Claiming Disability Living Allowance (DLA) for children

If your child has Crohn's or Colitis, they may be able to claim Disability Living Allowance (DLA).

This information is for people living in England or Wales. In Scotland, you can apply for Child Disability Payment. In Northern Ireland, you can apply for DLA for children in Northern Ireland.

This guide explains what DLA is, who may be eligible and how to apply. It includes information on how to increase your chance of a successful claim. You may find this information helpful even if you do not think you will qualify for DLA. People sometimes miss out on benefits for years because they don't realise they are entitled to claim or don't think their claim will be successful.

PLEASE NOTE: DLA for children is a benefit and subject to change. This guide is not a full and authoritative statement of the law. The information in this guide is intended as general information only and is not intended to be relied upon by any individual in relation to their specific circumstances. It is not intended as a replacement for appropriate professional advice.

Contents

Key facts about DLA

- **DLA is a payment to help with extra living costs of looking after a child aged under 16 who needs much more looking after than a child of the same age who does not have a disability, or has difficulty walking or getting around.**
- **DLA is made up of two components – the care component and the mobility component.**
- **The Department for Work and Pensions (DWP) will decide whether your child will get one or both components, and which rate they will get, depending on the type of care your child needs.**
- **To claim DLA, you will need to fill in a form about your child's health condition and the care and help that they need.**

- **You will get a letter to say whether your child has been awarded DLA, at what rate and for how long. You can challenge this decision.**

What is DLA?

DLA is a payment to help with extra living costs if you look after a child who:

- Is aged under 16
- Has difficulties walking or needs much more looking after than a child of the same age who does not have a disability

Even if you don't consider your child to be disabled, if they have Crohn's or Colitis, you may have extra expenses. For example - higher heating bills, special diets, taxi fares and more laundry costs. DLA can help to meet these extra costs. But you can spend DLA on anything you wish. Some people use their child's DLA to provide treats and holidays and others put it away in a savings account for their child to use when they are older.

Making a claim for DLA on behalf of a child can take many months and some people can find the process emotionally draining.

How much could I get?

DLA is made up of two components, the care component and the mobility component. The care component has three weekly rates - lowest, middle and highest. The mobility component has two weekly rates - lower and higher.

Care component

The rate depends on the level of looking after your child needs.

- Lowest rate – help for some of the day
- Middle rate - frequent help or constant supervision during the day or supervision during the night
- Highest rate – help or supervision throughout both day and night, or a medical professional has said they might have 12 months or less to live.

Mobility component

The rate depends on the level of help your child needs getting about.

- Lowest rate (your child must be 5 years or over)– they can walk but need help or supervision when outdoors
- Highest rate (your child must be 3 years or over) – they cannot walk, can only walk a short distance without severe discomfort or could become very ill if they try to walk.

Find the latest DLA rates on the GOV.UK website.

The Department for Work and Pensions (DWP) will decide whether your child will get one or both components, and which rate they will get, depending on the type of care your child needs.

DLA is usually paid every four weeks into your bank, building society or credit union account. It is tax-free and you can get it whether or not you are working.

You can claim DLA even if you have a high income or a high level of savings. You can claim DLA for your child if you are working, unemployed or are claiming other benefits.

Eligibility

Age

If your child is under 16 you can make a claim for DLA on their behalf. If they are 16 or over, they can claim Personal Independence Payment (PIP) themselves. You can claim DLA for your child at any time, but there are some age restrictions regarding what can be paid.

Disability or health condition

Your child must have had a long–term disability or health condition, such as Crohn's Disease or Ulcerative Colitis, for at least three months, and be expected to have it for at least another six months.

The health problem must result in your child needing much more care or supervision than other children of the same age.

It doesn't matter if you do not consider your child to be 'disabled'. For the purposes of DLA, 'disabled' means that your child has a long–term chronic illness that adversely affects their everyday activities. It also doesn't matter if you've been told by anyone (including the DWP, your GP, a nurse, social worker), other than a professional welfare rights worker, not to make a claim because your child is not ill enough. If in doubt, make a claim.

Terminal illness

If your child has any medical condition that means they might have 12 months or less to live, your claim will be dealt with more quickly. You will be able to claim DLA straight away - you do not have to wait for the three-month qualifying period. Read Citizens Advice information on claiming DLA for a terminally ill child.

Residence

There are rules on whether you can apply for DLA if your child has lived outside of the UK. Check the GOV.UK DLA eligibility information to see if your child has met these rules.

Words used in the claim form

Here are some of the terms used in the claim form and what they mean:

Aids and adaptions: Any device that is used by your child to improve or help an impaired mental or physical function. Aids include incontinence pads, commodes, buggies and learning aids such as computer programmes. Adaptations include rails and other alterations to the home.

Danger: A situation where your child has a serious risk of harming themselves or others. This situation may arise infrequently or be a one–off.

Extra help: When your child needs more help or support than a child of the same age without a disability.

Guide: Someone present to physically lead or verbally direct your child to prevent any accidents or harm.

Night: Begins when everyone in the house goes to bed (including the adults) and ends when everyone gets up.

Personal care: is anything carried out in connection with bodily functions – which includes dressing, washing, bathing, toileting, eating, drinking, taking medicines and getting in and out of bed.

Supervise: Someone continuously present with your child to prevent any accidents or harm, and/or provide encouragement or prompting.

Before you begin

Before you begin your claim, you may want to do these things:

Keep a claim file

A claim file is simply a folder in which you keep notes and copies of everything to do with your DLA claim.

What to put in your claim file: A photocopy of everything you send to the DWP. Most importantly, keep a photocopy of your completed claim form. It is important because if your child's claim is successful, the award will either be for a limited period, for example three years, or it will be awarded up to your child's sixteenth birthday. When you reapply for DLA (or PIP if you child turns 16) you will have to fill out another claim form. If you don't give as much detail as you did in the original, the DWP may decide your child is getting better and stop the award. If you're not happy with the result of the claim, you will have difficulty challenging the decision effectively without a copy of your original form.

Keep every letter you receive from the DWP: File the letters in date order, along with copies of any letters you've sent to DWP. This may help if there is an issue and you need to request that your DLA payment be backdated to the beginning of your claim.

Keep a note of any phone calls to or from the DWP: Ask for the name of anyone you speak to and keep a note of it, along with the date and the subject. For example: 20/06/2023– Spoke to Gemma Watson at the DLA Unit. She said they have received my consultant's letter.

- Don't feel embarrassed about this. In the very unlikely event that anyone refuses to give you their first name and the section they work on, insist on speaking to their supervisor. You can use the Claim file record sheet (Appendix 2) to record your interactions with DWP.

Arrange support

Making a claim for DLA can be hard work mentally and emotionally. It may all go smoothly for you, or you may find it a difficult and drawn-out process. You may find it helpful to have someone with you when you complete the form to talk about each question and your answers. This could be a friend or family member, or a benefits advisor. You can find a benefits advisor at Citizens Advice or Turn2Us.

Start your claim

The first step in making a claim is to get a claim form.

You can apply by either:

- Printing off and filling in the DLA claim form. Your payments will only be backdated from the date the DWP receives the form.
- Phoning the Disability Living Allowance helpline number below and asking for a printed form. Your payments will be backdated to the date you phoned.

Disability Living Allowance helpline
Telephone: 0800 121 4600

Textphone: 0800 121 4523
Relay UK (if you cannot hear or speak on the phone): 18001 then 0800 121 4600
British Sign Language (BSL) video relay service

When you make the call, ask them to send you a DLA claim form for a child under 16. If, after asking you a few questions, the operator suggests you won't be eligible to claim DLA for your child, you can ask that they send you a form anyway. Ask for the full name, or first name and department, of the person you speak to. Make a note of it, along with the date, in your claim file. If you don't receive a claim form, you should be able to get one backdated to the day of your original call.

While you wait for the printed form to arrive in the post, you may wish to:

- Keep a diary. Citizens Advice have a diary that you can print out and use.
- Write a list of people who can provide supporting evidence.
- Make appointments to see your child's health professionals. Work out when you are likely to have completed the form, and ask for an appointment to take place soon afterwards.
- You can also get a claim form online. You may want to download a copy and begin drafting rough answers to the questions.

You have six weeks to return the claim form. Remember to allow several days for the form to reach DWP by post.

When the form arrives

Don't be put off by the size of the claim form. If you have received a date-stamped form, you've got over a month to complete it, depending on how long the DWP took to post it out to you. Before you start, please read the next section.

General tips for completing the claim form

Any evidence you can send to the DWP will help them understand how your child's health condition affects them. The form you are about to complete is evidence, and so are your diary and any letters from doctors, carers or relatives.

An effective claim includes evidence that is as clear and as detailed as possible. This is particularly important for Crohn's and Colitis, because they are not widely understood conditions. Take the time to fill in the form in as much detail as you possibly can. If you don't know where to write something, write it under any question that appears relevant, even if it means writing it on the form several times.

When you're filling out the DLA form you don't need to worry about spelling or making mistakes. If you fill the form in with a pen, use black ink. Do whatever works best for you, including any, or all, of the following:

- Write in note form.
- Write in bullet points.
- Write on additional sheets of your own paper. If you do, always write your child's name, date of birth and National Insurance number, if they have one, across the top of each extra sheet. Write the page numbers of the questions you're answering and fasten the sheet securely to the last page of the section you're completing.

We strongly recommend keeping a diary for at least a week, or 2–3 weeks if your child experiences fluctuating symptoms, before you fill in the form. This will help you determine how long, how often and how many times your child needs help. This is particularly important if the amount of help your child needs varies. You can send the diary as evidence with your claim form. You'll find an example of a diary in the claim form.

Talking to your child

If your child is older, they may want to be involved in completing the form. You may want to ask them questions about how their condition affects them and describe how they feel. Although, it can be challenging to list all the negative ways their Crohn's or Colitis affects them. You might feel that you need to complete a little bit of the form each day and take rests. Read our information on supporting your child for tips on looking after your child's emotional wellbeing.

How to explain fluctuating conditions

Explaining the fluctuating nature of Crohn's or Colitis can be challenging when claiming DLA. We suggest that you explain how your child is on their bad days and then how they are on their 'better days'. If you use expressions like 'good days' or 'normal days' it may be assumed that these are days on which your child has no problems whatsoever.

If your child is not awarded DLA and you choose to appear before a tribunal, they may ask you to describe how your child is on an average day.

For example:

On bad days, Simon cannot get out of bed at all because of fatigue and pain in his large joints and back. On better days he can get out of bed, but only slowly and painfully, resting several times. He has to sit up in bed first, and lean on the bedside cabinet when standing up. He then has to stand still for a moment before walking, otherwise he feels dizzy. The pain is in his … (etc.)

If your child has very few (or no) days when they can get out of bed easily and without pain then you can reasonably say that they need help seven days a week.

Be careful not to underestimate your child's condition. Are their 'better days' actually free of pain and discomfort, or just relatively so by their standards? It may be that, for the purposes of claiming DLA, you have to accept that your child doesn't have any 'good days' at all – they have just learnt to deal positively with their condition. Having to think about this may be upsetting, so it may be helpful to have someone available to offer you support if you need it.

If your child has periods when they are symptom–free, then average them out as follows:

If your child's condition varies from day to day, decide on average how many symptom–free days a week they have. If it's only one or two, then they need help five or six days a week.

If your child’s condition varies from week to week, again average it out. If they have about one good week a month, that’s a bit less than a quarter of the time, so they still need help, on average, every five to six days a week.

If your child’s condition varies from month to month and they have long periods of remission then you should decide whether they have no problems during the periods of remission, or whether they still suffer from symptoms such as pain, discomfort or fatigue. In order to qualify for the first time, your child’s condition needs to have lasted for three months and be likely to last at least another six months.

Completing the claim form

Some people prefer to fill in the claim form with a pencil first, whereas other people will use a pen straight away– it’s up to you. You may wish to photocopy the claim form and practice filling it in first. It might be helpful to read the form all the way through before you begin.

Completing the form - Questions 1 - 39

Questions 1 to 20 – About the child

These are factual questions, some just needing a simple yes or no answer. The form will ask about where your child lives and if they have spent any time abroad.

Questions 21 and 22 – Time in hospital, hospice, residential school or other similar accommodation

These questions ask whether your child is in hospital or has spent any time in a hospice, residential school or other similar accommodation

Questions 23 to 25 – Health professionals or specialist support

Q23: Has the child had or are they due to have any assessments by a health professional or specialist to help diagnose, manage or monitor their health condition or disabilities?

If you do not know the exact date of any test, put an approximate date. If your child is waiting for an appointment or waiting for test results, write this on the form.

Q24: Do you have any letters or assessment reports about the child's health conditions or disabilities?

If you have any helpful letters or reports about your child's condition that will support the claim, send a copy with the claim form. Assessment reports may provide very useful information about the difficulties your child has with everyday activities. Read through any letter or report you are considering submitting. If you decide that, for example, your child's care plan sets out an unreasonably optimistic assessment of how well they are likely to progress, then you may decide not to submit it. You should also be aware that the DWP may obtain a copy of the assessment directly from whichever organisation carried it out.

Q25: Does the child have any health professionals, who are not their GP, who supports them with their health condition or disabilities?

It is important to give the names and addresses of all the professionals your child has seen in the past 12 months. If there is more than one, make sure you add the extra information in question 89 - more information.

Questions 26 to 29 – About the child's GP

These are questions about your child's GP. It can be helpful to let your child's GP know you are making a claim as the DWP may write to them for further information.

Questions 30 to 37 – About nursery, school and educational or specialist needs

These are questions about your child's nursery, school and educational or specialist needs. Q32 asks for the name of someone they can contact at the school - write the person who knows the most about how your child is affected by their condition.

Question 38 – More information from someone who knows the child

This questions asks for a statement from someone who knows your child.

If possible, the person who completes this statement should be a professional involved in your child's care, for example, their specialist doctor, nurse or GP. Photocopy the sheet to give to the person you want to complete it. Make an appointment to see the person so you can answer any questions they might have and take the completed Health professional's sheet *(Appendix 4*) with you. Ask them to complete the statement there and then if possible. If they can't, or wish to write a longer report, ask them to send it to you and tell them when you need to have it by. If you are happy with what they write, attach the sheet to your form. If not, give them another blank copy and ask if it would be possible to change what they have written. If this is not possible, get someone else to fill in the statement instead. Don't delay returning the claim form if you don't receive a statement in time, send any additional evidence afterwards if necessary.

Question 39 – Sharing information

This question asks if you give consent for the DWP to ask your child's doctor, hospital consultant or other relevant professionals for information about your child's health condition.

Completing the form - Questions 40 - 53

Question 40 to 42 – About the child's health condition or disabilities

Q40: About the child's health condition or disabilities:

List all your child's health problems, not just Crohn's or Colitis, including any related problems such as arthritis, anaemia and skin problems. Also list any conditions that may not be related, such as asthma. Include any emotional or mental health problems, such as depression or anxiety. Your child's entitlement to DLA is based on the combined effects of ALL their health problems, so make sure you write them all down.

What treatment do they have? How often do they have treatment?

If you have a copy of a prescription, include it with the claim form. Although the question only refers to prescribed medicine and treatments, you may also wish to list any alternative, complementary or non–prescription medicine or treatments your child takes. Continue on a separate sheet if necessary.

Q41: Does the child use, or have they been assessed for, any aids or adaptations?

If your child uses any specialist equipment, write this in the table and explain what help they need to use the equipment. This could include anything from a walking stick or frame to complex communication support. It could include:

- Mobility aids such manual and powered wheelchairs, all terrain wheelchairs, walkers, trikes and orthotics.
- Equipment for transfers including ramps, portable hoists and ceiling tracking.
- Personal care aids including bath lifts, commodes and shower chairs, adaptive clothing and feeding aids
- Transport including wheelchair adapted vehicle (WAV); equipment to allow your child to enjoy their hobbies or interests.

Explain how much time and additional effort is needed to use these aids and adaptations.

Q42: When the child needs help

Only tick 'changes from day to day' if your child's needs clearly vary, and explain why they vary. We recommend you use the terms 'better days' and 'bad days'.

Questions 43 to 53: Mobility questions

Mobility can only be awarded to a child from age 3. If your child is under 3, skip to question 54.

These questions ask whether your child can physically walk and if they have difficulty with standing and moving around.

Q45: How far can they walk without having severe discomfort and how long does it take them?

Try timing your child rather than just guessing. Remember this is an average, so take into account your child's bad days. Can your child walk at all on their bad days? Are they in severe discomfort all the time when they walk, or does it begin after a certain distance? If possible, measure how far they can walk, rather than trying to estimate. If you find it difficult and cannot tick a box, explain the reason why in question 53.

Q46: Please tell us about their walking speed

If this varies, explain why in question 53.

Q48: Does the child have any other difficulties either during or after standing and moving around that affects their health?

If the answer is 'yes' explain why. For example, walking causes extreme fatigue or pain and your child is unable to do anything else for the rest of the day.

Q49: Do they need guidance or supervision most of the time when they walk outdoors?

If your child needs guidance or supervision outdoors, tick Yes at the top of the page and then tick the boxes that apply to your child. You can explain why they need this help in question 53. Even if your child is so young that you would not allow them to walk outdoors in unfamiliar places on their own, if they need much more help and support than another child of the same age they may be eligible for lower rate mobility. Only tick 'no' if you have read the examples on the form and read the box below and decided your child doesn't have these problems.

Q51: When did the child's mobility needs start?

If you do not know the exact date, put in an approximate date or month and year.

Q53: Anything else you want to tell us

Does your child have difficulties with walking because of joint pain and stiffness, abdominal pain, fistulas, soreness around the anus, extreme fatigue, breathlessness, increased likelihood of incontinence, or any other physical problem? Is your child in bed for most of the time and not able to walk outdoors? Does your child walk much more slowly than other children of the same age? Does your child use a buggy although other children of the same age do not? Give as much information as you can. For example, how can you tell when your child is becoming exhausted or is in severe discomfort or pain?

Explain why your child needs guidance and/or supervision when walking outdoors. Remember, this is about when your child is in an unfamiliar place, not places that they know well. If you run out of space, use an extra piece of paper and attach it to the claim form.

Step 1: Say what problems your child has with this activity, giving examples if you can. Does your child:

- Run out of energy, often quite suddenly
- Carry on walking even though they are exhausted
- Experience pain when walking, perhaps because of arthritic symptoms, a sore anus, fistulas or abdominal pains?

Step 2: Say what help your child gets, or would benefit from. Does your child:

- Sometimes need carrying, or help to find somewhere to stop and rest
- Need someone to make sure they do not over-exert themselves
- Need comfort and reassurance because of discomfort or pain
- Need someone to help them find a toilet, carry a change of clothing and a washing kit, offer comfort and reassurance if they have an episode of incontinence?

Step 3: Say why your child should not be expected to manage on their own. For example, would your child:

- Simply avoid walking in unfamiliar places if they were expected to do so on their own
- Find it a distressing experience
- Risk making themselves ill through over-exertion?

Step 4: Say how your child’s needs are different from those of other children of the same age.

Would another child of the same age be more likely to walk outdoors in unfamiliar places on their own? Even if your child is so young that you would not allow them to walk outdoors in unfamiliar places on their own, do they need much more help and support than another child of the same age?

Completing the form - Questions 54 - 72

Questions 54 to 69 – About help needed during the day

‘During the day’ means any time before you (the child’s parent or carer) go to bed. There are examples on the claim form to help. The form will ask about help needed during the night later, from question 70.

Q54: Does the child need encouragement, prompting, or assistance to settle in bed during the day?

Tick Yes, fill in how often and for how long each time and write an explanation in the box at the bottom of the page if:

- Your child takes longer than other children of the same age, or it causes them pain, discomfort or distress
- You have to provide more help, or help of a different kind, than for other children of the same age, or if your child has to be watched over more closely than other children of the same age.

Only tick No if:

- Your child does not have any difficulty with these activities compared to other children of the same age
- You have read the examples on the form and in the main box below and decided that none of them apply.

The next boxes ask you how often each day do they need encouragement, prompting or assistance to help them:

- Get out of bed
- Get into bed
- Settle in bed

And how many minutes does this take each time?

If your child is often at home because they are ill, you may need to wake them, get them up and put them back to bed several times during the day. For lower rate care, it doesn't matter how many times a day your child needs help, but for the middle rate you have to show that your child needs help several times throughout the day across all personal care activities. For example, in the morning, during the day and at night.

Roughly how long does it take your child to get out of bed or into bed to wake up or to settle?

In the morning, this should include the time from when your child wakes, or is woken, to the time when they are actually up and out of bed. At bedtime, if it takes a long time and repeated visits to settle your child, include the whole period until they are settled.

If you want to explain why they need help, how their needs vary or anything you think the DWP should know, write in the box at **question 72.**

Step 1: Say what problems your child has, giving specific examples if you can.

For example, does your child:

- Have such disturbed nights that they are too tired to wake or get up in the morning
- Get very depressed about their condition and so lack the motivation to get up
- Experience severe exhaustion, joint pain, stiffness or abdominal pain in the morning, making getting up a slow and painful experience
- Resist getting up in the morning because they are worried about being bullied at school because of their condition
- Resist going to bed because they suffer from anxiety or nightmares

- Get out of bed repeatedly during the night because of anxiety caused by their condition
- Often have to stay in bed for most of the day because of their condition

Step 2: Say what help your child gets, or would benefit from.

For example:

- Do you bring them medicine or a drink to help them wake up or get up?
- Do you encourage them to wake up or get up, perhaps having to return repeatedly?
- Do you offer them encouragement, support or reassurance in connection with getting up or going to bed?
- Do you have to watch over them to make sure they are safe when they get up or go to bed?
- Do they need physical help getting up or going to bed?
- Do you need to spend time settling them in bed before they are able to sleep?

Step 3: Say why your child should not be expected to manage without this help.

For example:

- Would they be physically unable to wake up, get up or go to bed without it?
- Would they become emotionally distressed if they did not receive it?
- Might they come to harm if they did not receive it?
- If it is help that they don't currently receive, in what ways would they benefit from it?

Step 4: Say how your child's needs are different from those of other children of the same age.

For example, can other children of the same age do these things:

- With less help or with no help at all
- More quickly

- Without pain, discomfort or becoming distressed
- With less encouragement or with no encouragement at all
- With less supervision or without being supervised at all
- If your child uses any equipment to help with this activity, give details.

Q55: Do they need encouragement, prompting or assistance to manage their toilet needs?

Tick Yes at the top of the page and any other boxes on the page that apply to your child.

If your child has a stoma, tick the box and use question 72 to explain any difficulties they have or help they need with it.

Think about if:

- Your child takes longer than other children of the same age, or it causes them pain, discomfort or distress
- You have to provide more help, or help of a different kind, than for other children of the same age
- Your child has to be watched over more closely than other children of the same age
- Your child needs more telling or encouragement in a different way to other children.

Only tick No if your child does not have any difficulty with these activities compared to other children of the same age, and you have read the examples on the form and decided that none of them apply.

If you want to explain why they need help, how their needs vary or anything you think the DWP should know, write in the box at **question 72.**

Step 1: Say what problems your child has with their toilet needs, giving specific examples if you can.

For example, does your child:

- Have difficulty getting to and from the toilet because of pain or fatigue
- Have episodes of incontinence
- Experience pain or distress in connection with bowel movements
- Have more frequent bowel movements than other children of the same age
- Become exhausted by the frequency of their bowel movements
- Have particularly noisy, smelly or explosive bowel movements
- Sometimes need to wash, shower or bathe after bowel movements
- Need to apply cream or change pads after bowel movements
- Need help in connection with leakage from a stoma appliance or with changing the bag

Decision Makers may argue that a child who needs help getting to and from the toilet should use a potty or commode instead. Are there reasons why you do not think your child should be expected to do this? If there are, you need to make your case as strongly as possible. For example,

- They would still have to get to the bathroom to wash after a bowel movement
- Their bowel movements have a very strong odour, and the potty or commode would have to be emptied immediately and would leave the room unpleasant to use
- They are old enough that using a potty or commode would add painfully and unnecessarily to the emotional distress their condition causes them.

Step 2: Say what help your child gets, or would benefit from.

For example, do you:

- Help them bathe and change after episodes of incontinence
- Offer them comfort, support or reassurance because of distress caused by pain, discomfort or episodes of incontinence
- Apply cream or change pads
- Check stools for blood or excessive mucus
- Clean the toilet

- Help them change their stoma appliance
- Empty a potty or commode

Step 3: Say why your child should not be expected to manage without this help.

For example:

- Would they be physically unable to attend to their toilet needs without it?
- Would they become emotionally distressed if they did not receive it?
- Might they come to harm if they did not receive it?

Step 4: Say how your child's needs are different from those of other children of the same age.

For example, can other children of the same age do these things:

- With less help or with no help at all
- More quickly
- Without pain or discomfort
- Without becoming distressed
- With less encouragement or with no encouragement at all
- With less supervision or without being supervised at all?

If you run out of space, write your extra information on a sheet and attach to the claim form.

Q56: Do they need encouragement, prompting, or assistance to help move around indoors, use stairs or get into or out of a chair during the day?

Tick Yes at the top of the page and tick any other boxes on this page that apply to your child.

Think about if:

- Your child takes longer than other children of the same age, or it causes them pain, discomfort or distress

- You have to provide more help, or help of a different kind, than for other children of the same age
- Your child has to be watched over more closely than other children of the same age
- If your child needs more prompting or reminding than other children of the same age.

Only tick No if your child does not have any difficulty with these activities compared to other children of the same age, and you have read the examples on the form and decide that none of them apply.

If you want to explain why they need help, how their needs vary or anything you think the DWP should know, write in the box at **question 72.**

Step 1: Say what problems your child has, giving specific examples if you can.

For example:

Moving around

- Does your child have to hang onto furniture to steady themselves?
- Do they suffer discomfort or pain if they stand for any length of time?
- Does standing make their bowel urgency worse?

Stairs

- Is it difficult/painful/exhausting going up or down stairs?
- Do they become dizzy or unsteady?
- Do they have to go very slowly, one step at a time?
- Do they need to hold on to the handrail?

Getting out of chairs and off sofas (and in and out of bed if they have periods when they stay in bed for a large part of the time)

- Do they take a long time to get in or out of chairs?
- Do they stiffen up if they sit or lay too long?

- Do they need someone to help them off chairs and sofas?
- Have they developed special techniques such as rolling off sofas onto their knees?
- Do they have to hold onto things to get upright?
- Are they sometimes too exhausted to get up?
- Is rising from sitting painful?
- Do they have to get up and down a lot because of pain and soreness around the anus or because of frequent trips to the toilet?

Step 2: Say what help your child gets, or would benefit from.

For example:

- Do you give them physical help with moving around? If so, explain in detail what it is you do
- Do you provide them with encouragement, comfort, reassurance or support in connection with moving around?

Step 3: Say why your child should not be expected to manage without this help.

For example:

- Would they be physically unable to move around without it?
- Would they be in pain, or more pain, without it?
- Would they become emotionally distressed if they did not receive it?
- Might they come to harm if they did not receive it?

Step 4: Say how your child's needs are different from those of other children of the same age.

For example, can other children of the same age do these things with less help or with no help at all:

- More quickly
- Without pain or discomfort
- Without becoming distressed

- With less encouragement or with no encouragement at all
- With less supervision or without being supervised at all?
- If your child uses any equipment to help with this activity, give details here.

If you run out of space, write your extra information in questions 54 or 70, or on a sheet and attach to the claim form.

Q57: Do they need encouragement, prompting, or assistance with washing, bathing, showering and cleaning themselves during the day?

Tick Yes at the top of the page if, in connection with washing, cleaning themselves or having a bath or shower:

- Your child takes longer than other children of the same age, or it causes them pain, discomfort or distress
- You have to provide more help, or help of a different kind, than for other children of the same age
- Your child has to be watched over more closely than other children of the same age
- Your child needs more telling or encouragement or needs to be told or encouraged in a different way to other children.

Only tick No if your child does not have any difficulty with these activities compared to other children of the same age, and you have read the examples on the form and in the main box below and decided that none of them apply.

The next boxes ask you how often each day do they need prompting or assistance to help them:

- **Wash or bathe**
- **Clean their teeth**
- **Wash their hair**
- **Get in or out of the bath**
- **Get in or out of the shower**

- **Clean themselves in the bath or shower**
- **Dry themselves after a bath or shower**
- **Check their appearance**

And how many minutes does this take each time?

If your child has to wash or bathe after using the toilet or following episodes of incontinence, remember to include all these times. If their condition varies, give an average or a range.

For lower rate care it doesn't matter how many times a day your child needs help, but for the middle rate it needs to be several times a day across all personal care activities, for example, in the morning, during the day and at night.

How long each time?

Remember this includes the time to get undressed, bathe, dry and dress again and includes any time spent resting in–between.

If you want to explain why they need help, how their needs vary or anything you think the DWP should know, write in the box at **question 72.**

Step 1: Say what problems your child has, giving examples if you can.

For example, does your child:

- Have problems, or suffer pain, getting in and out of the bath
- Get too fatigued to wash, bathe or have a shower
- Have problems or pain washing or drying their feet, hair or back. For example, they can't reach to dry their feet because of pain in their tummy or back.
- Have problems because they have dressings or a line into a vein that needs to be kept dry or sterile
- Need help replacing pads or applying cream after bathing
- Have problems or pain standing to wash
- Have to wash more often than other children
- Tend to wash too often or for too long because of concerns about personal hygiene

Step 2: Say what help your child gets, or would benefit from

For example, do you:

- Encourage them to wash or bathe
- Help them with washing or bathing
- Watch over them to make sure they are safe whilst they wash or bathe
- Offer them support or reassurance if they are in pain or become distressed whilst washing or bathing

Step 3: Say why your child should not be expected to manage on their own.

For example:

- Would they be physically unable to wash or bathe without it?
- Would they become emotionally distressed if they did not receive it?
- Might they come to harm if they did not receive it?

Step 4: Say how your child's needs are different from those of other children of the same age.

For example, can other children of the same age do these things:

- With less help or with no help at all
- More quickly
- Without pain or discomfort
- Without becoming distressed
- With less encouragement or with no encouragement at all
- With less supervision or without being supervised at all

Write down any special equipment that the child has to use, such as a shower seat or rail.

If you run out of space, write your extra information on a sheet and attach to the claim form.

Q58: Do they need encouragement, prompting, or assistance to dress and undress during the day?

Tick Yes at the top of the page if, in connection with getting dressed or undressed:

- Your child takes longer than other children of the same age, or it causes them pain, discomfort or distress
- You have to provide more help, or help of a different kind, than for other children of the same age
- Your child has to be watched over more closely than other children of the same age
- Your child needs more telling or encouragement or needs to be told or encouraged in a different way to other children.

Only tick No if your child does not have any difficulty with these activities compared to other children of the same age, and you have read the examples on the form and in the box below and decide that none of them apply.

The next boxes ask you how often each day do they need encouragement, prompting or assistance to help them:

- **Get dressed**
- **Undress**
- **Choose appropriate clothes**

And how many minutes does this take each time?

If your child has to change during the day due to episodes of incontinence, remember to include all these times as well. If your child's condition varies give an average or a range.

For lower rate care it doesn't matter how many times a day your child needs help, but for the middle rate it needs to be several times a day across all personal care activities, for example, in the morning, during the day and at night.

How long each time?

Remember to include any time your child spends resting, if they need to.

If you want to explain why they need help, how their needs vary or anything you think the DWP should know, write in the box at **question 72.**

Step 1: Say what problems your child has, giving specific examples if you can.

For example, does your child:

- Have problems or pain reaching down to put on underwear, socks or shoes
- Have to wear loose fitting clothes or ones that are easy to get on and off, such as ones with velcro or elasticated waists
- Sometimes have to get changed because of episodes of incontinence or leaks from a stoma appliance
- Find it distressing if they have to get dressed or undressed in front of other children, perhaps because they have a stoma appliance, because they are embarrassed at being physically less developed than other children, or because medicine has caused them to put on weight.

Step 2: Say what help your child gets, or would benefit from.

For example:

- Do you encourage them to dress or undress?
- Do they need physical help getting dressed or undressed?
- Do they need to be watched over to ensure they are not bullied by other children when dressing or undressing?
- Do they need emotional support to deal with distress caused by other children (or adults) in connection with dressing and undressing?

Step 3: Say why your child should not be expected to manage without this help.

For example:

- Would they be physically unable to dress or undress without it?
- Would they become emotionally distressed if they did not receive it?
- Might they come to harm if they did not receive it?

- If there is help that they don't currently receive, in what ways would they benefit from it?

Step 4: Say how your child's needs are different from those of other children of the same age.

For example, can other children of the same age dress and undress:

- With less help or with no help at all
- More quickly
- Without pain or discomfort
- Without becoming distressed
- With less encouragement or with no encouragement at all
- With less supervision or without being supervised at all

If you run out of space, write your extra information on a sheet and attach to the claim form.

Q59: Do they need encouragement, prompting, or assistance to eat and drink during the day?

Tick Yes at the top of the page if, in connection with eating or drinking:

- Your child takes longer than other children of the same age, or it causes them pain, discomfort or distress
- You have to provide more help, or help of a different kind, than for other children of the same age
- Your child needs more telling or encouragement, or needs to be told or encouraged in a different way to other children
- Your child has to be watched over more closely than other children of the same age.

Only tick No if your child does not have any difficulty with these activities compared to other children of the same age, and you have read the examples on the form and in the main box below and decide that none of them apply.

The next boxes ask you how often each day do they need encouragement, prompting or assistance to help them:

- **Eat**
- **Use a spoon**
- **Cut up food on their plate**
- **Drink using a cup**
- **Be tube or pump fed**

And how many minutes does this take each time?

If their condition varies give an average or a range. For lower rate care it doesn't matter how many times a day your child needs help, but for the middle rate it needs to be several times a day across all personal care activities.

Include any time spent preparing special diets and cleaning or maintaining special equipment.

If you want to explain why they need help, how their needs vary or anything you think the DWP should know, write in the box at **question 72.**

Step 1: Say what problems your child has, giving specific examples if you can.

For example:

- Do they have a very small appetite?
- Do they associate eating with abdominal pain?
- Do they feel sick when they eat?
- Does their medicine affect their appetite?
- Have they suffered from malnutrition or weight loss as a result of not eating?
- Do they have to eat smaller amounts but more often than other children?
- Do they have to stick to a special diet or avoid certain foods?

- Do they suffer from joint pains which make holding cutlery or cutting up food painful?
- Are they on parenteral nutrition or tube feeding?

Step 2: Say what help your child gets, or would benefit from.

For example:

- Do you have to remind or encourage them to eat or drink?
- Do you have to prepare special food or drinks for them?
- Do you offer support, comfort and reassurance in connection with pain or discomfort caused by eating?
- Do they need reminding or encouraging to avoid certain foods?
- If they are on parenteral nutrition or tube feeding, describe in detail what this involves, including keeping the equipment sterile and clearing blockages.

Step 3: Say why your child should not be expected to manage without this help.

For example:

- Would they be physically unable to eat or drink without it?
- Would they become emotionally distressed if they did not receive it?
- Might they come to harm if they did not receive it? For example, might they become very weak, malnourished, underweight or not develop physically at the proper rate?
- If there is help they don't currently receive, in what ways would they benefit from it? For example, would their health benefit if they received more supervision and encouragement around eating at school?

Step 4: Say how your child's needs are different from those of other children of the same age.

For example, can other children of the same age do these things:

- With less help or with no help at all

- More quickly
- Without pain or discomfort
- Without becoming distressed
- With less encouragement or with no encouragement at all
- With less supervision or without being supervised at all

If you run out of space, write your extra information on a sheet and attach to the claim form.

Q60: Do they need encouragement, prompting, or assistance with managing their medication or monitoring or managing any treatments carried out at home during the day?

Tick Yes if your child needs any help with medicine, treatments. Tick Yes if your child receives any therapy at all. Don't worry about whether they need more or less help than other children of the same age.

Only tick No if your child does not have any difficulty with taking medicine, and you have read the examples on the form and decide that none of them apply.

The next boxes ask you how often each day do they need encouragement, prompting or assistance to help them:

- **Take the correct medicine**
- **Know when to take their medicine**
- **Manage their therapy**
- **Remind them of when to do their therapy**

And how many minutes does this take each time?

If your child's condition varies give an average or a range.

For lower rate care it doesn't matter how many times a day your child needs help, but for the middle rate it needs to be several times a day across all personal care activities.

Remember to include any time spent making medicine more palatable. State how long they spend with the therapist and how long you spend helping them.

If you want to explain why they need help, how their needs vary or anything you think the DWP should know, write in the box at **question 72.**

If your child attends therapy and/or has to follow a programme of therapy at home, write down what they have to do, why they have to do it and what help they need.

Explain what therapy your child has, such as:

- Physiotherapy
- Hydrotherapy
- Counselling
- psychiatric treatment.

If you are involved in the therapy in any way, such as helping or encouraging your child to do exercises, give details here.

If your child takes medicine and they are too young to take it without help, explain everything you have to do related to this, including any ways that you try to make medicine more palatable and any comfort or reassurance you provide.

If your child takes medicine, and children of the same age might be able to take medicine themselves during the day, then follow the usual four steps:

Step 1: Say what problems your child has, giving specific examples if you can.

For example, does your child:

- Forget to take their medicine
- Try to avoid taking their medicine because of the side effects it has or because of an overwhelming fear or phobia of injections that cannot be overcome.
- Become angry or distressed about a life which involves having to take so much medicine
- Become upset when they have to do physiotherapy exercises at home

Step 2: Say what help your child gets, or would benefit from.

For example, do you:

- Remind or encourage them to take their medicine or do their therapy tasks
- Offer them comfort or reassurance in connection with the effects of their medicine
- Find ways to make their medicine more palatable

Step 3: Say why your child should not be expected to manage without this help.

For example:

- Would they be physically unable to take their medicine without it?
- Would they become emotionally distressed if they did not receive it?
- Might they come to harm if they did not receive it?

Step 4: Say how your child's needs are different from those of other children of the same age.

For example, can other children of the same age take medicine:

- With less help or with no help at all
- More quickly
- Without pain or discomfort
- Without becoming distressed
- With less encouragement or with no encouragement at all
- With less supervision or without being supervised at all

Q61: Do they have difficulty seeing?

This may not be relevant to your child, but if it is, tick the boxes and describe the difficulties your child has with seeing.

Q62: Do they have difficulty hearing?

This may not be relevant to your child, but if it is, tick the boxes and describe the difficulties your child has with hearing.

Q63: Do they have difficulty speaking?

This may not be relevant to your child, but if it is, tick the boxes and describe the difficulties your child has with speaking. If your child has difficulty speaking to people they do not know or if they find it difficult to speak to people involved with their care such as doctors, write this in the box at the bottom of the page.

Q64: Do they have difficulty and need help communicating?

This may not be a section that is relevant to your child. However, if your child does have difficulties in this area, tick Yes and the relevant boxes.

Only tick No if your child does not have any difficulty with communicating with other people compared to other children of the same age, and you have read the examples on the form and in the box below and decided that none of them apply.

If you want to explain why they need help, how their needs vary or anything you think the DWP should know, write in the box at **question 72.**

Step 1: Say what problems your child has with, giving specific examples if you can.

For example:

- Have they become solitary, shy or withdrawn because of their condition or the effects of their medicine on their appearance?
- Do they struggle to talk about their symptoms or difficulties due to embarrassment
- Do they find it easier to talk to adults than children their own age?
- Are they teased or bullied by other children as a result of their condition?
- Do they sometimes become anxious or aggressive when talking to other children or adults because of emotional difficulties caused by their condition or medicine?

Step 2: Say what help your child gets, or would benefit from.

For example:

- Do you spend more time talking with your child than you would with another child of the same age?
- Do you spend time trying to boost your child's self-confidence and self-image in order to help them feel able to talk to other children?
- Do you spend time encouraging your child to talk to other children?
- Do you offer your child support and reassurance if they are upset as a result of being teased or bullied by other children?
- Does your child need help explaining their needs to other people?

Step 3: Say why your child should not be expected to manage without this help.

For example: might they become more withdrawn or isolated without it?

Step 4: Say how your child's needs are different from those of other children of the same age.

For example, can other children of the same age communicate:

- With less help or with no help at all
- Without becoming distressed
- With less encouragement or with no encouragement at all
- With less supervision or without being supervised at all

Q65: Do they have fits, blackouts, seizures or something similar?

This may not be relevant to your child but if your child does have such difficulties, tick Yes and the other relevant boxes and describe their difficulties in detail at question 72.

Q66: Do they need to be supervised during the day to keep safe?

Tick Yes at the top of the page and all the boxes that apply to your child if your child needs more supervision, or supervision of a different kind to other children of the same age, to keep them safe.

Only tick No if you have read the examples on the form and read the boxes below and decided your child doesn't have any such problems.

If you want to explain why they need help, how their needs vary or anything you think the DWP should know, write in the box at **question 72.**

To be awarded DLA for supervision during the day, you need to show that your child needs continual supervision, which means that it must be frequent or regular throughout the day. You also need to show that there would be a risk of harm to your child if they did not receive this supervision.

Step 1: Say why your child needs supervision, giving examples if you can.

For example, does your child need someone to keep an eye on them because:

- They may become overtired
- They need someone to monitor their food and liquid intake
- They are on a nasal feeding tube or something similar throughout the day
- They may harm themselves

Step 2: Say how your child's needs are different from those of other children of the same age.

Would other children of the same age need supervising less closely, less frequently or not at all?

Q67: Do they need extra help with their development?

This may not be a section that is relevant to your child. If they have difficulty interacting with other children and the world around them, tick Yes at the top of the page and in all the boxes that apply to your child.

If you want to explain why they need help, how their needs vary or anything you think the DWP should know, write in the box at **question 72.**

Step 1: Say what problems your child has with the activities listed on the page, giving specific instances if you can.

For example, does your child:

- Have difficulty getting on with other children of the same age, for instance because of embarrassment about their illness or because they're not physically able to play the same games as other children their age
- Tend to be much more shy or aggressive than other children of the same age
- Have difficulty playing with other children because they missed out on a lot of play opportunities due to illness
- Have difficulty trusting other children
- Relate much better to adults than other children
- Spend most of their time alone

Step 2: Say what help your child gets, or would benefit from.

For example:

- Encouragement to spend time with other children
- Careful supervision when with other children.

Step 3: Say why your child should not be expected to manage without this help.

For example:

- Will it become harder to learn social skills as they get older?
- Will they become even more isolated as time passes by?
- Are they likely to become depressed?

Step 4: Say how your child's needs are different from those of other children of the same age.

Would other children of the same age require the same amount of support or encouragement in connection with development?

Q68: Do they need encouragement, prompting or assistance at school or nursery?

Tick Yes and all relevant boxes if your child needs more help at school or nursery. If your child has behavioural issues since becoming unwell, write that information in the box.

If you want to explain why they need help, how their needs vary or anything you think the DWP should know, write in the box at **question 72.**

Step 1: Say what problems your child has with the activities listed on the page, giving specific instances if you can.

For example, as a result of missing school and, whilst at school, often being unwell or frequently having to leave the room to go to the toilet, does your child:

- Need help to change a stoma during the school day
- Have problems with basic literacy or numeracy
- Find it hard to concentrate, for example because of fatigue or side effects of medicines like steroids
- Have difficulties keeping up with other children in their class
- Have difficulty changing for, or taking part in, sports at school due to ill health
- Need help to take medicine
- Need encouragement to eat or drink

Step 2: Say what help your child gets, or would benefit from.

For example:

- More one-to-one help at school from a teacher or teaching assistant
- Extra tuition at home
- Extra help, support or encouragement from you with their school work

Step 3: Say why your child should not be expected to manage without this help.

For example:

- Would they become emotionally distressed if they did not receive it?
- Would it seriously affect their self-esteem?
- Would they become more isolated at school?

- Would they fall behind with their school work?

Step 4: Say how your child's needs are different from those of other children of the same age.

Would other children of the same age require less help with school work?

Q69: Do they need encouragement, prompting or assistance to take part in hobbies, interests, social or religious activities?

Answering these questions can be very important if your child needs support and encouragement with play, socialising or other leisure activities. Don't hesitate to use separate sheets. If this applies to your child, tick Yes.

At home

This can be any activities that your child needs more help or encouragement with than other children of the same age. For example, this could be:

- Help with school work, because they have missed a lot of school through illness
- Encouragement to undertake any activities, because depression about their condition or physical pain make it difficult for them to motivate themselves
- Physical help with setting up or playing games.

When they go out

Does your child need more help or encouragement to go out than other children of the same age? Anywhere your child might go to is relevant. For example:

- Playing outdoors
- Going to the doctor, hospital, physiotherapist, counsellor
- Going shopping for pleasure (rather than for necessities),
- Going on holidays
- Visiting friends and relatives
- Other activities such as going to the library, cinema, religious activities, evening classes, local park, clubs, day-trips, swimming, gym or sports centre.

Help needed

Describe what help they get or would need in order to carry out this activity.

- Do they need someone to encourage them to undertake the activity?
- Do they need someone to drive them to and from places?
- Do they need someone to carry things for them, to lean on, to help them find a toilet, to help them get to and from the toilet?
- Do they need someone to offer them support and reassurance because of the possibility of an episode of incontinence?
- Do they need someone with them in case they have a dizzy spell or a fall?

How often?

Is this something they would do more than once a day?

For lower rate care it doesn't matter how many times a day your child needs help, but for the middle rate it needs to be several times a day across all activities.

How long each time?

Include, if relevant, the time needed to encourage them to undertake the activity, accompany them there, stay with them, throughout the activity and accompany them back.

Question 70 – About help needed during the night

Q70 Due to a health condition or disability do they wake and need assistance or supervision during the night?

If you have to get up during the night to help your child, then tick Yes.

This is a very important page. Even a small amount of help at night may be sufficient for your child to be awarded the middle rate of the care component. If they need help during the day and at night they may get the higher rate care component.

Remember, night means the time when the adults in your house normally go to bed.

Only tick No if you have read the examples on the form and decided that none of them apply.

The next boxes ask you how many nights each week, and how many times a night do they need encouragement, prompting or assistance to help them:

- **Get into, get out of or turn in bed**
- **Get to and use the toilet, manage nappies or pads**
- **Have treatment**
- **To settle or re-settle**

And how many minutes does this take each time?

The form also asks if your child needs supervision during the night.

If this varies, give an average or a range. To qualify for middle rate care your child has to need help for at least 20 minutes a night, or at least twice a night.

If you want to explain why they need help, how their needs vary or anything you think the DWP should know, write in the box at **question 72.**

Explain why the child needs someone awake with them during the night.

Step 1: Say what problems your child has, giving specific examples if you can.

For example, do they:

- Get hungry or thirsty
- Have episodes of incontinence
- Have bad dreams
- Suffer pain

Step 2: Say what help your child gets, or would benefit from.

For example, do you:

- Bring them medicine, drinks or anything else during the night. If so, explain at step 3 why these can't just be left within reach for them, in case they need them

- Help them with changing position or rearranging the bedding
- Strip the bed, put on fresh bedding and put the soiled bedding on to soak or wash after an episode of incontinence
- Make a hot water bottle for them to put on a painful joint or on their abdomen
- Massage painful areas of their body
- Give them comfort and reassurance to help them go back to sleep

Step 3: Say why your child should not be expected to manage without this help.

Would they:

- Be unable to sleep without it
- Become emotionally distressed if they did not receive it
- Come to harm if they did not receive it

Step 4 Say how your child's needs are different from those of other children of the same age.

- For example, can other children of the same age get through the night:
- With less help or with no help at all
- Without pain or discomfort
- Without becoming distressed
- With less supervision or without being supervised at all

If your child uses any equipment to help them during the night, give details here.

Step 4: Say how your child's needs are different from those of other children of the same age.

For example, can other children of the same age get through the night:

- With less help or with no help at all
- Without pain or discomfort
- Without becoming distressed
- With less supervision or without being supervised at all

If your child uses any equipment to help them during the night, give details here.

Questions 71 to 72 – Additional information about care needs

Q71: What date did the child's difficulties with their care needs start?

If you do not know the exact date, put in an approximate date or month and year. If your child had care needs before they were diagnosed with Crohn's or Colitis, write the date the care needs first started.

Q72: Tell us anything else we need to know about their difficulties with their daily living and care needs or how their needs change from day to day.

This is where you can write any information about questions 54-70.

Use this space to tell the Decision Maker anything else that will help to give a clearer picture of the impact IBD has had on your child's life. For example:

- Have they had to give up sports or other pursuits that used to mean a great deal to them?
- Have they changed from being outgoing and friendly to withdrawn, self–conscious and wary of other children or adults?
- Have they become very thin or has their medicine made them put on a lot of weight?

Is their condition very unpredictable and difficult to manage?

- Do they miss out on a lot of things, such as school trips and holidays, because of their condition?
- If they have had hospital admissions or surgery, you can give more details here.
- If they have a stoma, or have special treatments such as total parenteral nutrition that you have not already covered fully, give details here.

Middle rate care

Although the claim form asks lots of questions about how often your child needs help and how long for, it doesn't ask you about when in the day they need help. However, this information can be very important. If your child needs help for at least an hour a day, but only in one chunk, or only at the beginning and end of the day – perhaps help with washing, dressing and undressing – they are likely to qualify only for the lower rate of the care component. For example, if your child needs help and encouragement for 40 minutes in the morning with getting up, washing and dressing and 20 minutes in the evening to get them to bed, this may be enough for them to get lower rate care.

To get the middle rate you have to show that your child needs help 'frequently throughout the day', so they have to need help in the morning, during the day and in the evening.

'Frequently' has been defined for benefits purposes as meaning 'several times – not once or twice', but there is no clear definition of what 'frequently throughout the day' means. The Decision Maker has to decide each case on the facts, so it may be helpful if you make those facts as clear as possible. You can use this page to list when they need help on an average day.

For example:

Help my child needs throughout an average day

7.30am	Help with getting out of bed washing and dressing
8.30am	Encouragement to eat and help taking medicine
12.30pm	Encouragement to eat and help taking medicine
4.00pm	Encouragement to spend time with other children outside school hours, because my child has become quite withdrawn and isolated due to their condition.
5.00pm	Additional help with school work because my child has missed so much due to time off when unwell.

6.00pm	Encouragement to eat and help taking medicine.
8.00pm	Help with washing, undressing and getting into bed.

Completing the form - Questions 73 - 89: About you

These questions are about the adult who is making the claim on behalf of the child. Please remember to add your National Insurance number (question 76) and a daytime phone number (question 79) as the DWP may phone you and ask you a few questions.

Q89: Extra information

Tell us anything else you think we should know about the child's claim

Write down any additional information about the claim that you want the DWP to know.

Declaration

Sign and date the declaration.

You've done it. The claim form is complete. Remember to photocopy the form before you send it.

Supporting evidence

As well as your claim form, the Decision Maker has to take into account any other evidence you provide. This includes additional evidence from you and evidence from other people.

Medical evidence

Include supporting evidence from health professionals, such as your child's nurse, GP or other specialists involved in your child's care if you have it. Always let your child's GP know that you are making a claim for DLA. The DWP may contact your child's GP without telling you first, even if he or she has very little to do with dealing with your child's condition.

Ask the health professionals most involved in your child's care if they will write a letter supporting the claim. Make an appointment to see them so you can answer any questions they have and take the Health professional sheet (Appendix 4) at the back of this guide with you. Ask them to send the letter to you so you can keep a copy, and if necessary, ask them to change anything you think is inaccurate or unhelpful. It is up to you to decide what evidence you submit. Do not feel obliged to use a letter that may not be helpful or might actually harm your case.

Non-medical evidence

Carers, teachers, friends or relatives who help to look after your child can also submit letters as supporting evidence, but they should give them to you to submit so that you can keep a copy. If the letter says things that you think are unhelpful then ask the writer to change them or simply do not submit it. Don't feel obliged to submit a letter just because someone has been kind enough to write it. A letter that says the wrong things can be damaging to your claim.

It is important, if possible, to submit evidence from your child's nursery, school or college. Families have told us that their claims have been turned down because they didn't provide enough evidence from their child's school. You could ask your child's teacher to explain what help the school provides to overcome problems with absence, exams, school trips and toilet urgency.

Keeping a diary

- It is very useful to keep a diary for about seven days to detail all the difficulties your child experiences and all the help they receive. If you keep a diary before you fill in the claim form, it can make filling in the claim form a lot easier. You can send a copy of the diary in with your child's claim form as additional evidence. If your child has a fluctuating condition it may be helpful to keep a diary for a longer period of 2–3 weeks, to better reflect their condition.
- A diary may also prove invaluable if you need to attend a tribunal, as it will be evidence of what problems your child had at the time you made the claim.

Don't forget

You must send your claim form before the deadline. You can send other evidence later if necessary. Enclose a letter with your claim form telling the DWP that you intend to send further evidence, and when you hope to send it to them.

What happens next?

After you've applied, you'll get a letter within 3 weeks that explains how long it'll take to get a decision. Your claim will then be looked at by a Decision Maker, who may make a decision on the information you have sent or may decide they need more information. The Decision Maker may contact your child's GP, or more rarely your child's specialist, for further information. If more information is needed, they may ask the DWP to send a health professional to visit your child for a home visit and to write a report.

Preparing for a home visit

There's no way of knowing whether your child will have to have a home visit or not when you make your claim. Many claims are now decided on the basis of the claim form and additional evidence, but some families will be visited at home by an independent health professional (not a DWP official). The first you will hear about it is when you receive a letter, or possibly a phone call, requesting a home visit. If you refuse to allow your child to be examined, your child's claim for DLA may be turned down. The health professional may be a doctor, but they could be another health professional, such as a physiotherapist, occupational therapist or nurse.

You can tell the DWP that you want to have a friend or relative present and make sure that the visit is arranged for a time when they can be there.

The health professional will usually discuss your child's medical history and ask about a typical day. They may ask you or your child more questions, carry out a brief physical examination and ask your child to carry out simple activities such as standing up and walking across the room. If you know that something they ask will cause your child pain, you should tell the health professional you do not wish your child to do it and explain why.

After the home visit, the health professional will write a report about your child. They will explain and justify their opinions and return the report directly to the DWP.

If the decision based on this assessment goes against you, you can ask to see the report and query it with the DWP through the reconsideration and appeal process.

Having someone else present can provide moral support. It can also provide you with a witness to what happened at the home visit. You can use the Medical visit record sheet (Appendix 3) at the end of this guide to record what happens, as this can be used as evidence at an appeal. Look through the sheet before the home visit and fill it in afterwards if you want to have a record of what happened. Remember to make a note of the time the health professional arrived and left.

The decision

You will receive a decision letter telling you whether your child has been awarded DLA. If your claim has been successful the letter will tell you which components – care and/or mobility – your child has been awarded and at what rates. It will also tell you whether your child's award is for a fixed number of years or whether it will continue until your child reaches the age of 16, when they will have to apply for PIP. For information on claiming PIP, see our guide Claiming Personal Independence Payment (PIP).

If you are happy with the award then you don't need to do anything else, except check whether you qualify for other benefits, or increased amounts of other benefits. Citizens Advice have information on extra benefits and help you can get while on DLA.

If the award is for a fixed number of years, you should be sent another claim form to complete several months before it runs out. If the award is until the age of 16, you may still receive claim forms to fill in every few years and the award can still be reduced or stopped depending on what you write in the claim forms. You should always keep your child's original claim form for reference, whatever length of award you receive.

If your child’s circumstances change – their condition improves or deteriorates – you should tell the DWP as it may mean that their DLA should be reduced or increased.

Challenging the decision

If your claim is turned down, or if you are unhappy with the rate awarded or the length of time it has been awarded for, you can challenge the decision.

Mandatory reconsideration

The first step is to ask the DWP to look at their decision again. This is called a **mandatory reconsideration**. You usually need to do this within one calendar month of the date on the decision letter.
You can fill in and return a form asking for mandatory reconsideration. Complete the questions, explaining why you disagree with the decision. Send any new evidence or information to support your claim if you can.

The DWP will look at your claim again. They will write to you to respond to the points you have raised and to tell you their decision. The letter (called a mandatory reconsideration notice) will include details of how to appeal to a tribunal, if you are still unhappy with the decision.

Citizens Advice have more information on challenging a DLA decision – mandatory reconsideration.

Tribunal appeal

If you are still not happy with the result of your claim, you can appeal to an independent tribunal. You must do this within one month of the date on your mandatory reconsideration letter.

Citizens Advice have more information on challenging a DLA decision – appealing against the decision.

Visit the GOV.UK website for details of how to submit your appeal. The form asks you whether you want to go to a tribunal hearing or not. The tribunal will be informal, with only the judge, two independent people and possibly one person from the DWP. You may want to represent yourself if you feel you are the best person to explain your situation. You can ask someone to represent you, but make sure they fully understand Crohn's and Colitis and the problems your child faces in their daily life.

You may want to speak to a benefits advisor if you are considering making an appeal. You can find a benefits advisor at Citizens Advice or Turn2Us.

If you have been awarded DLA but are considering challenging the decision to try to get your award increased, be aware that there is some risk that your existing award could be reduced or ended, instead of being increased. If you are unsure what to do, seek advice from the organisations listed at the end of this guide.

Other organisations

Making a claim

Department for Work and Pensions (DWP): www.gov.uk/disability-living-allowance-children

DLA new claims

Disability Living Allowance helpline
Telephone: 0800 121 4600
Textphone: 0800 121 4523
Relay UK (if you cannot hear or speak on the phone): 18001 then 0800 121 4600
British Sign Language (BSL) video relay service if you’re on a computer - find out how to use the service on mobile or tablet Monday to Friday, 9am to 5pm

Getting support and advice

Advice Now: www.advicenow.org.uk

Citizens Advice: www.citizensadvice.org.uk

Motability: www.motability.org.uk

Turn2us: www.turn2us.org.uk

Your MP

You can find contact details for your local MP from your local library or online.

Help and support from Crohn's & Colitis UK

We're here for you whenever you need us. Our award-winning information on Crohn's Disease, Ulcerative Colitis, and other forms of Inflammatory Bowel Disease have the information you need to help you manage your condition.

We have information on a wide range of topics, from individual medicines to coping with symptoms and concerns about relationships and employment. We'll help you find answers, access support and take control.

All information is available on our website: crohnsandcolitis.org.uk/information

Our Helpline is a confidential service providing information and support to anyone affected by Crohn's or Colitis.

Our team can:

- Help you understand more about Crohn's and Colitis, diagnosis and treatment options
- Provide information to help you live well with your condition
- Help you understand and access disability benefits
- Be there to listen if you need someone to talk to
- Help you to find support from others living with the condition

Call us on **0300 222 5700** or email helpline@crohnsandcolitis.org.uk.

See our website for LiveChat: crohnsandcolitis.org.uk/livechat.

Crohn's & Colitis UK Forum

This closed-group community on Facebook is for everyone affected by Crohn's or Colitis. You can share your experiences and receive support from others at: facebook.com/groups/CCUKforum.

Help with toilet access when out

Members of Crohn's & Colitis UK get benefits including a Can't Wait Card and a RADAR key to unlock accessible toilets. This card shows that you have a medical condition, and will help when you need urgent access to the toilet when you are out. See crohnsandcolitis.org.uk/membership for more information, or call the Membership Team on **01727 734465.**

Crohn's & Colitis UK information is research-based and produced with patients, medical advisers and other professionals. They are prepared as general information and are not intended to replace advice from your own doctor or other professional. We do not endorse any products mentioned.

About Crohn's & Colitis UK

We are Crohn's & Colitis UK, a national charity fighting for improved lives today – and a world free from Crohn's and Colitis tomorrow. To improve diagnosis and treatment, and to fund research into a cure; to raise awareness and to give people hope, comfort and confidence to live freer, fuller lives. We're here for everyone affected by Crohn's and Colitis.

This information is available for free thanks to the generosity of our supporters and members. Find out how you can join the fight against Crohn's and Colitis: call **01727 734465** or visit crohnsandcolitis.org.uk.

About our information

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We hope that you've found this information helpful. You can email the Knowledge and Information Team at evidence@crohnsandcolitis.org.uk if:

- You have any comments or suggestions for improvements
- You would like more information about the research on which the information is based
- You would like details of any conflicts of interest

You can also write to us at **Crohn's & Colitis UK, 1 Bishops Square, Hatfield, Herts, AL10 9NE** or contact us through the **Helpline: 0300 222 5700**.

Claiming DLA, edition 6

Last review: July 2023

Next review: July 2026

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Patient Information Forum

Appendix 1: 2 minute DLA test for children

Step 1: Look through this list of some (but not all) of the activities that are relevant to DLA:

- Walking outdoors (especially in unfamiliar places)
- Getting into or out of bed or settling in bed
- Going to or using the toilet
- Washing, bathing, showering and checking their appearance
- Dressing and undressing
- Eating and drinking
- Talking to other people
- Being left alone
- Taking medicine or doing therapy
- Someone keeping an eye on them
- Help with their development – play, behaviour
- Extra help at school or nursery
- Social and leisure activities
- Help during the night – toilet, someone to watch over them

Step 2: Choose one of the activities above that your child has difficulties with.

For example, your child may have difficulties with walking because of fatigue; talking to other people because they have become very withdrawn; going to the toilet because of soreness around the anus.

Step 3: With your chosen activity in mind, answer the following true or false questions:

My child can do it,

- But it hurts them - true or false?
- But only more slowly than other children of the same age - true or false?
- But only with more help than other children of the same age - true or false?
- But not as safely as other children of the same age - true or false?

- But only because they've got a special technique of their own - true or false?
- But they need more encouragement than other children of the same age - true or false?
- But they need a closer eye kept on them than other children of the same age - true or false?

My child can't do it,

- But other children of the same age can - true or false?

Step 4: If you haven't answered True to any of the questions, try the test again with another activity from the list and so on, until you find a statement that is true or you decide that there aren't any.

Step 5: If the answer is True to any of the questions above in relation to any activity then your child may be entitled to DLA. If your child's condition is a variable one, so the answer is sometimes True and sometimes False, then they may still be eligible for DLA.

If the answer isn't True to any of the questions, your child may still be eligible for DLA. You can get advice from one of the agencies listed in other organisations.

CROHN'S & COLITIS UK

Appendix 2: Claim file record sheet

Example:

Date	Letter		Phone		Name and section	Details
	To	From	To	From		
10/06/2023	✓				DLA unit	Sent claim form and letters from GP and consultant
20/06/2023				✓	Gemma Watson - DLA Helpline	Confirmed they had received my claim form

Date	Letter		Phone		Name and section	Details
	To	From	To	From		

Appendix 3: Medical visit record sheet

Date of healthcare professional's visit:	
Time healthcare professional arrived:	
Time healthcare professional left:	
Who else was present?	

Did you feel that you had time to answer the healthcare professional's questions fully?
Did the healthcare professional phrase questions in a way that suggested a particular answer?
Did anything the healthcare professional do, or ask your child to do, cause your child pain?
Anything else you wish to record

Signed (your signature)	**Date**
Signed (friend or carer who was present)	**Date**

Appendix 4: Health professional sheet

Information for healthcare professionals providing evidence about a Disability Living Allowance claim for the DWP

In order to make a fair decision about a claim, the DWP requires very specific evidence from health professionals.

The DWP wishes to know:

- Length of time over which the patient has been treated
- Confirmation of any diagnoses (not just IBD diagnosis)
- Likely future clinical course

However, the most important information is a description of the consequences of symptoms and their cause. For example:

Symptom: Weakness and lethargy due to anaemia from chronic disease and blood loss.

Effect: Breathless and unsteady, even when walking a short distance or using stairs. Poor concentration; very slow performing daily activities; needs help to take medicine and safely carry out activities of daily living such getting in and out of bed.

In order to help the health professional supply this evidence, on the reverse of this sheet is a checklist of activities of daily living. The patient's parent or carer may have already completed this form. You may wish to go through it with them.

Parents or carers may not have previously revealed to their child's health professional the extent to which the disease affects their child's everyday their life. This may be because much of the additional care they provide for the child is in connection with non–medical activities such as school, social activities, washing, dressing, etc.

It is important to bear in mind that Ulcerative Colitis and Crohn's Disease are largely 'hidden' conditions – the disabilities which arise from them are not usually obvious. The evidence from health professionals can help make it clear that this does not reduce their importance.

Components and rates of DLA

It needs to be shown that the child’s need for attention or supervision is substantially in excess of that of other children of the same age who do not have a health condition or disability.

DLA is made up of two components, the care component and the mobility component.

Care component

The rate depends on the level of looking after the child needs.

- Lowest rate – help for some of the day
- Middle rate - frequent help or constant supervision during the day or supervision during the night
- Highest rate – help or supervision throughout both day and night, or a medical professional has said they might have 12 months or less to live.

Mobility component

The rate depends on the level of help the child needs getting about.

- Lowest rate (your child must be 5 years or over)– they can walk but need help or supervision when outdoors
- Highest rate (your child must be 3 years or over) – they cannot walk, can only walk a short distance without severe discomfort or could become very ill if they try to walk.

Checklist

For the parent/carer to complete concerning their child, to help the health professional's understanding of the problems their child is experiencing.

Activity	Very brief details of the problem your child had with this activity, including variability. '*Wakes up in the night because of abdominal and joint pains. At least once a night, sometimes four or more times'*
Walking outdoors	
If your child needs someone with them when they are outdoors	
Someone keeping an eye on your child	
Your child's development	
Waking, getting up and going to bed	
Washing and bathing	
Dressing and undressing	
Help with toilet needs	
Communicating with other people	
Eating and drinking	
Help with medicine	

Help with therapy	
Help with medical equipment	
Blackouts, fits and seizures	
Your child’s mental health	
Movement, co–ordination and moving about indoors	
When your child is in bed at night	
Social and leisure activities in the day	