

Personal Independence Payment (PIP)



Information and tips
booklet

What is a Personal Independence Payment (PIP)?

Disability Living Allowance (DLA) has been replaced by PIP for those who are aged 16-64. Children who are already in receipt of DLA and about to turn 16 will gradually be re-assessed for PIP. Personal Independence Payment (PIP) is a new benefit for people who need help taking part in everyday life or find it difficult to get around.

How does PIP work?

The PIP assessment aims to test your ability to participate in everyday life. It is points assessed and based on your ability to perform 12 activities related to your daily living needs and mobility.

The number of points you score will determine whether or not you are entitled to either component (mobility and daily living) of PIP and if you are, at which rate. You can qualify for either or both components and each can be paid at different rates. You can only score one set of points from each activity. If two or more apply, you will receive the highest point score.

What is assessed?

10 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

2 mobility activities:

- Planning and following journeys
- Moving around

What is the process?

The first step will be to call the Department for Work and Pensions (DWP) PIP claim line: 0800 917 2222.

The DWP will ask you a few questions, to ensure you meet the basic rules for claiming PIP. These include if you have a mental health condition, a behavioural condition, learning disability or developmental disorder. These questions are designed to highlight additional help you might need throughout the PIP process.

- After phoning the DWP, you will be sent a claim form, PIP2, called 'How your disability affects you'
- You will need to complete the form with supporting evidence
- The DWP passes your form to a healthcare professional (HCP), who will decide if more information is required
- The HCP will decide if a face to face assessment is needed or if they have enough evidence to make a paper decision
- The HCP send a report to DWP and a decision is made
- You will then receive a letter from the DWP with a decision
- If you disagree with the decision, you can request a mandatory reconsideration and can send further reports or information
- If you further disagree, you can appeal to an independent tribunal

You can only claim PIP on behalf of someone else if:

- You hold Power of Attorney for that person, or
- You are an appointee who's been authorised by the DWP to claim benefits on behalf of that person, or
- You are applying to become an appointee, or
- The person you are claiming for is terminally ill.

The forms

PIP is made up of two parts, Daily Living and Mobility. Each part can be paid at either a standard or enhanced rate. You may have to attend a face to face medical assessment, as part of the claim process. When you return your claim form, you should send as much supporting evidence as you can because PIP is awarded on a point scoring system. Your claim is decided on a 12 month period, looking back at a 3 month period and forward to a 9 month period.

To get the standard rate for either component you will score between 8 and 11 points, for all the activities in that group. To receive the enhanced rate for either component, you will score 12 or more points for all the activities in that group.

You have one month to return the PIP claim form

Remember decision makers at the DWP do not know the person claiming PIP, so they can only go on the information submitted on the form. If you have completed the form on behalf of someone else, it is important that you state this on the form, or by adding a covering letter.

*You can request an extension of your PIP2 form which is usually an additional two weeks.

PIP1 form

PIP1 is the initial claim form, which can be completed by either phone or in writing. Once you have completed this, a further detailed form is sent to you, a PIP2. You must complete and return a PIP2 form which asks about your disability, the difficulties you have and the help you need.

PIP2 form

The PIP2 form consists of the following sections:

Q1 Professionals you see

List the professional(s) best placed to advise on your circumstances. This could include a GP, hospital doctor, specialist nurse, community psychiatric nurse, occupational therapist, physiotherapist, social worker, counsellor, or support worker.

Q2 About your health conditions or disabilities

List all your health conditions or disabilities and ensure you list all health conditions or disabilities, even if you think they are small.

Q3 Preparing food

Many people use microwaves and convenience foods, but the question is about preparing and cooking a meal for one person from fresh ingredients.

If you do not use fresh ingredients to cook with, say so. The outcome of a meal is cooked food for one, which is properly cooked and edible; it is not about your cooking ability, nor the nutritional value of the meal, **it is about the ability to prepare and cook a meal.**

If you get exhausted from preparing and cooking a meal and can only do it once a day, then you cannot do it repeatedly. You may wish to include some of the following points:

- I have a ritual, meaning meals take a long time to prepare
- I am at risk of cutting myself or another person

- I do not understand the fire risk involved; electrical appliance and / or burning / scolding from pans
- I do not think about food, mealtimes do not mean anything to me
- Anxiety makes me feel sick, so I go without food
- When I do eat, it is junk food like biscuits and chocolate
- I starve myself as a control issue and cannot prepare food
- I shake so spill food a lot and need help to clean up afterwards
- Everything has to be in line with my rigid thinking, or I have to start from the beginning again
- I have to be encouraged to eat and I need help to prepare food. Ensure you state how someone prepares food for you

Q4 Eating and drinking

This question is not just about the process of eating and drinking, but can include cutting up food, the act of getting food and drink to the mouth, chewing food and swallowing. Include aids or adaptations used for this activity. Some examples include:

- I cannot eat in front of other people and binge on junk food in private
- When my anxiety is bad, I get up in the night and binge eat
- I only eat certain textures, for example, beige coloured food and set menus
- I have to look, smell and feel food before eating it
- I have always been hypersensitive to food
- I have a fear of contamination and have to prepare food in certain ways
- I cannot touch food when eating it, if this happens I have to throw the food away
- I am on a casein / GF / Wheat Free diet, this was recommended by the autism research unit after they carried out IgE levels
- I have chronic digestive problems, so need to follow my diet very carefully
- If I do not follow my diet I will have constipation or diarrhea

Q4 Extra information – Eating and Drinking

Important for those with autism; you may be able to feed yourself, but you might spill food, or only eat with visual prompts or someone telling you to eat.

Remember to explain if you miss meals because you forget. The following may also be applicable:

- I need someone to help me with support strategies to eat
- I need someone to motivate me to eat
- I use a special plate with compartments / dinner winner plate etc
- I stuff food in my mouth and choke
- I need to be reminded to drink
- I need someone to help me follow my special diet

Q5 Managing treatments

If you use a pill box, alarms, and visual reminders because of autism and not as a convenience, you must explain why they are needed. Any therapy must be carried out at home and not in a medical centre. If you go somewhere elsewhere for Speech and Language Therapy, this will not count. If you require help to carry out Speech and Language Therapy at home, this will count. The length of time prompting and assistance takes, not the length of time the therapy takes, will count. The following may be applicable:

- If I failed to carry out my therapy and / or take my medication it would lead to a deterioration in my health and wellbeing
- I forget to take my medication
- I will not take my medication
- I can get violent if I am made to take my medication
- I forgot how many tablets I have taken
- I have a phobia / problem going to the dentist / doctor / opticians which I have to do on a regular basis
- I don't believe I have autism (plus other conditions), so I do not take my medication or attend therapy
- The side effects of my medication make me drowsy
- I have overdosed on my medication
- I have to be supervised that I do not take too many tablets or become fixated on my therapy

Q6 Washing and Bathing

This section is about your ability to keep your body clean. The following may be applicable:

- I am obsessive around cleanliness and take a long time to complete washing / bathing activity
- I have to have the water excessively hot
- I stay in the shower / bath longer than normal
- I have to use a timer / aids / adaptations
- I have a wet room
- After I have washed / bathed / showered I am not clean to an acceptable standard and I am reminded to go back and wash
- I can go days / weeks without washing / shaving / washing my hair
- I am supposed to put creams on my skin and I forget to do this
- I have to wash my hands and body in a certain way and a certain number of times
- I think my body is changing and I get distressed

- I cannot look in mirrors because I might see something that causes me stress / melt down
- I read the bible and shaved all my hair in the shower to find the bad mark

Q7 Managing toilet needs

This includes the ability to go to the toilet and manage incontinence. This section also includes any assistance needed during periods:

- I am unable to motivate myself to clean up after an accident
- I need help to clean the toilet
- I suffer with incontinence
- I am unable to use the toilet as other individuals of the same age. Explain how you use the toilet
- I go to the toilet in inappropriate places
- I do not always realise I need the toilet and someone else will tell me
- I cannot transfer the knowledge and routine I have in my toilet at home to unfamiliar toilets
- I remove all my clothes when I go to the toilet
- I do not remember to wipe myself and then get sore
- I forget / don't use sanitary protection
- I don't dispose of sanitary protection
- I have poor co-ordination and motor skills and cannot use tampons independently
- I cannot open the packaging of sanitary towels
- Someone has to draw on my underwear where the sanitary towel should be placed
- Due to sensory issues, I can only wear sanitary products for a short time
- I do not know how often a sanitary product needs changing

Q8 Dressing and undressing

This is about the ability to dress or undress yourself:

- I need reminding to get dressed and undressed
- Someone has to physically dress and undress me
- I wear unsuitable clothing for the weather. This is because of my autism and is not a personal choice. I then get too cold or too hot
- I wear the same things every day, unless I am told to put different / clean clothes on
- I dress in flamboyant clothes which means people stare and laugh at me and then take advantage of me
- I go to bed without undressing
- I take my clothes off at the same time, because I have a set ritual

- I have taken all my clothes off in the street and then someone has had to re-dress me
- My anxieties are often so extreme that I cannot make decisions about what clothing to put on
- I need a lot of encouragement and persuasion to get dressed / undressed
- I need someone to check that I am properly dressed and wearing clean clothes
- I can only wear clothes that are free of tags, buttons and zips
- I need a visual sheet that shows me the process of getting dressed and undressed
- I have numbered stickers on my clothes, so I know in which order to get dressed
- I have to put my clothes in the drier before putting them on, cold clothes stress me and cause me to have a meltdown

Q9 Communicating

The ability to understand is also part of this section:

- I cannot / I struggle to understand spoken information and to be understood myself
- I become agitated and frightened talking to people
- I get so anxious that I cannot concentrate on what people are saying to me
- I cannot say what I want to say
- I cannot ask for help
- I get confused between what someone has said and what is inside my head
- I get angry with people and then become verbally / physically abusive
- I forget things I have been told and I need things to be written down
- I cannot answer the phone or door due to high levels of anxiety
- I forget messages I have been given
- I hide and do not open my post
- I have to have someone with me to help me understand and be understood
- I telephone my parents / siblings / carers at strange hours, looking for reassurance or to go over something that is bothering me
- I call emergency services for trivial things
- I have rapid speech, which means people do not understand what I am saying
- I have difficulty communicating my needs and wants

Q10 Reading

You can score points in this section because your autism means you cannot read and understand, not because of lack of education. For example, did you require extra help at school?

- I cannot read and understand written information
- I have difficulty understanding bank statements. *If you can understand a bank statement, this will be accepted that you can read and understand.*
- I cannot read or understand forms or official letters, I need help
- I attend / I attended a SEN school / college and had / have a Statement of SEN / EHC Plan
- I attended a mainstream school and have / had a Statement of SEN / EHC plan
- I was given a scribe and reader for my exams, because I struggle with reading / do not understand the exam questions
- I have dyslexia
- I wear coloured glasses when reading
- My autism means I have difficulty understanding language and communication, which affects my ability to read
- Although I can read, I often do not understand what I have read and I have poor comprehension

Q11 Mixing with other people

Use examples of any incidents that have happened when mixing and interacting with other people:

- I cancel appointments because of anxiety and I am unable to engage with other people
- I become agitated and / or aggressive around other people. *This must be because of your autism and not through preference*
- If someone talks to me, I panic and become very anxious
- I have had to leave shops without the items I need to buy because of other people
- I have no desire to socialise
- I do not like people, they make me feel unsafe
- It is a challenge for me to mix and interact with other people
- I would like to mix with other people, but I do not have the skills or know how to socialise
- I only meet with people I know every couple of weeks
- I cannot see something from another person's point of view and this causes people to get angry with me
- I am over confident and this irritates people

Q12 Making decisions about money

This is about your ability to make decisions regarding spending and managing your money:

- I cannot make budgeting decisions
- I forget / do not understand that I have to pay bills
- I make bad decisions about what I buy. *If you make a bad decision over a purchase, this should be a direct result of your autism.*
- I often lose control of my decision making ability
- I spend all my money without the thought of consequence
- I would be easily exploited over money matters
- I am not interested in money, it does not mean anything to me
- Budgeting and money management is very difficult for me and I need another person to help me
- I have ended up in debt because I am unable to manage and make decisions about money
- I can add and subtract but do not understand / get confused about the value of money; I cannot apply maths to money and everyday life
- I give my money away to other people because I am very trusting and believe what people tell me
- When I am paying for something, I empty all my money on the counter and then start counting it. This annoys the person serving me and people in the queue, but this is the only way I can pay for things

Q13 Going out

Your ability to work out and follow a route to another place, including using public transport:

- I cannot cope with unexpected changes to a journey
- I cannot cross roads safely in familiar and unfamiliar areas
- I cannot get home safely from an unfamiliar place as I cannot approach people to ask for directions
- I require a journey to be planned by someone else for me
- Due to my autism, I have difficulty following directions
- Someone needs to keep reminding and prompting me on a journey
- I lack an awareness of danger for example, running into the road, getting lost and ending up in an unsafe situation
- I often feel like I might hurt people, so avoid going out
- When I have been out, I have been taken to the police station / hospital because I have become agitated and anxious
- I think I can stop the traffic and will walk into the road without warning
- I cross the road to avoid people and do not check the road is safe first

- I have to follow a ritual, like touching things or not stepping on certain parts of the pavement
- The intensity of the fear and anxiety I feel when I go out makes my life miserable and unhappy
- I cannot cope with loud noises / bright lights / car horns / sirens
- I cannot go out when it is windy in case a tree falls on me or a meteorite falls from the sky
- I think I might catch a disease from going on public transport
- I have a GPS tracker on my phone, so that people know where I am
- I cannot anticipate problems outside and plan for them
- I have to have a visual strategy when going outside, so I know in advance what I will be doing and how long I will be out

Q14 Moving around

The difficulties or help you need to physically move around. Guidance states walking should be carried out in an upright position:

- I have an unusual gait when walking, I walk on my tip toes
- I cannot sit still and I stim
- I cannot stay in bed and need someone to make sure I stay safe in the night time at home
- I wear orthotics
- Because I have hypermobility I get very tired
- I have poor posture and this means I cannot walk upright
- I have poor co-ordination skills and bash into objects
- I have difficulty processing sensory information

Q15 Additional information

This is your chance to send in all relevant reports about your condition. If you are known to a charity or independent organisation, ask them to write a letter.

It is important and, cannot be emphasised enough, that the more information you have about how your autism affects you, the better.

Send in details of any current medication you are taking, or repeat prescription(s).

If you use visual aids, timers etc. send details of these.

If you have used a diary to support your claim, send that.

If you are going to send in letters marked 'confidential,' ensure you black out the word 'confidential,' otherwise they will not be forwarded to the assessing organisation.

Write a synopsis of 'issues I face daily due to my autism.'

Ensure you make copies of everything you are sending for your own records. You may want to add some of the points below to above descriptors or to your 'additional information.' It does not matter that you repeat yourself:

- People find it hard to understand me because I say strange things
- I have hurt myself
- I get urges to set fire to objects / buildings
- I have gone off without telling people where I am going
- I spend money I have not got
- I offend people all the time by saying / asking inappropriate things / questions
- I have to wear ear defenders / earplugs
- I have stalked someone because I misread the signs of them being kind to me
- In order to fit, in I mimic mannerisms and behaviours of other people
- I will often just agree with what people are saying to me
- I cannot go to bed or get up without someone encouraging me
- My sleep is very poor and I feel exhausted when I wake up
- I like to shut myself off from the world
- Day and night feel the same to me and I am often stimming into the early hours
- I cannot switch off my thoughts / worries / anxieties
- Because I need routines and 'sameness', this makes acquiring life skills difficult for me
- Because of my social difficulties, I need help understanding not just what needs doing, but why
- I have considerable anxiety and insecurity
- I have difficulty understanding what is happening around me
- I have the inability to predict what will happen
- I have broken the law and committed crimes
- I struggle to learn life skills
- I can only go to the shops on quiet days and when I have somebody to help me
- I have obsessions and repetitive behaviour, which prevents me from learning new skills

- I do not understand the concept of waiting, this causes me great anxiety
- I use a timer and visual timetables
- I cannot live independently and require support and supervision
- I am over / under sensitive to touch, I cannot shake hands
- I easily become overwhelmed in loud or crowded settings
- Due to my autism, I dislike certain clothing or layers of clothes
- I have great difficulty understanding and following spoken instructions
- I will often seek out stimulation in the form of touching, stimming, moving, smelling and crashing into things. This causes stress and upset to people around me
- I cannot process multiple information simultaneously
- I cannot start and finish a task
- I have poor planning and organisational skills
- I will often act on impulse and this causes me to get into trouble
- I will display intense emotional reactions and often over exaggerate
- I have shutdowns where I will withdraw and be unresponsive
- I have meltdowns where I will become aggressive, disrupt others and / or self-harm
- I need tasks broken down with visual strategies so they are clear and concise to me
- My home has motion detectors, because I run out of the house then wander off

Remember

- If you are not fit to travel you can ask for the face to face assessment to take place at your home.
- You can take someone with you to the assessment.
- You can submit additional information at the assessment
- You can record your assessment, but must provide a copy to the HCP at the end of the session
- If you do not turn up for your face to face assessment without good reason, your claim will be turned down-unless you did not get 7 days notice.

Personal Independence Payment Enquiry Line

Tel: 0800 121 4433