PIP – the assessment criteria

This guide looks at the second stage of applying for Personal Independence Payment (PIP) – completing the application form. It covers the assessment criteria for each part of the form and how epilepsy might be relevant. It is important to consider how your epilepsy affects you *individually* when completing the form.

'how your disability affects you' application form

If you have contacted the Department for Work and Pensions (DWP) to apply for Personal Independence Payment (PIP), and you meet the eligibility criteria to apply for this benefit, the DWP will send you a form to complete. This form is designed to find out how your condition affects you in relation to 12 everyday activities. Your answers will be used to assess whether you are eligible to receive PIP and, if so, at what rate your benefit will be paid.

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This guide is specific to epilepsy. It explains the different activities assessed for PIP, and what these might mean for someone with epilepsy, including some examples of how epilepsy might affect each activity. These suggestions may or may not apply to you, but they might help you think about how *your* condition affects *you*. This guide might also be helpful if you are filling in the PIP form on behalf of someone else. We cannot guarantee that these suggestions will help you to get a good outcome from your application.

This guide focuses on examples relating to epilepsy. If you have other disabilities or conditions that affect your daily activities, remember to include how these other conditions affect you, in your answer to each question.

Please note: this guide has been prepared using information from the DWP, Disability Rights UK and Citizens Advice.

how your condition affects you

Having epilepsy does not necessarily mean that you will receive PIP. Being eligible for PIP does not depend on what condition you have, but on how your condition affects you. Although epilepsy is a physical condition, it can also have effects which are sensory (affecting your senses), cognitive (such as your thinking, understanding, concentration, and memory), and psychological (such as impact on mood). Being eligible for PIP also includes any help you need, whether or not you currently get that help.

It is useful to think about how your epilepsy affects you in **all these ways** when you are filling in your form. For example, your epilepsy may affect your mood, your thinking, or your memory, which may in turn affect how well you recover from seizures.

Your answers to each section or 'activity' on the PIP form need to explain fully and clearly how your condition affects you and your ability to do that activity. So, for example, rather than saying 'I can't do this because I have epilepsy...' you might say 'my epilepsy means that I can't do this because...' and give specific examples.

When completing the form, it is important that you answer all of the questions honestly and as fully as possible. Try to avoid 'putting on a brave face' and be clear in explaining any difficulties you have, even if it feels embarrassing or uncomfortable to do so. Equally, be honest about how likely problems are, or how frequently they occur. Where you can, include real-life examples of how your condition affects you, so that the DWP assessors can understand how your epilepsy impacts on your daily life.



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How your condition affects you could include the following:

- how your epilepsy and seizures affect you, for example, during or after seizures;
- how long it takes for you to recover after a seizure, for example if you feel drowsy or disorientated after a seizure you can include the time it takes for you to feel 'back to normal' again;
- how your epilepsy and seizures affect people around you, for example if you have to rely on help from people around you;
- how any medication or treatment for your epilepsy affects you, for example if it makes you tired or causes headaches or nausea (feeling sick); and
- whether your condition, or medication, affects your concentration, memory, motivation or mood.

filling in your form

It is important that you fill in your form promptly and try not to put it off, even if it looks difficult. There is a short time frame for filling in and returning the form (**usually one month**). This should be explained in the information you get from the DWP, which will include the deadline for returning the form.

You could ask a friend or relative to help you fill out the form. It can be helpful to talk things through with someone who knows you and how your epilepsy affects you. They might also be able to remind you how your epilepsy or seizures have affected your day-to-day life. It is also helpful to talk to someone who is objective (not personally involved in your situation) about how your condition affects you.

The form is long and it can feel like a daunting task to fill it in. It might also bring up lots of issues for you about the impact your epilepsy has on your life. If you would like to talk to someone about how your epilepsy affects you, or about the experience of filling in the form, you can ring our confidential epilepsy helpline. Although the helpline is not able to complete the form for you, they can give you details of other organisations, such as Citizens Advice, which may be able to offer practical help with filling in the form or act as a representative for you.

 $\stackrel{\mathrm{OP}}{\amalg}$ Contact our helpline on 01494 601 400 (national call rate). See back page for opening hours.

For each question, explain how your epilepsy may be a risk to your safety. The person who reads your form may not know a lot about epilepsy, and epilepsy can be different for everyone. So explain about your epilepsy and how it affects you **in every question**. When considering the 'risks' due to your epilepsy, how serious the risks are is important, but it also has to be a likely risk for you. For example, the result of having a seizure where you lose consciousness when you are cooking could be a serious burn, but if you are not likely to have a seizure where you lose consciousness, then this risk may not apply to you. This is why it is helpful to include real examples where you can, to show what is a real risk for you.

When answering each question, include:

- how your epilepsy, your seizures, and any impact from your medication, affects you in relation to the activity. Remember to include any impact during your recovery from a seizure;
- what help or support you need, for example to carry out the activity or to keep you safe;
- how often you need this help;
- for how long you need help; and
- what could happen if you did not have help or couldn't do the activity (for example, the impact of having a seizure during an activity, and how this could result in accident or injury).

Wherever possible, include any real examples of how your condition has affected you.

Remember to repeat this information **for each question** every time that it is relevant. You can use the same wording each time if you like. It might help to imagine that each question is looked at by a different person: so you need to explain how your condition affects you in every answer.

N See our guide *completing benefit forms* for more information.

The DWP's booklet 'How your disability affects you – Information booklet' has useful information about filling in the form, and explains what each question means. You might like to use it alongside this guide. You should be sent a copy of this booklet with your application form.

Wisit gov.uk/guidance/the-personal-independence-payment-pip-toolkit

additional information or 'evidence'

When you return your form to the DWP, you can include additional 'evidence' to support your claim. This might be information from your GP, neurologist, epilepsy specialist nurse, or any other medical professional you see for your epilepsy. It might include a copy of your prescription for your anti-epileptic medication, a care plan, or reports from your doctors. If you use a diary to record your seizures, or how your epilepsy affects you, you can send in a copy of your diary with the form. If you get any other support, for example from an occupational therapist or social worker, you can include information from them too. Send in **photocopies** of this information, **not the original copy**.

If you do not already have this additional information to use as supporting evidence, do not delay your claim by asking for and waiting for new documents to arrive. A late claim may not be assessed. You can send documents on later, or if the DWP need more information, they can ask your doctors or other professionals for this directly.

how PIP is assessed

Whether or not you qualify for PIP depends on how your condition affects you in two ways: your 'daily living' and your 'mobility' (how you physically move). Questions 1 - 12 of the form ask about everyday activities and points are scored if your condition affects your ability to do that activity. Questions 1 - 10 cover daily living activities and questions 11 - 12 cover mobility activities. The points scored for each activity are added up to give one final score for daily living and one for mobility.

how activities are described and assessed

For each question on the form there is a description of an activity, and what it covers. There are some specific questions and space for you to write about how your condition affects you in relation to the activity. Your answers will then be used to score you against certain criteria called 'descriptors'. These descriptors will not be included on your form. However, the descriptors are listed on pages 5 - 17 of this guide, with the points you would score if you meet each descriptor. In some cases, you may feel that your condition does not affect you doing the activity at all. However, it is important to give enough information about all the ways in which your condition affects you, and all the help or aids you need, so that the assessor can accurately decide which descriptor best applies to you.

You will receive one score for each activity. This will be the highest of the scores that apply to you (as you might meet different descriptors on different days, depending on how your condition affects you), or the one that applies for the most time. It will not be all the scores that apply to you within an activity added together. However, the scores from each activity will be added together at the end to get your overall 'daily living' and 'mobility' scores.

For more information about descriptors visit gov.uk/guidance/the-personal-independence-payment-pip-toolkit or disabilityrightsuk.org/personal-independence-payment-pip

definitions

The form includes some specific wording about 'aids and appliances' and '50% of the time'.

- Aids or appliances: things that help you to do an activity, such as a walking stick, wheelchair or walk-in shower. An aid or appliance is something specifically developed to help someone with disabilities, or it can be something else which you use to help you with an activity (where you wouldn't be able to do the activity without it).
- 50% of the time: In the PIP assessment, a descriptor will apply to you if it reflects your ability to carry out an activity, safely and reliably, at some stage during the day, for more than 50% of days over a 12 month period. This could include both at the time of a seizure and during the time it takes you to recover from the seizure. Using a seizure diary can be a good way of showing how frequently your seizures happen or how often you have difficulties due to your condition. If more than two descriptors apply to you, the highest score will be applied.

Visit epilepsysociety.org.uk/seizure-diaries to download our seizure diary or call our helpline on 01494 601 400.

rates and payments

If your claim is successful, you may be awarded PIP based on 'daily living', on 'mobility' or on both. PIP is paid at either a standard or enhanced rate, depending on the points you score. PIP is usually paid every four weeks. Currently, the weekly rates for PIP are:

- standard daily living rate (which needs at least 8 points) = £58.70 per week;
- enhanced daily living rate (which needs at least 12 points) = £87.65 per week;
- standard mobility rate (which needs at least 8 points) = £23.20 per week; and
- enhanced mobility rate (which needs at least 12 points) = £51.20 per week.

the reliability criteria

An important part of assessing your ability to carry out each activity is assessing whether you are able to do the activity 'reliably'. Here, 'reliably' means that **all** of the following points apply.

- 1. That you can do the activity 'safely'. This means that you can do the activity while keeping yourself and others safe, and avoid harm. For example, doing the activity in a way that would not cause any accident or injury if you had a seizure.
- 2. That you can do the activity to 'an acceptable standard' each time you do it. What is an acceptable standard will depend on the type of activity you are doing. For example, cooking food so that it is edible, or dressing appropriately for the weather.
- 3. That you can do the activity 'repeatedly'. This means being able to do the activity as frequently as reasonably required. For example, being able to take medication for your epilepsy every time that you need to during the day.
- 4. That you can do the activity in a 'reasonable time period'. This means taking no more than twice as long as the longest time it would take someone without a disability to do it. For example, if you are able to walk to the shop at the end of your street, but it takes you two hours to do this, this would not be considered a 'reasonable time period', if someone without a disability would be able to do this in 10 minutes, even if they were walking very slowly.

If you are not able to do an activity 'reliably' in all the four ways listed above, even with an aid or appliance, then you will be considered unable to do that activity.

How this applies to filling in the form

For each activity, include in your answer:

- whether you are able to carry out the activity reliably (as explained above) or not;
- what help you might need (whether you actually get that help or not) which could include someone else doing things for you, helping you to do things, or reminding you to do things; and
- the possible result (including any risks) of doing the activity, and of doing the activity without help. You can also include whether doing the activity causes you any pain or discomfort, breathlessness or anxiety, or causes you to be very tired.

It is also important to include:

- how often things happen (such as how often you have a seizure);
- how long things last (such as how long a seizure lasts or how long it takes to recover from a seizure); and
- how long it takes you to do things (see 'reasonable time period' above).

This is important because of the 50% rule (see page 3).

sending in your form

You should be given a return envelope with your form, which means you can return the form free of charge. You need to include your completed form (with the return address showing through the window in the envelope), and photocopies of all the additional information you are sending (see page 3). **Take a photocopy** of your completed form before you send it back, for your own records and in case the form goes missing.

If you receive additional information after you have sent in your form, and you would like this to be considered with your application, take a photocopy of it and send a copy to the DWP as soon as possible, with your name and the reference number on the top of your PIP form. The address to send it to should be on the covering letter you got with your application form.

the assessment criteria

Pages 5 – 17 of this guide looks at the assessment criteria included in questions 1 – 12 of the PIP application form. The assessment criteria are listed (for example from A – F) with the scores for each. This information is taken from the DWP's document PIP Assessment Guide which is for providers carrying out assessments.

The 'notes' and 'things to think about' are our suggestions for how the criteria might apply to someone with epilepsy.

activity 1 – preparing food (daily living activity)

This activity is about whether you can prepare and cook a simple, hot, one-course meal from fresh ingredients (not ready meals). It is not about how good you are as a cook, but about whether your medical condition(s) affects your ability to prepare a simple, hot meal.

| Can prepare and cook a simple meal unaided | 0 |
|--|---|
| Needs to use an aid or appliance to be able to either prepare or cook a simple meal | 2 |
| Cannot cook a simple meal using a conventional cooker but is able to do so using a microwave | 2 |
| Needs prompting to be able to either prepare or cook a simple meal | 2 |
| Needs supervision or assistance to be able to either prepare or cook a simple meal | 4 |
| Cannot prepare and cook food | 8 |
| | Needs to use an aid or appliance to be able to either prepare or cook a simple meal Cannot cook a simple meal using a conventional cooker but is able to do so using a microwave Needs prompting to be able to either prepare or cook a simple meal Needs supervision or assistance to be able to either prepare or cook a simple meal |

Notes

- 'Preparing' includes peeling and chopping ingredients, and opening tins and packets.
- 'Cooking' means using a cooker hob or microwave above waist height, but does not include bending down to open an oven door. If you never make yourself a hot meal, or you only use a microwave rather than a cooker, due to the risk of accident or injury during a seizure, include this in your answer and explain why you do this.
- 'Aids and appliances' include electric can openers if it would be unsafe for you to use a non-electric opener; specific types of containers or pans that you need to help you; a cooker guard on the cooker top; or a kettle tipper to pour hot water.
- 'Prompting' means motivating or reminding you to prepare and cook a meal, and 'supervision or assistance' means helping you if you cannot safely prepare food or use a microwave, or making sure you are safe while you are preparing or cooking a meal. If your seizures affect your conciousness without warning 1E might apply.

Things to think about

- What could happen to you if you have a seizure when preparing or cooking a meal? What is the likelihood of this happening? Include any real examples of when this has happened and how it affected you physically and mentally.
- Would a safety aid such as a cooker guard or kettle tipper help make cooking safer for you? If you have seizures, and are at risk of scalding or burning yourself while cooking, you can include on your form the *need* for safety aids, even if you don't currently use them.

$\stackrel{\mathrm{eff}}{\amalg}$ See our leaflet *safety* for more information about cooking and safety aids.

- Does anything else about your epilepsy (including your seizures, recovery from seizures, medication side effects, or impact of your condition) affect your ability to do any of this activity? You can include any impact on:

 your concentration or memory (for example, needing help to follow the process of preparing and cooking a meal);
 your mood (for example, anxiety, or depression, or fear about having a seizure during this activity); or
 any tiredness or confusion that you may have following a seizure.
- Remember: this question is asking about your ability to do this activity, not whether you want to do it. However, if someone else usually prepares your meals for you because of the risks of having a seizure, then explain why they do it for you, and what might happen if you did it yourself.

Remember to include:

- whether you can do this activity reliably (safely, to an acceptable standard, repeatedly and in a reasonable time period);
- whether you need aids, appliances or help from another person to do this activity;
- how often your condition affects your ability to do this activity (the 50% rule); and
- the impact of any other conditions or disabilities that you have on this activity.
- You will get just one single score for this activity, so make sure that you include as much relevant information as possible. You can continue on a separate sheet of paper if you need to.

activity 2 – taking nutrition (daily living activity)

This activity is about physically feeding yourself, eating and drinking, and whether you are able to do this unaided, or with help. It does not include preparing food (covered in activity 1). 'Nutrition' means food and drink.

| Can take nutrition unaided | 0 |
|---|--|
| Needs to use an aid or appliance to be able to take nutrition or supervision to be able to take | |
| nutrition or assistance to be able to cut up food | 2 |
| Needs a therapeutic source [such as a feeding tube] to be able to take nutrition | 2 |
| Needs prompting to be able to take nutrition | 4 |
| Needs assistance to be able to manage a therapeutic source to take nutrition | 6 |
| Cannot convey food and drink to their mouth and needs another person to do so | 10 |
| | Needs to use an aid or appliance to be able to take nutrition or supervision to be able to take nutrition or assistance to be able to cut up food Needs a therapeutic source [such as a feeding tube] to be able to take nutrition Needs prompting to be able to take nutrition Needs assistance to be able to manage a therapeutic source to take nutrition |

Notes

- 'Aids' might include non-spill cups or using plastic plates and bowls which do not break if you drop them.
- This activity can include the need for supervision from another person, for example if there is a risk of choking if you have a seizure while eating or drinking.
- If you do not have hot food or drinks because of the risk of accident or injury from having a seizure while eating or drinking something hot, include this.
- 'Prompting' might include someone having to remind you to eat or drink, for example, due to memory problems or your motivation.

Things to think about

- What could happen to you if you have a seizure when eating or drinking? What is the likelihood of this happening? Include any real examples of when this has happened and how it affected you physically and mentally.
- Does anything else about your epilepsy (including your seizures, recovery from seizures, medication side effects or impact of your condition) affect your ability to do any of this activity? You can include any impact on: your concentration or memory, your mood, or any tiredness or confusion that you may have following a seizure.

Remember to include:

- whether you can do this activity reliably (safely, to an acceptable standard, repeatedly, and in a reasonable time period);
- whether you need aids, appliances or help from another person to do this activity;
- how often your condition affects your ability to do this activity (the 50% rule); and
- the impact of any other conditions or disabilities that you have on this activity.

activity 3 – managing therapy or monitoring a health condition (daily living activity)

This activity is about taking medication, or managing any treatment, at home. It is also about your ability to notice any changes in your health, and know what to do about it.

| А | Either i) does not receive medication or therapy or need to monitor a health condition; | 0 |
|---|---|---|
| _ | or ii) can manage medication or therapy or monitor a health condition unaided | 0 |
| В | Needs any one or more of the following | |
| | i) to use an aid or appliance to be able to manage medication; | |
| | ii) supervision, prompting or assistance to be able to manage medication; | |
| | iii) supervision, prompting or assistance to be able to monitor a health condition. | 1 |
| С | Needs supervision, prompting or assistance to be able to manage therapy that takes no more than | |
| | 3.5 hours a week | 2 |
| D | Needs supervision, prompting or assistance to be able to manage therapy that takes more than | |
| | 3.5 hours a week but no more than 7 hours | 4 |
| E | Needs supervision, prompting or assistance to be able to manage therapy that takes more than | |
| | 7 hours a week but no more than 14 hours | 6 |
| F | Needs supervision, prompting or assistance to be able to manage therapy that takes more than | |
| | 14 hours a week | 8 |

Notes

- This is about taking medication at home which has been prescribed or recommended. It does not include any treatment that has not been prescribed or recommended, and includes complementary therapies only if they have been recommended by a professional. It does not cover any medication you might be given in hospital, but does include medication given by a professional if it is given at home (for example, given by staff in a care home).
- Managing your medication means taking it as prescribed: in the right way and at the right times. You can include why it is important for you to take your medication as prescribed, and the results of not doing this.
- 'Medication' includes tablets, capsules, sprinkles, syrups, liquids, and suppositories. It includes anti-epileptic medication you take, but also medication for other conditions, or which you might take due to side effects of medications (for example, anti-emetics to stop you feeling sick).
- If you have a vagus nerve stimulator, include this in your answer and explain what it does. If you need someone else to use the magnet for your stimulator, explain this and what could happen if you didn't have this help.
- If you need emergency medication (to treat prolonged or repeated seizures due to the risk of status epilepticus) explain this in your answer. Explain why this is urgent, how often you need it, and the risks of not having this medication given in time. Also say what help you need to receive emergency medication, how long you need this help for, and how often this might happen.
- 'Monitoring your condition' includes noticing any changes in your condition, either aided or unaided, and knowing what to do about this. For example, you might use a seizure diary to note when you have seizures, and talk to your neurologist about changing your medication if your seizures are not controlled. It could also include remembering and attending medical appointments for your condition. If you need someone to go to medical appointments with you, for example if you have memory problems, you can explain this.
- This activity is not about how controlled your condition is (how often you have seizures) but it does include how your condition impacts your ability to manage or monitor it. For example, if your seizures or medication means that you have problems remembering to take your medication, you can include this in your answer.
- 'Aids and appliances' could refer to drug wallets (pill boxes), medication reminders, or a seizure diary to monitor your condition. 'A' refers to managing medication and monitoring a health condition without the use of any aid or appliance (for example, without the need for drug wallets or medication reminders, and with no help from anyone else). If you have examples of when you have missed medication, or taken too much, you can include this, and explain what happened.

activity 3 – managing therapy or monitoring a health condition (continued)

- 'Supervision, prompting or assistance' means help from someone else. This could include them reminding you to take your medication, helping you to collect your prescription, filling a drug wallet for you, or writing in a seizure diary to help you monitor your condition.
- C F refers to the length of time you need to receive help, measured in hours per week. This could be all in one go, or could be spread over the whole week. For example, '3.5 hours' a week could be 3 ½ hours on one day, or ½ hour each day of the week.
- 'Therapeutic activities' include physiotherapy which might be recommended following an accident or injury.

Things to think about

- Include in your answer what would happen if you didn't have help, or didn't use aids or appliances that you
 need. Explain what could happen if you miss your medication or don't effectively manage your condition. Include
 any real examples of when this has happened and how it affected you physically and mentally. You can also
 explain why taking your epilepsy medication is important to you, and how your seizures affect your life.
- Does anything else about your epilepsy (including your seizures, recovery from seizures, medication side effects, or impact of your condition) affect your ability to manage your medication or monitor your condition?
 You can include any impact on:
 - your concentration or memory (for example, needing someone to remind you to take your medication, or using an aid to remind you);
 - your mood (for example, if feeling anxious or depressed affects your motivation to manage your medication or monitor your condition); or
 - any tiredness or confusion that you may have after a seizure and how this might affect this activity.

Remember to include:

- whether you can do this activity reliably (safely, to an acceptable standard, repeatedly, and in a reasonable time period);
- whether you need aids, appliances or help from another person to do this activity;
- how often your condition affects your ability to do this activity (the 50% rule); and
- the impact of any other conditions or disabilities that you have on this activity.

activity 4 – washing and bathing (daily living activity)

This is about your ability to keep your body clean, including washing your whole body and getting in and out of a non-adapted bath or shower.

| А | Can wash and bathe unaided | 0 |
|---|---|---|
| В | Needs to use an aid or appliance to be able to wash or bathe | 2 |
| С | Needs supervision or prompting to be able to wash or bathe | 2 |
| D | Needs assistance to be able to wash either their hair or their body below the waist | 2 |
| E | Needs assistance to be able to get in or out of the bath or shower | 3 |
| F | Needs assistance to be able to wash their body between the shoulders and waist | 4 |
| G | Cannot wash and bathe at all and needs another person to wash their entire body | 8 |
| | | |

Notes

- This may be an important activity to consider, due to the risks of having a seizure while in the bath or shower. If you have seizures where you lose awareness or consciousness, and there is a risk that you could have an accident or injury while washing or bathing, explain it here. Explain how serious these risks could be for you, for example, if there is a risk of drowning if you have a seizure in the bath.
- 'Needing assistance or supervision' could include having someone else in the bathroom with you when you wash or bathe. If due to the risk of having a seizure, you only have a bath or shower when someone else is in the house, explain this. For example, saying 'unless someone else is in the house, I am unable to have a bath safely because...' will help the assessor to understand the impact of your condition on this activity, and why you need help. If you only have a strip wash or you never have a bath because of these risks, it is helpful to explain this. Include help that you currently get, as well as help that you *need* to wash safely but that *you don't currently get*.
- This activity is about being able to use, and get into and out of, a non-adapted bath or shower. If you have aids or appliances to help you with washing or bathing, include these. These might be grab rails, shower chairs or bath boards, recessed soap holders, bath mats, thermostatically controlled taps, having adapted doors so that they open outwards, or using a safety monitor or call alarm. If you include any aids or appliances, explain why you need them and what could happen if you didn't use them. If you have to use a wet room, this may be seen as evidence that you cannot access an unadapted shower.

Things to think about

- What could happen to you if you have a seizure when washing or bathing? What is the likelihood of this happening? Include any real examples of when this has happened and how it affected you physically and mentally.
- Does anything else about your epilepsy (including your seizures, recovery from seizures, medication side effects, or impact of your condition) affect your ability to do any of this activity? You can include any impact on:

 your concentration or memory;
 - your mood (for example, anxiety or depression, how any supervision makes you feel about your privacy, or fear about having a seizure during this activity); or
 - any tiredness or confusion that you may have after a seizure.

Remember to include:

- whether you can do this activity reliably (safely, to an acceptable standard, repeatedly, and in a reasonable time period);
- whether you need aids, appliances or help from another person to do this activity;
- how often your condition affects your ability to do this activity (the 50% rule); and
- the impact of any other conditions or disabilities that you have on this activity.

activity 5 – managing toilet needs or incontinence (daily living activity)

This is about your ability to get on and off the toilet, to clean yourself afterwards and to manage emptying your bladder and/or bowel, including the use of collecting devices. This activity does not include the ability to manage clothing, for example fastening and unfastening zips or buttons, as this is covered in activity 6.

| А | Can manage toilet needs or incontinence unaided | 0 |
|-------------|---|-------------|
| В | Needs to use an aid or appliance to be able to manage toilet needs or incontinence | 2 |
| С | Needs supervision or prompting to be able to manage toilet needs | 2 |
| D | Needs assistance to be able to manage toilet needs | 4 |
| E | Needs assistance to be able to manage incontinence of either bladder or bowel | 6 |
| F | Needs assistance to be able to manage incontinence of both bladder and bowel | 8 |
| D E F | Needs assistance to be able to manage toilet needs Needs assistance to be able to manage incontinence of either bladder or bowel | 4 6 8 |

Notes

- This activity is not about whether you are incontinent (lose control of your bladder or bowels), but about how you are able to manage this if you are. 'Collecting devices' include catheters.
- 'Aids' might include commodes or incontinence pads.
- This activity might apply to you if you are incontinent (wet or soil yourself) during seizures. If so, explain:
 - whether you are incontinent of urine (wee) or faeces (poo);
 - during which types of seizure this happens to you, and how likely it is to happen during this type of seizure;
 - how often it happens; and
 - whether you need any help, for example to clean yourself afterwards. If you need help, explain how often you
 need this and for how long you need this help.
- You can include the social impact that this has on you. For example, some people are reluctant to go out due to the risk of having a seizure and being incontinent, and the embarrassment of this happening.
- If you use any aids or appliances at home due to the risks from having a seizure while using the toilet, you could explain this. This might include having grab rails beside the toilet, having a toilet door that opens outwards, or using an 'engaged' sign rather than locking the door so that someone can help you if you have a seizure.

Things to think about

- What could happen to you if you have a seizure when using the toilet? What is the likelihood of this happening? Include any real examples of when this has happened and how it affected you physically and mentally.
- Does anything else about your epilepsy (including your seizures, recovery from seizures, medication side effects, or impact of your condition) affect your ability to do any of this activity? You can include any impact on your confidence, or any anxiety about this happening to you.

Remember to include:

- whether you can do this activity reliably (safely, to an acceptable standard, repeatedly, and in a reasonable time period);
- whether you need aids, appliances or help from another person to do this activity;
- how often your condition affects your ability to do this activity (the 50% rule); and

• the impact of any other conditions or disabilities that you have on this activity.

activity 6 – dressing and undressing (daily living activity)

This is about your ability to dress and undress, including choosing, and putting on appropriate and non-adapted clothing that is suitable for the situation, including socks and shoes. This may include dealing with fastenings such as zips or buttons.

| А | Can dress and undress unaided | 0 |
|---|--|---|
| В | Needs to use an aid or appliance to be able to dress or undress | 2 |
| С | Needs either | |
| | i) prompting to be able to dress, undress or determine appropriate circumstances for remaining clothed; or | |
| | ii) prompting or assistance to be able to select appropriate clothing | 2 |
| D | Needs assistance to be able to dress or undress their lower body | 2 |
| Е | Needs assistance to be able to dress or undress their upper body | 4 |
| F | Cannot dress or undress at all | 8 |

Notes

- This activity may not be a problem for most people with epilepsy most, or all, of the time. However, if your epilepsy means that you are ever unable to dress or undress yourself, select appropriate clothing, or remain clothed, then explain this in your answer.
- If your epilepsy, or any injury related to it, means that you have any difficulty dressing or undressing, or means that you need to avoid certain types of clothing or fastenings, explain this.

Things to think about

- What could happen to you if you have a seizure when dressing or undressing? What is the likelihood of this happening? Include any real examples of when this has happened and how it affected you physically and mentally.
- Does anything else about your epilepsy (including your seizures, recovery from seizures, medication side effects, or impact of your condition) affect your ability to do any of this activity?

Remember to include:

- whether you can do this activity reliably (safely, to an acceptable standard, repeatedly, and in a reasonable time period);
- whether you need aids, appliances or help from another person to do this activity;
- how often your condition affects your ability to do this activity (the 50% rule); and

• the impact of any other conditions or disabilities that you have on this activity.

activity 7 – communicating verbally (daily living activity)

This is about speaking and being understood, and about listening and understanding. It means speaking and listening in your native language, which may not be English. It includes sign language and text relay, but not Braille.

| А | Can express and understand verbal information unaided | 0 |
|---|--|----|
| В | Needs to use an aid or appliance to be able to speak or hear | 2 |
| С | Needs communication support to be able to express or understand complex verbal information | 4 |
| D | Needs communication support to be able to express or understand basic verbal information | 8 |
| E | Cannot express or understand verbal information even with communication support | 12 |
| | | |

Notes

- 'Aid or appliance' might include hearing aids, picture symbols, assistive computer technology or voice aids.
- 'Communication support' might be a person trained in communicating with people with specific needs, or it might be someone experienced in communicating with you (and so could be a family member or carer).
- This activity will not be a problem for many people with epilepsy most of the time. But it could be affected during or after a seizure. For example, during a focal impaired awareness seizure (previously called complex focal seizure), someone may be unable to understand what people are saying to them, which could mean a higher risk of accident or injury to them or to others. Following a seizure, someone might be very tired and confused, which might affect their ability to communicate or understand what is being said to them. Memory issues could also cause a problem. For example, if you need to give information to an ambulance crew or doctor during or after a seizure and this is difficult, you can explain this.
- If your epilepsy or seizures affect your ability to communicate in any way you can explain it here. Include what happens to you, how this affects you physically and mentally, what the risk is to you, what help you need and for how long, and how often this happens.

Things to think about

- What could happen to you if you have a seizure while either talking or listening during a conversation? What is the likelihood of this happening? Include any real examples of when this has happened and how it affected you physically and mentally. For example, some people are anxious about having seizures in public if their seizures cause them to act in an unusual way (such as during a focal impaired awareness seizure, previously called a complex focal seizure), and if they might be confused when people talk to them during a seizure.
- Does anything else about your epilepsy (including your seizures, recovery from seizures, medication side effects, or impact of your condition) affect your ability to communicate? This could include:
 - your concentration or memory;
 - your mood (for example, anxiety or depression, or fear about having a seizure during this activity); or
 - any tiredness or confusion that you may have after a seizure.

Remember to include:

- whether you can do this activity reliably (safely, to an acceptable standard, repeatedly, and in a reasonable time period);
- whether you need aids, appliances or help from another person to do this activity;
- how often your condition affects your ability to do this activity (the 50% rule); and
- the impact of any other conditions or disabilities that you have on this activity.

activity 8 – reading and understanding signs, symbols and words (daily living activity)

This is about understanding written or printed information, including signs and symbols, in your native language (which may not be English).

| А | Can read and understand basic and complex written information either unaided or using spectacles | |
|---|--|---|
| | or contact lenses | 0 |
| В | Needs to use an aid or appliance, other than spectacles or contact lenses, to be able to read or | |
| | understand either basic or complex information | 2 |
| С | Needs prompting to be able to read or understand complex written information | 2 |
| D | Needs prompting to be able to read or understand basic written information | 4 |
| E | Cannot read or understand signs, symbols or words at all | 8 |
| | | |

Notes

- 'Basic information' includes signs, symbols and dates. 'Complex information' means more than one sentence of standard sized text, for example information on a gas or phone bill.
- 'Needs assistance' might include needing someone to read or explain information to you.
- This activity will not be a problem for many people with epilepsy most of the time. But it could be affected during or after a seizure. For example, during a focal impaired awareness seizure, (previously called complex focal seizure) someone may be unable to understand signs or symbols. Or after a seizure, they might be very tired and confused, which could affect their ability to read or understand signs, symbols and words. If your vision is affected during your seizures, you can also include this here.
- If your epilepsy or seizures affect your ability to do this activity in any way, you can explain it here. Include what happens to you, how this affects you, physically and mentally, what the risk is to you, what help you need and how long for, and how often this happens.

Things to think about

- What could happen to you if you have a seizure when you need to read and understand signs, symbols and words to keep safe? Include any real examples of when this has happened and how it affected you physically and mentally. For example, if someone has a focal impaired awareness seizure they might not be able to read or understand road signs, which could be dangerous.
- Does anything else about your epilepsy (including your seizures, recovery from seizures, medication side effects, or impact of your condition) affect your ability to do this activity? This could include:

 your concentration or memory;
 - your mood (for example, anxiety or depression, or fear about having a seizure during this activity); or
 - any tiredness or confusion that you may have after a seizure.

Remember to include:

- whether you can do this activity reliably (safely, to an acceptable standard, repeatedly, and in a reasonable time period);
- whether you need aids, appliances or help from another person to do this activity;
- how often your condition affects your ability to do this activity (the 50% rule); and
- the impact of any other conditions or disabilities that you have on this activity.

activity 9 - engaging with other people face to face (daily living activity)

This is about how well you get on with other people (people you know and people you don't know). It includes behaving appropriately with other people and understanding how they behave towards you, including whether severe anxiety or stress stops you from doing this. It also includes understanding body language and establishing relationships.

| А | Can engage with other people unaided | 0 |
|---|---|---|
| В | Needs prompting to be able to engage with other people | 2 |
| С | Needs social support to be able to engage with other people | 4 |
| D | Cannot engage with other people due to such engagement causing either overwhelming psychological distress to the claimant or the claimant to exhibit behaviour which would result in a substantial risk of harm to the claimant or another person | 8 |

Notes

- Any problems need to be related to your condition (not because you don't want to mix with other people).
- 'Prompting' (reminding) and 'support' can be something that you get from your family or carers, to support you in situations with other people. 'Social support' might be needing someone with you to reassure you, encourage you to mix with others, or help you to understand how people are behaving towards you.
- This activity might apply to you if you need to have someone with you when you go out; if you are only able to go to places that you know or to see people you know; if you don't leave the house at all; or if your epilepsy affects how you get on with others. It might apply if you are anxious about the risk of having seizures, for example when you are in social situations or around people you do not know.
- It might also apply to you if you have seizures which affect how you interact with others. It might affect your ability to mix with others during or after a seizure, or might affect you if your seizures are triggered by stress or anxiety. If this does apply to you, you can explain what happens during your seizures and how this, or the risk of having a seizure, makes you feel when you are mixing with other people.

Things to think about

- What could happen to you if you have a seizure around other people (you might feel differently depending on whether you know the people)? For example:
 - Do you need to take someone with you when you go out, to help you mix with other people?
 - Do you need someone with you when you have a seizure, to keep you safe and to explain to other people what is happening?
 - Does it cause you psychological distress (feelings of anxiety or depression) to mix with other people?
 - Do you become uninhibited (unrestrained) during a seizure which could be seen as socially inappropriate?
- What is the likelihood of this happening? Include any real examples of when this has happened, including how it affected you. If you have been diagnosed with anxiety or depression, remember to include this in your answer, as well as any treatment you are having for it.
- Does anything else about your epilepsy (including your seizures, recovery from seizures, medication side effects, or impact of your condition) affect your ability to do any of this activity? You can include any impact on:

 your concentration or memory;
 - your mood (for example, anxiety or depression, or fear about having a seizure during this activity); or
 - any tiredness or confusion that you may have after a seizure.

Remember to include:

- whether you can do this activity reliably (safely, to an acceptable standard, repeatedly, and in a reasonable time period);
- whether you need aids, appliances or help from another person to do this activity;
- how often your condition affects your ability to do this activity (the 50% rule); and
- the impact of any other conditions or disabilities that you have on this activity.

activity 10 – making budgeting decisions (daily living activity)

This is about your ability to make everyday decisions about spending and managing your money.

| А | Can make complex budgeting decisions unaided | 0 |
|---|--|---|
| В | Needs prompting or assistance to be able to make complex budgeting decisions | 2 |
| С | Needs prompting or assistance to be able to make simple budgeting decisions | 4 |
| D | Cannot make any budgeting decisions at all | 6 |

Notes

- This activity is only about your ability to make decisions about money, it is not about any physical issues of managing money.
- A 'simple budgeting decision' could be working out the cost of things, and 'complex budgeting decisions' could be paying bills.
- This activity will not be a problem for many people with epilepsy most of the time. But if your epilepsy or seizures affect your ability to do this activity in any way, you can explain it here. Include what happens to you; how this affects your ability to do this activity; what help you need to do this activity and for how long; and how often you need help.

Things to think about

- Does anything about your epilepsy (including your seizures, recovery from seizures, medication side effects or impact of your condition) affect your ability to do any of this activity? You can include any impact on: – your concentration or memory;
 - your mood (for example, anxiety, depression or lack of motivation); or
 - any tiredness or confusion that you may have after a seizure.

Remember to include:

- whether you can do this activity reliably (safely, to an acceptable standard, repeatedly, and in a reasonable time period);
- whether you need aids, appliances or help from another person to do this activity;
- how often your condition affects your ability to do this activity (the 50% rule); and
- the impact of any other conditions or disabilities that you have on this activity.

activity 11 – planning and following journeys (mobility activity)

This is about planning (working out) and following a journey, including using public transport, and whether severe anxiety or distress stops you from being able to go out. It is not about your physical mobility (covered in activity 12).

| А | Can plan and follow the route of a journey unaided | 0 |
|---|--|----|
| В | Needs prompting to be able to undertake any journey to avoid overwhelming psychological distress | |
| | to the claimant | 4 |
| С | Cannot plan the route of a journey | 8 |
| D | Cannot follow the route of an unfamiliar journey without another person, assistance dog, | |
| | or orientation aid | 10 |
| E | Cannot undertake any journey because it would cause overwhelming psychological distress to | |
| | the claimant | 10 |
| F | Cannot follow the route of a familiar journey without another person, assistance dog, | |
| | or orientation aid | 12 |
| | | |

Notes

- 'Journey' means a local journey, whether familiar or unfamiliar. 'Follow' means having the mental ability to reliably follow a route, it does not mean the physical act of moving. If you need someone with you to prevent you harming yourself or others when making a journey, 11F might apply.
- This activity may not apply to you at all, or not all of the time. However, it might apply to you if your epilepsy or seizures affect your ability to think clearly or affect your senses, so that the activity is difficult or dangerous. It might only affect your ability to do this activity at certain times, such as during and after a seizure. It might also affect you if, for example, your medication affects your thinking, concentration, memory, or taking in information. It might also apply if you need supervision to be able to plan or follow a journey.
- Your safety is important. For example, this activity might apply to you if you always need someone with you when going out to keep you safe if you have a seizure, or if you are confused after a seizure and need help to complete your journey safely.
- 'Psychological distress' could mean severe anxiety about making a journey or going out alone. For example, the possibility of having a seizure and the risks associated with this, including accident and injury, might cause anxiety for some people which stops them going out.

Things to think about

- What could happen if you have a seizure when planning or following a journey? For people with focal impaired awareness seizures (previously called complex focal seizures) this might include wandering into the road. For people with tonic, atonic, or tonic clonic seizures this might include falling into the road. What is the likelihood of this happening? Include any real examples of when this has happened and how it affected you physically and mentally. This is important if the risks of having a seizure cause you anxiety, or mean that you do not go out of your house alone. If this applies to you, state clearly what could happen to you if you have a seizure. For example, rather than saying 'I don't go out alone' you might say 'I only go out if someone comes with me because...'
- Does anything else about your epilepsy (including your seizures, recovery from seizures, medication side effects, or impact of your condition) affect your ability to do any of this activity? You can include any impact on:

 your concentration, motivation, thinking, or memory (for example if your awareness of danger is affected);
 your mood (for example, anxiety or depression, or fear about having a seizure during this activity); or
 any tiredness or confusion that you may have after a seizure.

Remember to include:

- whether you can do this activity reliably (safely, to an acceptable standard, repeatedly, and in a reasonable time period);
- whether you need aids, appliances or help from another person to do this activity;
- how often your condition affects your ability to do this activity (the 50% rule); and
- the impact of any other conditions or disabilities that you have on this activity.

activity 12 – moving around (mobility activity)

This is about being able to physically move around, focusing on being able to stand up and walk unaided, without severe discomfort such as breathlessness, pain or fatigue.

| А | Can stand and then move more than 200 metres, either aided or unaided | 0 |
|---|---|----|
| В | Can stand and then move more than 50 metres but no more than 200 metres, either aided or | |
| | unaided | 4 |
| С | Can stand and then move unaided more than 20 metres but no more than 50 metres | 8 |
| D | Can stand and then move using an aid or appliance more than 20 metres but no more | |
| | than 50 metres | 10 |
| E | Can stand and then move more than 1 metre but no more than 20 metres, either aided or unaided | 12 |
| F | Cannot (either aided or unaided) stand; or move more than 1 metre | 12 |
| | | |

Notes

- This activity is judged on the type of surface you would expect to walk on out of doors, such as pavements and kerbs, rather than indoors.
- This activity may not apply to you at all, or not all of the time. However, it might apply to you if your seizures affect your ability to move either during or after the seizure. If you are unable to stand and walk during or after a seizure, or you are able to stand and walk but with difficulties, explain this in your answer. If moving causes you any pain, discomfort, difficulty, tiredness, or breathlessness, include this in your answer too.

Things to think about

- What could happen to you if you have a seizure when moving around? You might like to think about different scenarios both inside and outside your home. What is the likelihood of this happening? Include any real examples of when this has happened and how it affected you physically and mentally.
- Does anything else about your epilepsy (including your seizures, recovery from seizures, medication side effects, or impact of your condition) affect your ability to do any of this activity? You can include any impact on:

 your concentration, motivation, thinking or memory;
 - your mood (for example, anxiety or depression, or fear about having a seizure during this activity); or
 - any tiredness or confusion that you may have after a seizure.

Remember to include:

- whether you can do this activity reliably (safely, to an acceptable standard, repeatedly, and in a reasonable time period);
- whether you need aids, appliances or help from another person to do this activity;
- how often your condition affects your ability to do this activity (the 50% rule); and
- the impact of any other conditions or disabilities that you have on this activity.

what happens next?

Most people will be asked to attend a face-to-face consultation to assess their condition against the criteria. This will be with a health professional (an 'assessor') chosen by the DWP, not with your own doctor. They will look at your form, and any other evidence you have, for example from your GP or consultant. You can take someone with you to your consultation, such as a family member, carer, advocate or professional adviser.

If you cannot attend the face-to-face consultation, tell the DWP as soon as possible. The assessors may be able to arrange a consultation at your home if you are unable to travel. If you do not attend without giving a good reason, you will lose your claim for PIP.

The health professional (assessor) will be assessing you as soon as you arrive at your appointment. It is important that you are open, honest and as clear as possible about how your condition affects you so that they can understand what your condition is like, and how the activity criteria apply to you.

The assessor will report back to the DWP to decide whether you should receive PIP and at what rate. If you are awarded PIP, you will be told how much benefit you will receive and for how long this will last. At the end of this time, you may have to apply for, or be assessed for, PIP again.

what happens if my claim is unsuccessful?

If you are not awarded PIP, the DWP will write to you to explain why this decision was made. If your claim for PIP is unsuccessful, or if your situation has changed and you want the DWP to look at this again, you can challenge this within one month of the date of the decision, by asking for 'mandatory reconsideration'.

Bear in mind that if you have been awarded PIP but at a lower rate than you wanted, and you ask for a reconsideration, the DWP will reconsider your whole award, and you may lose what you have been awarded.

If you are not happy with the reconsideration outcome, you can appeal, and you need to do this within one month of the mandatory reconsideration decision letter that you have received.

 $\stackrel{\text{O}}{\sqcap}$ For more information see our guide *benefit decisions and appeals*.

h further information

Epilepsy Society information Benefit decisions and appeals Completing benefit forms PIP – making a claim Safety Seizure diary

 $eal}{in}$ To check when you can make a claim for PIP, see the online PIP checker at gov.uk/pip-checker

- For more details on the assessment criteria and the process for PIP, see the DWP's Personal Independence Payment handbook at gov.uk/government/publications/personal-independence-payment-fact-sheets
- For more about PIP, visit

 disabilityrightsuk.org/personal-independence-payment-pip
- $eal}{m}$ For help completing the application form, visit citizensadvice.org.uk or call 03444 111 444

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helpline

Monday and Tuesday 9am to 4pm Wednesday 9am to 7.30pm Confidential (national call rate)