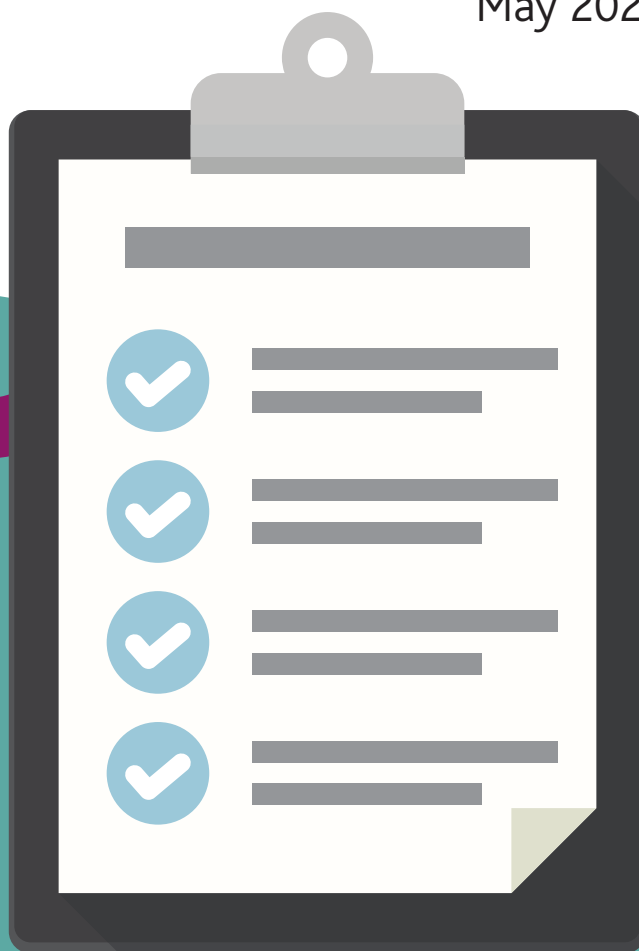




**nras**  
National Rheumatoid  
Arthritis Society

How to claim  
**Personal  
Independence  
Payment**

May 2021



A self-help guide to claiming Personal Independence Payment  
for adults with Rheumatoid Arthritis

# Foreword

Since the foundation of the National Rheumatoid Arthritis Society, we have been aware of the difficulties faced by people with rheumatoid arthritis when the severity of their disease caused them to have to consider applying for Disability Living Allowance (DLA) and now when applying for Personal Independence Payment (PIP).

I remember only too well how many times I re-wrote my own application many years ago and I did not have a clinical nurse specialist (CNS) or anyone, apart from my husband who knew no more than I about it, to help me. It is stressful enough having to come to terms with the many daily activities you struggle to do or find impossible to do without then having to justify why you need additional help.

This is why I am particularly pleased that we have been able to commission the writing of this booklet specifically for people with RA which will, I hope, be of significant help to you if and when you apply for PIP. We would like to thank Ian Greaves and colleagues of Disability Rights UK for their help in compiling and reviewing this booklet. We, at NRAS, are also aware that many of the nurse specialists and other healthcare professionals in rheumatology units around the UK spend many hours helping their patients to fill in the forms and we hope that this booklet will be of value to them too.

I know from talking to our members that many of them are self-effacing and prone to saying things like 'well, there are people who are worse off than me'. Amongst some, there is almost a view that they don't deserve to receive PIP. I would like to try and dispel that view. PIP is intended to be a benefit which enables you to gain a little more independence and help you to achieve things which you can no longer do and **YOU DO NOT NEED TO FEEL GUILTY OR UNDESERVING** about applying for it! Please be aware that this booklet is a guide to applying for this benefit. To obtain the necessary PIP application form you will need to contact the Department for Work and Pensions for England, Scotland and Wales or, the Department for Communities in Northern Ireland. For contact details see page 7.

If there is anything on which you would like further clarification in this booklet, please contact NRAS and we will be pleased to help. If any of your rheumatology team would like a copy of this booklet to enable her/him to provide help for other patients, please ask them to contact NRAS for a complimentary copy.

With best wishes



Ailsa Bosworth, MBE  
National Patient Champion, NRAS

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# Introduction

Personal Independence Payment (PIP) is an important benefit for people with rheumatoid arthritis. It helps cover the extra costs you may face if you need help in taking part in everyday life or find it difficult to get around.

It is the effect of rheumatoid arthritis on you, rather than the fact that you have been diagnosed with this condition, that is central to the benefit. You do not need to have a carer or someone helping you to qualify. PIP is not taxable and you don't need to have paid National Insurance contributions to get it. PIP payments are made directly to you, and you can spend them on anything you like.

You can still claim PIP if you are working, and it is not means-tested. This means that it is not affected by any earnings or benefits you receive or savings you may have. Neither is it treated as income for other benefits that are means-tested, such as Universal Credit, income-related Employment and Support Allowance, Housing Benefit and tax credits. In fact an award of PIP can lead to higher levels of these benefits being paid. PIP can also act as a passport to other benefits, such as Carer's Allowance.

PIP has replaced an earlier benefit, Disability Living Allowance (DLA), for people of working age (ie between the ages of 16 and pension age). Most adults still getting DLA will be re-assessed under PIP at some stage.

A claim for PIP involves completing a long form: 'How your disability affects you'. On the plus side, it means that your opinion is extremely important, and you can give detailed information about your needs.

This booklet aims to provide people of working age who have rheumatoid arthritis with a brief explanation of PIP and a guide to making a claim. It can also be used by carers of anyone with rheumatoid arthritis and any professionals working with people with the condition.

Children under 16 can continue to claim DLA. If you have reached pension age, you may be entitled to Attendance Allowance; more information about this benefit can be found in the NRAS *Benefits and RA* booklet, please contact NRAS for a copy.

Ian Greaves (Disability Rights UK)

Information contained in this booklet is a general guide only.

Whilst every effort has been made to check the information is correct at time of publishing, May 2021, no responsibility can be taken for any omission or error. The National Rheumatoid Arthritis Society, its trustees, employees and agents and anyone else involved in the publication of this booklet will not be liable for any damages or loss occasioned by use of this information.

The information is not a substitute for seeking guidance for individual circumstances from the appropriate agency.



# 1 About the Personal Independence Payment

## Who is eligible?

Personal Independence Payment (PIP) is not paid simply because you have rheumatoid arthritis, but because of the effect that the symptoms of rheumatoid arthritis have on your life.

There are basic qualifying conditions that you must meet before you can qualify for PIP, which we list in Appendix 1.

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

You must normally have met the disability conditions for a 'qualifying period' of three months before you can be paid. You will not have to wait three months for payment on making your claim if you have already met the disability conditions for three months or more. You must also be likely to continue to meet the disability conditions for a period of nine months in the future. The qualifying period conditions will not apply if you are terminally ill; i.e. if your death is expected within the next six months.

## How is PIP made up?

PIP comes in two parts: the 'daily living component' and the 'mobility component'. You can be awarded either, or both, of these components. Each component is paid at two different rates: a standard rate and an enhanced rate.

## The daily living component

The daily living component helps cover the extra costs that you may face if you need help taking part in everyday life. The rate you are paid depends on whether your ability to carry out daily living activities is limited or severely limited. This is tested under the PIP assessment.

## The mobility component

The mobility component helps cover the extra costs that you may face if you have difficulties in getting around. The rate you are paid depends on whether your ability to carry out mobility activities is limited or severely limited. This is tested under the PIP assessment.

## The PIP assessment

The PIP assessment tests your ability to take part in everyday life. It is a points-related assessment. It is based on your ability to perform ten different 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 are entitled to either component of PIP and, if you are, at which rate.

## The ten daily living activities

Your ability to carry out daily living activities is assessed by focusing on ten types of such activity. These 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

Details of these activities, the points you can score from them, and the way that the points are added up, are contained in Appendix 2.

### The two mobility activities

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

- Planning and following journeys
- Moving around

Details of these activities, the points you can score from them, and the way that the points are added up, are contained in Appendix 3. (NB The majority of people with rheumatoid arthritis will gain points on the 'moving around' activity only.)

### How much do you get?

Each component of PIP has two rates, a standard rate and an enhanced rate. You will always get the highest rate to which you are entitled.

<b>Daily living component</b>	<b>per week</b>
Standard	£60.00
Enhanced	£89.60

### Mobility component

Standard	£23.70
Enhanced	£62.55

These figures apply from April 2021 to April 2022.

### What if you go into hospital or a care home?

#### Hospital stays

If you are in hospital, you can make a claim for PIP but if you are aged 18 or over you cannot be paid it during your stay; payment can only start once you leave. If you are already getting PIP when you go into hospital (and are aged 18 or over on the day you enter), it will stop after a total of four weeks (either in one stay, or several stays, where the gaps between stays are no more than four weeks each time). It can restart when you return home.

#### Care home stays

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

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

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

## 2 Applying for PIP

### Starting the claim

You can start your PIP claim by calling 0800 917 2222 (textphone 0800 917 7777; Relay UK, if you cannot hear or speak on the phone, 18001 then 0800 917 2222) or in Northern Ireland 0800 012 1573 (textphone 0800 587 0937). If you are deaf and use British Sign Language, you may be able to claim using a video relay service. For details, see: [www.gov.uk/pip/how-to-claim](http://www.gov.uk/pip/how-to-claim) or, in Northern Ireland, [www.nidirect.gov.uk/contacts/personal-independence-payment-pip-centre](http://www.nidirect.gov.uk/contacts/personal-independence-payment-pip-centre). Someone else can make this call on your behalf, but you need to be with them when they do so. During the call, basic details will be obtained from you, including:

- Your full name, address and telephone number
- Your National Insurance number
- Your date of birth
- Your bank or building society account details
- Details of your GP and any other health professionals who support you, and which would be the best to contact
- Details of any recent stays in hospital or care homes
- Your nationality or immigration status
- Details of any time spent abroad over the last three years
- Whether you find it difficult to return forms (for instance if you have memory problems)

If you can, have this information ready when you make the call. The information you provide should allow the Department for Work and Pensions (DWP), or the Disability and Carers Service (DCS) in Northern Ireland, to decide whether or not you meet the basic qualifying conditions for PIP (see Appendix 1).

**Please note:** If you are already getting Disability Living Allowance, you will not be automatically transferred to PIP but will be invited to claim PIP at some point so that you can be re-assessed under the new benefit. A letter advising you of the changes and inviting you to claim will be sent out before the re-assessment.

### Paper claims

You can ask for a paper claim-form. To request the form, write to: Personal Independence Payment New Claims, Post Handling Site B, Wolverhampton, WV99 1AH (or in Northern Ireland, Personal Independence Payment Centre, Castle Court, Royal Avenue, Belfast BT1 1HR).

### What happens next?

If it is clear from the information that you have provided that you do not meet the basic qualifying conditions for PIP, the DWP or DCS will send you a letter stating that your claim has been disallowed. If you do meet the basic qualifying conditions, you will normally be sent a form to complete: *'How your disability affects you'*.

### Not ready to claim yet?

If you're not yet ready to claim PIP, but have a general enquiry about it, don't call the new claims number, but use the PIP enquiry line instead:

#### Department for Work and Pensions

##### Personal Independence Payment Enquiry Line

Tel: 0800 121 4433

Textphone: 0800 121 4493

Relay UK: 18001 then 0800 121 4433

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**2 in 5 lonely or desperate calls to  
our helpline would go unanswered  
without Gifts in Wills**



# 3 Completing the 'How your disability affects you' form

The 'How your disability affects you' form gives you the chance to describe how your condition affects your daily life. You should receive an information booklet with the form. Read both before you start filling the form in. You may wish to write in pencil first, or make notes on paper or on a photocopy of the form, before committing yourself to pen.

The bulk of the form asks questions relating to the points-based PIP assessment (see Chapter 1 and *Appendices 2 to 4* in this booklet). You score points for what you cannot manage, not for what you can. This can seem negative, but try not to be discouraged. It is important to be clear about your difficulties and that you do not underplay the impact of any of these, so that you are assessed accurately. Give yourself plenty of time to complete the form - you don't need to do it all at once.

## How long do you have to complete the form?

You have one calendar month in which to return the 'How your disability affects you' form from the date it was sent to you. If you do not return the form within the month without good reason (taking into account your health and the nature of your disability) your claim will be disallowed. If you are not able to return the form within one month (eg because you need help to complete it but cannot get an appointment with an advice centre in time), contact the Department for Work and Pensions (DWP) or the Disability and Carers Service (DCS) in Northern Ireland, to explain this. They can extend the one-month\* time limit if they agree there is a good reason to do so.

\* during the coronavirus pandemic, this period is extended to three months.

We now look at the questions in detail.

### Question 1

The first question on the form asks for details of the professional(s) who are best placed to provide advice on how your disability or health condition affects you. This could be your GP, consultant rheumatologist or a specialist nurse. If possible, make an appointment with them, so that you can discuss the claim with them. They will need to know about your daily living needs and any mobility problems you may have. If you have written a diary (see Chapter 4 in this booklet), give them a copy.

### Question 2

The second question asks about your health conditions or disabilities and approximately when each of these

started. You do not need to go into detail about how they affect you; there is room later in the form for that. You are asked to list any tablets or other medication you are taking or treatments you are having; if you have a printed prescription list, you can attach that. If you have any side effects from the medication, you should list these.

## THE DAILY LIVING COMPONENT

The next ten questions relate to the daily living component activities. Each activity has a set of 'descriptors'. These describe related tasks of varying degrees of difficulty and different types of help you need to complete each task. You score points for the descriptor that best describes the level at which you can complete the task safely, to an acceptable standard, repeatedly and in a reasonable time. The activities, the descriptors and the points allocated to each descriptor are listed in Appendix 2 of this booklet. Note that the wording in the form is sometimes different from the wording in Appendix 2, in which we use the exact wording of the law.

Each question occupies a couple of pages. The first page introduces the activity and explains what is relevant; a tick box section follows.

### The tick box section

Firstly, you are asked if you use an aid or appliance to complete the activity. If it is accepted that you do and using it is necessary, you will usually be awarded at least two points under that activity.

Secondly, you are asked if you need help from someone with that activity. If it is accepted that you do need help, you will get between one and ten points under the activity, depending on the activity concerned and the nature of the help that you need (from just supervision or prompting to physical assistance).

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

### The extra information box

The second page of each question has a box where you can explain what difficulties you face with each activity. Examples are given above the box and in the information booklet that comes with the form.

You should write down in the box which descriptor you believe applies to you and explain why it applies. Use *Appendix 2* in this booklet, which lists the descriptors and the points allocated to each one. In each case, you need to consider whether or not you can do the activity **safely, to an acceptable standard, as often as you need to and in**



**a reasonable time** (see *Appendix 4* in this booklet for how these terms are defined).

Different descriptors may apply to you at different times. This is most likely to be the case if you are prone to flare ups. A descriptor will apply to you if it reflects your ability for the majority of days.

Where one descriptor is satisfied on over half of the days, that descriptor will apply. Where two or more descriptors are satisfied on over half the days, the descriptor which scores the highest number of points will apply. If you are not sure which descriptor applies to you, keeping a diary over a week may help you to choose the correct one – see Chapter 4 in this booklet.

We now look at the questions in more detail, focusing on those questions that are most likely to be relevant to you, suggesting the kind of things you need to mention in the 'extra information' box for each question. It is always worth bearing in mind whether you can do all of these activities **safely, to an acceptable standard, as often as you need to and in a reasonable time.**

### Question 3 – Preparing food

This question focuses on your ability to prepare and cook a simple meal. A 'simple meal' is a cooked, one-course meal for one using fresh ingredients. It is not intended to be a meal made up of convenience foods, such as pies or frozen vegetables, that involve no real preparation. 'Preparing' food means making the food ready for cooking and eating. This could include opening packaging (including opening tins with a tin opener), checking the food is not out of date, peeling and chopping the food and serving the meal. 'Cooking' food means heating food safely at or above waist height (eg using a cooker hob or a microwave oven); any difficulties you may have in bending down to use an oven will not be relevant here.

Describe any part of cooking such a meal that you would have difficulties with. For instance, if your finger or wrist joints are painful then you may have difficulties with peeling and chopping vegetables, using cooking utensils, opening tins, bottles and packets or turning taps on and off. If you need to buy pre-chopped vegetables, say so.

Poor grip could make it dangerous for you to use hot pans. Painful knee or hip joints may make it difficult to stand to use the oven. If your eyesight is damaged, you may have problems in finding and measuring the correct ingredients and other aspects of cooking might be dangerous. List any incidents that may have happened in the past. Have you cut yourself mishandling knives or burnt yourself on hot pans?

### Question 4 – Eating and drinking

This activity is called '*Taking nutrition*' in *Appendix 2* of this booklet. Write down if pain in your finger or wrist joints or poor grip make it difficult for you to use cutlery properly or manage hot drinks safely. If you can cut up some food, but cannot cut up tougher items, such as meat, write this down. Write down if you use any aid to help you eat or

drink (such as adapted cutlery). If you tend to drop food or spill drinks, let them know if you then need any help in cleaning up afterwards.

### Question 5 – Managing treatments

This activity is called '*Managing therapy or monitoring a health condition*' in *Appendix 2*. 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 support managing therapy.

Let them know if you have pain in your finger or wrist joints or poor grip which causes difficulties with things like opening pill bottles, injecting yourself or pouring out medicine. If your eyesight is damaged, you might need someone to read the labels and instructions on your medication. Explain if there are side effects from any of the medications that you take and if you need any extra help because of these. Also write down if you have been advised to do physiotherapy or exercises at home, and if you need help doing them.

Write down how many hours on average each week you need supervision or assistance with your therapy. You may find it helpful to keep a diary over a typical week to answer this correctly (see Chapter 4 in this booklet). Check *Appendix 2* to see what points you get for particular time periods; eg if you need such help for more than 7 hours, but no more than 14 hours a week, you would get 6 points.

### Question 6 – Washing and bathing

Write down any aids or adaptations that you use to wash or bathe yourself. These could include a long-handled sponge, a shower seat or a bath rail. Let them know if there are any parts of your body that you cannot reach even using such aids (eg if you could not wash your back properly). If you have fallen trying to get in or out of the bath or shower by yourself, mention this.

### Question 7 – Managing toilet needs

This activity is called '*Managing toilet needs or incontinence*' in *Appendix 2*. 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.

Mention any difficulties you may have in using the toilet, including sitting down or getting back 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. It might be due to the medication you are on.

Write down if you need to use any aids, such as a commode, raised toilet seat, bottom wiper or bidet. Write down if you still need help even when you use such an aid.

If you are incontinent, write about the help that you need in dealing with it. This can include cleaning yourself afterwards.

### Question 8 – Dressing and undressing

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

If you have any pain in your finger or wrist joints or poor grip, then you may well have difficulties with laces, buttons and other types of fastening. Pain or stiffness in elbow, shoulder, hip or knee joints or in your back 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 article of clothing.

If you live by yourself, write down if there are days when you do not dress because of the pain or discomfort involved. Also, state if you avoid putting on certain clothes, which you would 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 does not take long. Let them know if you need someone to choose clothing that is clean and appropriate (for instance if your eyesight is damaged and you cannot see stains or marks on clothing).

### Question 9 – Communicating

This activity is called '*Communicating verbally*' in *Appendix 2*. It focuses on your ability to convey and understand verbal information.

### Question 10 – Reading

This activity is called '*Reading and understanding signs, symbols and words*' in *Appendix 2*. If your eyesight is damaged, 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, reading radio and TV listings or the newspaper.

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

### Question 11 – Mixing with other people

This activity is called '*Engaging with other people face to face*' in *Appendix 2*. It considers your ability to engage socially. Any inability you have to mix with other people must result from your condition (eg fatigue), rather than shyness.

### Question 12 – Making decisions about money

This activity is called '*Making budgeting decisions*' in *Appendix 2*. It focuses on your ability to spend and manage money.

## THE MOBILITY COMPONENT

The next two questions relate to the mobility component activities. Each activity has a set of '*descriptors*'. These describe related tasks of varying degrees of difficulty. You score points for the descriptor that best describes the level at which you can complete the task safely, to an acceptable standard, repeatedly and in a reasonable time. The activities, the descriptors and the points allocated to each descriptor are listed in *Appendix 3* of this booklet. Note that the wording in the form is sometimes different from the wording in *Appendix 3*, in which we use the exact wording of the law.

Each question occupies a couple of pages. The first page introduces the activity and explains what is relevant. A tick box section follows. The second page of each question has a box where you can explain what difficulties you face with each activity. Examples are given above the box and in the information booklet that comes with the form.

You should write down in the box which descriptor applies to you and explain why it applies. Use *Appendix 3*, which lists the descriptors and the points allocated to each one. In each case you need to consider whether or not you can do the activity **safely, to an acceptable standard, as often as you need to and in a reasonable time** (see *Appendix 4* for how these terms are defined).

A descriptor will apply to you if it reflects your ability for the majority of days. Where one descriptor is satisfied on over half of the days, that descriptor will apply. Where two or more descriptors are satisfied on over half of the days, the descriptor which scores the highest number of points will apply. If you are not sure which descriptor applies to you, keeping a diary over a week may help you to choose the correct one - see Chapter 4 in this booklet. Also mention how often your disease flares, especially if it is cyclical in nature and describe how a flare might affect this activity.

### Question 13 – Going out

This activity is called '*Planning and following journeys*' in *Appendix 3* in this booklet. It assesses your ability to work out and follow a route safely and reliably. If your eyesight is damaged, you may need to be accompanied by another person, particularly on an unfamiliar journey. Would you need such 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 do not go out alone, make this clear. Explain where you would like to go if you had someone to accompany you.

### Question 14 – Moving around

This activity focuses on your physical ability to stand and then move around without severe discomfort. Severe discomfort does not just mean pain, but can also include extreme fatigue.

Normally, when you are in severe discomfort you would not 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 box section

The tick box section for this question asks you to identify how far you can walk, using, if necessary, any aids such as a walking stick, frame or crutches. **It is important that you consider 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 'It varies' box if none of the other boxes apply for **at least half of the time**. If you do tick the 'It varies' box, explain why in the 'extra information' box (eg "*On an average week, on three days I can manage to walk about 40 metres before I can go no further; on another three days this distance is 20 metres, and on one day I cannot walk at all without severe discomfort*"). A diary kept over a week, identifying your walking limit on each day, may help clarify matters.

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

### 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 your knee or ankle joints frequently give way or if you cannot bear to put all your weight onto either one leg or the other.

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 joint stiffness, or because one of your legs gives way at the knee or the ankle. Alternatively, you may fall over things because your vision has been affected. You may fall at different times for different reasons, or for a combination of reasons. List any injuries that you have suffered when you have fallen and any treatment that you may have 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

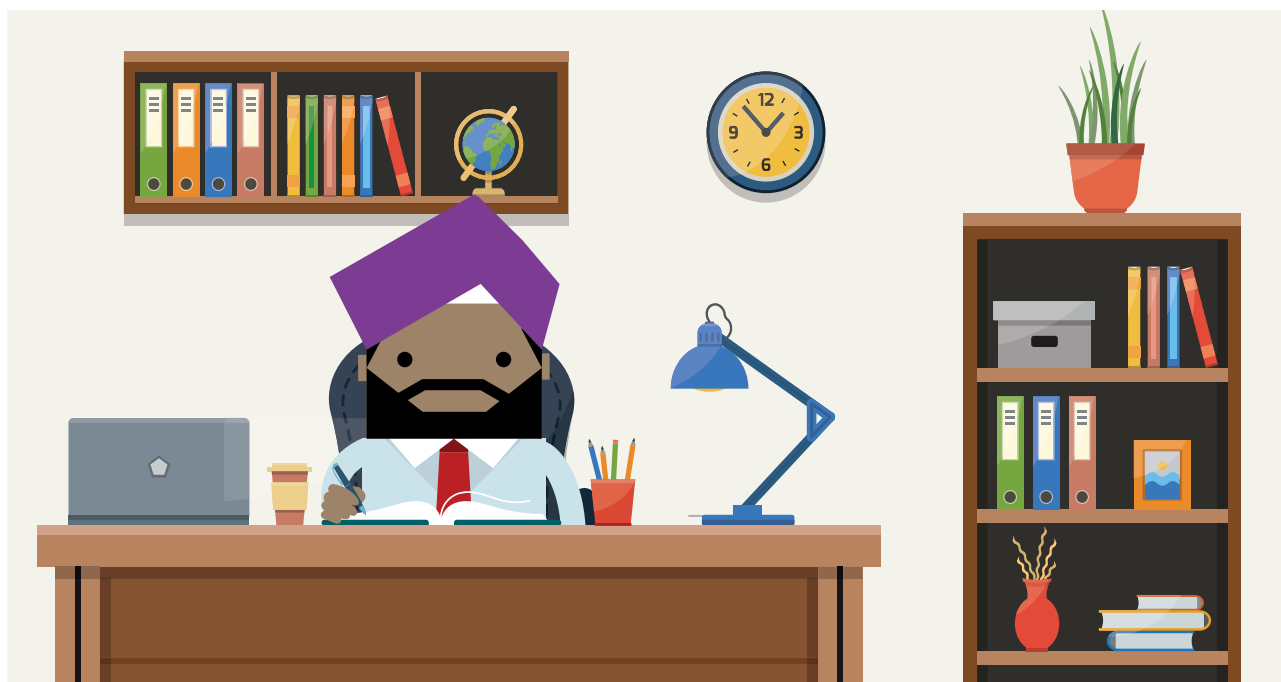
This box provides more space for you to explain your problems. If you run out of space, use extra sheets of paper, which you need to write your name and National Insurance number on.

### The declaration

Once you are satisfied that what you have written on the form is a true and accurate reflection of your situation, sign and date the declaration. It's important to send photocopies of any additional evidence that you have to the DWP or DCS with the form. For example, this could include copies of: prescriptions, care and support plans and information from professionals such as a GP, hospital doctor, specialist nurse, occupational therapist, physiotherapist, social worker, support worker or counsellor.

If you have produced a diary (see the next Chapter), attach a copy of that.

You should make a copy of the form and any evidence that you attach to it before sending it off. This is for your future reference or in case the DWP or DCS loses any of the documents.



## 4 Keeping a diary

A diary is useful as evidence to help the Department for Work and Pensions (DWP), or Disability and Carers Service (DCS) in Northern Ireland, 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.

The simplest form of diary would be a one-day diary. Start from the time you get up in the morning, through a 24-hour period, ending with the time you get up the following morning. *Appendix 5* provides an example of a one-day diary and *Appendix 6* provides a template you can use to write your own.

If your condition varies from day to day, it would be a good idea to keep the diary over several days. For instance, a diary covering a typical week should give the DWP or DCS an idea of what you are like both on good days and bad days.

### What to include in your diary

Focus on the activities listed in Appendices 2 and 3 of this booklet. 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 are unsafe managing on your own – accidents have happened or nearly happened

- You cannot complete the activity to an acceptable standard
- You are not able to repeat the activity as often as you need to
- 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.

### Longer diaries

If your condition varies from week to week or month to month, which may well be the case if you are prone to flare ups, you may want to write a simple diary over a longer period to give an impression of how you are over time. *Appendix 7* gives an example of such a diary.

### 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' actually applies to you.

You can give a copy of the diary to any of the people that you have mentioned on the 'How your disability affects you' form (see Chapter 3 in this guide). Finally, you could attach a copy of the diary to the form when you send it off.

# 5 How your claim is assessed

Once your 'How your disability affects you' form has been returned, your case will be passed to one of the two companies contracted to carry out the PIP assessments on behalf of the Department for Work and Pensions (DWP) or the Disability and Carers Service (DCS) in Northern Ireland: Capita and Independent Assessment Services (IAS). Capita covers Wales, Central England and Northern Ireland and IAS covers the rest of the UK. Once your case has been passed to one of the two companies, they will allocate it to a healthcare professional working for them.

This healthcare professional may initially contact your doctor, rheumatologist, specialist nurse or occupational therapist for further information. However, in most cases, the healthcare professional will arrange for you to take part in a telephone, video or face-to-face consultation'.

## Where will the consultation take place?

The telephone, video or face-to-face consultation will be carried out by the healthcare professional assigned to your case. At time of writing, all consultations are taking place by video or over the phone, due to the coronavirus pandemic.

A face-to-face consultation will normally take place in an Assessment Centre. You can claim travel expenses for yourself and a companion or carer. You can also make a claim if you have a young child who needs to come with you if they cannot be left unattended. A home visit, video or telephone consultation should be arranged if you provide evidence from your doctor, rheumatologist or specialist nurse that you are unable to travel on health grounds.

## How much notice will you be given?

You must be given at least seven days' notice of the consultation, unless you agree to accept a shorter notice period. If you cannot take part, inform the office arranging the consultation as soon as possible..

## Can you get help with travel costs?

The company carrying out the assessment can pay your travel costs for you to attend the assessment. When they send you the appointment, they will include a travel expenses claim form. You can also claim travel expenses for someone to accompany you, and for young children who would otherwise be left alone.

If you cannot travel by public transport, you can claim for taxi fares. You need to get approval in advance for this.

## What will happen if you do not take part?

If you do not attend or take part in the assessment without good reason (taking into account your health and the nature of your disability), your claim will be disallowed. You should first be contacted and asked to explain your reasons. If the DWP or DCS decides that you did not have a good reason, you can ask them to reconsider the decision. If you are unhappy with their reconsidered decision, you then have a right to appeal (see Chapter 6).

## Can anyone else take part?

If you have a carer, you could ask them to join a video or phone consultation (even if you are based in different locations) or attend a face-to-face consultation with you. Your carer will not be able to answer questions on your behalf (unless the healthcare professional cannot understand your speech or you cannot understand their questions), but they will be able to add to what you have to say, particularly with respect to their role as carer..

## What happens at the consultation?

At the consultation, the healthcare professional will identify the descriptors that they consider apply to you with respect to the PIP assessment (see *Appendices 2 and 3*). To do this, they will ask questions about your day-to-day life, your home, how you manage at work if you have a job, and about any social or leisure activities that you take part in (or have had to give up).

They will often ask you to describe a typical day in your life.

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. Also consider how you would feel if you had to do the same task repeatedly.

Don't overestimate your ability to do things. If your condition varies, let them know about what you are like on bad days as well as good days and how often you have good and bad days. The healthcare professional's opinion should not be based on a snapshot of your condition on the day of the consultation; they should consider the effects of your condition over time.

At a face-to-face consultation, the healthcare professional will be able to see you stand, sit and move around. They may watch you getting on and off the examination couch or your settee and bending down to pick up your belongings. They will check whether you have any aids or appliances, and the extent to which you use them.



The healthcare professional may carry out a brief physical examination. They should explain each stage of the examination to you and ask your permission before carrying anything out. They should test 'active' rather than 'passive' movements – an active movement is entirely voluntary and done without any help, whereas a passive movement is one where someone helps you. You should not be asked to do anything that will cause you pain either during or after the consultation.

Before the consultation ends, the healthcare professional should give you an overview of their findings and invite you to ask questions or add to what you have told them. You will not be told during the consultation whether or not you will be awarded PIP. At a face-to-face consultation, if you have written evidence that you've not yet sent to the DWP or DCS, such as a letter from your doctor or other health or social care professional, you can give it to the health professional. They should take a copy of it and consider it with the other evidence.

## The decision

Following the consultation, the healthcare professional will complete their report. Once they have done this, they will send it to a DWP or DCS case manager who will decide whether or not to award you PIP and, if it is awarded, at what rate and for how long.

## If you are awarded PIP

If the case manager decides to award you PIP, you will be sent a letter telling you about the decision. Your 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 (ie one that does not have a fixed term) would only be considered if the case manager considers that it is unlikely that your needs will change in the future.

If you have been awarded PIP but consider that you should have been awarded a higher rate, you can ask for a mandatory reconsideration (see the next chapter).

## If your claim is turned down

If the case manager decides to disallow your claim, you will be sent a letter notifying you of the decision. The letter will tell you which descriptors they think apply and why they have chosen them. If you disagree with the decision, you can ask for a mandatory reconsideration (see the next chapter).

# 6 If you are not happy with the decision

## Mandatory reconsiderations

If your claim is turned down, you have one calendar month from the date of the decision in which to ask the Department for Work and Pensions (DWP), or the Disability and Carers Service (DCS) in Northern Ireland, to look at the decision again. This is called a '*mandatory reconsideration*'. You can also ask for a mandatory reconsideration if you are unhappy with:

- The level of the benefit that has been awarded (for example, if you are awarded the standard rate of the daily living component, but believe you are entitled to the enhanced rate); or
- The period for which it has been awarded.

Be careful however, because when you ask for a mandatory reconsideration, the DWP or DCS will look at the whole award and they can take away the rate of PIP you have already been granted. If you are in any doubt, seek advice from a local advice centre, such as Citizens Advice (see Useful organisations at the end of this booklet).

NB: You cannot appeal against the decision (see the next page) without having gone through the mandatory reconsideration process first.

## How to ask for a mandatory reconsideration

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

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

You can also do this using a CRMR1 '*mandatory reconsideration request form*' (available at: [www.gov.uk/government/publications/challenge-a-decision-made-by-the-department-for-work-and-pensions-dwp](http://www.gov.uk/government/publications/challenge-a-decision-made-by-the-department-for-work-and-pensions-dwp)).

If you phone, put your request in writing as well; keep a copy for yourself. If you have not received the evidence after two weeks, call the DWP or DCS again to remind them to send it.

## Building a case

When you do receive the evidence, you should gain 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 will also be a report produced by the healthcare professional at the consultation. Compare their report with what you wrote on your form.

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 healthcare professional noted in their report that they thought you could manage by yourself. Now try to get medical evidence showing that what you said on the form was correct – for example a letter from your doctor or rheumatologist confirming the difficulties and risks you have getting on and off the toilet unassisted.

Once you have obtained evidence to support your case, send it to the address on the decision letter. If you need more time to obtain the evidence, you must inform the DWP or DCS how long this is likely to take, so they do not make a decision straight away. A case manager will look at any further evidence you send. They will then either change the decision in your favour or let you know that they have been unable to change the decision; they will do this on a '*mandatory reconsideration notice*'. You now have one calendar month from the date of the notice to appeal to an independent tribunal.

## Lodging the appeal

You cannot appeal unless you have first asked for a mandatory reconsideration of the decision (see above). You can appeal against a decision on the official appeal form SSCS1 (or the NOA1(SS) in Northern Ireland) – the mandatory reconsideration notice will tell you how to get one of these. You must appeal within one calendar month of the date on the mandatory reconsideration notice. It is important to appeal in time, otherwise you might lose the chance to challenge the decision.

On the appeal form, give your name and address and that of your representative, if you have one. Give details of the decision you are appealing against (i.e. 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 form will ask whether you want to take part in your appeal hearing. If you take part, it is an 'oral hearing' and can be by telephone, video or face-to-face. It is better to take part in your hearing if you can. Make a copy of the completed form.

You should attach a copy of the mandatory reconsideration notice to the completed appeal form. Send the appeal form to HM Courts and Tribunals Service (HMCTS) or The Appeals Service (TAS) in Northern Ireland; the relevant address will be listed in the form.

## What happens next?

When HMCTS or TAS receive your appeal form, they will send you an acknowledgement letter. A copy of your appeal will also be sent to the Department for Work and Pensions (DWP) or the Disability and Carers Service (DCS) in Northern Ireland. The DWP or DCS will write a response to your appeal and return it to HMCTS or TAS with copies of all the documents that are 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; they are not like courts. If you have a carer, they can take part in the hearing as well to provide their account of your needs. You can contact a local advice centre, such as Citizens Advice (see *Useful organisations* at the end of this booklet) to see if they can give you any support with an appeal and possibly provide you with a representative to present your case at the hearing.

## What if your condition changes in the future?

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

Be aware that the DWP or DCS 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 Appendices 2 and 3 in this booklet to make sure that you meet the conditions for the new component or the higher rate. You will have to have met 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 Citizens Advice (see *Useful organisations*).

If there is an improvement in your condition and consequently an improvement in your mobility or a reduction in your daily living needs, you have to inform the DWP or DCS. Forms will duly be sent out and your benefit reviewed.



## A.1 The basic qualifying conditions

To be entitled to PIP, you must meet all of the following basic qualifying conditions:

- You must be aged 16 or over and under pension age when you first claim. You will not be able to claim PIP for the first time once you have reached pension age but you will be able to stay on PIP if you claimed it before you reached that age.

If you have reached pension age (currently 66), you can claim Attendance Allowance instead if you have care needs. If you have a child under 16 who has care needs or mobility problems, they can claim Disability Living Allowance instead.

- You must normally have been present in Great Britain (GB) for 2 out of the last 3 years before claiming. If you are terminally ill, you only have to be present in GB; you do not need to have been present for 2 out of the last 3 years.
- You must be habitually resident (i.e. normally live) in the United Kingdom, the Channel Islands, the Republic of Ireland or the Isle of Man. You must not be subject to immigration control.

## A.2 Daily living activities: descriptors and scores

Each activity has a set of '*descriptors*'. These describe related tasks of varying degrees of difficulty and different types of help you need to complete each task. You score points for the descriptor that best describes the level at which you can complete the task safely, to an acceptable standard, repeatedly and in a reasonable time period. 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 daily living component, you need to score at least 8 points; to be entitled to the enhanced rate, you need to score at least 12 points. These points can be scored in just one activity or from any of the activities added together.

For the meaning of the terms and phrases used in this table, see *Appendix 4*.

	DESCRIPTOR	SCORE
<b>Activity 1: Preparing food</b>		
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	Cannot 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	Cannot prepare and cook food.	8
<b>Activity 2: Taking nutrition</b>		
a	Can take nutrition unaided.	0
b	Needs <ul style="list-style-type: none"> <li>(i) to use an aid or appliance to be able to take nutrition; or</li> <li>(ii) supervision to be able to take nutrition; or</li> <li>(iii) assistance to be able to cut up food</li> </ul>	2
c	Needs a therapeutic source to be able to take nutrition.	2

	DESCRIPTOR	SCORE
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### Activity 2: Taking nutrition

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	Cannot 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 condition.	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 7 hours a week.	4
e	Needs supervision, prompting or assistance to be able to manage therapy that takes more than 7 but no more than 14 hours a week	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	Need 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 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	Cannot 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

DESCRIPTOR		SCORE
<b>Activity 6: Dressing and undressing</b>		
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	Cannot dress or undress at all.	8
<b>Activity 7: Communicating verbally</b>		
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	Cannot express or understand verbal information at all even with communication support.	12
<b>Activity 8: Reading and understanding signs, symbols and words</b>		
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	Cannot read or understand signs, symbols or words at all.	8
<b>Activity 9: Engaging with other people face to face</b>		
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	Cannot engage with other people due to such engagement causing either (i) overwhelming psychological distress to the claimant; or (ii) the claimant to exhibit behaviour which would result in a substantial risk of harm to the claimant or another person.	8
<b>Activity 10: Making budgeting decisions</b>		
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	Cannot make any budgeting decisions at all.	6

## A.3 Mobility activities: descriptors and scores

Each activity has a set of 'descriptors'. These describe related tasks of varying degrees of difficulty. You score points for the descriptor that best describes the level at which you can complete the task safely, to an acceptable standard, repeatedly and in a reasonable time period. 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 8 points; to be

entitled to the enhanced rate, you need to score at least 12 points.

NB The majority of people with rheumatoid arthritis will gain points on Activity 2 only. To be eligible for a Blue Badge you will need to score at least 8 points and for the Motability Scheme at least 12 points.

For the meaning of the terms and phrases used in this table, see *Appendix 4*.

	DESCRIPTOR	SCORE
<b>Activity 1: Planning and following journeys</b>		
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	Cannot plan the route of a journey.	8
d	Cannot follow the route of an unfamiliar journey without another person, assistance dog or orientation aid.	10
e	Cannot undertake any journey because it would cause overwhelming psychological distress to the claimant.	10
f	Cannot follow the route of a familiar journey without another person, an assistance dog or an orientation aid.	12
<b>Activity 2: Moving around</b>		
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 1 metre but no more than 20 metres, either aided or unaided.	12
f	Cannot, either aided or unaided, (i) stand; or (ii) move more than 1 metre.	12

## A.4 Definitions

The following is a list of meanings of the words and phrases that are used in Appendices 3 and 4.

**Acceptable standard** This means of a standard that most people would normally expect to achieve. An example of not completing a task to an acceptable standard would be where someone can physically wash themselves but does not realise they have done so badly and are still not clean after they have finished.

**Aid or appliance** This means any device which improves, provides or replaces your impaired physical or mental function (e.g. walking sticks). In assessing your ability to carry out a task, you will be assessed as if wearing or using any aid or appliance that you would normally wear or use, or which you could reasonably be expected to wear or use if you do not currently do so.

**Aided** This means with

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

**Assistance** This means physical intervention by another person and does not include speech.

**Assistance dog** This means a dog trained to guide or assist a person with a sensory impairment.

**Basic verbal information** This means information in your own language conveyed verbally in a simple sentence.

**Basic written information** This means signs, symbols and dates of written or printed standard size text in your own language.

**Bathe** This includes getting into or out of an un-adapted bath or shower.

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

**Complex budgeting decisions** This means decisions involving:

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

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

**Complex written information** This means more than one sentence of written or printed standard size text in your own language.

**Cook** This means heat food safely at or above waist height.

**Dress and undress** This includes putting on and taking off socks and shoes.

**Engage socially** This means

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

**Manage incontinence** This means managing involuntary evacuation of your bowel or bladder, including using a collecting device (such as a bottle or bucket) or catheter, and cleaning yourself afterwards.

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

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

**Medication** This means medication to be taken at home which is prescribed or recommended by a registered:

- (a) doctor;
- (b) nurse; or
- (c) pharmacist.

**Monitor health** This means

- (a) detecting significant changes in your health condition which are likely to lead to a deterioration in your health; and
- (b) taking action advised by a: (i) registered doctor; (ii) registered nurse; or (iii) health professional who is regulated by the Health and Care Professions Council, without which your health is likely to deteriorate.

**Orientation aid** This means a specialist aid designed to assist disabled people to follow a route safely.

**Prepare** In the context of food, this means make food ready for cooking or eating.

**Prompting** This means reminding, encouraging or explaining by another person.

**Psychological distress** This means distress related to an enduring mental health condition or an intellectual or cognitive impairment.

**Read** This includes reading signs, symbols and words but does not include reading Braille.

**Repeatedly** This 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.

Consequently, if the effort it takes you to complete a task then makes you tired and/or in pain so much that you would not be able to do it again or take on another task, then you cannot perform the task 'repeatedly'. For example, if you are able to prepare breakfast unaided, but the exhaustion caused to you by doing this would mean that you could not prepare another meal that day, you should be treated as being unable to prepare a meal unaided.

**Reasonable time period** This means no more than twice as long as someone without a disability would normally take.

**Safely** This means in a manner unlikely to cause harm to you or to another person, either during or after the completion of the task.

**Simple budgeting decisions** This means decisions involving:

- (a) calculating the cost of goods; and
- (b) calculating change needed after a purchase.

**Simple meal** This means a cooked one-course meal for one using fresh ingredients.

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

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

**Supervision** This means the continuous presence of another person to ensure your safety.

**Take nutrition** This means

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

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

**Therapy** This means therapy to be undertaken at home which is prescribed or recommended by a

- (a) registered – (i) doctor; (ii) nurse; or (iii) pharmacist; or
- (b) health professional regulated by the Health and Care Professions Council.

**Toilet needs** This means

- (a) getting on and off an un-adapted toilet;
- (b) evacuating your bladder and bowel; and
- (c) cleaning yourself afterwards.

**Unaided** This means without

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

## A.5 One-day diary

This is a diary for a 47 year old man who was diagnosed as having rheumatoid arthritis eight years ago. Whilst most of his joints have at some time been affected, his knees and elbows cause him the most problems and his right knee and left elbow have permanent damage. He lives by himself and has written about the help that he really needs rather than the help he actually currently gets.

ACTIVITY	MORNING 7am-12pm	AFTERNOON 12pm-6pm	EVENING 6pm-11pm	NIGHT 11pm-7am
<b>Cooking</b>	Although I would like a cooked breakfast, I do not have one, as there is usually no-one to help me.	A friendly neighbour calls round at 12.45pm to cook me a meal. I cannot safely cook a main meal. My fingers are stiff, so I have difficulty peeling and chopping vegetables properly. There is limited movement in my left elbow, so I cannot drain pans or lift them safely off hobs.	I normally have a salad at teatime, which I can prepare myself (my neighbour cuts a few tomatoes up for me at dinnertime).	
<b>Eating</b>		My neighbour cuts up the beef as it is quite tough.		
<b>Medication and therapy</b>		1.30pm: I do some leg exercises that my physio has recommended. My neighbour helps me with these. These take about twenty minutes; I should do them every day.	I had trouble opening pain-killing tablets, which ended up on the floor.	
<b>Washing/ bathing</b>	8.55-9.10am: Help needed climbing into the shower, which is in the bath, mainly because of the pain and limited movement in my right knee. The general stiffness makes it worse. I need help washing and drying those parts of my body that I cannot reach with my good (right) arm.		Needed to wash myself (see below). I don't think I did this very well.	
<b>Going to the toilet</b>	I always use a grab-rail and raised toilet seat. My joints are particularly stiff in the morning. I find it difficult to get on and off the toilet; last week my right knee gave way when doing this and I ended up on the toilet floor.		3.45pm Had a small accident; did not get to the toilet in time. I had to change my wet under-pants. Not easy.	3.15am Needed to go to the toilet. I am very stiff at night and need steadying when rising from the toilet. I do not think I wiped myself properly.

ACTIVITY	MORNING 7am-12pm	AFTERNOON 12pm-6pm	EVENING 6pm-11pm	NIGHT 11pm-7am
<b>Dressing/ Undressing</b>	<p>Help needed putting on trousers, underpants and shirt because of the pain and limited movement in my right knee and left elbow.</p> <p>I need a hand with buttons, zips and laces as my fingers tend to be stiff in the morning (I often do not attempt to dress myself until after lunch).</p>			
<b>Walking</b>		<p>I walked to the local shop for a paper. I am lucky, it is only about 80 metres away, with somewhere where I can rest every 20 metres (for ten minutes or so until the pain in my right knee goes down).</p> <p>I could not do this again today. I use two sticks.</p>		



# A.6 Your activity diary template

NAME: .....

ADDRESS: .....

.....

NATIONAL INSURANCE NUMBER .....

ACTIVITY	MORNING 7am-12pm	AFTERNOON 12pm-6pm	EVENING 6pm-11pm	NIGHT 11pm-7am
Cooking				
Eating				
Managing therapy				
Medication				
Washing/ bathing				
Going to the toilet				
Dressing/ Undressing				
Communicating				
Reading				
Meeting people				
Budgeting				
Planning journeys				
Walking				

## A.7 Long-term diary

This is a long-term diary produced by a 34-year-old woman, detailing which of her joints have been affected over different periods, and to what extent. She will have also produced a one-day diary.

### January

**Week commencing 5th:** Left ankle (moderate), both knees (severe), both elbows (moderate), fingers (moderate).

**w/c 12th:** Both knees (severe), both elbows (moderate), fingers (moderate).

**w/c 19th:** Both knees (severe), both elbows (moderate), right shoulder (mild), fingers (moderate).

**w/c 26th:** Both knees (moderate), both elbows (moderate), fingers (moderate).

### February

**w/c 2nd:** Both knees (moderate), lower back (moderate), both elbows (moderate), fingers (moderate).

**w/c 9th:** Both knees (severe), lower back (moderate), both elbows (moderate), fingers (moderate).

**w/c 16th:** Both knees (severe), lower back (moderate), both elbows (mild), fingers (moderate).

**w/c 23rd:** Both knees (severe), lower back (mild), both elbows (mild), fingers (moderate)

### March

**w/c 2nd:** Both knees (severe), fingers (moderate).

**w/c 9th:** Both knees (severe), neck (mild), fingers (mild).

**w/c 16th:** Both knees (moderate), neck (mild), fingers (mild).

**w/c 23rd:** Both knees (moderate), fingers (moderate).

**w/c 30th:** Both knees (severe), both elbows (mild), fingers (moderate).

# Useful organisations

## New PIP claims only

### England, Wales and Scotland

Telephone 0800 917 2222

Textphone 0800 917 7777

Relay UK 18001 then 0800 917 2222

### Northern Ireland

Telephone 0800 012 1573

Textphone 0800 587 0937

## Citizens Advice

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

[www.citizensadvice.org.uk](http://www.citizensadvice.org.uk)

## Turn2Us

A charitable service which helps people access the money available to them – through welfare benefits and other help.

[www.turn2us.org.uk](http://www.turn2us.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.

[www.lawcentres.org.uk](http://www.lawcentres.org.uk)

## St Bernard Support

St Bernard Support provides information for people with life affecting illnesses, regarding welfare benefits, pensions, insurances, wills, lasting powers of attorney, trusts, tax and estate planning.

Telephone: 0800 772 0723

email: [admin@s-b-s.org.uk](mailto:admin@s-b-s.org.uk)

[www.s-b-s.org.uk](http://www.s-b-s.org.uk)

## Further Reading

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

Telephone 020 3687 0790 or

[www.disabilityrightsuk.org](http://www.disabilityrightsuk.org)



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**nras**  
National Rheumatoid  
Arthritis Society




Helpline: **0800 298 7650**  
General: **01628 823 524**  
e: **helpline@nras.org.uk**  
w: **www.nras.org.uk**

Ground Floor  
4 Switchback Office Park  
Gardner Road  
Maidenhead Berkshire  
SL6 7RJ

 /nationalrheumatoidarthritisociety  
/jiaatnras

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