Personal Independence Payment and blood cancer



KNOW YOUR RIGHTS **TOOLKIT**





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Introduction

Personal Independence Payment (PIP) is one of the benefits you may be apply to claim for if you are affected by blood cancer. Knowing whether you are eligible and navigating the PIP process can be complicated.

Finances can be a worry, whatever stage of your leukaemia journey you are at. From our survey, "Living with Leukaemia", we found that:

- 43% of all patients report a negative impact on finances AND:
- 64% of those said this was due to an increase in their costs
- 70% of those said this was due to a reduction in income

One of the reasons for a reduction in income is that you may be unable to work as much or at all following a diagnosis. Some people experience long term side effects of their

treatment; the most common ones we hear about are fatigue and pain in the bones and joints. If these kinds of symptoms are impacting on your day-to-day life, you may be eligible for extra financial help in the form of PIP.

In this "Know your Rights" toolkit, we will look at when PIP is relevant for you because of how a blood cancer diagnosis affects your day-to-day activities. This toolkit will also give you a step-by-step guide for claiming PIP, tips for the claim form and the assessment, which will give you a better understanding of PIP and this process.

Version 1

Printed: 05/2021

Summary of key points

Should I apply for PIP?

It is possible to be eligible to claim PIP if suffering from a blood cancer diagnosis, but it depends on how blood cancer affects you, as everyone is different and not affected in the same way.

A blood cancer, like other illnesses, can affect your income, particularly if you have to give up work or cut down hours. Having a bit more extra money could help you to pay for things you need or want, such as towards a car, if you have limited mobility. Being eligible for PIP may also lead to "passporting", where you become eligible for other benefits such as free prescriptions.

What is PIP?

Personal Independent Payment (PIP) is a non means tested benefit, aiming to provide extra money if you need help with daily activities or have difficulty getting around (mobility) as a result of a disability or longterm illness. You can make a

claim if you have a long-term health condition and are aged 16 and over or under pension age.

There are two parts, called components.

- Daily living needs
- Mobility needs

You may get one part or both parts.

PIP process

There are three stages to claim PIP. It can take up to four months to make a claim for PIP from the initial phone call to DWP to getting you money, unless you have a terminal diagnosis.

How do I apply for PIP?

Step 1 - To start your claim contact the Department Working Pensions (DWP) on **0800 917 222**. You will need to give them some basic information and then they will send you the claim form.

Step 2 - The second step to claiming PIP is to complete the "how does your disability affect

you" form. The form asks for examples of how your condition affects your daily life. Providing these examples may be challenging for you. We can help you with this.

For each activity, there is a list of descriptors and depending on your answers, you will get points. You will receive a score based on how much help you need, which will affect how much PIP you'll receive. Depending on your answers to the questions and the number of points you are awarded, you will receive either the standard or the enhanced rate of each component. You need a total of 8 points for standard and 12 points for enhanced.

You will be informed of the decision on your claim. If you claim has been turned down, you can challenge it. Talk to our welfare officer, or read the full toolkit for our advice on how to challenge a benefits decision.

Step 3 -Send your completed form by recorded delivery to

DWP, making sure you keep a copy of the form. A health care professional will then assess the form, and you could be invited to attend a face-to-face assessment. You can request a home visit for the assessment.

You can take someone with you for support, such as a family member, friend or relative, or it can be an advocate such a benefit adviser.

You will then get a final score.

Challenging a decision

DWP will be inform you of the decision on your claim. If you claim has been turned down, you can challenge it. Talk to our welfare officer or read our advice on challenging a benefit decision in our next toolkit.

Changes to your health

If your health condition or situation changes, you should report changes to DWP as this may affect your entitlement.

Applying for PIP - a case study

We asked Denise, a patient with a diagnosis of the chronic condition myelofibrosis, to tell us about their experience of applying for PIP.

Why did you want to apply for PIP?

I had/have many symptoms, some of which are chronic pain, fatigue, dizziness and brain fog. In addition, I have anxiety and depression due to not gaining the support I obviously needed. I was desperate, physically, mentally, emotionally, spiritually and financially.

I wasn't sure if I was entitled to any help at all, and to be honest I knew nothing about PIP. Before contacting Leukaemia Care, I had only just been refused ESA. Unfortunately, I was unaware of the benefit system as I had always worked and was informed that I should have applied for ESA when I had to give up my job role several years prior to my application.

Almost as a last attempt, I reached out online to Leukaemia Care and was introduced to a Welfare Officer.

How did you feel before you started applying for PIP?

I was initially relieved to find a Leukaemia Care Welfare Officer that was prepared to help me through the whole process. She broke it down into many phone calls and emails, as and when I was well enough to proceed. Of course, the PIP system has strict targets to get various paperwork returned by, which was difficult when I felt ill, thus the almost giving up at various stages of the process.

On reflection, I would not have gained a positive outcome without the support and guidance from my Welfare Officer. Happily, at the end I was awarded the enhanced rate so obviously was glad I had pushed through.

How did Leukaemia Care's advice help with the process?

Leukaemia Care were the strength and support I needed at a very vulnerable time in my life. The care, empathy and knowledge were invaluable to me. I cannot thank them enough for their input as I now feel I have a life worth living, if not somewhat compromised.

How was the process overall? Any tips for other patients?

I sent my paperwork via signed for recorded delivery and kept proof of postage so that all paperwork could be accounted for. I also kept a date diary of calls to the DWP who I spoke to and what was said by them and me. This all proved to be invaluable in written evidence. I

would recommend the process not to be treated lightly and that it almost works like a court of law where evidence not only of one's daily life needs to be recorded but also evidence of the process you have taken in fighting for yourself.

Keeping a diary and writing my own letters was a long process, but they did make me start to think about the whole being ill thing and notice that actually I really wasn't coping in certain areas, like being too exhausted to bath or shower.

Should I apply for PIP?

Most patients, whether they have an acute or chronic diagnosis, will at some point feel too unwell to work. This is normal and to be expected; even if you feel physically fit before diagnosis or do not immediately need treatment, you might feel the need to take some time off to deal with the psychological impact of a diagnosis.

You may have mixed feelings about applying for PIP or heard negative things about receiving it in the press. It is important to remember that you did not choose to be ill and having less to worry about in terms of finances will leave you less stressed and better able to focus on getting better. Some people feel that claiming benefits lessens their sense of independence but claiming PIP may actually have the opposite effect; for example, if you receive PIP because you have limited mobility, you can put towards the cost of a car that can be

used to help you get out and about more.

Benefits are there to help those most in need, so try not to be harsh on yourself for needing to accept some help. Being eligible for some benefits can also lead to a process known as "passporting"; this is where entitlement to one form of help can lead to automatic entitlement for other forms of help, such as fee school meals, free prescriptions or a blue badge. For more information, please read our other benefits toolkits: https://media. leukaemiacare.org.uk/wpcontent/uploads/BENEFITS-V2for-web.pdf.

What is Personal Independence Payment (PIP)?

Personal Independence Payment (PIP) is a non-means tested disability benefit. Non-means tested means that your income and savings are not considered when you apply. You can claim PIP if you are working. It is paid when someone has a long-term health condition or disability; leukaemia is one example of a health condition that might affect your day-to-day life in the long term. However, whether you receive PIP is based on how your diagnosis affects you, not what your diagnosis is (i.e., you won't receive PIP automatically when you get a diagnosis of leukaemia).

How much could I get?

The weekly daily living component is £59.70 at the standard rate, and £89.15 at the enhanced rate.

The weekly mobility component is £23.60 at the standard rate, and £62.25 at the enhanced rate.

Who is eligible?

Age

PIP is only available to people between 16 and 65 years old (please see our information on disability living allowance (DLA) and attendance allowance if you are outside this age range), or if you have a child with an illness or disability.

How long you are affected for

You become eligible for PIP if you need help with everyday tasks or getting around and have needed this help for at least three months and expect to need it for another nine months or more. The amount you get depends on how your condition affects you, and the level of help you need, not the condition itself or the medication you take.

Residence

Eligibility for PIP applies if you are living in the UK when you apply.

Note: PIP is gradually replacing the Disability Living Allowance (DLA) for

What is Personal Independence Payment (PIP)? (cont.)

new claimants between the ages of 16 to 64. If you are already receiving DLA, contact our Welfare Officer for advice before you make any changes to your benefits.

What are the criteria for receiving PIP?

PIP is made up of two parts or components that describe different ways your illness affects you. You can qualify for one or both components, depending on the result of your assessment. The amount of PIP you get depends on how many points you score in each component. If you are successful with an award for each component, you will be awarded and paid the enhanced rate if you score 12 points or more, or the standard rate if you score between 8 and 11 points.

Daily living: The daily living component is concerned with activities that everyone must do to live a comfortable life, such as cooking, washing or dressing.

Note: If you receive the daily living component and someone cares for you, they may then be eligible to claim for Carer's Allowance. Please discuss with our Welfare Officer is this applies to you.

Mobility: The mobility component is concerned about your ability to physically move as well as your physical and/ or mental ability to undertake journeys outside the house (e.g. get to the shops yourself).

Having a disability or illness, such as leukaemia, does not automatically qualify you; PIP is assessed on how your leukaemia affects your ability to do everyday things.

How does the process of applying for PIP work?

The standard PIP process has three stages and can take a few months to complete, including waiting for a response to the application. It is important to start the application as soon as possible. If your claim is successful, your payments will be backdated from the date you place the phone call to DWP to log the claim.

Step 1 – Call to begin your claim

In order to apply for PIP, you will first need to contact the Department for Work and Pensions (DWP) PIP Centre. Someone else can call on your behalf, but you need to be there with them at the time.

When you call, it is important to have the following information to hand:

- Your contact details, e.g., telephone number, address
- Your date of birth
- Your National Insurance number (found on letters

- about tax, pensions, or benefits)
- Details of your bank or building society (account number and sort code)
- Your GP, consultant, or other relevant healthcare professionals' details
- Details of any time you have spent abroad, in a care home or in a hospital in the last three years

You can call the PIP claim line on 0800 917 2222 or use textphone 0800 917 7777, if you live in England, Scotland or Wales. In Northern Ireland, you call the Department for Communities (DFC) PIP centre instead on 0800 012 1573 or use textphone 0800 012 1574.

You will not have to answer any detailed questions about your health when you make this first call. Instead, you will be sent a form called "how does your disability affect you" to fill in instead. This may take some time to arrive.

How does the process of applying for PIP work? (cont.)

If you have a terminal illness- fast tracking

Receiving the news that your leukaemia is terminal can be very shocking. Any extra financial help during this time would allow you to be comfortable in the last few months of your life, without needing to worry about money or working. It could also mean you have the finances to do activities you might not otherwise have had the resources to do.

Terminal illness can allow you to be fast tracked for certain benefits, including PIP, which are then automatically paid at the highest rate possible. This is called the special rules. If you have been given a terminal diagnosis, these special rules will ensure that you get the support you need as soon as possible with less form filling. You won't have to go to a face-to-face consultation and you should get PIP paid within 2 weeks of applying.

A doctor must confirm that you are reasonably expected to die within the next 6 months to qualify as a terminal diagnosis. If you are in this position, you will be given a form called DS1500. This is a factual statement made by your medical team, hospital, or specialist nurse which you can send to the assessors. The application process can be started before the form is received from the doctor. When you phone the DWP to make a PIP claim, you will be asked if you want to claim under the special rules. Just say yes and then you will need to send the DS1500 form to the assessor once you have it from the doctor.

If you are already receiving PIP before you are aware you are terminally ill, you do not need to submit another claim. You can simply contact the DWP to update them with the DS1500. This may increase the amount of PIP you get. If you live beyond the initial 6 months diagnosis,

then you will keep receiving PIP as benefits awarded under the special rules are usually reviewed every 3 years.

Step 2 - The form

The "how your disability affects you" form will ask personal questions about how your health problems affect your daily life. The claim is long and can be overwhelming; you should set aside a good amount of time to complete it. We recommend you get help from our welfare officer to fill in the form; you can find their contact details at the end of this toolkit. The whole form usually takes about two hours to discuss.

The PIP application form is a points-based system, where you get more points the more severely you are affected. There are 14 activities that you can be awarded points for; 12 are for daily living activities and two are for mobility. Not everyone will have difficulties in every single area. Examples

of activities tested include: washing and bathing, dressing and undressing, eating, cooking food and mobility. For each activity you are asked to tick whether you can do an activity or not, how often you are affected and then asked to give further details.

When the assessor is checking your application form, each activity has a set of descriptors, which are statements that describe your ability to fulfil that activity. The assessor then must interpret your description of how you are affected and decide which descriptor you fit into. An example of the descriptors for the activity "preparing food" is on the next page.

How does the process of applying for PIP work? (cont.)

Activity	Descriptor	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

Therefore, it is important that when you fill out the application form for PIP, you make yourself aware of the descriptors for each activity. You must not lie, as this will be considered fraud and you are likely to have a face-to-face assessment too, so they can check your abilities. However, it is good practice to describe your circumstances in the way that makes it easier for the assessor to match your circumstances to a descriptor. If how you are affected varies, give a description of yourself on your worst day and then indicate how often this happens; the score you get will be determined by the percentage of the time you are at your worst.

You can view all the descriptors on the link at the bottom of the toolkit. The score for each activity is added together to make an overall score; you get one score for the daily living part and another score for mobility, so you can qualify for one, both, or neither part. A

total score of between 8 and 11 points (per part) qualifies you for the standard rate, 12 or more points (per part) means you will receive the enhanced rate. If you get less than 8 points in either component, you will not be awarded that part of PIP.

It can be difficult to know what to put in those big blank boxes on the self- assessment form. Difficulties may not always be easy to explain, such as chronic fatigue, low mood, lack of concentration or "chemo fog", but these can still be very limiting. We recommend enlisting the help of our welfare officer, who can help you to get it all down and explain it in a way that helps the assessors.

Here are some top tips to help you keep complete the form:

1. Give detailed information

It is extremely important to give as much information as you can about how you condition impacts on your everyday life and how your life has changed

How does the process of applying for PIP work? (cont.)

since diagnosis. Before you can apply for PIP, you must have had your leukaemia for three months, so many people adapt during this time and find solutions. You may need to use aids to complete tasks, but have normalised these, so feel that you do not have any difficulties as a result. This is not true; even if you have found ways to adapt, you can still qualify for PIP to help you.

The assessment looks at how well you can move around and do daily activities. It looks at whether you can carry out these activities safely, repeatedly, to an acceptable standard and within a reasonable time. For assessors to deem you having been 'unsuccessful' at completing an activity, all the above would need to apply. For example, washing and bathing would be 'unsuccessful' if you cannot have a shower without using a grab rail or shower seat, because you need the use of an aid to complete the task.

For each aid used, you will be awarded one point towards your application.

When filling out the form, do not just mention you have difficulty with a task. You need to explain, in detail, why you have difficulty. The more information you can give, the more the assessor making the decision can understand what life is like. For example, rather than saying "I have difficulty showering", you should say "I have difficulty showering because I can't stand up for that long" instead. It would even more helpful to go into further details; for example "Also my medication makes me feel dizzy so it would be dangerous for me to get in and out of the bath on my own. The last time I had a bath by myself I slipped and fell in and banged my head."

You should also make it clear on your application if you have common symptoms for those diagnosed with blood cancer, such as fatigue, bone pain, memory problems or side effects from your medication, as your assessor won't assume you have these symptoms or may not know much about your specific blood cancer.

In summary, each section should include the following:

- Which condition causes the difficulty
- What difficulties you have with a specific activity
- The support that you need to do the activity
- How long it takes you to complete an activity

Remember: We recommend that you contact our Welfare officer who would be happy to help you complete the form and ensure that it is detailed enough.

2. Provide evidence

Ensure that you collect as much evidence as you can about your illness from the people treating you, such as your GP, haematologist, or a support

worker. It would be useful if the evidence submitted by the health professional confirms how your condition affects you, so it gives the assessor a better understanding, rather than just confirmation of your condition or the medication you take. To explain what you need, it might be worth discussing in an appointment with them, rather than requesting the information by email.

Evidence could be a letter, report, or care plan and you can send it any time before the DWP makes the decision on your claim. Ideally you should submit this evidence with your claim form, or as soon as you can afterwards.

You could also ask anyone who helps care for you, such as friends, family members or a professional carer, to provide a statement with how you are experiencing difficulties with your daily activities and how you satisfy each descriptor.

How does the process of applying for PIP work? (cont.)

3. Keep a diary

It may be useful for you to use a diary, showing how your condition affects your daily living and mobility every day. You can also log your symptoms. This may be especially helpful if your condition varies from day to day. We know that symptoms like fatigue can be worse on some days than others for blood cancer patients, especially those who are receiving transfusions. It is a good way to reflect your bad days and can be used as evidence as well as to use it to help you fill in your PIP claim form. You can also attach the diary to the completed form. You can access a PIP diary from the links at the bottom of the toolkit.

Step 3 - Return your form

Once you have completed your form, send it to the DWP/PIP centre (the address is on the form). You will have one calendar month to complete and return it. Always keep a copy of any forms

you complete before sending back. Your claim will then be assessed.

Assessment

After you submit the form, you may be asked to meet with a health professional for an assessment. The health professional could be a doctor, nurse, physiotherapist, paramedic or occupational therapist. Here they will ask you to describe how your condition affects you, what a typical day might look like and your work or social life history. The assessment lasts about an hour. They may also ask you to move around or undergo a short examination. It is very important to prepare for your assessment because they will use anything discussed in the assessment to decide whether you get PIP. Using your PIP claim form, the assessor will also make their own assumptions about what you say and do on the day. They will make notes and record your mental state during the assessment, for example how you coped with the interview, whether you were relaxed, tense, or happy.

You can request a home appointment if this would make you feel more comfortable. You can also take someone with you; this can be a friend, family member, carer or professional advocate. The health professional will then make a report and send it to the Department of Work and Pensions, where it will be added to your application for the assessment. You can also make a complaint about the examination if you are unhappy about how it was conducted. We recommend you contact our Welfare Officer for advice on making a complaint.

Tips to help prepare for your assessment

- Take a copy of your 'How your disability affects you' PIP claim form, so you can refer to it. Talk about how your condition affects you, even if you have already detailed it on your PIP claim form.
- 2. Explain what a bad day is

Assessment (cont.)

like for you – for example, 'on a bad day, I can't walk at all because I am experiencing intense fatigue, dizziness and pain'. Be honest - don't underplay the effect of your leukaemia because this will make it harder for the assessor.

- 3. Don't let the assessor rush you and when they ask you questions try not to just answer 'yes' or 'no'. Always try to explain how doing something makes you feel afterwards and the impact it has on you. Citizen's Advice have a help sheet you can have with you on the day of the assessment. To download the help sheet, please see the link at the end of the toolkit.
- 4. Take someone with you for support, someone you feel comfortable with, such as a family member, friend or relative. You can also take an advocate with you (e.g., benefits advisor, mental health advocate, or social

worker) for extra support, especially if you have mental health conditions but let the assessment centre know if you are doing this.

After your assessment

After your assessment, you should then receive a letter stating whether you are being awarded PIP, how long for and at what rate. If you are awarded PIP, it will be regularly reviewed at suitable intervals to make sure you continue to get the correct amount. These intervals will depend on your condition and the likelihood of it improving or worsening.

If you are unhappy with the outcome of you PIP decision and have been turned down, or you feel you haven't been awarded enough points, don't give up! We know this can be so disappointing. There is an appeals system that you can access if you feel the decision made is the wrong one. Please see our toolkit, challenging a benefit decision.

Reporting changes

It is important to notify the Department for Work and Pensions of any changes affecting your entitlement to PIP. The Department of Work and Pensions may want to reassess you to check you are receiving the correct amount. You can be penalised if you fail to notify them of changes that are relevant.

If you go abroad, or into hospital, or a care home for more than four weeks, your benefit payments may be affected. This includes if you have one stay, as well as several stays. The rules are complex, so it is a good idea to get advice from our welfare officer. (Contact details of the welfare officer are at the bottom of the toolkit.)

Supersession

A supersession is where the Department of Work and Pensions looks again at your PIP award because your condition gets worse. You may want DWP to look at your award again in light of this. For consideration of

an increased award, you would need to experience the increased symptoms (e.g., worse fatigue) for at least three months. DWP will look at the whole award again, so it's important to remember that they can reduce your award or keep it at the same level, as well as increase it.

Further information

We recommend you contact our Welfare Officer for advice. We are best able to help if you contact us before you start the process, but we can help regardless of the stage. Do not hesitate to get in touch with us. You can call us on 07903 219525, email us at advocacy@leukaemiacare.org. uk or fill in our online form here: https://www.leukaemiacare.org.uk/support-and-information/support-for-you/advocacy-caseworker/.

To download a diary to use with your PIP application: https://www.macmillan.org.uk/assets/benefits-diary.pdf

https://www.citizensadvice. org.uk/Documents/Advice%20 (public)/pip-diary.pdf To see a copy of the descriptors please see the following links; https://www.citizensadvice. org.uk/Global/PIP%20 descriptors.pdf

https://www.citizensadvice. org.uk/Global/Guide%20 to%20the%20language%20 used%20in%20the%20PIP%20 assessment%20criteria%20 2019.pdf

To download the help sheet to use on the day of your assessment please see the following link: https://www.citizensadvice.org.uk/Documents/Advice%20 (public)/pip-helpsheet-assessment.pdf

About Leukaemia Care

Leukaemia Care is a national charity dedicated to ensuring that people affected by blood cancer have access to the right information, advice and support.

Our services

Helpline

Our helpline is available 9:00am – 5:00pm Monday - Friday and 7:00pm – 10:00pm on Thursdays and Fridays. If you need someone to talk to, call **08088 010 444**.

Alternatively, you can send a message via WhatsApp on **07500068065** on weekdays 9:00am – 5:00pm.

Nurse service

We have two trained nurses on hand to answer your questions and offer advice and support, whether it be through emailing support@leukaemiacare.org.uk or over the phone on **08088 010 444**.

Patient Information Booklets

We have a number of patient information booklets like this available to anyone who

has been affected by a blood cancer. A full list of titles – both disease specific and general information titles – can be found on our website at www.leukaemiacare.org.uk/support-and-information/help-and-resources/information-booklets/

Support Groups

Our nationwide support groups are a chance to meet and talk to other people who are going through a similar experience. For more information about a support group local to your area, go to www.leukaemiacare.org.uk/support-and-information/support-for-you/find-a-support-group/

Buddy Support

We offer one-to-one phone support with volunteers who have had blood cancer themselves or been affected by it in some way. You can speak to someone who knows what you are going through. For more information on how to get a buddy call **08088 010 444** or email support@leukaemiacare.org.uk

Online Forum

Our online forum, www.healthunlocked.com/leukaemia-care, is a place for people to ask questions anonymously or to join in the discussion with other people in a similar situation.

Webinars

Our webinars provide an opportunity to ask questions and listen to patient speakers and medical professionals who can provide valuable information and support. For information on upcoming webinars, go to www.leukaemiacare.org.uk/support-and-information/support-for-you/onlinewebinars/

Website

You can access up-to-date information on our website, www.leukaemiacare.org.uk.

Campaigning and Advocacy

Leukaemia Care is involved in campaigning for patient wellbeing, NHS funding and drug and treatment availability. If you would like an update on any of the work we are currently doing or want to know how to get involved, email advocacy@leukaemiacare.org.uk

Patient magazine

Our magazine includes inspirational patient and carer stories as well as informative articles by medical professionals: www.leukaemiacare.org.uk/communication-preferences/

Leukaemia Care is a national charity dedicated to providing information, advice and support to anyone affected by a blood cancer.

Around 34,000 new cases of blood cancer are diagnosed in the UK each year. We are here to support you, whether you're a patient, carer or family member.

Want to talk?

Helpline: **08088 010 444**

(free from landlines and all major mobile networks)

Office Line: **01905 755977**

www.leukaemiacare.org.uk advocacy@leukaemiacare.org.uk

Leukaemia Care, One Birch Court, Blackpole East, Worcester, WR3 8SG

Leukaemia Care is registered as a charity in England and Wales (no.1183890) and Scotland (no. SCO49802). Company number: 11911752 (England and Wales).

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