

Government Allowances and Sources of Financial Help Birth to 2 years



Government Allowances

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



The government is currently carrying out a major overhaul of welfare benefits.

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 leaflet for updated information.

Disability Living Allowance

See next pages 2-5 for full details on this allowance which is payable from birth and is not means-tested.

Please note:

It is beyond the scope of this leaflet to give more than a basic outline of the various sources of financial help available.

If you need more information, there is a list of organisations and useful publications at the end of the leaflet which should be able to help.

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



Disability Living Allowance (DLA)

Disability Living Allowance (DLA) is a benefit to help with the extra costs involved in caring for a child under the age of 16 with a disability, and is not included in Universal Credits as it is not means tested (anyone with a child with a disability can claim). In order to be considered for DLA, a child must normally:

- Live in and be present in Great Britain, or, live in the European Economic Area or Switzerland and the UK is responsible for paying them sickness benefits
- Be allowed to enter or stay in the UK and not be stopped from getting benefits
- Need extra looking after or have walking difficulties
- Need much more day-to-day help than children of the same age, and
- Have had these needs for at least 3 months and these needs are likely to last for at least another 6 months

It has two components:

- **A care award**, paid at three rates, depending on the level of care needed.
- **A mobility award**, paid at two rates, depending on the degree of difficulty in getting around. The higher rate is payable from 3 years of age, and the lower rate is payable from 5 years of age.

Who can claim DLA?

You can claim the **care** component of DLA from birth up to the age of 16. At 16, the benefit will change to Personal Independent Payment (PIP). However, to get payment from birth a baby must be terminally ill. For all other babies, including those with severe feeding problems, payment will start from the day the baby reaches 3 months old. In all cases, a claimant must have needed help for three months, but a claim can be made before the three months is up.

Up to the age of 16, it is paid to the parent. DLA is not taxable, is paid on top of other benefits, and is not means-tested - your income and savings do not count.

Criteria for claiming DLA Care Component

In order to claim DLA, there are different criteria for different levels of payment: For the disability test for the **lowest rate DLA care component** your child must satisfy the following condition:

- need attention in connection with bodily functions for a significant part of the day which can be during one or more periods.

For the disability test for the **middle rate DLA care component** your child must satisfy one of the following conditions:

- need frequent attention throughout the day in connection with their bodily functions.
- need continual supervision throughout the day to avoid substantial danger to themselves or others.
- need prolonged or repeated attention at night in connection with their bodily functions.—i.e. another person to be awake at night for a prolonged period or at frequent intervals to watch over them in order to avoid substantial danger to themselves or others.

Criteria for claiming DLA Care Component (continued)

For the disability test for the **highest rate DLA care component** your child must satisfy either of the following:

- have one of the day needs and one of the night needs shown in the middle rate conditions.
- be terminally ill.

In addition to the above tests their care, supervision or watching-over needs must also be greater than those of a child of the same age who is in normal physical and mental health.



Why claim DLA for children with PWS?

Parents of children with PWS sometimes feel that their child does not “merit” a disability allowance, because their difficulties seem to be very light.

However, it is important to compare your son or daughter’s abilities with those of a child of similar age, and do not forget that things you do as a matter of course for your son or daughter with PWS may not be what you would do for another similarly aged child.

Even if you feel you do not need the money now, there may come a time when a “nest-egg” of money saved will help provide your son or daughter with equipment or help in the future. The vast majority of people with PWS will be eligible for DLA, although it will be at varying levels, depending on the person’s ability. However, having PWS does not give an automatic right to DLA, and the seriousness of the syndrome should be emphasised when applying.

Completing the DLA 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 which you should include alongside the considerations we have given. It is important to answer all of the questions as if describing a bad day, and try not to be too positive.

Question 22 - List the child’s illnesses or disabilities in the table below.

As well as Prader-Willi Syndrome, list all associated problems for which treatment or management is required. For example, your son or daughter will also have hypotonia and the treatment for this may be physiotherapy. Hyperphagia can also be listed, with the treatment being restricted access to food and if your child receives growth hormone, the disability would be listed as short stature or poor growth.

Continued ...

How to claim DLA

You can claim DLA by completing a claim pack.

You can get a claim form by downloading it from the internet at www.gov.uk/government/publications/disability-living-allowance-for-children-claim-form

Or by phoning the Disability Living Allowance Helpline:
Telephone: 0345 712 3456
Text phone: 0345 722 4433
Monday to Friday, 8am to 6pm.

The claim will be backdated to the date of your call if you return your pack within 6 weeks.



Completing the DLA form – PWS specific considerations (continued)

Question 23 - Does the child use, or have they been assessed for, any aids or adaptations?

List all of the equipment you use - For example, when feeding you may use a tumbleform chair, or it may be that you need to place a pillow underneath your son or daughters head to help maintain their airway while feeding. If your baby requires tube-feeding the syringes, feeding pump and tubes can all be added as aids. You may have a standing frame or adapted buggy, or you may use Makaton to help with communication. If you use any kind of support when bathing your child, this will also be included. Remember to compare your child with a baby or toddler of the same age.

Question 24 - When the child needs help

Mark the box 'is the same most of the time'. Although needs do vary on a day to day basis, the overall support required for the baby or toddler with PWS will remain the same.

Care questions

Question 37 - Do they need encouragement, prompting, or physical help to get into or out of or settle in bed during the day?

The answer to this will be yes, even if you have a baby with PWS. Babies and children with PWS have poor temperature control, meaning that the environment has to be right for them to settle, and this takes extra time. In addition to this, due to poor muscle tone, babies are unable to change position and some may need extra support around the head and neck area, and will often sleep for hours without waking for a feed. Toddlers with PWS are likely to need physical help getting in and out of bed as well as help settling—tailor your answer to the individual needs of your child.

Question 39 - Do they need encouragement, prompting, or physical help to move around indoors, use stairs or get into or out of a chair during the day?



This question will not apply to babies with PWS, but will apply to toddlers. Think about how your child moves around—do they bum shuffle or crawl? Are they able to manoeuvre around furniture such as coffee tables? How stable are they when walking up and down the stairs?

Question 42—Do they need encouragement, prompting or physical help to eat and drink during the day?

The answer to this will invariably be yes, regardless of whether you have a baby that is tube fed or a toddler who is fully weaned. Mention here the need for low calorie healthy eating plans and smaller portion sizes, and the risk of choking when eating—this is even when the food is cut into small pieces. How well can he or she: coordinate sucking/chewing, swallowing and breathing; coordinate hand to mouth movements; hold a bottle, spoon etc. Is there a need for specialised feeding methods or special bottles?

Question 43—Do they need encouragement, prompting or physical help to take medicine or have therapy during the day?

This question covers speech and language therapy, physiotherapy and any other therapies used to help muscle tone such as swimming and play. Does your child need: extra or special exercises; stimulation and repetition; help to cooperate; physical equipment such as splints or supports? Most toddlers with PWS will need prompting and encouragement to take part—use the additional information box to describe your son or daughters behaviour if they are tired and unwilling to co-operate.

Question 46 - Do they have difficulty speaking?

How well can your son or daughter: form basic word sounds or cry? It is worth mentioning here about the sticky viscous saliva that can occur in those with PWS, and that this affects an individuals ability to speak clearly.



Question 47—Do they have difficulty and need help communicating?

Mention here anything you use to help with communication, including picture boards, Makaton and PECS. Use the information box to explain why you use it and be specific.

Question 49—Do they need to be supervised during the day to keep safe?

The answer to this will always be yes, due to needing supervision around food. Your son or daughter may not be at the stage where the overwhelming appetite has presented itself, but you will still need strategies in place for when it does come. This would include making sure no food is left out, supervision when others are eating, supervision around bins etc. Use the information box to explain the feelings of anxiety associated with food and how your child behaves if there is a change to their routine.

Question 50 - Do they need extra help with their development?

Again, the answer to this would be yes, and we would advise that you tick every box. You can give specific information about your child in the information box, and can include the following:

How well can your baby or toddler:

- grasp, hold and manipulate;
- throw; pull, push; jump;
- take part in interactive games;
- hold his or her attention span; complete tasks; repeat tasks?

Question 53 - Do they wake and need help at night, or need someone to be awake to watch over them at night?

Consider all of the following points, and be specific in your answers:

Does your baby or toddler :

- get into the right position? If not, why not?
- Keep covered and warm (or are they able to indicate when they are too hot?)
- Need waking for feeds and stimulation?
- Are they able to move the blanket away from their face?
- Do you use any extra support whilst they are sleeping, such as rolled up towels or wedges?
- Do any of the problems relating to daytime care also cause problems at night? If so, in what ways?
- Is breathing (sleep apnoea) a problem at night? Do you have to use special monitoring equipment?
- Do you have to set the alarm to wake during the night to feed your baby?

Continued ...

Local welfare rights help

Your local welfare rights officer or Citizens Advice will be able to give you general advice about other benefits you may be entitled to if you are on a low income, 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.

PWSA UK

We will be pleased to offer advice, but as we are unlikely to know your child personally, we regret we cannot comment on individual cases.



Question 54: Extra information about care - some points to consider:

It can sometimes be difficult to describe how having a baby with PWS is more of a challenge than having a baby without it. There is a need to focus on the degree of support you give which is in excess of that which is normally offered to a baby. Below are some points to consider when filling in Question 54.

- How well can your baby or toddler: maintain interest; maintain self control; understand simple commands?
- How much watching over or supervision does he or she need with regard to social activities and diet?
- Does your baby take a long time to feed? This requires extra attention, as well as extra skills required in ensuring he takes his feed safely, due to possible problems in coordinating sucking and breathing.
- Many babies will cry if they are wet, cold or uncomfortable. In the case of a baby with PWS, this is unlikely to occur, so you will spend extra time checking and monitoring their general well-being.
- Babies and young children are generally capable of moving themselves to get into a comfortable sleeping position, but a baby with PWS is unlikely to be able to do this, due to poor muscle tone.
- You will probably have many extra hospital appointments and visits from professionals, which are an extra call on your time. These will include regular check-ups, physiotherapy, speech therapy, Portage etc.
- Remember: the person reading your application is unlikely to have any previous knowledge of PWS, and how it affects your child. It is important to be as specific as possible and to describe a bad day when filling in your form.

Going to appeal

You can appeal against any decision, but you will need reasons. If there were items you forgot to mention on the first form, you can still appeal. Enlist the help of as many influential people as possible (eg teacher, health visitor, doctor, social worker, MP or the PWSA UK). But make sure they give a realistic view of your child, not a positive one.

Carer's Allowance

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.

Other sources of funding and help

The Family Fund



The Family Fund is the UK's largest independent provider of grants to low-income families raising a disabled child or young person with additional complex needs or children and young people with a serious illness.

You can apply to the Family Fund if:

- You live in England, Northern Ireland, Scotland or Wales.
- You are the parent or carer of a disabled or seriously ill child or young person aged 17 or under.
- You have evidence of your entitlement to one of the following: Universal Credit, Child Tax Credit, Working Tax Credit, Income based Job Seekers Allowance, Income Support, Incapacity Benefit, Employment Support Allowance, Housing Benefit and Pension Credit. If you do not receive any of the above, further information may be needed to complete your application.
- You have permanent legal residency in the UK and have lived in the UK for six months.

Help from the Family Fund is discretionary and subject to available funding. The Fund also retains discretion to decline an application where a family has a significant level of capital or household income.

They are unable to help children and young people in local authority care, including those living with foster carers. Where a statutory agency has a responsibility to pay for the item needed, the Fund cannot help.

Due to limited funding, they are unable to help all disabled children and use their own disability criteria when establishing eligibility.

However, many families with a child with PWS have received help from The Family Fund in the past. For more information, visit their website at www.familyfund.org.uk



Newlife provides grants for essential equipment such as: pain relieving beds, wheelchairs, communication aids, and much more.

For more information, see www.newlifecharity.co.uk or call Newlife Nurses on 0800 902 0095

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Useful Websites and Publications

Cerebra

Cerebra is a charity set up to improve the lives of children with brain related conditions. It has some very useful information about Disability Living Allowance.

<http://w3.cerebra.org.uk/help-and-information/guides-for-parents/dla-guide/>



Contact a Family

Contact a Family is a great resource for parents of children with disabilities. Its website has a section called Advice and Support with a wide range of information, including benefits.

<https://contact.org.uk/advice-and-support/benefits-financial-help/>

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

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