 1

(b) Usually 2

(c) Sometimes 3

(d) Never 4

• **How many of the things you want to do have your attacks stopped you doing?** **Circle one**

(a) All of them 1

(b) A lot of them 2

(c) A few of them 3

(d) None of them 4

In this next section, we would now like to ask you some questions about how you have been feeling.

**9 This questionnaire is designed to help your clinician know how you feel. Read each item below and circle the number next to each answer which comes closest to how you have been feeling in the past week.**

**Don't take too long over the replies, your immediate reaction to each item will probably be more accurate than a long thought-out response.**

**• I feel tense or 'wound up'**

- (a) Most of the time 1
- (b) A lot of the time 2
- (c) From time to time, occasionally 3
- (d) Not at all 4

**• I still enjoy the things I used to enjoy**

- (a) Definitely as much 1
- (b) Not quite so much 2
- (c) Only a little 3
- (d) Hardly at all 4

**• I get a sort of frightened feeling as if something awful is about to happen**

- (a) Very definitely and quite badly 1
- (b) Yes, but not too badly 2
- (c) A little, but it doesn't worry me 3
- (d) Not at all 4

**• I feel as if I am slowed down**

- (a) Nearly all the time 1
- (b) Very often 2
- (c) Sometimes 3
- (d) Not at all 4

**• I get a sort of frightened feeling like 'butterflies' in the stomach**

- (a) Not at all 1
- (b) Occasionally 2
- (c) Quite often 3
- (d) Very often 4

**• I have lost interest in my appearance**

- (a) Definitely 1
- (b) I don't take as much care as I should 2
- (c) I may not take quite as much care 3
- (d) I take just as much care as ever 4

• **I can laugh and see the funny side of things**

- (a) As much as I always could 1
- (b) Not quite so much now 2
- (c) Definitely not so much now 3
- (d) Not at all 4

• **Worrying thoughts go through my mind**

- (a) A great deal of the time 1
- (b) A lot of the time 2
- (c) Not too often 3
- (d) Very little 4

• **I feel cheerful**

- (a) Never 1
- (b) Not often 2
- (c) Sometimes 3
- (d) Most of the time 4

• **I can sit at ease and feel relaxed**

- (a) Definitely 1
- (b) Usually 2
- (c) Not often 3
- (d) Not at all 4

• **I feel restless as if I have to be on the move**

- (a) Very much indeed 1
- (b) Quite a lot 2
- (c) Not very much 3
- (d) Not at all 4

• **I look forward with enjoyment to things**

- (a) As much as I ever did 1
- (b) Rather less than I used to 2
- (c) Definitely less than I used to 3
- (d) Hardly at all 4

• **I get sudden feelings of panic**

- (a) Very often indeed 1
- (b) Quite often 2
- (c) Not very often 3
- (d) Not at all 4

• **I can enjoy a good book or radio or television programme**

•

- (a) Often 1
- (b) Sometimes 2
- (c) Not often 3
- (d) Very seldom 4

**10 Below are some statements about how you feel with or towards other people.**

**For each statement, please ring the number that corresponds to your answer.**

- Because of my epilepsy I feel that some people are uncomfortable with me** **Circle one**

  - (a) Not at all 1
  - (b) Yes, maybe 2
  - (c) Yes, probably 3
  - (d) Yes, definitely 4
  
- Because of my epilepsy I feel some people treat me like an inferior person** **Circle one**

  - (a) Not at all 1
  - (b) Yes, maybe 2
  - (c) Yes, probably 3
  - (d) Yes, definitely 4
  
- Because of my epilepsy I feel some people would prefer to avoid me** **Circle one**

  - (a) Not at all 1
  - (b) Yes, maybe 2
  - (c) Yes, probably 3
  - (d) Yes, definitely 4

**- Please turn over -**

The following questions ask about your quality of life.

Please choose one number for each question. 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 this form.

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

• Have you had a lot of energy?

Circle  
one

- |                          |   |
|--------------------------|---|
| (a) All of the time      | 1 |
| (b) Most of the time     | 2 |
| (c) Some of the time     | 3 |
| (d) A little of the time | 4 |
| (e) None of the time     | 5 |

• Have you felt downhearted and blue?

Circle  
one

- |                          |   |
|--------------------------|---|
| (a) None of the time     | 1 |
| (b) A little of the time | 2 |
| (c) Some of the time     | 3 |
| (d) Most of the time     | 4 |
| (e) All of the time      | 5 |

• Has your epilepsy or antiepileptic medication caused you trouble with driving?

Circle  
one

- |                  |   |
|------------------|---|
| (a) Not at all   | 1 |
| (b) A little     | 2 |
| (c) Somewhat     | 3 |
| (d) A lot        | 4 |
| (e) A great deal | 5 |

12 During the past 4 weeks, how much have you been bothered by....

• **Memory difficulties?**

**Circle  
one**

- (a) Not bothered at all
- (b) A little
- (c) Somewhat
- (d) A lot
- (e) Extremely bothered

1  
2  
3  
4  
5

• **Work limitations?**

**Circle  
one**

- (a) Not bothered at all
- (b) A little
- (c) Somewhat
- (d) A lot
- (e) Extremely bothered

1  
2  
3  
4  
5

• **Social limitations?**

**Circle  
one**

- (a) Not bothered at all
- (b) A little
- (c) Somewhat
- (d) A lot
- (e) Extremely bothered

1  
2  
3  
4  
5

• **Physical effects of antiepileptic medication?**

**Circle  
one**

- (a) Not bothered at all
- (b) A little
- (c) Somewhat
- (d) A lot
- (e) Extremely bothered

1  
2  
3  
4  
5

• **Mental effects of antiepileptic medication?**

**Circle  
one**

- |                         |   |
|-------------------------|---|
| (a) Not bothered at all | 1 |
| (b) A little            | 2 |
| (c) Somewhat            | 3 |
| (d) A lot               | 4 |
| (e) Extremely bothered  | 5 |

**13 How fearful are you of having a seizure during the next month? Circle one**

- |                         |   |
|-------------------------|---|
| (a) Not bothered at all | 1 |
| (b) A little            | 2 |
| (c) Somewhat            | 3 |
| (d) A lot               | 4 |
| (e) Extremely bothered  | 5 |

**14 How has the quality of you life been during the past 4 weeks? That is, how have things been going for you? (Please circle one number)**

- |                                      |   |
|--------------------------------------|---|
| Very well:<br>Could hardly be better | 1 |
|                                      |   |
| Pretty good                          | 2 |
|                                      |   |
| Good and bad parts:<br>About equal   | 3 |
|                                      |   |
| Pretty bad                           | 4 |
|                                      |   |
| Very bad:<br>Could hardly be worse   | 5 |
|                                      |   |

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

• **Mobility** **Tick one**

- (a) I have no problems in walking about
- (b) I have some problems in walking about
- (c) I am confined to bed

• **Self-care** **Tick one**

- (a) I have no problems with self-care
- (b) I have some problems washing or dressing myself
- (c) I am unable to wash or dress myself

• **Usual activities** (*e.g., work, study, housework, family or leisure activities*) **Tick one**

- (a) I have no problems with performing my usual activities
- (b) I have some problems with performing my usual activities
- (c) I am unable to perform my usual activities

• **Pain/ Discomfort** **Tick one**

- (a) I have no pain or discomfort
- (b) I have moderate pain or discomfort
- (c) I have extreme pain or discomfort

• **Anxiety/ Depression** **Tick one**

- (a) I am not anxious or depressed
  - (b) I am moderately anxious or depressed
  - (c) I am extremely anxious or depressed
-



**16** The next set of statements describe how people sometimes feel about the impact of their epilepsy and its treatment on their lives. Thinking about your own life, do you strongly agree, agree, disagree, or strongly disagree with the statements?

Please ring the number that corresponds to your answer.

	Strongly agree	Agree	Disagree	Strongly disagree
<ul style="list-style-type: none"> <li>• There is really no way I can solve some of the problems I have with my epilepsy</li> </ul>	1	2	3	4
<ul style="list-style-type: none"> <li>• Sometimes I feel that my epilepsy controls my life</li> </ul>	1	2	3	4
<ul style="list-style-type: none"> <li>• Despite my epilepsy, I can do almost anything I set my mind to</li> </ul>	1	2	3	4
<ul style="list-style-type: none"> <li>• I often feel helpless in dealing with my seizures</li> </ul>	1	2	3	4
<ul style="list-style-type: none"> <li>• The course of my epilepsy in the future most depends on me</li> </ul>	1	2	3	4
<ul style="list-style-type: none"> <li>• There is little I can do to change how much my seizures affect the important things in my life</li> </ul>	1	2	3	4

- Please turn over -

**17 Please circle one number for each statement to show how often you do the following.**

**17. As you answer the questions, please think about your activities in the past year.**

	Never	Rarely	Sometimes	Most of the time	Always
<b>When my seizure medication is running out, I spread out the time between doses.</b>	1	2	3	4	5
<b>When my seizure medication is running out, I take less medication at each time.</b>	1	2	3	4	5
<b>I take my seizure medication the way my doctor orders it.</b>	1	2	3	4	5
<b>I take my seizure medication at the same time each day.</b>	1	2	3	4	5
<b>I have to put off having my seizure medication refilled because it costs too much money.</b>	1	2	3	4	5
<b>I miss doctor or clinic appointments.</b>	1	2	3	4	5
<b>If I had side effects from the seizure medications, I would skip a dose without asking my doctor.</b>	1	2	3	4	5
<b>I plan ahead and have my seizure medication refilled before I run out.</b>	1	2	3	4	5
<b>I miss doses of my seizure medication because I do not remember to take it.</b>	1	2	3	4	5
<b>I skip doses of seizure medication.</b>	1	2	3	4	5

**18 We would like to ask you about the information you have received about your medicines.**

**Please rate the information you have received about each of the following aspects of your medicine. If you use more than one medicine, please give your overall feeling about information you have received about all your medicines.**

	None needed	None received	Too little	About right	Too much
<b>What your medicine is called</b>	1	2	3	4	5
<b>What your medicine is for</b>	1	2	3	4	5
<b>What it does</b>	1	2	3	4	5
<b>How it works</b>	1	2	3	4	5
<b>How long it will take to act</b>	1	2	3	4	5
<b>How you can tell if it is working</b>	1	2	3	4	5
<b>How long you will need to be on your medicine</b>	1	2	3	4	5
<b>How long to use your medicine</b>	1	2	3	4	5
<b>How to get a further supply</b>	1	2	3	4	5
<b>Whether the medicine has any unwanted effects (side effects)</b>	1	2	3	4	5
<b>What are the risks of you getting side effects</b>	1	2	3	4	5

	None needed	None received	Too little	About right	Too much
<b>What you should do if you experience unwanted side effects</b>	1	2	3	4	5
<b>Whether you can drink alcohol whilst taking this medicine</b>	1	2	3	4	5
<b>Whether the medicine interferes with other medicines</b>	1	2	3	4	5
<b>Whether the medication will make you feel drowsy</b>	1	2	3	4	5
<b>Whether the medication will affect your sex life</b>	1	2	3	4	5
<b>What you should do if you forget to take a dose</b>	1	2	3	4	5

**- Please turn over -**

**19** In this next section we would like you to tell us which of the following statements about epilepsy are true and which are false.

Is the statement true or false?  
(Please circle only one answer for each statement)

**Section 1 – MEDICAL ASPECTS OF EPILEPSY**

**TRUE**

**FALSE**

**T**

**F**

- **Epilepsy is always caused by brain damage**
- **Epilepsy is not infectious**
- **Epilepsy is a symptom of mental illness**
- **All people with epilepsy have similar symptoms**
- **Almost anyone can have a seizure given the appropriate circumstances**
- **An E.E.G can be used to help diagnose epilepsy**
- **If an E.E.G is abnormal, there is a definite sign of epilepsy**
- **An E.E.G is designed to detect electrical activity from the brain**
- **All people with epilepsy lose consciousness during seizures**
- **An epileptic seizure can be described as a temporary lack of oxygen to the brain**

T

F

T

F

T

F

T

F

T

F

T

F

T

F

T

F

T

F

T

F

**TRUE**

**FALSE**

**T**

**F**

<ul style="list-style-type: none"> <li>• <b>Some seizures may last for a matter of seconds and not be noticed by others</b></li> </ul>	T	F
<ul style="list-style-type: none"> <li>• <b>All seizures affect both sides of the brain</b></li> </ul>	T	F
<ul style="list-style-type: none"> <li>• <b>Certain forms of brain damage always cause epilepsy</b></li> </ul>	T	F
<ul style="list-style-type: none"> <li>• <b>A normal E.E.G means that you do not have epilepsy</b></li> </ul>	T	F
<ul style="list-style-type: none"> <li>• <b>For most people, doctors can effectively treat epilepsy with drugs</b></li> </ul>	T	F
<ul style="list-style-type: none"> <li>• <b>All those who start drugs for their epilepsy have to take them for life</b></li> </ul>	T	F
<ul style="list-style-type: none"> <li>• <b>Increasing the dose of anti-epileptic drugs increases the chances of side-effects</b></li> </ul>	T	F
<ul style="list-style-type: none"> <li>• <b>An epileptic seizure can be described as an abnormality in the function of nerve cells in the brain</b></li> </ul>	T	F
<ul style="list-style-type: none"> <li>• <b>In order for anti-epileptic drugs to be successful, they must be taken regularly</b></li> </ul>	T	F
<ul style="list-style-type: none"> <li>• <b>If you forget to take anti-epileptic drug for a day, it is usually OK to take 2 doses together</b></li> </ul>	T	F
<ul style="list-style-type: none"> <li>• <b>Some people get a warning or feeling shortly before a seizure</b></li> </ul>	T	F
<ul style="list-style-type: none"> <li>• <b>Blood samples can be used to measure the concentration of anti-epileptic drugs in the system</b></li> </ul>	T	F
	<b>TRUE</b>	<b>FALSE</b>
	<b>T</b>	<b>F</b>

<ul style="list-style-type: none"> <li>• People taking a combination of anti-epileptic drugs are more likely to have side-effects than those on only one</li> </ul>	T	F
<ul style="list-style-type: none"> <li>• Most people with seizures are well controlled soon after starting regular drug treatment</li> </ul>	T	F
<ul style="list-style-type: none"> <li>• It is always helpful to take extra doses of anti-epileptic drugs when not feeling well</li> </ul>	T	F
<ul style="list-style-type: none"> <li>• If seizures stop with anti-epileptic drugs, this means that your epilepsy has been cured</li> </ul>	T	F
<ul style="list-style-type: none"> <li>• Few people with a diagnosis of epilepsy are on anti-epileptic drugs</li> </ul>	T	F
<ul style="list-style-type: none"> <li>• Some people have been taught to control their seizures by psychological methods</li> </ul>	T	F
<ul style="list-style-type: none"> <li>• There is no need to continue taking anti-epileptic drugs if your seizures stop</li> </ul>	T	F
<ul style="list-style-type: none"> <li>• Brain surgery is still used as a method of preventing seizures</li> </ul>	T	F
<ul style="list-style-type: none"> <li>• Most mothers on anti-epileptic drugs are able to breastfeed</li> </ul>	T	F
<ul style="list-style-type: none"> <li>• Too much alcohol may make seizure more likely</li> </ul>	T	F
<ul style="list-style-type: none"> <li>• Most seizures result in brain damage</li> </ul>	T	F
	<b>TRUE</b> T	<b>FALSE</b> F

<ul style="list-style-type: none"> <li>• <b>Stress may cause some seizures</b></li> </ul>	T	F
<p><b>Is the statement true or false? (Please circle only one answer for each statement)</b></p>		
<p><b>Section 2 – SOCIAL ASPECTS OF EPILEPSY</b></p>	<p><b>TRUE</b> T</p>	<p><b>FALSE</b> F</p>
<ul style="list-style-type: none"> <li>• <b>If you drive you must inform the Driving and Vehicle Licensing Centre (D.V.L.A.) about the diagnosis of epilepsy</b></li> <li>• <b>It is possible that a person whose seizures only happen during sleep may hold a drivers licence</b></li> <li>• <b>If a person has been seizure free for 10 years and has the correct licence he/ she is allowed to drive heavy goods vehicles, public service vehicles, taxis, trains or aircraft</b></li> <li>• <b>People with epilepsy are able to join the armed forces, police and fire services in an active capacity</b></li> <li>• <b>It is illegal not to disclose a diagnosis of epilepsy on all job application forms</b></li> <li>• <b>Most children with epilepsy can attend normal schools</b></li> </ul>	<p>T</p> <p>T</p> <p>T</p> <p>T</p> <p>T</p> <p>T</p>	<p>F</p> <p>F</p> <p>F</p> <p>F</p> <p>F</p> <p>F</p>
	<p><b>TRUE</b> T</p>	<p><b>FALSE</b> F</p>



<ul style="list-style-type: none"> <li>• If a person with epilepsy has a seizure you should put a hard object, such as spoon or a pen in his/ her mouth</li> </ul>	T	F
<ul style="list-style-type: none"> <li>• If a person with epilepsy has a simple, uncomplicated seizure, there is no need to call a doctor or ambulance</li> </ul>	T	F
<ul style="list-style-type: none"> <li>• People with epilepsy are more prone to violent anti-social behaviour than those without epilepsy</li> </ul>	T	F
<ul style="list-style-type: none"> <li>• Most people with epilepsy are of low intelligence</li> </ul>	T	F
<ul style="list-style-type: none"> <li>• Most people with epilepsy should avoid flashing lights, T.V screens, computers and V.D.U s</li> </ul>	T	F
<ul style="list-style-type: none"> <li>• Most people with epilepsy are capable of full-time employment</li> </ul>	T	F
<ul style="list-style-type: none"> <li>• Most people with epilepsy are able to go swimming as long as someone is with them</li> </ul>	T	F
<ul style="list-style-type: none"> <li>• Having a diagnosis of epilepsy prevents immigration to some countries</li> </ul>	T	F
<ul style="list-style-type: none"> <li>• Most people with epilepsy should avoid taking an active part in most sports</li> </ul>	T	F
<ul style="list-style-type: none"> <li>• Most people with epilepsy should avoid working with open machinery</li> </ul>	T	F
<ul style="list-style-type: none"> <li>• Most people with epilepsy should avoid working at heights</li> </ul>	T	F
	<b>TRUE</b> T	<b>FALSE</b> F
<ul style="list-style-type: none"> <li>• Most people with epilepsy should avoid all factory and</li> </ul>	T	F

<p><b>building work</b></p> <ul style="list-style-type: none"> <li>• <b>Over half of the population with epilepsy will have their first seizure by the age of 15</b></li> <li>• <b>In medical terms, epilepsy is a fairly recent phenomenon</b></li> </ul>	<p>T</p> <p>T</p>	<p>F</p> <p>F</p>
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**What proportion of the population do you believe have active epilepsy? (Please circle below)**

1 in 20	1 in 100	1 in 200	1 in 500	1 in 1000
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**20. In this next section, we would like to know if you are working, how your epilepsy might have changed this and also what contact you have had with health care services.**

**a). Please could you let us know about your current employment status?**

(please circle one from below)

- |                                 |   |
|---------------------------------|---|
| Employed full-time              | 1 |
| Employed part-time              | 2 |
| Unemployed                      | 3 |
| Self employed                   | 4 |
| Retired (because of age)        | 5 |
| Retired (because of ill health) | 6 |
| Student                         | 7 |
| Housewife/husband               | 8 |
| Other (please write): _____     | 9 |

***b) If you are not working***

Do you receive any type of Incapacity Benefit? Yes \_\_\_\_\_ No \_\_\_\_\_

***c) If you are currently employed:***

What is your occupation? \_\_\_\_\_ (please write here)

Have you had to stop or reduce work due to your state of ill-health?

Yes or No

***If yes:***

How many days in the **last 12 months** have you had off work because of ill health?

\_\_\_\_\_ *days*

**or:**

How many fewer hours per week have you worked because of ill health?

\_\_\_\_\_ *hours*

d) In the last 12 months, have you been admitted to any inpatient service (hospital, nursing home or hospice ?

Yes or No (please circle)

If Yes, please tell us about these below

Admission	Type of ward or Department	Duration of the stay (Total days)
1st admission		days
2nd admission		days
3rd admission		days

e) Provide details of other hospital and day care services you have used over the last 12 months.

Service	Have you had contact? No Yes	Number of contacts
1-Casualty / A&E visit	<input type="checkbox"/> <input type="checkbox"/>	attendances
2- A&E's mini-ward called the Clinical Decision Unit (CDU) or Rapid Access Treatment Unit (RATU) (please see * below for further details)	<input type="checkbox"/> <input type="checkbox"/>	attendances
3-Neurology outpatient appointment	<input type="checkbox"/> <input type="checkbox"/>	attendances
4-Other outpatient visit, including tests (please write what below) _____	<input type="checkbox"/> <input type="checkbox"/>	attendances
5-Any other hospital or day care services (please write what below) _____	<input type="checkbox"/> <input type="checkbox"/>	attendances

\*Some patients who go to A&E are after while moved to the mini-ward in A&E called either 'CDU' (this stands for Clinical Decision Unit) or 'RATU' (this stands for Rapid Access Treatment Unit). This might happen if you have been in A&E for longer than 4 hours and the doctors need to observe you for longer, or wait for some test results.

**f) Please provide details of primary and community care services you have used over the last 12 months?**

Service	Have you had contact?		No. contacts of	Average duration (minutes)
	No	Yes		
1-General Practitioner	<input type="checkbox"/>	<input type="checkbox"/>		
2-Practice Nurse	<input type="checkbox"/>	<input type="checkbox"/>		
3-Epilepsy nurse	<input type="checkbox"/>	<input type="checkbox"/>		
4-Physiotherapist	<input type="checkbox"/>	<input type="checkbox"/>		
5-Social worker	<input type="checkbox"/>	<input type="checkbox"/>		
6-Home help (household tasks)	<input type="checkbox"/>	<input type="checkbox"/>		
7-Home help (personal care)	<input type="checkbox"/>	<input type="checkbox"/>		
8-Other service/professional (1) (specify) _____	<input type="checkbox"/>	<input type="checkbox"/>		
9-Other service/professional (2) (specify) _____	<input type="checkbox"/>	<input type="checkbox"/>		

**g) Please give details of any help you have received from friends or family members in the last 12 months as a result of your illness (this is specifically unpaid carers – if paid, please add to ‘home help’ on previous page)?**

Type of help (If more than one person helps at a time, please add up the total hours)	Have you had contact?		Average no. of hours per week
	No	Yes	
1-Personal care (e.g. bathing, dressing)	<input type="checkbox"/>	<input type="checkbox"/>	
2-Help with medical procedures	<input type="checkbox"/>	<input type="checkbox"/>	
3-Help inside the home (e.g. cooking, cleaning)	<input type="checkbox"/>	<input type="checkbox"/>	
4-Help outside the home (e.g. shopping)	<input type="checkbox"/>	<input type="checkbox"/>	
5-Time spent ‘on-call’	<input type="checkbox"/>	<input type="checkbox"/>	
6-Other (specify) _____	<input type="checkbox"/>	<input type="checkbox"/>	

**h). Please list below use of any medications for epilepsy taken over the last 12 months (including non-prescribed medication you have purchased yourself).**

<b><i>Name of drug</i></b>	<b><i>Dosage (if known)</i></b>	<b><i>Dose frequency (e.g. daily)</i></b>	<b><i>How long during the last 12 months did you take this for (in weeks)?</i></b>
1.	<i>mg</i>		
2.	<i>mg</i>		
3.	<i>mg</i>		
4.	<i>mg</i>		
5.	<i>mg</i>		
6.	<i>mg</i>		
7.	<i>mg</i>		
8.	<i>mg</i>		
9.	<i>mg</i>		
10.	<i>mg</i>		
11.	<i>mg</i>		
12.	<i>mg</i>		

**21. Finally,**

**Do you not tell some people that you have epilepsy because of the way they might react?**

Yes

No

**Do you think people with epilepsy are treated differently from other people by society?**

Yes

No