



Disability Living Allowance (DLA) for children with bleeding disorders

This factsheet gives an overview of DLA for children, as well as guidance on how to complete the claim form and how to appeal a decision. Families of children with bleeding disorders may wish to apply for DLA to cover additional costs of living with their condition and should do so at the earliest opportunity. However, while many families are successful in claiming DLA **not all children** with bleeding disorders will be eligible for the support.

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For everyone affected by a genetic bleeding disorder



Section 1: Overview of DLA for children

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

We suggest that before completing the claim form you read this information, together with the guidance on completing the form in section 2.

What is DLA?

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

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

The amount of DLA you are awarded can change as your child gets older.

Awards for children are 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 them reaching the age of 16. Each renewal claim is treated the same as a new claim.

Eligibility

To qualify for Disability Living Allowance (DLA) for children the child must:

- be under 16
- have their main home in the UK, although you can leave the UK for short periods, like holidays
- be in Great Britain, another 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 two of the last three years, if over three years old
- have had these difficulties for at least three months and expect them to last for at least six months. If they're terminally ill (that is, not expected to live more than six months), they do not need to have had these difficulties for three months

- need extra looking after or have difficulty walking
- not be [subject to immigration control](#) (that is, you may need permission to enter or stay in the UK but haven't yet received it or have permission to enter or remain in the UK only if you don't claim benefits).

Children under three

- A child under six months old must have lived in Great Britain for at least 13 weeks
- A child aged between six months and three years must have lived in Great Britain for at least 26 of the last 156 weeks

Northern Ireland has an equivalent process where eligibility is slightly different.

Components

DLA is made up of two parts, called components.

Care component

This looks at whether your child has additional care needs and would benefit from financial help towards care.

The care component:

- can be paid at one of three rates
- all three rates can be claimed from when your child is three months old
- will be paid at the highest rate for which your child qualifies.
- If your child has an inhibitor

Mobility component

This looks at whether your child has mobility needs and would benefit from financial help towards helping them get around.

The mobility component:

- can be paid at one of two rates
- the higher rate can be claimed from a child's third birthday
- the lower rate can be claimed from a child's fifth birthday
- will be paid at the highest rate for which your child qualifies.

(See the section on rates of DLA on page 5 for the current amounts.)



Care component (middle and higher rates)

To qualify for the care component at the middle or higher rate you will need to show that your child needs either **a lot of supervision or a lot of attention** in connection with their bodily functions, for example washing themselves, changing bedding after an accident, eating and drinking, brushing their teeth, dressing or any other activity. You will need to list what bodily functions are impaired, how often attention is required and how long it takes. (These are referred to below to as the 'supervision' condition and the 'attention' condition.)

These conditions apply for both **day and night** although the test is slightly different for night: If your child meets one of the conditions **during the day** you will be awarded the **middle rate**. If your child meets one of the conditions during **both day and night** you will be awarded the **higher rate**.

We've put the important words (that are listed in the DLA regulations) in *italics*. When you're filling in the form, keep these words in mind, so that you can make it really clear what help your child needs.

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

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

Care component (lower rate)

This is awarded if your child: in connection with their bodily functions needs attention from another person for a *significant portion* of the day (whether during a single period or a number of periods).

The major difference between the lower rate and the middle rate is that to qualify for the lower rate you only need to show that your child needs help for much less of the day.

Bleeding disorders and the care component

Remember, you will not be awarded DLA just because your child has a bleeding disorder.

However, feedback from our members shows the following trends for children with severe or moderate haemophilia and those with von Willebrand disease (vWD) type 3: younger children usually qualify if their supervision needs are well described. Most receive the middle rate of the care component; some receive the higher rate.

Children with other bleeding disorders may also qualify depending on the amount of care they need.

Primary school age children usually continue to qualify for the middle rate until they reach the age of 12. It's rare for children in this age group to qualify for the higher rate. Although describing the supervision needs continues to be important, it's also advisable to give full information about:

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

At the age of 12 (and early teens) things tend to change. 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, but it can take a lot of work on your part in putting together the supporting evidence. This evidence will need to describe:

- 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 will need to 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. At this point 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. This is that your child's care needs are: substantially in excess of the normal requirements of persons 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 serious bleed arising in the future.
- Your child will need supervision from someone in order to avoid the substantial danger and the need for the supervision will be continual.

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, then keep a record of what attention is provided, how often and on which nights, and how long you are awake in order 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 factor and hence optimal early treatment, resulting in decreased pain, dysfunction and long-term disability and significantly decreased hospital admissions for complications. While clotting factor concentrates should be administered as quickly as possible to stop bleeding, additional pain relief medication is often needed for pain control. Other measures include 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, greatly 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 now at risk of bleeding simply through the act of walking. However, joint damage remains a major complication associated with severe bleeding disorders.

The higher rate may be awarded 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.

Rates of Disability Living Allowance (DLA)

These are the current weekly rates of DLA for April 2018 – April 2019.

- Your child can be awarded one component or both.
- You will be paid the highest rate of each component for which your child qualifies.
- The total weekly DLA is worked out by adding together the two components.

Care component	Weekly rate
Lowest	£22.65
Middle	£57.30
Highest	£85.60

Mobility component	Weekly rate
Lower	£22.65
Higher	£59.75

The higher rate of mobility component can only be awarded from age three.

The lower rate of mobility component can only be awarded from age five.

DLA is usually paid every four weeks.

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 is awarded either the middle or higher rate of 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>

Claiming Disability Living Allowance (DLA)

To make a fresh 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, 8am to 7.30pm

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 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 from the number above, as none of the other ways of claiming seem 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 who may have little or no knowledge about your child's condition. Do not assume that the decision maker will have any understanding of your child's condition, and make clear all the extra care and support that 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 **DLA1A Child July 2018**

- read the overview of DLA in the first section of this factsheet
- read through these notes and the claim form together to get an idea of which questions are most important and the information you will need to give.

There are three types of question on the form:

Questions about your child's care needs and mobility 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. Some questions will not apply to your child at all.

Details of other people who can provide information

(e.g. a specialist or professional who knows your child). It is important that they have actual knowledge of 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 appropriately support your application. 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.

Administrative questions. These are usually quite straightforward to answer. We give some guidance notes at the end of this section.

The important questions for children with a bleeding disorder

Our experience shows that **question 70**, 'Tell us anything else you think we should know about the child's claim', is the most important question to answer.

- We suggest you start by answering this question and take your time to think about what you want to write. If you can, plan what you are going to write before you write it on the actual form.
- Make notes and make a draft of what you want to write before completing the form.
- Once you have a clear idea of what you will say in question 70, the other questions on the form are easier to answer.

In **question 70** you should try to describe your understanding of the **substantial (serious) danger** your child is in. Stress the **unpredictability** of bleeding episodes.

- Describe the **'supervision'** you give to your child. What do you do to prevent a bleed? How do you monitor them to check if they may be having a bleed? Give examples of when you have step in to stop your child hurting themselves, when you have had to take them to hospital for treatment or have given them treatment yourself.
- If your child is at nursery or school, describe the arrangements you have with staff. Do you have a written care plan for them? What do the staff do when they think your child is in danger or having a bleed? Again, **give examples** of when this has happened.
- If you get up during the night to check on your child because you fear they may have a bleed, report this as well. Don't worry about repeating yourself.

(NB: This information really answers **questions 49, 51 and 53** as well. There is not enough space on the form to answer these questions fully so answer them fully in question 70. We suggest writing 'see question 70' in the boxes for questions 49 and 53.)

- You should also include information about the **supervision you give your child when you are outside with them**. We suggest you repeat this information in **questions 32-34**. Although these questions are about the mobility component (lower rate) it also gives you an opportunity to provide information that is relevant to the care component.
- Include information about **the treatment your child needs** for their bleeding disorder:
 - Describe their prophylaxis regime if they are on one. (Prophylaxis is the regular infusion of clotting factor concentrates in order to prevent bleeding.)
 - Describe what you do in the case of a bleed.
 - If you give them the injection, give a description of the stages involved and how much time this takes.
 - Do injections always go well? Does your child co-operate with injections or do they need coaxing and settling before they let you inject them? Include the time taken to settle your child before an injection.

(NB: this information really answers **question 43** as well, but there may not be enough space to answer in question 43. You could write 'see question 70' in answer to question 43.)

- Include any 'help' you give with medical equipment. This could be checking a port-a-cath, if your child has one, but also includes the practicalities of ordering, taking delivery of, and storing their treatment if they are on home treatment.
- Also include any information about routine physiotherapy exercises prescribed by the haemophilia centre. 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 (include outside clinic hours).
- List medications. List times taken and dosage. How does the 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 favourite drink, need for sticker chart or other incentive.
- Time-consuming to prepare medicines e.g. crushing tablets, cleaning and sterilising syringes. 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 happen if you don't help them take treatment/medication. What are the consequences of not taking treatment/medication?

Question 24 asks when your child needs help. We suggest ticking both 'most of the time' **and** 'varies'. Explain in the box that your child's supervision needs are continual but that their 'attention' needs vary depending upon the bleeds they have.



Questions 35 and 54 ask for any further information you want to add about your child's mobility or care needs. As the space given is small, we suggest writing 'see question 65' in the boxes and then giving full information in question 70. Can they walk to and from school? Do they have problems climbing stairs? Do they ask to be carried?

The less important questions

Questions 25-31 are about your child's walking ability when walking outside on a reasonably flat surface. These questions test whether your child meets the higher rate of mobility component.

Please note, very few children with a bleeding disorder qualify for the mobility component at the higher rate. However, if your child can walk it is important to describe how they walk (e.g. with a limp or shuffle). It is important that you document the total distance your child can walk before they have discomfort, e.g. count the steps they have walked or how far (metres). Is your child likely to stumble or fall without someone's help? What aids do they need to help with their walking (e.g. crutches)?

However, **question 30** specifically asks about bleeds into knees and ankles, so give a list of these types of bleeds that 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. Give the reason why your child has these bleeds: for example, they have an inhibitor, or they 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 co-ordination 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 will be able to walk? Do you need to take a pushchair or wheelchair every time you go out?

Questions 19, 37-43, 44-48, 50, 52

Question 19 will only apply to some children.

In **question 29** list aids if your child uses them all the time and not just when they have a bleed.

Questions 37-43 and question 47

- Describe problems your child has with this activity.
- List what help your child either gets or needs.
- Why your child can't manage without this help.
- What is different compared to peers?

Some of these questions will only be important for those days when your child has a bleed or is recovering from a bleed. It's a good idea to include a diary of the extra care your child receives, especially during the time of a bleed or recovering from a bleed. Ensure you give as much information as you can about bleeding episodes: how often do they happen; is there a pattern, does child know if they have a bleed etc?

Other questions may be important if your child has another health condition as well as a bleeding disorder. Include all the information you can.

Details of other people who can provide information

In general, it is better to **send supporting letters** from your haemophilia centre, nursery, school and so on **with your claim form** rather than wait for the Department for Work and Pensions to write to them requesting further information.

- **Question 14:** We recommend putting the name of either the clinical nurse specialist (CNS) or the consultant from the haemophilia centre where your child is treated. Check with your haemophilia centre whose name they would prefer you to put.
- **Question 15:** A GP is very unlikely to have a good knowledge of your child's bleeding disorder. We suggest adding a note below the question stating that the GP is not the best person to ask and that further information should be requested from the people listed in question 14.
- **Question 18:** Put the name of the staff member you think will clearly describe the way in which they 'supervise' your child and what they do if they suspect your child has a bleed. It may be better to include a copy of any written care plan you have in place with the school or nursery. It is important that you use someone who knows your child well. Make sure you tell them that they will be contacted for information.



Question 20: It can be useful to get someone else to add their viewpoint, but you don't have to complete this part. You could ask your GP, health visitor, haemophilia centre, classroom assistant or special educational needs co-ordinator (SENCO), school nurse etc.

However, you may wish to leave out their statement if you don't think they have made a strong enough case for you to get DLA.

The 'administrative' questions

- **Questions 1-13, 16 and 17** are straightforward. If this is a first claim for DLA, you will not know your child's reference number (question 2). If you are making a renewal claim you will find the reference number on your current award letter.
- **Question 22:** List all your child's health conditions and disabilities in the first box. In the second box describe treatment as 'intravenous injections of replacement factor VIII' (or other factor) and say if this is on demand or prophylaxis or both. Include all other medications (e.g. tranexamic acid) as well as any physiotherapy programme you help your child with.
- **Questions 36 and 55:** For question 55 this will usually be the date your child was born. For question 36 our suggestion is when your child first started to walk.
- **Question 54:** List your child's diagnosis, treatments and lifestyle: are your child's needs different on different days; does your child need support at school (regardless of whether they actually have it); how does your child's condition affect the family, school, friends? Remember not to leave anything out.
- **Questions 56-63** are also straightforward. However, it is not compulsory to give a daytime phone number (question 61) and we suggest that you don't. We suggest you provide all information in writing rather than over the phone.
- **Question 69** is for details of the bank account you want DLA paid into.
- **Question 70** is for extra information. You can use this section to repeat the important points you have made in questions 35 and 54. Give

information about surgery or other hospital care your child has received. You can also use this to describe the difficulties your child's bleeding disorder has on their mental health, e.g. if they feel frustrated, isolated or upset. You can use this section to explain how you help your child, e.g. encouragement, special behavioural techniques, planning the day ahead, discussing feelings, etc. Give as much additional information as you can.

- You must sign the declarations in **questions 21 and 71** to make your legal claim for DLA.
- Finally, list all the extra information you are sending with the form in the box provided on **page 41**.

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 are awarded can change. This is particularly so as children grow older and the impact their bleeding disorder has 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. We suggest you read the information in the first section of this factsheet. This gives an idea of which levels of each component are commonly awarded for children with bleeding disorders.

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

For example: your son has had two bleeds in an ankle in the last three months, but no other bleeds. Each time he was unable to walk for four or five days. He also needed a lot of care for those days.

- Although he would probably meet the conditions for the higher rate of the mobility component on 10 days, this is not the majority of days. He doesn't qualify for the mobility component higher rate.
- He probably also met the daytime qualifying condition for the care component because he needed frequent 'attention in connection with his bodily functions'. However, over a three-month period, he did not meet this condition on the majority of days and so does 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 there is any **additional information** you can provide 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 physiotherapist's 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, try to describe fully how many days over a period are involved and how much time is taken on these days. One way of doing this is to present the information in the form of 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 be sending.

Challenging a DLA decision – mandatory reconsideration

If you disagree with a benefits decision your child has received, you have to 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 post by completing the CRMR1 form.

The DWP will send you a 'mandatory reconsideration notice' telling you if the decision has been changed or not. 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

Making an appeal 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 the result of your child's claim for DLA. 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.
3. 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 benefit adviser, [for example Citizen's Advice](#).
4. Use the [SSCS1 form](#) 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 need to prepare for your appeal and send in 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 of the needs of disabled people. A DWP officer may also be present.

Preparing for a tribunal

Before going to the tribunal it's a good idea to prepare some notes in advance. Doing this about two weeks before the tribunal is a good idea.

- Read through the Secretary of State's submission, particularly the reasons given for the decision. Make a note of 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 that the decision maker may have ignored or not fully considered.

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

Making an appeal

You must make an 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 then add 'my child's mobility needs have not been fully considered'.
- Section 6 asks about your choice of hearing. We suggest that you attend the hearing rather than have it decided on the papers. Attending the hearing will give you the chance to give 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>