Personal Independence Payment – A guide for people with a bleeding disorder

Part 2 – The assessment process

If you have a long-term ill-health or disability you may be able to get help with some of the extra costs. PIP (Personal Independence Payment) is a welfare benefit that is non-means tested and is not affected by earnings, other income or savings. PIP is the benefit that is gradually replacing DLA (Disability Living Allowance). You will carry on getting DLA if you were 65 or over on 8 April 2013. You will not automatically move over to PIP. You will get a letter from the Department for Work and Pensions (DWP) asking you to make a new claim.

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For everyone affected by a genetic bleeding disorder

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haemophilia.org.uk
What happens next?

Once you have sent your form to the DWP, your form and any other evidence you have provided will be passed to a health professional. Health Professionals are contracted by the Department of Work and Pensions (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. The DWP will usually follow their recommendations.

In most cases they will look for more information in addition to your completed PIP2 form and the evidence you’ve already sent. They do this by:

- contacting your haemophilia centre (or anyone else you listed), and
- arranging a face-to-face interview.

The assessment process

The assessment will consider how well you can carry out a series of everyday activities. It’s worth remembering here that your inability to carry out activities must be because of a health condition or disability and not simply because you choose not to/don’t like to do them.

PIP is not a compensation payment for ill-health/disability; it is to help people with the increased costs of daily living in cases of long-term ill health or disability. PIP sits alongside support provided by the NHS and local authorities and is not meant to duplicate that support.

Your conditions or disabilities may be physical, sensory, mental, intellectual or cognitive or any combination of these.

The DWP can decide on your claim by using just the written information you sent if they believe you have provided enough evidence in your claim file. But you should be aware you can be asked to attend a face-to-face consultation with a health professional.

What is being assessed?

You will not be entitled to PIP just because you have a bleeding disorder.

You will need to show the difficulties you experience with day-to-day living because of your bleeding disorder.

The nature and extent (how serious) the disability is, particularly with a bleeding disorder can vary greatly from person to person. Some people have extensive joint damage and may even have had joints replaced. Others may have no joint damage at all. Some may also be living with hepatitis C and/or HIV. You will have to show how your bleeding disorder and other health conditions affect you individually.

The activities explored during the PIP assessment are for daily living and mobility (how well you can move around).

Remember, while filling in your form the DWP assessor will look at how your disability and health condition affect the way you carry out different activities (daily living and mobility).

For more information visit [http://www.pip-assessment.support/#about-pip](http://www.pip-assessment.support/#about-pip)

This website provides useful information about the PIP assessment so that you can build up your confidence about the kinds of things you might be asked, before you apply/attend a face-to-face assessment.
**Mobility component (how well you can move around)**

Most people who have contacted us are concerned about their mobility component and how the DWP assess this section. Here we look at the descriptors for **moving around** in detail.

**Daily Living Activities**

<table>
<thead>
<tr>
<th>Activity</th>
<th>Descriptors</th>
<th>Points</th>
</tr>
</thead>
</table>
| 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 either –  
  (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. | 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      |

- **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. Need supervision or prompting to be able to wash or bathe                2
  d. Need assistance to be able to wash either their hair or body below the waist. 2
  e. Need assistance to be able to get in or out of a bath or shower          3
  f. Need assistance to be able to wash their body between the shoulders and waist. 4

- **Dressing and undressing**
  a. Can dress and undress unaided                                            0
  b. Need 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. Need assistance to be able to dress or undress their lower body.         2
  e. Need assistance to be able to dress or undress their upper body.         4
  f. Cannot dress or undress at all.                                          8
### The ‘moving around’ descriptors

<table>
<thead>
<tr>
<th>Activity</th>
<th>Descriptors</th>
<th>Points</th>
</tr>
</thead>
<tbody>
<tr>
<td>Moving around</td>
<td>a) Can stand and then move more than 200 metres, either aided or unaided.</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>b) Can stand and then move more than 50 metres but no more than 200 metres,</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>either aided or unaided.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>c) Can stand and then move unaided more than 20 metres but no more than 50</td>
<td>8</td>
</tr>
<tr>
<td></td>
<td>metres.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>d) Can stand and then move using an aid or appliance more than 20 metres</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td>but no more than 50 metres.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>e) Can stand and then move more than 1 metre but no more than 20 metres,</td>
<td>12</td>
</tr>
<tr>
<td></td>
<td>either aided or unaided.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>f) Cannot, either aided or unaided, (i) stand; or (ii) move more than 1</td>
<td>12</td>
</tr>
<tr>
<td></td>
<td>metre.</td>
<td></td>
</tr>
</tbody>
</table>

**Remember:** to qualify for the enhanced rate of mobility component you need 12 points. This means 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.

Please note: If you have PIP for the enhanced rate of mobility you can continue to access the Motability Scheme.

Twenty metres isn’t far. On the face of it, few people with a bleeding disorder are unable to walk this far.

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?**

The regulations define ‘safely’ as ‘in a manner unlikely to cause harm to the claimant... either during or after completion of the activity’ – so you can move in a way that is unlikely to cause you harm either during or after you’ve completed the activity.

### The Mobility Component

Your mobility will be reassessed when you move over to PIP. You will only qualify for the Motability Scheme if you are given the higher rate for mobility (known as the ‘enhanced rate mobility component’). **This rate is harder to get on PIP, which means you might not be able to keep your vehicle.**

If you qualify for the enhanced rate and you wish to take part in the Motability scheme, some or all of your mobility component will go directly to Motability. To be eligible to join the Motability Scheme, you need to receive one of the following mobility allowances and you must have at least 12 months’ award length remaining. Please note that the Attendance Allowance cannot be used to lease a car through the Scheme.
Higher Rate Mobility Component of Disability Living Allowance (HRMC DLA)
As of 11 April 2018, this is £59.75 per week.

Enhanced Rate Mobility Component of Personal Independence Payment (ERMC PIP)
As of 09 April 2018, this is £59.75 per week.

War Pensioners’ Mobility Supplement (WPMS)
As of 11 April 2018, this is £66.75 per week.

Armed Forces Independence Payment (AFIP)
As of 11 April 2018, the mobility element of this is £59.75 per week.

https://www.motability.co.uk/about-the-scheme/allowances/


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 DLA rules (where you need at least three years left of your enhanced rate award). For more information call 0300 456 4566 (textphone 0300 037 0100) or go to www.motability.co.uk

Unsuccessful PIP reassessment – if you are an existing recipient of the higher rate mobility component of DLA but are then not awarded the enhanced rate of the mobility component of PIP you will no longer be eligible to lease a vehicle on the Motability Scheme.

If you have an unsuccessful DLA to PIP re-assessment and have a vehicle from the Motability Scheme, they will be in touch with you to help support you through this transition. You will have around eight weeks from when your allowance payments end to return your car. Motability will write to you giving you all the information you need, including details of their transitional support package. You may also be eligible for a pro-rata refund of any Advance Payment you made.

A summary of the Government’s planned changes and the transitional support package
https://www.motability.co.uk/PIP_Information_Leaflet.pdf

More information about the Motability Scheme
https://www.motability.org.uk/advisors/useful-downloads/

Information about the transitional support package
https://www.motability.co.uk/about-the-scheme/personal-independence-payment/unsuccessful-reassessment/transitional-support-package/

Staying mobile after the Motability Scheme
https://www.motability.co.uk/about-the-scheme/personal-independence-payment/unsuccessful-reassessment/

Other mobility options after leaving the Motability Scheme
https://www.motability.co.uk/about-the-scheme/personal-independence-payment/unsuccessful-reassessment/staying-mobile/other-mobility-options/

Information for leaving the Motability Scheme

Why is this important for people with a bleeding disorder?

Many people have joint damage caused by repeated bleeding episodes into joints (called haemophilic 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.

So, it’s 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 isn’t 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.

Also say if you have had had bleeds into either psoas muscle (a large muscle that attaches at the bottom of the thoracic spine), or into calf or quadriceps muscles. Walking can also cause these bleeds. For instance, bleeds in calf muscles are often caused by walking on a damaged ankle.

Think about whether you’ve had any surgery on leg joints, such as knee or hip replacements? Or an ankle fused? Or a synovectomy (surgery to remove the tissue that lines a joint)? All of this information will be relevant to this part of your assessment.

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

And think carefully about how you describe any treatment with clotting factors. It’s important to describe how treatment works (or not) for you individually.

Even if you are on a prophylactic regime (regular treatment to prevent bleeds) 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 don’t 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. The assessors will not be experts in haemophilia, so you will have to do some of the work to help them understand all of these details and the effect that they have on your daily life and ability to move around.

However, if you choose on demand treatment for yourself, even if prophylaxis is possible, don’t 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’s 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.

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, then you should say so.

However, it’s 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?
- 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 (getting tired)? Breathlessness?
Assessment process and assessment providers

Your PIP assessment will be carried out by a Disability Assessor (experienced health professional) working in partnership with the DWP. The Disability Assessors are fully trained to undertake functional assessments of the impacts of a health condition or disability on daily living or mobility.

If you receive a letter about the face-to-face consultation this will be carried out by a Disability Assessor who considers the evidence provided by you, along with any further evidence they think is needed. This assessment will focus on how your life is affected by the challenges you face as a result of your health condition or disability. You will not be asked to do anything that will cause you discomfort.

The assessment looks at you as an individual and focuses on the impact your condition has on your daily life and over a range of different activities.

The Disability Assessor will complete the assessment and will send a report back to the DWP. It is important to give them as many relevant details as possible. The Disability Assessor will not decide on your PIP entitlement. The DWP Health Assessment Advisor will then use all the information provided at the assessment to decide your entitlement to PIP.

For more information about PIP Face to Face Assessment see:

http://www.capita-pip.co.uk/en/assessment-process.html

If you need more help regarding your face-to-face assessment, please phone Capita PIP on 0808 1788 114.

Practical arrangements for the face-to-face interview

You will receive a letter telling you when and where your interview will be. You should be given at least seven days’ notice.

You can:
• rearrange 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 health professional to visit you at home.

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

The assessment provider must ensure that you travel no more than 90 minutes (single journey) by public transport to your assessment.

You can also:
• ask to see a Disability Assessor who is the same gender as you
• ask for an interpreter if you think you will have difficulty explaining yourself well in English.

The Disability Assessor may come to your home if you clearly have a specific health condition or disability that would make travelling to the appointment difficult. This will be decided by the assessor, or when you provide confirmation through your hospital consultant that you are unable to travel on health grounds.

If you don’t attend your assessment, your claim will not be processed. However, the DWP should contact you before doing this and give you an opportunity to explain why you didn’t attend.

Preparing for the face-to-face interview

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

Look at the complete list of descriptors and try think in terms of how the language that they use. The health professional’s 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 Disability Assessor when you arrive, together with any other evidence you’ve collected. And make sure that you also send a copy to the DWP.

For more help see: http://www.capita-pip.co.uk/en/assessment-process.html

If you need a translator or a British or Irish Sign Language interpreter; or need to check that the premises are disabled accessible; or need a hearing loop available, please contact the Capita PIP Centre on 0808 1788 114

If you cannot attend your appointment or for cultural or religious reasons or you need a same-sex assessor please contact Capita PIP Centre on 0808 1788 114 as soon as possible.

Remember, if you have new evidence about how your condition affects your daily life, which you have not already sent to the DWP, please bring this to your assessment.

Your evidence should show the Disability Assessor how your condition affects you and not be just confirmation of your condition or the medication you take. This is because PIP is based on how your condition affects you and not the condition itself.

On the day

Make sure you attend the assessment with someone you know like a friend, relative or carer.

The Assessment Provider will make sure that the Disability Assessor has the right skills and experience to assess claimants (the people like you who are making the claim) referred to them. If the Disability Assessor feels they need more support before the assessment (e.g. they do not know about your condition) the person carrying out the assessment will provide someone with the appropriate skills to either assist the original Disability Assessor or carry out the assessment.

Your assessment will take as long as it takes to reach the evidence-based conclusion, there is no time limit for face-to-face consultations. The Disability Assessor will take notes throughout the whole consultation.

The Disability Assessor will ask questions about your circumstances, e.g. health condition or disability and how this affects your daily life. Make sure you understand what is being asked and ask for the question to be repeated or explained in more detail if you need. Think about your answer carefully; don’t rush.

The Disability Assessor 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. The Disability Assessor may also carry out a short physical examination, but you will not be forced to do anything that causes you pain, embarrassment or discomfort. 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 the Disability Assessor accurately records your understanding of how your bleeding disorder affects your day-to-day life.

Remember that the Disability Assessor 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 Disability Assessors 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.

For more information on the assessment process please see http://www.capita-pip.co.uk/en/assessment-process.html
The decision

You should receive a decision letter about three to four weeks after the interview.

The decision is in two parts:
- the rating of each component you are entitled to (if any)
- the length of the award (how long you will receive it for before you have to reapply).

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 a while after the PIP decision. The rules are difficult to understand, but we believe you should receive two more payments of DLA after the date of the decision:
- one covering a four-week period as usual, and
- one covering a three-week period (DLA is usually paid three weeks in arrears and one week in advance; the final payment should cover the three weeks of arrears).

Your entitlement to PIP (if any) starts the day after this final DLA payment. PIP is paid four weeks in arrears, so you should receive your first PIP payment four weeks after your final DLA payment.

What if you aren’t 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.


https://www.gov.uk/mandatory-reconsideration/if-you-disagree-with-the-outcome

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 do not think you have considered the risks to me of walking or carrying out the activities of daily living.
- Ask for a copy of the evidence that they used to make the decision. (This will include the Disability Assessor’s report, together with any reports provided by healthcare professionals.)
- Ask for them to take no action until you have had a chance to look at the evidence and respond.
- Put your request in writing as well and send this to the address on the decision letter.
- You should receive the papers within two weeks. If you do not call the DWP again.
When you receive the papers

You will need to write a reply to the decision and provide any further evidence you can gather. Read the Disability Assessor’s report carefully:

• Make a note of any conclusions you disagree with.
• Look for any evidence you have that you think they haven’t considered.
• Think about if there’s any further evidence you could provide (for example, a ‘bleed diary’) that may help you?
• Contact your haemophilia centre for a support letter. Try to get them to comment on specific points made in the Disability Assessor’s report. For example, the report may conclude that you can move more than 20 metres, and that you can do this both safely and repeatedly. You could ask your centre to say if they disagree with this conclusion.

https://www.gov.uk/mandatory-reconsideration/how-to-ask-for-mandatory-reconsideration

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 hearing

If you disagree with the outcome of the mandatory reconsideration notice you can appeal this decision. Start your appeal immediately. If you start your appeal after a month you will have to explain why you did not do it earlier. Your appeal might not be accepted.

You can appeal to the hearing within one month of getting your mandatory reconsideration decision. Your appeal will be reviewed at a hearing made up of a judge, doctor and disability expert. They will consider everything you tell them and make a decision on your entitlement to the PIP benefit.

When you reach this stage, you will need to complete an appeal form (SSCS1).

You can download an appeal form 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.

For more information - https://www.gov.uk/appeal-benefit-decision/submit-appeal

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 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.

At the tribunal you will be asked questions about your condition or circumstances by the judge or the experts. Make sure you get the support you need for this hearing, for example an interpreter, hearing loop or accessible tribunal room. You cannot use your own interpreter during the hearing. You can request support when you make an appeal.

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.
Further help with your claim

If you were affected by contaminated blood products the support schemes will be able to refer you to a specialist benefits adviser whose services will be free. They recommend contacting them as soon as possible after receiving the invitation to claim PIP.

If you have any queries about the England Infected Blood Support Scheme (EIBSS), you can contact them by:
Email: nhsbsa.eibss@nhs.net
Phone: 0300 330 1294
https://www.nhsbsa.nhs.uk/england-infected-blood-support-scheme

You can write to them at:
EIBSS, NHS Business Services Authority,
80 London Road,
London, SE1 6LH

If you have any queries about the Wales Infected Blood Support Scheme (WIBSS), you can contact them by:
Email: wibss@wales.nhs.uk
Phone: 02920 902280
https://wibss.wales.nhs.uk/

You can write to them at:
Wales Infected Blood Support Scheme (WIBSS)
4th Floor, Companies House
Crown Way, Cardiff, CF14 3UB

If you have any queries about the Scottish Infected Blood Support Scheme (SIBSS), you can contact them by:
Email: NSS.SIBSS@nhs.net
Phone: 0131 275 6754
You can write to them at:
Scottish Infected Blood Support Scheme
Practitioner Services
Gyle Square, 1 South Gyle Crescent
Edinburgh, EH12 9EB

If you have any queries about Infected Blood Payment Scheme for Northern Ireland, you can contact them by:
Email: bso.ibss@hscni.net
Phone: 028 9536 3817

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 can 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. The benefits cap will not apply to you if anyone in your household (you, your partner and any child or young person you are responsible for) is getting PIP.

More benefits

You may get a top-up (called a premium) on the following benefits if you get PIP:

- Employment and Support Allowance - but only if you get the PIP daily living component
- Housing Benefit
- Income Support
- Jobseeker’s Allowance
- Pension Credit - but only if you get the PIP daily living component
- 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

The Motability Scheme will enable you to get mobile by exchanging your mobility allowance to lease a new car, scooter or powered wheelchair.

https://www.motability.co.uk/about-the-scheme/

Blue Badge

In England, if you have been awarded 8 points or more in the ‘moving around’ activity you can get a Blue Badge. In Scotland and Wales, you can get the badge if you have been awarded 8 points or more in the ‘moving around’ activity or 12 points in the ‘planning and following journeys activity’ (for more detail see Appendix 1).

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 call 0300 123 4321 (textphone 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 don’t.

Changes that affect your PIP

You must contact the PIP enquiry line if there is a change in circumstance to your PIP. This includes if you go into hospital or a care home; you go abroad or you are imprisoned or held in detention.

Hospital stays

Your PIP will stop after a total of 28 days in a row in hospital or care home. This applies to both the daily living and mobility components. Payment can be resumed when you leave hospital/care home, providing all the other qualifying conditions are still met.

If you make a claim for PIP when you are already in hospital, it can’t 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 four weeks. However, our understanding is that you can claim PIP for up to 13 weeks while you’re going abroad.

Contact the PIP enquiry line to report a change of circumstances

PIP enquiry line
Telephone: 0800 121 4433
Textphone: 0800 121 4493
NGT text relay (if you cannot hear or speak on the phone): 18001 then 0800 121 4433
Video relay service for British Sign Language (BSL) users
Monday to Friday, 8am to 6pm
## Appendix 1: Mobility activities descriptors

Below are the descriptors for the activities that they use to assess whether you are eligible for motability, 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](http://www.legislation.gov.uk/uksi/2013/377)

<table>
<thead>
<tr>
<th>Activity</th>
<th>Descriptors</th>
<th>Points</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1. Planning and following journeys</strong></td>
<td>a. Can plan and follow the route of a journey unaided.</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>b. Needs prompting to be able to undertake any journey to avoid overwhelming psychological distress to the claimant.</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>c. Cannot plan the route of a journey.</td>
<td>8</td>
</tr>
<tr>
<td></td>
<td>d. Cannot follow the route of an unfamiliar journey without another person, assistance dog or orientation aid.</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td>e. Cannot undertake any journey because it would cause overwhelming psychological distress to the claimant.</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td>f. Cannot follow the route of a familiar journey without another person, an assistance dog or an orientation aid.</td>
<td>12</td>
</tr>
<tr>
<td><strong>2. Moving around</strong></td>
<td>a. Can stand and then move more than 200 metres, either aided or unaided.</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>b. Can stand and then move more than 50 metres but no more than 200 metres, either aided or unaided.</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>c. Can stand and then move unaided more than 20 metres but no more than 50 metres.</td>
<td>8</td>
</tr>
<tr>
<td></td>
<td>d. Can stand and then move using an aid or appliance more than 20 metres but no more than 50 metres.</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td>e. Can stand and then move more than 1 metre but no more than 20 metres, either aided or unaided.</td>
<td>12</td>
</tr>
<tr>
<td></td>
<td>f. Cannot, either aided or unaided, – (i) stand; or (ii) move more than 1 metre.</td>
<td>12</td>
</tr>
</tbody>
</table>
## 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


<table>
<thead>
<tr>
<th>Activity</th>
<th>Descriptors</th>
<th>Points</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1. Preparing food</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>a. Can prepare and cook a simple meal unaided.</td>
<td></td>
<td>0</td>
</tr>
<tr>
<td>b. Needs to use an aid or appliance to be able to either prepare or cook a simple meal.</td>
<td></td>
<td>2</td>
</tr>
<tr>
<td>c. Cannot cook a simple meal using a conventional cooker but is able to do so using a microwave.</td>
<td></td>
<td>2</td>
</tr>
<tr>
<td>d. Needs prompting to be able to either prepare or cook a simple meal.</td>
<td></td>
<td>2</td>
</tr>
<tr>
<td>e. Needs supervision or assistance to either prepare or cook a simple meal.</td>
<td></td>
<td>4</td>
</tr>
<tr>
<td>f. Cannot prepare and cook food.</td>
<td></td>
<td>8</td>
</tr>
<tr>
<td><strong>2. Taking nutrition</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>a. Can take nutrition unaided.</td>
<td></td>
<td>0</td>
</tr>
<tr>
<td>b. Needs –</td>
<td></td>
<td>2</td>
</tr>
<tr>
<td>(i) to use an aid or appliance to be able to take nutrition; or</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(ii) supervision to be able to take nutrition; or</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(iii) assistance to be able to cut up food.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>c. Needs a therapeutic source to be able to take nutrition.</td>
<td></td>
<td>2</td>
</tr>
<tr>
<td>d. Needs prompting to be able to take nutrition.</td>
<td></td>
<td>4</td>
</tr>
<tr>
<td>e. Needs assistance to be able to manage a therapeutic source to take nutrition.</td>
<td></td>
<td>6</td>
</tr>
<tr>
<td>f. Cannot convey food and drink to their mouth and needs another person to do so.</td>
<td></td>
<td>10</td>
</tr>
<tr>
<td><strong>3. Managing therapy or monitoring a health condition</strong></td>
<td></td>
<td>0</td>
</tr>
<tr>
<td>a. Either –</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(i) does not receive medication or therapy or need to monitor a health condition; or</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(ii) can manage medication or therapy or monitor a health condition unaided.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>b. Needs either –</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(i) to use an aid or appliance to be able to manage medication; or</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(ii) supervision, prompting or assistance to be able to manage medication or monitor a health condition.</td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>c. Needs supervision, prompting or assistance to be able to manage therapy that takes no more than 3.5 hours a week.</td>
<td></td>
<td>2</td>
</tr>
<tr>
<td>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.</td>
<td></td>
<td>4</td>
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<td></td>
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<td>---</td>
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<td></td>
</tr>
<tr>
<td>4. Washing and bathing</td>
<td></td>
<td></td>
</tr>
<tr>
<td>a. Can wash and bathe unaided.</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>b. Needs to use an aid or appliance to be able to wash or bathe.</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>c. Needs supervision or prompting to be able to wash or bathe.</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>d. Needs assistance to be able to wash either their hair or body below the waist.</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>e. Needs assistance to be able to get in or out of a bath or shower.</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>f. Needs assistance to be able to wash their body between the shoulders and waist.</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>g. Cannot wash and bathe at all and needs another person to wash their entire body.</td>
<td>8</td>
<td></td>
</tr>
<tr>
<td>5. Managing toilet needs or incontinence</td>
<td></td>
<td></td>
</tr>
<tr>
<td>a. Can manage toilet needs or incontinence unaided.</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>b. Needs to use an aid or appliance to be able to manage toilet needs or incontinence.</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>c. Needs supervision or prompting to be able to manage toilet needs.</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>d. Needs assistance to be able to manage toilet needs.</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>e. Needs assistance to be able to manage incontinence of either bladder or bowel.</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>f. Needs assistance to be able to manage incontinence of both bladder and bowel.</td>
<td>8</td>
<td></td>
</tr>
</tbody>
</table>
6. Dressing and undressing

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
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</tr>
</thead>
<tbody>
<tr>
<td><strong>a. Can dress and undress unaided.</strong></td>
<td>0</td>
</tr>
<tr>
<td><strong>b. Needs to use an aid or appliance to be able to dress or undress.</strong></td>
<td>2</td>
</tr>
<tr>
<td><strong>c. Needs either -</strong></td>
<td><strong>2</strong></td>
</tr>
<tr>
<td>(i) prompting to be able to dress, undress or determine appropriate circumstances for remaining clothed; or</td>
<td>(ii) prompting or assistance to be able to select appropriate clothing.</td>
</tr>
<tr>
<td><strong>d. Needs assistance to be able to dress or undress their lower body.</strong></td>
<td>2</td>
</tr>
<tr>
<td><strong>e. Needs assistance to be able to dress or undress their upper body.</strong></td>
<td>4</td>
</tr>
<tr>
<td><strong>f. Cannot dress or undress at all.</strong></td>
<td>8</td>
</tr>
</tbody>
</table>

7. Communicating verbally

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
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</tr>
</thead>
<tbody>
<tr>
<td><strong>a. Can express and understand verbal information unaided.</strong></td>
<td>0</td>
</tr>
<tr>
<td><strong>b. Needs to use an aid or appliance to be able to speak or hear.</strong></td>
<td>2</td>
</tr>
<tr>
<td><strong>c. Needs communication support to be able to express or understand complex verbal information.</strong></td>
<td>4</td>
</tr>
<tr>
<td><strong>d. Needs communication support to be able to express or understand basic verbal information.</strong></td>
<td>8</td>
</tr>
<tr>
<td><strong>e. Cannot express or understand verbal information at all even with communication support.</strong></td>
<td>12</td>
</tr>
</tbody>
</table>

8. Reading and understanding signs, symbols and words

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
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</thead>
<tbody>
<tr>
<td><strong>a. Can read and understand basic and complex written information either unaided or using spectacles or contact lenses.</strong></td>
<td>0</td>
</tr>
<tr>
<td><strong>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.</strong></td>
<td>2</td>
</tr>
<tr>
<td><strong>c. Needs prompting to be able to read or understand complex written information.</strong></td>
<td>2</td>
</tr>
<tr>
<td><strong>d. Needs prompting to be able to read or understand basic written information.</strong></td>
<td>4</td>
</tr>
<tr>
<td><strong>e. Cannot read or understand signs, symbols or words at all.</strong></td>
<td>8</td>
</tr>
<tr>
<td>9. Engaging with other people face to face</td>
<td></td>
</tr>
<tr>
<td>------------------------------------------</td>
<td>---</td>
</tr>
<tr>
<td>a. Can engage with other people unaided.</td>
<td>0</td>
</tr>
<tr>
<td>b. Needs prompting to be able to engage with other people.</td>
<td>2</td>
</tr>
<tr>
<td>c. Needs social support to be able to engage with other people.</td>
<td>4</td>
</tr>
<tr>
<td>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.</td>
<td>8</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>10. Making budgeting decisions</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Can manage complex budgeting decisions unaided.</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>b. Needs prompting or assistance to be able to make complex budgeting decisions.</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>c. Needs prompting or assistance to be able to make simple budgeting decisions.</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>d. Cannot make any budgeting decisions at all.</td>
<td>6</td>
<td></td>
</tr>
</tbody>
</table>