



Personal Independence Payment – A guide for HCPs

Introduction

As you will know, Personal Independence Payment (PIP) is being introduced as a replacement for Disability Living Allowance (DLA). The transition process is now in full swing: all adults under the age of 65 who have been receiving DLA, often for many years, are being 'invited' to claim PIP. As part of their claim process they are (or will be) asking staff at their Haemophilia centre for a letter in support of their claim. We have received feedback from both patients and staff that staff are not sure what is needed when asked to provide a support letter.

The aim of this guide is to help you to include relevant (and exclude irrelevant) information when asked to write support letters. Below we:

- Discuss what is being assessed, particularly with regard to mobility;
- Give a short overview of the legislation we believe is relevant to people with bleeding disorders;
- Discuss how this applies to people with bleeding disorders;
- Provide a list of information that we believe should be included in a support letter.

What is being assessed?

The Descriptors

The core of the assessment process is that the difficulties faced by a claimant in performing a range of activities are compared with a list of 'descriptors' which, as the name implies, describe differing degrees of difficulty with each activity. Each descriptor carries a number of points. The assessor chooses the descriptor that best matches the claimant's situation and points accumulated.

This process is more easily shown if we look at the descriptors under the heading "Moving Around"

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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

So, if the assessor thinks that either descriptor (e) or (f) best matches the claimant's situation, then 12 points will be scored. Likewise, if descriptor (c) is thought the best match, then 8 points are scored. (These are important scores: a claimant needs 12 points to be awarded the enhanced rate of Mobility Component, which can be used to

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lease a car through the Motability scheme. 8 points will lead to an award of the standard rate of Mobility Component, but this will not be enough to lease a car).

We discuss the other descriptors later in this guide.

However, the assessment is not simply whether a claimant can perform the activity on a single occasion. The assessor should also take into account the claimant's ability to perform each action safely and repeatedly. We discuss what this may mean in the next section.

A Bit of Legislation

The Personal Independence Payment Regulations state that:

(A claimant) is to be assessed as satisfying a descriptor only if (the claimant) can do so—

- (a) safely;
- (b) to an acceptable standard;
- (c) repeatedly; and
- (d) within a reasonable time period.

and defines these terms:

- (a) "safely" means in a manner unlikely to cause harm to C or to another person, either during or after completion of the activity;
- (b) "repeatedly" means as often as the activity being assessed is reasonably required to be completed; and
- (c) "reasonable time period" means no more than twice as long as the maximum period that a person without a physical or mental condition which limits that person's ability to carry out the activity in question would normally take to complete that activity.

(Note: the regulations do not define 'to an acceptable standard').

And What It Means For People with Bleeding Disorders

In essence this means that if a claimant is at risk of starting a bleed in a joint through repeating an activity as often as reasonably required, then they cannot perform that activity 'safely' within the meaning of the regulations. So, to make a well-considered

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decision the DWP assessor will need information that enables them to assess how *safely* a claimant can walk the distances stated in the descriptors.

What to Include In Your Letter

When writing your letter it is best to presume total ignorance on the part of the assessor appointed by the DWP and the DWP's own decision makers.

We recommend that you do not express opinions about which descriptors are applicable to your patient. Also, general statements such as "their condition is well-managed" are not helpful. Instead, we recommend that you include specific, factual information that is recorded about the patient - recorded bleed history, joint scores and assessments using the Haemophilia Activities List (HAL) are particularly relevant. Here is a list of what we believe to be the most important points to include:

Treatment and bleed history

- A description of the patient's bleeding disorder, including type, severity, and whether they have an inhibitor.
- A description of treatment 'regime': which factors; whether 'prophylactic' or 'on demand'; is treatment self-administered or given by someone else, or both.
- Details of treatment given for bleeds, including 'breakthrough' bleeds, drawn from treatment records completed by the patient. It is best if details of the site of each bleed can be listed, particularly if a patient is having repeated bleeds into the same joint. Ideally, all bleeds occurring in the last 12 months should be listed.
- Details of the consequences of these bleeds – i.e. requiring intravenous treatment; post-bleed care; did any result in hospitalisation?

Joint damage

- 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. Joint scores and details of range of movement could be given.
- It will be useful to note the impact of any joint damage on the patient's ability to carry out day-to-day activities: for example, 'he cannot put on his shoes and socks unaided because his knees don't bend' or 'he cannot put on his shirt or jacket

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unaided because of the restrictions in his upper limbs'. The patient's most recent Haemophilia Activities List (HAL) may already contain this information.

- Details of any operations the patient has had, or which are planned, such as knee or hip replacements, ankle fusing, or synovectomies.
- Details of wastage in muscles supporting a joint.
- Information about any pain and discomfort you know they experience regularly or frequently.

Issues with walking

- A description of the way (gait) in which they walk and their speed compared with a 'normal' person.
- If they habitually use crutches or a walking stick, is this simply to aid their balance or is it to reduce weight bearing through leg joints with the aim of reducing the risk of bleeding?
- Are there any risks when using crutches, such as starting a bleed in wrists, elbows or shoulders?

It will also be helpful if you 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.

Other Information to Include

We have stressed above the information we think is most relevant for the assessment under the "Moving Around" heading. We have done this because it is the potential loss of the Mobility Component (and Motability cars) that most concerns our members. We have also focused on the impact of having a bleeding disorder. There are two other areas of information you can usefully include:

Activities of Daily Living

There is also a list of descriptors the assessor has to score. Sufficient points here can also lead to an award of the Daily Living Component of PIP (in addition to any Mobility Component awarded). The descriptors cover activities such as preparing and cooking a meal, washing and bathing, getting dressed and undressed, and managing toilet needs, amongst others.

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It will be useful if you can include any information concerning joint damage, and tendency to have bleeds, in the upper body as well as in the lower limbs – see the suggestions about using the Haemophilia Activities List we make above. An occupational therapist's report (if available) can be another useful source of information.

Motivation and fatigue

With some of the descriptors, the need for the claimant to be 'prompted' to carry out an activity is important. Fatigue is also a consideration the assessor should take into account. Such difficulties may arise for people who are HIV positive or who have Hepatitis C. The healthcare professionals responsible for this aspect of the patient's care could be asked to contribute to a supporting letter or, alternatively, asked to provide a separate letter.

Women with a bleeding disorder can also suffer prolonged fatigue if they are anaemic as a consequence of menorrhagia.

When to provide a supporting letter

There is a common misconception that the DWP will contact a haemophilia centre to request additional information about a claimant. In fact, they rarely, if ever, do so. Therefore we urge you to give a support letter to the claimant (your patient) when they first request it. We urge our members to contact you as early as possible to request a supporting letter.

It is best if the letter is ready for them to send in with their own statement (the "How your disability affects you" form, known as the PIP2 form). If the letter cannot be ready in time, then they do have another chance to hand it in when they attend the face-to-face interview with the DWP appointed assessor.

If the letter is not available to the assessor, then it will not be fully considered if it is sent to the DWP later.

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