



Claiming Benefits for Individuals with Ectodermal Dysplasia

If you or your child has been diagnosed with Ectodermal Dysplasia you are entitled to apply for Disability Living Allowance or Personal Independent Payment. The earliest you can apply is when your child is 3 months old, but it is worth thinking about applying when you feel that your child needs a lot more help than other children of their age.

The Ectodermal Dysplasia Society has found that many Disability Living Allowance (DLA) and Personal Independent Payment (PIP) applications are turned down due to lack of information and the use of weak wording. In an attempt to ensure you are successful the ED Society will be happy to help you complete the forms – all you need to do is photocopy the form, complete the photocopy as best you can and send to the ED Society office where we will amend the form and send back to you enabling you to complete the original form.

Should you be turned down the ED Society will be happy to help you appeal and if this is not granted, we will be happy to accompany you to a tribunal.

So what is DLA and PIP?

Disability Living Allowance (DLA) is for children under 16 who need extra looking after or have walking difficulties. Personal Independent Payment (PIP) helps with some of the extra costs caused by long-term ill-health or a disability if you're aged 16-64. If you are over 65 then Attendance Allowance is the equivalent benefit.

DLA is a tax-free benefit made of 2 components (parts) 'the care component' and 'the mobility component'. You may be entitled to receive one component or both.

PIP is tax free and you can get it whether you're in or out of work. PIP also has 2 components 'the daily living component' and 'the mobility component'. You may be entitled to receive one component or both.

To be eligible for DLA you must need help for 3 months prior to making a claim, and are likely to need it for at least another 6 months. It is not necessary to wait for the three month qualifying period to be completed before making the claim. Children can only get DLA for help with personal care if they are 3 months old or over and need more help or supervision than other children of the same age. The



rate of DLA received depends on the amount of attention needed and the sort of help or supervision needed. For example, someone to keep an eye on them, help with things such as washing, dressing, communicating with other people, reminding or prompting or encouraging to do things (but this may depend on how much help they need) or other similar activities. There are 3 rates:

DLA Care Component

The rate the child gets depends on the level of looking after they need eg:

High Rate - help or supervision throughout both day and night, or they're terminally ill

Middle Rate - frequent help or constant supervision during the day or supervision at night

Low Rate - help for some of the day or night

DLA Mobility Component

Children can only get DLA for help with getting around if they are aged 3 or over. Remember all children need some help and supervision when they are out of doors, therefore the child must need more help or supervision than others of the same age. There are 2 rates.

High Rate - they can't walk, can only walk a short distance without severe discomfort, could become very ill if they try to walk, they're blind or severely sight impaired

Low Rate - they can walk but need help and or supervision when outdoors

Children under 16 must require substantially more guidance than other children of the same age in normal health. The term "virtually unable to walk" is assessed by

considering the distance, speed, length of time a person can walk, the manner of walking and the degree of discomfort caused. For example, the child is aged 5 or over and can walk, but needs someone with them to make sure they are safe or to help them find their way around in places they do not know well.

It may be possible to claim mobility allowance if the child is restricted by tightness of skin, if the soles of their feet are badly affected, if they are too hot or cold to the extent that their muscles are painful and will not function normally, if they are lethargic from the heat or cold, or are unable to walk without discomfort or in danger of overheating.

As at April 2023 the weekly rates of payment are:

DLA Mobility Component per week		DLA Care Component per week	
High Rate	£71.00	High Rate	£101.75
Low Rate	£26.90	Middle Rate	£68.10
		Low Rate	£26.90

Personal Independent Payment

Personal Independence Payment (PIP) is usually paid every 4 weeks. It's tax free and you can get it whether you're in or out of work.

It's made up of 2 components (parts). Whether you get one or both of these depends on how your condition affects you.

You'll need an assessment to work out the level of help you'll get. Your rate will be regularly reassessed to make sure you're getting the right support.

PIP Mobility Component per week

Enhanced	£71.00
Standard	£26.90

PIP Help !

PIP Daily Living Component per week

Enhanced	£101.75
Standard	£68.10

DLA and PIP can act as a gateway to additional types of financial help. For example, if you are in receipt of income support or housing benefit and you successfully claim DLA or PIP, you should qualify for the relevant disability premiums used in calculating entitlements to these benefits (e.g. disability premium, disabled child premium). This should lead to higher payments.

Carer's Allowance

You can claim Carer's Allowance if you are aged 16 or over and spend at least 35 hours a week caring for a person who receives Attendance Allowance (at either rate), Disability Living Allowance (at the middle or higher rate for the care component), Personal



Independent Payment daily living component, Attendance Allowance, Constant Attendance Allowance at or above the normal maximum rate with an Industrial Injuries Disablement Benefit, Constant Attendance Allowance at or above the basic (full-day) rate with a War Disablement Pension or Armed Forces Independence Payment.

You cannot claim Carer's Allowance if you are on a course of full-time education, and studying for 21 hours a week or more, (this includes supervised study and things like coursework and experiments, not just time spent with a tutor) or earn more than £123 a week (after tax, National Insurance and allowable expenses, which include care costs while you're at work and 50% of any payments into a pension). Please visit <https://www.gov.uk/carers-allowance> for further information.

The weekly rate is £76.75 (as at April 2023). This is reduced by the amount of certain other benefits, including State Pension, which you receive. If you receive certain other benefits you may not get Carer's Allowance.

If you think a decision about your claim is wrong



If you think a decision about your benefit claim is wrong, you can ask the officer who made the decision to explain it and ask to have the decision reconsidered. If you are still unhappy, you can appeal against the

decision in most cases. For more information and help with completing the DLA forms please look at our DLA Guidance notes in the member's section of our website or contact the ED Society Office who will be happy to help you complete them.

Disabled Tax Disc

If you receive either the higher rate of the mobility component of DLA, the enhanced mobility rate of PIP, War Pensioners' Mobility Supplement or Armed Forces Independence Payment you are entitled to tax your vehicle in the disabled tax class. For more details please visit:

<https://www.gov.uk/financial-help-disabled/vehicles-and-transport>

Driving at age 16

The usual minimum age for driving cars is 17, but if you receive the enhanced rate of the mobility component of PIP, you can drive at 16. For more information visit:

<https://www.gov.uk/apply-first-provisional-driving-licence>

Motability Scheme

The Motability Scheme helps disabled people get mobile by exchanging their mobility allowance to lease a car, scooter or powered wheelchair. To be eligible to join the Scheme, you need to receive one of the following mobility allowances and you must have at least 12 months' award length remaining. Please note that the Attendance Allowance cannot be used to lease a car through the Scheme.



- **Higher Rate Mobility Component of Disability Living Allowance (HRMC DLA)**

As of April 2023, this allowance is £64.50 per week.

- **Enhanced Rate Mobility Component of Personal Independence Payment (ERMC PIP)**

As of April 2023, this allowance is £64.50 per week.

- **War Pensioners' Mobility Supplement (WPMS)**

As of April 2023, this allowance is £72.00 per week.

- **Armed Forces Independence Payment (AFIP)**

As of April 2023, the mobility element of the allowance is £64.50 per week.

For more information please visit <http://www.motability.co.uk>

Blue Badge Scheme

A Blue Badge is awarded to an individual and not a vehicle, therefore anyone aged two or older automatically qualifies for a Blue Badge if they are registered blind; are receiving a War Pensioner's Mobility supplement; receive the higher rate of the mobility component of Disability Living Allowance; have been awarded 8 points or more in the 'moving around' activity of Personal Independence Payment (12 points in Scotland).



The Blue Badge scheme is for people with mobility problems. It allows Blue Badge holders to park close to where they need to go. The scheme operates throughout the UK and is managed by local

authorities, who deal with applications and issue Blue Badges. The application of the scheme differs in England, Wales, Scotland and Northern Ireland. Please see the relevant website below for more information.

In England, Blue Badge holders may generally park on single or double yellow lines for up to three hours, except where there is a ban on loading or unloading; at 'on-street' parking meters and pay-and-display machines for free and for as long as they need to.

For more information, please visit:

<https://www.mygov.scot/apply-blue-badge/?via=http://www.bluebadgescotland.org/>

<http://gov.wales/topics/transport/road-users/bluebadgeschemeinfo/?lang=en>

<https://www.gov.uk/apply-blue-badge>

<https://www.nidirect.gov.uk/information-and-services/motoring-and-transport/blue-badge-scheme>

Disabled Student Allowance

As a higher education student living in England, you can apply for a Disabled Students' Allowance (DSA) if you have a disability, including a:

- long-term health condition
- mental health condition
- specific learning difficulty, e.g. dyslexia

You must also:

- be an undergraduate or postgraduate student (including Open University or distance learning)
- have a condition that affects your ability to study
- qualify for student finance from Student Finance England
- be studying on a course that lasts at least a year

What DSAs can pay for

You can get help with the costs of:

- specialist equipment, e.g. a computer if you need one because of your disability
- non-medical helpers

- extra travel because of your disability
- other disability-related costs of studying

You may get a new computer if you don't already have one, or your current one doesn't meet the required specification. More information will be provided to you if you're assessed as needing a new computer.

You'll need to pay the first £200, which is the minimum cost that any student is likely to incur when buying a computer.

DSAs don't cover disability-related costs you'd have if you weren't attending a course, or costs that any student might have.

What you'll get

Disabled Students' Allowances (DSAs) are paid on top of your other student finance. They help you pay the extra costs you may have because of your disability. They don't have to be repaid.

How much you get depends on your individual needs - not your household income. If you're a part-time student your 'course intensity' can affect how much you get.

For more information, please visit:

<https://www.gov.uk/disabled-students-allowances-dsas/overview>

To enable the ED Society to help you with any applications for allowances please ensure you complete our Symptoms Questionnaire and return to the office. This will be found in your Welcome Pack or you can download a copy from the website www.edsociety.co.uk

The Ectodermal Dysplasia Society,
Unit 1 Maida Vale Business Centre,
Cheltenham, Glos. GL53 7ER England

Tel: +44 (0) 1242 261332 Mobile: +44 (0) 7774 465712

www.edsociety.co.uk
Email: info@edsociety.co.uk

Supporting a normal lifestyle

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