



children's heart
FEDERATION

Disability Living Allowance Babies and Children with Heart Disorders

You may not have realised that if your baby or child is badly affected by a heart disorder, you could be entitled to Disability Living Allowance on his or her behalf. If your child suffers from any other condition which causes disability, such as 22q11 or Downs Syndrome, you may be entitled to get DLA even if the heart disorder is not disabling itself.

The amount of DLA you can get for your child depends on how much personal care (Care) he or she needs, and whether he or she needs help with getting around (Mobility).

From the 11th April 2006 the rates will be as follows:

Care:

Higher £62.25

Middle £41.65

Lower £16.50

Mobility:

Higher £43.45

Lower £16.50

If you are claiming Income support or job seekers allowance already, you may not be aware that these benefits also have extra premiums if you have a disabled child. They are carer's premium which is £25.80 and disabled child premium which is £43.89 from April 2004.

Best Chance of Success

To give your claim the best chance of success you will need to spend quite some time on the form, preferably with someone who can help you through it. This could be your partner or a close friend to whom your child is important and who knows your difficulties. Often

two heads are better than one for structuring shorter sentences with greater impact, remembering little details - just providing you with company can make the form easier as it is 26 pages long and very time consuming.

1. Get the claim pack for a child under 16 from your local Social Security office (Under DWP in phone book) or from the Benefits Enquiry line: 0800 88 22 00. People with speech or hearing problems using a text phone can dial 0800 24 33 55. There is no time limit to claiming, but the sooner you get the form completed and back the sooner it can be paid. If DLA is awarded you will get the money from the date they received the completed form.

2. Read the form through thoroughly. With 26 pages of questions you might find it quite daunting at first, especially since you will notice that a lot of the questions appear to be repeating information you will have already given.

It is a good idea to keep a diary for a few days after you have looked at the form. Write down all the problems your child has with the heart condition and the extra care this generates – include things like - transport, poor concentration, do they have difficulty turning on taps, does your child need diuretics which keep them up at night, stand-by oxygen, frequent blood tests, frequent tube feeds. Make a note of how long you spend giving this extra care as you will be asked how long this takes. Note how many times you

give this care as again you will be asked for this information.

Remember things like soothing your child to sleep at night as it counts as a care need. Include the extra time spent preparing the food for special diets, cleaning up. Do you have to sit with your child to encourage him/her to eat? Does your child suffer with reflux, or have intolerance's to medication. These things should be recorded in your diary, noting the time you spend sitting with your child during vomiting, cleaning up etc.

Does your child need help with dressing and undressing? This might simply be helping to choose appropriate clothing due to weather conditions.

Do you monitor your child's condition and/or the effects of medication? How many times do you check that your child is well, has no symptoms that may indicate a worsening of the condition or an intolerance to medication? Note what symptoms you are looking for, weight loss, breathlessness, sweating, tiredness, dizzy spells etc.

3. You should also get someone in the medical field to help you with some of the questions that are more to do with your child's medical condition. This could be your Health Visitor, GP or Hospital Social Worker.

Your Local Authority should have someone who deals with welfare who can help you, but they may not know very much about your child's condition. Your support group may be able to offer an experienced member, especially if they deal with your child's particular condition.

If you have a school age child who has been statemented or reviewed because of special educational needs, the educational psychologist, or special needs advisor in your local

authority may be able to help you. The Citizens Advice Bureau will nearly always be able to offer expert help.

4. Write out your answers in draft, separately from the form, or get someone to do this for you. The Benefits Enquiries line (0800 88 22 00) offers help and will draft a form and send it for you if you can give them the information needed over the telephone.

DLA and Other Benefits

DLA is **not** taxable and does not reduce the amount of any other benefits you may be getting. In fact if you are already receiving JSA, Income Support, Housing Benefit or Council Tax Benefit, you will be entitled to extra benefit in the form of disabled Child Premium and Carers Premium.

If your child gets DLA at the middle or higher rate you will be able to claim Carers Allowance for looking after your child for 35 hours a week.

Would your child qualify

Where you live: Your child must normally live in Great Britain (England, Scotland and Wales), and should have been living in the European Community for 26 of the last 52 weeks. If your child is under 6 months old he or she needs only to have been living in Great Britain for 13 weeks.

There are different rules if you are a service family, or if your child has been abroad for medical treatment.

Three month rule: Help with personal care or getting around should have been needed by your child for the three months before the date of your claim, and must expect to be needed for the next six months – but if, sadly you have heard that your child may not live for more than six months, or if he or she is waiting for a heart transplant, the three month rule only applies to DLA for the mobility component.

Need for care rule: To qualify your child must need one or more of the following:

- attention to his or her bodily functions (such as tube feeding, or help with washing or dressing in an older child) for a significant part of the day.
- continual supervision throughout the day to avoid substantial damage to his or her self (such as may occur when a child sometimes has a very fast, or very slow heartbeat), or,
- needs prolonged or repeated attention at night to his or her bodily functions (for example when oxygen has to be given), or
- needs someone to be awake during the night for a prolonged period, or at frequent intervals in order to avoid substantial damage to him or her
- but if sadly, your child may not live for more than six months, or if he or she is waiting for a heart transplant, this care rule should not apply.

DLA cannot be paid for *the first time* while your child is in hospital.

Need for help with mobility rule: To qualify children who are between three and five can only get mobility allowance if they qualify for the higher rate. Your child must be at least five years of age to be eligible for the lower rate. For the higher rate he or she must need considerably more help with getting around than other children of the same age, and either:

- needs guidance or supervision for most of the time when outdoors in unfamiliar areas (for example because of the danger of fits, or because of loss of sight) or,
- is unable or virtually unable to walk or has to exert him or herself to walk to such an extent that it would constitute a danger to life or would be likely to lead to a serious deterioration in health (for example breathlessness and exhaustion).

The claim pack

Check that you have the right claim pack (DLA1A *Child November 2003* in the left coloured margin), and that it has all the right pieces of paper:

- A pink form - *Notes about claiming Disability Living Allowance for a child under 16* - you need to read this.
- A blue form - *How to claim for a child under the special rules*.
- An orange form – *Section 1* – you must complete this form.
- A green form – *Section 2: How the child's disability or illness affects them* – you must complete all of this form (unless you are claiming for a child under the special rules and for mobility, in which case you will only need to fill in pages 1 –4 and 25). Ask for help completing this if you are at all unsure, but always keep in mind what you would expect from a child of a similar age without your child's problems.

What to look out for on the forms

The orange form

1. On the front of this form it asks you for the 'Child Reference Number'. This is the National Insurance number. If you don't know it, you may find the number on your child's birth certificate and/or

Child Benefit book or letter from the Child Benefit Centre if your child benefit is paid directly into your bank account. If not, complete the form without the number and the DWP will issue the number when they reply to you.

2. On page 6 you are asked 'is someone getting Job Seekers Allowance or Income Support for the child...?' This is because if you are receiving one of these benefits when the JSA or Income Support is worked out, you will be entitled to a higher child premium for your 'disabled' child if you are awarded DLA for either care or mobility at any rate.

If your child receives DLA care at the highest rate, you will be entitled to an 'Enhanced' disabled child premium. If you or your partner are also getting Carers Allowance for looking after your child, you may also be entitled to the Carers Premium. You can apply for the Carers Allowance once DLA is in payment).

3. On page 8 you are asked the names of your child's **main** illnesses or disabilities. When you are filling in the box below about medicines, include those for the less serious illness – for example sunblock because drugs make your child sensitive to sunlight, treatment for conditions such as eczema or asthma, special diets and of course oxygen if your child needs a supply.

4. On pages 11 and 12 you are asked to give details of people who can be approached for information about your child. Let these people know they may be asked to give this information and tell them why you are claiming. Your GP may not know the full details of your child's heart condition and your cardiac specialist may not know of all the difficulties your child has.

The green form

1. You will need to fill in this form so that both the care and the mobility problems your child has can be taken into account – but if sadly, your child may not live for 6 months you only need to fill in pages 1 – 4, and 25 if claiming mobility help.

2. Page 1 – Your child's reference number. This is your child's National Insurance number. If the number is not on any Child benefit correspondence don't worry, leave it blank and the DWP will notify you of it on their letters to you.

3. On page 2 – for a child with a heart disorder you will probably tick 'has physical disabilities' and also 'has a long term illness'. Think about ticking 'has a learning difficulty' if your child is

slow or behind at school or, for a younger child who is not meeting his or her milestones for turning, reaching, sitting talking etc. You may want to tick 'has a mental health problem' if your child changes, e.g. after surgery and, for example, becomes very insecure, obsessive or has frequent nightmares.

4. Fill in pages 3 and 4 whether you are claiming mobility for the child or not.

5. Page 5 is about why your child needs someone to keep an eye on them. Examples of this could be that you are constantly monitoring your child for symptoms that will indicate a worsening of his or her condition - attacks of arrhythmia, needing oxygen or regular medication and possibly intolerance's to medication, constipation problems and urine output need regular monitoring too.

6. Pages 6 and 7 concern your child's development. Remember the difficulties of club fingers, or muscle weakness, or nerve damage – most common needs for help are turning on taps, getting washed or dressed, using the toilet and getting up or going down stairs.

The social skills are also as important. Ask your child's school or playgroup what the current situation is. Remember ask them to compare your child to other children of the same age when talking eating, playing outside, taking knocks for example. Remind them when your child is vulnerable. The help school provide could be for example, staying with your child so that he or she can remain in their group for some activities, having indoor access in the cold weather, compensating for the isolation from class mates this can cause.

7. On pages 8 – 19 you may have already covered some of these points, but it is important you repeat them here in as much detail as possible.

This is where your diary will be very useful. On page 15 cover the time it takes to get medicines and draw them into the syringes and so on. Sterilising afterwards and clearing up. Sitting with your child while he or she takes them and waiting for any reaction if your child has any intolerance's. Don't forget the sun-block if your child has a drug induced sensitivity to sunlight. On page 18 cover the details of what can happen when your child has a very fast or slow heart rate.

8. On page 19 you can give more details of how your child's condition is affecting his or her mental health. Is your child more anxious since surgery, worried about some activities affecting his abilities. Is he or she worrying more than usual about relatively normal activities and how much is this affecting his or her daily life. Is your child suffering with disturbed sleep and needing reassurance during the night? Does your child need to be accompanied when going out of the house even for short distances?

9. On pages 22 and 23 you will need to show how your child's illness or disability affects him or her. Think about how your child's activities are limited – are you happy for him or her to go out alone or with other children, or do you prefer a responsible adult to be available. You may want to mention, for example,

- going to school – perhaps by taxi to avoid waiting for a bus or a long walk.
- swimming – with a carer
- Making special trips with the school, such as a field trip – with someone to deal with medicines
- Attending a social club, such as cubs or brownies – with a carer
- Visiting a library – with a carer

For younger children you may want to concentrate on travelling with the family in a safe environment such as by car or taxi, special seats to avoid reflux etc.

10. On page 24 try and cover all the points you have already made, especially where problems have arisen for arrangements for the child or for the family.

11. On page 25 – this section is trying to establish by what date your child will have needed care or mobility for three months.

12. Page 26 – you may want to ask someone who often sees 'normal' children to complete this. Doctors and nurses may compare your child with children who have more severe problems rather than with ordinary children, and therefore underestimate the problems and difficulties your child has.

When you should claim

Put in the claim as soon as you can, so that your child can get DLA as soon as he or she is entitled to it – this will be:

If your child is under three months old

If you have had the sad news that your baby may not live for more than six months, or if your child is awaiting a heart transplant, you should get DLA straightaway and it should be awarded at the highest care rate.

If your baby has a good chance of survival, but has needed a lot of care since birth and will go on needing extra care for at least six months, you can get DLA for care when he or she is three months old. Put in your claim as soon as you know that your baby will go on needing care for six months.

The earliest you can get DLA for mobility is when your child is three years old.

If your child is three months to three years.

You can get DLA for care but not for mobility.

For three months your child must have needed much more care, or help with getting around, than for a child of his or her age would normally need, and expect to need such care for at least a further six months. But if sadly, your child may not live for longer than six months, or he or she is awaiting a heart transplant, you could get DLA for care straightaway.

If your child is three years or older.

You can get DLA for your child for care and/or mobility at the higher rate.

For three months your child must have needed much more care, or help with getting around, than a child of his or her age would normally need and must expect to go on needing such care for a further six months. But if, sadly, your child may not live for longer than six months, or he or she is awaiting a heart transplant, you could get DLA for care straightaway.

If your child is five years or older.

You can get DLA for care and/or mobility at the lower or higher rate.

POINTS TO REMEMBER

1. Keep a diary for a few days before completing the claim form.
2. If your child is walking, *measure* the distance he or she can walk before becoming breathless and/or sweaty. It is easy to over estimate distances.
3. Time yourself preparing medications from start to finish. Finish being when you are completely satisfied your child is not going to vomit and you have cleaned everything away ready for the next dose. Include time taken to obtain syringes or prescriptions that are off licence.
4. For once, unfavourably compare your child to 'normal' children of a similar age and note what extra care your child needs.

5. Note how many times each day and night you check your child for symptoms that may indicate a

worsening of his or her condition. This is called monitoring and is a very important point to remember. Many parents do it constantly.

6. It is considered to be night-time when the whole family has gone to bed. Everything you do after that time is night care.
7. Does your child choose appropriate clothing for his or her condition and the weather?
8. What special attention is given to your child's education. Does he or she need to go inside during cold weather, hot weather or windy weather and who stays with him or her?
9. Last but crucial. Think about the days your child needs the most care and use those days to complete the claim form.

Although it is natural to want to concentrate on how your child is improving, for the purpose of claiming DLA it is vital to remember your child's needs don't go away just because one day is better than the one before. DLA assessors will be looking at the whole claim and if they think your child's needs are much less on some days you may find the claim either disallowed or the lowest rate awarded. By indicating your child's needs are not as great on some days will almost guarantee a claim being disallowed on the basis that your child can i.e. 'walk 100 yards' on one day despite being unable to the other six days. So make sure you make it clear your child needs this care for seven days every week. Though the time each care gets will be variable, **don't** be

tempted to *underestimate* how long everything takes.

One thing worth remembering is that the people who assess your claim are not medically trained and have no idea about heart conditions or any other serious illness. So always explain in as much detail as possible how any condition affects him or her. For example if your child has reflux say this means he or she needs frequent small feeds, a special diet and medication but tends to vomit after feeds, becomes dehydrated and possibly constipated.

Also remember that the person looking at your claim today will have been dealing with a completely different condition yesterday. There is no specialist department for each disability or condition.

Each assessor has a list of criteria to assess care and mobility needs. It is a very ambiguous process as one person may view something completely differently from another. The more information you give the easier it is for the person looking at your claim to make the assessment.

Please contact CHF if you have any amendments or changes to suggest so that we can keep our information sheets relevant and up to date.