



Claiming PIP

(Personal Independence Payment)



This publication is available in large print.
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The Multiple Sclerosis Society

More than 100,000 people live with multiple sclerosis (MS) in the UK. Every one of them shares the uncertainty of life with MS.

We're funding research and fighting for better treatment and care to help people with MS take control of their lives.

With your support, we will **beat MS**.

The MS Society provides this information free of charge but if you would like to help cover the cost, which will help towards our essential work, please call 0800 100 133 or visit the fundraising section of our website to make a donation. Anything you can give will be greatly appreciated.

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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're eligible to claim, as well as looking in detail at the assessment process, including completing the PIP questionnaire, the face-to-face 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 is eligible?

Your eligibility for 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 anything you like.

There are basic qualifying conditions that you must meet before you can claim PIP, which are listed in the box below.

Do I need to read this booklet?

PIP is replacing Disability Living Allowance (DLA) for people of working age (between the ages of 16 and 64 inclusive).

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

- For more information about the switchover from DLA to PIP, see our factsheet *Changing from Disability Living Allowance (DLA) to Personal Independence Payment (PIP)*.

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 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).

The basic qualifying conditions

- You must be aged 16–64 when you claim.
- You live in the UK (PIP is now also available in Northern Ireland).
- You have been present in Great Britain for at least 104 weeks in the last 156 weeks and are not subject to immigration control.

How is PIP made up?

PIP has two parts: the daily living component and the mobility component. You can be awarded either, or both, of these components. Your eligibility is determined by the PIP assessment.

The daily living component

The daily living component helps cover the extra costs that 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 an enhanced rate. The rate you are paid depends on whether your ability to carry out daily living activities is 'limited' or 'severely limited', as 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 that 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, which 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 will determine whether or not you're entitled to either component of PIP and, if you are, at which rate.

The 10 daily living activities

Your ability to carry out daily living activities is assessed by focusing on 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 an enhanced rate, which will change each year. For the current rates, call the PIP helpline on 0345 850 3322, textphone 0345 601 6677 or visit the government website: www.gov.uk

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

Hospital stays and respite care

Payments of PIP will stop after 28 days in hospital or respite care. There's a 28-day linking rule which

Keeping a diary

Because MS is a fluctuating condition, it can be difficult to know how to answer some of the questions in the assessment, so 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 filling in the PIP form. There's more information on keeping a diary later. An example diary is included in the pull-out section and you can download a blank template from the MS Society website.

means that different periods spent in hospital or respite care separated by 28 days or less are 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 is 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 (not counting, in each case, the days she goes in and the day she leaves the hospital).

Because PIP payments stop after 28 days in hospital, this would mean 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.

Care homes

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

If you self-fund your stay in the care home, you may be entitled to both components of PIP. The mobility component is not payable (after 28 days) for people receiving full funded NHS continuing healthcare in a nursing home (considered to be 'hospital or similar institution').

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

Hospice

PIP will usually be paid if you have less than six months to live and you're in a hospice.

Applying for PIP

How do I start my claim?

You start your PIP claim by calling 0800 917 2222 (textphone 0800 917 7777). The lines are open between 8am and 6pm Monday to Friday and calls are free on landlines and most mobiles.

Someone else can make this call on your behalf, but you need to be with them when they do so.

This call is to take basic information about you to make sure you qualify to claim. You won't be asked for any detailed information about your MS at this stage, 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 including:

- 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 (see page 4)
- which of the health care professionals supporting you is the best to contact about your MS
- information about your nationality and whether you have spent time abroad over the last three years
- details of your bank or building society (for payment purposes)
- whether you find it difficult to return forms, for instance because you have memory problems

It will help if you have this information ready when you make the call. It may also help to have somebody with you while you have this conversation in case it is hard to remember what you have said, or what you have been asked. This person can also help you think about the questions and give a considered answer.

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 to it. This will confirm the information you have given 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 this can delay your claim.

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 will send you a letter telling you why you're not eligible. If you do satisfy the basic qualifying conditions, they'll send you the 'How your disability affects you' form to complete.

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

To claim PIP you'll need to complete the 'How your disability affects you' form. This form will be sent to you in a pack that will also include an information booklet that discusses each section of the form in detail.

When completing the form, you may wish to write in pencil first, or make some notes on paper or on a photocopy of the form, before committing yourself to pen. You can ask a friend, family member, or support worker to help you. Or you can 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 so, on the positive side, it means your opinion is extremely important. On the negative side, the form is long and often asks highly personal questions. Completing the form can feel like a negative thing to do. The bulk 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 experience, so you're assessed accurately. Give yourself plenty of time to complete the form. And don't feel you need to do it all in one sitting.

Home visit

The DWP visiting team can visit you at home to complete the form for you, but only if you can't attend the office, or use their online services or telephone helpline and you have no one who can do it for you. Contact them using the telephone number on the letter that comes with the form and booklet. If you live in Wales, the 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 along 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 you already have.

How long do I have to complete the form?

You have one month to return the 'How your disability affects you' form from the date it was sent to you. If you don't return the form within the month without good reason (taking into account your health and the nature of your disability), your claim will be turned down and you'll have to start again.

If you're not able to return the form within one month, for example because you need help to complete it but can't get an appointment with an advice centre in time, contact the DWP to explain. They can extend the one-month time limit if there's a good reason to do so.

Where can I get support?

Local advice agencies can help such as a Citizens Advice, Turn2us or a local authority welfare rights service.

Your local MS Society branch may also know of other local benefits advice agencies that may be able to help. Through its Helpline and branches, the MS Society offers information, emotional support and a listening ear, but it can't give advice on benefits claims.

How do I complete the 'How your disability affects you' form?

It may be useful to check you have all the information you need before you begin filling out the form. This can include details of the health and social care professionals involved in your

care, the diary you have been keeping and a list of all the medications you're taking.

The first two questions on the form 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 would most like the DWP to contact. Let the professional(s) know that you have listed them on the form. That way, they won't be surprised if the DWP do get in touch.

Questions 3 to 14 all follow a similar format, which is explained below. The activity headings, the descriptors under each heading, and the points allocated to each one, are listed in the 'PIP assessment scores'.

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 concerned and what help you need. This might range from just needing supervision or prompting, to needing physical assistance.

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 would tick the 'yes' box. For anything less than 50% you would tick 'sometimes', or '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 how your MS affects your ability to carry out the activity.

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.

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

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 consider whether or not you can do the activity safely, to an acceptable standard, repeatedly and in a reasonable time period (see the 'Jargon buster' in the pull-out section).

As my MS varies from day to day, 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 will award 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 to choose the correct one – see the section on 'Keeping a diary' on page 13.

The questions in detail

Question 1

The first question asks for details of the professional(s) best placed to provide 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 13), 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're taking or treatments you're having. 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. If you have any side effects as a result of the medication, list these 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 focuses on your ability to prepare and cook a simple one-course meal for one person from fresh ingredients. This includes your ability to:

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

Describe any stages of cooking a simple meal that you'd find difficult. If you have any hand tremor, weakness, or if MS affects your dexterity, then you may have difficulties with peeling and chopping vegetables, using cooking utensils, opening cans or turning taps on and off.

If you need to buy pre-chopped vegetables,

say so. Balance problems, poor coordination or blurred or double vision could make it dangerous for you to use hot pans. List any incidents 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 in planning meals, checking the ingredients, timing the cooking and making sure the food is cooked properly. Mention if the 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)

This activity is called 'Taking nutrition' in the 'PIP assessment scores'. Write down if hand tremor or poor dexterity makes it difficult for you to use cutlery properly or manage hot drinks safely.

If you can cut up some food but can't cut up tougher items, such as meat, write this down. If you tend to drop food or spill drinks, let them know if you then need any help in cleaning up afterwards. If you have difficulty in swallowing and need your food or drink to be specially prepared, mention this.

Question 5: Managing treatments (Activity 3)

This activity is called 'Managing therapy or monitoring a health condition' in the 'PIP assessment scores'. 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 dexterity that causes difficulties with tasks 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 require supervision, prompting or assistance with the above. You may find it helpful 'Keeping a diary' over a typical week to answer this correctly.

Also, write down if you have been advised to do physiotherapy or exercises (such as leg bending) at home, 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, if you need such help for more than seven hours, but no more than 14 hours a week, you'd receive six points).

Question 6: Washing and bathing (Activity 4)

Write down any aids or adaptations that 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 such aids (for example, if you can't wash your back properly). If you have fallen trying to get in or out of the bath or shower by yourself, note this down. Mention if you need to bathe or shower more often due to either bladder or bowel problems and if you need someone's help to get washed and bathed.

Question 7: Managing toilet needs (Activity 5)

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

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 to do so. You might have to take several rests, or even give up the attempt until you have found more energy. Or the activity may leave you so fatigued you are unable to do anything else for some time. Write down if any of this applies to you.

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

If you need to visit the toilet more often than is usual, explain why. A symptom of your MS may be bladder or bowel frequency. If you don't get enough warning that you need to use the toilet due to bladder or bowel urgency, write that down. If you have bladder or bowel incontinence, write about the help you need in dealing with it. This can include cleaning yourself afterwards.

Question 8: Dressing and undressing (Activity 6)

This question looks at your ability to select, put on and take off un-adapted clothing (which could include using fastenings such as zips or buttons). It includes putting on and taking off socks and shoes.

It also looks at your ability to select clothing appropriate to your culture, the weather and time of the day, and to put your clothes on in the right order.

If you have any hand tremor or MS affects your dexterity, then you may well have difficulties with laces, buttons and other types of fastenings.

Muscle pain or coordination problems can create difficulties with other articles of clothing. Write

down if it takes a long time to dress yourself, or if you have to rest after putting on each piece of clothing due to fatigue. Also, mention if you need to change your clothes during the day if you have either bladder or bowel problems.

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

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

Question 9: Communicating (Activity 7)

This activity is called 'Communicating verbally' in the 'PIP assessment scores'. It focuses on your ability to convey and understand verbal information.

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, and you may need help 'word-finding'. Alternatively, you may have difficulties concentrating during conversations, remembering what has been said, or adequately processing the information you have been given.

In any of these circumstances, list examples where you might need help either understanding or being understood when having 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)

This activity is called 'Reading and understanding signs, symbols and words' in the 'PIP assessment scores'. 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 any official letters, or reading radio and TV listings or the newspaper.

Write down if you need to use aids to help you read, such as a magnifier or magnifying glass. If you can manage indoors, but can't adequately read signs out of doors, let them know.

Question 11: Mixing with other people (Activity 9)

This activity is called 'Engaging with other people face to face' in the 'PIP assessment scores'. It considers your ability to engage socially. Any inability you have to mix with other people must result from your condition, rather than shyness. If you can only mix with people you know well, and can't deal with strangers, write this down.

If you avoid mixing with other people because you have no one to help you, write this down. How would you feel mixing with others without any support? Write down how you would feel: would you get panicky or angry, or do you have difficulty understanding the way that people behave towards you?

Question 12: Making decisions about money (Activity 10)

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

If going to the local shop would pose no problems, but you'd have problems with more complex budgeting decisions, such as working out the household budget for the month or sorting out a gas bill, write this down. 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)

This activity is called 'Planning and following journeys' in the 'PIP assessment scores'. It assesses your ability to work out and follow a route safely and reliably.

If you have difficulties with your memory or concentration, you may find it impossible to plan the route of a journey or to follow a route without another person. If you have blurred or double vision as a result of your MS, you may need to be accompanied by another person, particularly 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 would you also need it in places you know well? If you have no one to accompany you outdoors and therefore don't go out alone, make this clear. Explain where you would like to go if you had someone to accompany you.

List any incidents that have already occurred when you have been outdoors. For example, if you have become lost, confused or disorientated, or where dangerous situations have arisen that could have been avoided if help had been at hand.

Write down if you're unable to use buses or trains due to stress or anxiety. Let them know if you'd find small disruptions or unexpected changes difficult to deal with, such as road works where you normally cross the road or if your bus stop has been moved.

Question 14: Moving around (Activity 2)

This activity focuses on your physical ability to stand and move around without severe discomfort. 'Severe discomfort' doesn't just mean pain, but can include muscle tightness and rigidity or extreme fatigue.

Normally, when you're in severe discomfort, you wouldn't want to go any further, until the symptoms subside. Your ability to move around should be judged in relation to the type of surface normally expected out of doors, such as 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 necessary, any aids such as 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

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 varies, don't choose a good day to perform the test.

Find a safe location on level ground. Walk until you feel you're unable to continue (if it's safe for you to do so). 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 pain, dizziness, spasms, uncontrollable actions or reflexes, and fatigue. Note how long it takes you to recover before you feel able to walk again. Write down your findings in the extra information box.

your walking limit on each day, may help you to complete 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 another person to help you walk. You may need such support if you have poor coordination or balance, or if one of your legs keeps giving way due to spasm 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 because one of your legs gives way due to spasm or muscle weakness. Alternatively, 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 have received when you have fallen and any treatment that you needed afterwards. Give examples of occasions when you were unable to get up for any length of time following a fall. Why were you unable to get up? Did someone have to help you? Alternatively, 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 previous questions.

If you run out of space here, you can use extra sheets of paper, on which you need to write your name and National Insurance number.

Declaration

Once you're satisfied that what you have written on the form is a true and accurate reflection of your situation, sign and date the declaration. Attach any evidence you may have, for example 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 with getting around. You are 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 (and explain in the 'How your disability affects you' form that your diary has been completed with their help).

If your MS varies from day to day, it is a good idea to keep the diary for a longer period, such as a week. A diary covering a typical week should give the DWP an idea of what you're like both on good days and bad days.

What do I include in my diary?

There's an example of a diary in 'PIP assessment scores', in the pull-out section. 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 'diary template') or the Helpline will be able to 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 assistance 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're not able to 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 have 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 complete the 'How your disability affects you' form whenever you are unsure which descriptor applies to you.

You can give a copy of the diary to any of the professionals you have 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

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

The face-to-face consultation

Once you have returned your 'How your disability affects you' form, your case will be passed to one of the two companies contracted to carry out the PIP assessments on behalf of the DWP: Capita and Atos Healthcare.

Once your case has been passed to one of these companies, they will allocate it to a health care professional working for them.

This health care professional may initially contact your doctor, neurologist or MS nurse for further information. They may just talk to them on the phone or they may ask them to produce a report.

In most cases, the health care professional will arrange to see you at a face-to-face consultation.

Where will the consultation take place?

The face-to-face consultation will usually take place in an Examination Centre. However, a home visit can be arranged if you provide evidence from your doctor, neurologist or MS nurse that you're unable to 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, 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 you receive from them.

Can I take someone with me?

If you need or want the help or support of a carer, relative or friend, you can bring them to the consultation with you. While they're not able to answer questions on your behalf (unless the health care professional can't understand your speech or you can't understand their questions), they will be able to add to what you have to say.

Can I record the consultation?

The DWP has stated that although they do not offer audio recordings, you can record the

consultation with your own equipment if you wish. You will need to let the Examination Centre know beforehand that you wish to record your consultation. You can find the number to call on any letters you receive from them.

They are quite strict on how these recordings are done. For example, recordings taken on personal devices such as mobile phones or MP3 players won't be allowed. Whatever equipment you use, it must be able to produce two identical copies of the recording either on cassette or CD at the end of the consultation. You can't go home and make a copy of it – they have to know that the two versions are identical and have not been tampered with in any way.

What will happen if I don't attend?

If you don't attend or take part in the consultation without good reason (taking into account your health and the nature of any disability) your claim will be disallowed. 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?

At the face-to-face consultation the health care professional will identify the descriptors they consider apply to you. To do this, they will ask questions about your day-to-day life, your home, how you manage at work if you have a job, and about any social or leisure activities that you engage in (or have had to give up). They will 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, while carrying out each task, and after you have carried it out
- Consider how you would feel if you had to do the same task repeatedly

- Tell them if you need reminding or encouraging to complete each task

Don't overestimate your ability to do things. If your condition varies, let them know about what you're like on bad days as well as good days. The health care professional's opinion should not be based on a snapshot of your condition on the day of the consultation. They should consider the effects of your condition over time.

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

Will there be a medical examination?

At the consultation, the health care professional will be able to observe your ability to 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 the extent to which you use them. They'll also be able to assess your levels of concentration and your ability to understand them and how well you express yourself.

The health care professional may carry out a brief physical examination. They should explain each stage of the examination and ask your permission before carrying anything out. You should not be asked to do anything that will cause you pain, either during or after the consultation.

What happens after the consultation?

After you leave the face-to-face consultation, the health care professional will complete 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 will send you the decision in a letter.

If you're awarded PIP

The letter will detail what rate of PIP you're being granted and the award 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 (i.e one that doesn't have a fixed term) would only be considered if the case manager thinks that 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 have chosen the descriptors that they consider apply to you. It may not tell you the number of points you have scored for each activity, however, 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 request that the DWP looks 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 of your request for yourself.

When requesting a mandatory reconsideration, you have the right to ask for copies of all the evidence that was used in making the decision. You can also ask them not to take any further action until you have 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 have already granted.

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

Building a case

Once you have seen the evidence 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. In most cases, however, there'll also be a report produced by the health care professional following the face-to-face consultation. If you compare their report with what you wrote on your form, you might see where the difference of opinion arises.

For example, you may have written on the 'How your disability affects you' form that you could not 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 showing that what you said on the form was correct. For example, a letter from your GP or neurologist confirming the difficulties and risks you have getting on and off the toilet unassisted.

Send the evidence to the address on the decision letter. If you need more time to get the evidence, you must inform 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 to you explaining that they have 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 contain 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). The form you need is the 'SSCS1'. The mandatory reconsideration notice will have details of how to get an SSCS1 form.

You can't make an appeal unless you have first asked for a reconsideration of the decision. You will need to attach a copy of the mandatory reconsideration decision to the SSCS1 form before you send it off.

On the SSCS1 form, give your name and address and that of your representative, if you have one. Give details of the decision you're appealing against, including 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 consider that you should have been awarded and your reasons for this.

The SSCS1 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 greatly improve your chances of a successful outcome.

What happens after I've lodged the appeal?

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

Your appeal will be heard by an independent appeal tribunal. These tribunals are informal and are not like courts. If you have a carer, they can attend the hearing as well to provide their account of your needs.

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, and they can take away the rate of PIP you have already been granted. Before you do anything, check the 'PIP assessment scores' to make sure you satisfy the conditions for the new component or the higher rate.

You will have to have satisfied the conditions for the new component or the higher rate for at least three months before your award can be increased. If you are in any doubt, seek advice from a local advice centre, such as a Citizens Advice.

How does PIP affect my other benefits and tax credits?

PIP is not taxable 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 is not means tested. In other words your PIP payment is not affected by your earnings, savings or other benefits.

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

In fact, receiving PIP can enable you to access higher levels of these benefits. PIP can also be a 'passport' to other benefits, such as Carer's Allowance. It's worth getting a benefits check if you are awarded PIP to make sure you're claiming everything you are entitled to.

There are various benefits checker tools available online, such as the government tool available at www.gov.uk/benefits-calculators. You can speak to your local Citizens Advice Bureau or Jobcentre Plus for advice on how to get a benefits check. 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 the MS Society booklet *Benefits and MS* or the MS Society 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, and not the person with MS. In order for your carer to receive Carer's Allowance, you must be getting the daily living component of PIP. If your carer works, they must not earn more than £110 a week. Claim forms can be obtained from the Carer's Allowance Unit by calling **0345 608 4321**. You can also claim online at: www.gov.uk/apply-carers-allowance

Employment and Support Allowance

Employment and Support Allowance (ESA) is paid if you have a limited capability for work. In certain circumstances, you can still receive it if you're in part-time work. A higher amount may be payable once you have been awarded PIP. You can claim by calling the Jobcentre Plus claim line: **0800 055 6688**. For more information, see the MS Society booklet *Employment and Support Allowance*

Housing Benefit

Housing Benefit is paid by local authorities to help those on low incomes to cover their rent. A higher rate may be payable once you have been awarded PIP. Claim forms are available from your local authority.

Motability

If you're awarded 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

If you're awarded eight points or more in the 'Moving around' activity or, in Scotland and Wales only, 12 points in the 'Planning and following journeys' activity, you qualify automatically for a Blue Badge for parking concessions.

Contact your local authority for details, or go to:

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

Exemption from Vehicle Excise Duty

You're exempt from Vehicle Excise Duty, including the first registration fee, for one car if you receive the enhanced rate of the mobility component of PIP.

If you receive the standard rate of the mobility component of PIP, you will 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 **0345 850 3322**.

Officially, the vehicle is exempt only when used by, or for the purposes of, the disabled person. This could include someone else running errands for them. But this area has never been clearly defined. Using an exempt car for something totally unconnected with the disabled person is illegal. If you're concerned about this, contact the Driver and Vehicle Licensing Agency (DVLA).

Tax Credits

If you're in relatively low-paid work, you may be able to claim Working Tax Credit to top up your wages. Once you have been awarded PIP, a higher rate of Working Tax Credit may be payable. If you're responsible for children you may be able to claim Child Tax Credit. You can claim both types of tax credit by calling the Tax Credit Helpline on **0345 300 3900**.

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

Support for you – useful organisations

Benefits Shop (Northern Ireland)

Run by the Northern Ireland Department for Social Development, the Benefits Shop offers information and advice about benefits, including help with completing forms.

Ground Floor Castle Court Royal Avenue
Belfast,
BT1 1DF

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:

www.citizensadvice.org.uk

(England and Wales)

www.cas.org.uk (Scotland)

In Scotland, telephone advice is available on **0808 800 9060** (weekdays 9am–8pm and Saturdays 10am–2pm). Or for email enquiries and live web chat visit:

www.citizensadvisedirect.org.uk or

www.citizensadvice.co.uk (Northern Ireland)

Government websites

England, Scotland and Wales www.gov.uk

Northern Ireland www.nidirect.gov.uk

Disability Rights UK

Disability Rights UK provides information on benefits through publications (for example, the Disability Rights Handbook), and free factsheets from its website. It campaigns for improvements to the social security system. It cannot answer questions over the phone.

Disability Rights UK

CAN Mezzanine

49–51 East Road

London N1 6AH

020 7250 8181

www.disabilityrightsuk.org

DVLA (England, Scotland and Wales)

0300 790 6806

www.gov.uk/health-conditions-and-driving

DVA (Northern Ireland)

0845 4024 000

www.nidirect.gov.uk/motoring

Disability Law Service

National charity providing 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**

www.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.

020 3637 1330

www.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.

0141 572 0237

Email info@moneyadvicescotland.org.uk

www.moneyadvicescotland.org.uk

Motability

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

0300 456 4566

www.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: **response@scope.org.uk**

www.scope.org.uk/support/disabled-people/local/about

Turn2us

An online charity that helps people find out what benefits and grants they are eligible for. It has some useful tools and resources to help you understand what your options are.

0808 802 2000

www.turn2us.org.uk

Update (Scotland)

Disability-related information, advice and signposting in Scotland.

0300 323 9961

Email **info@update.org.uk**

www.update.org.uk

Further information from the MS Society

Library

For more information, research articles and DVDs about MS, contact our librarian.

020 8438 0900

librarian@mssociety.org.uk
mssociety.org.uk/library

MS Helpline

The Freephone MS Helpline offers confidential emotional support and information for anyone affected by MS, including family, friends and carers.

Information is available in over 150 languages through an interpreter service.

0808 800 8000 (closed on weekends and bank holidays)

helpline@mssociety.org.uk

Resources

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

020 8438 0999

shop@mssociety.org.uk
mssociety.org.uk/publications

Employment toolkit

A collection of forms, case studies and best practice examples.

mssociety.org.uk/worktoolkit

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With thanks to all those who tested and reviewed this guide. 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.

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Suggestions for improvement in future editions are welcomed. Please send them to resources@mssociety.org.uk

This resource is also available in large print format.
Call 020 8438 0999 or email shop@mssociety.org.uk

Notes:

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Contact us

MS Helpline

Freephone 0808 800 8000
(closed on weekends and bank holidays)
helpline@mssociety.org.uk

MS National Centre

0300 500 8084
info@mssociety.org.uk
supportercare@mssociety.org.uk

Online

mssociety.org.uk
facebook.com/MSSociety
twitter.com/mssocietyuk

MS Society Scotland

0131 335 4050
msscotland@mssociety.org.uk

MS Society Northern Ireland

028 9080 2802
nireception@mssociety.org.uk

MS Society Cymru

0300 500 8084
mscymru@mssociety.org.uk

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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 completing 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're not able to complete 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 will only score for the one that gives you the highest number of points.

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 in just one activity or from any of the activities added together.

! See the **jargon buster** on page 7 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: 0
- 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.
- B** Needs any one or more of the following: 1
- 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
- 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: 2
 - 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.
- 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: 8
 - 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.

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're not able to complete 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 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. 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 overwhelming psychological distress to the claimant. | 4 |
| C | For reasons other than psychological distress, can't plan the route of a journey. | 8 |
| D | For reasons other than psychological distress, 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 | For reasons other than psychological distress, can't follow the route of a familiar journey without another person, an assistance dog or an 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:
i stand or
ii move more than one metre | 12 |

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 have done so badly and are 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 a prosthesis). It shouldn't 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 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 get into or out of an unadapted bath or shower.

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 heat food at or above waist height.

dress and undress includes to put on and take off socks and shoes.

engage socially means:

- mix with others in a way that's right for where you are and who you are with
- understand body language
- establish relationships.

manage incontinence means manage involuntary evacuation of your bowel or bladder, including using a bag or self-catheterisation, and clean yourself afterwards.

manage medication or therapy means take medication or undertake therapy, where a failure to do so is likely to result in a deterioration in your health.

monitor health means:

- detect significant changes in your health condition, which are likely to make your health worse, **and**
- take 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 (such as a long cane if you have a visual impairment) designed to assist disabled people to follow a route safely.

prepare food means to make food from fresh

ingredients ready for cooking or eating.

prompting means reminding, encouraging or explaining by another person.

psychological distress means distress related to an enduring mental health condition or an intellectual or cognitive impairment.

What does it mean if a descriptor says something like 'For reasons other than psychological distress, you can't plan a journey'? This means 'you can't plan a journey but the reason isn't because it causes you a state of distress (such as anxiety), it's because of something else'. In other words, for this descriptor, if something like anxiety stops you doing something, you won't be able to score points for that.

You could still score points on the descriptor if a physical disability caused by MS stops you doing something, or you can't do it because MS affects your memory or thinking (your 'cognition').

read includes read 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 complete 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 required. Consideration should be given to the cumulative effects of symptoms such as pain and fatigue. If the effort it takes you to complete a task then makes you tired and/or in so much pain that you would not be able to do it again or take on another task, then you can't perform the task repeatedly. For example, if you're able to prepare a meal once unaided, but the exhaustion caused to you by

doing this would mean that you couldn't prepare another meal that day, you should be treated as being unable to repeat that activity.

safely means in a way that's unlikely to cause harm to yourself or others either during or after the completion of the activity.

simple budgeting decisions means decisions involving:

- calculating the cost of goods **and**
- calculating change required after a purchase.

simple meal means a cooked, one-course meal for one using fresh ingredients.

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

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

supervision means the continuous presence of another person who makes sure you are safe.

take nutrition means:

- cut food into pieces, put food and drink into your mouth and chew and swallow **or**
- take 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 an un-adapted toilet
- emptying your bladder and bowel **and**
- cleaning yourself afterwards.

unaided means without:

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

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 a minimum of a week.

Date: 25th April

Activity	Morning 7am - 12pm
Going to the toilet (always use grab rails and raised toilet seat)	Managed by myself
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
Cooking (always use perching stool)	Made toast for breakfast on my own
Eating	Managed to eat toast by myself
Medication	
Reading	
Walking	Went to local shops - 400 metres - used electric wheelchair

Date: 26th April

Activity	Morning 7am - 12pm
Going to the toilet (always use grab rails and raised toilet seat)	Managed by myself - stiff and slow first thing
Having a shower	Managed by myself - 35 minutes
Dressing/Undressing	Managed myself - 20 minutes
Cooking (always use perching stool)	
Eating	Had toast that my partner made me
Medication	
Reading	Read paper on the tablet using magnifier
Walking	

Afternoon 12pm - 6pm	Evening 6pm - 11pm	Night 11pm - 7am
	Managed by myself	Unsteady - helped to toilet
Help from friend at swimming pool	Coordination bad - needed help to get pants and tights off	
Cut myself chopping salad	Made evening meal from pre-prepared vegetables. Didn't have potatoes though as I couldn't mash them	
Ate a salad and jacket potato for lunch, which I prepared myself	Help needed chopping up meat	
	Needed help getting pills out of dosette box	
Read paper on tablet using magnifier		
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	

Afternoon 12pm - 6pm	Evening 6pm - 11pm	Night 11pm - 7am
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
Took me nearly an hour to shower after my accident		
Put on pyjamas as had no energy to get dressed again properly	Coordination bad - needed help to get pants and tights off	
	Didn't cook today - too tired	
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	
	Help getting pills out of dosette box	
Read paper on tablet using magnifier		
Exhausted so used indoor wheelchair		

National MS Helpline

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