

Epilepsy and PIP

Please see below the tips on applying for PIP and spend time familiarising yourself with the Disability Rights UK guide before reading this, specifically the points criteria.

This form assesses 10 areas of care needs (Daily Living Activities) and 2 areas of mobility. Based on your answers, you will be awarded a number of points. The amount of points you score determines the payment you receive. Please see the Disability Rights UK PIP guide for breakdowns and payment scales.

When applying for PIP it is important **not** to apply with your best day in mind. You should instead consider your ability to carry out a task **most of the time**- i.e. does your condition affect your ability to cook/dress/wash more than 15 days out of 30?

Working out averages

You can work out an average by keeping a diary and taking a period of time and looking at how many seizures you had and how long recovery period lasts. It is helpful to use at least a one month period, but even a week can be helpful if you can back it up with a diary. For example -

Mon – 1 complex seizure, 2 petit mals – felt poorly most of the day, confused, headache, fatigued

Tuesday – seizure free

Wednesday – seizure free

Thursday – 1 grand mal seizure in the morning – no hospitalisation needed – bit tongue, hurt arms and legs when falling

Friday – spent the day in recovery – slept 16 hours, woke to take meds and eat, went back to sleep for further 4 hours

Saturday – had clusters of petit mal seizures so had to rest due to confusion. Slept from 10am – 6pm and went back to bed at 10pm until 6am

Sunday - seizure free

Total seizures for the week – 4 and clusters of petit mals

You can then say, based on a standard week, you have on average at least one seizure every 2 days, causing you to be incapacitated for at least four of your day and night periods across the week.

We find it quite helpful to phrase answers in this general rough format –

My condition affects me for X amount of hours, X amount of days per week (come up with an average if they aren't predictable by using the above instructions, and include the time you spend preparing/recovering from a seizure). The seizures lead to exhaustion, depression and (any other symptoms/side effects) which affects my ability to bathe/cook/dress myself/socialise independently/anything else, both because of low motivation and poor mood and also due to fear that I may suffer a seizure while carrying out the task. I require X support currently to carry out X task.

- If the form asks about your ability to do something and you are not able to do so without symptoms of your condition causing problems, **do not say that you can**. Answer 'no' and explain the reasons why this is difficult for you to execute.
- If you cannot reliably do something – i.e. you sometimes shower alone but more often than not you are unable to do so due to how severe, unpredictable and debilitating your seizures are, then your answer should be no. Again, explain why.
- Consider whether you would feel safer if you had another person to help you with tasks. We meet a lot of people who manage elements of their care alone – i.e. cooking and dressing – despite being relatively unsafe to do so. The PIP assessment should look at the care **you think you need and should get**, rather than the care you actually receive on a day to day basis. If you bathe alone every day but feel that you are actually putting yourself in danger by doing so, make this clear in your answer and state the reasons why you would be unsafe.

Reliability

The Department of Work and Pensions states that 'If an individual cannot reliably complete an activity in the way described in a descriptor then they should be considered unable to complete it at that level'

They go on to describe reliability as follows:

'Considering reliability involves looking at whether the claimant can complete the activity as described:

- Safely – in a manner unlikely to cause harm to themselves or to another person, either during or after completion of the activity
 - To an acceptable standard – i.e. being able to perform a task well
 - Repeatedly – able to repeat the activity as often as is reasonably required
 - In a reasonable time period – no more than twice as long as the maximum period that a non-disabled person would normally take to complete that activity'.
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General Tips

- Practice – don't write straight on to the form. Use some paper to write and phrase your answers before putting them on the form
 - Photocopy the completed form before you send it off (to remember what you wrote).
 - Try to get someone to check the form over for you – preferably someone who knows you well.
 - Enclose statements from medical professionals, or friends/family etc. to support your answers. This helps the assessor understand your condition from both a medical and personal perspective.
 - Enclosing repeat prescriptions or a diary may also be beneficial.
 - When filling in each section, if you cannot complete a task reliably (see notes above) do not just tick 'yes' – tick 'no' and explain the conditions and problems you encounter when trying to complete a task.
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Just to remind you that the examples above are theoretical and you may be able to do the tasks listed - these tips are just to help you understand how to approach questions.