

Patient-Reported Outcomes – Epilepsy (PRO-EPI) version 3.0

Sent to the user every 6 months

The user is free to send in a new response on their own initiative at any time

All green: No follow-up required as yet.

One or more responses yellow: The nurse reads the case notes and contacts the user if required.

One of more responses red: The doctor must be informed.

1. SEIZURES

1.1 Have you had any generalized tonic-clonic (GTC) seizures in the last 6 months?

Yes No Don't know

1.2 Have you had generalized tonic-clonic (GTC) seizures at night/while sleeping in the last 6 months?

Yes No Don't know

1.3 Have you had any focal epileptic seizures or absence seizures in the last 6 months?

Symptoms of a focal epileptic seizure may be: staring into blank space, often combined with repetitive movements, lip smacking, deja vu, or small twitches in a part of the body.

Yes No Don't know

1.4 Have your seizures increased in frequency or duration in the last 6 months?

Yes No Don't know

2. MEDICINES

2.1 Do you take any medicine for epilepsy?

No Yes (proceed to secondary questions a-c)

a) Does your epilepsy medicine cause you unpleasant side effects?

Yes No Don't know

b) Over the last 6 months, how much have you been troubled by
Headache

Not at all, a little, a lot, to a very large degree

Dizziness

Not at all, a little, a lot, to a very large degree

Trembling hands

Not at all, a little, a lot, to a very large degree

Double vision or other visual disorders

Not at all, a little, a lot, to a very large degree

Poor appetite and/or weight loss

Not at all, a little, a lot, to a very large degree

Weight gain

Not at all, a little, a lot, to a very large degree

Difficulty concentrating

Not at all, a little, a lot, to a very large degree

Feeling easily irritated or impatient

Not at all, a little, a lot, to a very large degree

Tiredness

Not at all, a little, a lot, to a very large degree

Sadness

Not at all, a little, a lot, to a very large degree

c) Do you ever forget to take your epilepsy medicine?
Daily, weekly, monthly, rarely/never

2.2 Have you started taking any new medicine (not medicine for epilepsy) in the last 6 months?
Yes No

2.3 What kind of anti-convulsive medication are you currently taking? (*Name(s) of the medication and dosage*).

Free text field. Must not be colour-coded.

3. LIVING WITH EPILEPSY

3.1 How is your quality of life?
Very good, good, fairly good, poor

3.2 Are your family members worried about your epilepsy?
Never, rarely, sometimes, often, don't know

3.3 Do you live alone?
Yes No

- 3.4 Do you have any challenges at school or at work that you think are connected to your epilepsy?
No I do not work/go to school Yes (proceed to secondary questions a-b)
 a. I am increasingly absent from school or work.
Yes No
 b. I don't think school or work have much understanding of my illness and situation
Yes No
- 3.5 Are you pregnant? (Only women are asked this question).
Yes No
- 3.6 Are you planning a pregnancy within the next 12 months? (Only women are asked this question).
Yes No
- 3.7 Do you have a driver's licence?
Yes No
- 3.8 Over the last 6 months, how much have you been troubled by
 a. Being afraid of having a seizure
 i. **Not at all, a little, a lot, to a very large degree**
 b. General anxiety (not just anxiety about a new seizure)
 i. **Not at all, a little, a lot, to a very large degree**
 c. Suicidal thoughts
 i. **Not at all, a little, a lot, to a very large degree**
 d. Difficulty getting up in the morning
 i. **Not at all, a little, a lot, to a very large degree**
 e. Poor memory
 i. **Not at all, a little, a lot, to a very large degree**
- 3.9 Roughly how much alcohol do you drink each week (number of units)?
One alcohol unit equals 0,33l beer, one glass of wine, or one shot glass of liquor.
>14 units (women) / >21 units (men)
- 3.10 Do you use any intoxicants other than alcohol/oral snuff/cigarettes?
Yes No
- 3.11 Do you feel secure and well looked-after with respect to your diagnosis?
Yes No Don't know

4. APPOINTMENT

4.1 Would you like contact with the outpatient clinic now?

No, I don't need to be contacted right now

Yes, I would like an epilepsy nurse to call me

Yes, I would like an appointment to be made with the doctor

Don't know

4.2 Are you getting follow-up for epilepsy with your general practitioner (GP)?

Yes

Yes, but only for measuring the epilepsy medicine in my blood

No

4.3 If any more information is needed, would you prefer us to ring:

You

I would prefer you to ring a family member

Name/relationship/telephone number:

Comments, if any:

Free text field. Must not be colour-coded.