

# **DISABILITY LIVING ALLOWANCE FOR CHILDREN**

A guide for parents/carers

**Disability Living Allowance (DLA) is a non-means tested, tax free benefit. This means your income is not taken into consideration when your application is assessed. This guide aims to help parents/carers to understand the application process for DLA and how their child's care needs may mean that they meet the eligibility criteria.**

**DLA is available for children under 16 who have care or mobility needs which are above those another child of the same age would require. This is for care they require from another person, not that which they can provide themselves.**

**DLA cannot be claimed sooner than three months following diagnosis, so you must wait for this time to elapse before submitting your application. DLA cannot be back dated, so any award will only be paid from the time your form is received. If you request a paper application form, your application will be backdated to the date you requested the form – though your application must be returned within six weeks of this date.**

You can request a paper application form by calling the DLA helpline on **08457 123456**, Mon–Fri between the hours of 8am–6pm, or if you are in Northern Ireland **0800 200 674**. If you prefer you can download a claim form and print this yourself or complete an interactive form which can be submitted online. Both of which are available from the government website; <https://www.gov.uk/disability-living-allowance-children/how-to-claim>

There are two components to DLA; Mobility and Care.

Children with diabetes requiring additional care needs may be awarded the Care component. This has three possible rates.

- **LOW RATE**

This is awarded if a child needs extra looking after for a **significant portion** of the day.

- **MIDDLE RATE**

This is awarded if a child requires **frequent attention** throughout the day or **prolonged and repeated attention** at night for help with bodily functions. Or, a child needs **continual supervision throughout the day** to prevent danger to themselves or others, or at night they require another person to be awake to watch over them for a prolonged period of time, or at frequent intervals in order to avoid danger to themselves or to others.

- **HIGH RATE**

This is awarded if a child needs care as outlined for middle rate, but for both the daytime and during the night.

**Significant portion** – this has been taken by tribunals to mean around an hour.

This can be all at once or spread out over a longer period.

**Frequent attention** – means several times, not once or twice.

**Throughout the day** – means not just in the morning or the evening. The attention needed must be spread throughout the day, although it can be more frequent at one particular time.

**Continual supervision** – is less than continuous but more than just occasional.

**Prolonged attention** – means at least 20 minutes.

The guidance given here relates to completing form ‘DLA Child January 2014’. This is for a child aged under 16. The information provided relates only to Type 1 diabetes and you will need to consider any other condition your child has independently of this information. Though you may wish to consider any impact other conditions may have on diabetes management.

When providing details of your child's condition, it is important not to play down the effects. It can be hard to focus solely on the things your child cannot do for themselves or has difficulty with, however it is important that the impact of the condition for your child is adequately explained. The person assessing your claim is very unlikely to have any prior knowledge of diabetes and certainly won't know the specific care requirements of your child. It is therefore important that you explain everything in detail and write as you would if explaining to someone who knows nothing about diabetes management whatsoever.

DLA applications are detailed and complex. Even the most competent of form fillers can find them a challenge. It is therefore really important to prepare before committing pen to paper as there is a lot of information to consider.

- **Read the notes that come with the application form** – It can be tempting not to do this, they are long and it is time consuming. Doing so can help to understand what information the DWP are looking for and the sort of language they use.
- **Prepare** – Take time to read through the form and make notes. If any questions are particularly confusing or you are not sure how to approach, spend time thinking about those and discuss with others prior to completion.
- **Keep in mind what DLA is for** – Remember that DLA is paid for the care your child needs from another person. If they manage some aspects of their diabetes management themselves, this information may not be relevant. If there are elements which they sometimes manage themselves but at other times don't, just detail the times they need assistance.

For example a child may monitor their blood glucose themselves most of the time. However they may need someone else to do this when they are hypo or during the night or they may need prompting to do this. It is this support from someone else that needs to be detailed. Also be mindful of the support your child needs as opposed to that which they actually receive – if your child needs support at school or clubs which they don't actually get, then do detail this as a care need even though it is not being provided.

- **Keep a diary** – In the time before completing the form it can be useful to keep a diary and document everything that is done in relation to your child's diabetes. Include every single detail, such as calibrating test strips, changing lancets, disposing of sharps appropriately and any distress or resistance from your child. This can be helpful when it comes to completing the form to ensure you don't forget anything. As unlikely as that may seem there is so much involved in diabetes care that it can be easy to miss everyday things when trying to recall it all at once. This may also help to identify what your child does for themselves and what they require from someone else. It may be relevant to include this diary with your application if the content gives a good example of the care required.
- **Seek help** – Ask for support from your child's diabetes specialist nurse, but also others involved in their day to day care, such as relatives or school staff. If they can provide a short statement detailing the care they provide or that your child needs, this could be helpful. They may have thought of things you haven't. It can also be helpful to have someone just read over the form before you send it; this will help identify any areas that require extra clarity. If anything on the form is unclear to someone who knows your child's needs, then it is likely to be unclear to the assessor.

- **Keep a copy** – DO make sure you copy the form and any supporting evidence before you send it, or print it before you submit it online. If any queries arise, you will need to be able to look at exactly what you have written. It is also important to have this information available should you need to appeal a decision later.

It may also be helpful to have a look at the Department for Work and Pensions (DWP) guidance for assessors and directly address any points which are not accurate for your child when completing the application. This can be viewed here:

[www.dwp.gov.uk/publications/specialist-guides/medical-conditions/childrens-medical-guides/diabetes/treatment](http://www.dwp.gov.uk/publications/specialist-guides/medical-conditions/childrens-medical-guides/diabetes/treatment)

When you come to completing the form do not be afraid to write outside of the boxes if space is insufficient. You can also add additional pages if you need to.

Once your form has been received you will be sent an acknowledgement of receipt. As part of this you will be given a timescale within which to expect your decision. New claims can take up to 40 working days to deal with. DLA awards are usually made for a fixed period of at least one year, towards the end of that time the DWP will write inviting you to reapply for DLA.



## **COMPLETING THE APPLICATION FORM**

### **Questions 1-12**

These questions relate to your child's personal details, fill in as appropriate.

### **Question 13**

This question asks about who your child has seen regarding their diabetes apart from the GP. Provide details of your child's consultant. You can also provide details of other professionals your child has seen in question 70. You may wish to include your child's PDSN, psychologist, dietitian or anyone else they have seen in relation to their diabetes.

### **Question 14**

This is information specific to your child. Fill in as appropriate.

### **Question 15**

#### **HAS YOUR CHILD HAD OR ARE THEY WAITING FOR TESTS TO HELP DIAGNOSE, TREAT OR MONITOR THEIR CONDITION?**

Tick the 'yes' box. Include here HbA1c and any screening tests such as kidney function, eye screening and foot tests. Emphasise here that these are routine tests carried out as part of regular monitoring of the long term effects of diabetes.

## **Question 16**

### **DO YOU HAVE ANY REPORTS, LETTERS OR ASSESSMENTS ETC?**

This may include a summary of the last clinic visit or other report from related appointments.

If you have such documentation tick 'yes' and provide a copy with your application.

## **Questions 17 & 18**

This is information specific to your child, fill in as appropriate.

## **Question 19**

### **STATEMENT FROM SOMEONE WHO KNOWS THE CHILD**

If possible have this completed by your PDSN, or another person included in your child's care, such as teaching staff or family members.

## **Question 20**

### **CONSENT**

This asks if you agree to contact being made with your child's healthcare team regarding your claim. Tick 'yes' or 'no'.

## **Question 21**

### **ABOUT THE CHILD'S ILLNESSES OR DISABILITIES**

List Type 1 diabetes and how long they have had it.

When answering what treatment they have, put everything they are prescribed including insulin and specify if this is administered by injections or pump. Also include hypo treatments they are prescribed such as Glucagon or Glucogel.

Complete 'how often they have treatment' as applicable for your child. For injections be sure to include any long acting doses, along with injections at times relevant to eating and additional injections if required when blood glucose levels are high. For an insulin pump, treatment is constant with extra insulin delivery at times relevant to eating and extra boluses required when levels are high.

If you have an up to date prescriptions list (and consumables list for a pump) send a copy with your claim.

## **Question 22**

### **AIDS AND ADAPTATIONS**

Children with diabetes generally do not require these. Tick the 'no' box.

## **Question 23**

### **CLAIMING UNDER THE SPECIAL RULES**

This is for children who have terminal conditions. Diabetes is not a terminal condition, tick 'no'.

## **Question 24**

### **WHEN THE CHILD NEEDS HELP**

Tick varies, as it will do at times of illness, activity etc.

In the 'tell us' box provide as much detail as possible, further detail can be given on a separate sheet of paper or in question 70 if necessary. Include information about treating highs/lows, how treatment changes when ill, or before or after exercise. Include pump set changes and any problems which may occur with a pump such as bubbles/kinks in the tubing. This should also detail any additional testing which may be required at these times. Remember to include checking for ketones when levels are high or your child is unwell.

## **Questions 25–31**

Complete questions 25 & 26. The rest of these questions relate to mobility problems. This is not usually relevant to a child with diabetes. If relevant to your child, complete as appropriate.

## **Question 32**

### **DO THEY NEED GUIDANCE OR SUPERVISION MOST OF THE TIME WHEN THEY WALK OUTDOORS?**

If your child has hypos, tick 'yes'. Tick all boxes that apply to your child when hypo.

## **Question 33**

### **DO THEY FALL DUE TO THEIR DISABILITY?**

If your child falls due to their diabetes, (when hypo for example), then tick 'yes' and provide details as asked in the question. If not, tick 'no'.

## **Question 34**

This is space to elaborate on mobility needs or supervision your child requires outdoors. If you have ticked 'yes' to question 32, use this space to explain in more detail how hypos can affect your child when walking outdoors. For example, if your child needs supervision because they become unsteady on their feet whilst hypo, explain this here. Use this space to explain the help needed when your child is hypo and the dangers of not treating this.

## **Question 35 & 36**

Fill in as relevant to your child, if they have mobility needs.

## **Question 37**

### **DO THEY NEED HELP TO GET INTO OR OUT OF OR SETTLE IN BED DURING THE DAY?**

Tick 'yes' if applicable to your child.

This refers to times when the rest of the household is awake. So getting up in the morning or going to bed at night. Not all children with diabetes will need this help. You may wish to consider things such as getting up in the morning following a night time hypo and the effects this has on your child, if any. You can elaborate in the box given, providing information relating to bed time routines, such as blood glucose monitoring and snacking/injecting as needed.

## **Question 38**

### **DO THEY NEED HELP TO GO TO THE TOILET DURING THE DAY?**

This usually does not apply to children with diabetes. However, some young children may need assistance, for example some children experience difficulty with pump tubing getting in the way when using the toilet, and may need additional help.

## **Questions 39–41**

These questions refer to help with dressing, personal care and getting around indoors. Children with diabetes do not usually have difficulties in this regard over and above the needs of others their age. Tick 'no'

## **Question 42**

### **DO THEY NEED ENCOURAGEMENT, PROMPTING, OR PHYSICAL HELP TO EAT AND DRINK DURING THE DAY?**

Tick 'yes' and complete the 'eat' box as relevant. In the box for further details provide information about eating sufficient amounts of carbohydrate, weighing foods and calculating the carbohydrate content of meals. Explain the consequences of getting this wrong. Also include information about getting a child to eat or drink when hypo and the difficulties that can be involved with this as well as encouragement to drink enough fluids when blood glucose levels are high. If your child has coeliac disease then you can also include the encouragement needed to make the right food choices and the importance of it.

## **Question 43**

### **DO THEY NEED ENCOURAGEMENT, PROMPTING, OR PHYSICAL HELP TO TAKE MEDICINE OR HAVE THERAPY DURING THE DAY?**

Tick 'yes' unless your child does this independently with no prompting.

Fill in every box below. 'Do their therapy' includes blood glucose monitoring. When thinking about how often this is required, include all routine injections and correction injections. If on a pump include all bolus doses and correction doses. Also include setting temporary basal rates or switching between basal patterns.

In the additional information box provide as much detail as possible. This should include any difficulties caused by distress or discomfort, and encouragement to rotate injection/insertion sites. Include pump infusion set changes and connecting CGM. Detail any times when this may be more difficult such as when hyper or hypo, or at times of illness or very active days. Remember testing for ketones when levels are high or at times of illness.

## **Questions 44–47**

These questions are about hearing, eyesight and communication. These things do not generally apply to children with diabetes. Tick 'no'.

### **Question 48**

#### **DO THEY HAVE FITS, BLACKOUTS, SEIZURES OR SIMILAR?**

Tick 'yes'.

In the box below write hypos and explain what happens.

Complete the tick boxes as relevant to your child, where you see the word 'fit' think hypo.

In the box at the bottom of the page provide any further relevant information such as comforting any feelings of anxiety or distress. If your child's hypo awareness varies, provide details of this here too. Also explain the consequences of leaving a hypo untreated.

### **Question 49**

#### **DO THEY NEED TO BE SUPERVISED DURING THE DAY TO KEEP SAFE?**

If your child needs to be observed for hypo symptoms, due to either their age or lack of awareness, tick 'yes'. Answer the remaining questions as relevant to your child, thinking about how they behave when hypo. Explain in the space provided, how it could affect them or others if a hypo occurred without supervision and what the outcomes of not treating it could be.

### **Question 50**

#### **HELP WITH DEVELOPMENT**

Diabetes does not affect development. Tick the 'no' box.

### **Question 51**

#### **DO THEY NEED ENCOURAGEMENT OR PHYSICAL HELP AT SCHOOL OR NURSERY?**

Fill this in for the help they need, not the help they receive. Tick 'yes'.

Tick, 'eat meals' and 'take medicine or do their therapy'.

Explain in the box provided what help they need. Consider blood glucose monitoring and prompting/physical help to do so; help with injecting; help with delivering bolus doses.

As well as physical help, consider help with calculating doses and carbohydrate counting. Also include help to make the right food choices (if applicable). Provide details of assistance in treating hypos.

## **Question 52**

### **DO THEY NEED ENCOURAGEMENT, PROMPTING OR PHYSICAL HELP TO TAKE PART IN HOBBIES ETC.**

Tick 'yes' or 'no' as appropriate for your child.

The details here are likely to be very similar as for school.

For more physical hobbies, consider and detail here any changes to insulin doses; additional testing or snacks; setting temporary basal rates on a pump; disconnecting a pump for relevant activities.

Again this is help they need even if they do not get this help.

## **Question 53**

### **DO THEY WAKE AND NEED HELP AT NIGHT, OR NEED SOMEONE TO BE AWAKE TO WATCH OVER THEM AT NIGHT?**

Tick 'yes' if your child needs help.

Fill in the 'have treatment' box; you may also need to tick 'settle'. Also tick the box 'are unaware of danger...'. When completing this think about testing, hypo treatment, correction doses and visual checks.

Elaborate on this in the box provided. Include the difficulty in getting a sleepy child to treat a hypo/inject or deliver a correction bolus. Include details of what you are observing if doing visual checks. Provide details of any further blood glucose checks to ensure treatment has worked. Also consider whether it is hard to settle your child after providing help during the night. If your child bed wets due to high levels, give details of this here also and remember ketone checking.

## **Question 54**

### **EXTRA INFORMATION ABOUT CARE**

Put as much detail as possible in here about your child's care needs.

Think about; taking medication, testing blood glucose and ketone levels, help with eating, carbohydrate counting, treating/identifying hypos/hypers. Pump set changes and connecting continuous glucose monitor (CGM).

## **Question 55**

### **WHEN DID THE CARE NEEDS START?**

Fill in as appropriate to your child.

## **Questions 56–69**

### **ABOUT YOU**

Fill in as appropriate.

## Question 70

### EXTRA INFORMATION

Put as much information here as you can. Include anything you have not been able to throughout the rest of the form, but don't worry about repeating anything. Include every single detail no matter how small it may seem, from calibrating test strips to disposing of sharps.

Provide information about any healthcare professionals involved in your child's care additional to those detailed in question 13.

In the box provided, list any documents you are enclosing (such as prescription lists or medical report) and whether you want them returned.

## Question 71

### DECLARATION

Read through this and be certain you understand it. Sign and date the application and print your name.

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### THE DECISION

If your child is refused DLA or it is awarded at a lower rate than expected, you can challenge this. The time limit for challenging a decision is one month from the date on the DLA decision letter. It is very important that you respond within this timescale as late challenges are only accepted in certain circumstances.

It is helpful to have a written explanation for the decision; if this is not received you can request one. This will enable you to be clear about whether information you have provided might have been misunderstood by the assessor or whether you think the decision is fair.

Stage 1 in challenging any decision is by 'mandatory reconsideration'. You may be offered the opportunity to do this by phone. Whilst this is a quicker process it does have some disadvantages. Making your request in writing gives you the chance to consider the points you wish to make and gather any supporting evidence. It also means your communications are documented. It is important to remember that at every stage of appeal, your application is being reconsidered in its entirety. **This can result in a reduction of the amount awarded as well as an increase.**

At this point it can be helpful to source support from a specialist benefits advisor. This may be available from your local Citizens Advice Bureau or from an organisation called Turn 2 Us: [www.turn2us.org.uk](http://www.turn2us.org.uk). Another source of useful information about DLA is the [Contact a Family' booklet: A guide to claiming Disability Living Allowance for children.](#)

The DWP provide guidance for their assessors to refer to when making decisions about what rate to award, if any, as well as the length of time DLA should be awarded for. The individual needs of your child as presented on your application and any supporting evidence are what the decision should be assessed on as well as the DWP's own guidance for assessors. You can view this guidance via the following links;

[www.dwp.gov.uk/publications/specialist-guides/medical-conditions/childrens-medical-guides/diabetes/treatment](http://www.dwp.gov.uk/publications/specialist-guides/medical-conditions/childrens-medical-guides/diabetes/treatment)

[www.dwp.gov.uk/publications/specialist-guides/medical-conditions/childrens-medical-guides/diabetes/how-long-will-needs-last](http://www.dwp.gov.uk/publications/specialist-guides/medical-conditions/childrens-medical-guides/diabetes/how-long-will-needs-last)

If anything in the DWP guidance is contrary to your experience of the care needs of your child, then you can address these points directly. For example the details of treatment suggest that for both injecting and blood glucose monitoring, 'Children will be able to do this themselves from diagnosis'. In reality we know this is not often the case. It is also only under 'Difficult to control/Brittle diabetes' that the DWP suggest a child will need night time monitoring. Again, this is not often the case in reality.

Getting written evidence from other people involved in your child's care at this stage can be really helpful. Unfortunately, due to the tight time scale and their own workloads, some PDSNs can decline to comment unless reconsideration has already proved unsuccessful and the information is for use at tribunal. Some PDSNs may only give very general statements such as 'this child has Type 1 diabetes treated by a pump', which though well-meaning is unlikely to be much help. You may find it useful to provide our document '**DLA for children – A guide for Healthcare Professionals**' to your child's healthcare team and ask if they could consider the information given when providing a supporting statement.

Evidence from other people such as school staff, babysitters or relatives would also be helpful. They can detail the support they provide or the needs they see your child having when in their care.

If no changes are made to your award following mandatory reconsideration, the next stage is to have your appeal heard by an independent tribunal. Details of how to arrange this will be included when you are notified of the outcome of mandatory reconsideration.

Further sources of support for preparing for tribunal can be found at the end of this document.

The panel hearing a tribunal appeal is made up of a legally qualified tribunal judge and tribunal members. Tribunal members are trained volunteers and may include a doctor.

You will be offered either an Oral or Paper hearing. An oral hearing requires you or your representative to attend court and put your case to the panel. A paper hearing is considered on the evidence you submit to the court prior to the hearing date without the need for you or your representative to attend.

The easiest way to appeal a decision at tribunal is with specialist advice and/or representation. This is not always possible but people can represent themselves at tribunal and often do.

Any support you can gain from others who care for your child such as school staff or your child's PDSN is very important at this stage. If they are able to attend the tribunal hearing this could be very helpful, but even if they cannot attend, they can provide a written statement which you can read to the panel.

The outcome of the tribunal may be decided on the day in some cases, but you will always receive a written outcome within one month.

## **FURTHER SOURCES OF INFORMATION/SUPPORT**

Contact a Family: [www.cafamily.org.uk](http://www.cafamily.org.uk)

Turn 2 Us: [www.turn2us.org.uk](http://www.turn2us.org.uk)

Citizens Advice Bureau

England and Wales: [www.citizensadvice.org.uk](http://www.citizensadvice.org.uk)

Northern Ireland: [www.citizensadvice.co.uk](http://www.citizensadvice.co.uk)

Scotland: [www.cas.org.uk](http://www.cas.org.uk)

Department for work and pensions:

<https://www.gov.uk/disability-living-allowance-children>