MS Society

Claiming PIP

Personal Independence Payment

We're the MS Society and we're here for you. Funding world-leading research, sharing information, making voices heard and campaigning for everyone's rights.

Together we are a community.
And together we will stop MS.

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- Calling us on: **0300 500 8084**.
  Lines are open Monday to Friday, 9am – 5pm
- Visiting us at: **donate.mssociety.org.uk**
- Posting your donation to: MS Society, Carriage House, 8 City North Place,
  London N4 3FU.
- Please make cheques payable to the 'MS Society.'

MS Society

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Pull-out section: PIP assessment scores

The pull-out section includes the PIP activities and scores that are used on the 'How your disability affects you' form.

About PIP

Many people with multiple sclerosis (MS) can claim Personal Independence Payment (PIP). PIP is a benefit that can help cover the extra costs you may face if you need help doing everyday tasks or find it difficult to get around outside your home.

This booklet has been written for people with MS who are going through the PIP claims process. It looks at whether you qualify to claim. It also looks in detail at the assessment process. This includes completing the PIP questionnaire, the consultation, and how to challenge a decision if you're unhappy with it.

The language used for this benefit can often be complicated. In the pull-out section of this booklet, there's a jargon buster that explains some of the more specialist terms.

Who qualifies to get PIP?

Whether you can have PIP depends on what help you need with daily tasks or getting around outside your home. It doesn't matter if you don't actually get this help, as long as you can show you need it.

Payments are made directly to you, and you can spend them on whatever you need. There are basic qualifying conditions that you must meet before you can claim PIP. These are listed in the box below.

You must also meet the disability conditions.

The disability conditions look at your daily living needs and your mobility needs. These are looked at in 'What is the PIP assessment?'

The basic qualifying conditions:

- you must be aged 16-64 when you claim
- you live in England, Wales or Northern Ireland. If you live in Scotland, you should apply for Adult Disability Payment (ADP) instead
- you have been in Great Britain for at least 104 weeks in the last 156 weeks and you're not subject to immigration control

Moving from DLA to PIP

In England, Wales and Northern Ireland, PIP is replacing Disability Living Allowance (DLA) for people of working age (between the ages of 16 and 64 inclusive).

If you're currently getting DLA, you don't have to do anything about switching over to PIP until the Department for Work and Pensions (DWP) contacts you.

If you were aged between 16 and 64 on 8 April 2013 and receive DLA you'll be reassessed for PIP at some time.

- For more information about the switchover from DLA to PIP, search our website for 'Disability Living Allowance and PIP'.

If you live in Scotland, you're of working age and you're getting DLA now, you'll be moved over to Adult Disability Payment (ADP) instead of PIP. Social Security Scotland will contact you to switch you over. They won't reassess or review your award during the move.

The qualifying period

You must have met the disability conditions for a qualifying period of at least three months before you can be paid. You must also be likely to continue to meet them for a period of nine months into the future. These conditions won't apply if you're terminally ill. In other words, if your death can reasonably be expected within the next six months.

What is PIP made up of?

PIP has two parts: the daily living component and the mobility component. You can be awarded either, or both, of these components. The PIP assessment decides if you qualify for them.

The daily living component

The daily living component helps cover the extra costs you may face if you need help doing everyday tasks. These are described as the 10 daily living activities.

The daily living component is paid at two different rates: a standard and a higher 'enhanced' rate. The rate that you're paid depends on whether your ability to carry out daily living activities is 'limited' or 'severely limited'. This is defined by the Department for Work and Pensions (DWP). See the pull-out section for more information on the descriptors used in the assessment.

The mobility component

The mobility component helps cover the extra costs you may face if you have difficulties in getting around. It's paid at two different rates: a standard and an enhanced rate. The rate you're paid depends on whether your ability to carry out mobility activities is limited or severely limited.

See 'PIP assessment scores' for more information on the descriptors used in the assessment.

What is the PIP assessment?

The PIP assessment is a points-based assessment. This means you score points depending on how you perform different activities. There are 10 activities relating to your daily living needs and two activities relating to your mobility.

The number of points you score decides whether or not you qualify to get either component of PIP and, if you do, which rate you get.

The 10 daily living activities

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

The 10 daily living activities are:

- preparing food
- taking nutrition
- 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 two mobility activities

Your ability to carry out mobility activities is assessed by focusing on two types of activity.

These are:

- planning and following journeys
- moving around

Details of these activities, the points you can score from them, and how the points are added up, are contained in 'PIP assessment scores', in the pull-out section.

How much can I get?

Each component of PIP has two rates: a standard and a higher 'enhanced' rate. These will change each year. For the current rates, call the PIP helpline on **0800 121 4433**, textphone **0800 121 4493** or visit the government website at **gov.uk**

What happens if I have to go into hospital or a care home?

Hospital stays and respite care

Payments of PIP stop after 28 days in hospital or respite care. There's a 28 day 'linking rule'. This means that different periods spent in hospital or respite care that are separated by 28 days or less get treated as one period. You count days in hospital from the day after you're admitted to the day before you go home. The day you go in and the day that you leave don't count as days in hospital.

For example, Jan is admitted into hospital for 16 days. She's discharged and returns home for five days, but has to go back to hospital

for another 20 days. Although separated by a period at home, this is still classed as one hospital stay lasting 32 days. In each case, the days she goes in and the day she leaves the hospital aren't counted.

Because PIP payments stop after 28 days in hospital, this means she wouldn't be paid for the final four days. If you're in hospital when you apply for PIP, you'll not be allowed to claim it until you return home.

Keeping a diary

Because MS is an 'up and down' condition, it can be difficult to know how to answer some of the questions in the assessment. It helps to have a record of how your symptoms affect you from day to day. The easiest way to do this is to keep a symptom diary for at least a week before you fill in the PIP form. There's more information on keeping a diary later on. An example diary is included in the pull-out section. You can download a blank template for this from our website. Search for 'PIP diary template'.

Care homes

If your council or the NHS pay for you to stay in a care home, you'll only be allowed to claim for the mobility component of PIP. The daily living component will stop after 28 days.

If you pay for your stay in the care home yourself ('self fund'), you may qualify for both components of PIP. The mobility component is not payable (after 28 days) for people who get fully funded NHS 'continuing healthcare' in a nursing home. A nursing home is classed as a 'hospital or similar institution'.

The rules are complicated if you switch between days in hospital or a care home and days at home. So you may wish to seek advice from your local Citizens Advice, the Turn2us charity or a local authority welfare rights service.

Hospice

As of May 2022 the special rules can apply for benefit claims if a person is likely to have less than 12 months to live.

Applying for PIP

How do I start my claim?

You start your PIP claim by calling **0800 917 2222** (textphone **0800 917 7777**). During the phone call, if you're getting DLA and want this evidence to be looked at, you can ask for this evidence to be included in your claim for PIP. The lines are open between 8am and 5pm Monday to Friday. Calls are free on landlines and most mobiles.

Someone else can make this call on your behalf. But you need to be with them during the call.

This call is to take basic information about you to make sure you qualify to claim. At this stage you won't be asked for any detailed information about your MS. But you'll be asked general questions about how MS affects you to see if you need support throughout the claims process. You'll also be asked for information that includes:

- your personal and contact details and National Insurance number
- whether you're in hospital, a hospice or a care home or have been in one of these over the last four weeks
- which of the health care professionals supporting you is the best to contact about your MS
- information about your nationality and whether you've spent time abroad over the last three years
- details of your bank or building society (so that they can get the money to you)
- whether you find it difficult to return forms, for instance because you have memory problems

It helps if you have this information ready when you make the call. It may also help to have somebody with you during the call in case it's hard to remember what you've said, or what they asked you. This person can also help you think about the questions and how to answer them.

The information you give should allow the DWP to decide whether or not you meet the basic qualifying conditions for PIP.

At the end of the phone call, the DWP agent will read you a declaration and ask you to agree with it. This confirms the information you gave them is true and accurate.

Paper claims

You can write to the DWP and ask for a paper claim form to send the information by post. But doing this can delay your claim.

Online claims

You can only apply for PIP online in some areas. Find out if you live in one of these areas by checking your postcode on **gov.uk**.

What happens next?

If it's clear from the initial claim information that you don't satisfy the basic qualifying conditions for PIP, the DWP sends you a letter saying why you don't qualify. If you do satisfy the basic qualifying conditions, they send you the 'How your disability affects you' form to fill in.

A guide to the 'How your disability affects you' form

To claim PIP you need to fill in the 'How your disability affects you' form. It's sent to you in a pack with an information booklet that goes through each section of the form in detail.

When filling in the form, you may wish to write in pencil first, or make some notes on paper or on a photocopy of the form, before finally writing in pen. You can ask a friend, family member, or support worker to help you. Or contact one of the organisations at the end of this booklet to support you with your claim.

The form gives you the chance to describe how MS affects your daily life. On the positive side, it means your opinion is extremely important. On the negative side, the form is long and often asks very personal questions. Filling the form in can feel like a negative thing to do. Most of it is given over to questions relating to the points based PIP assessment. You score points for what you can't do, not for what you can.

Try not to be discouraged. It's important to be clear about the difficulties you have, so that you're assessed accurately. Give yourself plenty of time to fill in the form. And don't feel you need to do it all in one go.

Home visit

The DWP visiting team can come to you at home to fill in the form for you. But they only do this if you can't go to the office, or you can't use their online services or telephone helpline and you have no one who can do it for you. Contact them on the telephone number on the letter that comes with the form and booklet. If you live in Wales, MS Society Cymru can contact them for you. Contact the MS Society Cymru for more information on this service.

What does 'supporting evidence' mean?

To support your claim you can send the DWP photocopies of any documents that show how MS is affecting you. For example, it could be a diary together with a letter from your neurologist, a report from your occupational therapist, or a care plan from your social worker. The DWP stress that you should only send in photocopies of evidence that you already have.

How long do I have to fill in the form?

From the date the 'How your disability affects you' form is sent to you, you have one month to send it back. Your claim will be turned down if you don't return the form within the month without a good reason (taking into account your health and the nature of your disability). Then you'll have to start again.

Contact the DWP to explain if you can't send the form back within one month. For example, maybe you need help to fill it in but can't get an advice centre appointment in time. If there's a good reason, they can extend the one month time limit.

Where can I get support?

Local advice agencies can help, like Citizens Advice, Turn2us or a local authority welfare rights service. Your local MS Society group may also know of other local benefits advice agencies that might help. Through our MS Help Hub and local groups, the MS Society offers information, emotional support and a listening ear. Call our MS Help Hub to speak to our benefits advisers.

How do I fill in the 'How your disability affects you' form?

It may be useful to check you have all the information you need before you begin filling in the form. This can include details of the health and social care professionals involved in your care, the diary you've been keeping and a list of all the medications you take.

The form's first two questions ask for details of professionals involved in your care, and about your disability or condition. If you list more than one professional, make it clear which one you prefer the DWP to contact. Let the professional(s) know that you've listed them on the form. That way they won't be surprised if the DWP contact them.

Questions 3 to 14 follow a similar format, explained below. Listed in the 'PIP assessment scores' are the activity headings, the descriptors under each heading, and the points for each one.

The tick boxes

Each question begins by asking you if you need an aid or appliance to complete the activity. If you do, you'll usually be awarded at least two points under that activity.

You're then asked if you need help from someone to do that activity. If you do need help, you'll be awarded between two and eight points, depending on the activity and what help you need. This might range from just needing supervision or prompting, to needing physical help.

In each case, you're offered one of three boxes to tick: 'yes', 'no' or 'sometimes'.

You should tick the 'yes' box if the descriptor applies to you for more than 50% of the time. So, for example, if you need help going to the toilet four days a week, you tick the 'yes' box. For anything less than 50% you tick 'sometimes'. Tick 'no' if it doesn't affect you at all.

The extra information box

This is the part of the question where you can tell the DWP exactly how your MS affects your ability to manage each activity. Use the space to write as much as you can about that.

Examples are given above the extra information box and in the information booklet that comes with the form.

Note

To try to make the 'How your disability affects you' form easy to understand, the DWP have used different wording in the form to that used in the law. We have used the official terms used in the law in the pull-out section.

You can use the descriptors listed in the 'PIP assessment scores' to decide which descriptor applies to you and why. In each case you need to think about whether or not you can do the activity:

- safely
- to an acceptable standard
- repeatedly
- in a reasonable time period

The 'Jargon buster' in the pull-out section explains what this wording means.

My MS varies from day to day. So which descriptor should I pick?

If more than one of the descriptors apply to you for over 50% of the time, say this in the 'extra information' box. The DWP awards the points for whichever of the descriptors scores highest. If you're not sure which descriptor applies to you, keeping a diary may help you choose the right one. See the section on 'Keeping a diary' on page 15.

The questions in detail

Question 1

The first question asks for details of the professional(s) who are best placed to give advice on your circumstances. This could be your GP, neurologist or MS nurse. If possible, make an appointment with the professionals you list, so you can discuss the claim with them. They'll need to know about your daily living needs and any mobility problems you may have. If you have written a diary (see page 15), give them a copy of it.

Question 2

The second question asks about your health conditions or disabilities and roughly when each of these started. You don't need to go into detail about how they affect you at this point. There's room in the form to give details later.

List any medications you take or treatments you have. If you have a printed prescription list, you can attach that. You can also ask your GP or specialist for a list if you don't have one. List any side effects of the medication, too.

The daily living component

The next 10 questions relate to the activity headings of the daily living component. Below we look at the kinds of things you need to mention in the extra information box for each question. The activity numbers refer to the descriptor headings listed in the pull-out section.

Question 3. Preparing food (Activity 1)

This question looks at how well you can prepare and cook a simple one course meal for one from fresh ingredients. This includes how well you can:

- prepare the food. This covers things like chopping and peeling vegetables, pouring a drink, opening cans, and checking that food is not out of date
- cook the food. This includes things like safely using a hob or microwave above waist height. It doesn't include any difficulties you have in bending down to use an oven

Describe any stages of cooking a simple meal that you'd find difficult. You may have difficulties doing certain things if you have any hand tremor, weakness, or if MS affects how well you can use your hands. This includes peeling and chopping vegetables, using cooking utensils, opening cans, or turning taps on and off.

Say if you need to buy pre-chopped vegetables. It could be dangerous for you to use hot pans if you have balance problems, poor coordination or blurred or double vision. List any accidents that have happened in the past. Have you cut yourself mishandling knives, or burnt yourself on hot pans?

If you have difficulties with your memory or concentration, you may have problems planning meals, checking ingredients, timing the cooking and making sure food is cooked properly. Mention if heat from cooking affects your MS symptoms.

Write down if you have difficulty timing the cooking correctly. Let them know if you're so exhausted after cooking a meal that you couldn't do it again that day.

Question 4. Eating and drinking (Activity 2)

In the 'PIP assessment scores' this activity is called 'Taking nutrition'. Write down if hand tremor or poor control of your hands makes it difficult to use cutlery or handle hot drinks safely.

Write down if you can cut up some food but not tougher things like meat. If you tend to drop food or spill drinks, let them know if you need help cleaning up afterwards. Mention it if swallowing is difficult and you need your food or drink to be specially prepared.

Question 5. Managing treatments (Activity 3)

In the 'PIP assessment scores' this activity is called 'Managing therapy or monitoring a health condition'. It focuses on the support you need from another person to manage your medication or therapy, or monitor your health condition. It also looks at the amount of time that you need such support.

Let them know if you have hand tremor or poor hand control (poor dexterity) that causes difficulties with things like opening pill bottles or pouring out medicine. Write down if you need reminding to take medication at the right time or to take the right amount. Give examples of any occasions when you've missed taking medication or have taken too much.

If you have blurred or double vision, you may need someone to read the labels and instructions on your medication. Explain if there are side effects from any of the medications you take, and if you need any extra help because of these.

Write down how many hours on average each week you need supervision, prompting or help with the above. You may find it helpful keeping a diary over a typical week to answer this correctly.

Also, write down if you've been advised to do physiotherapy or exercises at home (like leg bending), and if you need help doing them.

Check 'PIP assessment scores' in the pull-out section to see what points you get for particular time periods. For example, you get six points if you need such help for more than seven hours, but not more than 14 hours a week.

Question 6. Washing and bathing (Activity 4)

Write down any aids or adaptations you use to wash or bathe yourself. These could include a long-handled sponge, shower seat or bath rail. Let them know if there are any parts of your body that you can't reach even using aids like these (for example, if you can't wash your back properly). Note down if you've fallen when trying to get in or out of the bath or to shower by yourself. Mention if you need to bathe or shower more often due to bladder or bowel problems, and if you need someone's help to get washed and bathed.

Fatigue

Fatigue could well be a symptom that affects you more than any other. If this is the case, you must write it down. You might be able to carry out an activity, but it takes a great deal of time. You might have to take several rests, or even give up trying until you've found more energy. Or the activity may leave you with such fatigue that you can't to do anything else for some time. Write down if any of this is true for you.

Question 7. Managing toilet needs (Activity 5)

In the 'PIP assessment scores' (the pull-out section) this activity is called 'Managing toilet needs or incontinence'. This is one of the most difficult parts of the form to fill in because the questions are so personal. Try to put as much information down as you can. The forms are treated with strict confidentiality.

Mention any difficulties you have using the toilet. This includes sitting down or getting up from it, wiping yourself, adjusting your clothing, and washing afterwards.

If you need the toilet more often than is usual, explain why. This may be a symptom of your MS. Write down if you don't get enough warning that you need the toilet. If you have bladder or bowel incontinence, write about the help you need to deal with it. This can include cleaning yourself afterwards.

Question 8. Dressing and undressing (Activity 6)

This question looks at your ability to pick, put on and take off clothing that's not specially adapted. This could include using fastenings like zips or buttons, and putting on and taking off socks and shoes.

It also looks at your ability to choose clothing that's fitting to your culture, the weather and the time of the day, and to put your clothes on in the right order.

You may well have difficulties with laces, buttons and other types of fastenings if you have any hand tremor or if MS affects your control of your hands.

Muscle pain or coordination problems can create difficulties with other pieces of clothing. Write down if it takes a long time to dress yourself. Write down if you have to rest after putting on each piece of clothing. Also, mention if you need to change your clothes during the day because of bladder or bowel problems.

If you live by yourself, write down if there are days when you don't get dressed because it causes you pain or discomfort. Also, state if, for the same reason, you avoid putting on certain clothes that you'd like to wear.

List any aids that you use to dress, like modified buttons, zips, front fastening bras, trousers, velcro fastenings and shoe aids. Write down if you still need help, despite using aids like this, even if this doesn't take long. Let them know if you need someone to choose clothing that's clean and appropriate. For example, you might have blurred or double vision and can't see stains or marks on clothing.

Question 9. Communicating (Activity 7)

In the 'PIP assessment scores' this activity is called 'Communicating verbally'. It looks at how well you can get across verbal information and understand it.

You may have difficulties communicating with people if your speech is slurred or slow. It may be difficult to find the right words to express your thoughts. Or you may have difficulties concentrating during conversations, remembering what's been said, or making sense of information you've been given. List examples where you might need help understanding or being understood during a conversation. These could include dealing with visitors to your door, telephone calls, or communicating in places like shops, buses or taxis.

Question 10. Reading (Activity 8)

In the 'PIP assessment scores' this activity is called 'Reading and understanding signs, symbols and words'. If you have blurred or double vision, list examples where you need someone to read things to you. These could include checking labels on medication and sell-by dates on food, reading your post, dealing with official letters, or reading the newspaper or radio and TV listings.

Write down if you need to use aids to help you read, like a magnifier or magnifying glass. Let them know if you can manage indoors, but can't read signs outdoors well enough.

Question 11. Mixing with other people (Activity 9)

In the 'PIP assessment scores' this activity is called 'Engaging with other people face to face'. It considers how well you can deal with people socially. Any problems you have with mixing with other people must be because of your condition, not shyness. Write down if you can only mix with people you know well, and can't deal with strangers.

Write down if you avoid mixing with other people because you have no one to help you. How would you feel mixing with others without any support? Write down how you'd feel. Would you get panicky or angry? Or do you have difficulty understanding how people behave towards you?

Question 12. Making decisions about money (Activity 10)

In the 'PIP assessment scores' this activity is called 'Making budgeting decisions'. Write down if you'd have problems buying a few items from your local shop. Would you be able to give the shop assistant the right amount of money? Would you know if the change was right?

A walking test

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 is changeable, don't choose a good day to do the test.

Find a safe location on flat ground. Walk until you feel you can't walk anymore (if it's safe to do this). Measure how far this is and how long it takes. You may find it helpful to have someone with you to record both of these.

Include factors such as uncontrollable actions or reflexes, pain, fatigue, dizziness and spasms. Note how long it takes you to recover before you feel you can walk again. Write down your findings in the extra information box.

Write down if going to the local shop would pose no problems, but you'd have problems with more complex budgeting decisions. These could be working out the household budget for the month or sorting out a gas bill. Let them know if you can do most of the job yourself, but would still need some support to finish it properly.

The mobility component

The next two questions relate to the activity headings of the mobility component.

Question 13. Going out (Activity 1)

In the 'PIP assessment scores' this activity is called 'Planning and following journeys'. It looks at how well you can work out and follow a route safely and reliably. This might be affected by your mental health or by MS symptoms that affect your memory and thinking.

If you have problems with your memory or concentration, you may find it impossible to plan the route of a journey or follow a route without another person. If your MS gives you blurred or double vision, you may need another person with you, especially on an unfamiliar journey.

Write down if you need to have someone else with you to get somewhere. Would you need support just on unfamiliar routes, or in places you know well, too? Make it clear if you have no one to go outdoors with you and so don't go out alone. Explain where you would like to go if you had someone to go with you.

List any incidents that have already happened when you've been outdoors. For example, if you got lost, confused or disorientated, or where dangerous situations happen that could have been avoided if help had been at hand.

Write down if you can't use buses or trains because of stress or anxiety. Let them know if you find small disruptions or unexpected changes difficult to deal with, like road works where you normally cross the road, or if your bus stop has moved.

Question 14. Moving around (Activity 2)

This activity looks at your physical ability to stand and move around without severe discomfort. 'Severe discomfort' doesn't just mean pain. It can include muscle tightness and stiffness or extreme fatigue.

Normally when you're in severe discomfort, you wouldn't want to go any further, until the symptoms go away. Your ability to move around should be judged in relation to the type of surface that's normal outside, like pavements, roads and kerbs.

The tick boxes

The tick box section for this question allows you to identify how far you can walk, using, if you need them, any aids like a walking stick, frame or crutches. It's important that you identify how far you can walk safely, in a reasonable time and without severe discomfort. For instance, if you could walk 50 metres, but would be in severe discomfort over the last 30 metres, then your walking ability will be considered to be limited to 20 metres.

Only tick the box 'It varies' if none of the other boxes apply for at least 50% of the time. If you do tick the 'It varies' box, explain what you mean in the 'Extra information' box. For example, 'On an average week, on two days I can manage to walk about 40 metres before I can go no further; on another four days this distance is 20 metres, and on one day I can't walk at all without severe discomfort.' A diary kept over a week, identifying your walking limit on each day, may help you to fill in this section.

The extra information box

Describe the way you walk. For example, do you find it hard to balance, or do you limp? Let them know if you need physical support from someone else to help you walk. You may need support like this if you have poor coordination or balance. Or if one of your legs keeps giving way because of spasms or muscle weakness.

Give an idea of your speed. If you walk slowly and were to cover 20 metres, what distance would someone without a disability or health condition cover in that time?

You may fall or stumble because of poor coordination or balance. Or you do this because one of your legs gives way due to spasms or muscle weakness. On the other hand, you may fall over things because you have blurred or double vision. You may fall at different times for different reasons, or for a combination of reasons. List any injuries you've got from falling and any treatment you needed afterwards. Give examples of times when you couldn't get up for any length of time after a fall. Why couldn't you get up? Did someone have to help you? Or has someone else stopped you from falling?

Question 15. Additional information

The box provides you with more space to explain how MS affects you. You can use it to explain in more detail any of the difficulties you mention in the earlier questions. If you run out of space here, use extra sheets of paper. You need to write your name and National Insurance number on these sheets.

Declaration

Once you're happy that what you've written on the form is a true and accurate reflection of your situation, sign and date the declaration. Attach any evidence you may have, like a letter from your neurologist outlining your condition, a report from an occupational therapist or a certificate of visual impairment.

If you've produced a diary (see next page), attach a copy of that too.

Keeping a diary

A diary is useful as evidence to help the DWP understand how you manage day to day, both with your daily living and getting around. You're the best person to provide this evidence. If you find it difficult to keep a diary, you could ask a relative, carer or friend to help you. In the 'How your disability affects you' form explain that your diary was filled in with their help.

If your MS changes from day to day, it's a good idea to keep the diary for longer, like a week. A diary that covers a typical week should give the DWP an idea of what you're like, both on good and bad days.

What do I include in my diary?

In the pull-out section of 'PIP assessment scores' you'll find an example of a diary. It only covers two days, so you can get an idea of the kinds of things you need to record. You can also download a template of the diary from the MS Society website. Search for 'PIP diary template'. Our MS Help Hub can also send you a copy.

Remember, you can score points for an activity if any of the following apply:

- you need aids or appliances to help you manage the activity on your own
- you need supervision or prompting
- you need help from someone else
- you're unsafe managing on your own. Accidents have happened or nearly happened
- you can't complete the activity to an acceptable standard
- you can't repeat the activity as often as is reasonably required
- you can manage on your own, but it takes you more than twice as long as someone without your condition

If any of these apply to you, include them in your diary.

Once you've finished writing the diary, put your name and National Insurance number at the top of each page and make several copies of it. Most post offices and local libraries have a photocopier that you can use. Keep one copy of the diary for yourself.

Making use of the diary

You can use the diary to fill in the 'How your disability affects you' form whenever you're unsure which descriptor applies to you.

You can give a copy of the diary to any of the professionals you've mentioned on the 'How your disability affects you' form. Finally, you could attach a copy of the diary to the form when you send it off.

Making a copy

You'll have a record of what you've sent in if you make a copy of the form and any evidence that you attach to it before sending it off. This is both for your future reference and in case the DWP loses any documents.

The consultation

Once you've returned your 'How your disability affects you' form, your case will be passed to one of four companies who have contracts to carry out the PIP assessments for the DWP: Capita, Ingeus, Maximus and Serco. In a very small number of postcode areas, the DWP does assessments itself.

Once your case has been passed to one of these companies, they'll give it to a health care professional working for them for them to carry out.

To begin with this health care professional may contact your doctor, neurologist or MS nurse for more information. They may just talk to them on the phone or ask them to produce a report.

In most cases the health care professional will arrange to speak to you in a consultation.

Where will the consultation take place?

The consultation usually takes place on the phone or by video call. If they can't assess you in this way, they'll invite you to a face-to-face consultation at an assessment centre.

A home visit can be arranged if you provide evidence from your doctor, neurologist or MS nurse that you can't travel on health grounds.

How much notice will I be given?

You must be given at least seven days' notice of the time and place for the consultation. That's unless you agree to accept a shorter notice period. If you can't attend, contact the company that arranged the consultation as soon as possible. You'll find the number to call on any letters they send you.

Can I take someone with me?

If you need or want the help or support of a carer, relative or friend, you can have them with you during the consultation. They can't answer questions on your behalf unless the health care professional can't understand your speech or you can't understand their questions. But they can add to what you have to say.

Can I record the consultation?

You may find it helpful to record your consultation in case you want to challenge the decision you get after your assessment. If your assessment is by phone or face-to-face, you and the assessor can both make an audio recording. You can't make a video recording.

You must ask if you can record it. You should phone the assessment company as soon as possible before your assessment. You'll need to agree that you'll only use the recording for certain things. The assessor will ask you to sign a form or verbally agree to this.

What will happen if I don't attend?

Your claim will be rejected if you don't attend the consultation without a good reason (taking into account your health and the nature of any disability). You should be contacted and asked to explain your reasons. If the DWP decides that you didn't have a good reason, you can ask them to reconsider. If you're unhappy with their reconsidered decision, you then have a right to appeal.

What happens at the consultation?

In the consultation the health care professional will identify the descriptors that they think apply to you. To do this, they'll ask questions about your day-to-day life, your home, and how you manage at work if you have a job. They'll also ask about social or leisure activities that you do (or had to give up). They'll often ask you to describe a typical day in your life.

When answering, explain your difficulties as fully as you can.

- Tell them about any pain or tiredness you feel, or would feel, when you carry out each task, and afterwards
- Consider how you'd feel if you had to do the same task a lot of times
- Tell them if you need reminding or encouraging to finish each task

Don't overestimate how much you can do things. If your condition changes, let them know what you're like on bad days as well as good days. The health care 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.

Before the consultation ends, the health care professional should give you an overview of their findings. They should invite you to ask questions and add or make clear anything you wish. You'll not receive a formal decision at the consultation of whether you'll be awarded PIP.

Will there be a medical examination?

In a face-to-face consultation, the health care professional will be able to see how well you can stand, sit and move around. They may watch you getting on and off the examination couch and bending down to pick up your belongings. They'll check whether you have any aids or appliances, and how much you use them. They'll also be able to work out what your levels of concentration are, and how well you can understand them and express yourself.

The health care professional might carry out a short physical examination. They should explain each stage of the examination and ask your permission before doing anything. You shouldn't be asked to do anything that will cause pain, either during or after the consultation.

What happens after the consultation?

After you finish the consultation, the health care professional will finish their report and send it to a DWP case manager. The case manager will decide whether or not to award you PIP and, if it's awarded, at what rate and for how long. They'll send you the decision in a letter.

If you're awarded PIP

The letter will detail what rate of PIP you'll get. This will usually be set for a fixed period of time. This could be for a short period of one or two years, or a longer period of five or 10 years. An ongoing award is one that doesn't have a fixed term. This is only an option if the case manager thinks it's unlikely that your condition will change in the future, so your needs will remain broadly the same.

If your claim is turned down

If the case manager turns down your claim, the letter will tell you why they've chosen the descriptors that they think apply to you. It may not tell you the number of points you've scored for each activity, but you should be able to work them out by reading the 'PIP assessment scores' (in the pull-out section).

How do I challenge a decision?

If you're unhappy with the decision, you can ask the DWP to look at it again. This is known as a 'mandatory reconsideration'. You have one calendar month from the date on the original decision letter to ask for one. If you do ask them over the phone, it's also advisable to put your request in writing and keep a copy for yourself.

When you ask for a mandatory reconsideration, you have the right to ask for copies of all the evidence that was used in making the decision. You can ask for the report from your assessment, too. And you can ask them not to take any further action until you've had the chance to respond to that evidence.

If you ask for a mandatory reconsideration, the DWP will look at the whole award again. In theory, this could mean that they decide to turn down a claim they've already said yes to.

If you're in any doubt about what might happen during a reconsideration, seek advice from a local advice centre, like Citizens Advice.

Building a case

Once you've seen the evidence that the DWP has used, you should have a better idea of why the decision was made. Sometimes the only evidence used will be the information you gave on the 'How your disability affects you' form. But in most cases there'll also be a report produced by the health care professional after the consultation. If you compare their report with what you wrote on your form, you might see where the difference of opinion comes up. For example, you may have written on the 'How your disability affects you' form that you can't get on and off the toilet without support, but the health care professional noted in their report that they thought you could manage by yourself.

Where you find such differences, try to get medical evidence that shows what you said on the form was correct. For example, that might be a letter from your GP or neurologist that confirms the difficulties and risks you have getting on and off the toilet without help.

Send the evidence to the address on the decision letter. If you need more time to get the evidence, you must tell the DWP how long this is likely to take, so they don't make a decision straight away.

A second DWP case manager will look at any further evidence you send. They will then either change the decision in your favour, or write back explaining that they've been unable to change the decision. This is known as the 'mandatory reconsideration notice'.

If you're still unhappy with their decision, you can appeal to an independent tribunal. The mandatory reconsideration notice will have the details of how to lodge an appeal.

How do I appeal?

Lodging the appeal

You have one calendar month from the date on the mandatory reconsideration notice to lodge an appeal to the HM Courts and Tribunals Service (HMCTS). You can appeal by filling in an online form on gov.uk. Or you can print off the SSCS1 form from gov.uk, complete it by hand and send it to the DWP.

You can't make an appeal unless you've first asked for a reconsideration of the decision. You need to attach a copy of the mandatory reconsideration decision to the SSCS1 form before you send it off. If you appeal using the online form, you'll also need to include details of the mandatory reconsideration decision.

On the form, give your name and address and that of your representative, if you have one. Give details of the decision you're appealing against. This includes the date of the decision, the name of the benefit, and what the decision is about. You must also state clearly why you disagree with the decision. State what rate of PIP you think you should've been given and your reasons for this.

The form will ask whether you want your appeal to be decided with or without a hearing. Opting for a hearing and attending the tribunal can make your chances of a successful outcome much better.

What happens after I've lodged the appeal?

When the HMCTS receives your appeal form, they send you an acknowledgement letter. They also send a copy of your appeal to the DWP. The DWP write an answer to your appeal and send it back to the HMCTS with copies of all the documents relevant to their decision. You'll be sent a copy of all of this.

Your appeal is heard by an independent appeal tribunal. These tribunals are informal and aren't like courts. If you have a carer, they can attend the hearing as well to give their account of your needs.

Track your appeal

If you appeal your PIP decision online, you'll be asked if you want to join the 'track your appeal' service. This sends you regular email updates and reminders about your appeal. You'll also get a login, so you can check the progress of your appeal at any time.

If you applied by post, you can contact the HM Courts and Tribunal Service and ask them to send you updates and reminders by text message.

Getting support

You can contact a local advice centre, such as a Citizens Advice to see if they can give you any support with an appeal. They may also be able to provide you with a representative to present your case at the tribunal.

What if my condition changes in the future?

If your MS gets worse, you can ask the DWP to look at your award 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 DWP will look at the whole award. They can take away the rate of PIP you've already been given. Before you do anything, check the 'PIP assessment scores' to make sure you meet the conditions for the new component or the higher rate.

You must satisfy the conditions for the new component or the higher rate for at least three months before your award can be increased. If you're in any doubt, seek advice from a local advice centre, like Citizens Advice.

Your next PIP assessment

When you're awarded PIP, you'll be given it for a set length of time. When this time is about to end, the DWP will contact you about reassessing your claim. The DWP will send you a new claim form which will ask if your condition has changed.

How does PIP affect my other benefits and tax credits?

You don't pay tax on PIP. And you don't need to have paid National Insurance contributions to claim it. You can claim the benefit if you're working, and it's not means tested. In other words your PIP payment isn't affected by your earnings, savings or other benefits.

PIP won't reduce the amount of other means-tested benefits you receive, like Employment and Support Allowance, Housing Benefit or Tax Credits.

In fact, receiving PIP can let you get higher levels of these benefits. PIP can also be a 'passport' to other benefits like Carer's Allowance. It's worth getting a benefits check if you're awarded PIP to make sure you're claiming everything you qualify for.

There are various benefits checker tools online, like the government tool available at **gov.uk/benefits-calculators**. For advice on how to get a benefits check speak to your local Citizens Advice or Jobcentre Plus. Your local social care or social work department may also be able to offer you a benefits check.

We describe the main benefits here briefly. But you can get more detailed information from our 'Benefits and MS' booklet or our website.

Carer's Allowance

Carer's Allowance is a benefit for people who regularly spend 35 hours or more a week caring for a disabled person. This benefit is paid to the carer, not the person with MS. To get your carer to receive Carer's Allowance, you must be getting certain benefits like the daily living component of PIP or ADP. And your carer must not earn more than £151 a week (the figure in December 2024). You can check the full criteria for claiming on gov.uk.

You can get claim forms from the Carer's Allowance Unit by calling **0800 731 0297**.

Or claim online at: **gov.uk/carers-allowance/how-to-claim**

Universal Credit

Universal Credit is a benefit for people who aren't working or who are on a low income. People are often expected to look for work to get this benefit. People who can't work because they're disabled may be able to get an extra amount added to their Universal Credit and not have to look for work. You can claim online on gov.uk or by calling the Universal Credit Helpline on **0800 328 5644**.

Employment and Support Allowance

Employment and Support Allowance (ESA) is paid if you have a limited capability for work. You need to have paid enough National Insurance contributions, usually in the last two to three years.

In certain circumstances you can still get it if you're in part-time work. You can start your claim online on **gov.uk** or claim by calling the Jobcentre Plus claim line on **0800 055 6688**. For more information, search our website for 'Employment and Support Allowance'.

Housing Benefit

Housing Benefit is paid by local councils to help those on low incomes cover their rent. But it's being replaced by Universal Credit. You can only make a new claim if you've reached State Pension age or you're in supported, sheltered or temporary housing. Claim forms are available from your local council.

Motability

If you get the enhanced rate of the mobility component of PIP, you may be able to use it to lease a new car, powered wheelchair or mobility scooter from Motability. For more information, contact Motability.

Blue Badge

You automatically qualify for a Blue Badge for parking concessions if you get eight points or more in the 'Moving around' activity or (in Scotland and Wales only) 12 points in the 'Planning and following journeys' activity.

Contact your local council for details, or go to:

- England or Wales: **gov.uk/apply-blue-badge**
- Scotland: **bluebadgescotland.org/**

Exemption from Vehicle Excise Duty

You don't have to pay Vehicle Excise Duty, including the first registration fee, for one car if you get the enhanced rate of the mobility component of PIP.

If you get the standard rate of the mobility component of PIP, you'll be entitled to a 50% discount off your Vehicle Excise Duty. The car can be yours or you can nominate another person's vehicle (including a company car). A re-useable 'exemption certificate' should be sent to you when you're awarded the mobility component. If you haven't been sent a certificate, contact the PIP helpline on **0800 121 4433**.

Officially the vehicle is exempt only when the disabled person uses it or it's used for their benefit. This could include someone else running errands for them. But this area has never been clearly defined. It's against the law to use an exempt car for something totally unconnected with the disabled person. Contact the Driver and Vehicle Licensing Agency (DVLA) if you're concerned about this.

Tax Credits

If you're in relatively low-paid work, you may be able to claim Working Tax Credit to top up your wages. If you're responsible for children, you may be able to claim Child Tax Credit. But you'll only be able to claim Working Tax Credit if you already get Child Tax Credit, and vice versa. You should apply for Universal Credit instead if you don't already receive any tax credits and need support because you're on a low income.

You can claim both types of tax credit by calling the Tax Credit Helpline on **0345 300 3900**.

Disability Rights UK publishes the Disability Rights Handbook. It's updated every year. It gives more details on PIP and other social security benefits for disabled people, their families and carers. In particular, there's a section on the appeals process, should your claim be unsuccessful. You can buy a copy directly from Disability Rights UK.

Support for you. Useful organisations

Citizens Advice

Help with welfare rights, housing and disability advice. Local offices are listed in the telephone directory and on the national websites.

To find local offices:

England and Wales

citizensadvice.org.uk

Scotland

cas.org.uk

Adviceline (England): 0800 144 8848

Advicelink (Wales): 0800 702 2020

Helpline (Scotland): 0800 028 1456

Advice NI (Northern Ireland)

Advice NI and the Independent Advice Network can provide advice and information relating to benefits.

0800 915 4604
adviceni.net

Government websites

England, Scotland and Wales **gov.uk**

Northern Ireland **nidirect.gov.uk**

Disability Rights UK

Disability Rights UK provides information on benefits through publications like the Disability Rights Handbook, and free factsheets from its website. It campaigns for improvements to the social security system. It can't answer questions over the phone.

0203 687 0790
disabilityrightsuk.org/

DVLA (England, Scotland and Wales)

0300 790 6806
gov.uk/health-conditions-and-driving

DVA (Northern Ireland)

0845 4024 000
nidirect.gov.uk/motoring

Disability Law Service

A national charity that provides free, confidential legal advice and support in social welfare and disability discrimination law for disabled people, their families and carers.

The MS Society funds a dedicated MS legal officer who can provide legal advice and information.

Telephone/textphone 020 7791 9800
dls.org.uk

Law Centres Network

Law centres provide free advice and representation. The Law Centres Network can give you details of your local law centre in England, Northern Ireland and Wales.

lawcentres.org.uk

Money Advice Scotland

Includes a section where you can find contact details for free local money advice services including your local Citizens Advice Bureau and local authority welfare rights service.

Email info@moneyadvicescotland.org.uk
moneyadvicescotland.org.uk

Motability

A UK-wide charity that allows disabled people to use their government-funded mobility allowance to lease a car, scooter or electric wheelchair.

0300 456 4566
motability.co.uk

Scope

The disabled charity Scope's helpline offers disability-related advice and information. They'll find your nearest disability advice service.

Freephone: 0808 800 3333
Email: helpline@scope.org.uk
scope.org.uk/advice-and-support

Turn2us

An online charity that helps people find out what benefits and grants they are eligible for. They have an online 'PIP Helper' at **pip.turn2us.org.uk/** This includes video summaries for each stage of the process of claiming PIP.

turn2us.org.uk

Disability Information Scotland

Disability-related information, advice and signposting in Scotland.

0300 323 9961
Email info@disabilityscot.org.uk

Further information

Employment toolkit

For a collection of forms, case studies and best practice examples search the MS Society website for 'work toolkit'.

MS Help Hub

Our MS Help Hub gives emotional support and information to anyone living with MS. And through the hub you can also access our:

- MS nurses
- MS benefits advisers
- MS legal advisers
- Physical activity service
- Short breaks service

We can provide information in different languages through an interpreter service. And by text relay and British Sign Language interpreters.

Find out more at **mssociety.org.uk/ms-help**

Call **0808 800 8000**
(Mon-Fri 9am to 5pm closed weekends and bank holidays)
Email **helphub@mssociety.org.uk**

Or get in touch with webchat at
mssociety.org.uk

Resources

Our award winning information resources cover every aspect of living with MS.

You can read them online or download at **mssociety.org.uk/publications**

You can order printed resources from our onlineshop at

mssociety.org.uk

Thank you

Thank you to all the people affected by MS and professionals who contributed to this booklet.

About this resource

Written by Ian Greaves, Disability Rights UK. The diary was written by Daphne Hall. With thanks to all those who tested and reviewed this guide.

If you have any comments on this information, please send them to:
resources@mssociety.org.uk

Disclaimer: We have made every effort to ensure that information in this publication is correct. We do not accept liability for any errors or omissions, and policy and practice may change. Seek advice from the sources listed.

This resource is also available in large print format. Call **0300 500 8084** or email **shop@mssociety.org.uk**

Notes:

Notes:

Contact us:

MS Help Hub
Freephone 0808 800 8000
(weekdays 9am-5pm)
helphub@mssociety.org.uk
Webchat at mssociety.org.uk

MS National Centre
020 8438 0700
supportercare@mssociety.org.uk

MS Society Scotland
0131 335 4050
enquiries-scotland@mssociety.org.uk

MS Society Northern Ireland
028 9080 2802
nireception@mssociety.org.uk

MS Society Cymru
0208 438 0700
mscymru@mssociety.org.uk

Online
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Trusted Information Creator
Patient Information Forum

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This title will be reviewed within three years of publication (December 2027).

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The PIP assessment scores

This pull-out section includes the activities that are included in the PIP assessment and the scores for each one. It may help to read this when you fill in the 'How your disability affects you' form, or if you need to attend a face-to-face consultation.

Daily Living Activities: descriptors and scores

Each activity has a set of descriptors beneath it. These describe related tasks of varying degrees of difficulty. You score points when you can't finish a task safely, to an acceptable standard, repeatedly and in a reasonable time period. Within each activity, if more than one descriptor applies to you, you'll only score for the one that gives you the highest number of points.

To qualify for the standard rate of the daily living component, you need to score at least eight points. To qualify for the enhanced rate, you need to score at least 12 points. These points can be scored in just one activity or from any of the activities added together.

! See the **jargon buster** on page 8 for the meanings of some of the words and phrases used in this section.

Activity 1: Preparing food

		Score
A	Can prepare and cook a simple meal unaided.	0
B	Needs to use an aid or appliance to be able to either prepare or cook a simple meal.	2
C	Can't cook a simple meal using a conventional cooker but is able to do so using a microwave.	2
D	Needs prompting to be able to either prepare or cook a simple meal.	2
E	Needs supervision or assistance to either prepare or cook a simple meal.	4
F	Can't prepare and cook food.	8

Activity 2: Taking nutrition

A	Can take nutrition unaided.	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.	2
C	Needs a therapeutic source to be able to take nutrition.	2
D	Needs prompting to be able to take nutrition.	4
E	Needs assistance to be able to manage a therapeutic source to take nutrition.	6
F	Can't convey food and drink to their mouth and needs another person to do so.	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.	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 problem	1
C	Needs supervision, prompting or assistance to be able to manage therapy that takes no more than 3.5 hours a week.	2
D	Needs supervision, prompting or assistance to be able to manage therapy that takes more than 3.5 but no more than seven hours a week.	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.	6
F	Needs supervision, prompting or assistance to be able to manage therapy that takes more than 14 hours a week.	8

Activity 4: Washing and bathing

A	Can wash and bathe unaided.	0
B	Needs to use an aid or appliance to be able to wash or bathe.	2
C	Needs supervision or prompting to be able to wash or bathe.	2
D	Needs assistance to be able to wash either their hair or their body below the waist.	2
E	Needs assistance to be able to get in or out of a bath or shower.	3
F	Needs assistance to be able to wash their body between the shoulders and waist.	4
G	Can't wash and bathe at all and needs another person to wash their entire body.	8

Activity 5: Managing toilet needs or incontinence

A	Can manage toilet needs or incontinence unaided.	0
B	Needs to use an aid or appliance to be able to manage toilet needs or incontinence.	2
C	Needs supervision or prompting to be able to manage toilet needs.	2
D	Needs assistance to be able to manage toilet needs.	4
E	Needs assistance to be able to manage incontinence of either bladder or bowel.	6
F	Needs assistance to be able to manage incontinence of both bladder and bowel.	8

Activity 6: Dressing and undressing

A	Can dress and undress unaided.	0
B	Needs to use an aid or appliance to be able to dress or undress.	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.	2
D	Needs assistance to be able to dress or undress their lower body.	2
E	Needs assistance to be able to dress or undress their upper body.	4
F	Can't dress or undress at all.	8

Activity 7: Communicating verbally

A	Can express and understand verbal information unaided.	0
B	Needs to use an aid or appliance to be able to speak or hear.	2
C	Needs communication support to be able to express or understand complex verbal information.	4
D	Needs communication support to be able to express or understand basic verbal information.	8
E	Can't express or understand verbal information at all even with communication support.	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.	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.	2
C	Needs prompting to be able to read or understand complex written information.	2
D	Needs prompting to be able to read or understand basic written information.	4
E	Can't read or understand signs, symbols or words at all.	8

Activity 9: Engaging with other people face to face

A	Can engage with other people unaided.	0
B	Needs prompting to be able to engage with other people.	2
C	Needs social support to be able to engage with other people.	4
D	Can't 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.	8

Activity 10: Making budgeting decisions

A	Can manage complex budgeting decisions unaided.	0
B	Needs prompting or assistance to be able to make complex budgeting decisions.	2
C	Needs prompting or assistance to be able to make simple budgeting decisions.	4
D	Can't make any budgeting decisions at all.	6

Mobility activities: descriptors and scores

Each activity has a set of descriptors. These describe tasks of varying levels of difficulty.

You score points when you can't finish a task described safely, to an acceptable standard, repeatedly and in a reasonable time period.

Within each activity if more than one descriptor applies to you, you only include the score from the one that gives you the highest number of points.

To qualify for the standard rate of the mobility component, you need to score at least eight points.

To qualify for the enhanced rate, you need to score at least 12 points. The points can be scored in just one activity or from any of the activities added together.

! See the jargon buster on the next page for the meanings of the words and phrases used in this section.

Activity 1: Planning and following journeys Score

A	Can plan and follow the route of a journey unaided.	0
B	Needs prompting to be able to undertake any journey to avoid over whelming psychological distress to the claimant.	4
C	Can't plan the route of a journey.	8
D	Can't follow the route of an unfamiliar journey without another person, assistance dog or orientation aid	10
E	Can't undertake any journey because it would cause overwhelming psychological distress to the claimant.	10
F	Can't follow the route of a familiar journey without another person, assistance dog or orientation aid.	12

Activity 2: Moving around

A	Can stand and then move more than 200 metres, either aided or unaided.	0
B	Can stand and then move more than 50 metres but no more than 200 metres, either aided or unaided.	4
C	Can stand and then move unaided more than 20 metres but no more than 50 metres.	8
D	Can stand and then move using an aid or appliance more than 20 metres but no more than 50 metres.	10
E	Can stand and then move more than one metre but no more than 20 metres, either aided or unaided.	12
F	Can't, either aided or unaided:	12

i stand **or**

ii move more than one metre

Notes:

Jargon buster

acceptable standard means that you can complete the activity, to a 'good enough' standard. For example, if you can wash yourself but don't realise that you've done so badly and you're still not clean, this wouldn't be seen as an acceptable standard

aid or appliance means any device that improves, provides for, or replaces your impaired physical or mental function (for example, walking sticks, spectacles or an artificial limb). It shouldn't be considered reasonable for you to wear or use an aid or appliance if it's too expensive, difficult to get or isn't appropriate for your culture

aided means with:

- the use of an aid or appliance or
- supervision, prompting or assistance

assistance means help from another person but doesn't include speech

assistance dog means a dog trained to guide or help a person with a sensory impairment

basic verbal information means information in your own language spoken in a simple sentence

basic written information means signs, symbols and dates written or printed in a standard-size text in your own language

bathe includes getting into or out of a bath or shower that's not been specially adapted

communication support means support from a person trained or experienced in communicating with people with specific communication needs, for example, a sign language interpreter

complex budgeting decisions means decisions involving:

- working out household and personal budgets
- managing and paying bills
- planning future purchases

complex verbal information means information in your own language spoken in either more than one sentence or one complicated sentence

complex written information means more than one sentence of written or printed standard-size text in your own language

cook means heating food while sitting or standing at or above waist height

dress and undress includes putting on and taking off socks and shoes

engage socially means:

- mixing with others in a way that's right for where you are and who you're with
- understanding body language
- establishing relationships

manage incontinence means managing the times when you can't stop your bowel or bladder from emptying. This includes using a bag or self-catheterisation, and cleaning yourself afterwards

manage medication or therapy means taking medication or having therapy, where, if you don't do this, it's likely to mean your health gets worse

monitor health means:

- detecting significant changes in your health condition, which are likely to make your health worse, and
- taking action advised by a registered doctor, registered nurse or a health professional who is regulated by the Health Professions Council

orientation aid means specialist equipment (like a long cane if you have a sight problem) designed to help disabled people follow a route safely prepare food means making food from fresh ingredients ready for cooking or eating

prompting means when another person reminds, encourages or explains to someone

psychological distress means distress related to a lasting mental health condition or an intellectual or cognitive impairment

read includes reading signs, symbols and words but doesn't include reading Braille

reasonable time period means no more than twice as long as the maximum period that a person without a physical or mental condition would normally take to finish that activity

reliably means you can do an activity:

- safely
- to an acceptable standard
- repeatedly
- in a reasonable time period

repeatedly means being able to repeat a task as often as is reasonably needed. Consideration should be given to the cumulative effects of symptoms such as pain and fatigue. You can't perform the task repeatedly if the effort you need to finish it makes you tired and/or in so much pain that you wouldn't be able to do it again or take on another task. For example, you should be treated as being unable to repeat that activity if you can prepare a meal once without help, but the exhaustion this causes means you couldn't prepare another meal that day

safely means in a way that's unlikely to cause harm to yourself or others either during or after you've finished the activity

simple budgeting decisions means decisions involving:

- working out the cost of goods and
- working out the change you should get after buying something

simple meal means a cooked, one-course meal for one person that uses fresh ingredients

social support means support from a person trained or experienced in helping people to mix socially

stand means standing upright with at least one foot (but not an artificial one) on the ground

supervision means having someone always there to make sure you're safe

take nutrition means:

- cutting food into pieces, putting food and drink into your mouth and chewing and swallowing or
- taking nutrition by using a therapeutic source

therapeutic source means a feeding tube that includes a pump or delivery system

therapy means therapy at home prescribed or recommended by a registered doctor, nurse or pharmacist or a health professional regulated by the Health Professions Council

toilet needs means:

- getting on and off a toilet that's not been specially adapted
- emptying your bladder and bowel and
- cleaning yourself afterwards

unaided means without:

- the use of an aid or appliance or
- supervision, prompting or assistance

Notes:

Diary example

Turn the page for an example of a two-day diary of a 49-year old woman with secondary progressive MS. Please note, you're recommended to keep a diary for at least a week.

Date: 25th April

Activity	Morning 7am-12pm	Afternoon 12pm-6pm	Evening 6pm-11pm	Night 11pm-7am
Going to the toilet (always use grab rails and raised toilet seat)	Managed by myself		Managed by myself	Unsteady - helped to toilet
Having a shower	Managed by myself – 40 minutes			
Dressing/Undressing	Managed myself by wearing clothes that had no zips or buttons. It took me 20 minutes	Help from friend at swimming pool	Coordination bad - needed help to get pants and tights off	
Cooking (always use perching stool)	Made toast for breakfast on my own	Cut myself chopping salad	Made evening meal from pre-prepared vegetables. Didn't have potatoes though as I couldn't mash them	
Eating	Managed to eat toast by myself	Ate a salad and jacket potato for lunch, which I prepared myself	Help needed chopping up meat	
Medication			Needed help getting pills out of dosette box	
Reading		Read paper on tablet using magnifier		
Walking	Went to local shops - 400 metres - used electric wheelchair	Swimming with friend. Walk from car to leisure centre (about 40 metres). I used stick on one side, friend on other - very slow	Coordination bad and exhausted after swim using indoor wheelchair	

Date: 26th April

Activity	Morning 7am-12pm	Afternoon 12pm-6pm	Evening 6pm-11pm	Night 11pm-7am
Going to the toilet (always use grab rails and raised toilet seat)	Managed by myself - stiff and slow first thing	Slight accident on one occasion as didn't get there in time. Needed to shower and change, which was a struggle on my own	Managed by myself	Unsteady - helped to toilet x 2
Having a shower	Managed by myself - 35 minutes	Took me nearly an hour to shower after my accident		
Dressing/Undressing	Managed myself - 20 minutes	Put on pyjamas as had no energy to get dressed again properly	Coordination bad - needed help to get pants and tights off	
Cooking (always use perching stool)			Didn't cook today - too tired	
Eating	Had toast that my partner made me	Didn't eat - I was on my own and too tired to make anything	Partner prepared main meal. Had to help me cut up the meat to eat	
Medication			Help getting pills out of dosette box	
Reading	Read paper on tablet using magnifier	Read paper on tablet using magnifier		
Walking		Exhausted so used indoor wheelchair		

Notes:

Notes:

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This title will be reviewed within three years of publication (December 2027).

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