

Benefits series

A to Z Benefits and Finance

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Please see our website for up-to-date information: www.downs-syndrome.org.uk

If you have concerns, please ring the DSA's Benefits Adviser: Helen Wild

Mon & Thurs 10am-4pm & Weds 10am-12.30pm | Telephone: 0333 1212 300

Appointees

From age 16, the Department for Work and Pensions (DWP) will deal directly with your son or daughter. However, if the young person is unable to manage their own benefit, you can apply to become their appointee. This means the DWP will correspond directly with you as their appointee.

Becoming an appointee is usually a formality which happens around the time that PIP is claimed. You can also apply in writing to the DWP.

For information about becoming an appointee, visit GOV.UK <https://www.gov.uk/become-appointee-for-someone-claiming-benefits>

Benefits and Work – see the DSA resource Benefits and Work Benefits Cap

The benefit cap places a limit on the total amount working age people can receive in benefit.

Some people are exempt from this cap if they, their partner or child (who they receive child benefit for) are receiving working tax credit, attendance allowance, disability living allowance, personal independence payment, carer's allowance, in receipt of the support component within employment and support allowance or receiving a carer amount within universal credit.

For people living in Northern Ireland refer to NI Direct: <https://www.nidirect.gov.uk/articles/the-benefit-cap>

Benefits for babies – see the DSA resource Benefits for babies

Benefits in supported living, residential college or care home –see the DSA resource Benefits in supported living, residential college or care home

Blue Badge – see the DSA resource Blue Badge Scheme

Budgeting Advance on Universal Credit

If you don't have enough to live on while you wait for your first payment you may be able to get an advance of your first UC payment <https://www.gov.uk/guidance/universal-credit-advances>

Budgeting Loans

You may be able to get a budgeting loan if you have been on certain benefits for 6 months.

<https://www.gov.uk/budgeting-help-benefits>

Carer's Allowance – see the DSA resource Carer's Allowance

Challenging decisions – reconsiderations, supersessions and appeals

If you disagree with a decision made by the DWP, there are steps you can take. What to do next depends on which benefit you are claiming. Contact us for advice if:

- you have just claimed a benefit and do not agree with the decision
- you have been receiving a benefit for some time, but now think it is wrong
- the DWP decide they want to reconsider your benefit.

Mandatory reconsiderations – A mandatory reconsideration is one which has to be asked for within one month of the decision maker's letter being sent to you. The case is looked at again by a different decision maker. The decision can be revised. If the decision is maintained then you can go on and ask for an appeal if you think their decision is wrong.

Appeals for benefits administered by DWP and HMRC have to be made to HM courts and Tribunal Service. You appeal on form SSCS1. You can download a form

<https://www.gov.uk/government/publications/appeal-a-social-security-benefits-decision-form-sscs1>.

You also need to send a copy of the mandatory reconsideration letter and a statement of reasons for the decision maker's decision. If the reconsideration letter did not include reasons, you can ask for a written statement of reasons within one month of that decision letter. The one month time limit will be extended by an additional 14 days should you wish to appeal after receiving the written reasons.

If your appeal is for housing benefit, your local authority will have a form and you will need to contact them for one.

Child Benefit

You may get Child Benefit if you are responsible for a child under 16 (or under 20 if the child is in approved education or training). Getting Child Benefit depends on your household income.

Go to the HMRC website <https://www.gov.uk/child-benefit> for information on Child Benefit.

Child Tax Credit

Child Tax Credit has been replaced by Universal Credit for most people.

For those not in a Universal Credit area, Child Tax Credit is payable if you are responsible for a child under 16 (or under 20 if the child is in approved education or training). Child Tax Credit is means-tested.

If you are still on child tax credit and your child starts to get Disability Living Allowance (DLA), you may be entitled to more Child Tax Credit. Tell HMRC that your child is now on DLA.

You can only make a new claim for Child Tax Credit if you get the severe disability premium or got it in the past month and are still eligible for it.

Go to Gov.UK <https://www.gov.uk/child-tax-credit> for information.

Child Trust Fund

A Child Trust Fund is a long-term, tax-free savings account. You can no longer open a Child Trust Fund, but you can continue to pay money into an existing Fund. Go to Gov.UK <https://www.gov.uk/child-trust-funds> for information.

Cold Weather Payments – This runs from November to March the following year. For more information visit <https://www.gov.uk/cold-weather-payment>

Contributory and Means-tested benefits

Whether or not you qualify for a contributory benefit will depend on your National Insurance contribution record. You need to pay enough contributions to qualify for the payment. Examples are Retirement pension, New-style Employment and Support Allowance and New style Jobseeker's Allowance. The latter of the 2 are time limited to 26 weeks after which time you may then qualify for Universal credit if your income is low.

Benefits which are not contributory are means-tested. This means you will only receive the benefit if your income and savings are low enough. Examples are Universal credit,

Income support and Housing benefit. Benefits have different means-tests.

Some people may qualify for contributory benefit and a means-tested benefit at the same time. This is because there are extra payments available within the means tested benefits which are not present in contributory benefit. If you satisfy the National Insurance conditions for ESA, you will get new style ESA and be topped up with Universal credit depending on your income and circumstance.

Disability Living Allowance and Personal Independence Payment are not contributory and not means-tested. You get them if you met the criteria about your sickness or disability.

Council Tax – [see the DSA resource on Council tax](#)

Disabled Facilities Grant and Other Grants

You may be eligible for a Disabled Facilities Grant to help with the costs of adapting your home to make it suitable for someone with a disability. Grants are given by your local authority.

For information, go to <https://www.gov.uk/disabled-facilities-grants>

Disability Living Allowance (DLA) – [see the DSA resources DLA for children 0 -3 and 3 - 16 years](#)

Discretionary trusts - [see the DSA resource Wills and Trusts](#)

Parents and carers of young people with Down's syndrome often worry about what to do in a situation where their family member with Down's syndrome has savings. This could happen through an inheritance or gift, or through arrears of benefits.

Setting up a discretionary trust will help a person who has Down's syndrome to manage their savings. The money is put in a trust and managed by trustees. The person with Down's syndrome does not have legal control over the money. It is given out at the discretion of the trustees. For it to be disregarded by the DWP, there needs to be more than one beneficiary of the trust so the

fund cannot be seen as solely theirs.

This safeguards the person who has Down's syndrome. It also means that these savings are disregarded when the young person applies for means-tested benefits, such as Universal credit. It is probably a good idea to set up a discretionary trust in good time, before your child turns 16. Seek a solicitor dealing in trust law and ask about setting up a trust which can be there to receive money from whoever has bequeathed it to go directly rather than to the person (This would need to be specified in their will).

Education Maintenance Allowance (Wales, Scotland and Northern Ireland)

Education Maintenance Allowance (EMA) is available in Wales, Scotland and Northern Ireland. In England, EMA has been replaced by the 16 – 19 bursary.

<https://www.gov.uk/1619-bursary-fund>

For details about EMA, if you live in Wales, Scotland or Northern Ireland, go to Education Maintenance Allowance at <https://www.gov.uk/education-maintenance-allowance-ema>

Employment and Support Allowance (ESA) – Now replaced by Universal credit for new claimants - [see the DSA resource on ESA](#)

Extra help from other benefits when you get Disability Living Allowance or Personal Independence Payment:

- Child Tax Credit – Now replaced by Universal credit for new claimants
If you are still receiving child tax credits and you made a claim for DLA, it is always worth checking your notification to see whether the disabled child element has been added to the calculation.

There are 2 rates within child tax credits

- the disabled child rate if you receive PIP or DLA, (standard, middle or lower rate care) for your child; and
- the severely disabled child rate which is payable if your child receives the enhanced rate PIP care or HR DLA care.

Even if you have reached the 2 child limit and you do not receive any child tax credit for this child, you can receive this extra element if you have another child who receives DLA or PIP.

- Universal Credit

If you are in receipt of Universal Credit, you can check whether you receive the disabled child amounts, as with child tax credits, there is a lower amount for those children on standard middle or lower rate care DLA/ PIP and a higher amount for those receiving the enhanced rate PIP care or higher rate DLA care.

There is a two child limit, but you will receive the disabled child addition if you have a third child who qualifies for this because they receive a disability benefit such as DLA or PIP.

Funeral payments - [visit https://www.gov.uk/funeral-payments](https://www.gov.uk/funeral-payments)

Healthy Start

If you are pregnant or have children under 4 and you are on means-tested benefits, you may be able to get food vouchers and free vitamins. You also qualify if you are under 18 and you are pregnant. All applications must be supported by a midwife or health visitor. For details, call Healthy Start on 0300 330 2090 or visit www.healthystart.nhs.uk

Housing Benefit

Housing Benefit (HB) helps people on a low income to pay their rent. You can get Housing Benefit whether you are working, or claiming other benefits, such as Income Support or Employment and Support Allowance. Universal Credit (UC) has housing costs included so you may have to claim this unless you are in accommodation that is classed as *specified accommodation*, in which case you should still be able to make a claim for housing benefit, even though you may have to claim UC for your personal amounts. Specified accommodation includes supported accommodation and accommodation provided by the local authority which provides care support or supervision.

For information, go to GOV.UK's section on Housing Benefit <https://www.gov.uk/housing-benefit>

Housing – Support for mortgage interest in Universal credit (SMI)

Mortgage interest loan qualifying conditions have changed from 3 April 2023 for the better. This payment, although regrettably a loan, could help some people at risk of losing their home. Prior to April 3rd, help could only be accessed for those out of work. The scheme has been changed and can now be claimed by people who are in work. In addition, the waiting period is now 3 months rather than 9 months.

If you come off UC, go back into work but then return to UC within 6 months, the 3 months qualifying period is waived.

The standard rate charged by the government is currently 2.09% but could change. Obviously as a benefit advisor I cannot advise on the best financial decision for you, but it may be useful for some families. <https://www.gov.uk/support-for-mortgage-interest>

Immigration status and benefits

Your immigration status affects which benefits you can claim. If you are not a British citizen, EEA national, or don't have indefinite leave to remain, get advice before claiming any benefits. You may risk your right to stay in the UK.

Income Support

Income Support can help you cover your costs if you're on a low income. It is the safety net of the benefits system. Only certain groups of people can now claim Income Support. It has been replaced by Universal credit. It is means-tested and the amount you get will depend on your circumstances. You can do a limited amount of work while on Income Support, but your earnings are taken into account. Visit GOV.UK <https://www.gov.uk/income-support>

Jobseekers Allowance

Income based JSA is no longer available to new claimants. It has been replaced by Universal Credit. New style JSA can still be claimed as this is a contributory benefit and payable for 6 months if you have lost your job and have paid sufficient national insurance contributions.

Local Welfare Assistance schemes

Help from your local authority when you are short of money and need help with essentials like food or paying your bills. Please look at the range of support options at turn2us

<https://www.turn2us.org.uk/Benefit-guides/Emergency-Information/don-t-have-enough-to-eat>

Mortgage Interest Support – help with paying the mortgage -(SMI) Loans

If you are paying a mortgage, you may get help with your mortgage interest costs through Income Support, income-related Employment and Support Allowance, income-based Jobseekers Allowance, Pension Credit or Universal credit. These loans have to be repaid once your property is sold. The scheme is voluntary. For information, go to Mortgage Interest Support on GOV.UK

<https://www.gov.uk/support-for-mortgage-interest>

Motability

If you get the higher rate of the mobility component of Disability Living Allowance, or the enhanced rate of the mobility component of Personal Independence Payment, you may be able to get a vehicle through the Motability scheme.

For information, go to Motability <https://www.motability.co.uk/>

National insurance credits

You may be able to get National Insurance credits if you're not paying National Insurance, for example when you're claiming benefits because you're ill or unemployed. For information go to Gov.UK <https://www.gov.uk/national-insurance-credits>

NHS health benefits – **see the DSA resource Health Benefits for NHS payments**

PDSA – free care for your pets if you are on a low income

The animal charity PDSA gives free vet care to pets whose owners are on a low income. (You will be asked to make a donation.)

To qualify, you have to:

- Live in the catchment area of a PDSA PetAid hospital or PetAid practice, and
- Get Housing Benefit/ UC housing costs or Council Tax support, and provide proof.

For information, visit <https://www.pdsa.org.uk/taking-care-of-your-pet/eligibility>

Permitted work – **see the DSA resource Benefits and Work**

Personal Independence Payment (PIP) - **see the DSA resource PIP Guide**

Personal Independence Payment (PIP) has replaced Disability Living Allowance (DLA) for people aged 16 to 64.

Children under 16 continue to claim DLA. PIP is not means-tested.

If you are already on DLA and you are over 16, you will be asked by DWP to claim PIP instead.

Presence and residence rules

Benefits have rules about being in the UK, and how long you have been here. If you frequently

leave the UK for long periods, or have not been here long, check the presence and residence rules for the benefits you are applying for at <https://www.turn2us.org.uk/Benefit-guides/Presence-and-Residence-Tests/What-are-the-Presence-and-Past-Presence-Tests>

16-19 Bursary Fund

If someone who has Down's syndrome is aged 16-19, in full time education and getting both Employment and Support Allowance or Universal credit and Disability Living Allowance or Personal Independence Payment they can receive a bursary of up to £1200 per year through the vulnerable student bursary. There is no means-test for the young person.

The 16-19 Bursary will be administered by the school or college from a centrally held fund. Schools and colleges are responsible for identifying students who qualify. Schools and colleges will decide if a course is "full time education".

Young people without disabilities but in financial need can apply for another type of bursary, a discretionary bursary. Schools and colleges will be responsible for giving these bursaries. Some form of means-test is likely. For more information, go to 16-19 Bursary Fund on GOV.UK <https://www.gov.uk/1619-bursary-fund> or contact your child's school or college

Transport to school – see the DSA resource on school and college transport

Universal Credit – see the DSA resource on Universal Credit

Vehicle tax exemption - visit <https://www.gov.uk/vehicle-exempt-from-vehicle-tax>

WaterSure

The WaterSure scheme is available for some people with a water meter. It allows you to have your bills capped. This is to make sure that you don't cut back on how much water you use because they are worried about how you will pay your bill.

You have to be getting a qualifying benefit, and in addition, you have to be responsible for three or more children under 19 in full time education who live with you; OR you or someone living with you must have a medical condition that significantly increases the amount of water used.

If you qualify for WaterSure, you will pay no more than the average household bill for your company, even if you use more than the average amount of water.

For details, go to <https://www.unitedutilities.com/watersure>

Wills and Trusts – see the DSA resource on Wills and Trusts**Winter Fuel Payment**

If you are over the pension credit qualifying age (currently 60) on the third Monday in September, you can get a winter fuel payment for the following winter. If you get retirement pension or most other social security benefits, you will get a payment automatically, so most people don't need to claim. For details, go to Winter Fuel Payment on GOV.UK. <https://www.gov.uk/winter-fuel-payment>

Working Tax Credit

Universal Credit (UC) has now replaced tax credits.

Working Tax Credit (WTC) is to help people with children, or people with a disability, or people

age 25 plus working full-time, on low income. Those on working tax credit will not be affected by the benefits cap.

People with Down's syndrome may have claimed Working Tax Credit if they work were not eligible for Employment and Support Allowance.

For details, go to Working Tax Credit on GOV.UK. <https://www.gov.uk/working-tax-credit>.

Contact us

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