

Government Allowances and Sources of Financial Help Adults



Personal Independence Payment (PIP) replacing Disability Living Allowance (DLA)

Personal Independence Payment (PIP) is replacing DLA for people aged 16 to 64, even for those with an indefinite or lifetime DLA award. If you're already claiming DLA, you'll continue to get DLA until the Department for Work and Pensions (DWP) writes to tell you when your DLA will end and invites you to apply for Personal Independence Payment (PIP).

Unless your circumstances change, you don't need to do anything until you hear from DWP about your DLA.

Components of PIP

There are two components to PIP:

- Daily Living Component
- Mobility Component

Each component has two levels:

- Standard
- Enhanced

Your claim will be assessed by an independent health professional to help DWP work out the level of help your son or daughter needs. This may be a face-to-face consultation - you'll get a letter explaining why and where you must go. DWP makes the decision about your claim based on the results of the assessment, your application and any supporting evidence you include.

The application form allows the claimant or someone supporting them to tell how the condition affects them in their own words. The form is shorter than the DLA application form and the Department for Work and Pensions provide advice and guidance on how to complete it.

To find out more, and to check when PIP will affect your son or daughter, go to www.gov.uk/pip and see next pages for how to complete the application form with reference to PWS.



It is beyond the scope of this

leaflet to give more than a basic outline of the various sources of financial help available.

Amounts of money for each benefit are generally not given, as they tend to change over time.

The government is currently carrying out a major overhaul of the welfare benefits system. Although the information in this leaflet was correct at time you received it, you are advised to check with the various helplines and publications given at the end of this article for updated information.

How a PIP payment is determined



Payment depends on sufficient points being scored. For the Standard rate, a claimant will need 8 points, for the Enhanced rate it will be 12 points. The points total comes from 11 sections – 9 for daily living and 2 for mobility.

Considerations when completing the PIP application form “How your disability affects you”

The PIP application form is divided into various sections and general guidance is given on how to complete them. Keep a copy of the completed form and any supporting evidence you send for your future reference or in case documents are lost. Send as much additional evidence, eg reports from health and social services, as you can.

Keeping a diary

Disability rights organisations recommend that you keep a diary for several days, focussing on the questions on the form. This is particularly important if your son or daughter’s needs vary from day to day. You can make a copy of your diary and attach it to the application form.

PWS-specific considerations

Below are some PWS specific considerations relating to some of the questions which you may wish to include if they apply to your son or daughter. Other questions will apply more individually to your son or daughter’s needs, and they are also likely to have individual needs which you should include alongside the considerations we have given.

Q2a – Tell us about your health condition or disability

Include Prader-Willi syndrome in this (since birth) but also additional disabilities such as epilepsy, asthma, scoliosis, diabetes, leg or feet problems, heart problems or sleep apnoea.

Q3b – Do you need help from another person to prepare or cook a simple meal?


For most people with PWS, the answer to this will be “Yes” (ie cooking meals or choosing ingredients if supervised, or meals are cooked for the person)



Q3c – Extra information – Preparing food

Consider the following and include in your answer if they apply:

- If you cook all his meals, explain about the excessive appetite associated with PWS and that access to kitchen and food must be restricted. Explain that, because of low muscle tone, he needs fewer calories than other adults. If food is not restricted, then potentially life-threatening obesity will result.
- Explain that, because of the hypothalamic dysfunction and consequent drive to eat, people with PWS lack capacity to make decisions around food and enclose the article on Mental Capacity and PWS from our website at <https://www.pwsa.co.uk/assets/files/Mental-capacity.pdf>
- If he cooks some or all of his meals, explain that he requires supervision to ensure he does not give himself too large a portion or high calorie meals (for the reasons given above).
- Explain why you buy particular lower calorie alternatives to normal foods.
- He may have additional dietary needs due to allergies – include these if he does.
- Is he likely to eat foods such as raw meat or other uncooked or frozen items whilst preparing them? Give examples if this has happened. Emphasise that additional risks are present here because of poor vomiting ability.
- Is using a knife or other kitchen implements potentially dangerous?

 **For ease of reading this section refers to he/him/his etc, but applies equally to women.**

Continued ...

PWS-specific considerations when completing the PIP form (continued)



Q4c – Do you need help from another person to eat and drink?

For most people with PWS, the answer to this is “Yes” or “Sometimes”

Q4d – Extra information – Eating and drinking

Consider the following and include in your answer if they apply:

- Do you supervise him while he is eating the meal?
- Do you have to lock the kitchen or restrict access to food in other ways? Explain what you have to do.
- If he eats with the family, what alterations have you had to make to the way meals are served to ensure he does not over-eat?
- Do you have to check that he is not helping himself to food from other people’s plates or eating leftovers?
- How do you manage when eating out? (Or are you prevented from eating out?)
- Do you have to remind him not to eat food too fast to prevent risk of choking?
- Is he able to chew food? Does it need cutting up for him or softening?

Q5b – Do you need help from another person to monitor your health conditions, take medication or manage home treatments?

In addition to describing individual medications or treatments he takes, does he have a high pain threshold or does not recognise hot or cold temperatures? Does he have a history of rarely vomiting?

Tick “Yes” or “Sometimes” if this applies.



Q5c – Extra information – Managing treatments

Consider the following and include in your answer if they apply:

- Does he have a high pain threshold which means that he does not always know if he is ill or hurt himself?
- Provide an example of when he was ill and did not complain, or was not sick
- Is he likely to refuse to take medication or comply with a treatment?
- Is he likely to overdose on medications? – either because of mental health problems or because tablets are viewed as food.
- Does he pick at sores? Emphasise the necessity for supervision to avoid danger of infection.

Q6b – Do you need help from another person to wash and bathe?

Apart from any obvious help to wash hair and body, do you also need to check the temperature of the water because he cannot tell when it is too hot or too cold? Are they likely to slip or experience problems getting in and out of the bath or shower? Tick “Yes” if these apply.

Government allowances and sources of financial help

General guidance

Disability Rights UK provide some very useful general guidance on completing the form at <https://www.disabilityrightsuk.org/personal-independence-payment-pip>

Citizens Advice also provide general information about how to complete the PIP form at <https://www.citizensadvice.org.uk/benefits/sick-or-disabled-people-and-carers/pip/help-with-your-claim/how-to-claim/>



Northern Ireland

The PIP process is different for claims in Northern Ireland. To find out more about PIP, about claims in Northern Ireland, and to check when it will affect your son or daughter, go to <https://www.nidirect.gov.uk/articles/personal-independence-payment>

Continued ...

PWS-specific considerations when completing the PIP form (continued)



Q6c – Extra information – Washing and bathing

- Do you have to help him or remind him to get washed or to take a bath or shower? Do you need to check the temperature of the water? Explain that the hypothalamic dysfunction is the reason why he cannot tell when water is too hot or too cold.
- If he is obese, is he able to dry himself properly? What help would he need to do this – even if he does not actually receive it.

Q7c – Extra information – Managing toilet needs

People with PWS vary considerably in this respect, so your answer will need to be based on your son or daughter's individual needs. Many adults with PWS spend a long time in the toilet. This could be a behavioural issue, or it may be because of constipation – explain how long they stay in the toilet and why you think (or know) they are doing it.

Q8b – Do you need help from another person to dress or undress?

Apart from obvious help to dress or undress including buttons, zips and shoelaces, do you need to prompt him to wear the right amount of clothing for the weather outside? If so, tick “Yes” or “Sometimes” and add to the extra information.

Q9c – Extra information – Communicating

Your son or daughter may have a very obvious issue with communicating. For example, they may have articulation problems. Even where this is not obvious, their understanding may not be as good as it appears. If possible, give an example of this. Other considerations:

- Does he misunderstand, or only partially listen to what others are saying? Might he become upset because of this?
- Does he butt into conversations with off-topic observations?
- Does he say the same thing or ask the same question over and over again? – how do you deal with this?
- Can he make phone calls? If not, why not?
- Do you need to accompany him to meetings with professionals because he finds it difficult to understand the conversation and the implications of what is being said?
- Does he give the appearance of understanding, but in fact does not really understand? Give an example of this.



Q10 – Reading

People with PWS vary in this respect. Provide details of your son or daughter's individual abilities.

Q11a – Do you need another person to help you mix with other people?

For most people with PWS, the answer will be “Yes” or “Sometimes”

Q11c – Extra information – Mixing with other people

Include all behaviours which make mixing with others difficult. This might include food-stealing, angry or aggressive outbursts, refusing to move or comply with a request from another person, and not being able to adapt to change. If these behaviours put him at risk, explain what the risks are. Give examples.

- Do noisy environments upset him?
- Do issues around food make celebrations and gatherings problematic? What happens at this type of event and how much supervision do you provide?
- Do poor social skills cause problems?
- Is he vulnerable to abuse or being taken advantage of because of immature emotional development and willingness to comply with inappropriate relationships in return for food?

Continued ...

Q12 – Making decisions about money

Understanding about money varies considerably from one person with PWS to another. However, even those who understand money, can count money, give the right amount and check change, will almost always need support to ensure that it is not spent on extra food and help to budget.



Government allowances and sources of financial help

Q12c – Extra information – Making decisions about money

- Does he have limited or no access to money?
- How is his money managed?
- Would he spend money on extra food instead of buying more necessary items? (Refer again to the desire to eat)
- Is he liable to send off for items from the internet which he does not need?
- Does he have a credit card? If not, why not – explain what might happen if he did have one

Q13a and Q13b – Help planning and getting somewhere

Apart from more obvious help in not getting lost, most people with PWS will need supervision when going out and about to keep them safe and from accessing food.



Q13d – Extra information – Going out

- Is he likely to shoplift or take food out of bins or off the ground? Explain again that this is due to the drive to eat.
- Would he be vulnerable to approaches from strangers, especially those offering food?
- How good is his road sense?
 - How would he react if there was some sort of change to his normal route?
- Explain how he normally gets out and about, especially if you have to take him everywhere or to certain places.
- Does mood or behaviour impact on whether the journey can be undertaken or completed? Do you sometimes have to turn around and go home because of these?
- Would he panic or get lost in crowds?
- Can he cope with escalators and lifts?
- Does he need help with public transport?
- Can he be understood by others if he gets lost or loses his money or bag? Remember that even if his speech is usually clear, he may be too upset to express himself coherently. Would he be able to give his name, address and phone number?
- Does going out cause anxiety? Eg does he ask lots of questions prior to the journey about what to expect?

Q14d – Extra information – Moving around

- Does he need help to go upstairs? Does he walk up or down one step at a time?
- Does he need help to get into vehicles or onto buses and trains?
- Does he need physiotherapy or occupational therapy?
- Does he have poor balance? Is there a danger of his falling over and hurting himself?

Appointees

If you feel that your son or daughter does not have skills to handle money or, if they do, are likely to spend it on food, then you can be made an appointee.

As an appointee, it is your responsibility to deal with the claim, including notifying changes of circumstances. Contact the office dealing with their claim to arrange this.



If you experience difficulties completing the form, contact the PWSA UK. We will be pleased to offer advice, but as we are unlikely to know your son or daughter personally we cannot comment on individual cases.

Continued ...

Considerations when completing the PIP application form (continued)



Q14d – Extra information – Moving around (continued)

- Does poor muscle tone cause problems with walking, running, climbing etc?
- If his inability to walk far is the result of obesity, emphasise that this is due to factors inherent in PWS, and not just overeating. If you know that dieting is likely to be unsuccessful or impossible, point this out.
- Does he have additional physical problems such as arthritis, dislocated or loose joints, oedema or foot problems?
- Can he get up on his own if he falls?
- Does walking cause breathlessness?
- Explain again if high pain threshold is liable to mask injuries or pain.

Q15 – Additional information

You should list again all the problems of PWS that affect him. The main ones are:

- Excessive eating (hyperphagia)
- Low muscle tone (hypotonia)
- Obesity because of lower calorific requirement
- Immature social and emotional development
- Immature sexual development
- Sleep disturbance /sleep apnoea
- High pain threshold
- Behavioural problems – easily angered or upset

Other considerations to add

Do you have to supervise his general activities during the day?

Remember to mention if you have to keep a watch to prevent him from raiding the kitchen or pantry, or extra supervision in food shops, at friends' houses etc.



- Does he have an obsession with potentially dangerous objects? eg, cigarettes and lighters
- Would you allow him to stay in the house on his own whilst you went out? If not, why not? For example, he may eat extra food; he may have problems relating to a physical disability; he may be unaware of danger from normal household articles such as fires, cookers, irons, hot water etc; he may be unable to respond appropriately when answering the door or telephone.
- Does he need a regular routine?
- Can he cope with change? What does he do if things do not go according to plan?
- Describe any behavioural problems he has which you have not already included on the form, both social and emotional.
- Does he have a disturbed sleep pattern – waking during the night, sleeping during the day. Is there a danger of his falling or coming to harm if he wanders around alone at night?
- Do you have to lock external doors to prevent him from leaving the house because of behaviour or searching for food?
- Emphasise that if he is not supervised continually around food, it will lead to morbid obesity with all the associated problems and death at an early age.

How to claim PIP if your son or daughter is not already receiving DLA or PIP

Phone the Department for Work and Pensions (DWP) to make a new Personal Independence Payment (PIP) claim if you're in Great Britain. Telephone: 0800 917 2222 Textphone: 0800 917 7777 Mon to Fri, 8am to 6pm

You'll be asked for:

- contact details and date of birth
- National Insurance number
- bank or building society details
- doctor's or health worker's name
- details of any time your son or daughter has spent abroad or in a care home or hospital

Your son or daughter will need to be with you when you call. Once the call is completed, you will be asked to agree a declaration. The date of claim will be the date of your phone call, provided all the required information has been supplied.

You can also write asking for a form to send the above information by post (this can delay the decision on your claim). Write to:
Personal Independence Payment New Claims
Post Handling Site B, Wolverhampton WV99 1AH

If, on the basis of the evidence you gave in your phone call or letter, the DWP considers that your son or daughter does not satisfy the basic entitlement conditions for PIP, they will send you a letter saying that your claim has been disallowed. If basic entitlement conditions are satisfied, then you will be sent a form to complete: "How your disability affects you" – the PIP application form.

Government allowances and sources of financial help

Carer's Allowance (CA)

You can claim CA if you spend at least 35 hours a week looking after someone who gets the higher or middle rate of the DLA care component, and if you earn less than £120 (currently) a week, after allowable deductions.

CA is not means-tested and does not depend on past National Insurance contributions, but it is taxable and gives you Class 1 NI contribution credits.

If you receive certain benefits you may not be eligible for CA or they may be treated as an overlapping benefit. To check if you are eligible go to www.gov.uk/carers-allowance or pick up a leaflet from your local Job Centre Plus or library. There are other criteria which may affect your claim. Citizens Advice can help if you are unsure if you qualify.

Employment and Support Allowance (ESA)

jobcentreplus

This allowance is currently claimable by those aged 16 and over, but will ultimately be included in the Universal Credit (UC) (see page 1). If your son or daughter is eligible for UC, they will not be able to make a new claim for income-related ESA (see below), and will need to claim UC instead.

Employment and Support Allowance (ESA) is a benefit paid to people whose ability to work is limited by ill-health or disability. It has two elements: contributory ESA (linked to national insurance contribution records, so unlikely to apply to most people with PWS) and income-related ESA – a means-tested element.

To qualify for ESA, a person must:

- Have a limited capability for work
- Be aged 16 or over
- Be under state pension age
- Be in Great Britain
- Not in work
- Not be entitled to job-seekers allowance
- Not be within a period of entitlement to statutory sick pay.

Continued ...

Employment and Support Allowance (ESA) (continued)

A 13 week assessment phase applies to all new ESA claimants, during which the person undergoes a work capability assessment (WCA). The first part of WCA looks at whether you have a “limited capability for work”. If you do, you are entitled to ESA. The second part of WCA looks at whether the person has a “limited capability for work-related activity”. It determines whether the person is placed in the support group or the work-related activity group.

The support group

With some exceptions, this is the group which people with PWS are most likely to be placed in. The person does not have to undertake work-related activities, but can volunteer to do so. It has a higher rate of ESA.

The work-related activity group

If the person is found not to have limited capability for work, they are placed in this group, in which they must meet work-related conditions, including attending work-focused interviews.

Claiming ESA

ESA can be claimed by ringing the Jobcentre Plus claim line 0800 055 6688. This claim line will put you through to a regional Jobcentre Plus contact centre. They will need some initial information. For more information about the process, see <https://www.gov.uk/employment-support-allowance>

Universal Credit (UC)

Universal Credit is a monthly payment to help with your living costs. You may be able to get it if you're on a low income or out of work. Universal Credit is being introduced in stages across the UK. You don't need to do anything until you hear from the Department for Work and Pensions (DWP) about moving to Universal Credit, unless you have a change in circumstances. For more information about Universal Credit, go to www.gov.uk/universal-credit or look for government information leaflets at your post office, benefits office or library.

Council Tax Reduction

One benefit which is not included within UC is Council Tax reduction. This will be set by Local Authorities and hence rates will vary across the country. You can find out if you are eligible by asking your local council, or see www.gov.uk/council-tax

Local help with equipment and aids

Ask your GP, community nurse or social worker about extra equipment you need.

Local welfare rights help

Your local welfare rights officer or Citizens Advice Bureau will be able to give you general advice and help completing forms, but do not expect them to know about Prader-Willi syndrome. The checklist in this leaflet should help, or contact the PWSA UK if you are having problems.

Useful Websites and Publications

Disability Grants

Disability Grants provides information on charities and trusts to help you find a grant for yourself, your family or anyone you are supporting with a disability for things like equipment, holidays, housing etc.

www.disability-grants.org

Disability Rights Handbook

Published by Disability Rights UK, this handbook gives extensive details about all the benefits available in the UK. There is also extensive information on their website.

www.disabilityrightsuk.org

Gov UK

Gov UK is the government's site and gives information about the range of financial help available to those with disabilities.

www.gov.uk/financial-help-disabled

Turn2us

Helps people to find out what is available to them in benefits, grants for individuals and other financial help or funding.

www.turn2us.org.uk



Government allowances and sources of financial help

PWSA UK

**Suite 4.4 ,
Litchurch Plaza
Litchurch Lane
Derby DE24 8AA**

**01332 365676
admin@pwsa.co.uk
www.pwsa.co.uk**

**Reg Charity No:
1155846**

© PWSA UK

