

Personal Independence Payment

If you have Parkinson's, you may have some concerns about how you'll manage financially. If you need help with your day-to-day needs or if you have trouble getting around, this can lead to extra costs. But there is some financial support available, so it's important to find out what benefits you're entitled to.

This information explains what Personal Independence Payment (PIP) is, who qualifies and how to claim.

What is Personal Independence Payment?

If you need extra help with day-to-day activities or have trouble getting around due to your health or disability, you may be able to claim Personal Independence Payment (PIP).

If you are making a new claim for PIP, you must be under 65, or under State Pension age, if that is later (see section on age rules, below, for more details).

PIP is for you, not for a carer (if you have one), and you don't need to have someone looking after you to qualify. If you are awarded this benefit, it is entirely up to you how you use it.

PIP is not taxable and you don't need to have paid National Insurance contributions to get it. You can claim PIP whether you are in or out of work. PIP is not means-tested. In other words, it is not affected by earnings or other benefits you receive or by any savings you have.

Getting PIP may increase the amount of any means-tested benefits you receive, such as Housing Benefit, Working Tax Credit or income-related Employment and Support Allowance.

The age rules for claiming PIP

If you are making a fresh claim for PIP and you don't already get Disability Living Allowance, then you must start the claim either before you reach the age of 65 or before you reach State Pension age, if that is later. You can check your State Pension age using the online calculator at www.gov.uk/state-pension-age.

If you already get Disability Living Allowance and you were born on or after 8 April 1948, at some point your Disability Living Allowance award will be ended and you will be invited to claim PIP instead. If you already get Disability Living Allowance and you were born before 8 April 1948, you can continue getting Disability Living Allowance regardless of your age, and you cannot claim PIP.

Once you are awarded PIP, you can carry on receiving the benefit regardless of your age.

If the age rules above prevent you from claiming PIP, you may be able to claim Attendance Allowance instead.

Find out more: see our information on [Attendance Allowance](#).

The PIP components

PIP has two parts: a 'daily living component' and a 'mobility component'. You can get either component or both together, depending on your needs.

The daily living component

The daily living component helps cover the extra costs you may face if you need help carrying out daily living activities. It is paid at two different rates – a standard rate and an enhanced rate. The rate you are paid depends on whether your ability to carry out daily living activities is limited or severely limited. This is tested under the PIP assessment (see page 3).

The mobility component

The mobility component helps cover the extra costs that you may face if you have difficulties getting around. It is paid at two different rates – a standard rate and an enhanced rate. The rate you are paid depends on whether your ability to carry out mobility activities is limited or severely limited. This is tested under the PIP assessment (see page 3).

If you qualify for the enhanced rate, you may be able to join the Motability scheme. This enables disabled people to use the enhanced rate to obtain a new car, powered wheelchair or scooter. You may also qualify automatically for the Blue Badge scheme, which allows people with mobility problems to park closer to places they wish to visit.

Find out more: see our information on [Help with getting around](#).

Do I qualify?

To qualify for PIP, you must meet the following basic conditions.

- You must meet the age rules for claiming PIP detailed above.
- You must have been present in Great Britain (or Northern Ireland, if you live there) for two out of the last three years before claiming. If you are terminally ill, you need to be present in Great Britain but the time conditions don't apply.
- You must normally live in the United Kingdom, the Channel Islands, the Republic of Ireland or the Isle of Man. Your immigration status must not prevent you from claiming.

You must also meet the disability conditions. The disability conditions look at your daily living needs and your mobility needs. These are considered under the PIP assessment (see below).

You must have met the disability conditions for at least three months before a PIP award can be made (you won't have to wait a further three months for payment if you have already met the conditions for three months or more before making the claim). You must also be likely to continue to meet the disability conditions for a period of nine months in the future.

What is the PIP assessment?

The PIP assessment is a test of your ability to take part in everyday life. It is a points-related assessment and is based on your ability to perform different activities relating to your daily living needs and your mobility.

The number of points you score will determine whether or not you are entitled to either component of PIP and, if you are, at which rate.

The daily living activities

Your ability to carry out daily living activities is assessed by looking at 10 types of activity. These are:

- preparing food
- taking nutrition (eating and drinking)
- managing therapy or monitoring a health condition
- washing and bathing
- managing toilet needs or incontinence
- dressing and undressing
- communicating verbally
- reading and understanding signs, symbols and words
- engaging with other people face-to-face
- making budgeting decisions

The mobility activities

Your ability to carry out mobility activities is assessed by looking at two types of activity. These are:

- planning and following journeys
- moving around

Scoring points

Within each of the above activity headings are a series of 'descriptors' with scores ranging from 0 to 12 points. The descriptors describe related tasks of varying degrees of difficulty and the different types of help you need to complete each task.

You score points for the descriptor that best describes the level at which you can complete the task safely, to an acceptable standard, repeatedly and in a reasonable time period. The highest descriptor score from each activity heading is added together to work out your points for each component.

We list the descriptors and scores for the daily living activities in Appendix 1 on page 10. We list the descriptors and scores for the mobility activities in Appendix 2 on page 13.

How many points do you need?

To be entitled to the standard rate of the daily living component, you need to score at least 8 points under the 10 daily living activity headings. To be entitled to the enhanced rate, you need to score at least 12 points.

Likewise, to be entitled to the standard rate of the mobility component, you need to score at least 8 points under the two mobility activity headings, and at least 12 points for the enhanced rate.

What if my condition fluctuates?

A descriptor will apply if you are unable to complete a task on the majority of days (ie on over half of days). This will be considered over a 12-month period, looking back three months and forward nine months. Where one descriptor is satisfied on over half the days in that period, that descriptor will apply. Where two or more descriptors are satisfied on over half the days, the descriptor which scores the highest number of points will apply.

If you are not sure which descriptors apply to you, keeping a diary over a week may help you to choose the correct ones.

Find out more: see our information on [Monitoring your Parkinson's](#) for more advice on keeping a diary.

How much will I get?

Each component of PIP has two rates – a standard rate and an enhanced rate. The rate you receive depends on how many points you score in the PIP assessment.

Daily living component	per week
Standard rate	£57.30
Enhanced rate	£85.60

Mobility component	per week
Standard rate	£22.65
Enhanced rate	£59.75

How do I claim?

To make a claim call **0800 917 2222** (Monday–Friday, 8am–6pm) or textphone **0800 917 7777**. In Northern Ireland call **0800 012 1573** or textphone **0800 012 1574**. Someone else can make this call on your behalf, but you need to be with them when they do so.

During this call, you'll need to provide basic details including your personal and contact details, National Insurance number and details of your bank or building society (for payment purposes). It will help if you have this information ready when you make the call.

You will be asked for details of your GP and hospital specialist, and if you have a mental health or behavioural problem (you are asked this in case you may need help to complete the claim form). You should not be asked what your medical condition is or how it affects you at this stage.

If you find it difficult to use the telephone and do not have someone who could help give the answers, it is possible to use a paper claim form (although this can delay the decision on your claim).

To request the PIP1 form, write to:

**Personal Independence Payment New Claims
Post Handling Site B
Wolverhampton
WV99 1AH**

In Northern Ireland the address to request a paper claim form is:

**Personal Independence Payment Centre
Castle Court
Royal Avenue
Belfast, BT1 1HR**

What happens next?

If you meet the basic qualifying conditions for PIP (see page 2), you will be sent a form to complete called 'How your disability affects you'. If it is clear from the information you have provided when you started the claim that you do not satisfy the basic qualifying conditions for PIP, the Department for Work and Pensions will send you a letter stating that your claim has been disallowed.

Completing the 'How your disability affects you' form

The form gives you the chance to describe how your condition affects your daily life. An information booklet comes with the form. Read this first, and have a look through the form before completing any of it. We have also provided extra guidance and examples in Appendix 3 (see page 14) as well as definitions of some of the terms used, in Appendix 4 (see page 18).

You may wish to write in pencil first, or make some notes on separate sheets of paper, before filling in the form in pen. Unfortunately, there is no way to fill this form in online at the moment. If you have difficulty writing and do not have someone who could help fill in the form for you, contact the Parkinson's UK helpline for support on **0808 800 0303**.

The form will first ask you for details of the professionals who are best placed to provide advice on how your disability or health condition affects you. Examples are given – they can include social workers and support workers, as well as medical professionals, such as your GP. It's best to put details of the professionals who know your problems best, such as your Parkinson's nurse (if you have one). Whoever you put down, contact them and let them know that you're applying for PIP and have included their contact details on the form. Make it clear that you give permission for them to discuss your condition, as this will help to speed up the medical evidence gathering process and may help you avoid having a face-to-face consultation.

Most of the form is made up of questions on your day-to-day life, relating to the points-based PIP assessment (see page 3). You get points for what you cannot manage, not for what you can. It is important to be clear about the difficulties you experience, so that you are assessed accurately. Give yourself plenty of time to complete the form – you do not have to do it all in one sitting.

Questions 3 to 12 relate to the activity headings of the daily living component. Questions 13 and 14 relate to the activity headings of the mobility component. The activity headings, the 'descriptors' under each heading, and the points allocated to each one, are listed in Appendices 1 and 2 on pages 10 and 13. When thinking about which descriptor should apply to you, ask yourself the following questions:

- Would you have problems with this sort of task at some point in the day?

- Do you need help from another person to complete the task? If you do need help, what kind of help do you need? Does someone physically help you, reassure you, encourage you, remind you or explain to you how to do something? Or do they need to supervise you?
- Do you use aids or appliances to help with a task? If you do, say what they are and how useful they are.
- Can you do some parts of the task but not others?
- Are you unable to do the task at all? Explain why.
- Can you do a task but it takes you at least twice as long as it should?
- Can you do this task as often as you need to throughout the day?
- Do your needs change? Describe in what way and how often. Explain about good and bad days or how your needs vary throughout the day.
- Do you regularly have accidents (such as falls) or are you at risk of accidents if attempting the task alone?
- Do you have any side effects from doing the task? Do you experience pain, breathlessness, tiredness or stress and anxiety either during or after performing the task?

For some of these points, it may help to keep a diary of your needs.

Find out more: see our information on [Monitoring your Parkinson's](#) for more advice on keeping a diary.

The extra information box

The second page of each question has a box where you can explain what difficulties you face with each activity. Examples are provided above the box and in the information booklet that comes with the form. For more detailed guidance on the questions, including examples of what could be written in the extra information box, please see Appendix 3 on page 14.

Before you send off the form

If you can, attach photocopies of any additional evidence that you have to the form. Anything that helps an assessor understand how your condition impacts your day-to-day life is useful. For example, this could include copies of:

- prescriptions
- care and support plans
- information from professionals such as your specialist, Parkinson's nurse, occupational therapist, physiotherapist, social worker, support worker or counsellor.

If you keep a diary of how your condition affects you, this is also helpful.

Find out more: see our information on [Monitoring your Parkinson's](#) for more advice on keeping a diary.

A face-to-face consultation will usually be arranged (see below). So if you would prefer this to take place in the morning or in the afternoon, put this on your form, as it may help you avoid being given an inappropriate time.

You should return your completed form as soon as possible, as there is a time limit for its return. If you get new evidence that could help your claim after you've sent the form back, you should make a copy and send it to the Department for Work and Pensions. Make a photocopy of the form once you have completed it, along with any supporting evidence you are sending with the form. Keep this safe.

How the claim is assessed

Once your 'How your disability affects you' form has been returned, your case will be passed to one of the two companies contracted to carry out the PIP assessments on behalf of the Department for Work and Pensions – Independent Assessment Services (previously Atos Healthcare) and Capita. Once your case has been passed to one of these companies, they will allocate it to a healthcare professional working for them.

This healthcare professional may contact your GP or specialist for more information first. However, in most cases the healthcare professional will arrange to see you at a face-to-face consultation, unless they feel they have enough supporting evidence to make a decision on paper.

The face-to-face consultation

The face-to-face consultation will usually take place at an Assessment Centre. You can ask for a home visit if you are unable to attend the Assessment Centre. Independent Assessment Services and Capita are also able to offer and arrange a taxi at their cost to and from the Assessment Centre.

At the face-to-face consultation, the healthcare professional will identify the descriptors that they believe apply to you (see Appendices 1 and 2 on pages 10 and 13). To do this, they will ask questions about your day-to-day life, your home, how you manage at work if you have a job, and about any social or leisure activities that you take part in (or have had to give up). They will often ask you to describe a typical day in your life.

Keep in mind that the healthcare professional is there to build a picture of how your condition affects you on a day-to-day basis over the course of one year. So it's important not to be concerned that you will be judged on how you may be feeling on the day of your consultation. Don't stop taking your medication as a way of showing how your condition affects you, as this can be dangerous.

If you can't do something at one particular point in the day, the healthcare professional should take this into account, even if you can do that task at other times in the day. Make sure they know how the changing nature of Parkinson's affects you, including how you manage when your symptoms are at their worst.

- Tell them about any pain or tiredness you feel, or would feel, while carrying out each task they ask you about, and after you have carried it out. Consider how you would feel if you had to do the same task repeatedly.
- Tell them how long it takes you to do things if your Parkinson's slows you down, or if you would avoid doing the task they are asking you about because you have had accidents in the past. For example, if you don't cook with hot pans anymore because of problems with your grip or because your tremor makes it dangerous.
- Don't overestimate your ability to do things. If your condition varies, let them know what you are like on bad days as well as good days. The healthcare professional's opinion should not be based on a snapshot of your condition on the day of the consultation – they should consider the effects of your condition over time. If you have problems at some stage of the day, for example if mornings are difficult for you but you feel better once you have taken your medication, this is relevant. Intermittent problems can still help you get an award of PIP.
- You should only be treated as being able to perform a task if you can do so safely, to an acceptable standard, repeatedly and in a reasonable time period. Try to make it clear to the healthcare professional if this is not the case.

After the consultation

After the consultation, the healthcare professional will complete their report and send it to a Department for Work and Pensions case manager. They will then decide whether or not to award you PIP and, if it is awarded, at what rate and for how long.

How is PIP paid?

PIP is normally paid every four weeks in arrears into a bank, building society or Post Office card account.

Find out more: if you don't have a bank account, see our [General information about benefits](#). This explains how to get a bank account.

If you are not happy with the decision

Asking for your claim to be looked at again

If your claim is turned down, you have one calendar month from the date of the decision in which to ask the Department for Work and Pensions to look at the decision again. This is called a 'mandatory reconsideration'. You can also ask for a mandatory reconsideration if you are unhappy with the level of the benefit that has been awarded or the period for which it has been awarded.

Don't be discouraged from asking for a mandatory reconsideration. Be careful, however, because when you ask for one, the Department for Work and Pensions will look at the whole award and they can take away the rate of PIP you have already been granted. If you are in any doubt, contact the Parkinson's UK helpline on **0808 800 0303**.

How to ask for a mandatory reconsideration

To ask for a mandatory reconsideration, write to the address (or ring the number) on the decision letter and do the following:

1. Request a mandatory reconsideration of the decision. Explain why you disagree with their decision simply at this stage, for example, "I believe that you've underestimated the effect of my disability and consequently underestimated the extent of my mobility problems and the difficulties I have in carrying out daily living activities".
2. Ask them to send you copies of all the evidence that was used in making the decision.
3. Ask them not to take any further action until you have had the chance to respond to that evidence.

If you phone, put your request in writing as well. You can use a CRMR1 mandatory reconsideration request form (www.gov.uk/mandatory-reconsideration/how-to-ask-for-mandatory-reconsideration) but you are not obliged to do so. Keep a copy of your request. If you have not received the evidence after two weeks, telephone the Department for Work and Pensions again to remind them to send it.

Building a case

When you do receive the evidence, you should get a better idea of why the decision was made. In most cases, there will be a report produced by the healthcare professional at the face-to-face consultation. Compare their report with what you wrote on the 'How your disability affects you' form. Look for where there is a difference of opinion.

For example, you may have written on the 'How your disability affects you' form that you could not walk more than 20 metres without severe discomfort, but the healthcare professional noted in their report that they thought you could manage about 100 metres.

Where you find such differences, try to get medical evidence showing that what you said on the form was correct. For example, a letter from your GP, specialist or Parkinson's nurse describing the difficulties you have in walking and confirming that your estimate of the limit of your walking abilities tallies with their understanding of your condition.

Once you have got evidence to support your case, send a copy of it to the address on the decision letter. If you need more time to get the evidence, inform the Department for Work and Pensions how long this is likely to take, so they do not make a decision straight away.

A Department for Work and Pensions case manager will look at any further evidence you send. They will then either change the decision in your favour or let you know that they are unable to change the decision. You now have one calendar month from the date of this 'mandatory reconsideration notice' to appeal to an independent tribunal.

How to appeal

You can appeal against a decision using the official appeal form, the SSCS1 (or the NOA1(SS) in Northern Ireland). You must appeal within one month of the date on the mandatory reconsideration notice. The appeal form will ask if you would like your appeal to be considered with or without a hearing. Choosing a hearing and attending the tribunal can greatly improve your chances of a successful outcome.

Your appeal will be considered by an independent appeal tribunal. These tribunals are informal – they are not like courts. If you have a carer, they can attend as well to provide their account of your needs. You can contact a local advice centre such as Citizens Advice to see if they can give you any support with an appeal and possibly provide a representative to present your case at the hearing.

What if my condition gets worse in the future?

If you are awarded PIP and there is a change in your condition sometime in the future, you can ask for the award to be looked at again. This is worth doing if you think you might qualify for another component or a higher rate of either component.

Be aware that the Department for Work and Pensions will look at the whole award and they can take away the rate of PIP you have already been granted. Before you do anything, make sure that you meet the conditions for the new component or the higher rate (see Appendices 1 and 2). You need to have satisfied the conditions for the new component or the higher rate for at least three months before your award can be increased. If you are in any doubt, contact the Parkinson's UK helpline on **0808 800 0303**.

What if I go into hospital or a care home?

Hospital stays

You can make a claim for PIP if you are in hospital, but payment can only start once you leave. If you are already getting PIP and you go into hospital, payment will stop after a total of four weeks (either in one stay, or several stays, where the gaps between stays are no more than four weeks each time). It can restart when you go home.

If you are under 18, your PIP can be paid for the whole time you are in hospital.

Care homes

If you pay your own fees for the care home without help from the council or health service, your PIP can continue to be paid.

If the council helps with the fees, the PIP daily living component will stop after a total of four weeks. This can be in one stay, or several stays, where the gaps between stays are no more than four weeks each time. It can restart if you return home. The mobility component is not affected even if the council helps with the fees.

If a nursing home is paid for by the health service, both the PIP daily living and mobility components will usually stop after four weeks and can restart when you return home.

APPENDIX 1. Daily living activities: descriptors and scores

Each activity heading has a set of 'descriptors'. These describe related tasks of varying degrees of difficulty and different types of help you need to complete each task. You score points when you are not able to complete a task described safely, to an acceptable standard, repeatedly and in a reasonable time period. For the meaning of the terms and phrases used, see Appendix 4 on page 18.

For each activity heading, if more than one descriptor applies to you, only the score from the one that gives you the highest number of points is included. To be entitled to the standard rate of the daily living component, you need to score at least 8 points. To be entitled to the enhanced rate, you need to score at least 12 points. These points can be scored from just one activity heading or from any of the activity headings added together.

Activity 1. Preparing food

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

Activity 2. Taking nutrition

- a. Can take nutrition unaided. **Score 0**
- b. Needs
 - (i) to use an aid or appliance to be able to take nutrition
 - (ii) supervision to be able to take nutrition, **or**
 - (iii) assistance to be able to cut up food. **Score 2**
- c. Needs a therapeutic source to be able to take nutrition. **Score 2**
- d. Needs prompting to be able to take nutrition. **Score 4**
- e. Needs assistance to be able to manage a therapeutic source to take nutrition. **Score 6**
- f. Cannot convey food and drink to their mouth and needs another person to do so. **Score 10**

Activity 3. Managing therapy or monitoring a health condition

- a. Either
 - (i) does not receive medication or therapy or need to monitor a health condition, **or**
 - (ii) can manage medication or therapy or monitor a health condition unaided. **Score 0**
- b. 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. **Score 1**

- c. Needs supervision, prompting or assistance to be able to manage therapy that takes no more than 3.5 hours a week. **Score 2**
- d. Needs supervision, prompting or assistance to be able to manage therapy that takes more than 3.5 but no more than 7 hours a week. **Score 4**
- e. Needs supervision, prompting or assistance to be able to manage therapy that takes more than 7 but no more than 14 hours a week. **Score 6**
- f. Needs supervision, prompting or assistance to be able to manage therapy that takes more than 14 hours a week. **Score 8**

Activity 4. Washing and bathing

- a. Can wash and bathe unaided. **Score 0**
- b. Needs to use an aid or appliance to be able to wash or bathe. **Score 2**
- c. Needs supervision or prompting to be able to wash or bathe. **Score 2**
- d. Needs assistance to be able to wash either their hair or body below the waist. **Score 2**
- e. Needs assistance to be able to get in or out of a bath or shower. **Score 3**
- f. Needs assistance to be able to wash their body between the shoulders and waist. **Score 4**
- g. Cannot wash and bathe at all and needs another person to wash their entire body. **Score 8**

Activity 5. Managing toilet needs or incontinence

- a. Can manage toilet needs or incontinence unaided. **Score 0**
- b. Needs to use an aid or appliance to be able to manage toilet needs or incontinence. **Score 2**
- c. Needs supervision or prompting to be able to manage toilet needs. **Score 2**
- d. Needs assistance to be able to manage toilet needs. **Score 4**
- e. Needs assistance to be able to manage incontinence of either bladder or bowel. **Score 6**
- f. Needs assistance to be able to manage incontinence of both bladder and bowel. **Score 8**

Activity 6. Dressing and undressing

- a. Can dress and undress unaided. **Score 0**
- b. Needs to use an aid or appliance to be able to dress or undress. **Score 2**
- c. 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. **Score 2**
- d. Needs assistance to be able to dress or undress their lower body. **Score 2**

- e. Needs assistance to be able to dress or undress their upper body. **Score 4**
- f. Cannot dress or undress at all. **Score 8**

Activity 7. Communicating verbally

- a. Can express and understand verbal information unaided. **Score 0**
- b. Needs to use an aid or appliance to be able to speak or hear. **Score 2**
- c. Needs communication support to be able to express or understand complex verbal information. **Score 4**
- d. Needs communication support to be able to express or understand basic verbal information. **Score 8**
- e. Cannot express or understand verbal information at all even with communication support. **Score 12**

Activity 8. Reading and understanding signs, symbols and words

- a. Can read and understand basic and complex written information either unaided or using spectacles or contact lenses. **Score 0**
- b. Needs to use an aid or appliance, other than spectacles or contact lenses, to be able to read or understand either basic or complex written information. **Score 2**
- c. Needs prompting to be able to read or understand complex written information. **Score 2**
- d. Needs prompting to be able to read or understand basic written information. **Score 4**
- e. Cannot read or understand signs, symbols or words at all. **Score 8**

Activity 9. Engaging with other people face-to-face

- a. Can engage with other people unaided. **Score 0**
- b. Needs prompting to be able to engage with other people. **Score 2**
- c. Needs social support to be able to engage with other people. **Score 4**
- d. Cannot engage with other people due to such engagement causing either (i) overwhelming psychological distress to the claimant, **or** (ii) the claimant to exhibit behaviour which would result in a substantial risk of harm to the claimant or another person. **Score 8**

Activity 10. Making budgeting decisions

- a. Can manage complex budgeting decisions unaided. **Score 0**
- b. Needs prompting or assistance to be able to make complex budgeting decisions. **Score 2**
- c. Needs prompting or assistance to be able to make simple budgeting decisions. **Score 4**
- d. Cannot make any budgeting decisions at all. **Score 6**

APPENDIX 2. Mobility activities: descriptors and scores

Each activity heading has a set of 'descriptors'. These describe related tasks of varying degrees of difficulty. You score points when you are not able to complete a task described safely, to an acceptable standard, repeatedly and in a reasonable time period. For each activity heading, if more than one descriptor applies to you, only the score from the one that gives you the highest number of points is included.

To be entitled to the standard rate of the mobility component, you need to score at least eight points. To be entitled to the enhanced rate, you need to score at least 12 points. These points can be scored from just one activity heading or from both headings added together.

Activity 11. Planning and following journeys

- | | |
|--|-----------------|
| a. Can plan and follow the route of a journey unaided. | Score 0 |
| b. Needs prompting to be able to undertake any journey to avoid overwhelming psychological distress to the claimant. | Score 4 |
| c. Cannot plan the route of a journey.* | Score 8 |
| d. Cannot follow the route of an unfamiliar journey without another person, assistance dog or orientation aid.* | Score 10 |
| e. Cannot undertake any journey because it would cause overwhelming psychological distress to the claimant. | Score 10 |
| f. Cannot follow the route of a familiar journey without another person, an assistance dog or an orientation aid.* | Score 12 |

*In March 2017 the government tried to change the wording of the above 'Planning and following journeys' activity. This was challenged, deemed unlawful and reverted back to the wording above. If you think you've been affected by the government using the incorrect criteria for this activity, you should get advice. Call our helpline on **0808 800 0303**, or visit advice.local.uk to find an independent local advice service

Activity 12. Moving around

- | | |
|--|-----------------|
| a. Can stand and then move more than 200 metres, either aided or unaided. | Score 0 |
| b. Can stand and then move more than 50 metres but no more than 200 metres, either aided or unaided. | Score 4 |
| c. Can stand and then move unaided more than 20 metres but no more than 50 metres. | Score 8 |
| d. Can stand and then move using an aid or appliance more than 20 metres but no more than 50 metres. | Score 10 |
| e. Can stand and then move more than one metre but no more than 20 metres, either aided or unaided. | Score 12 |
| f. Cannot, either aided or unaided,
(i) stand, or
(ii) move more than one metre. | Score 12 |

APPENDIX 3. 'How your disability affects you' form: explanations and examples

The 'How your disability affects you' form gives you the chance to describe how your condition affects your daily life. Most of the form is made up of questions relating to the points-based PIP assessment (see Appendices 1 and 2). We now look at the questions on the form in more detail, providing examples that could be written in the extra information box in each case.

These examples are intended as a guide only. Parkinson's affects everyone differently, so before writing your answers, consider carefully how your condition affects you from day to day.

Daily living activities

Question 3. Preparing food (Activity 1 in Appendix 1)

Some people with Parkinson's may have problems with their grip, such as holding a hot pan. They may need a perching stool or have other issues with balance around the kitchen. They may also need to use chopped or prepared food, or need to have someone there to help or supervise in case of accidents, or to prompt if they have memory problems.

Example response:

"Because of my tremor I don't feel confident handling pans full of food or hot water. I cannot grip utensils properly, and don't have the muscle control to be able to cut or chop food. I also have balance problems, so standing in the kitchen for any period of time is difficult. This is why I need supervision or assistance to be able to prepare and cook a simple meal."

Question 4. Eating and drinking (Activity 2 in Appendix 1: Taking nutrition)

Some people with Parkinson's will need help to eat food or drink because of swallowing problems, which can cause choking. They may also need prompting because of memory problems. In some cases, people are able to eat their food and drink liquids unsupervised, but might need some help with preparation, such as chopping up food.

Example response:

"I have problems eating because I have swallowing problems. This causes a fear of choking, so I don't eat unless I have help, which has led to weight loss. I use various aids and appliances to help me eat and often need help to cut up food, as I find it difficult to grip cutlery."

Question 5. Managing treatments (Activity 3 in Appendix 1: Managing therapy or monitoring a health condition)

Some people with Parkinson's need to take lots of medication, for which they may need a pill box or a pill timer. Some people may be on apomorphine injections or infusions. Some may need physiotherapy, which can count towards the total number of hours' therapy needed each week.

Example response:

"I need apomorphine injections, which I take between doses of my usual medication. I can't do this myself so my partner is trained in how to use it. I have a ready-to-use injection pen that works within 10 minutes and is often used as a 'rescue' measure, which is usual when I have a sudden 'off' period. Because of this, I need constant, 24-hour supervision to manage my Parkinson's."

Question 6. Washing and bathing

(Activity 4 in Appendix 1)

Many people with Parkinson's are likely to need assistance getting in and out of a bath or shower. They may also need some form of adaptation, for example, a shower seat, walk-in shower, or grab handles by the bath. Some people may have difficulties washing their body.

Example response:

"I have very limited mobility and spend most of the day in a wheelchair. I need two carers to visit me twice a day – one in the morning and one in the evening. I need the evening carer to help me get in and out of the bath."

Question 7. Managing toilet needs

(Activity 5 in Appendix 1: Managing toilet needs or incontinence)

Some people with Parkinson's will develop incontinence problems, or have difficulties reaching the toilet in time, due to mobility and dexterity issues. Many people with Parkinson's may need to use continence pads, or need someone to prompt, supervise or assist them in going to the toilet.

Example response:

"I have a lot of difficulty with bladder and bowel problems. I have to visit the toilet several times during the night. This can be incredibly difficult, because sometimes I can't move quickly enough to get to the toilet on time. I have an 'accident' at least once a week, and need help cleaning myself afterwards. I need to keep a hand-held urinal next to my bed. I also experience terrible constipation. I have a raised toilet seat because it is difficult to get down on to it and to get up again."

Question 8. Dressing and undressing

(Activity 6 in Appendix 1)

Some people with Parkinson's have problems with dexterity and fine finger movements, such as tying laces or doing up buttons. Some people use adapted clothing. Some will have balance problems or pain with dressing and undressing, including issues such as putting on socks and shoes.

Example response:

"I need a lot of help getting dressed. My body is always very rigid in the mornings and until my medication kicks in, moving is very difficult. Dexterity is a huge problem and I have great difficulty with fine finger movements – tying laces or doing up buttons is sometimes almost impossible. Due to rigidity and stiffness, bending down can be difficult, so I need help putting on shoes and socks. It takes about three times as long to get dressed as it did before I had Parkinson's."

Question 9. Communicating

(Activity 7 in Appendix 1: Communicating verbally)

Some people with Parkinson's have problems with hearing and use a hearing aid. Others need a communication aid for their voice.

Example response:

"I find verbal communication very difficult. My voice is very quiet and sometimes my speech is slurred. I also find it hard to begin speaking and experience slowness of thought, so following fast-changing topics, interrupting conversations or even giving answers to simple questions can be very challenging. I often end up giving minimal responses, which leaves me feeling isolated."

Question 10. Reading

(Activity 8 in Appendix 1: Reading and understanding signs, symbols and words)

Some people with Parkinson's have problems with memory and understanding, including slowness of thought, recalling memories or making decisions.

Example response:

"Because of memory problems I have severe problems with attention and concentration. I also get very fatigued, so I need a lot of help and support to be able to read or understand newspaper or magazine articles or instructions for how to use household appliances."

Question 11. Mixing with other people

(Activity 9 in Appendix 1: Engaging with other people face-to-face)

Some people with Parkinson's may get extremely anxious or distressed meeting people and may need constant support to engage. This may be due to cognitive issues such as dementia.

Example response:

"Anxiety is a symptom of Parkinson's and I experience this quite often, especially when in crowds of people. Because I often 'freeze' this makes anxiety a lot worse, so social situations are difficult for me. I have difficulty making facial expressions because of rigid facial muscles. This makes it difficult to express my emotions, and I am often misunderstood. This can cause distress, so I need support from my husband."

Question 12. Making decisions about money

(Activity 10 in Appendix 1: Making budgeting decisions)

Some people with Parkinson's experience impulsive and compulsive behaviour due to the side effects of Parkinson's medication, or cognitive issues perhaps related to Parkinson's dementia.

Example response:

"Parkinson's has caused me to have memory problems, so I have a lot of difficulty with activities such as planning. I also have problems with attention and concentration. I need visual prompts, such as notices around the house to remind me to do everyday tasks. Therefore I need help to sort out household bills or ensure that I have the right amount of money when I am at the local shop."

Mobility activities

Question 13. Going out

(Activity 11 in Appendix 2: Planning and following journeys)

Some people with Parkinson's will get extremely anxious or distressed when going out and need someone to accompany them – especially on an unfamiliar journey. They may also avoid going out because of the fear of freezing (where they suddenly cannot move) or falling. Some people may have visual problems due to Parkinson's and feel unsafe getting out and about without help.

Example response:

"I can't follow the route of an unfamiliar journey without my carer. I easily get confused, and being in unfamiliar situations or places can cause stress, which makes my symptoms worse. I also freeze and fall often, so I am afraid to go out by myself."

Question 14. Moving around (Activity 12 in Appendix 2)

Most people with Parkinson's experience problems with movement. They may not be able to physically move, or may feel so fatigued by doing so that they need to stabilise themselves by leaning on furniture. Some people may feel so nauseous, exhausted and 'switched off' that they have to lie down often. If you receive eight points or more on this activity, you may automatically qualify for a Blue Badge.

Find out more: see our information on [Help with getting around](#).

When completing this part of the form, do not make guesses. If you are not sure how far you can walk before feeling severe discomfort, go outside on an average day and test yourself (if your condition varies, do not choose a good day to perform the test). Find a safe location on level ground. Walk until you feel that you are unable to continue (if it is safe for you to do so). Record what happens and when, in terms of distance and time (you may find it helpful to have someone with you to record both of these). Include factors such as pain, dizziness, co-ordination difficulties, stumbles and tiredness. Note how long it takes you to recover before you feel able to walk again. Write down your findings on the form in the 'extra information' box.

Example response:

"On most days, I can stand and walk using a Zimmer frame and manage between 10 and 20 metres. I get fatigued very easily, and so need a recovery time after walking this distance (usually around 10 minutes). My condition fluctuates from day to day, and sometimes I can't manage to walk at all. I fall often if I don't use my Zimmer frame, and my balance is badly affected."

APPENDIX 4: Definitions

Acceptable standard – you may be able to complete the activity, but not to a good enough standard. For example, where someone can physically wash themselves but does not realise they haven't done it well and are still not clean after they have finished.

Aid or appliance – this means any device which improves, provides or replaces your impaired physical or mental function (for example walking sticks or frames). You will be assessed while wearing or using any aid or appliance that you would normally wear or use, or which you could reasonably be expected to wear or use if you do not currently do so. It should not be considered reasonable for you to wear or use an aid or appliance if it is too expensive, difficult to obtain or is culturally inappropriate for you.

Aided – this means with:

- (a) the use of an aid or appliance, **or**
- (b) supervision, prompting or assistance.

Assistance – physical intervention by another person. This does not include someone just speaking to you.

Assistance dog – a dog trained to guide or assist a person with a sensory impairment.

Basic verbal information – information in your own language conveyed verbally in a simple sentence.

Basic written information – signs, symbols and dates of written or printed standard-sized text in your own language.

Bathe – getting into or out of an unadapted bath or shower.

Communication support – support from a person trained or experienced in communicating with people with specific communication needs, including interpreting verbal information into a non-verbal form and vice versa (eg using sign language).

Complex budgeting decisions – decisions involving:

- (a) calculating household and personal budgets
- (b) managing and paying bills, **and**
- (c) planning future purchases.

Complex verbal information – information in your own language conveyed verbally in either more than one sentence or one complicated sentence.

Complex written information – more than one sentence of written or printed standard-size text in your own language.

Cook – heating food safely at or above waist height.

Engage socially

- (a) interact with others in a contextually and socially appropriate manner
- (b) understand body language, **and**
- (c) establish relationships.

Manage incontinence – this means managing involuntary evacuation of your bowel or bladder, including using a collecting device (such as a bottle or bucket) or catheter, and being able to clean yourself afterwards.

Manage medication – this means taking medication (in the right way and at the right time), where a failure to do so is likely to result in a deterioration in your health.

Manage therapy – this means undertaking therapy, where a failure to do so is likely to result in a deterioration in your health.

Medication – medication to be taken at home which is prescribed or recommended by a registered doctor, nurse or pharmacist.

Monitor health

(a) detecting significant changes in your health condition that are likely to lead to your health getting worse, **and**
(b) taking action advised by a registered doctor, nurse, or health professional who is regulated by the Health and Care Professions Council, without which your health is likely to get worse.

Orientation aid – a specialist aid designed to help disabled people follow a route safely.

Prepare – in the context of food, this means make food ready for cooking or eating.

Prompting – reminding, encouraging or explaining by another person.

Psychological distress – distress related to an enduring mental health condition or problems with thinking and memory.

Read – this includes reading signs, symbols and words but does not include reading Braille.

Repeatedly – this means being able to repeat the task as often as is reasonably required. The combined effects of symptoms such as pain and tiredness are relevant because the effort of completing a task could make it harder for you to repeat it or to complete other tasks. For example, if you are able to prepare breakfast without help, but the exhaustion from doing this means that you could not prepare another meal that day, you should be treated as being unable to prepare a meal unaided. This is because it is reasonable to expect someone to be able to prepare more than one meal a day.

Reasonable time period – this means no more than twice as long as a person without your physical or mental condition would normally take to complete that task.

Safely – this means in a way that is unlikely to cause harm to you or anyone else, either during or after you have performed the task. In assessing whether you can carry out a task safely, the Department for Work and Pensions must consider whether there is a real possibility of harm occurring that cannot be ignored, having regard to the nature and gravity of the harm in question. If the severity of harm is very high then an activity may be considered unsafe, even if the frequency of the adverse event is quite low.

Simple budgeting decisions – decisions involving:

- (a) calculating the cost of goods, **and**
- (b) calculating the change required after a purchase.

Simple meal – a cooked one-course meal for one, using fresh ingredients.

Social support – support from a person trained or experienced in assisting people to engage in social situations.

Stand – stand upright with at least one biological foot on the ground.

Supervision – the continuous presence of another person for the purpose of ensuring your safety.

Take nutrition – this means:

- (a) cut food into pieces, convey food and drink to your mouth and chew and swallow food and drink, **or**
- (b) take nutrition by using a therapeutic source.

Therapeutic source – parenteral or enteral tube feeding, using a rate-limiting device such as a delivery system or feed pump.

Therapy – this means therapy to be undertaken at home which is prescribed or recommended by:

- (a) a registered doctor, nurse or pharmacist, **or**
- (b) a health professional regulated by the Health and Care Professions Council.

It does not include taking or administering medication or anything related to the monitoring of your health condition.

Toilet needs

- (a) getting on and off an unadapted toilet
- (b) evacuating your bladder and bowel, **and**
- (c) cleaning yourself afterwards.

Unaided – this means without:

- (a) the use of an aid or appliance, **or**
- (b) supervision, prompting or assistance.

More information and support

Parkinson's nurses

Parkinson's nurses provide expert advice and support to people with Parkinson's and those who care for them. They can also make contact with other health and social care professionals to make sure your needs are met.

The role of the Parkinson's nurse varies. Each will offer different services, aiming to meet local needs. Some nurses are based in the community, whereas others are based in hospital settings.

Many Parkinson's nurses are independent prescribers. This means they can prescribe and make adjustments to medication, so someone with Parkinson's doesn't always need to see their specialist for changes to or queries about their Parkinson's drugs.

Parkinson's nurses may not be available in every area, but your GP or specialist can give you more details on local services.

You can find out more at parkinsons.org.uk/nurses

Information and support from Parkinson's UK

You can call our free confidential helpline for general support and information. Call **0808 800 0303** (calls are free from UK landlines and most mobile networks) or email hello@parkinsons.org.uk.

We run a peer support service if you'd like to talk on the phone with someone affected by Parkinson's who has faced similar issues to you. The service is free and confidential – ring the helpline to talk to someone about being matched with a volunteer.

Our helpline can also put you in touch with one of our Parkinson's local advisers, who give one-to-one information and support to anyone affected by Parkinson's. They can also provide links to local groups and services.

We also have a self-management programme for people with Parkinson's, partners and carers. It is an opportunity to reflect on life with the condition, learn about self-management and think about the future. To find out if there is a group near you, visit parkinsons.org.uk/selfmanagement

Our website parkinsons.org.uk has a lot of information about Parkinson's and everyday life with the condition. You can also find details of your local support team and your nearest local group meeting at parkinsons.org.uk/localtoyou

Visit parkinsons.org.uk/forum to chat to other people with similar experiences on our online discussion forum.

Thank you

Thank you to Disability Rights UK for updating this information sheet. Disability Rights UK also have a wide range of online factsheets on disability-related issues including Access to Work, education, the Blue Badge scheme, independent living and disabled facilities grants.

Visit their website: www.disabilityrightsuk.org

Can you help?

At Parkinson's UK, we are totally dependent on donations from individuals and organisations to fund the work that we do. There are many ways that you can help us to support people with Parkinson's.

If you would like to get involved, please contact our Supporter Services team on **0800 138 6593** or visit our website at parkinsons.org.uk/donate. Thank you.

Our information

All of our most up-to-date information is available at parkinsons.org.uk/information-support. If you'd prefer to read one of our printed leaflets or booklets, find out how to place an order at parkinsons.org.uk/ordering-resources or by calling **0300 123 3689**.

We make every effort to ensure that our services provide current, unbiased and accurate information. We hope that this will add to any professional advice you receive and help you to make any decisions you may face. Please do continue to talk to your health and social care team if you are worried about any aspect of living with Parkinson's.

If you'd like to find out more about how we put our information together, including references and the sources of evidence we use, please contact us at publications@parkinsons.org.uk

Personal Independence Payment (WB20/2018)

Do you have any feedback about this information? Your comments will help us ensure our resources are as useful and easy to understand as possible. Please return to [Information Content team, Parkinson's UK, 215 Vauxhall Bridge Road, London SW1V 1EJ](#), or email publications@parkinsons.org.uk. Thank you!

1. Please choose the option that best fits you.

- I have Parkinson's and was diagnosed in I care for someone with Parkinson's
 I have a friend or family member with Parkinson's I'm a professional working with people with Parkinson's
 Other (please specify)
-

2. Where did you get this information from?

- GP Specialist Parkinson's nurse Parkinson's UK local group Parkinson's UK local adviser
 Ordered directly from us Call to the helpline
 Other (please specify)
-

3. Has it answered all your questions?

- Yes, completely Yes, mostly Not sure Partly Not at all

4. How easy was it to understand?

- Very easy Easy Not sure Quite difficult Very difficult

5. Has it helped you manage your condition better, or make choices that have improved your life in some way?

- It helped a lot It helped a little No change It didn't help It made things worse

6. What is your ethnic background?*

- Asian or Asian British Black or Black British Chinese Mixed White British White other
 Other (please specify)
-

*We ask about your ethnicity to ensure our information is reaching a broad range of people. However, this question is optional.

Want to hear more from us?

- I would like a response to my feedback I would like to be a member of Parkinson's UK
 I'm interested in joining the Information review group, to offer feedback on Parkinson's UK information

If you've answered yes to any of these options, please complete your details below.

Name

Address

Email

Telephone

How would you prefer us to contact you? Email Post Phone

We will not pass on your details to any other organisation or third party. To find out more, read our privacy policy at [parkinsons.org.uk/termsandconditions](https://www.parkinsons.org.uk/termsandconditions)

Every hour, two people in the UK are told they have Parkinson's – a brain condition that turns lives upside down, leaving a future full of uncertainty.

Parkinson's UK is here to make sure people have whatever they need to take back control – from information to inspiration.

We want everyone to get the best health and social care. So we bring professionals together to drive improvements that enable people to live life to the full.

Ultimately, we want to end Parkinson's. That's why we inspire and support the international research community to develop life-changing treatments, faster. And we won't stop until we find a cure.

Together we can bring forward the day when no one fears Parkinson's.

Parkinson's UK

Free confidential helpline **0808 800 0303**

Monday to Friday 9am–7pm, Saturday 10am–2pm. Interpreting available.

NGT Relay **18001 0808 800 0303** (for use with smart phones, tablets, PCs and other devices).

For more information see www.ngts.org.uk

hello@parkinsons.org.uk

parkinsons.org.uk

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Please check our website for the most up-to-date versions of all our information.

WB20