

Long Covid and Personal Independence Payment (PIP)

how to save your spoons when claiming.

This information sheet has been written by an occupational therapist living with Long Covid who has personal experience of claiming PIP. It is for young people and adults who have Long Covid, but it may also be of value to anyone who is seeking advice and support about how to make a claim.

You will find six steps to claiming PIP outlined below, FAQs and links for seeking advice and guidance.



PIP is a UK benefit that is non means tested to support people with the additional costs associated with having a long term health condition or disability who struggle with their everyday activities of daily living or moving around because of their condition. For more details see: <https://www.gov.uk/pip>

It is likely that many people living with Long Covid aged between **16-state pension age** will be eligible for PIP if their symptoms have lasted for three months, they are not getting better and expect their symptoms to last 12 months. See this video from Benefits and Work for more details: <https://www.youtube.com/watch?v=qspwV2j9s28>

When claiming PIP, you will need to complete a form and undergo a medical assessment, more commonly being carried out by telephone at present but it may be face to face or paper based. The PIP award decision is based on a points system following your medical assessment. You can see how the points are awarded here: <https://www.legislation.gov.uk/uksi/2013/377/schedule/1>

There are two payment rates based on the points scored:
- lower weekly rate daily living part £61.85 and higher weekly rate daily living part £92.40. Mobility part lower weekly rate £24.45 and higher weekly rate £64.50.

You can check for any updates and changes here:
<https://www.gov.uk/pip/how-much-youll-get>

Dan Manville from GMLAW (<https://www.gmlaw.org.uk>) kindly checked the answers to the FAQs and provided additional information.

There are some changes in Scotland and if you live in these areas: Dundee City, Perth and Kinross or the Western Isles then you need to apply for **Adult Disability Payment (ADP)** instead.

You do not pay tax on PIP and may be entitled to other benefits too.

How can I use the least spoons (energy) possible to claim PIP?

SIX STEPS:

1. Try to be organised by setting up a system to keep track of your claim

For example, start an A4 File to keep a full record of your claim. Things will be easier if you keep a record throughout the process.

2. Consider who is best to advise and support you to make a PIP claim, and plan when you will make first contact



There are local and national advice services that may include face to face, email, text, and telephone options too. Some services are free, but others do charge a fee. Some of these services may have a waiting list so it's best to make contact early on and find out.

The Long Covid community recommend lots of different services via social media. However, it is recommended that you search for a trusted service here: <https://advice.local.uk>

There are various guides on how to claim PIP but reviewing these may demand considerable spoons.

An example is Benefits and Work See: <https://www.benefitsandwork.co.uk>. There is an annual fee of £19.95 to access written guides, one specific to Long Covid but some information is free via their website too.

The Citizens Advice service also have information about PIP see:
<https://www.citizensadvice.org.uk/benefits/sick-or-disabled-people-and-carers/pip/>

Family, friends, and professionals involved in your care may be able to support you too.

3. Plan and prioritise when you will make the call to Department for Work and Pensions (DWP) to start your claim

See: <https://www.gov.uk/pip/how-to-claim> for all contact details

Telephone: **0800 917 2222** Monday to Friday **8am-5pm**

You might be best to try calling on a less busy period such as Tuesday-Friday and first thing in the morning if possible.

You must make the initial call yourself, but you can have someone present during the call and give them consent to speak on your behalf.

The Government website states you need to give the following information when you call:

- your contact details, for example telephone number
- your date of birth
- your National Insurance number, if you have one (you can find this on letters about tax, pensions, and benefits)
- your bank or building society account number and sort code
- your doctor or health worker's name, address, and telephone number
- dates and addresses for any time you've spent in a care home or hospital
- dates for any time you spent abroad for more than 4 weeks at a time, and the countries you visited

This initial call may take an hour or longer so try to ensure you are in a comfy chair/bed, have a drink /snack if needed to hand and someone in the house in case you need to go to the toilet and your call can be answered.

There is an option to make a claim by post please see:

<https://www.gov.uk/pip/how-to-claim>



4. Start to gather your evidence (medical and from significant others) to support your claim

Plan some time to make notes about how your Long Covid symptoms impact your everyday activities. You may want to keep a diary of how you spend your day.

Seek support with this task if needed.



If you are attending a Long Covid clinic or service, ask for copies of reports and letters. You can also tell the occupational therapist and physiotherapist you are making a claim.

Ask healthcare professionals involved in your care for copies of any letters or reports that you can submit as evidence.

You could ask your GP for your last two years medical records make sure that these include clinic letters. However, it is wise to read through these medical records first to make sure you are happy to include these.

If you have paid for any private healthcare, you could ask for copies of any medical evidence.

Ask family and friends to write a statement about the impact of Long Covid on your everyday life. Be prepared that reading these statements may be upsetting. Think about how you can be best supported if you are upset e.g., peer support such as the Facebook group via

<https://www.longcovid.org> and
<https://www.longcovidkids.org>

You can still submit evidence once you have returned your form, but you cannot submit any further information once you have had your PIP medical assessment.



5. Start to complete your application form

The form can be completed online but you can still request a paper copy if preferred. Keep a copy of your form in your file. So, you will need to photocopy or scan this if you have opted to use the paper version.

It might be easier to think about how you can pace when answering the questions, for example, you could plan to answer one question a day, or one question every other day.

This can be a tough task for many of us and upsetting, so plan some rest time after answering your questions, and if possible do something relaxing that you enjoy.

For Top tips on thinking about how you answer each question see the everyday activities section on page 5.

You can find out how the points are awarded here in **Part two** and make comments on your form where you know you have difficulties:

<https://www.legislation.gov.uk/uksi/2013/377/schedule/1>

If you have medical evidence that relates to a question then state this on your form and highlight the section of the evidence, for example an occupational therapist's report.

6. Be prepared for your medical assessment

Seek support and ask someone to join you on the telephone call or face to face assessment if needed. This person can mention things that you may forget.

Make key points that you want to get across to the assessor during your medical assessment. Try to tick these off once you have mentioned them, so you do not forget important points if possible.

Have your file of information ready and a copy of your completed assessment form.

You can ask for this assessment to be recorded, but it is unlikely this recording will be listened to externally if you make a mandatory reconsideration or appeal see below.

Beware that some providers may not have enough recorders, and this may delay your assessment if they need to locate one.

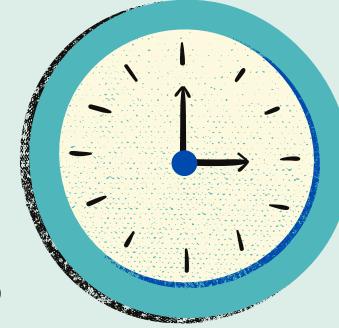
Tell the assessor that you are reading from your notes too and ask for a pause if needed. It is OK to tell the assessor how you feel during the call too, for example, if you are upset, or anxious or need to take a break.



Everyday activities

Remember to think about whether and how you can carry out your everyday activities.

If you need prompts to think about each activity, then there is an example below. You can think about each question on the form in relation to whether you can do this ***safely, timely, accurately, and reliably***.



Let's use making a hot drink as an example:



Can you make yourself a hot drink ***safely***, and in a ***reasonable time frame***?

Can you lift the kettle safely or are you at risk of burning yourself when lifting it? Do you have problems standing? Do you lose your balance? Do you feel faint? Do you have loss of sensation in your hands or poor grip?

Do you need to sit down while the kettle boils and have a rest?



Do you struggle to move around your kitchen? Can you carry items such as the milk carton from the fridge?

Does it take you twice as long or longer to make a hot drink now than it did before you had Long Covid?



Do you feel so unwell after making a hot drink that you cannot drink it? Or do you need to rest and forget to drink it?

Can you make a hot drink ***accurately*** or for example, do you forget to add the milk or sugar?

Does anyone have to prompt you to make a drink? Or does someone supervise you with this task? Or does someone give your assistance with this task?

Think about whether you can ***repeat*** this task. So, can you make yourself hot drinks throughout the day as and when you want and need one?

So, let's think about ***reliably*** too, and the ***cumulative effect*** of making hot drinks throughout the day on your Long Covid symptoms.

For example, can you make a hot drink consistently well, have you got enough energy to also get washed and dressed, make a phone call, make your lunch, wash up and tidy the kitchen?

Think about how you feel during and after carrying out an activity:



Are you able to 'push through' but will feel the consequences immediately or for next day or days?

Do you experience post exertional malaise (PEM) "payback" or post exertional symptom exacerbation (PESE) during or after undertaking a task or several tasks? For example, do you notice chest pains or feel fatigued when making a hot drink or sometime afterwards?

Do you use a perching stool or chair in the kitchen to rest and conserve your energy while making a hot drink?

Do you have help with any everyday tasks?

Are you unable to make a hot drink? Does someone else do this for you? e.g., do they leave you a hot drink in a flask? Or do you go without a hot drink always or sometimes if you are too tired to undertake this task.

Remember you need to give the details on your form and even if you can make a hot drink once it doesn't mean that you can do this safely, timely, accurately, and reliably throughout the day or week.

My claim has been closed by DWP can it be reopened?

It may be possible to reopen your claim if you have a good reason and you may be able to ask to speak to a case manager to have your claim reinstated. If this is not possible then you can apply again.

Are you running out of time to return your claim form?

You can extend the deadline for completing your claim form by calling the DWP: the extension is usually for two weeks at a time. But you could ask if they will extend this period for longer and they may agree for example one month. There is no time limit to extending the time if you have a good reason, e.g., you are unable to get support to help you complete the form.

Frequently Asked Questions

I have Long Covid can I claim PIP?

Yes, if your symptoms such as fatigue, pain and breathlessness are impacting on your ability to carry out everyday activities such as getting washed and dressed and moving around.

There are delays in the claims process so it is best to claim as soon as possible. Don't be overly concerned about whether your Long Covid symptoms will last for 12 months.

I have savings or a regular income can I claim PIP?

Yes, PIP is non means tested so you can have savings and other income e.g., from a partner's salary or your own job.

I have been awarded PIP mobility component how do I claim a vehicle tax refund?

<https://www.gov.uk/vehicle-tax-refund>. Plan when you will apply for additional benefits and seek support if needed.

It has been months since I had my PIP assessment, but I haven't heard anything yet. What should I do?

It is best to call the DWP to check what has happened with your claim.

Is it worth claiming when I hear people with Long Covid are not being awarded PIP?

Yes, and although you don't have to look far on social media to read that someone with Long Covid has not been awarded PIP, some people are being awarded this benefit following their assessment. Other people are needing to seek a mandatory reconsideration or appeal to be successful. Therefore, if possible seek advice to ensure you provide the best information to support your application.

I have been awarded PIP are there other benefits that I may be entitled to?

Yes.
See: <https://www.citizensadvice.org.uk/benefits/sick-or-disabled-people-and-carers/pip/before-claiming/extrahelp-pip-entitles-you-to/>

For example, you might be able to claim vehicle tax reductions/exemption, blue badge, council tax reduction

What do I do if I am not awarded PIP or feel I should have received a higher rate?

You can request a mandatory reconsideration usually within a month. See:
<https://www.citizensadvice.org.uk/benefits/sick-or-disabled-people-and-carers/pip/appeals/mandatory-reconsideration-pip/> but this timeframe may be extended, up to 13 months with good reason.

How do I appeal DWP's decision?

Please see <https://www.citizensadvice.org.uk/benefits/sick-or-disabled-people-and-carers/pip/appeals/apply-to-tribunal/> You need to have asked for a mandatory reconsideration first. Welfare rights experts can cite case law when they support you with an appeal. If you appeal, you will be sent a copy of your medical report and any evidence that you submitted with your claim.

I didn't send in any medical evidence with my claim form what should I do?

You can still send in medical evidence after your claim has been submitted, but you cannot add any further evidence once you have had your medical assessment.

Should I ask healthcare professionals involved in my care to provide me with medical evidence?

Yes, especially if you are involved with an occupational therapist or physiotherapist. Ask for copies of your reports and letters they may have written to your GP.

Can I delegate tasks for my PIP claim to save my spoons?

You can search for advice and guidance for trusted support here: <https://advicelocal.uk>

Where can I get advice and support for my PIP claim?

Please see <https://advicelocal.uk> There are a range of organisations that can offer support, some are free and other organisations may charge a fee to access their resources such as letter templates, benefit guides and individual support with your mandatory reconsideration or appeal.

I only have medical evidence from my GP is this enough?

GPs don't often write about your functional abilities with everyday activities, but you can ask your GP for your last two years of medical records. If you are attending a Long Covid clinic you could ask for copies of reports and letters.

You can also add supporting evidence from significant others

I haven't seen an occupational therapist or been issued any aids or equipment, but I have adapted the way I do things and purchased my own equipment, should I include that detail on my form?

Yes, for example:

- You use a chair to sit at the sink to wash or in the kitchen to prepare food.
- You use a shower board over your bath.
- You use a garden chair in your shower. (This is not recommended).
- You push up or pull on a toilet roll holder, sink or radiator to get up from the toilet. (This is not recommended).
- You lean on your crutches to get up from the armchair. (This may be unsafe).

Some of these strategies above are unsafe and if you need or want to self-refer to occupational therapy please see: <https://otforlc.com/about-ot4longcovid/>

Final point please remember <https://advicelocal.uk> Advice local is maintained by London Advice Services Alliance, so it is deemed as a trustworthy way to search for support.