

## Appendix 14 - Social security benefits

**IMPORTANT: Please check whether you are eligible for benefits before submitting a claim. Your residency and eligibility status can affect whether or not you are entitled to support. Contact [a benefits advisor](#) if you are uncertain.**

We would recommend contacting a [benefits advisor](#) to find out what else you and your family might be entitled to.

### **1. Disability Living Allowance (DLA) - for children up to the age of 16**

DLA provides help with the extra costs of bringing up a child with disability, if they have difficulties walking, or need much more looking after than other children of the same age, due to their disability or condition. DLA is not means-tested, so your income or savings will not be taken into account, and you don't have to pay any tax on it. DLA can entitle you to other types of support too.

The best way to make a new claim for DLA is to call 0800 121 4600 (Monday to Friday, 8am to 7:30pm) to order an application form. [\[call charges\]](#) If you return the completed application form within 6 weeks, and are awarded DLA, those DLA payments can be paid back to when you ordered the application form on the phone.

You can also [download an application form](#) to fill out, but the start date of the claim will be the date the form is received.

You can read the most up to date information about DLA on [the government website](#), and read more hints and tips on [the Cystic Fibrosis Trust website](#).

*Terminal Illness* - There are special rules for claiming DLA if a child is not expected to live more than 6 months, so that they can get DLA more quickly, and don't have to fill out every page of the application form. You will need to ask your doctor, or another healthcare professional to fill out form DS1500.

There are two parts to DLA:

- **Care component** - for children needing a lot of extra personal care, supervision or watching over because of their condition. This is paid at 3 different rates: a lower rate, a middle rate, or a higher rate, depending upon how much help and supervision is required because of the child's disability. It can be paid from the age of 3 months, or from birth for a terminally ill baby.
- **Mobility component** - for children aged 3 or over who cannot walk, or have walking difficulties, for children aged 5 or over who need extra guidance or supervision walking outdoors. The higher rate can be paid from the age of 3 years, the lower rate can be paid from the age of 5 years.

### **TOP TIPS**

1. You can claim and receive payment from DLA while your child is in hospital.

2. It might be useful to keep a diary for a few days to note what type of care your child requires (both day and night) and how much time this takes. This is because the DLA application needs to show what extra care and help your child needs because of their disability or sickness.
3. The application form is long. It is a good idea to get help to fill out the application. The Cystic Fibrosis Trust have a helpline (0300 373 1000) that you can contact them for assistance on, and they also have a dedicated email help service too (helpline@cysticfibrosis.org.uk).
4. A local advisor might be able to help you to fill out the application form too. You can search for local Benefits advisors [here](#).

Keep a photocopy of the application form before you send it. Send supporting evidence, but don't send your original documents, as DLA won't be able to send these back to you.

When a child who receives DLA turns 16, they will be sent a letter inviting them to claim Personal Independence Payment (PIP). If the child was in hospital when they turned 16, they won't be invited to claim PIP until after they leave hospital. If the child was awarded DLA under the special rules for terminal illness, they will be invited to claim PIP about 20 weeks before their DLA claim ends. Your child's DLA payments will stop unless they apply for PIP by the date in their invitation letter, they will continue to receive DLA until their PIP claim is assessed.

## **2. Personal Independence Payment (PIP) - for children aged 16 and above**

PIP can provide help with the extra costs of living with a long-term health condition or disability, for people who have difficulties getting around, or with daily living. PIP is not means-tested, so your income or savings will not be taken into account, and you don't have to pay any tax on it. PIP can entitle you to other types of support too.

You can claim PIP by calling the new claims line (0800 917 2222, Monday to Friday, 8am to 6pm) [\[call charges\]](#). You can also claim by writing to PIP, but it will delay your claim. At this stage you will just need to provide basic information like your contact details, National Insurance number, time spent in hospitals or residential care, and bank account details for PIP to be paid into if awarded. After you contact PIP you will be sent a personalised form to fill out. You might be invited to an assessment with an independent health professional, this could be at an assessment centre, or in your own home.

You can read the most up to day information about PIP on [the government website](#), and read more hints and tips on [the Cystic Fibrosis Trust website](#).

*Terminal Illness* - There are special rules for claiming PIP if you are not expected to live more than 6 months, so that you can get PIP more quickly. You will need to ask your doctor, or another healthcare professional to fill out form DS1500.

There are two parts to PIP

- **Daily living part** – if you need help more than half of the time with daily tasks. These include things like preparing food, taking nutrition, using the toilet, washing and bathing,

dressing and undressing, reading, communicating and managing medicines or treatments. This is paid at two different rates: the standard rate and the enhanced rate.

- **Mobility part** – if you need help to move around, and/or plan and follow journeys. This is paid at two different rates: the standard rate and the enhanced rate.

## TOP TIPS

1. You can claim and receive payment from PIP while your child is in hospital, if their admission began before they turned 18. If your child is above the age of 18, their PIP will end after they've been in hospital for 28 days.
2. PIP has a point scoring system on each question and looks at your ability to carry out different activities. You can contact The Cystic Fibrosis Trust for a copy of the 'descriptors' of abilities to carry out activities. You might find this a helpful indicator of how many points you might get. The Cystic Fibrosis Trust can help you to identify which descriptors might apply to you and might be able to write you a supporting letter based on these.
3. The application form is long. It is a good idea to get help to fill out the application. The Cystic Fibrosis Trust have a helpline (0300 373 1000) that you can contact them for assistance on, and they also have a dedicated email help service too ([helpline@cysticfibrosis.org.uk](mailto:helpline@cysticfibrosis.org.uk)).
4. A local advisor might be able to help you to fill out the application form. You can search for local Benefits advisors [here](#).
5. Keep a photocopy of the application form before you send it.
6. Send supporting evidence. It's a good idea to get a supporting letter. You might be able to get a supporting letter from a health care professional, or from the Cystic Fibrosis Trust. Don't delay sending in your application form if you haven't got a supporting letter yet, you can send in medical evidence later.

### **3. Carer's Allowance**

If a child receives either middle or higher rate of DLA care component, or either rate of the daily living component of PIP, someone who cares for them for at least 35 hours a week may be able to claim Carers Allowance. Carers Allowance is taxable, but this will generally won't affect you unless you have other sources of taxable income, such as occupational or personal pensions or part time earnings which bring your combined income above the [personal allowance](#).

You can read more about the eligibility criteria for claiming Carers Allowance on the [government website](#).

N.B Applying for benefits and appeals against decisions can be complex and we recommend that families access appropriate specialist advice, from a [local benefits advisor](#) or the Cystic Fibrosis Trust.

The higher rate of the DLA mobility, or enhanced rate of the PIP mobility, can be exchanged for lease of a vehicle through [the Motability scheme](#). If your child has mobility difficulties, they may also qualify for a [Blue Badge](#).

### **3. The Family Fund**

The Family Fund is the UK's largest charity providing grants for families raising disabled or seriously ill children and young people. Families can apply for clothing, breaks and days out, computers and tablets, furniture and white goods, sensory toys and equipment, games, books, specialist trikes or bikes and garden improvements, amongst other items and services.

The Family Fund may be able to offer a grant once every 12 months. You can find out more about eligibility criteria for a Family Fund grant, and how to apply, on [their website](#).