

Disability Living Allowance (DLA) for children with bleeding disorders

This factsheet gives an overview of DLA for children, together with guidance on completing the claim form and appealing a decision. We hope it will be a good starting place if your child has a bleeding disorder and you are thinking about claiming DLA for them.

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For all people affected by bleeding disorders

Section 1: Overview of DLA for children

In this section we aim to 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
- 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 benefit aimed to help you with the additional costs of raising a child with a medical condition or disability. It can be claimed for children under the age of 16.

It's important to remember that you will not 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 **care needs** arising from their bleeding disorder.

It's also important to remember that 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 can expect to have to make at least one **renewal** claim between your child being diagnosed with a bleeding disorder and reaching the age of 16. Each renewal claim is treated as a fresh claim.

Components

DLA is made up of two parts, called components. It consists of the care component and the mobility component.

Care component:

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

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
- you will be paid the highest rate for which your child qualifies

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

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Care component (middle and higher rates)

To qualify for the care component at either the middle or higher rates 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**. (Referred to below to as the ‘supervision’ condition and the ‘attention’ condition.)

Also, 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**.

It’s important to be aware of the wording of these conditions as given in the DLA regulations. Keep them in mind when you are preparing to fill in the claim form. We have put some important words in italics.

The **daytime conditions** are that your child needs: ‘*continual supervision throughout the day* in order to avoid substantial danger to himself (or herself)’ OR ‘*frequent attention throughout the day* in connection with their bodily functions’.

The **night-time conditions** are that: ‘in order to avoid substantial danger to (them)self ... (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: ‘needs ... in connection with their bodily functions 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 will 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, in supporting our members with DLA claims we have noticed 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 care component: some receive the higher rate.

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- 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
 - 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

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:

- the child's treatment regime
- how injections are given and who gives them
- the number and frequency of breakthrough bleeds
- the impact of bleeding episodes

When your child reaches age 16: DLA for adults is being replaced by the new Personal Independence Payment (PIP). Whether the DWP 'invites' you to re-apply for DLA (adult) or for PIP depends on where you live. The DWP will let you know which to apply for:

- if re-applying for DLA, use our guidance for teenagers in the previous paragraph
- if applying for PIP, see our information on PIP

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 condition is sometimes quoted by the DLA decision maker to say that the child doesn't qualify for DLA. This may happen if your child has not yet reached their first birthday.

Mobility component

There are two rates of the mobility component:

- The **higher rate** can be claimed from your child's third birthday. However, very few claims for young children with a bleeding disorder are successful. This is because modern treatment has greatly reduced the number of bleeds into ankles and knees that children experience and joint damage is therefore much less than in the past. Children now spend much less of their time unable to walk and prophylactic care means that few are now at risk of bleeding simply through the act of walking. However, the higher rate may be awarded if your child:
 - has an inhibitor

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- has repeated breakthrough bleeds in ankles, knees and/or hips despite being treated prophylactically
 - is not treated prophylactically and has repeated breakthrough bleeds in ankles, knees or hips
 - already had some damage to a knee, ankle, or hip
- 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.

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Rates of DLA

These are the current weekly rates of DLA for April 2014 – April 2015.

- 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

- higher rate..... £82.30 per week
- middle rate..... £55.10
- lower rate..... £21.80

The higher rate is paid if you meet both day **and** night care conditions.

The middle rate is paid if you meet either day **or** night care conditions.

The conditions for the lower rate are separate from those for the higher and middle rates.

Mobility component

- higher rate..... £57.45 per week
- lower rate..... £21.80

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 and other benefits

DLA isn't taken into account as income for income-related benefits such as Housing Benefit, Council Tax Reduction (which replaced Council Tax Benefit in April 2013) and Tax Credits.

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Claiming DLA

To make a fresh claim for DLA, order a claim form from the Disability Living Allowance helpline on 0345 712 3456. The day you call will be taken as the date of 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.
- Any DLA you are awarded will be backdated to the date you ordered the form.
- It usually takes 40 working days to deal with a DLA claim.

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 may also need to make a **renewal claim** for DLA. This is if your current award of DLA is for a fixed period. 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. The DLA number is 08457 12 34 56.

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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 be **DLA1A Child June 2016**.
- 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.**
- **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 starting here and taking your time to think about what you want to write.
- 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 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 stepped in to stop your child hurting themselves and 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 with them? What do they 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.

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(NB: This information really answers **questions 49, 51 and 53** as well. There isn't enough space on the form to answer these questions fully so answer them fully in question 65. We suggest writing 'see question 65' 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
 - Describe what you do in the case of a 'breakthrough' 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 65' in answer to question 43.)

- Include any 'help' you give with medical equipment. This could be checking a portacath, 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 they take?

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 65.

The less important questions

Questions 25-31 are about your child's walking ability when walking outside. They are about entitlement to the higher rate of mobility component. Very few children with a bleeding disorder qualify for the mobility component at the higher rate, but see the information in the first section of this factsheet for more information.

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.

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Questions 18, 37-42, 44-48, 50, 52

Question 18 will only apply to some children.

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 **attention in connection with bodily functions** you have given your child over a recent period of between two and four weeks. Pages 29-31 of the information booklet that comes with the claim form may give you some ideas of how to do this.

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

In **question 22** only list aids if your child uses them all the time and not just when they have a bleed.

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 DWP to write to them requesting further information.

- **Question 13:** 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 the centre whose name they would prefer you to put.
- **Question 14:** 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 13.
- **Question 17:** 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.
- **Question 19:** It can be useful to get someone else to add their viewpoint but you don't have to complete this part.

The 'administrative' questions

- **Questions 1-12, 15 and 16** are fairly straightforward. If this is a first claim for DLA you won't 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.
- **Questions 56-64** are also straightforward. However, it isn't 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.

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- **Questions 21:** 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 69** is for details of the bank account you want DLA paid into.

You must sign the declarations in **questions 20 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**.

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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 arbitrary. 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
- 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).

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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 2-4 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.

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.

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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. Your appeal will be heard by an independent tribunal. You can expect to wait several months before a tribunal will hear your appeal.

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 telephone 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/uploads/system/uploads/attachment_data/file/181311/SSCS1.pdf
- 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.

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>

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.

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