



Disability Living Allowance (DLA)

As more and more children with complex congenital heart conditions survive, it becomes increasingly important to ensure that any support that they need to help them lead full and enjoyable lives is easily found and secured.

Disability Living Allowance is a grant that may be paid every four weeks, on application, by the Department for Work and Pensions (DWP), to help families achieve the extra care that children with these complex conditions require to ensure that they fulfil their potential. The allowance does not depend on how much the family earns (ie it is not means tested), it is paid where the needs of a child are over and above the normal needs of a child of the same age.

DLA consists of two components: Personal Care and Mobility. The components each have separate rules about eligibility, and also have separate rates. They can be awarded separately. Your child's diagnosis of a heart condition does not make them automatically eligible for support, instead the DWP look at how the diagnosis affects the child.

There are three levels of **Personal Care** allowance, the highest being paid to families who have to provide care both during the day and night.

Higher rate

Day and night care – during day, child needs frequent attention in connection with bodily functions or constant supervision to avoid substantial danger to self or others

- During night, repeated or prolonged attention in connection with bodily functions and / or supervision to avoid harm. 20 minutes plus (prolonged) or at least three times (repeated).

Middle rate

Day or night care – one of these – child needs frequent attention with bodily functions throughout day or needs constant supervision during day to avoid danger to self / others or needs attention at night (repeated, prolonged or frequent supervision).

Lower rate

If child requires help with bodily functions for a significant part of the day – at least one hour per day – either a single period or on a number of occasions.

Bodily functions – most questions relate to this, eg eating, communicating.

Care needs must be substantially in excess of the normal requirements for a child of the same age.

Extra attention could be either physical help or verbal encouragement.

Day / night definitions – when the adults in the house are normally awake / asleep.

Supervision – watching the child to prevent harm to self or others.

Help must be required for at least 4 / 5 days or nights every week.

There are two different levels of financial support available for the **Mobility** component, depending on your child's mobility needs. The higher rate is the only possibility from age three to five, and is awarded if the child is "unable or virtually unable to walk" (the DWP will look at speed, length of time taken, manner of walking, any discomfort or pain, as well as distance). From the age of five, two rates are available. The lower rate is for children who need guidance or supervision when walking out of doors or in unfamiliar places.

Little Hearts Matter has been asked to help with these claims by both parents and members of the cardiac teams that look after them, as the questions can be complex and daunting.

Over the following pages we hope to offer help to all those who have to complete these complex forms. Included in the information are some sample answers and points to consider when thinking about your answers to the questions.

It is important to remember when completing DLA forms that each child with complex heart disease is different. The following suggestions of information to include in your application are only general rules and ideas. Some children will have a better quality of life, some a more difficult one.

For some parents it is difficult to understand that their child has any special needs at all. It would, however, be unusual for a family of a child with this complexity of heart disease not to need to give extra support to help a child fulfil their potential to live a useful and fun-filled life.

Before you start to complete the forms it can help to write a diary of the care that you give your child for one week. This serves a number of purposes.

- It will clearly show whether you do extra care or not.

- It will help you to understand how much you do for your child both through day and night.
- It can help you to think about bad days and 'better' days, and think through whether the 'better' days are actually OK or just not as bad as the really bad ones!
- It will help you to understand how long each task takes.
- It can be included in your DLA claim.

Why should I claim?

Although a parent offers all care to their children whatever they need, very often children with complex heart conditions require a great deal more attention than other children of their age.

They need very careful supervision as their cardiac condition can change causing increasing heart failure or their anti-coagulation medication may put them at risk if they fall. These problems need swift and skilled attention. Until these children reach adulthood they will be unable to respond themselves to a change in their condition.

Their nutritional needs are greater than other children, they require a higher number of calories to keep their body running, and more to grow but they don't have the energy to take in the food they need easily. Lots of time and imagination is needed to help these children grow.

They need medication day and night.

They need to be kept warm: during the cold weather the heart has to work harder to circulate blood to the hands and feet and the children can get very cold.

Some parents think that they should not claim because they don't need the money, but it is important to remember that in the future your child may. It can be saved for them for use in adulthood; remember it may be difficult for them to get a mortgage because they are probably not eligible for life insurance. The whole family may deserve a holiday because of all the stress and worry involved in caring for a child with these complex problems. It can help to cover the expenses of time spent in the hospital. It can also help to raise the profile of the needs of children with complex heart problems, as sadly many people do not understand that these children do have special needs.

It can open the door to other benefits such as Carer's Allowance, and can make applying for a Blue Badge easier. Please refer to our Benefits leaflet for further information.

When should I claim?

Claims can be submitted anytime after the birth of a child with special care needs but unless your claim has been made under special rules (an allowance made for children who are terminally ill), the allowance will not be paid until the child is three months old (you can submit the claim forms when your child is aged between 10 and 13 weeks old). The allowance is not paid whilst a child is in the hospital so once an allowance has been granted, long stays in the hospital must be reported to the DWP.

The allowance, if granted, will be paid for different lengths of time, such as one, two or three years - rarely is it granted for life. Six months before the allowance expires the DWP will re-issue claim forms for re-application.

Where do I get the claim forms?

Benefits Enquiry Line **0800 88 22 00**

You should phone to request a form as soon as you know you might apply, even if you then subsequently complete an electronic version of the claim form, as the date you requested the form is the earliest the claim could be backdated to.

Download a form from www.direct.gov.uk - visit the section 'Disabled People', then you'll see DLA as a link under 'Financial Support'.

How do I complete the Forms?

You need to write a great deal about your child's needs, and you may think that the form asks you to repeat yourself. Just keep writing - the more they know the more likely they are to grant you the allowance.

Remember 1

DLA is granted on the care needs of your child and not on their condition or syndrome, however severe. Using the diary as a guide you should be able to clearly state what type and amount of care you deliver.

Although we all like to talk about the positive development of our children this is not the time to write about just their best days. Think about the difficult things that you do.

- How long it takes to feed the baby.

- How long it takes to clean through any special feeding equipment.
- How often you have to get up at night.
- How you need to take the pushchair with you for your school-age child.
- How difficult it is to stop tree climbing when the children are on anti-coagulation treatment.

Remember 2

As you add the details of care on each DLA question, remember that the person in the DWP office does not know your child, will not understand congenital heart disease and cannot imagine the amount of care you give.

It is better to give too much information than too little. You may need to write the same information many times as it relates to more than one question. Don't worry that you will bore the reader. They need to know how much of the child's and carer's life is affected by the child's disability. You need to provide evidence of their needs and what you do differently. You can write in full sentences or note form, whatever works for you.

Don't be tempted to lie though, as a medical may be requested.

Remember 3

Seek help if you find that parts of the application form are difficult to complete. The hospital cardiac social work team, the Cardiac Liaison Sister service or Little Hearts Matter will willingly offer support. If at all possible, use a computer to complete the form so that you can add to each question as necessary, and to make future claims more manageable. If you don't have access to a computer, you might want to complete a draft copy of the form in pencil which can then be discussed with whoever is supporting your application. Advice can be sought from the Disability Living Allowance Helpline on **0800 88 22 00**.

Remember 4

Part 26 - who can give more information on care needs, these people are a good source of support.

- Cardiac Liaison Sister
- Named ward based nurse
- Health Visitor

Part 37 - Statement from a person who knows the child.

- The Cardiac Consultant

Consultants are very busy and it can take them time to complete their section of the form but from experience the DWP is more likely to award an allowance if the cardiac consultant completes the form than any other member of the medical team.

(Take the form with you to an outpatient visit or send it to the consultant, with everything else completed and signed, asking them to complete their section and then send it on to the DLA office in the envelope provided.)

Remember 5

To take two photocopies of the completed forms and any supporting information before you post the application. Keep a note of the date that it was sent.

What else shall I include in support of the application?

The more information the better

- Information on your child's cardiac condition.
- Reports on the physical and mental ability of your child (if these have been assessed) – eg school IEPs or statement if in place
- The care diary
- Letters from major carers e.g. teachers, social workers, and liaison sisters.

Good luck with your application.

What do I do if my claim is turned down?

Firstly don't despair. Many, many claims for DLA are turned down or the allowance is reduced on re-application.

Reasons: -

- Not enough information was included in the original claim.
- The wrong person was asked to complete the medical parts of the form.
- The wrong person read the form when it reached the DWP.
- The care needs of the child have changed and the allowance has been altered.
- No help was given when the forms were completed.
- Someone without enough specialist knowledge helped with the application.

You can either ask by telephone for a reconsideration or you can make a written request for an appeal. Asking for a reconsideration means that a completely different person ('decision maker') will look at your form and supporting documents again, and may come to a different decision about your award.

When an allowance has been denied or the level of payment has been changed it is a good idea to ask someone knowledgeable in completing the applications to help you look through the forms to see if improvements can be made in the information submitted. If you feel that more can be added to improve the application or you feel that someone who has supported the original application can write more about your child, then tell the DWP that you wish to appeal. The details of how to appeal will be on the rejection or reduction in allowance letter.

Ask the DWP for the medical reports and all the documentation they hold on file. You can also ask for an explanation of how they arrived at their decision.

Then, work with an advisor to collect information from medical, social and support sources to send to enhance your application. For example ask the team at LHM to write a letter explaining the needs of children with complex heart conditions. Ask your consultant to write in support of your claim. Ask a teacher to explain what extra care is needed in the classroom.

If the allowance is still refused it may be necessary to attend a tribunal. Don't go alone, if a social worker or a cardiac liaison sister is available to support you then ask them to attend, if not a good friend who knows the needs of the child. The word tribunal is frightening but it just means that you will be given the opportunity to explain the care needs of your child to a panel of experts: someone connected to law, a doctor and someone involved with the care of disabled people. They will not know about complex heart disease,

or the special needs of your child so plan what you are going to tell them before you go. There may also be a member of the DWP there to explain why they have turned down the claim. It is always recommended that you attend the tribunal yourself, so that you have the opportunity to explain your child's needs.

If at any time you would like more information or support don't hesitate to contact the Little Hearts Matter Team, we will always try to help.