



Little Hearts Matter



Personal Independence Payment (PIP) - a guide



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Introduction

In June 2013 a new benefit called the Personal Independence Payment (PIP) was introduced to help with some of the extra costs caused by long-term ill-health or disability. It is expected to be in place across England, Scotland and Wales by September 2017. The dates for Northern Ireland are still to be confirmed.

Adults aged 16 to 64 living with a single ventricle heart condition should apply for this new benefit, which replaces Disability Living Allowance (DLA).

To find out when PIP will be introduced in your area, visit **www.gov.uk/pip-checker**.

At age 16 the application is being made for an adult so the allowance is paid to the young person. However you can nominate someone to help you complete the application form and the allowance can be paid to someone else if you give permission.

It is a good idea for young adults to start to take an active role in the application process, if they are able to, because they need to gradually take on more responsibility for their own condition and lifestyle restrictions. This benefit, and other benefits, are part and parcel of achieving as much independent living as possible.

The following facts and tips have been written to help young adults and their parents/carers as they negotiate the process of applying for PIP. The aim of this publication and the support services available from the Little Hearts Matter team will be to improve adults' access to Personal Independence Payment support enabling them to achieve as independent an adulthood as possible.

The two routes for a PIP application

1. New applicants

If you are not currently receiving DLA or PIP any application for this benefit will be seen as a new application and will follow a new application route. This involves a three stage application which includes an assessment before an allowance will be granted. The process starts with a phone call to the Department for Work and Pensions (DWP) on 0800 917 2222 – for more information on the application process look at page 8. The PIP process is already in place across England, Wales and Scotland for new applications.

2. Existing benefit recipients

If you are an adult currently receiving DLA you will be invited to apply for PIP by the DWP. Following receipt of the DWP letter you will have 28 days to start the application process otherwise existing allowances will be stopped. Once you have started the application process the DWP will not stop your current allowance until your new PIP process is complete. If you have been assessed for DLA within the last six months they will not start a reassessment process immediately.

If you have a child who will soon be 16 and moving from the child DLA to an adult allowance the DWP will contact you to explain the new application process when your child is 15 years and seven months old. They will ask if the young person wants someone appointed to help them with the form. Parents will be sent another letter when their child is 15 years and ten months old explaining that their child will be sent PIP application details at the age of 16.

Starting your PIP claim

The new allowance process aims to make application for an allowance easier but it is very different from the old application form for DLA so take some time to think about the process before you start to complete any forms.

It is very important to remember that the award will be made for the support needed to live independently not on the condition itself so just relying on the assessment team's understanding that you live with only half a heart is not enough, they need to understand how the condition affects your daily living.

There are two areas where a benefit may be granted.

Help needed with Daily Living

Paid at two rates: Standard and Enhanced

Help needed with Mobility

Paid at two rates: Standard and Enhanced

There are a total of 12 activities assessed

Daily Living activities:

- Preparing food
- Taking nutrition
- Managing therapy or monitoring a health condition
- Washing and bathing
- Managing toilet needs or incontinence
- Dressing and undressing
- Communicating verbally
- Reading and understanding signs, symbols and words
- Engaging with other people face-to-face
- Making budgeting decisions.

Mobility activities:

- Planning and following journeys
- Moving around.

Individuals will receive a point score for each activity, depending on how well they can carry them out and the help they need to do so. The total scores will determine whether a component is payable, and if so, whether at the Standard or Enhanced rate. The entitlement threshold for each component is eight points for the standard rate and 12 points for enhanced.

You need to achieve a high score before any award is made so it is essential to complete the forms thoroughly and fairly.

PIP Rates

| Daily Living component | Weekly rate |
|-------------------------------|--------------------|
| Standard | £55.10 |
| Enhanced | £82.30 |

| Mobility component | Weekly rate |
|---------------------------|--------------------|
| Standard | £21.80 |
| Enhanced | £57.45 |

(Rates correct as of March 2017)

The three stages of an application

Stage one

Contact the DWP to say you want to claim

This might be a new claim or a reapplication for a past claim.

You start your claim by either:

- Ringing the DWP on 0800 917 2222 (or if communication is a problem Textphone 0800 917 7777)

Or

- Follow the instructions on your PIP information letter.

New claims

When a claim for the Personal Independence Payment has been made the DWP will first check basic eligibility conditions.

To qualify for help, new PIP claimants must have needed added care or mobility help for three months or more (this is known as the qualifying period) and be likely to need help for the next nine months (this is the prospective test period).

It is important that you have all of the following basic information ready before phoning the DWP or it may delay progress of the claim. Whoever is speaking to the DWP (remember that you will have needed to organise for anyone other than the young person to make the call) needs to have:

- Full name of the person claiming PIP.
- National Insurance number.

- Full address including postcode.
- Date of birth.
- Bank or building society account details so that the DWP can arrange any payments if you qualify for the benefit.
- Daytime contact number.
- GP or other health professionals' details.
- Details of any recent stays in hospitals, care homes or hospices.
- Details of time spent abroad, if they have been abroad for more than four weeks at a time over the last three years.
- Details of any pensions or benefits that they or a family member may receive from another European Economic Area (EEA) state or Switzerland.
- Details if they are working or paying insurance to another EEA state or Switzerland.
- Nationality or immigration status.

If you are worried about whether you qualify or not visit the DWP site to check your eligibility www.gov.uk/pip/eligibility.

If English is not your first language the DWP will provide an interpreter.

Claims for ongoing support

If you have made a previous claim for DLA the qualification process should be fairly simple because your basic eligibility should already have been confirmed. This does not mean you will get the benefit, it just means you are eligible to apply for it.

Stage two

Complete the 'How your disability affects you' form

If you qualify to make a full application, the DWP team will post a 'How your disability affects you' form with a PIP information booklet. The form will be bar-coded and contains your basic details so it should only be used by you.

You should read the PIP information booklet and the Little Hearts Matter guide to completing the form if you have a single ventricle heart condition, before you start to fill the form in.

In order to be paid PIP you must show that you met the relevant disability tests for the previous three months and also expect to continue to meet them for at least a further nine months. This does not mean that you will necessarily have to wait three months for a payment as you may be able to show that you (or your son or daughter) met this test in the three months before they claimed.

If you are moving from DLA to PIP (or ceased to qualify for DLA within the last two years) you won't have to show that you met the tests in the previous three months. But your needs must still be expected to last for at least nine months.

These tests do not apply to either component if a claim is made on the grounds of a terminal illness.

When completing the application form there are a number of overarching points and tips that should be considered.

- This allowance is to help with personal independence so would the allowance help you achieve more than you could without it?
- How much added care do you need in comparison to

other people of your age? This is help with preparing food, getting washed and dressed, communicating with other people.

- How difficult is it to get around independently? How far can you walk, do you get breathless and stressed by getting around, is personal transport the only way that you can access any outside life?
- How do you mentally cope with having your disability?
- Are you able to access school, college or work with the support the PIP could give you?
- Write a lifestyle diary for a week or two that includes everything that you do every day and how long it takes you to do it. Use this diary to help you complete the form.
- The DWP need you to prove that you need this allowance. It is not up to them to understand your needs, you need to clearly and repeatedly tell them.

The application form

It is very difficult telling other people about how your medical condition affects every day of your life. We all work to be as upbeat and positive about life with a disability as possible but on these forms you must tell the reader everything that makes you different from your peers otherwise they will not understand any of your needs.

Step-by-step through the form

Use the example form attached and the information below to help you complete the form.

Q1 About professionals you may see

Think carefully about which professionals really know about about your lifestyle needs and mobility restrictions.

For example, cardiologist, GP, specialist nurse, school or college nurse, special educational needs co-ordinator (SENCO), social worker, physiotherapist.

Make sure that you tell them that you have put their name on the form as the DWP may contact them. Talk to them about your claim and the support that you may need from them to clarify how your condition affects you.

Q2 About your health condition or disabilities

By health conditions or disabilities the DWP means physical, sight, hearing or speech difficulty, learning, developmental or behavioural difficulties or mental health problems.

Remember to put down everything, the cardiac condition in full (this has been from birth), added problems like a syndrome or other chronic conditions like kidney disease. Tell them about arrhythmias and pacemakers, heart failure, protein losing enteropathy, issues with fine and gross motor control, balance, poor circulation leading to leg cramps or ulcers, strokes and the effects that a stroke has had, serious mobility issues and the mode of transport needed because of exercise tolerance issues. Tell them about any immunity problems that you have or any risk of having repeated infections. Tell them about any growth restrictions.

Don't assume that the claim assessor knows anything medical.

Q2b Treatments and medications

Tell them about all of the medications you take and why.

Tell them about any other medical treatment such as physiotherapy or occupational health.

Tell them about pacemakers.

Tell them if you need oxygen.

Tell them about wheelchair use if relevant.

Q3 Preparing food

This section is about ability to prepare and cook a simple one course meal for one from fresh ingredients. This includes things like: food preparation such as peeling, chopping or opening a can; and safely cooking or heating food on a cooker hob or in a microwave oven.

Aids and appliances in this section might include things like prostheses, perching stool, lightweight pots and pans, easy grip handles on utensils, adapted cutlery and single lever arm taps.

Remember do you need to sit down when you cook? Could you buy the food and then prepare it, do you have the energy? Would you be too tired if you did not have help? Are you able to look after yourself and go to school/college or work? Do you have the energy for all these activities? Are there risks to using knives because you are taking Warfarin?

Q4 Eating and drinking

This section is about ability to eat and drink, including cutting food into pieces, getting food and drink to the mouth, chewing food and swallowing. It includes the use of therapeutic sources such as feeding tubes.

A highly nutritious calorie intake is essential if you have only half a working heart but eating and digesting food can be very difficult as it requires energy. Reiterate that you need lots of small meals packed with calories to support your energy needs. Are you on a special diet such as MCT or high protein? Talk about maintaining hydration to ensure a good circulation. Talk about food restrictions if you are prescribed Warfarin. Talk about eating if you are extremely breathless and tired because of your heart failure.

Q5 Managing treatments

This section is about ability to monitor any health conditions, manage medication and manage treatments.

Remember to include the impacts of taking Warfarin such as cuts and bruises, INR testing either at home or at the clinic.

Talk about the signs and symptoms of heart failure and arrhythmias. Do your other conditions require observation?

Do you remember to take your medications? Do you know what your medications are for?

Q6 Washing and bathing

This section is about ability to wash and bathe, including getting in and out of a normal bath or shower.

Is your balance adequate for taking a bath independently? Do you tire in the shower? Does someone else need to be in the house when you have a bath?

Q7 Managing toilet needs

This section is about ability to manage toilet needs, including getting on or off and being able to use a normal toilet, being able to pass water or solids, dealing with incontinence, including any aids and appliances used, and cleaning afterwards.

Are you taking diuretics that create urgency?

Q8 Dressing and undressing

This section is about ability to dress and undress, including selecting, putting on and taking off appropriate and unadapted clothing, which may include fastenings such as zips or buttons. This includes putting on and taking off socks and shoes.

Do you have small issues with fine or gross motor control (being able to do small and large tasks)? Is balance an issue when you get dressed? Is breathlessness or tiredness an issue when you are getting dressed or undressed? Do you have a limb weakness following a stroke? Do you have problems with circulation in your lower limbs making it difficult to dress yourself?

Q9 Communicating

This section is about communicating with people in your native language, including speaking to people and hearing and understanding what others are saying.

Q10 Reading

This section is about ability to read and understand signs, symbols and words written or printed in your native written language and includes help you might need, like someone reading for you. It does not include Braille.

Q11 Mixing with other people

This section is about ability to get on with other people and your understanding of how others are behaving towards you and behaving appropriately to others, including whether severe anxiety or stress prevents you from doing this.

Do you have the energy to socialise? Are you able to get out of the house to meet friends? Is your social activity controlled by your tiredness?

Q12 Making decisions about money

This section is about ability to make decisions about spending and managing money. This includes being able to understand how much things cost, how much change you should get in a shop, managing budgets, paying bills and planning future purchases. It looks only at your decision making ability, not the physical elements of managing your money.

Q13 Going out

This section is about ability to get to work, follow a route to another place, including using public transport, and whether severe anxiety or distress prevents you from being able to go out. It does not look at your physical ability to get around as this is covered in the next section.

Q14 Moving around

This section is about your ability to physically move around. The questions ask how far you are able to walk and whether you use aids and appliances to get around, including walking sticks, frames, prostheses or wheelchairs.

It is important that you detail how long it takes, whether you have any side effects like pain, breathlessness, lack of energy and the speed at which you can get from A to B. If you travel independently to school/college or work, do you then have enough energy to work effectively or have you used up all of your energy to get there?

It is essential that you think very carefully about this section because you may be more restricted than your peers. If you are it must be reflected in your answers to these questions.

Supporting information

Unlike previous applications the DWP encourages you to send in letters and evidence that will support your claim when you send in your completed form.

This can include:

-  Your lifestyle diary.
-  Letters from the doctor, cardiologist, GP or other specialist.
-  Results of complex tests.
-  Letters from specialist or community nurses.
-  Letters from school or college special educational needs co-ordinators (SENCOs).

 Letters from anyone involved in ongoing treatment e.g. a dietitian, physiotherapist or occupational therapist.

 Letters from organisations involved with cardiac or other conditions like Little Hearts Matter.

Sending the last clinic letter may not be good enough as it may give a sweeping 'everything is going well' impression rather than an in-depth letter about the ongoing needs of a young adult in comparison with their peers.

Make sure that anyone that you ask to submit information understands what your day-to-day needs really are. Sometimes the head of a department writes the letter not the person who actually knows your needs. Make sure the right person supports your claim.

Stage three

Face-to-face assessment

Under the new application system most people will be expected to either attend an assessment or have a visit at home to assess their needs. The assessor will compile a report in line with your application information. The assessor will be a health professional.

NB The health professional who undertakes this test may not have a cardiac care background and so may well need help to understand the restrictions that affect your everyday life.

You may not have to attend an assessment if your supporting medical information clearly sets out your physical or mental needs. This will be decided on a case by case basis.

What do you do if your application is turned down?

If the Department for Work and Pensions turns down your application they will write to you setting out their reasons for refusing the allowance.

Read through the letter carefully.

If you feel that they have assessed your claim unfairly then you are able to take a number of steps to get them to look again at your claim.

Step one

Mandatory reconsideration

You need to formally ask the DWP to reconsider your claim. Contact them using the number on the bottom of your application decision letter.

You will need to be clear about why you are questioning their judgment. Set out your reasons and they will then initiate a reassessment.

You will then receive a Mandatory Reconsideration notice setting out their findings and the outcome of your reconsideration request.

If the DWP decide again that your claim will not be met read their reasons and if you still feel that their decision making is unfair move on to step two.

Step two

PIP appeal

Follow the appeal information set out at the bottom of the Mandatory Reconsideration notice. You will need to complete a new form setting out your reasons for the appeal and be able to produce further supporting information that clearly answers all the questions they have about your care and or mobility needs.

This needs to be done within a month of the reconsideration decision.

Further support

Little Hearts Matter

Telephone: 0121 455 8982; Email: info@lhm.org.uk
www.lhm.org.uk

Department for Work and Pensions (DWP)

Tel: 0800 917 2222
Textphone: 0800 917 7777
www.gov.uk/pip/overview

Contact A Family

Freephone: 0808 808 3555
www.cafamily.org.uk

Your local Citizens Advice

Visit **www.citizensadvice.org.uk**

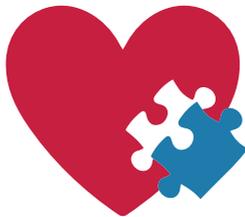
Diary notes

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Little Hearts Matter
Half a heart, not half a life

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