

Personal Independence Payment - A guide for people with a bleeding disorder.

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Introduction

We have written this guide because more and more members are contacting us to ask for support with making a claim for Personal Independence Payment (PIP).

The aim of this publication is to help you identify and describe the information you will need when you are:

- Completing the PIP2 form (How your disability affect you)
- Preparing for the face-to-face interview with a health professional that is part of the assessment process.

We have written this guide for:

- People who are currently receiving Disability Living Allowance (DLA) and have been 'invited' to claim PIP by the Department of Work and Pensions (DWP). This will be:
 - Adults who were aged 16 - 64 on 8th April 2013 who have been receiving DLA.
 - Young people who are 15 and have been receiving DLA. They will no longer be entitled to DLA from their 16th birthday (although it will continue to be paid while a decision is made on a PIP claim).
- Adults aged 16-64 who are not receiving either DLA or PIP and wish to make a claim for PIP.

The initial claim process is different for each of these three groups. Please see the **Making your claim** section below.

The process in this guidance applies to people living in Scotland, Wales and England. There is an alternative process in Northern Ireland which is explained at: <https://www.nidirect.gov.uk/articles/personal-independence-payment>.

If you were aged 65 or over on 8th April 2013, you won't be invited to make a claim for PIP. You will continue to be paid any DLA you already receive as long as you still meet the rules.

If you're aged 65 or older and haven't received DLA or PIP in the last year, you won't be able to apply for DLA or PIP but may be able to claim Attendance Allowance instead. There are a lot of websites that give information and guidance about Attendance Allowance. Here is a link to just one: <http://www.ageuk.org.uk/money-matters/claiming-benefits/attendance-allowance/>

History

Personal Independence Payment (PIP) was first introduced as a replacement for Disability Living Allowance (DLA) in April 2013. Existing DLA recipients started being re-assessed under the PIP regulations in July 2015. These are different to the DLA rules and many people who were receiving DLA are being turned down for PIP or awarded it at a lower rate.

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Overview of PIP

PIP is made up of two components:

- The Mobility Component;
- The Daily Living Component.

The DWP will assess information from:

- The “How your disability affects you” form (PIP2) you will have to complete.
- A face-to-face interview with a health professional appointed by them.
- Any further evidence you can obtain from health care professionals who support you.

They will compare this information with lists of ‘descriptors’ – statements that describe varying degrees of difficulties with mobility and activities of daily living – and decide which descriptors (if any) best match the information collected. Each descriptor scores points that are added together to give a total score for each of the two components.

You will need 12 mobility points to qualify for the enhanced rate of Mobility Component. It is this rate that can be used to lease a car through the Motability scheme.

You will need 8 mobility points to qualify for the standard rate of Mobility component.

In the same way, the standard rate of Daily Living Component is paid for 8 points scored on the daily living descriptors. The enhanced rate is paid if you score 12 points.

The current weekly rates (April 2017 – April 2018) are:

	Standard Rate	Enhanced Rate
Mobility Component	£22.00	£58.00
Daily Living Component	£55.65	£83.10

If you are awarded both a Mobility Component and a Daily Living Component, the two will be added together to make up your total PIP.

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Making your claim

How you make a claim for PIP depends on your age and whether you already receive DLA:

If you are an adult receiving DLA

You will be invited to make a claim for PIP. You will receive a letter from the DWP telling you this and giving you a date by which you must make your claim. You will need to make your claim by the date stated in the letter. This letter is also known as the PIP1 form.

You will need to call the DWP and give them some basic information. This will include contact details of health care professionals who support you, such as a Clinical Nurse Specialist at your haemophilia centre, a physiotherapist, a doctor overseeing Hepatitis C treatment or HIV treatment. We recommend that you contact your haemophilia centre first to ask whose contact details you should give to the DWP. This is also a good time to ask for a supporting letter to go with your claim.

If you do not make your claim by the deadline or you tell the DWP you don't wish to make a claim for PIP, payments of your DLA will soon stop. However, if you make a claim for PIP, your DLA will continue to be paid until a decision is made on your claim for PIP.

Making a claim will keep your DLA in payment for longer. You do not need to rush to make the claim, as long as you make it by the deadline. Use the time to collect together the information asked for in the PIP1 letter.

We recommend that you get help and further advice as early as possible with making your claim (see the section on Further Help below).

If you under 16 and receiving DLA

You will be invited to claim PIP once you become 16. You become a 'young person' and can claim and receive benefits in your own name.

Your parent (or guardian) should receive a letter about 5 months before your 16th birthday. This letter will warn them of the change and asking for the information needed to pay DLA when you reach 16. They should also receive another letter 2 months before your 16th birthday.

When you become 16 you will receive an invitation to claim PIP. The process is then the same as described in the box above. If you make a claim for PIP, your DLA will be paid until a decision is made on your PIP claim. If you choose, your DLA can be paid directly to you instead of your parent.

We advise that you make the claim yourself rather than let your parents do it for you.

If you are not already receiving DLA

- Check that you meet the eligibility rules, such as immigration status, presence and age. These are online at www.gov.uk/pip. Be very careful about claiming if you are subject to immigration control. If this is your situation, you will not

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normally be entitled to claim PIP and if you do claim it may affect your visa status.

- Collect the information you will need to start your claim (also listed at www.gov.uk/pip).
- Call 0800 917 222 to start your claim
- Once you have made your claim the assessment process will start. The DWP will send you a form “How your disability affects you”. This form is also known as the PIP 2 form.

If you are making a claim for PIP because you have been told you are terminally ill

In this case the claim process will be simpler and processed more quickly. You will still call the DWP as above to claim but will then send them a DS1500 form provided by your doctor or other healthcare professional. Your care team are the best people to advise you further.

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The Assessment Process

It is very important that you fill in the PIP2 form as fully as you can. It is likely that your claim will be turned down by the first decision maker and you will need the decision to be reconsidered. It is most likely you will need to go one stage further and appeal against the decision. At the appeal stage, more importance is given to what you say on the PIP2 form (and at the face-to-face interview) than to information you try to introduce at a later stage.

So that you have more time to think about your answers, here a few things you could do while waiting for the PIP2 form to arrive:

- Print out a copy of the form. The form from the DWP may take up to two weeks to arrive. If you print out a copy of the form you will have more time to read the questions and think about your answers. You can find a sample of the PIP2 form on our website.
- Read the section below (What is being assessed?) to get a clearer idea of what you need to include on the form.
- Use the time available. Doing a little every day is best.
- Gather evidence.
- Make notes of what you want to say.
- Write drafts of your answers.
- Get help. Someone who knows you well can often spot difficulties you don't notice.
- If English is not your native language or you are not confident about your writing then get help!

What is being assessed?

You will not be entitled to PIP just because you have a bleeding disorder. Instead, you will need to show the difficulties you experience with day-to-day living because of our bleeding disorder.

The nature and extent of disability arising from a bleeding disorder varies greatly from person to person. Some of us have extensive joint damage, and may even have had joints replaced. Others may have no joint damage whatsoever. Some of us may also be living with the burden of Hepatitis C and/or HIV. You will have to show how your bleeding disorder and other health conditions affect you individually

Mobility Component

As most people who have contacted the Society are concerned about their Mobility Component, we start by looking at how your entitlement to the Mobility Component will be assessed. In particular, we are going to look at the descriptors for MOVING AROUND in detail. These are the descriptors relevant to answering question 14.

The Moving Around Descriptors

	Descriptor	Points scored
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

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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

REMEMBER: To qualify for the enhanced rate of Mobility Component you need 12 points. In other words, the DWP decision maker needs to find that either descriptor (e) or descriptor (f) applies to you. In other words, if it is decided that you can move more than 20 metres you will not qualify for the enhanced rate.

Twenty metres is not far. On the face of it, few people with a bleeding disorder are restricted to this degree.

However, the regulations say that you should be assessed as satisfying a descriptor only if you can do so -

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

What does 'safely' mean?

Why is this important for people with a bleeding disorder?

The regulations define 'safely' as "in a manner unlikely to cause harm to the claimant ... either during or after completion of the activity".

Many people have joint damage caused by repeated bleeding episodes into joints (called Haemophilia Arthropathy in medical jargon). The bones of the joint become misshapen and the tissue around the joint (the synovium) thickens. The muscles that support the joint become weak and the joint becomes unstable. Walking can cause an unstable joint to bleed. Further bleeding into a joint causes further joint damage, making the joint even more unstable.

This joint damage becomes worse with time, even if there are relatively few bleeding episodes into a joint. Walking on a damaged joint will, with time, make the damage worse. This may even result in a need for surgery, such as knee or hip replacements, or for ankles to be fused.

It is important to describe fully any joint damage you have in your knees, ankles or hips and to list any bleeding episodes you have into these joints. Supporting evidence from your centre (for example, a physiotherapist's report) will help you make your point.

Be sure to stress that it is not just the risk of a joint giving way and you stumbling or falling that makes walking unsafe, but that the very act of walking itself puts you at risk of a bleed.

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Also say if you have had had bleeds into either groin (the psoas muscle), or into calf or thigh muscles. These bleeds can also be caused by the act of walking. For instance, bleeds in calf muscles are often caused by walking on a damaged ankle. Have you had any surgery on leg joints, such as knee or hip replacements? Or an ankle fused? Or a synovectomy?

A list of times you have treated yourself, or have been treated, for bleeds into leg joints and muscles will also support your point that bleeds can start from walking.

Think carefully about how you describe any treatment with clotting factors. It is important to describe how treatment works (or not) for you individually.

Even if you are on a 'prophylactic' regime this may not guard you against all bleeds. It may reduce the number of bleeds you get but not prevent all bleeds, particularly if your joints are already badly damaged. Describe any way in which you may alter your prophylactic regime because you think you have a bleed. For example, you may treat yourself earlier than usual or give yourself extra treatment between your usual prophylactic injections.

If your treatment is 'on demand', say so and stress that this means you do not have the 'cover' provided by a prophylactic regime and that this puts you at continual risk of a bleed. On demand treatment is more common for people with an inhibitor or the rarer bleeding disorders because of the short half-life of the clotting factors used. A prophylactic regime is not possible.

However, if you choose on demand treatment for yourself, even if prophylaxis is possible, do not feel you have to justify your choice; simply say that your treatment is 'on demand'.

What does 'repeatedly' mean?

'Repeatedly' means as often as reasonably necessary. If you think you are at risk of causing a bleed through walking, it is important to point out that the risk of causing a bleed is as high for the first time in a day you walk as it is the second, third and so on. If you feel your joints become less stable as the day goes on, and the risk of starting a bleed more likely, then say so.

The point you are trying to get over is that if you walk repeatedly then it is likely that you will start a bleed at some time. It is not important how often you walk (it may be several times a day or just once a day) or how often you start a bleed through walking. One way of saying this is that the risk is always present.

What does 'within a reasonable time period' mean?

Generally, this seems to mean that if it takes you more than twice as long as a 'normal' person to walk the distance.

However, it is probably better just to concentrate on the reasons why you walk slowly, rather than your actual speed. For instance:

- Do you walk slowly because you are scared you might do something that will start a bleed?

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- Do you stop because you are anxious about your balance, or that you may be harming yourself by walking? Thinking of the 20 metre distance, do you stop once, or several times?
- Do you stop because of pain? Fatigue? Breathlessness?

Try keeping a walking diary

Keeping a diary over a couple of weeks can help you identify your mobility problems and help you to answer question 14:

Make a note of the distance you walk each time, particularly of any walking you do often. For example, you could measure from your front door to where your car parked. Time yourself over this distance.

Do you stop and rest? Include the time you are resting in the total time to cover the distance. Make a note of why you stop. Is this because you are anxious that you are risking a bleed by carrying on? Is the way in which you are walking unsteady, making you anxious because a joint might 'give way', or you might stumble or fall? Make a note of any pain that comes on suddenly or is different to your usual level of pain.

Women with a bleeding disorder frequently feel fatigued and get out of breath easily because they are continually anaemic. So do people who are HIV positive or have Hepatitis C. If this applies to you, then make a note of when, and how often, you feel fatigued or breathless.

How do you manage kerbs? Are you unsafe stepping up or down at kerbs or doorsteps? How do you manage with uneven pavements?

Make a note if you cancel a plan, or don't do something you want to do, or need to do, because you feel the risk of causing a bleed by walking is too high?

Remember, you are keeping this diary to help make yourself aware of your mobility problems so that you can describe them in answering question 14. What you are trying to describe are the risks you take when walking. It is NOT a 'good days, bad days' diary.

If you think it will help, you can include a copy with your PIP2 form when you return it.

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What to put where on the PIP2 form

We recommend using the space in question 15 (additional information) to give a full description of your bleeding disorder and other medical conditions, including type, severity, and complications such as having an inhibitor. Include a joint-by-joint description of any joint damage. Also describe what clotting factors you use and how these are given. Give as much detail as you can – the important thing is not to leave anything out. You can always add extra pages if you need to.

Then answer the other questions. Don't be afraid of repeating anything you say in question 15.

Answering question 14

Question 14a asks you how far you can walk. You are asked to tick a box that best describes the distance you can walk. Bearing in mind what we say above, it is best to answer this question as if it was written:

“How far can you walk safely, repeatedly, within a reasonable time period and to an acceptable standard (taking into account any aids that you use)?”

In fact, question 14 does use very similar wording.

Question 14b asks you about any aids that you use. If you use a walking stick or crutches, then say so, but be clear about why you use them. If you use crutches, is this only to steady yourself or do you actually reduce weight bearing on your legs? Are you at risk of starting a bleed in your wrists, elbows or shoulders when you use crutches?

Question 14c asks if you use a wheelchair. If you do, say so.

Question 14d provides space for you to add further information about your walking ability. It is here that you should report any joint damage in your leg joints and describe the risks to you of walking, and any other problems you have with walking.

If you need more space, you can continue in Question 15.

Planning and following journeys

There is a second list of descriptors that deal with mobility issues. These come under the heading of 'Planning and following journeys'. They cover the difficulties experienced by people with a cognitive impairment, visual impairments or extreme psychological impairments.

People who are HIV positive, have Hepatitis C or who have continual anaemia may have difficulties that fall under this heading. If you have any difficulties from these types of impairment, then check the list of descriptors we have attached as Appendix 1. Any points scored from these descriptors will be added to points scored from the 'Moving around' descriptors to give your total points for mobility.

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Activities of daily living

Your entitlement to the Daily Living Component will be decided by comparison to a list of descriptors of some activities of daily living. The list is very long and is organised under 10 different headings. You can find the complete list of descriptors at Appendix 2. Questions 3 to 12 on the form ask you for information about your difficulties with these activities.

We suggest that you approach these questions systematically. Citizens Advice have a very useful tool on their website which may help you. Here is the link address: <https://www.citizensadvice.org.uk/benefits/sick-or-disabled-people-and-carers/pip/help-with-your-pip-claim/fill-in-form/>

We recommend you put together your answer for each question by:

- reading each question
- reading the descriptors related to each question
- using the CAB website to systematically make a list of things you may say in answer to each question
- reading the points below, and building them into your answers

General considerations

Remember, you should be assessed as satisfying a descriptor only if you can do so:

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

We think it is also important to note that the questions on the form only ask for some of the information important in each area. We recommend reading the descriptors for each area and providing all the information you think is relevant. You can do this in the 'Extra information' box for each question. If there is not enough space continue your answer in Section 15 of the form.

Some of the descriptors refer to 'prompting'. If you lack motivation to carry out any of the activities described because of fatigue, 'brain fog' or the psychological impact that can be a consequence of anaemia, having Hepatitis C, or being HIV positive then these descriptors may apply to you.

We have made some specific comments below on each group of descriptors.

Preparing food (question 3)

DWP guidance suggests that 'preparing a simple meal' means peeling, chopping and boiling two large potatoes, opening a tin of vegetables, and frying a small piece of meat or fish'.

Think about the actions involved in preparing such a meal. Can you do this safely? Do you have damaged joints (elbows, wrists or shoulders) and risk a bleed if you carry out these tasks (e.g. lifting a pan of boiled potatoes off the hob and draining the water?). Can you stand long enough to prepare such a meal? Does standing risk a bleed? Do you get bleeds after preparing a meal?

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Descriptor (d) refers to prompting from another person.

Taking nutrition (question 4)

These descriptors deal with the actions needed to eat and drink. Joint damage may be relevant to descriptors (b – iii) and (f). A restricted range of movement in both elbows may, for example, make it difficult or impossible to lift a spoon or fork to your mouth.

Descriptor (d) refers to prompting.

Managing therapy or monitoring a health condition (question 5)

We advise reporting:

- All help you need with giving treatment of clotting factors. This could include someone actually giving you injections, or someone simply sitting by you to help you and encourage you to treat yourself, or able to take over if you do not succeed. Any difficulties you have with finding a vein should be reported here.
- If you miss routine prophylaxis injections because you fear missing a vein, causing a bleed, or because you are 'needle phobic'.
- If your treatment is 'on demand', if anyone helps you decide to treat yourself? Even if you have no-one, do you need this help? Do you let bleeds develop dangerously before treating, or getting treatment?
- If you need prompting (reminding) to take medication for HIV or for Hep C. Describe the dangers if you did forget to take these treatments.

Any physiotherapy exercise routine you have been prescribed, or told to follow, is also relevant. Give details of any personalised physiotherapy exercise routine aimed at avoiding joint damage or reducing the development of further joint damage. Do you follow this routine, or do you need to be encouraged or prompted by someone else?

This is relevant to descriptors (c), (d), (e) and (f). The amount of time each week taken in therapy is important so add up the number of hours your physiotherapy regime takes, or would take if you did it, and include these details in your answer.

Washing and bathing (question 6)

The first question to ask yourself is, "can I do this safely, repeatedly, and within a reasonable time period?"

The second is "can I actually reach all the parts of the body covered by the descriptor? For example:

- Descriptor (d) refers to 'the body below the waist'. Can you actually reach your feet?
- Descriptor (f) is referring to the upper body. You might be able to wash your chest, but what about between your shoulder blades?

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Managing toilet needs or incontinence (question 7)

Think about what is involved for you when you use the toilet. A limited range of movement in joints may make it difficult for you to undo clothing (and do it up again when you have finished), to sit on the toilet and to stand again afterwards, and, of course, to wipe your backside.

Try to describe fully any difficulties you have and, in particular, if you need help from someone else to use the toilet.

Dressing and undressing (question 8)

A key question to ask yourself is, “Do I need help from someone else to dress or undress?” A limited range of movement in damaged joints could make dressing and undressing difficult or impossible for you. Describe any help you do get. If you do not usually have someone to help you, describe how long it takes for you to dress and undress.

Communicating verbally (question 9)

This group of descriptors refers to difficulties arising from hearing impairments, cognitive impairments, and speech and language impairments. These descriptors do not apply if your difficulties arise because English is not your first language. But if you have difficulty communicating verbally in your native language, then you should describe these difficulties.

Reading and understanding signs, symbols and words (question 10)

These descriptors refer to visual impairment.

Engaging with other people face to face (question 11)

These descriptors refer to psychological impairments.

Making budgeting decisions (question 12)

These descriptors refer to cognitive or psychological impairments.

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Supporting Evidence

We recommend getting a support letter from your centre as soon as possible. It is best if you have this letter in time to send it with your completed PIP2 form. If this is not possible, then try to have the letter for your face-to-face interview. Some haemophilia centres may say they prefer to wait for the DWP to contact them. However, in most cases we have heard about this does not happen.

It is important to remember that the staff at your centre are not the people making the decision about your entitlement to PIP. They cannot make statements saying you are entitled. What they can do is provide factual information drawn from your medical records. Ask that the letter includes:

- A description of your bleeding disorder, including type, severity, inhibitors and treatment plans.
- A joint by joint description of any joint damage (Haemophilic Arthropathy), and likely development, particularly if the joint damage is likely to get worse with time.
- Details of any operations you have had such as knee or hip replacements, ankle fusing, or synovectomies.
- Details of wastage in muscles supporting a joint.
- Information about any pain and discomfort they know you experience.
- A description of the way in which you walk and your speed compared with a 'normal' person.
- If you use crutches or a walking stick is this simply to aid your balance rather than to reduce weight bearing through leg joints? Are there any risks to you using crutches, such as starting a bleed in wrists, elbows or shoulders?

It will also be helpful if they can include a description of what happens in a target joint at the time of a bleed and the long term consequences of repeated bleeding into the same joint.

If you have are HIV positive have Hepatitis C, or have any other medical conditions you may need to ask for separate letters of support.

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Returning the PIP2 form

- Don't miss the deadline for returning the form - allow a few days for postage.
- Don't delay sending it because you are waiting for a supporting letter from your centre. You can always send this to the DWP later.
- Keep copies of the form and any supporting evidence you send.

We recommend sending the form using the 'to be signed for' service (recorded delivery). You will have to pay for this service, but you can check the Royal Mail tracker online after a few days to make sure your form has been received by the DWP. It also gives you proof that they received the form should this be in dispute later. You can still use the envelope provided by the DWP.

If, when you check, there is no evidence of delivery (a signature) shown then call the DWP number immediately to check if the form has been received. If it hasn't, then you will need to send it again.

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What Happens Next?

Your form and any other evidence you have provided will be passed to a Health Professional (HP). Health Professionals are contracted by the DWP to give guidance to the DWP decision maker. Although they are not the person who finally makes the decision on your claim, they do recommend which descriptors apply in your case. Their recommendations will usually be followed by the DWP.

The HP will almost certainly arrange a face-to-face interview with you.

The face-to-face interview

Practical arrangements for the face-to-face interview.

You will receive a letter giving you an appointment time and place for the interview. You should be given at least 7 days' notice.

You can:

- Re-arrange the date and time if you have a good reason.
- Ask questions about parking, distance from parking spaces to the interview room, and information about steps, ramps, and lifts.

If you think these arrangements will be difficult for you, or unsafe, then say so and ask for another venue to be arranged. You can also ask for the HP to visit you at home, although most people do not like this idea.

If you will be unable to drive yourself, or have no-one to drive you, then ask permission to use a taxi. If you ask permission first, you can claim back the cost (but get receipts). Our advice is that you do not use public transport to get to the interview.

You can also:

- Ask for the HP to be the same gender as you.
- Ask for an interpreter if English is not your native language. We recommend that you do this as it will help you describe your situation clearly.
- Ask to make an audio recording of the interview. You must request this before your assessment. When you do also ask the assessment centre about the rules for using recording equipment.

If you do not attend, your claim will be disallowed. However, the DWP should contact you before doing this and give you an opportunity to explain why you did not attend.

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Preparing for the face-to-face interview

- Find someone to go to the interview with you.
- Look at any supporting letters you sent.
- Go through your copy of your claim form (PIP2) and refresh your memory of what you said.

Ask yourself if you would say anything differently, or if there is anything more that you might not have put on the form but wish you had.

Look at the complete list of descriptors and think in terms of how they are stated. The HPs main task will be to decide which descriptors apply to you. Think of how you can describe the risks you face when doing the things listed. Can you do them safely?

Think about your social and leisure activities and make a note of any restrictions you have in taking part. Think about any you may have given up, or take part in less often than you would like because of your bleeding disorder.

If there is anything you feel you must say at the interview – for example, something you didn't say on the form, or something you think needs stressing – you could write it down (keep a copy for yourself) and hand it to the HP when you arrive, together with any other evidence you have collected since sending in the PIP2 form. Send a copy to the DWP.

On the day

The HP will ask questions: make sure you understand what is being asked, and ask for the question to be repeated if you need. Think about your answer, don't rush.

The HP will observe you: they will be watching as you enter the room, sit down, stand up, and how you use your arms. Don't allow yourself to be rushed; do all these things as you would if you were at home. Get your companion to help you in the same way as they would at home.

Keep in mind that your goal at the interview is to make sure that your understanding of how your bleeding disorder affects your day-to-day life is accurately recorded by the HP.

Remember that the HP will still be observing you when you get up and leave the room, and possibly as you make your way to your car.

After the interview you can order a copy of the HP's report. It can be useful to already have a copy of the report when you receive the decision letter. You will have more information in front of you to help you decide if you want to ask for a Mandatory Reconsideration.

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The Decision

You should receive a decision letter about 3 to 4 weeks after the interview.

The decision is in two parts:

- The rate of each component you are entitled to (if any).
- The length of the award.

What happens to your DLA?

Once a decision is made on your PIP claim, your entitlement to DLA will come to an end.

Your DLA entitlement will continue for four weeks from the date of the decision letter. You should receive one more payment covering four weeks. You may also receive a final small payment, depending on how your DLA has been paid in the past.

Your entitlement to PIP (if any) starts the day after DLA ends. PIP is paid 4 weeks in arrears.

If you lease a car through the Motability scheme you will have to return it if you are not awarded the enhanced rate of Mobility Component with PIP. There is a scheme of financial support to help you with the transition from Motability. Here is a link to more information:

<http://www.motability.co.uk/about-the-scheme/personal-independence-payment-and-the-scheme/q-and-a-transitional-support-package>

What if you are not happy with the decision?

If you are unhappy with either the amount of PIP awarded or the length of the award then you can request a Mandatory Reconsideration.

If you have not been awarded any PIP, then this is not a difficult choice. Many people who are turned down at this stage are then successful after a Mandatory Reconsideration (or a later appeal stage), particularly if they provide further evidence or get support from an advice agency.

However, if you are awarded some PIP and you request a reconsideration because you believe you should have been awarded more, any PIP you have been awarded can be reduced (or lost completely). For example: if you are awarded the Enhanced Rate of the Mobility Component, but no Daily Living Component (DLC), you may want to request a reconsideration because you believe you should be awarded DLC. But this does risk your Mobility Component being reduced or lost.

We strongly recommend getting further advice before asking for a Mandatory Reconsideration if you have been awarded some PIP but feel you should have been awarded a higher rate.

How to ask for a Mandatory Reconsideration

First, call the telephone number on the decision letter.

Give your reasons for wanting a reconsideration. These reasons can be quite general; for example, 'I don't think you have taken into account the risks to me of walking or carrying out the activities of daily living'.

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Put your request in writing as well and send this to the address on the decision letter. Include the contact details of a representative if you have managed to find one – most representatives will have a standard form for you to complete and send to the DWP.

If you have followed our advice above, you will already have a copy of the HP's report, your completed PIP2 form and supporting letters, but we recommend that you still for a copy of the evidence used to make the decision (with a copy sent to your representative). You should receive the papers within 2 weeks. If you don't, call the DWP again.

When you receive the papers

You will normally be given one month from the day you call the DWP to ask for a reconsideration to write and send a response to the decision and provide any further evidence you can gather.

Read the HP's report carefully:

- Make a note of any conclusions you disagree with
- Look for any evidence you have provided that has not been taken into account. It is very likely that only some of what you said at the face-to-face interview has been noted by the assessor.
- Is there any further evidence you could provide (for example, a 'bleed diary') that may help you?
- Your haemophilia centre may be willing to give you a further support letter.

If possible, get help with writing a response to the decision (see section on Further Help with your claim).

Read the Disability Rights UK factsheet: F36 - Appeals and mandatory reconsideration (<https://www.disabilityrightsuk.org/appeals-and-mandatory-reconsideration>).

Send your response to the DWP address given in the decision letter.

You will then receive a new decision. If you still disagree with the new decision (probably because it is unchanged) then you can appeal to a tribunal.

Appealing to a tribunal

You will need to complete an appeal form (SSCS1).

You can download a copy from www.gov.uk/social-security-child-support-tribunal/appeal-tribunal

Or you can phone your local HM Courts & Tribunals Service to order a copy. The numbers are:

- England and Wales - 0300 123 1142
- Scotland - 0141 354 8400

On the form you will be asked if you want to attend the tribunal or if you are happy for a tribunal to decide your appeal on the paperwork alone. We recommend that you attend the

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tribunal in person as this gives you another chance to discuss your situation. There is strong evidence that attending in person increases your chances of success at the tribunal.

The Disability Rights UK factsheet: F36 - Appeals and mandatory reconsideration (<https://www.disabilityrightsuk.org/appeals-and-mandatory-reconsideration>) has some very useful advice on making an appeal.

Look for help with making your appeal (see the next section).

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Further help with your claim

If you were affected by contaminated blood products and are a registrant of the Caxton Foundation or Macfarlane Trust they may be able to refer you to a specialist benefits adviser whose services will be provided free of charge. They recommend contacting them as soon as possible after receiving the invitation to claim PIP.

To discuss a referral, contact either:

- Nicole Hornby on nicole@caxtonfoundation.org.uk - 020 7808 1174; or
- Keisha Hanchard on Keisha@macfarlane.org.uk - 020 7808 1171.

The Disability Rights UK factsheet: F15 – getting advice (<https://www.disabilityrightsuk.org/getting-advice>) may help you find an advice and support service in your area. It will be useful if you give a copy of this Haemophilia Society guide to anyone offering you support with your claim.

Other support if you are awarded PIP

Carer's allowance

If you are getting either rate of the daily living component of PIP, your carer may be able to claim carer's allowance. The benefit is paid to your carer.

Benefits cap

There is a cap on the total amount of benefits you can receive. You are exempt from this benefits cap if anyone in your household (you, your partner and any child or young person you are responsible for) is getting PIP.

More benefit

If you are entitled to PIP, it may also help to increase the amount you receive from any of the following benefits:

- child tax credit;
- employment and support allowance;
- housing benefit;
- income support;
- jobseeker's allowance;
- universal credit;
- working tax credit.

Be sure to let whoever is dealing with your claim for these benefits know that you get PIP.

Council tax

You can get help with your council tax bill from your local authority. In many cases, you will be able to get more help if you are getting PIP. Contact your council for more information.

The Motability scheme

If you are getting the enhanced rate of the mobility component of PIP, you can exchange it to lease a new car, scooter or powered wheelchair from Motability. There must be at least 12 months left of your enhanced rate award. This is a change from the 3 years needed under

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DLA rules. For more information, telephone: 0300 456 4566 (textphone 0300 037 0100) or go to www.motability.co.uk.

Blue Badge

If you have been awarded the mobility component you may be entitled to a Blue Badge to help with parking. The rules differ in different parts of the UK – please see our factsheet

INSERT LINK

Vehicle tax

You can be exempt from having to pay vehicle tax if you get the enhanced rate of the mobility component. You can also get a 50% discount on your vehicle tax if you receive the standard rate of the mobility component.

For more information phone 0300 123 4321; Text phone: 0300 790 6201) or go to www.gov.uk/financial-help-disabled/vehicles-and-transport

Other Issues

The decision letter will include a list of circumstances and changes you should report to the DWP. It is important to know these and report them. You may be fined if you do not.

We would like to draw your attention to two in particular. In both cases the rules are stricter than the old DLA rules:

Hospital stays

Your PIP will stop after a total of four weeks in hospital. This can be either one stay of four weeks, or several stays. If you have repeated stays in hospital, they will be added together if they are no more than four weeks apart. This limit does not apply if you are aged under 18 on the date of admission.

If you make a claim for PIP when you are already in hospital, it cannot be paid until you leave.

Holidays abroad

The decision letter states that you should report any holiday you are planning abroad if you will be away for more than 4 weeks. However, our understanding is that you can receive PIP for up to 13 weeks while you are abroad.

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Appendix 1: Mobility Activities Descriptors

Below are the descriptors for the mobility activities as laid out in Schedule 1 Part 3 of The Social Security (Personal Independence Payment) Regulations 2013 (<http://www.legislation.gov.uk/uksi/2013/377>).

Activity	Descriptors	Points
1. Planning and following journeys.	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
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 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

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Appendix 2: Activities of daily living

Below are the descriptors for the daily living activities as laid out in Schedule 1 Part 2 of The Social Security (Personal Independence Payment) Regulations 2013 (<http://www.legislation.gov.uk/uksi/2013/377>).

Activity	Descriptors	Points
1. Preparing food.	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
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. Cannot convey food and drink to their mouth and needs another person to do so.	10
	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.
b. Needs either –		1

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	(i) to use an aid or appliance to be able to manage medication; or (ii) supervision, prompting or assistance to be able to manage medication or monitor a health condition.	
	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
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 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
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
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

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	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
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. Cannot express or understand verbal information at all even with communication support.	12
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. Cannot read or understand signs, symbols or words at all.	8
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. Cannot engage with other people due to such engagement causing either – (i) overwhelming psychological distress to the claimant; or	8

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	(ii) the claimant to exhibit behaviour which would result in a substantial risk of harm to the claimant or another person.	
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. Cannot make any budgeting decisions at all.	6

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