

A GUIDE TO BENEFITS



If your child has been affected by retinoblastoma, they may be eligible for certain benefits. This leaflet gives you an introduction to this, in particular the Disability Living Allowance (DLA), and will help guide you through what can often seem like a daunting process. Do remember that support is available to ensure families are receiving all the benefits they are entitled to...

HELPING YOU THROUGH THE BENEFITS PROCESS

There are different benefits that you may be entitled to, and DLA is one of them. This is a benefit for people with an illness or disability who need help with personal care, getting around or both. It is not means-tested, so it's not affected by your income or savings. The DLA rate is between £21.80 and £139.75 a week and depends on the level of help the child needs.

To be successful in getting DLA, your application form must demonstrate that you provide substantially more supervision and care to your child than you would do for a child of the same age who is not sick or living with a disability.

The form is very lengthy and can be difficult to fill out,

so it's best to get help with this as you stand a better chance of being successful with your claim. Getting tips from someone who has experience in answering the questions relating to the effects of cancer treatment is strongly advised.

Some parents say filling out the DLA form made them feel quite down but that they were glad they kept at it because they now receive the benefit.

Parents of children who are receiving chemotherapy or have a visual impairment often make successful claims for DLA. However, parents of children who do not need chemotherapy but have had an enucleation find it more difficult to

SUPPORT:

If you have questions or need help with the benefits process please get in touch with your CHECT support worker who will be happy to help.

demonstrate that they provide very much more care and support for their child. If you're in this latter group and you still want to claim DLA, make sure you get some help with filling out the form.

How to claim

It really does help to speak to someone who is familiar with the benefits system before you begin, as they will help you with your application.

We would recommend that you get in touch with a CLIC Sargent social worker, nurse specialist, community nurse and/or CHECT support worker as they are familiar with the issues of children's cancer and welfare rights.

A DLA form is available from

your local benefits office or by calling the DLA helpline on 0345 712 3456. Call to ask for alternative formats, such as braille, large print or audio.

You can also download and fill in the form online via the gov.uk website.

Completing the form

DLA has two parts - the Care Component and the Mobility Component; either or both can be claimed.

The **Care Component** is awarded at three different levels, higher, middle and lower rate depending on the level of personal care the child needs.

The Care Component relates to how much time and help you have to give your child for their personal care, eg washing, dressing, eating, toileting, sleeping, communication, keeping an eye on their medical condition or diet, and similar activities. This is in addition to what you would normally do for a child the same age.

If you're claiming for a baby it may be harder to demonstrate what you do for them is extra to the supervision and care you would normally give a child of that age. It will be really helpful if you give examples and anecdotes because the more you tell them, the easier it is to get a clear picture of your child's needs.

When you fill in the form give plenty of details: for example, if your baby has a central line you will need to take extra time and care when bathing them. Explain

that this is because you need to stop your baby from pulling the line and ensure both the line and the dressing stays dry and away from the nappy area.

All babies need help with feeding but if it takes longer due to your child's condition or vision, make sure you include all the details as it makes your case "real" to the assessor. If your child's needs fluctuate, use the terms 'bad days' and 'better days' because using terms like 'good days' and 'normal days' implies they do not have any additional needs on some days.

"It can help to keep a diary for a few days before filling in the form, noting the amount and types of care your child requires during the day and night."

Remember that providing extra reassurance, prompting or encouragement to your child when doing something or when settling them to sleep may also be part of the additional care you provide.

If you are claiming for a child who has a visual impairment or is blind then explain the extra stimulation you need to give them. They will lack the visual stimulation necessary to learn about the world around them and for development of their communication and social awareness skills.

When filling in the form, consider the headings of Stimulation, Communication and Supervision because you'll be providing lots of

extra verbal reassurance and physical contact to compensate for their lack of vision.

"There are two factsheets you may find helpful when completing the DLA form which you can get from the RNIB and Action for Blind People (see Resources)."

Towards the end of the application form there is a section where you can explain anything else about the way your child's illness or disability affects them. If you haven't already mentioned it, you can use this space to inform them about your child's regular attendance at EUA (examination under anaesthetic) clinics; mention how regular they are and what is involved for you and your child. Don't forget to describe any preparation, play prep or reassurance you do before you arrive.

It is also good to talk about what happens if your child has cryotherapy and needs to be given medication and eye drops afterwards and how much time this takes up.

If your child has an artificial eye and visits the ocular prosthetist you can put it in this section; and if you have to do any preparation or aftercare this is relevant too. If you haven't mentioned medication for eye infections or visits you have to make to school to help with your child's artificial eye, do so in this section.

The **Mobility Component** is for children who are unable to walk or need someone to guide or supervise them.

There are two rates, higher and lower. If you are eligible for the higher rate you can claim this once your child is three years old. If you are only eligible for the lower rate it is payable after your child is five years old.

If your child has a visual impairment which makes it difficult to move around unfamiliar areas unsupervised, you may be entitled to the Mobility Component. We recommend that you get help from one of the vision charities when filling out your DLA form.

To do list

- Read through the form before you send it and check if you have included enough evidence to convince someone who has not met your child.
- Keep a photocopy of the form and any supporting evidence.
- Reward yourself for completing the form as it can be time consuming and stressful but hopefully it will all be worth it!

DLA and other benefits

If you receive DLA you may be entitled to other benefits or an increase in the benefits and tax credits you currently receive.

If you are receiving middle or higher rate DLA and you, or someone else, cares for your child for 35 hours a week, then you may be entitled to Carer's Allowance (CA).

This can be backdated up to three months, to be in line with when your DLA started. Application forms are available from your benefits office or online at gov.uk.

CA can affect other entitlements such as income support and tax credits. Let the office dealing with your benefits and tax credits know you have been awarded DLA as you may get enhancements which increase the entitlements you already receive.

There is a very good factsheet which explains DLA and how it affects other benefits. It is available from Contact a Family (see our Resources section on the right for contact details).

RESOURCES:

The **gov.uk** website has information about DLA and CA. These organisations can also help and some can provide useful guides:

CLIC Sargent

clicsargent.org.uk
0300 330 0803

RNIB

rnib.org.uk
0303 123 9999

Action For Blind People

actionforblindpeople.org.uk
Same number as RNIB

Contact a Family

cafamily.org.uk
0808 808 3555

Turn2Us Helpline

0808 802 2000

Macmillan Helpline

0808 808 00 00



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