## Disability Living Allowance (DLA) for children with bleeding disorders



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This factsheet gives an overview of DLA for children and guidance on how to complete the claim form and how to appeal a decision. You can claim DLA to help with the extra costs because of your child's health condition or disability. However, while some families successfully claim DLA, not all children with bleeding disorders will be eligible for support.

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## **Section 1: Overview of DLA for Children**

If you have a child with a health condition or disability, you may be able to claim Disability Living Allowance (DLA) to help with the extra costs you face. DLA is available if your child requires more care, attention or supervision than a child of the same age who does not have a disability or health condition. However, claiming DLA is now more challenging for children with bleeding disorders as modern treatments allow children to grow up with the opportunity of a good quality of life and every prospect of fulfilling their potential.

Additionally, if your child has difficulty walking or getting around outdoors in unfamiliar places, you may also be eligible for DLA. This benefit is designed to provide financial support to those who need it most, so if you believe your child meets the criteria, it is worth exploring your options. In this section, we give an overview of DLA. It will help you if you are making:

- a first claim for DLA because your child has recently been diagnosed with a bleeding disorder, or
- a renewal claim for your child before the end of your current award.

Before completing the DLA form, we suggest you read this information and the guidance on completing the form in section 2.

## What is DLA?

Disability Living Allowance (DLA) is a government benefit to help you with the extra costs of raising a child with a medical condition or disability. DLA can be claimed for children under the age of 16.

# You won't receive DLA just because your child has a bleeding disorder. You will need to show how their bleeding disorder affects your lives and that they have additional care needs because of their bleeding disorder.

The amount of DLA you receive can change as your child ages.

DLA for children is usually made for a **fixed period.** This means that you'll probably have to reapply at least once, known as a **renewal claim**, between your child being diagnosed with a bleeding disorder and reaching 16. Each renewal claim is treated the same as a new claim.

## Eligibility

Usually, to qualify for Disability Living Allowance (DLA) for children the child must:

- be under 16 anyone over 16 must apply for Personal Independence Payment (PIP)
- need extra looking after or have walking difficulties
- be in England, Wales, a European Economic Area (EEA) country or Switzerland when you claim there are some exceptions, such as family members of the Armed Forces
- have lived in Great Britain for at least 6 of the last 12 months, if over 3 years old
- be habitually resident in the UK, Ireland, Isle of Man or the Channel Islands
- not be subject to immigration control
- A child under 6 months must have lived in Great Britain for at least 13 weeks.
- A child aged between 6 months and 3 years must have lived in Great Britain for at least 26 of the last 156 weeks.

## **Children under three**

Getting DLA for a baby or infant can be difficult due to the high level of care required for children of that age. However, if your child needs more care, attention or supervision than a non-disabled child of the same age or a child without a health condition, it is still worth applying. For instance, while it is normal for babies to wake up at night if you have to wake up 2-3 times to administer treatment, it indicates that your child requires more care and attention than a baby who does not need such treatment.

## Components

DLA is made up of two parts called components.

#### **Care component**

The rate your child may get depends on the level of care that they require. For instance, if your child needs help for some of the day, they may receive the lowest rate. On the other hand, if your child needs frequent help or constant supervision during the day, supervision at night, or someone to help them, they may receive the middle rate.

However, if your child needs help or supervision throughout both day and night they may receive the highest rate. It is important to determine the appropriate rate based on your child's specific needs to ensure that they receive the care and attention that they require.

The **daytime conditions** are that your child needs: continual supervision (supervision at all times) throughout the day to avoid substantial danger to themselves OR frequent attention throughout the day in connection with their bodily functions.

The **night-time conditions** are that to avoid significant danger to themselves, your child requires another person to be awake for a prolonged period or at frequent intervals to watch over them, OR they need prolonged or repeated attention in connection with their bodily functions.

## **Mobility component**

The rate at which your child can receive mobility support depends on their needs when getting around.

For instance, the lowest rate would be given to a child who can walk but still requires help or supervision when outdoors. On the other hand, the highest rate would be given to a child who cannot walk at all or can only walk a short distance before experiencing severe discomfort or becoming ill. This would also include children who are blind or have severe visual impairments.

In terms of age limits, a child must be at least 5 years old to receive the lowest rate of mobility support, while a child must be at least 3 years old to receive the highest rate.

If you claim Disability Living Allowance (DLA) for your child under these ages, you should expect to receive a claim pack 6 months before they turn 3 years old and another 6 months before they turn 5 years old. If you believe your child may be eligible for the mobility component, you can apply for it during these periods.

## Bleeding disorders and the care component

Remember, your child will not receive DLA just because they have a bleeding disorder.

Your child may qualify, depending on the amount of care they need.

**Primary school-age children** may qualify for the middle rate until they reach the age of 12. Although describing the supervision needs continues to be necessary, it's also advisable to give complete information about the following:

- any 'nursing' care you give your child when they have a bleed
- any bleeds your child has had recently
- any routine physiotherapy you have been prescribed for your child.
- home treatment
- if your child has an inhibitor
- prophylaxis (the regular infusion of clotting factor concentrates to prevent bleeding)

**Things tend to change at the age of 12 (and early teens).** Often only the lower rate of care component is awarded. Much depends on individual circumstances. It's possible to keep the middle rate of care component. It can take a lot of work on your part to put together the supporting evidence. This evidence will need to describe the following:

- your child's treatment regime
- how injections are given, and who gives them
- the number and frequency of breakthrough bleeds
- the impact of bleeding episodes (joint damage, chronic pain, anaemia, periods of absenteeism from school, lost workdays for parents/carers etc.).

**When your child reaches age 16**, they must claim the new Personal Independence Payment (PIP). The Department for Work and Pensions (DWP) will contact you some months before your child's 16th birthday to start the transition process. We recommend looking at our guide to claiming Personal Independence Payment.

## Comparison with a 'normal' child

There is one further condition for the care component. Your child's care needs are substantially more than the typical requirements of other children their age. This means:

- Your child's bleeding disorder gives rise to a substantial danger over and above that of a child without a bleeding disorder (there must be a specific likelihood that without supervision, your child could seriously risk harming themselves).
- There is always a likelihood of a severe bleed arising in the future.
- Your child will need supervision from someone to avoid substantial danger, and the need for care will be continual.
- It is advisable to provide detailed information in each relevant section about their fluctuating needs, including how their abilities change and how they function during their worst symptoms.

As your child's care needs are unpredictable or sporadic, it might be a good idea to:

- Keep a diary to show what help has been provided. If your child needs attention at night, keep a record of what attention is provided, how often and on which nights, and how long you are awake to provide that care.
- Document how often your child needs help rather than how often they get help. Again, if your child needs supervision to prevent substantial danger, keep a diary to show what has happened on previous occasions or what might have happened if someone had not been there to prevent it. Prolonged care means that you must be watching over your child for at least 20 minutes. This could mean intervals where the care has been performed at least three times during the night (it's worth documenting any night activity, even if less than three times a night).
- Describe the changes in their condition if your child's bleeding fluctuates; use terms like 'bad days' and 'better days'.
- Document that acute bleeds should be treated as quickly as possible, preferably within two hours, so prevention of bleeding is achieved by prophylactic factor replacement given by the parent/carer. If your child is on home treatment, this will allow for immediate access to clotting factors and optimal early treatment, resulting in decreased pain, dysfunction and long-term disability and significantly reduced hospital admissions for complications. While clotting factor concentrates should be given as quickly as possible to stop bleeding, additional pain relief medication is also needed for pain control. Other measures include P.R.I.C.E, cold packs, immobilisation, splints, and crutches.

## **Mobility component**

There are two rates of the mobility component:

The **higher rate** can be claimed from your child's third birthday. However, because current treatments offer good bleed protection, significantly reducing the number of bleeds into ankles and knees that children experience, joint damage is much less than in the past, which means claims for young children with a bleeding disorder are less likely to be successful.

Prophylactic care means that few children are at risk of bleeding simply by walking. However, joint damage remains a major complication associated with severe bleeding disorders.

You might receive a higher rate if your child:

- already has some damage to a knee, ankle or hip
- has an inhibitor
- has repeated breakthrough bleeds in ankles, knees and/or hips despite being treated prophylactically or is on 'on-demand' treatment and has repeated bleeds (e.g. once a month or more), particularly into joints.
- prophylaxis: regular treatment to prevent bleeds
- on-demand: treatment given when bleeds occur

#### Don't play down your child's condition.

The **lower rate** can be claimed from your child's fifth birthday. More claims for the lower rate are successful because the conditions for being awarded the lower rate are similar to the supervision condition for the care component. The focus is on any danger your child may face when outside and the possibility that your child may need medical treatment at any time if a bleed starts. Bleeds include joint/muscle bleeds or injuries; injuries to the mouth, tongue, face, eyes or neck; severe knocks to the head; vomiting or coughing up blood; open wounds requiring sutures (stitches) etc.

## **DLA and other benefits**

DLA is not taken into account as income for income-related benefits such as Universal Credit, Housing Benefit, Council Tax Reduction (which replaced Council Tax Benefit in April 2013) and Tax Credits. In some situations, receiving DLA for a child can increase your entitlement to an income-related benefit, so it is always a good idea to report an award for DLA – don't take it for granted that the DWP has informed all parts of the benefits system.

If your child receives either the middle or higher rate of the care component of Disability Living Allowance, then you (or another adult) may be able to claim Carer's Allowance. Read more at: https://www.carersuk.org/images/Factsheets/Carers-Allowance-2018-19-FINAL.pdf

## What evidence can I use with my claim?

Please do not send any original documents as the DWP cannot return them. **Only send copies.** Do not send a CD, DVD, memory stick or any type of electronic media, as the DWP cannot access these.

#### Reports, care or treatment plans from:

- occupational therapists
- GPs or consultants
- social workers

- learning disability support teams
- district nurses
- physiotherapists
- reports, statements or diaries from carers or family members
- hospital discharge or outpatient clinic letters about the child's condition or diagnosis
- letters from the child's consultant(s) about their condition or diagnosis.

Test results from: • scans • diagnostic tests • hearing or vision tests.

Other:

- the child's current repeat prescription list
- statement of special educational needs, Education, Health and Care (EHC) plan
- certificate of visual impairment.

What evidence <u>NOT</u> to send:

- appointment cards or letters
- letters arranging hospital admissions
- general information or fact sheets about the child's condition
- fact sheets about the child's medication
- information about tests the child is going to have
- bus or train tickets
- directions or maps for appointments the child has attended.

## Claiming Disability Living Allowance (DLA)

To make a new claim for DLA, you'll need to order a claim form from the Disability Living Allowance helpline:

Telephone: 0800 121 4600 Textphone: 0800 121 4523

Families in Northern Ireland can call:

Telephone: 0300 123 3356 Textphone: 028 9031 1092

There is also a service for people whose first language is not English:

Telephone: 0345 712 3456 Textphone: 0345 722 4433

NGT text relay (if you cannot hear or speak on the phone): 18001, then 0800 121 4600 Monday to Friday, 8 am to 7.30 pm

## Other important facts about your DLA claim

- DLA cannot be backdated
- The date of your claim will usually be the date the form is received or the date you call the enquiry line
- It usually takes 40 working days to deal with a DLA claim
- You should receive the form in 7-10 days
- You will have six weeks from the date of the claim to fill in the form and return it

There are other ways to get a form. You can also claim online. However, we recommend ordering a paper form (see page 6), as none of the other claims seems to offer the security of backdating. You should make a copy of your claim form before sending it back in case you need to refer to it later or in case it gets lost.

Please remember that a decision on your child's claim will be made by someone who has never seen your child, is not a medical expert, and may have little or no knowledge about your child's condition. Do not assume the decision-maker will understand your child's condition and clarify all the extra care and support your child needs. This will increase the chance of your child being awarded the right level of DLA.

You may also need to make a **renewal claim** for DLA. This is reapplying at the end of the fixed period of your current award. You should be sent a new form automatically several months before the end of your current award. If you haven't received the form by four months before the end of your award, call the DLA number to make sure one is sent.

DLA can only be claimed for children under 16 – anyone over 16 must apply for Personal Independence Payment (PIP).

## Section 2: Completing the claim form

This section will help you to complete the form to claim DLA for your child.

Before using this information:

- check the bottom left-hand corner of the claim form to make sure you have the current form: it should say DLA1 Child (ALT)
- read the overview of DLA in the first section of this factsheet
- read through these notes and the claim form to understand which questions are most important and the information you will need to give.

There are **three** types of questions on the form.

- **Questions about your child's <u>care</u> needs and <u>mobility</u> problems**. These are the important questions. However, remember that the claim form is designed to collect information about a wide range of disabilities and health conditions. Not all questions are equally important for your claim, and some questions will not apply to your child.
- **Details of** <u>other people</u> who can provide information (e.g. a specialist or professional who knows your child). It is essential that they know your child's needs during a typical day and can talk about the additional help your child needs because of their bleeding disorder.

We suggest you contact your haemophilia centre in plenty of time to allow them to support your application appropriately. Some centres have social workers who will support you in applying; in other centres, a nurse or physio may be able to help you present the required evidence.

## Questions 1-37: General information about your child

These questions gather general information about your child. You will be asked about their identity, nationality, disability, and if they have any medical or health professionals involved in their care. Additionally, you will be asked if your child has stayed in hospital or residential care within the last 12 months.

## The important questions for children with a bleeding disorder

Question 38 - Is there anyone else who knows the child and can tell us about their difficulties?

When asking someone about your child's condition, choosing someone who knows your child's needs is essential. Your haemophilia nurse or physiotherapist may be the best person to ask if your child has a bleeding disorder.

If your child's condition is also related to learning difficulties or behavioural problems, their teacher or specialist support worker may be a good choice. You could also include a 'Special Educational Statement' as evidence, which you can obtain from your child's school.

Before asking them to fill out the question, talk to them about how you care for your child and how much time you spend caring for them. Let them know that the DWP is interested in understanding how your child requires more care than a child of the same age without disabilities or health conditions.

If you ask someone from your child's school to fill out the question for you, they must know your child's needs during a typical school day. While they may want to highlight positive aspects of your child's progress, it will be more helpful if they focus on the additional help your child needs. It may be worth leaving the statement if you don't feel that they've made a strong enough case for your child to receive DLA.

The individual composing this statement must be someone significantly involved in caring for your child. This may include a paid caregiver, a family member, a friend, a healthcare provider, a social worker, or a specialised teacher. The statement must be supportive and not detrimental to your case. You may attach the blank statement page to your claim, and if you are dissatisfied with the content, you have the right to request revisions or enlist the assistance of another professional.

**Question 40** - Please tell us about the child's health condition or disabilities:

You don't need to enter a lot of detail here. But make sure you write the name of each condition your child has been diagnosed with, for example, 'Haemophilia' or 'Von Willebrand Disorder' etc, the treatment they have and how often they are treated.

**Question 41** - Does the child use, or have they been prescribed or had an occupational health assessment for any aids or adaptations?

Include any medical equipment your child has received from their physiotherapist such as crutches, wheelchair, supports, boot etc.

## Question 42 - When the child needs help

If your child's condition varies, don't worry, you can still receive DLA if there is a consistent pattern of substantial care needs or mobility problems. Sometimes your child may have days or weeks when they require less assistance.

Make sure to tick any box that applies to your child, even if it doesn't apply all the time. You can further describe any variation in needs in the boxes below each set of tick box questions and at question 65 concerning "more information". Keeping a diary over a week or more can be helpful if your child's condition fluctuates a lot. When describing changes, use the terms "bad days" and "better days" instead of "good days" or "normal days" to better reflect your child's needs.

- Also, include any information about routine physiotherapy exercises your haemophilia centre prescribes. How long do the exercises take, and how often are these done?
- How often does your child have to attend hospital appointments (routine appointments and when a bleed occurs etc.)? Also, explain what happens in an emergency (including outside clinic hours).
- List medications. List times they are taken and dosage. How does your child cope with taking treatment/medication?
- Do they have any treatment which only needs to be given if you observe certain signs?
- Finding ways to make them take medicine (e.g. tranexamic acid used to treat or prevent excessive blood loss), for example, crushed with yoghurt, followed by a favourite drink, need for sticker chart or other incentives.
- Time-consuming to prepare medicines, e.g. crushing tablets, cleaning and sterilising syringes and the aseptic technique (the clean technique is to reduce the number of germs whenever possible to minimise the risk of contaminating an invasive device, e.g. port-a-cath).
- Do they need medicines during the school day? How is this managed?
- Would your child receive treatment/medication without your intervention? What harm could hap-pen if you don't help them take treatment/medication? What are the consequences of not taking treatment/medication?

#### Questions 43-53: Mobility needs

When evaluating your child's ability to walk, it's essential to consider the impact it has on their condition. Walking may cause fatigue, breathlessness, or nausea, worsening their condition. To accurately measure how far your child can walk, it's important not to count any distance covered after experiencing severe discomfort. Some things to consider when assessing their walking ability include their walking speed compared to other children their age, whether their walking style makes it difficult for them to get around, how quickly they become tired or uncomfortable, whether they fall or stumble frequently, and whether walking has a significant impact on their overall health. It's also important to note if your child regularly refuses to walk and if overcoming these episodes is difficult.

If your child's condition varies, don't worry, you can still receive DLA if there is a consistent pattern of substantial care needs or mobility problems. Sometimes your child may have days or weeks when they require less assistance. Make sure to tick any box that applies to your child, even if it doesn't apply all the time.

Keeping a diary over a week or more can be helpful if your child's condition fluctuates a lot. When describing changes, use the terms "bad days" and "better days" instead of "good days" or "normal days" to better reflect your child's needs.

## Question 47 - Please tell us about the way they walk

It's important to note that not many children with a bleeding disorder will qualify for a higher rate of the mobility component. However, if your child can walk, it's still important to describe how they walk, such as if they have a limp or shuffle. It's also helpful to document how far your child can walk before experiencing discomfort, whether counting their steps or measuring in meters. Do they have any issues with their joints due to joint bleeds? Do you think your child is at risk of stumbling or falling without assistance? Additionally, it's important to note any aids your child may need, like crutches, to help with their walking.

**Question 48** - Does the child have any other difficulties either during or after standing and moving around that affects their health?

This question specifically asks about bleeds into knees and ankles, so give a list of these types of bleeds your child has had in the last six months, together with information about any joint damage your child has in their knees, ankles or hips. Please explain why your child has these bleeds: for example, they have an inhibitor or are not on prophylaxis. Explain also what treatment is necessary if they do get a bleed.

Think about the issues of walking:

- Does your child have walking difficulties such as loss of balance, lack of coordination, and so on?
- Do they have pains in their legs?
- Do they have poor muscle tone?
- Do they have an unusual walk?
- How difficult is it to predict how far your child can walk? Do you need to take a pushchair or wheelchair whenever you go out?

**Question 53** – Tell us anything else we need to know about their difficulties with standing and moving around or how their needs change from day to day.

Before filling out the form, we recommended you plan what you want to write and make notes or a draft. Describe the supervision you give your child and how you prevent and monitor bleeds. Provide examples of instances where you have intervened to avoid harm or sought medical treatment for your child.

## Questions 54 to 69: The help your child needs during the day

Daytime is any time before the child's parents or carer goes to bed. For example, the child wakes up at 7am and goes to bed at 8pm.

The child's parents get up at 7am and go to bed at 11pm. Daytime would be 7am till 11pm.

Any help needed after 11pm would count as help during the night and you can answer in question 70.

If your child attends nursery or school, detail any written care plans and the actions staff take in the case bleeds or injuries.

If you check on your child during the night, include this information.

Additionally, provide information about your child's treatment for their bleeding disorder, including their prophylaxis regime, how you handle bleeds, and any injection issues.

Consider including a diary of extra care during and after a bleed and any patterns or frequencies of bleeding episodes. Finally, include any relevant information about other health conditions your child may have.

Question 70: Any help your child needs during the night

Complete this section if you must get up at night to help with your child's care needs.

Night-time is the time between when you go to bed and you get up. If you stay up later than you want

to because your child does not settle in bed, or if you get up very early, these times also count as night-time.

Question 72: More information about their daily living and care needs

You may wish to use the space provided to explain more about your child's condition and how it affects them. For example, how their condition might vary or how their mental health is affected by their bleeding disorder.

Think about attaching any document, letter or statement with the claim. It is essential to check that any evidence you send accurately describes your child's needs, and if it doesn't, this may harm your claim.

Evidence can include information from a health professional involved with your child's care, like a haemophilia doctor or nurse, physiotherapist, paediatrician, speech and language therapist, or occupational therapist.

If you're nearing the six-week deadline, you should send the completed form without waiting for additional evidence. Attach a letter saying you will send more evidence and when they can expect it.

## **Section 3: The decision**

This section offers guidance on what to do once you have received a decision about the claim for DLA for your child.

## Introduction

**Decisions on a DLA claim can often feel unfair and random.** This can be particularly so if you have made a renewal claim and the new award is less than you were getting before.

At this stage, it's very important to remember:

- your child will not be awarded DLA just because they have a bleeding disorder, and
- the amount of DLA you receive can change because as children grow older, their bleeding disorder's impact on their life changes.

The decision letter will tell you:

- which components your child has been awarded
- the rates of components awarded
- the period of the award.

## Is it a 'good' decision?

This is a difficult question to answer because each child is different and the impact a bleeding disorder has differs from child to child.

**Be realistic:** it's essential to keep in mind that although your child **sometimes** meets the conditions for a particular rate, they will only receive that rate if a decision maker is convinced that they meet the requirements for the **majority** (i.e. more than half) of days over a period of time.

For example, your child has had two bleeds in an ankle in the last three months but no other bleeds. Each time they could not walk for four or five days, they also needed a lot of care for those days.

- Although they would probably meet the conditions for the higher rate of the mobility component on ten days, this is not the majority of days. They do not qualify for the mobility component higher rate.
- They probably also met the daytime qualifying condition for the care component because they needed frequent 'attention in connection with their bleeds'. However, over three months, they did not meet this condition on most days and so do not qualify for the care component middle rate.

## If you are unhappy with the decision

The first stage is to **ask the DWP for a written explanation of their decision**. You can do this by calling the phone number or writing to the address on the decision letter. Do this **within one month of the date** of the decision letter.

At the same time, **ask for a copy of the case papers** to be sent to you. This will include your claim form and any other information the DWP used to make their decision. This is important because they may have used information you haven't seen.

If you are still unhappy with the decision, you can ask for the decision to be looked at again (known as a **reconsideration**). Here is a **suggested action plan**.

- Phone or write to the DWP to ask for the decision to be looked at again.
- Ask yourself if you can provide any additional information that wasn't available to the decision maker.
  - \* The written explanation should list the information the decision maker used. Does this include a report from the haemophilia centre? Or anyone else you suggested the DWP contact? If anything is missing, you could ask these people to provide you with a supporting letter to send to the DWP.
  - \* See the guidance on completing the form in section 2 of this factsheet to check what other information you could provide. It's usually a good idea to provide the following:
    - » a physiotherapists or orthopaedic report
    - » a treatment record for the last three months, including both prophylactic and on-demand treatments.
    - » information about the time taken to give injections, including 'encouraging' your child to have them.
    - » information about the help you give your child with physiotherapy exercises (routine and recovery from a bleed)
    - » a history of bleeding episodes in the last 3-6 months, as well as injections, what other care did you need to give your child?
  - \* In all of this, describe fully how many days are involved and how much time is taken on these days. One way of doing this is to present the information as a diary of a recent period of two to four weeks.
- Look at anything the decision maker has given as reasons for their decision. Note any points you disagree with to include in a letter to go with the other information you will send.

## Challenging a DLA decision – mandatory reconsideration

If you disagree with a benefits decision your child has received, you must ask the DWP to look at their decision again (this is called a 'mandatory reconsideration') before you can appeal. You must ask for this within one month of the date on your decision letter, by phone using the number on the decision letter, or by post by completing the CRMR1 form.

The DWP will send you a 'mandatory reconsideration notice' telling you whether the decision has changed. If you are still unhappy, you can appeal against the decision.

## **Section 4: Appeals**

This section offers guidance on what to do if the DWP has looked again at the decision but you are still unhappy with their decision.

## Introduction

Appealing against a decision on DLA is the last stage of the decision-making process.

Here is an eight-step process you will have to go through:

- 1. You receive a letter notifying you of your child's DLA claim result. If you are told that your child is not entitled to anything, or you think your child has been given the wrong amount, you have one month from the date on the letter to ask for a 'mandatory reconsideration'.
- 2. Ask the DWP to look again at their decision. They will look at your claim again, any new evidence they have, and see if they will change their decision.
- You will receive two copies of the reconsideration decision from the DWP. If you wish to appeal the decision, use the second copy of the reconsideration decision. You have one month to appeal. Seek advice from a benefits adviser, for <u>example, Citizen's Advice</u>.
- 4. Use the <u>SSCS1 form</u> to ask for an appeal.
- 5. The DWP will send both you and the HM Courts & Tribunals Service (they organise the appeal hearing) the reason why your child was given the award they received.
- 6. You must prepare for your appeal and send more information about your child's difficulties.
- 7. You will be told the date of the hearing.
- 8. An independent tribunal called a Social Security and Child Support Tribunal will hear your appeal. The panel usually consists of a legally qualified tribunal judge, a doctor and a person with experience in the needs of disabled people. A DWP officer may also be present.

## **Preparing for a tribunal**

Before going to the tribunal, preparing some notes in advance is a good idea. Doing this about two weeks before the tribunal is a good idea.

- Read through the Secretary of State's submission, particularly the reasons for the decision. Please note any statements you disagree with and why you disagree with them.
- Read through the rest of the case papers. Highlight and tag any information that helps your claim. In particular, look for information the decision maker may have ignored or not fully considered.

If successful, you usually receive your money in four to six weeks.

## **Making an appeal**

You must appeal in writing within one month of the date of the decision letter.

- Make your appeal on the SSCS1 form. You can phone the DWP to ask them to send you a copy. You can also download and print a copy of the SSCS1 form from https://www.gov.uk/ government/publications/appeal-a-social-security-benefits-decision-form-sscs1
- If you have found a representative for the tribunal, give their contact details in section 4. But don't delay sending the SSCS1 form if you can't find a representative you can always send details later.

- Section 5 asks for the grounds for your appeal. A simple statement such as 'my child's care needs have not been fully considered' should be enough. If you think your child may be entitled to the mobility component, add 'my child's mobility needs have not been fully considered'.
- Section 6 asks about your choice of hearing. We suggest you attend the hearing rather than have it decided on the papers. Attending the hearing will allow you to provide more information that may not be clear from the case papers you will not need to take your child with you.

## Looking for further support

You may be able to find a representative to help you. The following links may help:

- Disability Rights UK: http://disabilityrightsuk.org
- Carers UK: http://www.carersuk.org/
- Advice Guide from Citizen's Advice: http://adviceguide.org.uk
- Benefits and Work: http://www.benefitsandwork.co.uk
- DWP: https://www.gov.uk/mandatory-reconsideration

Disability Living Allowance (DLA) for children with bleeding disorders

The Haemophilia Society