

PERSONAL INDEPENDENCE PAYMENT (PIP)

Money, grants and benefits

Find out more about
PIP and Adult Disability
Payment (ADP) in
Scotland, and how
to claim

PARKINSON'S^{UK}
CHANGE ATTITUDES.
FIND A CURE.
JOIN US.



PERSONAL INDEPENDENCE PAYMENT AND ADULT DISABILITY PAYMENT (SCOTLAND)

If you have Parkinson's, you may be worried 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 financial support available, so it's important to find out what benefits you're entitled to.

This information explains what Personal Independence Payment and Adult Disability Payment (Scotland) are, who qualifies and how to claim.

The information in this publication is correct as of June 2024, but is subject to change. Our most up-to-date information is on our website at parkinsons.org.uk.

uk/benefits. Our helpline can also give advice on benefits. Call **0808 800 0303** or email hello@parkinsons.org.uk

What are Personal Independence Payment and Adult Disability Payment?

If you need extra help with day-to-day activities or have trouble getting around due to your condition, you may be able to claim Personal

Independence Payment (PIP), or Adult Disability Payment (ADP) in Scotland.

ADP is the Scottish replacement for PIP, and can only be claimed if you live in Scotland.

The main difference between the two benefits is how claims are made and assessed. Payment levels and criteria are the same. Both benefits expect you to have had problems looking after yourself and/or with your mobility for at least 13 weeks and expect your problems to last another 39 weeks.

PIP or ADP are for you, not for a carer (if you have one), and you don't need to have someone supporting or caring for you to qualify. If you're awarded one of these benefits, it's up to you how you use it.

PIP and ADP are not taxable income and you don't need to have paid National Insurance contributions to get either. You can claim PIP or ADP

whether you're in or out of work. PIP and ADP are not means-tested. So they are not affected by your earnings, other benefits you receive, or by any savings you have.

Getting PIP or ADP 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.

Do I claim PIP, ADP, Attendance Allowance or Disability Living Allowance?

If you're making a fresh claim for PIP or ADP and you don't already get Disability Living Allowance, then you must start the claim before you reach State Pension age. 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 will end and you'll be asked to claim PIP or ADP instead. If you already get Disability Living Allowance and you were born before 8 April 1948, you'll continue getting Disability Living Allowance no matter what age you are, and you can't make a new claim for PIP or ADP.

Once you're awarded PIP or ADP, you can carry on receiving the benefit no matter what age you are.

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

If you're in Scotland and already get PIP you will be transferred across to the same rate and payment amount of ADP. The transfer started in summer 2022 and will finish by 2025. Social Security Scotland will send

you a letter when the process starts and again when it ends. You won't have to make a new claim or go through any assessment process. There will be a week when both PIP and ADP are paid. You won't have to repay this.

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

PIP and ADP components

PIP and ADP have 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 extra costs so you can carry out your daily living activities. It's paid at two different rates – a standard rate and an enhanced rate. The rate you're paid depends on whether your ability to carry out daily living activities is limited or severely limited.

This is tested under the PIP/ADP assessment.

The mobility component

This component helps cover the extra costs that you may face if you have difficulties getting around.

It's paid at two different rates – a standard rate and an enhanced rate. The rate you're paid depends on whether your ability to carry out mobility activities is limited or severely limited. This is tested under the PIP/ADP assessment.

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

across from PIP to ADP your Motability car will transfer with you. There will be no change to your car, payment levels or agreement.

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

Do I qualify?

To qualify for PIP or ADP, you must meet the following basic conditions:

- If you're making a new claim for PIP or ADP, you must be 16 or over and under State Pension age.
- You won't be able to make a new claim for PIP or ADP if you've reached State Pension age, but you will be able to stay on PIP or ADP if you claimed it for the first time before you reached State Pension age. If you've reached State Pension age and have care or supervision needs, then you may be able to claim Attendance Allowance.

- 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're 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 worked out by the PIP or ADP assessment (see below).

You must have met the disability conditions for at least three months before a PIP or ADP award can be made (you won't have to wait a further three months

for payment if you've 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. If you're terminally ill, the three and nine-month rules don't apply for either PIP or ADP.

For PIP, the terminally ill rule asks for a medical professional to confirm that they wouldn't be surprised if their patient dies in the next 12 months. If you meet these conditions, you'll automatically receive the enhanced rate for daily living and will be assessed on your mobility needs.

In Scotland ADP doesn't have such a time restriction. It simply asks a registered medical practitioner or registered nurse to confirm that "the individual has a progressive disease that can reasonably be expected to cause the individual's death".

If this is the case, you'll automatically receive the enhanced rate for both daily living and mobility with no assessment.

What are the PIP and ADP criteria?

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

The number of points you score will determine whether or not you're entitled to either component of PIP or ADP 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:

- 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 various levels 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 amount of time. The highest descriptor scores from each activity heading are 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 21 and for the mobility activities in Appendix 2 on page 27.

How many points do you need?

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

What if my condition fluctuates?

A descriptor will apply to you if you're unable to complete a task on the majority (more than 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're not sure which descriptors apply to you, keeping a diary over a week may help you choose.

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	£72.65
Enhanced rate	£108.55

Mobility

component	per week
Standard rate	£28.70
Enhanced rate	£75.75

How do I claim?

To make a claim call **0800 917 2222** (textphone **0800 917 7777**). In Scotland you can call **800 182 2222**. In Northern Ireland call **0800 012 1573** or textphone **0800 587 0937**. Someone else can make this call on your behalf,

but you need to be with them when they do so, unless you are terminally ill.

During these calls, you'll need to provide 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'll be asked for details of your GP and hospital specialist. 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 phone, and don't have someone to help, it's 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 is:

FREEPOST RTRT-EKUG-KXJR, PIP MOU, PO Box 42, Limavady, BT49 4AN

What happens next?

For PIP, if you meet the basic qualifying conditions (see previous section ‘Do I qualify?’), you’ll be sent a form to complete called ‘How your disability affects you’.

If it’s clear from the information you provided when you started the claim that you don’t 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.

If you’re claiming ADP you will be offered help to make a claim by Social Security Scotland Local Delivery, or your family, support worker or appointee can make the claim for you.

Completing the ‘How your disability affects you’ form

This 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 information, guidance, examples and definitions in Appendices 3 and 4 starting on page 28.

You may wish to write in pencil first, or make some notes on separate sheets of paper, before filling in the form in pen. You can now complete the form online before printing it off to send via post, or submit it electronically. If you have difficulty writing and don’t 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 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 advisable to put details of the professionals who know your problems best, such as your Parkinson's nurse.

Whoever you put down, contact them and let them know that you're applying for PIP or ADP 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 process and may help you avoid having a face-to-face consultation.

Most of the form is made up of questions about your day-to-day life, relating to the points-based PIP/ADP assessment. You get

points for what you can't manage, not for what you can. It's important to be clear about the difficulties you experience, so that you're assessed accurately. Give yourself plenty of time to complete the form – you don't have to do it all in one sitting.

The first 10 questions relate to the activity headings of the daily living component. The last two questions relate to the activity headings of the mobility component.

The activity headings, the 'descriptors', and the points allocated to each descriptor, are listed in Appendices 1 and 2 on pages 21 and 27. 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 to complete the task? If so, what kind of help do you need? Does someone need to physically help you, reassure you, encourage you, remind you or explain to you how to do something? Or do they need to supervise or watch over you?
- Do you use aids or appliances to help you with a task? If so, 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? Explain in what way and how often. Describe your 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 having 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 before, during or after the task?

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

The extra information box

The second part of each question asks you to 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 that could be written in the extra information box, please see Appendix 3 on page 28.

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, you 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, it may be helpful to include this.

What happens next will depend on whether you're claiming PIP or ADP. If you claim PIP a consultation will usually be arranged (see below). If you'd 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 appointment time. If you claim ADP you may be asked for more information on some of your answers or asked to find supporting information, but you won't have an assessment.

You should return your completed form as soon as possible, as there's a time limit for its return (one month for PIP and six weeks for ADP). 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 copy of the form once you've completed it, along with any**

supporting evidence you're sending with the form. Keep this safe.

How the claim is assessed

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

This healthcare professional may contact your GP or specialist for more information before deciding if a consultation is needed.

Social Security Scotland will make decisions about ADP without the need for a face-to-face consultation. They'll focus on the information in your claim form together with

information from the medical, social care and related professionals who support you. Social Security Scotland will ask them for supporting information that indicates you meet the criteria listed in Appendices 1 (page 21) and 2 (page 27).

The face-to-face consultation for PIP

Before Covid-19, the healthcare professional would usually arrange to see PIP applicants at a face-to-face consultation, but these were suspended in March 2020.

These face-to-face consultations at assessment centres are slowly being reintroduced, but you can ask for a home visit or telephone assessment if you can show you're unable to attend the assessment centre.

Independent Assessment Services and Capita are able to offer and arrange a taxi at their cost to and from the assessment centre. To make sure they will cover the

cost, you'll need to get their agreement before booking the taxi.

At the consultation, the healthcare professional will identify the descriptors that they believe apply to you (see Appendices 1 and 2 on pages 21 and 27). To do this, they'll 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'll often ask you to describe a typical day in your life.

The healthcare professional should consider whether you can complete daily activities repeatedly, in a reasonable amount of time, to an acceptable standard and safely. 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.

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 worry that you'll be judged on how you're 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.

Make sure you explain 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've 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're asking you about because you have had accidents in the past. An example could be 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're like on bad days as well as good days. The healthcare professional's opinion shouldn't be based on a snapshot of your condition on the day of the consultation – they should consider the effects of your condition over time.
- It's important to say if you have problems at some stage of the day, for example, if mornings are difficult for you but you feel better once you've taken your medication. 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's awarded, at what rate and for how long.

How are PIP and ADP paid?

They are normally paid every four weeks in arrears into a bank, building society or Credit Union card account.

If you're not happy with the decision

Asking for your claim to be looked at again

If your claim for PIP is turned down you have one calendar month from the date of the decision to ask the Department for Work and Pensions to look at the decision again. For ADP you have six weeks to ask Social Security Scotland to reconsider. This is called a 'mandatory reconsideration' for PIP and 'redetermination' for ADP.

You can also ask for the decision to be looked at again if you're unhappy with the level of the benefit you've been awarded or the period for which it's been awarded.

Don't be discouraged from asking for a mandatory reconsideration for PIP. 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've already been granted. If you're in any doubt, contact the Parkinson's UK helpline on **0808 800 0303**.

How to ask for a mandatory reconsideration/redetermination

To ask for a mandatory reconsideration for PIP, you should write to the address (or ring the number) on the PIP decision letter.

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're not obliged to do so. Keep a copy of your request.

For ADP call **0800 182 2222** on the form was correct. For example, you could ask for a letter from your GP, specialist or Parkinson's nurse describing the difficulties you have in walking, which backs up what you said.

Building a case

For PIP you can ask for a copy of the assessment and any other medical information used by the decision-maker. When you receive this 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 consultation. Compare their report with what you wrote on the 'How your disability affects you' form. Look for differences of opinion.

For example, you may have written that you couldn't walk more than 20 metres without severe discomfort, but the healthcare professional noted that they thought you could manage about 100 metres. Where you find such differences, try to get medical evidence showing that what you said

Once you've 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, tell the Department for Work and Pensions how long this is likely to take, so that they don't 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're unable to change the decision.

You then have one calendar month from the date of this 'mandatory reconsideration notice' to appeal to an independent tribunal.

For ADP, asking for the medical evidence the decision-maker used will allow you to challenge the decision in the same way as for PIP. You will have 31 days from the outcome of your redetermination to ask to make an appeal.

How to appeal

For PIP, you can appeal against a decision using the official appeal form, the SSCS1. For ADP call Social Security Scotland on **0800 182 2222**. You must usually appeal within one month of the date on the mandatory reconsideration/redetermination notice.

The appeal form will ask if you would like your appeal to be considered with or without an oral hearing. Choosing an oral hearing and attending the tribunal can greatly improve your chances of a successful outcome.

The appeal will be considered by an independent appeal

tribunal. These tribunals are informal – they're not like the courts. If you have a carer, they can attend as well to provide information they have about your needs. You can contact the Parkinson's UK helpline on **0808 800 0303** or a local advice centre such as Citizens Advice to see if they can give you any support and possibly provide a representative to present your case at the hearing.

What if my condition gets worse in the future?

If you're awarded PIP or ADP and there's a change in your condition sometime in the future, you can ask for the award to be looked at again due to a change in your circumstances.

Always get in touch with the Department for Work and Pensions immediately if you're receiving PIP and your circumstances change. They

can't take into consideration any deterioration in your health before the time you contact them.

Be aware that the Department for Work and Pensions and Social Security Scotland will look at the whole award and they can take away the rate of PIP/ADP you've 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 on pages 21 and 27). You need to have satisfied the conditions for the new component or the higher rate for at least three months and expect it to last for at least nine months more before your award can be increased. If you're in any doubt, contact the Parkinson's UK helpline on **0808 800 0303**.

Do PIP or ADP affect other benefits?

PIP and ADP can be paid in addition to other social security benefits. They are not counted as income in the calculation of means-tested benefits. However, your local authority can take PIP into account when considering whether you need to contribute towards the cost of any care and support services you receive.

What if I go into hospital or a care home?

Hospital stays

You can make a claim for PIP or ADP if you're in hospital, but payment can only start once you leave.

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

If you're already getting PIP or ADP 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 less than four weeks each time). It can restart when you return home, you won't have to make a new claim.

If you're under 18, your PIP or ADP can be paid for the whole time you're in hospital.

Care homes

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

If the council helps with your fees, the PIP or ADP daily living component will stop after 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 your fees.

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

APPENDIX 1. Daily living activities: descriptors and scores

Each activity heading has a set of 'descriptors'. These describe related tasks of varying levels of difficulty and different types of help you need to complete each task. You score points when you're not able to complete a task 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 daily living 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 or from any of the daily living activities added together.

For the meaning of the terms and phrases used, see Appendix 4 on page 34.

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, **or** (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 seven hours a week. **Score 4**

E. Needs supervision, prompting or assistance to be able to manage therapy that takes more than seven 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**
- 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 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**

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're 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 of the activity headings added together. For the meaning of the terms and phrases used, see Appendix 4 on page 34.

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**

F. Cannot, either aided or unaided,
(i) stand, **or**
(ii) move more than one metre. **Score 12**

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

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 on pages 21 and 27). We now look at the questions on the form in more detail, providing examples that could be written in the extra information boxes.

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

Preparing food (Activity 1 in Appendix 1: Taking nutrition)

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

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. You may also need prompting because of memory problems. In some cases, people are able to eat their food and drink liquids unsupervised, but you might need some help with preparation, such as cutting up food.

Example response:

“I have problems eating because I have swallowing problems and I have a hand tremor. 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 to help me eat and often need help to cut up food, as I find it difficult to grip cutlery.”

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 you may need a pill box or a pill timer. A special diet can be seen as therapy. Some people may be on apomorphine injections or infusions. Some may need physiotherapy, which can count towards the total number of hours of 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 has been trained how to do it. My partner administers my ready-to-use injection pen that works within 10 minutes and is often used as a 'rescue' measure, usually when I have a sudden 'off' period. Because of this, I need constant,

24-hour supervision to manage my Parkinson's."

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. You may also need some form of adaptation, for example a shower seat, walk-in shower, or grab handles by the bath. Some people 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 as I struggle to safely stand."

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, possibly due to mobility or 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 of my mobility problems. It is difficult to get down on to the toilet and to get up again."

**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 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."

Communicating (Activity 7 in Appendix 1:j8)

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."

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."

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, causing overwhelming distress. I often 'freeze'. This makes anxiety a lot worse, so social situations are difficult for me, sometimes causing overwhelming distress. 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."

Mobility activities

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. You may also avoid going out because of the fear of freezing (where you 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 often fall, so I am afraid to go out by myself."

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 often lie down.

If you receive eight points or more on this activity, you may automatically qualify for a Blue Badge.

When completing this part of the form, don't make guesses. If you're not sure how far you can walk before feeling severe discomfort, go outside on an average day and test yourself (if your condition varies, don't choose a good day to do the test). Find a safe location on level ground. Walk until you feel that you're unable to continue (if it's safe for you to do so).

Remember you'll need to return to your starting point. 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**

Appendix 4 gives you the legal definitions for each of the phrases used in Appendices 1 and 2, such as what 'assistance' actually means to the person who will make the decision on your PIP claim.

Acceptable standard – you may be able to complete the activity, but not to an acceptable standard. For example, where someone can

physically wash themselves but doesn't realise they haven't done it well and are still not clean afterwards.

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'll 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 don't currently do so. It should not be considered reasonable for you to wear or use an aid or appliance if it's 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 doesn't 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 (for example 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 at or above waist height.

Dress and undress – includes putting on and taking off socks and shoes.

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 making 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're able to prepare breakfast without help, but the exhaustion from doing this means that you couldn't prepare another meal that day, you should be treated as being unable to prepare a meal unaided. This is because it's 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 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 you 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, **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.

This page has been left intentionally blank

This page has been left intentionally blank

MORE INFORMATION AND SUPPORT

Parkinson's nurses

Parkinson's nurses have specialist experience and knowledge of Parkinson's. They can:

- support people coming to terms with their Parkinson's diagnosis
- help people to manage their medication, so they get the best results and fewer side effects
- make referrals to other professionals such as speech and language therapists and physiotherapists

Some nurses are based in the community, such as at your GP surgery. Others are based in hospital settings and clinics.

Talk to your GP or specialist for more details on speaking to a Parkinson's nurse.

Parkinson's UK information and support

You can read our most up-to-date information at **parkinsons.org.uk**

You can order printed information by calling **0330 124 3250** or visiting **parkinsons.org.uk/orderingresources**

If you'd like to speak to someone, our specialist adviser team can provide information about any aspect of living with Parkinson's.

They can talk to you about managing symptoms and medication, social care, employment rights, benefits, how you're feeling, and more.

Call our team on **0808 800 0303** or email **hello@parkinsons.org.uk**. We'll provide expert information over phone or

email or put you in touch with an adviser locally.

If you'd like to meet other people living with Parkinson's in your local area, you can find friendship and support through our network of volunteers and local groups. Go to **parkinsons.org.uk/localgroups** or call our helpline to find out more.

Our forum is also a very active space to share and chat with others who really understand, at a time that suits you. Visit **parkinsons.org.uk/forum**

Thank you

Thank you to benefits specialist Barbara Knight for helping to update this information.

Feedback

If you have any comments or feedback about our information, please call **0800 138 6593**, email **feedback@parkinsons.org.uk**, or write to us at Parkinson's UK, 215 Vauxhall Bridge Road, London SW1V 1EJ.

If you'd like to find out more about how we put our information together, please contact us at **healthcontent@parkinsons.org.uk** or visit our website.

Can you help?

At Parkinson's UK, we are totally dependent on donations from individuals and organisations to fund the work we do. There are many ways you can help us to support people with Parkinson's. If you would like to get involved, please contact our Supporter Care team on **0800 138 6593** or visit our website at **parkinsons.org.uk/donate**. Thank you.

We are Parkinson's UK.
Powered by people.
Funded by you.
Improving life for everyone
affected by Parkinson's.
Together we'll find a cure.

PARKINSON'S^{UK}

Free confidential helpline **0808 800 0303**
Monday to Friday 9am–6pm, Saturday 10am–2pm
(interpreting available)
NGT relay **18001 0808 800 0303**
(for textphone users only)
hello@parkinsons.org.uk
parkinsons.org.uk

Parkinson's UK, 215 Vauxhall Bridge Road, London SW1V 1EJ



Registered with
**FUNDRAISING
REGULATOR**

Last updated June 2024. Next review due 2025. Order Code INFOB0054

Parkinson's UK is the operating name of the Parkinson's Disease Society of the United Kingdom.
A charity registered in England and Wales (258197) and in Scotland (SC037554). © Parkinson's UK 06/24 (CS3750)