

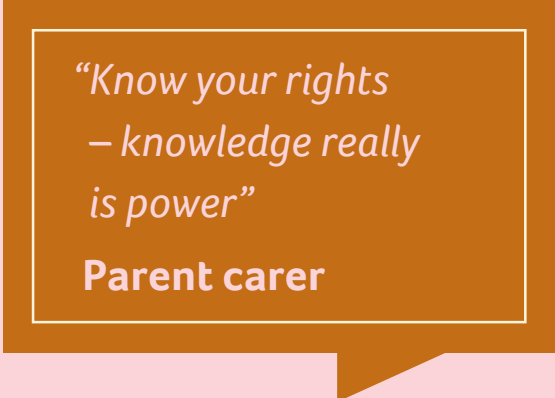
PERSONAL INDEPENDENCE PAYMENT



INFORMATION FOR PARENTS OF DISABLED CHILDREN



contact



*“Know your rights
– knowledge really
is power”*

Parent carer

The information in this guide is accurate as of August 2020.
This guide covers England, Scotland and Wales.

Written by Derek Sinclair and Marian Gell

CONTENTS

| | |
|---|----|
| WHAT IS PERSONAL INDEPENDENCE PAYMENT (PIP) | 5 |
| WHO CAN CLAIM PIP | 6 |
| WHEN WILL MY CHILD BE ASKED TO CLAIM PIP? | 8 |
| HOW DO I CLAIM PIP? | 12 |
| WHAT TESTS ARE USED TO DECIDE IF SOMEONE GETS PIP? | 17 |
| PIP ACTIVITIES AND POINTS SYSTEM | 18 |
| HOW THE POINTS SYSTEM WORKS | 27 |
| HOW MUCH IS PIP? | 30 |
| GETTING A DECISION ON A PIP CLAIM | 32 |
| PIP AND STAYS IN HOSPITAL OR RESIDENTIAL ACCOMMODATION | 34 |
| GETTING AN EXISTING PIP AWARD CHANGED | 35 |
| PIP REVIEWS WHEN YOUR EXISTING AWARD IS COMING TO AN END | 35 |
| PIP AND ITS EFFECT ON OTHER BENEFITS | 37 |
| WHEN A YOUNG PERSON IS UNABLE TO MANAGE THEIR BENEFIT CLAIMS | 42 |
| CLAIMING OTHER BENEFITS | 43 |



WHAT IS PERSONAL INDEPENDENCE PAYMENT?

Personal Independence Payment (PIP) is a benefit that replaces Disability Living Allowance (DLA) for adults.

Although PIP looks similar to DLA in some respects, it uses entirely different rules to decide whether you qualify for the benefit, and at what rate.

Most people will also be asked to attend a face-to-face meeting with a health professional when they are being assessed for PIP.

DLA will remain as a benefit for children aged under 16. In Scotland only, young people who turn 16 on or after 1 September 2020, and who already get DLA the day before their 16th birthday, can continue to get DLA until they turn 18.

PIP has two parts – called components. There is a daily living component and a mobility component. Depending on their needs, your son or daughter may qualify for one of these components, or for both at the same time.

PIP is not means-tested so it makes no difference what savings or income you or your son or daughter has. It can also be paid regardless of whether they are working, and it does not depend on National Insurance contributions.

If your son or daughter starts to get PIP this does not mean that you lose any benefits that you get for them as a member of your family. PIP can be paid alongside child benefit and any other payments that you get for them as a dependent child.

WHO CAN CLAIM PIP?

The main thing that will determine whether your child qualifies for PIP is how their condition affects their ability to carry out certain key activities necessary for independent living. See page 17 for more details of the activities that are considered.

Anyone who is applying for PIP must also:

- ***be aged between 16 and state pension age, and***
- ***meet the ‘required period’ condition (see page 7), and***
- ***not be subject to immigration control, and***
- ***meet certain tests linked to their residence and presence in the UK.***

“My son has complex needs which affect his development, motor skills and behaviour. However, it never entered my head that he may be able to claim a benefit. I made a claim which has now been granted. This will make a big difference to us as a family.”

Parent carer

WHAT IS THE 'REQUIRED PERIOD' CONDITION?

IF YOUR CHILD DOESN'T ALREADY GET DLA

If your child isn't already on DLA and makes a claim for PIP, you normally must show that they met the relevant disability tests for the previous three months (see page 17), 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 before payments start – as you may be able to show that they met the disability tests in the three months before they claimed.

IF YOUR CHILD ALREADY GETS DLA

If your child is moving from DLA to PIP, you won't have to show that they met the tests in the previous three months. But their needs must still be expected to last for at least nine months. They may also be exempt from meeting the three month test if reclaiming PIP within two years of a previous award ending. This will apply so long as they are claiming the same component of PIP, and they have the same condition (or a condition that has developed from the original condition) as before.

IF A CHILD IS TERMINALLY ILL

These tests do not apply to either component if a claim is made on the grounds of a terminal illness, see pages 9 and 31.

RESIDENCY RULES

Generally speaking, you can only claim PIP if you have spent at least 104 weeks in the UK over the last three years. But some people are exempt from this 'past presence' test, for example some EEA nationals, some UK nationals who have lived in another EEA country and refugees and their family members. Seek further advice from our freephone helpline.

WHEN WILL MY CHILD BE ASKED TO CLAIM PIP?

Disabled young people aged 16 or over who do not already get DLA will need to claim PIP. They do not have the option of claiming DLA instead. This is the case in Scotland as well as the rest of the UK.

Young people in England and Wales who are on DLA will normally need to claim PIP at age 16. If your child lives in Scotland, is already claiming DLA on the day before their 16th birthday, and they turn 16 on or after 1 September 2020, they can continue to get DLA until they turn 18.

ENGLAND AND WALES

Young people in England and Wales turning 16 who receive DLA will be reassessed under PIP – even if their DLA award was not due to run out at 16. This also includes young people with an indefinite award of DLA. The only exceptions to this are:

- ***if a young person is claiming DLA under the special rules for the terminally ill. In this case their DLA award will continue until their existing award expires. They should be invited to claim PIP about 20 weeks before their existing award ends.***
- ***if a young person is a hospital in-patient on the date they would normally be asked to claim PIP. In this case their DLA payments will be extended temporarily until they have been discharged from hospital.***

Before your child turns 16, the Department for Work and Pensions (DWP) will contact you as their parent to let you know how to claim PIP, and to find out if your child needs an appointee (a person responsible for making claims on their behalf, usually a parent – see page 42).

They should write to you:

- ***when your child is aged 15 years and 7 months***
- ***three months later – they will send you a reminder***
- ***shortly after your child turns 16. The DWP will then send a letter to your child (or to you if you have been made their appointee) inviting them to make a claim for PIP.***

If your child's current DLA award is due to run out on their 16th birthday, their DLA payments can continue temporarily until a decision has been made on their PIP claim. However, if they fail to claim PIP when invited to do so, their DLA payments will stop.

Normally a young person in England or Wales is asked to claim PIP within a couple of weeks of turning 16. However, during the Coronavirus outbreak, the DWP have been postponing PIP assessments. In these circumstances they have been extending DLA awards temporarily and telling young people that they will be contacted at a later date regarding their PIP assessment. At the time of writing it is not clear how long they will continue to postpone PIP assessments for.

SCOTLAND

New rules mean that young people in Scotland can continue getting DLA until they turn 18.

If a young person living in Scotland turns 16 on or after 1 September 2020 and they are getting DLA immediately before their 16th birthday, they won't be expected to claim PIP. Instead their DLA award should be automatically extended until they are 18, so long as they continue to meet the normal rules. They won't be asked to claim PIP until some point after their 18th birthday.

The DWP will still contact you before your child turns 16 in order to find out whether they have the capacity to manage their own DLA claim once they turn 16, or whether they need you to continue to deal with these payments on their behalf as an appointee. See page 42 for more details.

If a young person opts to move onto PIP

A young person on DLA in Scotland who turns 16 after 1 September can still opt to move onto PIP before age 18 if they want. However, they will not be automatically invited to claim. Instead they would need to choose to make an application for PIP themselves. Any young person in Scotland who is thinking about making a claim for PIP rather than staying on DLA until 18 should first seek detailed advice from a benefits adviser. This is because many disabled people are worse off under PIP. If your child chooses to make a claim for PIP before they turn 18 they won't be able to change their mind and revert back onto DLA.

Children turning 16 after 1 September who don't get DLA

If your child turns 16 after 1 September 2020 but does not already get DLA on the day before they turn 16, it will be too late to claim DLA after they turn 16. The new rules in Scotland extend existing DLA awards to age 18. They do not allow 16 or 17 year olds to claim DLA for the first time – instead a 16 or 17 who does not get DLA already will need to claim PIP.

Young people in Scotland who turned 16 before 1 September 2020 are invited to claim PIP at age 16 under the same rules as apply in England and Wales.

SPECIAL RULES FOR TERMINALLY ILL CHILDREN

Terminally ill children who turn 16 can continue to get DLA rather than PIP. A DLA award under the special rules for the terminally ill will continue until the end of the existing award, or until your child is selected to claim PIP as part of the process of moving all remaining adult DLA claimants onto PIP.

MOVING FROM DLA TO PIP

Just because your child gets DLA, it doesn't mean that they will automatically qualify for PIP. They will have to make a claim for PIP once invited to do so by the DWP. You need to do this within 28 days, by phoning the PIP claim line. If they don't claim when the DWP asks them to, their DLA payments will stop.

If you think that they will have difficulties making a claim within this deadline, they (or you) can ask the DWP for an extension, which they may agree to.

If your child doesn't make a claim within the 28 day period (or within any extended period that the DWP have agreed to) their DLA payments will be suspended. The DWP must write to them (or you) to tell them this is happening.

If your child's payments are suspended they will be given a further 28 days to claim PIP. If they claim PIP, their DLA award will be restored until a decision on their PIP claim is made.

If they still don't claim before the second 28 day deadline, their DLA award will end. They (or you) will not be able to appeal that decision. They will be able to make a claim for PIP instead.

"The money has eased the pressure on my husband. We were relying on his overtime to see us through but now he can spend more time with my daughter and little boy."

Parent carer

HOW DO I CLAIM PIP?

To claim PIP your son or daughter will need to complete two forms:

- ***a Personal Independence Payment claim form (PIP1 form) – normally completed over the telephone***
- ***How your Disability Affects You questionnaire (PIP2 form).***

To start a PIP claim, they must telephone the PIP new claims number on: 0800 917 2222 (textphone 0800 917 7777).

If you are your child's appointee (see page 42) you must make this call rather than them. If English is not your first language, ask the Department for Work and Pensions (DWP) staff member answering your call to use the DWP telephone interpreting service.

COMPLETING THE PIP1 CLAIM FORM

First, your son or daughter needs to complete a Personal Independence Payment claim form (PIP1 form). This is usually done over the phone with a DWP worker, and should take no more than 20 minutes. However, if they have difficulties using the phone, a paper form can be sent by post. Or you can ask someone from the DWP to make a home visit to help complete the form.

What information do I need?

The PIP1 form asks basic questions such as your child's name, contact details, nationality, bank account details and for details of the main health professional supporting them.

This form is also used to check that your child meets the main basic qualifying conditions. For example, that they are at least 16 and meet certain tests linked to their immigration status and presence in the UK.

COMPLETING THE PIP2 QUESTIONNAIRE

Once the DWP has received the signed PIP1 form and established that your child meets the basic qualifying conditions, you will then be sent a questionnaire called *How Your Disability Affects You* (PIP2). If they are told they do not meet the basic rules, seek advice from our helpline.

What information do I need?

The PIP2 questionnaire gathers information about a young person's ability to do a range of different activities. This is their (or yours as their appointee) opportunity to give a detailed explanation of how their condition affects them, so they should give as much detail as possible.

You can also attach additional evidence, such as information from health staff or other professionals supporting your son or daughter, or from friends or relatives who help with everyday activities. This is a good idea as the more supporting evidence you provide the better the chances that a decision can be made without the need for a face-to-face assessment.

When must I send the form back?

Your son or daughter, or you as their appointee, must complete and return the questionnaire within a month. The date for return will be stated in the covering letter. If the questionnaire is not returned by that date, the claim for PIP will normally be turned down. Any existing DLA payments will also stop. So, where possible, always try to return the questionnaire by the stated date to avoid delays and missed payments.

The DWP can make exceptions with late returns of PIP2 but only if it accepts that there was a good reason for not completing and returning the PIP2 questionnaire in time.

DWP guidance does state that if it knows a claimant has a mental or cognitive disability and does not return the questionnaire, it will refer the person directly to a healthcare professional rather than closing down the claim automatically.



For more information on completing the PIP questionnaire see Disability Rights UK's guide *Personal Independence Payment – a guide to making a claim* available free from disabilityrightsuk.org

ASKING FOR MORE TIME TO COMPLETE THE QUESTIONNAIRE

If more time is needed to complete the form, your son or daughter, or you as their appointee, should telephone the DWP and ask for an extension (a later return date). However, you must do this before the original one month deadline is up. The DWP is only likely to grant a long extension, or more than one extension, if it agrees that the young person, or you as their appointee, have good reasons for not completing the form sooner.

THE PERSONAL INDEPENDENCE PAYMENT 'CONSULTATION'

As well as having to complete the necessary claim forms, PIP1 and PIP2 (see page 12), most young people applying for Personal Independence Payment (PIP) will be asked to attend a face-to-face assessment by a healthcare professional. This is known as a 'consultation'. During the early months of the Coronavirus outbreak no face-to-face consultations have been taking place. During this period either a decision will be made without a consultation (based on the paperwork only) or you may have a consultation by telephone instead. At the time of writing it is not clear when face-to-face consultations will resume.

Who carries out the consultation?

Your son or daughter's usual GP will not carry out the consultation. Instead, a healthcare professional under contract to the Department for Work and Pensions (DWP) will carry it out. The healthcare professional will work for one of two companies, Capita or Independent Assessment Services (formerly known as Atos), depending on where in the UK you live. Most consultations take place in a medical centre, but they can be carried out at home. When deciding whether a home assessment is necessary Capita/IAS should take into account factors such as:

- *whether your child's condition precludes them from travelling, and*
- *whether this has been verified by a GP or consultant, and*
- *any accessibility issues at the planned location for the consultation.*

The healthcare professional assessing the young person will:

- *look at their ability to carry out a range of activities, and*
- *look at their PIP2 questionnaire, and*
- *look at any other medical evidence that has been gathered.*

You must be given at least seven days' notice of a face-to-face consultation (unless less notice has been agreed). The young person can bring someone to the consultation for support.

Is it always a face-to-face consultation?

In some cases, IAS or Capita may decide that there is no need for a face-to-face consultation. Reasons for this include the evidence they have already received or the distress a face-to-face consultation might cause.

Instead, they will make an assessment based on the questionnaire and any other evidence your son or daughter or the appointee has provided. Or they may carry out the consultation by phone. Those claiming under the special rules for the terminally ill won't have to take part in a consultation. During the Coronavirus outbreak, face-to-face consultations have been suspended.

WHAT HAPPENS AT THE CONSULTATION?

At the consultation, the healthcare professional will ask the young person about their condition, their day-to-day life and how they manage at home and out of doors. The healthcare professional may also carry out a brief physical examination. After the consultation, the healthcare professional will complete a report and send it to the DWP.

FAILURE TO TAKE PART IN THE CONSULTATION

If your child is asked to take part in a consultation (at a medical centre, at home or by phone), you should try to make sure they do so. If they don't take part and the DWP thinks they didn't have a good reason not to, they will be refused PIP.

When deciding whether someone has a good reason for not taking part, the DWP must take into account their disability and state of health. They will contact the young person to ask why they did not take part. If the DWP decides they did not have good reason for not taking part, you can ask them to reconsider (see page 32) and then appeal.



WHAT TESTS ARE USED TO DECIDE IF SOMEONE GETS PIP?

PIP is made up of two parts, called components: a daily living component and a mobility component. People applying for PIP are awarded points according to how well they can carry out 10 daily living activities and two mobility activities:

10 DAILY LIVING ACTIVITIES

- *preparing food*
- *taking nutrition (eating and drinking)*
- *managing therapy or monitoring a health condition*
- *washing and bathing*
- *managing toilet needs or incontinence*
- *dressing and undressing*
- *communicating verbally (speaking)*
- *reading and understanding signs, symbols and words*
- *engaging with other people face-to-face (mixing with people)*
- *making budgeting decisions (making decisions about money).*

TWO MOBILITY ACTIVITIES

- *planning and following a journey*
- *moving around.*

PIP ACTIVITIES & POINTS SYSTEM

The tables that follow outline the scoring system that is used to decide whether a young person qualifies for PIP, and at what rate. In making sense of the tests set out in the tables it is important to understand how certain words are interpreted by the DWP.

DEFINITIONS

- assistance:** means physical intervention by another person and does not include any help provided through speech
- supervision:** means the continuous presence of another person for the purpose of ensuring your safety
- prompting:** means reminding, encouraging or explaining by another person
- unaided:** means without supervision, prompting, assistance or the use of an aid or appliance
- aid or appliance:** means any device which improves, provides or replaces impaired physical or mental function

DAILY LIVING COMPONENT

| Activity 1. Preparing food | Points |
|--|--------|
| can prepare and cook a simple meal unaided | 0 |
| needs to use an aid or appliance to be able to either prepare or cook a simple meal | 2 |
| cannot cook a simple meal using a conventional cooker but is able to do so using a microwave | 2 |
| needs prompting to be able to either prepare or cook a simple meal | 2 |
| needs supervision or assistance to either prepare or cook a simple meal | 4 |
| cannot prepare and cook food | 8 |

prepare: in the context of food means make food ready for cooking or eating

cook: heat food at or above waist height

simple meal: a cooked, one-course meal for one using fresh ingredients

This activity aims to assess a claimant's physical or mental capacity to cook a simple main meal, and not whether or not they actually cook for themselves. Factors such as special dietary requirements or cultural/religious differences are not taken into account.

| Activity 2. Taking nutrition | Points |
|--|--------|
| can take nutrition unaided | 0 |
| 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 |
| needs a therapeutic source to be able to take nutrition | 2 |
| needs prompting to be able to take nutrition | 4 |
| needs assistance to be able to manage a therapeutic source to take nutrition | 6 |
| cannot convey food and drink to their mouth and needs another person to do so | 10 |

take nutrition: cut food into pieces, convey food and drink to one's mouth and chew and swallow food and drink, or take nutrition by using a therapeutic source

therapeutic source: parenteral or enteral tube feeding, using a rate-limiting device such as a delivery system or feed pump

Activity 3. Managing therapy or monitoring a health condition

Points

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

(i) therapy: therapy to be undertaken at home, prescribed or recommended by (a) registered (i) doctor; (ii) nurse; or (iii) pharmacist; or (b) health professional regulated by the Health Professions Council; but does not include taking or applying, or otherwise receiving or administering, medication (whether orally, topically or by any other means), or any action which, in the claimant's case, falls within the definition of 'monitor a health condition'

(ii) manage medication or therapy: take medication or undertake therapy where a failure to do so is likely to result in deterioration in health

needs either (i) to use an aid or appliance to be able to manage medication or (ii) supervision, prompting or assistance to manage medication or monitor a health condition

1

(i) medication: medication to be taken at home which is prescribed or recommended by a registered doctor, nurse or pharmacist

(ii) monitor health: detect significant changes in a health condition which are likely to lead to a deterioration in health and take action advised by a registered doctor, registered nurse or health professional who is registered by the Health and Care Professions Council, without which health is likely to deteriorate

needs supervision, prompting or assistance to be able to manage therapy that takes no more than 3.5 hours a week

2

needs supervision, prompting or assistance to manage therapy that takes more than 3.5 but no more than 7 hours a week

4

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

needs supervision, prompting or assistance to be able to manage therapy that takes more than 14 hours a week

8

Note: any action which falls under the definition of monitoring a health condition cannot be treated as therapy – no matter how much time is spent in monitoring the disabled person's condition

Note: It is the time taken to supervise, prompt or assist someone to manage therapy that is measured, not how long the therapy itself takes.

Note: Help with managing a special diet can count as therapy if the diet is recommended by a health professional and help is needed with both the nature and timing of food and drink, and a failure to follow the diet will lead to a deterioration in health within a short space of time

| Activity 4. Washing and bathing | Points |
|---|--------|
| can wash and bathe unaided | 0 |
| needs to use an aid or appliance to be able to wash or bathe | 2 |
| needs supervision or prompting to be able to wash or bathe | 2 |
| needs assistance to be able to wash either their hair or body below the waist | 2 |
| needs assistance to be able to get in or out of a bath or shower | 3 |
| needs assistance to be able to wash their body between the shoulders and waist | 4 |
| cannot wash and bathe at all and needs another person to wash their entire body | 8 |

bathe: includes getting into or out of an unadapted bath or shower. If you have an adapted bath you will need to explain what problems you would have in using an unadapted one

washing: means cleaning one's whole body, including removing dirt and sweat

| Activity 5. Managing toilet needs or incontinence | Points |
|--|--------|
| can manage toilet needs or incontinence unaided | 0 |
| needs to use an aid or appliance to be able to manage toilet needs or incontinence | 2 |
| needs supervision or prompting to be able to manage toilet needs | 2 |
| needs assistance to be able to manage toilet needs | 4 |
| needs assistance to be able to manage incontinence of either bladder or bowel | 6 |
| needs assistance to be able to manage incontinence of both bladder and bowel | 8 |

toilet needs: getting on and off an unadapted toilet, evacuating bladder and bowel, and cleaning oneself

Note: help in dressing or undressing is not taken into account

manage incontinence: manage involuntary evacuation of the bowel or bladder, including use of a collecting device or self catheterisation, and clean oneself afterwards

Note: incontinence pads and colostomy bags fall within the definition of an aid or appliance

| Activity 6. Dressing and undressing | Points |
|--|--------|
| can dress and undress unaided | 0 |
| needs to use an aid or appliance to dress or undress | 2 |
| 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 |
| needs assistance to be able to dress or undress their lower body | 2 |
| needs assistance to be able to dress or undress their upper body | 4 |
| cannot dress or undress at all | 8 |

this descriptor assesses the ability to put on and take off un-adapted clothing. Can include the need for fastenings, zips and buttons, and includes putting on and taking off socks and shoes

| Activity 7. Communicating verbally | Points |
|--|--------|
| can express and understand verbal information unaided | 0 |
| needs to use an aid or appliance to be able to speak or hear | 2 |
| needs communication support to be able to express or understand complex verbal information | 4 |
| needs communication support to be able to express or understand basic verbal information | 8 |
| cannot express or understand verbal information at all even with communication support | 12 |

communication support: support from a person trained or experienced in communicating with people with specific communication needs, including interpreting verbal information into a non-verbal form and vice versa. It is not limited to interpreters and can include friends or family

complex verbal information: information in native language conveyed verbally in either more than one sentence or one complicated sentence

basic verbal information: information in native language conveyed verbally in a simple sentence

Note: for the purpose of this test lip-reading is not considered an acceptable way to interpret verbal communication

Activity 8. Reading and understanding signs, symbols and words

Points

| | |
|---|---|
| can read and understand basic and complex written information either unaided or using spectacles or contact lenses | 0 |
| 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 |
| needs prompting to be able to read or understand complex written information | 2 |
| needs prompting to be able to read or understand basic written information | 4 |
| cannot read or understand sign, symbols or words at all | 8 |

read: includes reading signs, symbols and words but does not include reading Braille

complex written information: more than one sentence of written or printed standard size text in native language

basic written information: signs, symbols and dates written or printed in standard size text in native language

note: illiteracy which does not result from a physical or mental condition cannot be taken into account

Activity 9. Engaging with other people face-to-face

Points

| | |
|--|---|
| can engage with other people unaided | 0 |
| needs prompting to be able to engage with other people | 2 |
| needs social support to be able to engage with other people | 4 |
| 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 |

engage socially: interact with others in a contextually and socially appropriate manner, understand body language and establish relationships, and can be given before or during an activity

social support: support from a person trained or experienced in assisting people to engage in social situations. Can be provided by friends or family

psychological distress: distress related to an enduring mental health condition or an intellectual or cognitive impairment

Note: This activity assesses the ability to mix with people in small groups or in one-to-one situations rather than with others in a crowd. The test implies some engagement with people you do not know

| Activity 10. Making budgeting decisions | Points |
|--|--------|
| can manage complex budgeting decisions unaided | 0 |
| needs prompting or assistance to be able to make complex budgeting decisions | 2 |
| needs prompting or assistance to be able to make simple budgeting decisions | 4 |
| cannot make any budgeting decisions at all | 6 |

simple budgeting decision: decisions involving calculating the costs of goods, and calculating change required after a purchase

Complex budgeting decisions: decisions involving calculating household and personal budgets, managing and paying bills, and planning future purchases

MOBILITY COMPONENT

| Activity 11. Planning and following journeys | Points |
|--|--------|
| can plan and follow the route of a journey unaided | 0 |
| needs prompting to be able to undertake any journey to avoid overwhelming psychological distress to the claimant | 4 |
| cannot plan the route of a journey | 8 |
| cannot follow the route of an unfamiliar journey without another person, assistance dog or orientation aid | 10 |
| cannot undertake any journey because it would cause overwhelming psychological distress to the claimant | 10 |
| cannot follow the route of a familiar journey without another person, an assistance dog or an orientation aid | 12 |

psychological distress: distress related to an enduring mental health condition or an intellectual or cognitive impairment

assistance dog: dog trained to guide or assist a person with a sensory impairment

orientation aid: specialist aid designed to assist disabled people to follow a route safely

***Note:** Previous PIP rules made it difficult for those whose difficulties in planning and following a journey arose from psychological distress to score points. However, those previous rules were overturned by the High Court in December 2017. The government is currently in the process of reviewing 1.6 million existing PIP claims to see if claimants are on the correct rate of the mobility component. Contact our helpline for updates.

| Activity 12. Moving around | Points |
|---|-----------|
| can stand and then move more than 200 metres either aided or unaided | 0 |
| can stand and then move more than 50 metres but no more than 200 metres either aided or unaided | 4 |
| can stand and then move unaided more than 20 meters but no more than 50 | 8 |
| can stand and then move using an aid or appliance, more than 20 metres but no more than 50 metres | 10 |
| can stand and then move more than 1 metre but no more than 20 metres either aided or unaided | 12 |
| cannot either aided or unaided (i) stand or (ii) move more than 1 metre | 12 |

stand: stand upright with at least one biological foot on the ground

aided: with supervision, prompting, or assistance, or with the use of an aid or appliance

Note: in measuring how far someone can move around, any pain or breathlessness suffered will be a factor in deciding whether they can move around to an acceptable standard

“People saying ‘I wish I had all that money for nothing’ hurts – I’d give it all up just to see her walk.”

Parent carer



HOW THE POINTS SYSTEM WORKS

The DWP must take into account your child's ability not just to carry out an activity, but to carry it out 'reliably'. This means being able to carry out an activity:

- **safely** – in a manner that is not likely to cause harm to themselves or others. Not being able to carry out a task safely means that it is likely that harm will occur, rather than it simply being possible that harm will occur. A risk can be said to be likely if there is a real possibility of something happening which cannot be sensibly ignored. You do not have to prove that the risk is more likely than not. Instead the decision maker needs to take into account not only the likelihood of harm occurring, but also the consequences of the possible harm that may occur.
- repeatedly – as many times as reasonably required.
- in a reasonable time period – no more than twice as long as someone without any health problems.
- **to an acceptable standard** – of a standard that is 'good enough' and which most people would normally achieve. The effects of any pain and breathlessness experienced will be relevant in deciding whether an activity is carried out to an acceptable standard.

So if someone is able to wash and bathe themselves independently they would not normally score any points for that activity. However, if that person was at risk of falling when washing and bathing themselves, or couldn't wash themselves to an acceptable standard, or would take hours to do so, they may still score points.

If your child uses an aid or appliance, or could be reasonably expected to, this will be taken into account when assessing their ability to carry out an activity.

Every activity in the tables has a set of descriptions. For example, the first daily living activity above is called ‘preparing food’, and there are six descriptions in that activity:

- ***the first description is ‘can prepare and cook a simple meal unaided’***
- ***the second is ‘needs to use an aid or appliance to be able to either prepare or cook a simple meal’, and so on.***

Each of these descriptions has a number of points a person can score. The number of points varies depending on how limited a person’s abilities are.

How the points add up

If more than one description in an activity applies to your son or daughter, they are awarded the one that gives them the most points.

For example: in the activity ‘making budgeting decisions’, the descriptions are:

- ***can manage complex budgeting decisions unaided – 0 points***
- ***needs prompting or assistance to be able to make complex budgeting decisions – 2 points***
- ***needs prompting or assistance to be able to make simple budgeting decisions – 4 points***
- ***cannot make any budgeting decisions at all – 8 points.***

In this example, if a young person needs assistance to make complex budgeting decisions (worth 2 points) and also needs assistance to make simple budgeting decisions (4 points) they will be awarded the highest score that applies – 4 points.

The scores they have been awarded in each of the 10 daily living activities are then added together to decide whether the person qualifies for the daily living component and at what rate – standard or enhanced.

Their score in each of the two mobility activities is added together to decide whether they qualify for the mobility component and at what rate.

A young person will only be awarded points for an activity if their ability to carry it out is affected for at least half of the days over a 12 month period.

VARIABLE CONDITIONS

You don't need to show that an activity description applies to your son or daughter for the whole of the day. So long as it applies at some point during a day (and is more than momentary), it should be treated as applying to them.

If their condition varies on different days, then:

- ***if only one description applies on more than 50 per cent of the days, that is the description the DWP will use to award points***
- ***if two descriptions apply on more than 50 per cent of days, the description with the higher number of points applies.***

Where no single description applies on more than 50 per cent of days, you will still score points if two or more of the different descriptions (not counting the one that scores zero points) added together apply on over 50 per cent of days. If this applies, their score will be based on the description that applies for the greatest number of days.

So in the activity of preparing food, someone may need prompting to cook a simple meal on 33 per cent of days (2 points) but also need assistance to prepare a meal on an additional 25 per cent of days (4 points). Because the two descriptions added together apply on 58 per cent of days they will score points for this activity, and 2 points will be awarded since that description applies for the greater number of days. If 2 descriptions applied for an equal number of days, for example each applied on 33 per cent of days, then the higher score is awarded.

HOW MUCH IS PIP?

DAILY LIVING COMPONENT

The Department for Work and Pensions (DWP) adds together the young person's score from the 10 daily living activities to decide whether they get the daily living component. It also uses this score to decide whether they should get paid the daily living component at the standard or enhanced rate.

| POINTS | RATE | WEEKLY AMOUNT |
|--------|---------------|---------------|
| 0–7 | | no award |
| 8–11 | standard rate | £59.70 |
| 12+ | enhanced rate | £89.15 |

MOBILITY COMPONENT

The DWP adds together the scores from the two mobility activities to decide if they get the mobility component. This score also decides whether they should get the mobility component at the standard or enhanced rate.

| POINTS | RATE | WEEKLY AMOUNT |
|--------|---------------|---------------|
| 0–7 | | no award |
| 8–11 | standard rate | £23.60 |
| 12+ | enhanced rate | £62.25 |

TERMINALLY ILL APPLICANTS

If your son or daughter is terminally ill and not expected to live for more than six months, they will automatically qualify for the enhanced rate of the daily living component. They won't have to take part in a consultation.

If this applies to your child, ask their doctor for a DS1500 certificate and send this to the DWP after you have phoned to make a claim. Terminally ill claimants will be asked questions about their mobility during the initial telephone claim, however they are not expected to complete the PIP2 questionnaire.



GETTING A DECISION ON A PIP CLAIM

A case manager at the DWP will decide whether a young person is entitled to PIP, and at what rate. They take into account all of the information in the claim form, the IAS or Capita health professional's report, and any other information you or the young person have provided.

The DWP will send you a decision letter outlining the reasons for the decision. It will explain the number of points your son or daughter was awarded for each daily living and mobility activity.

If they are awarded PIP, the letter should also set out how long the award is for.

If they are refused PIP or awarded a lower rate than was paid under DLA, you may also get a telephone call from the case manager explaining the reasons for the decision.

Once a decision is made on a PIP claim, DLA continues to be paid for the first 28 days after the young person's next DLA pay day. After that the PIP decision comes into force.

HOW LONG WILL PIP BE AWARDED FOR?

Most awards will be made for a fixed period. Often this will be for up to two or three years if a condition is likely to change.

If it's unlikely your son or daughter's condition will change, awards can be made for longer. In a small number of cases, awards are made for an indefinite period. But even an indefinite award can be reassessed at any point if the DWP decide to check that a young person still meets the qualifying conditions.

WHAT IF I DISAGREE WITH THE DECISION?

If you disagree with the decision on your son or daughter's PIP claim, they (or you if you are their appointee) can ask the DWP to look at it again. This is known as a 'mandatory reconsideration'.

You can do this over the telephone or in writing but you must do this within one month of the date of the decision, although a late request may be accepted in certain circumstances. Another DWP decision maker will then have a fresh look at the case and give you a new decision in writing.

Once they have made a decision on your reconsideration request, the DWP will send you two mandatory reconsideration notices in the post. One is your copy, the other is to send to the Courts and Tribunal service if you decide to appeal.

If you are unhappy with the new decision

If you're not happy with the outcome of the mandatory reconsideration you can appeal directly to Her Majesty's Courts and Tribunals Service. But you can't appeal until after you have a decision on your request for a mandatory reconsideration. Your appeal request must be in writing on appeal form SSCS1 which you can download from the GOV.UK website. You need to ask for an appeal within one month of getting the mandatory reconsideration notice, and you must include a copy of the notice with your appeal request.



Advice Now has a free guide, *How to win a PIP appeal* available from their website at advicenow.org.uk.

PIP & STAYS IN HOSPITAL OR RESIDENTIAL ACCOMMODATION

PIP can be affected by overnight stays away from home. There are different rules depending on whether your child is in hospital or residential accommodation.

If a young person is in hospital and is aged 18 or over, payment of both the daily living and mobility components of PIP are suspended after 28 days.

If a young person is aged 16 or 17 when their period as a hospital in-patient started then they are not affected by these rules and their PIP payments should continue without interruption.

If a young person is in residential accommodation that is paid for out of public funds, including a residential school, the daily living component stops being paid after 28 days. This applies to all PIP claimants including those aged 16 or 17. The mobility component is not affected.

When working out when payments of a young person's PIP will stop, it is important to know that different stays in hospital or care separated by fewer than 28 days at home are added together to count the number of days they have been away.

For further information on these 'linking rules' contact our freephone helpline.

GETTING AN EXISTING PIP AWARD CHANGED

If your child is on PIP and their circumstances change so that they need more help, you can ask the DWP to look at your child's award again. This is known as a supersession request. You can ask for this at any time. However, you should seek advice before doing this as there is a risk that the award could go down instead of up. Seek further advice from Contact's free helpline or from a local advice project.

PIP REVIEWS WHEN YOUR EXISTING AWARD IS COMING TO AN END

If your child has a current PIP award that is fixed for a period of time, they will be sent a review form to complete up to a year before their existing award is supposed to run out. The DWP will then decide whether their PIP award should continue for a longer period and at what rates. If they have an award that lasts for a long time, for example 5-10 years, you may be sent a review form earlier than this, to check that their entitlement to PIP has not changed. Even if they have an indefinite award they may still be sent a review form to complete periodically.

"Getting the decision overturned was so important. It was the difference between my son being able to come home at weekends or having to stay in care."

Parent carer



PIP & ITS EFFECT ON OTHER BENEFITS

PIP is never treated as income in calculating other benefits. In fact getting PIP can actually lead to an increase in other benefits, or help you qualify for other entitlements.

The following is a brief checklist of benefits and entitlements which may become available following an award or increase of PIP. Call our freephone helpline for more detailed advice.

CARER'S ALLOWANCE

If a young person gets the daily living component of PIP at either rate (standard or enhanced) you may be able to get Carer's Allowance. You must be providing at least 35 hours of care each week. To get Carer's Allowance, you must not be a full-time student and not be earning more than a set amount after certain deductions and costs each week. At the time of writing this is £128 per week. If the only thing that stops you from getting Carer's Allowance is that your earnings are too high, you may still qualify for an extra payment known as the carer's element if you are getting Universal Credit.

CHILD TAX CREDIT

If a young person for whom you receive tax credits gets PIP, your Child Tax Credit payments will increase. This is because you will qualify for an extra disability element. You will also get a further severely disabled child element if they have been awarded the daily living component at the enhanced rate. The disability and severe disability elements can be backdated in line with the PIP award, but only if you tell the tax credit office within one month of the date on the decision letter awarding PIP.

UNIVERSAL CREDIT

Universal Credit is a new benefit that is replacing tax credits and other means-tested benefits for people of working age. If you are getting Universal Credit and a young person who is included in your claim receives PIP, you will qualify for extra Universal Credit payments. These extra payments will be made at a higher rate if your child gets the PIP daily living component at the enhanced rate. Make sure you let the office paying you Universal Credit know if your child is awarded PIP or has their PIP award increased to the enhanced rate for daily living.



See our free factsheet *Universal Credit – the essentials* available to download at contact.org.uk/universal-credit-essentials or from our helpline **0808 808 3555**.

INCOME SUPPORT

For families still getting payments for their children in their Income Support, an award of PIP can lead to extra money being added to your Income Support. This is known as the disabled child premium. If a young person is awarded the daily living component at the enhanced rate, the enhanced disability premium is also added. You will need to let the office dealing with the Income Support claim know about the PIP award.

EMPLOYMENT & SUPPORT ALLOWANCE

If a young person already gets Employment and Support Allowance, an award of the enhanced daily living component of PIP may lead to an increase in their Employment and Support Allowance. Let the office dealing with Employment and Support Allowance know about a new award of PIP, or any change to the existing award.

HELP WITH RENT & COUNCIL TAX

If you get Housing Benefit, an award of PIP for a dependent child or young person may lead to extra Housing Benefit if you are not already getting your rent met in full. Depending on the council tax reduction scheme, a PIP award for a dependant young person may also lead to more help towards your council tax bill.

If a young person is 18 or over and receives the daily living component of PIP at any rate (only the enhanced rate in Scotland) you might qualify to be 'discounted' as a carer for council tax. Depending on who else lives in your home this could lead to more help with your council tax.



See our guide ***Help with Council Tax bills***, available on our website contact.org.uk/council-tax or call our helpline **0808 808 3555**.

EXEMPTION FROM 'BENEFIT CAP'

If a young person for whom you claim benefits as part of your family gets PIP, you will be exempt from the household benefit cap which limits the amount of benefit that an out-of-work family can receive.

"The advice and reassurance from Contact has made me feel better as I know where to get advice and information. Knowing there is that support there at end of the line is very reassuring."

Parent carer

BLUE BADGE FOR DISABLED PARKING

A young person will be automatically entitled to a Blue Badge for disabled parking in England if they score eight points or more in the PIP activity of ‘moving around’ (see table on page 24). They will also qualify automatically if they score 10 points for planning and following a journey – but only if this is awarded on the specific basis that they ‘cannot undertake any journey because it would cause overwhelming psychological distress’ (see table on page 25). If they score 10 points or more for planning and following a journey for a different reason they will not qualify automatically but may still qualify via a local authority assessment instead. In Scotland and Wales PIP claimants are automatically eligible for a Blue Badge if they either get eight points or more for the PIP activity of ‘moving around’ or 12 points or more under the PIP activity of ‘planning and following a journey’.

If they don’t qualify for a blue badge automatically your son or daughter might still qualify via a local authority assessment. For instance in England they can qualify for a blue badge if your local authority assess that they are unable to undertake a journey without:

- ***it causing very considerable difficulty when walking, which may include very considerable psychological distress; or***
- ***being at risk of serious harm when walking; or it posing, when walking, a risk of serious harm to any other person.***



More information about the Blue Badge rules in the different nations is available at: [contact.org.uk/blue-badge](https://www.contact.org.uk/blue-badge)

HELP WITH ROAD TAX

If a young person is awarded the mobility component of PIP at the enhanced rate, you may be exempt from paying road tax. If they qualify for the mobility component at the standard rate you may be eligible for a 50 per cent reduction instead.

HELP WITH GETTING A CAR

If you're interested in getting a car and your son or daughter is awarded the mobility component of PIP at the enhanced rate, you can hire or buy a car through the Motability Scheme. To be eligible, their award of the enhanced rate mobility component must have at least 12 months left to run.

If you're unable to drive and need help to pay for lessons, or help to get a deposit for a car through the scheme, then you may qualify for grant assistance.

 To find out more contact Motability:
01279 635 999 [motability.org.uk](https://www.motability.org.uk)

HELP WITH BUS TRAVEL

All local authorities operate schemes that allow disabled people of any age to apply for a bus pass or voucher for free bus travel. In some areas, a named carer accompanying the disabled person is also entitled to free travel. Schemes operate differently from one local authority to another so contact your local council to check out what's available in your area.

OTHER CONCESSIONS

It is also worth checking to see if there are any special schemes, concessions or facilities available to families with disabled children in your area. Call our freephone helpline for local contacts 0808 808 3555.

WHEN A YOUNG PERSON IS UNABLE TO MANAGE THEIR BENEFIT CLAIMS

A child turning 16 is usually expected to take on responsibility for any benefits they claim in their own right, including PIP. But if they're unable to manage their affairs, you can become their 'appointee' for benefit claims.

WHAT IS AN APPOINTEE?

Becoming an appointee means you are responsible for making any claims, giving any information required, and telling the Department for Work and Pensions (DWP) about any changes that may affect your child's entitlement to benefits. The benefits will be paid to you on their behalf.

Becoming an appointee for benefit purposes does not mean you have any wider rights to deal with their affairs.

HOW DO I BECOME AN 'APPOINTEE'?

The DWP should write to you about this in the six months before your child turns 16. Usually they do this at the same time as giving you information about making a claim for PIP. If this doesn't happen contact the DWP to ask that an appointee be considered. The DWP should then arrange a home visit. This is usually a straightforward process and should not delay any claims that you are making.

You can't become an appointee simply because it is more convenient for you or your child. The DWP can only agree to you becoming their appointee if they believe that your child lacks the capacity to manage their affairs. Usually this will be due to mental incapacity but in exceptional circumstances it can be because of a physical disability.

If you have already been appointed by the courts to look after their affairs, you won't have to do anything else.

CLAIMING OTHER BENEFITS

Depending on your child's circumstances it may be possible for them to claim other benefits in addition to PIP once they turn 16. In most cases the benefit they are most likely to be able to claim will be Universal Credit. However, a small number of disabled people are exempt from Universal Credit and can still claim the older 'legacy benefits' being replaced by Universal Credit, such as income-related Employment and Support Allowance (ESA).



Call our helpline on **0808 808 3555** for detailed advice if your son or daughter is already getting a legacy benefit and this includes an amount known as the severe disability premium, or if they are likely to be moving into rented supported accommodation or other forms of special accommodation such as homeless accommodation.


PIP and Child Benefit

Claiming PIP for your child does not stop you getting Child Benefit or other benefits for them as a dependant. However, if your son or daughter gets Universal Credit or a legacy benefit like income-related ESA this DOES mean that any Child Benefit you get for them will stop, along with other benefits or tax credits you receive for them as a dependent child.

PIP and Universal Credit

Normally a young person who is still in school or college full-time cannot qualify for Universal Credit. However, a young person in education may be able to qualify if they are getting DLA or PIP and they are assessed as having a limited capability for work. This means most young people receiving education need to have a medical assessment known as the work capability assessment BEFORE they can be awarded Universal Credit. If your son or daughter is aged 20 or above, and is still in full time non-advanced education they may be able to claim Universal Credit

without first having a work capability assessment, but only if they can show their course is not incompatible with their Universal Credit claim.

 The rules are complex but you can find out more information in our free guide to ***Claiming Universal for a Young Disabled Person*** available from our website at **contact.org.uk**.

This means that some families will have a choice between continuing to claim benefits for their child as part of your family, or helping them to claim Universal Credit in their own right as a young disabled adult. Which option will leave your household better off will depend on your individual family circumstances. This is a complicated issue, so it is best to first get advice from the Contact helpline or from another service offering detailed benefits advice.



GET IN CONTACT

Our helpline advisers can support you with any issue about raising your disabled child: help in the early years, diagnosis, benefits, education and local support.

-  0808 808 3555
-  info@contact.org.uk
-  www.contact.org.uk
-  twitter.com/contactfamilies
-  facebook.com/contactfamilies
-  youtube.com/contactfamilies

Contact Head Office
209–211 City Road
London EC1V 1JN



We are Contact, the charity for families with disabled children.

We support families with the best possible guidance and information.

We bring families together to support each other.

We help families to campaign, volunteer and fundraise to improve life for themselves and others.

Contact is a trading name of Contact a Family. Charity registered in England and Wales (284912) and Scotland (SC039169). Company limited by guarantee registered in England and Wales (1633333). VAT registration GB 749 3846 82.

© Contact, August 2020

Order code i30

