

Cystic **Fibrosis** *our focus*

Completing the DLA form – hints and tips

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Claiming Disability Living Allowance (DLA) for a child under 16 with cystic fibrosis:

Tips for completing the claim form (DLA1A Child April 2021) in relation to care needs

What is DLA?

Disability Living Allowance (DLA) is a non-means tested and tax-free benefit paid to those who need help with their personal care or with getting around outdoors. It has two parts, Care and Mobility, and someone may claim one or both parts depending on the level of help they need. There are different rates of DLA. The rate you may get will depend on the amount of care or support you need with your personal care or mobility.

While you can make an application at any time, the care component is not payable before three months old; however, you can apply before three months and if you are successful the payments will start after your child reaches three months old.

Higher-rate mobility is not payable to children under three years old and lower-rate mobility is not payable to children under five years old.

This guide has been written for claims relating to children (under the age of 16) who have care needs. If your child is over three and has mobility problems (problems getting around) you may also be able to claim for this part of DLA. If you think you could apply for the mobility part of DLA please seek advice from your CF team and/or the Welfare and Rights Advisor at the Cystic Fibrosis Trust.

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Introduction

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 disabled.

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.

It can be very easy to forget all the things you do for your child as you may have started to accept these as part of your daily routine, but it is important that you demonstrate all the care and supervision required by your child and why it is needed.

Some parents say filling out the DLA form made them feel quite down, but they were glad they kept at it because receiving the benefit has really helped their family life.

Reward yourself after filling it out with a little treat, as it can feel like hard work and can make you think about things you don't always think about.

“Generally my son is very well with CF – but we work at it every day to make sure he stays that way. Filling in claim forms for welfare benefits can be really hard because you have to think about the way CF has changed your life, and all the little things you do differently because of it. I have to do it over two evenings, and I have to take myself to a ‘dark place’ where I let myself think about the true impact of my son having CF, on him and on us as a family. It can be quite upsetting to truly confront the realities of CF, but you have to do it because unless you do, you can’t really explain why that extra help is needed.”

– Mum of a nine-year-old with CF.

Get Help

The form is lengthy and can be difficult to fill out. To maximise your chances of being successful, we advise you to seek help from someone with experience of answering these questions in relation to cystic fibrosis. Your CF team may be able to help, or alternatively our Welfare and Rights Advisor can guide you through the process and can be contacted via our helpline at helpline@cysticfibrosis.org.uk or on 0300 373 1000.

Your child's CF team or Social Worker team may be able to write a supporting letter for you to include with your application. Ask them if it is possible to do this.

The form

We recommend obtaining a form directly from the Department for Work and Pensions (DWP), by calling 0345 712 3456. This is because the DLA can be backdated to the date of your call.

You can also get one online at <https://www.gov.uk/government/publications/disability-living-allowance-for-children-claim-form>.

Here are some tips, which may help you answer the questions.

Questions 1–24: general questions asking for information about your child.

Question 17: write down all dates of hospital admissions.

Question 80: (on page 38) to add further details about the reason for their admission and the treatment they received as an in-patient.

Question 19: Write down the name of the health professional your child has had the most contact with in the past 12 months (other than their GP). Use Question 80 (on page 38) to record all of the other professionals that your child has had contact with in the past 12 months. This could include consultants, nurses, physiotherapists, dietitians, social workers, sleep team, pharmacists or other disease-specific professionals.

Question 20: write down the name of the child's GP.

Question 21: include information on all of the tests your child has had, for example x-rays, cough swabs, blood tests, CF-related diabetes tests.

Question 22: request reports, letters or assessments (include copies) from your CF centre and child's school.

Question 25: (Statement from someone who knows the child) we recommend that this is completed by a professional involved in your child's care, such as their CF nurse or social worker. You can photocopy this sheet, add your child's name to the top and give it to the person you would like to complete it (and once completed, simply attach it to your form). Alternatively, you can make an appointment with them and ask them to complete it while you are with them if possible. If there is any delay in getting this part back, send the rest of the claim off before the deadline date, and send this sheet to DLA afterwards.

Question 29 is about 'Variability'.

If your child's needs vary depending on how poorly they can get, then you can say so here. However, the DLA award is based on how your child is 'most of the time', so it is important you complete the other questions based on this. If your child has a spell in hospital every six months, you could say so here. If your child has regular chest infections, you can say how often here, and how long they last for. Do stress the background level of care and treatment you provide that is always required regardless of whether your child is well or unwell.

Questions 42–60 are questions about Care.

We advise that it is more important to give detail in the boxes rather than worry about the tick boxes, if you're not sure about these.

You do not have to write something for every one of these questions, only the parts that are relevant to your child.

If your child is a baby, you may feel that he or she needs help with everything. You can tick 'yes' to all the questions but it is important that you say what 'extra' help your baby needs because of cystic fibrosis.

We would advise that you answer each question in four parts:

- What are the problems your child has with this activity?
- What help does your child require (reasonably need) with this activity?
- Why does your child need help with this activity? So, what would happen if you did not help with this?
- How does this differ from a child of the same age who does not have CF?

Question 42: think about your child's morning and bedtime routines. What support do you provide? Does your child become tired? Does this affect their physical abilities? Does your child require more reassuring at bedtime, due to coughing or vomiting? Or perhaps you have an older child who becomes more anxious at bedtime?

Question 43: think about your child's continence and any continence care you provide. This could include monitoring bowel movements and stools, adjusting medication accordingly, incontinence, extra washing due to incontinence, pain, any emotional and behavioural difficulties caused by toileting and continence. If you have a baby, state how many times you change a nappy or check the nappy in the day time. If your baby has explosive bowel movements, which require extra cleaning, a full wash and change afterwards, say so here. If your baby's skin gets sore after a bowel movement, this is relevant, as this will need constant checking. Do you have a child who gets stomach pains and needs reassurance in the toilet?

Question 44: does your child become breathless, and does this affect their movement indoors? If so, include supporting evidence such as how often this occurs, triggers and treatment responses.

Question 45: children with CF often need to be extra vigilant with brushing their teeth due to their high-sugar diet. It is also possible that they suffer with a lack of enamel caused by CF. This will need extra supervision from parents and carers. Children with a gastrostomy are likely to need help to ensure their stoma site is clean and free from infection. Children with CF can become overly hot and sweaty due to the high salt content in their skin. This means that they need to wash frequently but also their skin may become sore, which may need treatment.

Question 46: if your child suffers from excessive sweating, you may have to remind them to change their clothes more frequently.

Question 47: include information about your child's dietary needs. State that this is based upon advice from the CF dietitian and your involvement with them. For example, the need for your child to have a high calorie/fat diet, with vitamin supplements, NG tube feeds. Record information about the effect of CF on the digestive system and the impact this has on your child. Explain here if your child needs to take Creon and what help they must have with this, and why. State what would happen if they did not take the right amount of Creon at the right time. If your child has a low BMI or can suffer from weight loss, please say so. Explain what would happen if your child did not eat the right food at the right times. If your child is a baby or toddler, what extra measures do you take at mealtimes to incentivise them to eat? Does your baby struggle and resist feeding? If your baby is breastfed state how often you have to give more Creon during a feed. You could add that you need make sure none of the Creon granules are left on the skin, if they accidentally stay on the skin, maybe in the folds of a baby's neck or under clothes then they can cause sores, so add this if you have to check for Creon granules. You can add information about how long it takes for you to calculate the fat in a food and work out how much Creon to give and how long it takes to prepare the Creon and how often you do this.

Question 48: include information about all of the medication your child is prescribed, therapies and help needed. You should detail your child's cooperation with medicine and therapy, any difficulties you have, and the impact of non-engagement with medication and therapy. If you have to monitor your child's blood sugar levels or stools, then mention this here and say why. Don't forget to explain what help your child needs with physiotherapy and exercise and explain how long this takes and why your help is needed. If you spend time washing and sterilising and medical equipment such as syringes, physio equipment or nebulisers, mention this here too along with how long it takes you each time and how often you do it in a day. Also add in if you need to prepare any medications such as antibiotics from dry powder form and say how often and how long it takes you.

Question 54: if your child requires any supervision (in addition to the supervision a very young baby would need), this could be relevant here. The questions here are about the way your child reacts to things emotionally. This is not usually related to CF, but your child may have emotional or behavioural difficulties, or may be showing signs of this.

Question 55: children with CF are likely to need support to understand the condition and to cope with the impact of CF upon their life. They may need play therapy to cope with blood tests, for example, or other types of support. However, these issues should be explained in the question about 'extra information'. This question relates to your child's development, so you would complete this part if your child's physical or sensory skills are not developing as quickly as those of other children of the same age.

Question 56: consider any additional support your child receives from their education establishment. This could include input from school nursing, support with administration of medication, therapies, and access to toilet facilities, support with toileting, supervision and/or prompting at snack and lunch times, extra support with learning due to absences, extra time allowed for tests and exams, and managing other CF pupils in the school.

Question 57: here you could include information about your child's exercise or sports and why it is needed. State what help or support they need with this. You can also explain that leaders of any clubs or groups that your child attends must be aware of your child's CF and be skilled in managing it.

Question 58: think about whether your child's sleep is affected by CF and the impact of this on them and the whole family. Does your child need overnight feeds? Is your child's sleep affected by coughing, pain, incontinence, anxieties or behaviours? If your baby needs nappies changing at night or additional feeds and Creon, this is relevant here. If it takes some time to help settle your child to sleep in the night, please explain this here.

Question 59: this is where you can add anything that you feel you haven't been able to explain elsewhere. It is helpful to explain what the additional costs arising out of CF are. For example, special diet, exercise classes, additional nappies, fuel or travel costs to hospital. You can also state what your child has to miss out because of CF, or where special precautions have to be taken. If you have another child with CF, you may spend a lot of time keeping all their utensils separate. It is here that you can explain any background work you do to make sure you can care for your child with CF. Do you have to spend time organising repeat prescriptions for your child? Do you have to collect prescriptions, take them to a pharmacy and collect medication from the pharmacy? If you spot signs of infection in your child do you liaise with your child's CF team and change the care you provide based on what the team ask you to do? Do you have to go into nursery or school to give information about CF so that the staff can care for your child properly? Do you write a daily plan of how much Creon to give with a packed lunch? Do you liaise with the school to make sure they can give any day time medications your child has been started on? Does your child get thrush at times, perhaps when on new antibiotics? If you apply creams to treat thrush this can be stated here.

These are all things you do which you should explain as it demonstrates your child has needs that a child without this condition would not have.

You can add this information on additional sheets, or write outside the boxes.

Action points

- 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.
- Make sure any additional pages include the child's name and reference number.
- 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!

Finally, please let us know the outcome and seek advice if the decision is not what you hoped for; remember there is only one month within which to ask for the decision to be reconsidered.

You can ask your CF team or the Welfare and Rights Advisor at the Cystic Fibrosis Trust for help.



Further information

The Cystic Fibrosis Trust provides information about cystic fibrosis through our factsheets, leaflets and other publications.

Most of our publications are available through our helpline and can be downloaded from our website or ordered using our online publications order form. Visit cysticfibrosis.org.uk/publications.

The Cystic Fibrosis Trust Helpline can help you with a range of issues, no matter how big or small. Our trained staff can provide a listening ear, practical advice, welfare/benefits information or direct you to other sources of support. The Helpline can be contacted on 0300 373 1000 or helpline@cysticfibrosis.org.uk and is open Monday to Friday, 10am – 4pm.

Calls to 0300 numbers cost no more than 5p per minute from a standard BT residential landline. Charges from other landlines and mobile networks may vary, but will be no more than a standard geographic call and are included in all inclusive minutes and discount schemes. If you are worried about the cost of the call please let us know and we'll call you back.

You can also find more information at our website cysticfibrosis.org.uk.

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More factsheets available at:
cysticfibrosis.org.uk/publications

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The information included in this publication is not intended to replace any advice you may receive from your doctor or CF multidisciplinary team and it is important that you seek medical advice whenever considering a change of treatment.

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