



ME and PIP

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An overview of PIP

Personal Independence Payment (PIP) is a benefit for working-age people in England, Wales and Northern Ireland who have care and mobility needs. There is a different but broadly equivalent benefit for disabled people in Scotland, called Adult Disability Payment (ADP).

PIP has two components: the daily living component and the mobility component. Each component has two rates: the standard rate and the enhanced rate. It is possible to be eligible for one or the other component, or both at the same time. For people who are eligible for both components, it is possible to be eligible for the standard rate of both, the enhanced rate of both, or a combination.

PIP is designed to help with the additional costs of living with a disability. Unlike many other benefits, eligibility does not depend on your income and savings – it is possible to be a millionaire and get PIP!

This factsheet aims to supplement existing information provided by organisations with expertise in welfare benefits, by looking at the benefit from an ME-specific perspective.

There is a list at the end of this factsheet of places you can find general information about PIP.

Pacing while applying for PIP or renewing a claim

Applying for PIP can take a lot of energy. We suggest that you try to pace this process as much as you can. The same is also true for completing a renewal form.

The application form is long. Filling it in is likely to take a significant amount of cognitive energy. It may also take emotional energy: it requires you to be honest with yourself about how much you might be struggling. Sometimes we are so used to just “making the best of things” that to be confronted with a reminder of how hard things are can be challenging.

However, when applying for PIP it's important to give the full truth so that you can get the support you are entitled to.

When completing a renewal form, give as much information as if you were making an application for the first time.

There is a deadline for returning the PIP form or renewal form, so it's important to plan ahead. You can ask the Department for Work and Pensions (DWP) for an extension if you don't think you will be able to complete the form by the deadline. Remember that the form has to be *back with the DWP* by the deadline (not just posted off).

Way to pace the PIP applications and renewals process

Draft your answers in advance

Have a look at a [specimen copy of the big PIP form](#) before you make your claim, and start to make notes and draft answers in advance. You **CANNOT** submit this specimen form. The DWP will either send you a version of the form through the post, or a link to an online version, and you **CAN ONLY** continue your application using those versions of the form.

Ask for an extension

Ask the DWP for an extension to complete the form, by calling the number on the letter that came with the form. You will need to tell the DWP why you need more time. For example, this could be because you can only manage small periods of using mental energy per day without crashing or going into overwhelm due to the cognitive impact of your ME.

Get help filling in the form

This could be from a friend or relative, or from an agency (see possible sources of help below). Be prepared – services that can help with this are usually extremely busy.

Plan your time

Map out a plan for completing the form in good time to post it to the DWP so that they receive it by the deadline. Consider how many questions you will need to complete on which days, and what other things in your normal routine you may have to delay (or get help with) so that you can achieve this. You should also try to leave to leave some spare energy in your plan for managing anything unexpected that comes up, or any emergencies.

If you have an online claim form - remember that you can type your answers in a separate document first and then copy and paste them into the online form. This way you also have a record of your answers.

General tips for completing the PIP form

- Don't feel constrained by the amount of space they give you to write an answer. If you are filling in a paper form you can always use an additional sheet of paper. (If you do this, remember to write your name and national insurance number on each additional sheet, so that they don't get lost).
- Many people with ME also have other conditions. Throughout the process of applying for PIP (or renewing your claim) it's important to explain the cumulative impact of all your health conditions put together.

Medical evidence

We know that medical evidence can be helpful for people with ME applying for PIP. The most effective medical evidence is a letter from a medical professional that details your symptoms and the impact that they have on your day-to-day life and mobility. Other evidence will carry variable weight but may include:

- A letter confirming diagnoses
- A "patient print out" of your medical records (you can ask your GP practice for one of these)
- A copy of a report from a different assessment (for example, if you have had an occupational health assessment to see if you need adaptations to your home)
- Evidence from support workers
- A letter from a carer (for example a parent or your partner) outlining how they support you because you struggle to do things by yourself.
- A copy of your care plan from a social worker

(Action for ME has a separate factsheet on supporting evidence for PIP and WCA assessments.)

Diary of needs

A diary can be an effective way of communicating to a decision maker about the reality of your day-to-day life. This is different from an activity diary. The goal is not just to note what you have done, but also – more importantly – what you can't do. Specifically, a diary should look at your ability to do the PIP "activities" (see below) on each day and highlight when and how often you can't do them.

If you have a carer they can keep a diary of your needs and you can submit that as evidence.

Understanding the 'activity' questions

It is important that you understand how your eligibility will be assessed, so that you can ensure you include all the relevant information – both on your form and during any assessment appointment.

Whether or not you meet the disability criteria for PIP will be decided according to a very formulaic set of rules. The big PIP form and any assessment appointment you have both form part of this "assessment" in the wider sense.

The assessor and decision maker look at your ability to do a specific list of activities, and awards you points based on how much you struggle with each activity. They do this by comparing the difficulties you have to a number of "descriptor" phrases, and deciding which descriptor most closely describes your situation.

Therefore, in making the case that you should qualify for PIP **it's important to understand what these activities and descriptors are**. You can find a list of them, as well as the corresponding points, in the appendix at the end of this factsheet. We strongly recommend that you have a copy of the activities, descriptors and points next to you as you complete the PIP form or renewal form.

For each component of PIP (the Daily Living Component and the Mobility Component), if you score 8 points under the relevant activities you will be awarded the standard rate of that component. If you get 12 points under the relevant activities, you will be awarded the enhanced rate of that component. Points scored under the activities for one component only count towards eligibility for that component. For example, if you score 4 points under the "daily living" activities and 4 points under the "mobility" activities, you can't combine these to make 8 points overall.

It's worth noting that when the descriptors are looking at an ability to prepare a simple meal using a microwave, this doesn't mean a ready meal. It still means preparing a meal from fresh ingredients, just using the microwave rather than the hob to heat/cook those ingredients.

PIP and fluctuating conditions

Two key PIP rules are particularly important for people with fluctuating conditions such as ME:

- You shouldn't be considered able to do something if you can't do it "reliably", that is: **safely, repeatedly (i.e. as often as you need to), in a reasonable amount of time (no more than twice as long as it would take you if you were well), and to an acceptable standard.**
- You shouldn't be considered able to do something if you can't do it more than **50% of days.**

You should bear these rules in mind when you are completing the activity questions on the application form/renewal form.

Filling in the activity questions

You should bear these rules in mind when you are completing the activity questions on the application form/renewal form.

- Look at the descriptors sheet. What is the descriptor for this activity that best applies to you?
- Can you do this activity at all? Can you do the activity less than 50% of days? How many days in a week/in a month can you do it? Is there a time of day when you cannot do it? (An activity diary is a useful way to demonstrate these factors).
- Can you do it safely? This means: if you do it, will it cause symptoms such as pain and fatigue to flare up? If so, what with the impact on your health be of doing it? Or in some cases, if you do it, will you accidentally hurt yourself?

- Can you do this activity repeatedly? Meaning: can you do it *as many times as you need to* in the day? If you do it in the morning, will you be so exhausted that you can't do it in the afternoon if you need to?
- Can you do it in a reasonable amount of time? Will it take *you more than twice the amount of time* it would take someone without your health conditions to do it?
- Can you do it to an *acceptable standard*?
- Do you have to use anything or anyone to help do this activity? An example might be: do you use a grabber to reach things? Do you have a perching stool that you need to sit on to e.g. chop food? Do you need someone to support you to do the activity? (It doesn't matter whether you do or don't have someone to help you currently. The form is trying to capture what you *need*, not what your current arrangements are for having those needs met.)
- Can you link the above to your ME, any other health conditions you have, or the cumulative impact of health conditions? What symptoms in particular get in the way? For example pain, fatigue, difficulties with concentration, anxiety.

For each question you should also try to:

- Give a real-world example. For example: "I can't prepare a meal reliably without assistance, because it takes me twice as long as it would take a healthy person because I need to take rest breaks. E.g. last Tuesday it took me two and a half hours overall start to cook a meal of a chicken breast, potatoes and carrots, since I had to stop to rest between preparing the vegetables and cooking them, otherwise I would have been so clumsy from fatigue that I would have risked dropping a pan of boiling water."
- Can you make reference to the medical evidence and explain why it is relevant to this activity?

The assessment appointment

Once you have submitted your form, you may be contacted by the DWP to say that you will need to attend an appointment with a medical professional. This may be by phone, or possibly face-to-face. There is a section on the PIP form where you can specify your needs for adjustments in relation to this. If you would not be able to attend a face-to-face appointment, you should say so here and explain why. You can also explain if you are likely to need breaks during the appointment (whether it's face-to-face or over the phone) and again explain why.

Key things to know about the assessment

We suggest that you ask for your PIP assessment to be recorded. If possible, have someone with you at your assessment (whether your assessment is over the phone or face to face).

As well as recording your answers to questions, the assessor will make "informal observations" about you.

It's important to remember that the key information the assessor is looking for is the same information they are looking for from your form i.e., to what extent you can do the specified activities and, in particular, which descriptors best apply to you. They will be looking at whether your answers are *consistent with what you said on the form*.

It's still important to remember the rules that mean you shouldn't be considered able to do something if you can't do it reliably (see above), and over 50% of the time. You're trying to give the assessor a sense of what your life is like in practice day-to-day.

Where to get information about PIP

Benefits and Work

Benefits and Work have [good information about PIP](#) on their website. Members of Benefits and Work can also download their [PIP guides](#). They have a guide to [PIP and ME/CFS](#), as well as their comprehensive guide to PIP (note: this latter guide is 141 pages long).

Turn2 us

The [Turn2Us website](#) has information on PIP and guides you can download, as well as a step by step guide to applying for the benefits which includes videos.

Citizens' Advice

Citizens' Advice also have a lot of [good information about the benefit](#) on their website, including on [how to fill in the form](#), and they have a [factsheet on how to prepare for your assessment](#) on this page.

Disability Law Service

The Disability Law Service has a range of [resources on PIP](#), including a video that gives information about how to complete the form.

Advice Local

The [Advice Local website](#) is a directory you can use to find out if there are in-person advice services near you.

Appendix I: The activities, descriptors and points.

Daily Living Activities

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.	0
	b. Needs [F1 any one or more of the following] - (i) to use an aid or appliance to be able to manage medication; F2 ... (ii) supervision, prompting or assistance to be able to manage medication F3 ... [F4 (iii) supervision, prompting or assistance to be able to monitor a health condition.]	1
	c. Needs supervision, prompting or assistance to be able to manage therapy that takes no more than 3.5 hours a week.	2
	d. Needs supervision, prompting or assistance to be able to manage therapy that takes more than 3.5 but no more than 7 hours a week.	4
	e. Needs supervision, prompting or assistance to be able to manage therapy that takes more than 7 but no more than 14 hours a week.	6
	f. Needs supervision, prompting or assistance to be able to manage therapy that takes more than 14 hours a week.	8

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
	a. Can dress and undress unaided.	0

6. Dressing and undressing.	b. Needs to use an aid or appliance to be able to dress or undress.	2
	c. Needs either - (i) prompting to be able to dress, undress or determine appropriate circumstances for remaining clothed; or (ii) prompting or assistance to be able to select appropriate clothing.	2
	d. Needs assistance to be able to dress or undress their lower body.	2
	e. Needs assistance to be able to dress or undress their upper body.	4
	f. Cannot dress or undress at all.	8
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 (ii) the claimant to exhibit behaviour which would result in a substantial risk of harm to the claimant or another person.	8
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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Useful contacts:

C-App

Guides to applying for PIP and ESA

<https://c-app.org.uk>

Citizens Advice Bureau

Offers advice on a range of issues and may be complete a benefits check for you.

www.citizensadvice.org.uk

Disability Rights UK

Factsheets on benefits, tax credits and independent living.

www.disabilityrightsuk.org

PIP info

A guide to regulations and case law regarding PIP.

<http://pipinfo.net>

Registered office:

Action for ME

Unit 2.2 Streamline

436-441 Paintworks

Bristol, BS4 3AS

Telephone: 0117 927 9551

Info & Support: infosupport@actionforme.org.uk

Fundraising: fundraising@actionforme.org.uk

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