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# Claiming Disability Living Allowance

**A Guide For Children Under 16  
With Ulcerative Colitis And  
Crohn's Disease**

**Last updated: July 2007**

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#### PLEASE NOTE

While every care has been taken to ensure that the content of this work is accurate at the date of publication, no liability in respect of such content or any omission in this work is or will be accepted by any of the authors or by the National Association for Colitis and Crohn's Disease.

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.

## Welcome

In the summer of 2000 the National Association for Colitis and Crohn's Disease (NACC) produced a guide to help adults with Inflammatory Bowel Disease (Ulcerative Colitis or Crohn's Disease) to complete an application for Disability Living Allowance. The guide was very well received by people with IBD and advice agencies, many of whom contacted NACC to say how helpful they had found it. Following requests from parents of children with IBD, NACC commissioned this guide to claiming DLA for children and young people under 16. It has been written by Steve Donnison and Holiday Whitehead, members of the team of welfare benefits specialists who wrote the first guide. We hope you will find it just as helpful and we would welcome any feedback you care to send us. Steve Donnison, Holiday Whitehead

### Why claim DLA?

If your child has IBD this may create all sorts of extra expenses, such as higher heating bills, special diets, taxi fares, laundry, etc. DLA can help meet these. But you can spend DLA on anything you wish, not just the extra expense caused by illness. We spoke to people who used their child's DLA to provide treats and holidays and others who were putting it away in a savings account for their child to use when they are older. But you should be aware that making a claim for DLA on behalf of a child can be just as long drawn out and emotionally draining as making a claim for an adult.

However, the good news is that this guide will take you step-by-step through the process in even more detail than the guide for adults. The *Help!* Section also contains tips on how to get help and support from elsewhere. We very strongly recommend that you read the *Help!* Section and think about what support you can arrange before you start to make your claim.

### How to use this guide

This guide is designed to take you step-by-step through the whole process of making a claim for DLA right from getting a copy of the form through to getting a letter telling you the result of your application. Read it all through once if you want, or just read each section as you need it. But do please start with the *Before You Begin* section. You may also want to use the following sheets at the end of the guide:

**Medical Visit Record Sheet:** this is for you to fill out if your child has a Department of Work and Pensions (DWP, the new name for the former Department of Social Security) medical. (For more about this see *Preparing for a Medical*).

**Claim File Record Sheet:** this is for noting details of any letters and phone calls to and from the DWP. It is intended to form part of the Claim File which we very strongly recommend you keep. (See *Before You Begin* for further details).

**Health Professional's Sheet:** Read the Health Professional's Sheet through carefully along with the notes in the *Including Supporting Evidence* section, before contacting your GP and/or specialist for letters of support.

You can also include the NACC booklet on *Understanding Colitis and Crohn's Disease* to help the decision maker with your application. Download a copy from the NACC website at [www.nacc.org.uk](http://www.nacc.org.uk) or ring the NACC office (01727 830038) and ask to be sent one.

# Is My Child Eligible?

## What matters

**Health problem:** your child must have a long term health problem (in this case Crohn's or UC) that affects their everyday activities, that has lasted for at least three months and is expected to last at least another six. The health problem has to result in your child needing substantially more care or supervision than other children of the same age.

**Age:** if your child is under 16 you can make a claim on their behalf. Once they are 16 or over they can claim in their own right.

You can claim DLA for your child at any time, but the care component is not payable until they reach **3 months old**. Higher rate mobility is not payable to children under **3 years old** and lower rate mobility is not payable to children under **5 years old**. Don't worry about remembering these age limits, we'll remind you of them when you reach the appropriate pages of the claim pack.

The Two Minute DLA Test on the next page provides a quick and easy way for you to decide whether to fill out a claim pack on behalf of your child.

## What doesn't matter

### 1 About your child

It doesn't matter if you don't consider your child to be 'disabled'. For the purposes of DLA, 'disabled' simply means that your child has a long term illness which 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 etc), other than a professional welfare rights worker, not to make a claim because your child is not ill enough. People have all sorts of ideas about who 'should' and 'shouldn't' get DLA, and most of them are wrong. The question of entitlement is a legal one, not a medical one. If in doubt, make a claim.

### 2 About you (and your family)

When considering whether to award DLA, the Decision Maker is only interested in your child and the way their health problems affect them. (Decision Makers are DWP staff who make decisions about claims). Your circumstances are not taken into account in any way. So it doesn't matter if:

- you're working
- you're unemployed
- your partner works
- you don't have a partner
- you've never paid national insurance contributions
- you, or anyone else in your family, is claiming any other benefits (such as Incapacity Benefit, Income Support, Jobseekers Allowance or DLA)
- you have savings

Finally, your child will not be 'registered disabled' if they receive DLA and it will not make it more difficult to get a job when they become an adult.

# The 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:

- getting up and going to bed
- washing, bathing and showering
- dressing and undressing
- going to the toilet
- eating and drinking
- taking medication
- sleeping
- walking outdoors (especially in unfamiliar places)
- being left alone
- learning
- playing
- being with, or talking to, other people
- social and leisure activities

**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?*

**or**

- 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've found a statement that is true or decided that there aren't any.

**Step 5** If the answer is *True* to *any* of those questions 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. We explain how to deal with fluctuating conditions in the *Completing the claim pack* section.

If the answer wasn't true to any of the questions your child may still be eligible for DLA, you should try to get advice from one of the agencies listed in the *Help!* section.

# Before You Begin . . .

Before you begin your claim, please resolve to do two things:

## **1 Take control – keep a Claim File**

A claim file is just a folder, or a ring binder, in which you keep notes and copies of everything to do with your DLA claim. But it can save you months of frustration and lost benefits if the DWP lose your records.

What to put in your Claim File :

### **1 Keep a photocopy of EVERYTHING you send the DWP.**

Most especially, keep a photocopy of your completed claim form and keep it safe. We do know how difficult and expensive this can be, but if you don't you may regret it because

- The claim form may be lost by the DWP – it does happen.
- Even if your child's claim is successful the award will either be for a limited period, say three years, and you'll have to apply again towards the end of that period, or it will be awarded up to your child's sixteenth birthday. In either case you'll have to fill out more claim forms and if you don't give at least as much detail as you did in the original the DWP may decide your child is getting better and stop the claim.
- 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.

### **2 Keep every letter you receive from the DWP.**

Put them all in a folder in date order, along with copies of letters you've sent them. (We had one client who was able to claim thousands of pounds in backdated benefits because he had kept copies of letters right from the beginning of his claim).

### **3 Keep a note of any phone calls to or from the DWP**

Always ask for the name of anyone you speak to and keep a note of it, along with the date and the subject.

E.g. *16.2.07 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 at least their first name and the section they work on, insist on speaking to their supervisor.*

## **2 Arrange support**

Making a claim for DLA can be hard work mentally and emotionally. It may all go smoothly for you or you may end up climbing the walls in sheer fury or plunging into the depths of depression. So, turn to the *Help!* Section now, before you start your claim.

## Getting A Claim Pack

The first step in making a claim is getting a claim pack. The best way to do this is to make a freephone call to the Benefits Enquiry Line on **0800 882 200** (8.30 am to 6.30 pm Monday to Friday and 9.00 am to 1.00 pm on a Saturday) and ask them to send you a DLA claim pack for a child under sixteen.

You should then be sent a pack with two dates stamped on it. The first is the date you asked for the form and the second is the date, six weeks later, by which you should return it. (Which means you have to post it several days before that date). If they receive it after the six weeks your claim is still valid, but it starts from when the DWP get your form back instead of the date when you first asked for it.

When you make the call don't forget to get the full name, or first name and department in which they work, of the person you speak to. Make a note of it, along with the date, in your claim file. That way, if you don't receive a claim form, you should be able to get another one backdated to the day of your original call.

If you get a claim form from elsewhere, such as an advice agency, it won't be date stamped and your claim will start from when the DWP receives your completed form.

The form should arrive in 7-10 days. In the meantime you may wish to consider:

- keeping a diary (see *Including Supporting Evidence*);
- making a list of people who can provide supporting evidence (see *Including Supporting Evidence*);
- making 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);
- downloading a copy of the claim pack from the DWP website and drafting rough answers to the questions about problems your child has with everyday activities.

### When the pack arrives

Sadly, a lot of people take one look at the size of the claim pack and give up immediately. Please don't be one of them. We will help you every step of the way. And if you have got a date stamped pack you've also got over a month to complete it, depending on how long the DWP took to post it out to you. But before you actually put pen to paper, please read the next section.

# Completing the claim pack: handy hints and legal advice

Before you begin completing the pack, please read through the notes below, which are divided into four sections:

- 1 General tips on completing the claim pack
- 2 How to fill in the main boxes
- 3 How to fill in the smaller boxes
- 4 How to explain fluctuating conditions

## 1 General tips

The decision about whether to award DLA is based on evidence. The form you are about to complete is evidence and so are any letters from doctors, carers or relatives. The NACC booklet on *Understanding Colitis and Crohn's Disease* is also evidence. Download a copy from the NACC website at [www.nacc.org.uk](http://www.nacc.org.uk) or ring the NACC office (01727 830038) and ask to be sent one.

An effective claim is made up of evidence that is as clear and as detailed as possible. This is particularly so for Crohn's and Ulcerative Colitis because they are not widely known or understood conditions. You can include the NACC booklet on *Understanding Colitis and Crohn's Disease* to help the decision maker understand the condition. Please take the time to fill in the form in as much detail as you possibly can: many claims are rejected simply because there wasn't enough evidence for benefit to be awarded. If you don't fill in the claim pack fully and have to appeal, you will also have to explain to the tribunal why you are now saying that your child has problems that you didn't mention in your claim pack.

However, when you're filling out the DLA form you **don't** need to worry about handwriting, spelling, punctuation, grammar or staying inside the boxes. Do whatever works best for you, including any or all of the following:

- write in note form
- write in bullet points
- write outside the boxes and up the side of the page if you can't fit everything inside the boxes
- write on additional sheets of your own paper. But if you do, always write your child's name (and national insurance number if you know it) across the top of each extra sheet, give the page numbers of the questions you're answering and fasten the sheet to the last page of the claim pack.

## 2 How to fill in the main boxes

Parts 6-27 ask about various everyday activities. On most pages there is a main box for describing the problems your child has and smaller boxes for saying how long they need help for, how often and how many days or nights a week. You don't have to fill in pages relating to activities your child doesn't have problems with – but please check what we have to say about each page before deciding that you needn't complete it.

For the main boxes we recommend you use our four step system to ensure that you give detailed and relevant information. However, on some pages you will not need to use all four steps, and on some you will not need to use any, we will tell you which ones these are as we go through parts 6-27.

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

For example, does your child have difficulty with using the toilet because it is painful? Do they sometimes become distressed? Do they sometimes not make it to the toilet? Give as much detail as you possibly can about the problems your child has.

If you can give specific instances this will make your evidence all the more convincing.

**Step 2 Say what help your child gets (or would benefit from).**

The law looks at what attention or supervision your child ‘reasonably requires’. In other words it doesn’t have to be something they cannot possibly manage without, just something it’s reasonable for a parent or carer to provide. So say what you do, or would like done, for your child.

For example, do you help them clean themselves up after a messy bowel movement or offer them sympathy, understanding or encouragement when they are in pain or distressed? Would your child benefit from such support when they are at school, for example, even if they don’t get it?

**Step 3 Say why your child should not be expected to do without this help.**

Decision Makers are very fond of saying that, for example ‘There is no evidence that the child cannot manage to administer his own medication / apply cream himself / change his own dressings / eat meals without supervision’ or whatever the case may be. Often, the implication is that you are simply an over-protective parent or are exaggerating your child’s care needs.

It’s very important that you show why your child ‘reasonably requires’ someone to help them or supervise them. For example, your child may be physically able to apply cream to a sore anus or fistula, or change a dressing or stoma appliance, but it may be painful or distressing for them. So it is reasonable for you to be there to encourage and reassure them, make sure the task is done properly and finish it for them if necessary. After it’s done you may need to give them sympathy, attention, understanding and praise to encourage them to do it next time.

In the same way your child may be physically able to feed themselves, but they may associate food with pain and therefore be very reluctant to eat as much as they should. Your job may be to encourage them to eat and praise them for doing so, as well as showing that you understand the difficulties that they face. If you did not do so your child’s condition might worsen as a result.

**Step 4 Say how your child’s needs differ from those of other children of the same age.**

The law says that in order to get DLA, a child’s needs have to be ‘substantially in excess of the normal requirement’ of children of the same age. So, very briefly contrast your child’s needs with that of other children of the same age who do not have health problems. For example: ‘A child of seven does not usually need encouraging to eat’; ‘A child of nine does not usually become distressed when they go to the toilet and does not need help with cleaning themselves up afterwards’.

**3 How to fill in the smaller boxes**

Parts 6-27 also ask you to say how many days or nights a week, how often each day or night and how many times a day or night, your child needs help with each activity. Your answers will affect what rate of the care component they are eligible for. We explain the rules below, but the important thing to remember is just to fill in the form in as much detail as possible, without underestimating the difficulties they face. If the amount of help they need varies, see ‘Fluctuating conditions’ below.

**How long on average does your child need help during the day**

If they need help for *at least an hour* a day in total, they may qualify for the **lower rate**. It doesn’t matter if this help is needed all in one go or partly in the morning and partly in the

evening. So 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 with things in the morning, during the day and in the evening as well.

#### **How long on average does your child need help for at night**

Your child has to need help for *at least 20 minutes* a night, or at least twice a night, for it to count. If they only need help at night they may get the **middle rate** care component. If they need help during the day *and* at night they may get the **higher rate** care component.

#### **How many days / nights a week**

As a general guide, if they need help less often than *four or five days / nights* a week they will be less likely to qualify for DLA.

#### **How many times a day does your child need help**

As we said above, for lower rate care it doesn't matter how many times, but for the middle rate it needs to be '*frequent*' which has, rather unhelpfully, been defined as several times.

#### **How many times a night does your child need help**

As we said above, at night it needs either to be once for at least twenty minutes or it needs to be at least *twice* a night.

## **4 How to explain fluctuating conditions**

This is one of the biggest problems people with Crohn's and Ulcerative Colitis (UC) have with claiming DLA. Some agencies advise people to complete the claim pack thinking just of how your child is on bad days. However, Crohn's and UC are known to be fluctuating conditions, so if you present their condition as unvarying this may make your evidence less believable. (If, on the other hand, their condition actually doesn't vary then go out of your way to explain this on the claim form.)

In addition, if your child is not awarded DLA and you choose to appear before a tribunal they are likely to ask you to go back through the last week, day by day, explaining in great detail what difficulties your child had. If the previous week was one of their better weeks you will be faced with a difficult choice. You will either have to lie to the tribunal, or tell a truth so different from what you wrote on the claim form that you will have no credibility at all and the appeal will probably fail.

So what do we advise you to do?

We suggest that you explain how they are on their bad days and then how they are on their 'better, days'. Please note that if you use expressions like 'good days' or 'normal days' it will be assumed that these are days on which they have no problems whatsoever. So, for example you might say:

*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. The pain is in his ... (etc.)*

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

Be careful not to underestimate their 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 really have any 'good days' at all – they have just learnt to deal positively with their condition. Having to think about this may be very distressing for you, so please make sure there is someone available to offer you support if you need it.

If they do have periods when they are pain free, then average them out as follows:

**If your child's condition varies from day to day**, decide on average how many pain free days a week they have. If it's only 1 or 2 then they need help 5 or 6 days a week. (If they need help for fewer than 4 or 5 days a week it is less likely they will be awarded DLA).

**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 an average of 5 to 6 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 pain, discomfort or fatigue.

You should bear in mind that in order to qualify the first time your child's condition needs to have lasted for three months and be likely to last at least another six. After that, if they have a period of remission and their claim is stopped, then as long as they claim again within two years they don't have to serve another 3 month qualifying period; they can claim as soon as their condition deteriorates. We realise that's not much consolation. Sadly, the truth is that if your child does have long periods of remission it is much more difficult to make a claim for DLA and keep it going.

## Completing the claim pack – getting started

Some people prefer to fill the form in with a pencil first. Others just get stuck in – it's up to you. We will take you through each part of the DLA form page by page, so you will need the form open in front of you.

### Part 1 – About the child

These are straightforward factual questions about your child's name, address, date of birth, etc. The form asks for a daytime contact number.

*Child reference number. If you know it.*

This is your child's national insurance number. Don't worry if you don't know it, or your child doesn't have one yet. Their national insurance number will be found, or assigned, as part of the claim process and printed on any letters relating to the claim.

### Part 2 – About the person claiming Disability Living Allowance for the child

These are straightforward factual questions about your name, address, contact details, etc. The form asks for a daytime contact number. You may not wish to give one if you would prefer not to be phoned about your child's claim particularly if, for example, you are likely to be at work during the day. You should bear in mind that the DWP may already have your phone number, however, and that if they have to write to you to ask questions your claim may take longer to decide.

*Claiming under the special rules*

These special rules are for children who are terminally ill and not expected to live longer than six months.

### Part 3 – About where the child lives

If your child does not normally live in Great Britain, or if they have been abroad for a long period, this may affect their entitlement to benefits. If this proves to be a problem, get advice from one of the agencies listed in the *Help!* section.

### Part 4 – About the child's illnesses or disabilities

*What are the child's illnesses or disabilities?*

List **all** your child's health problems, not just Crohn's or Ulcerative Colitis. Remember any related problems such as arthritis, anaemia and skin problems. Also list any conditions that may not be related, such as asthma. In addition, 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 put them all down.

*If medicines, tablets or other medical treatments are prescribed for the child's illnesses or disabilities, tell us about them here.*

Although the question only refers to *prescribed* medication and treatments, you may also wish to list any alternative, complementary or non-prescription medication or treatments your child has. Continue on a separate sheet if necessary.

### Part 5 -More about the child

Tick the last box: *has a long term illness*

If your child suffers from depression, anxiety or something similar tick the box saying: *has a mental health problem*.

Tick any of the other boxes that apply to your child.

*has been assessed for things such as disability aids, or do they have a care plan or an occupational therapy report?*

Assessment reports may provide very useful information about the difficulties your child has with everyday activities. But bear in mind you are not obliged to submit such reports if you do not wish to. Read through any 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 you do not wish to submit it. You must still tick the box to say *Yes* your child has been assessed if this is the case. You should also be aware that the DWP may obtain a copy of the assessment directly from whichever organisation carried it out.

## **Part 6 - Walking outdoors**

*Does the child have difficulties walking?*

**Age limit.** The age limit for eligibility for higher rate mobility (this page only) was reduced from 5 years old to **three years old** from April 2001.

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

*Tell us about the difficulties they have with walking and about any equipment they use to help them*

Does your child have difficulties with walking because of such things as joint pain and stiffness; abdominal pain; fistulas; soreness around the anus; fatigue, breathlessness; the fact that movement increases the likelihood of incontinence; extreme fatigue or any other *physical* problem?

Is your child confined to bed for most of the time and so seldom able to walk outdoors? Does your child walk much more slowly than other children of the same age?

Imagine you are explaining your child's walking problems to someone very sceptical. 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?

*Equipment*

Does your child use a buggy although other children of the same age do not?

*How many days a week does the child have these difficulties?*

If your child always has these difficulties then the answer is 7 days, even if they don't actually walk outdoors very often. If there are days when they wouldn't have difficulties walking, then give an average. Under 5 days a week is less likely to count.

*How far can the child walk before they have to stop because of severe discomfort?*

(There is no precise definition of severe discomfort except that the law says it is less than severe pain). Can your child walk at all on their worse days? Are they in severe discomfort all the time when they walk or does it begin after a certain distance? People tend to have difficulty estimating distances so, if possible actually measure how far they can walk.

*How long does it take them to walk this far?*

Try actually timing your child rather than just guessing. Remember this is an average, so take into account your child's worse days.

## **Part 7 - If the child needs someone with them when they are outdoors**

*Does the child need to have someone with them when they are outdoors in places they do not know well?*

**Age limit.** To be eligible for lower rate mobility (this page only) your child must be at least **five years old**. However, it is still worth filling in this page if your child is under 5, if it helps to give a clear picture of their needs.

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 any such problems.

*Tell us why the child needs someone with them when they are outdoors in places they do not know well.*

Remember, this is about when your child is in an **unfamiliar** place, not places that they know well.

### **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 or fistulas, abdominal pains.

A change in the law in April 2002 means that if your child doesn't walk outdoors alone in unfamiliar places because of 'fear or anxiety' related to their physical (rather than mental) health, this will not entitle them to an award of lower rate mobility. So, for example, if your child doesn't go to unfamiliar places alone because they are afraid of having an episode of incontinence, this won't count. If, however, their fear or anxiety is so severe that your doctor's diagnosis is that it amounts to a mental health problem, such as agoraphobia, then they may be eligible for lower rate mobility on the basis of fear or anxiety related to their mental health. But if this is not the case, then it's best to avoid using words like frightened or anxious on this page.

### **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 lavatory, carry a change of clothing and a washing kit, offer comfort and reassurance if they do 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?

**Part 8 - Someone keeping an eye on the child**

*Does the child need someone to keep an eye on them?*

Tick **Yes** if your child needs more 'supervision', or supervision of a different kind to other children of the same age, to keep them safe. The tests for day and night time supervision are different (only 20 minutes may be required at night), so please make sure you look at both the main boxes below.

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.

*Why the child needs someone with them. **During the day.***

To be awarded DLA for supervision in 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 over tired;
- 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?

*How many days a week does the child need someone with them?*

If this is variable give an average, even if it is less than five days a week it may still be sufficient.

*How much of the day do they need someone with them?*

**During the day** the supervision needs to be continual, which means that you need someone available for most of the time, though not necessarily without any breaks.

*Roughly how long do they need someone with them each time during the day?*

You need to show that someone needs to be available for most of the time.

*Why the child needs someone awake with them. **During the night.***

The test for night time supervision is that your child needs someone awake to 'watch over' (or listen out for) them for at least twenty minutes a night *or* at least twice, and preferably three times, or more a night.

**Step 1 Say why your child needs someone awake to watch over them, giving specific instances if you can.**

For example:

- do you need to check if your child has had an episode of incontinence;
- do you need to check your child's tube feeding equipment;
- is your child often awake in pain or distress during the night, meaning that you go and check on them repeatedly;
- do you listen out for signs of distress during the night.

**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?

*How many nights a week does the child need someone to be awake with them?*  
If this is variable, give an average even if it is less than five days a week it may still be sufficient.

*How much of the night does someone have to be awake with them?*  
**At night** the supervision needs to be for at least twenty minutes or, at the very least twice, and preferably three times to count.

*Roughly how long do they need someone awake with them during the night?*  
**At night** the supervision needs to be for at least twenty minutes or at least twice a night to count.

## **Part 9 - About the child's development**

*Has the child's development of physical and sensory skills been delayed?*  
This may not be a section that is relevant to your child. However, if your child does have difficulties in this area, complete the box below using the four step system.

*Has the child's development of learning skills been delayed?*  
This box is mainly for children who do not learn new skills as easily as other children, which may not be relevant to your child. However, if your child has difficulties with school work because, for example, of frequent absence or because of bullying, then tick **Yes** and give details in the box below.

*(Empty box)*

**Step 1 Say what problems your child has with this activity, 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 lavatory, does your child:

- have problems with basic literacy or numeracy;
- have difficulties keeping up with other children in their class.

**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?

*Roughly how many times a day does the child need help?*

This might be frequently and throughout the day, if they need extra help in lessons or whilst studying.

*Roughly how long does it take each time?*

If this varies, give an average or a range.

*Has the child's development of social skills been delayed?*

Tick **Yes** and give details in the main box below if your child has difficulty getting on with other children or with adults, as a result of their health problems.

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.

*(Empty box)*

**Step 1 Say what problems your child has with this activity, 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;
- tend to be much more shy or aggressive than other children of the same age;
- 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:

- more support to prevent bullying at school;
- 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:

- might they be bullied, or hurt other children;
- will it become harder to learn social skills as they get older;
- will they become even more isolated as time passes;
- 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 social skills?

*Roughly how many times a day does the child need help?*

This might be frequently and throughout the day if they need support in connection with being bullied or because they are very withdrawn.

*Roughly how long does it take each time?*

If this varies, give an average or a range.

*Does someone need to help the child develop through play?*

This may not be a section that is relevant to your child. However, if your child does have difficulties in this area, complete the box below using the four step system.

## **Part 10 - Waking, getting up and going to bed**

*Does the child have difficulties waking, getting up and going to bed?*

Tick **Yes** and give details in the main box below if, in connection with waking, getting up and going to bed:

- 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.

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.

*Does someone have to wake the child up, or tell or encourage them to get up or go to bed?*

If most children of the same age would need telling or encouraging, tick **Yes** if your child needs more telling or encouragement, or needs to be told or encouraged in a different way to other children. Give details in the main box below.

*Tell us about the help the child needs to wake up or get up or go to bed. Tell us about any equipment the child uses and how it helps them.*

**Step 1 Say what problems your child has with these activities, giving specific instances if you can.**

For example, does your child:

- have such disturbed nights that they are too tired to wake up 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 medication or a drink to help them wake up or get up;
- do you encourage or cajole 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 whilst they get up or go to bed;
- do they need physical help getting up or going to bed;
- do you need to spend a lot of time settling them in bed before they are able to go 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 or discomfort;
- without becoming distressed;
- with less encouragement or with no encouragement at all;
- with less supervision or without being supervised at all.

*Equipment*

If your child uses any equipment to help with this activity, give details here.

*How many days a week does the child need this help?*

If your child always has difficulties then the answer is seven days. If not then give an average which takes into account bad or worse spells. Under 5 days is less likely to count.

*How many times a day does the child need this help?*

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.

*Roughly how long does it take the child to get out of bed or into bed?*

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.

**Part 11 - Washing and bathing**

*Does the child have difficulties washing or having a bath or shower?*

Tick **Yes** and give details in the main box below if, in connection with washing 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.

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.

*Does someone have to tell or encourage the child to wash or have a bath or shower?*

If most children of the same age would need telling or encouraging, tick **Yes** if your child needs more telling or encouragement, or needs to be told or encouraged in a different way to other children. Give details in the main box.

*Tell us about the help or encouragement the child needs washing or having a bath or shower. If they have bed baths, tell us about this here. Tell us about any equipment the child uses and how it helps them.*

**Step 1 Say what problems your child has with this activity, 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;
- have problems because they have dressings, a line into a vein or a stoma appliance 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.

*Equipment*

If your child uses any equipment to help with this activity, give details here.

*How many days a week does the child need this help?*

If your child always has difficulties then the answer is seven days. If not, then give an average which takes into account bad or worse spells. Under 5 days is less likely to count.

*How many times a day does the child need help with washing or having a bath or shower?*  
If your child has to wash or bathe after using the lavatory or following episodes of incontinence, remember to include all these times. If their condition varies give an average or a range.

*Roughly how long does the child take to have a bath or shower?*  
Remember this includes the time to get undressed, bathe, dry and dress again and includes any time spent resting in-between.

## **Part 12 - Getting dressed or undressed**

*Does the child have difficulties getting dressed or undressed?*  
Tick **Yes** and give details in the main box below 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.

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.

*Does someone have to tell or encourage the child to get dressed or undressed?*  
If most children of the same age would need telling or encouraging, tick **Yes** if your child needs more telling or encouragement, or needs to be told or encouraged in a different way to other children. Give details in the main box.

*Tell us about the help or encouragement the child needs getting dressed or undressed. Tell us about any equipment the child uses and how it helps them.*

### **Step 1 Say what problems your child has with this activity, giving specific instances 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 medication 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 watching 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. For example, would more support and supervision in changing rooms from teachers make them less likely to be picked on?

**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.

*Equipment*

If your child uses any equipment to help with this activity, give details here.

*How many days a week does the child need this help?*

If your child always has difficulties then the answer is seven days. If not then give an average which takes into account bad or worse spells. Under 5 days is less likely to count.

*How many times a day does the child need this help?*

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.

*Roughly how long does it take the child to get dressed or undressed?*

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

**Part 13 - Help with toilet needs**

*Does the child have difficulties coping with their toilet needs?*

If your child has a **stoma appliance**, use this page to explain any difficulties they have or help they need in connection with it.

Tick **Yes** and give details in the main box below if, in connection with toilet needs:

- 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.

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.

*Does someone have to tell or encourage the child to attend to their toilet needs?*

If most children of the same age would need telling or encouraging, tick **Yes**. If your child needs more telling or encouragement, or needs to be told or encouraged in a different way to other children, also tick **Yes**. Give details in the main box.

*Tell us about the help or encouragement the child needs and any equipment they use. During the day.*

**Step 1 Say what problems your child has with their toilet needs, giving specific instances 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.

**NB** Decision Makers will usually argue that a child who needs help getting to and from the lavatory 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 it would add painfully and unnecessarily to the emotional distress their condition causes for them to have to use a potty or commode as if they were a younger child, and in your judgement as a responsible adult it would be wrong to make them do this.

**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 mucous;
- 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.

*Equipment*

If your child uses any equipment to help with this activity, give details here.

*How many days a week does the child need this help?*

If your child always has difficulties then the answer is seven days/nights. If not then give an average which takes into account bad or worse spells. Under 5 days is less likely to count.

*How many times a day does the child need this help?*

If this varies give an average or a range.

*Roughly how long does it take each time?*

Include time getting to and from the lavatory, time needed to wash themselves and to clean the toilet if necessary.

*Tell us about the help or encouragement the child needs and any equipment they use. **During the night.***

Go through the steps in the daytime box above, only now writing about what help your child needs at night. It's very important that you fill this box in carefully – a relatively small amount of help at night can entitle your child to a higher rate of DLA.

In addition, to the help detailed in the daytime box:

- does your child need help getting into or out of bed to use the toilet or a potty or commode;
- does your child need help settling back to sleep;
- do you sometimes need to change the bedclothes after an episode of incontinence or leakage from a stoma device;
- do you have to empty the potty or commode;
- do they need to go to the toilet frequently because they are tube fed at night.

Once again, if you do not think your child should be obliged to use a commode or potty you will need to make a strong case. If there are other children who share the bedroom, this is obviously an important factor.

*How many nights a week does the child need this help?*

If your child always has difficulties then the answer is seven days/nights. If not, then give an average which takes into account bad or worse spells. Under 5 days is less likely to count.

*How many times a night does the child need this help?*

If this varies give an average or a range.

*Roughly how long does it take each time?*

Include time spent helping your child to and from the lavatory, cleaning the toilet if necessary, helping your child wash and settling them back in bed again.

**Part 14 - Communicating with other people**

*Does the child need help understanding other people?*

We have not come across this as a problem in connection with IBD. However, if your child does have difficulties complete the box below using the four step system.

*Does the child need help being understood by other people?*

This may not be a section that is relevant to your child. However, if your child does have difficulties in this area, complete the box below using the four step system.

*Is the child unwilling to communicate with other people?*

Tick **Yes** and give details in the main box below if your child is, for example, less confident or shy or more withdrawn than other children of the same age.

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 main box below and decided that none of them apply.

*Tell us about the encouragement the child needs to help them communicate with other people.*

*Tell us about any equipment the child uses to help them and how useful this is.*

**Step 1 Say what problems your child has with communicating with other people, giving specific instances if you can.**

For example:

- have they become solitary, shy or withdrawn because of their condition or the effects of their medication on their appearance;
- 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.

**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.

*Equipment*

If your child uses any equipment to help with this activity, give details here.

*How many times a day do they need help to communicate with other people?*

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

*Roughly how long does it take each time?*

Include any time you spend supervising your child to ensure they are not teased or bullied or do not become anxious or aggressive.

## **Part 15 - Eating and drinking**

*Does the child have difficulties eating or drinking?*

Tick **Yes** and give details in the main box below 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 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 decided that none of them apply.

*Does someone have to tell or encourage the child to eat or drink?*

If most children of the same age would need telling or encouraging, tick **Yes** if your child needs more telling or encouragement, or needs to be told or encouraged in a different way to other children. Give details in the main box.

*Tell us about the help or encouragement the child needs, and any equipment they use. **During the day.***

**Step 1 Say what problems your child has with eating and drinking, giving specific instances if you can.**

For example:

- do they have a very small appetite;
- do they associate eating with abdominal pain;
- do they become nauseous when they eat;
- does their medication 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 such things as 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 that 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.

*Equipment*

If your child uses any equipment to help with this activity, give details here.

*How many days a week does the child need this help?*

If your child always has difficulties then the answer is seven days. If not then give an average which takes into account bad or worse spells. Under 5 days is less likely to count.

*How many times a day does the child need this help?*

If their condition varies give an average or a range.

*Roughly how long does it take each time?*

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

*Tell us about the help or encouragement the child needs, and any equipment they use. **During the night***

Go through the steps in the daytime box above, only now writing about what help your child needs at night. It's very important that you fill this box in carefully – a relatively small amount of help at night can entitle your child to a higher rate of DLA.

In addition to the help detailed in the daytime box:

- do they often get hungry at night because they have been unable to eat adequately during the day;
- does their tube feeding equipment get blocked, or start beeping every time they roll over.

*How many nights a week does the child need this help?*

If your child always has difficulties then the answer is seven days. If not then give an average which takes into account bad or worse spells. Under 5 days is less likely to count.

*How many times a night does the child need this help?*

If their condition varies give an average or a range.

*Roughly how long does it take each time?*

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

## **Part 16 - Help with medication**

*Does the child need help with medication?*

Tick **Yes** if your child needs any help with medication 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 medication, and you have read the examples on the form and in the main box below and decided that none of them apply.

*Tell us about the help and encouragement the child needs with medication. **During the day.***

If your child is too young to take their medication without help, explain everything you have to do in this connection, including any ways that you try to make medication more palatable and any comfort or reassurance you provide.

If other children of the same age *might* be able to take medication themselves during the day then follow the usual four steps:

### **Step 1 Say what problems your child has with this activity, giving specific instances if you can.**

For example, does your child:

- forget to take their medication;
- try to avoid taking their medication because of the side effects it has;
- become angry or distressed about a life which involves having to take so much medication.

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

For example, do you:

- remind or encourage them to take their medication;
- offer them comfort or reassurance in connection with the effects of their medication;
- find ways to make their medication 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 medication 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 medication:

- 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.

### *Equipment*

If your child uses any equipment to help with this activity, give details here.

*How many days a week does the child need this help?*

If your child always has difficulties then the answer is seven days. If not, then give an average which takes into account bad or worse spells. Under 5 days is less likely to count.

*How many times a day does the child need this help?*

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

*Roughly how long does it take each time?*

Remember to include any time spent making medication more palatable.

*Tell us about the help and encouragement the child needs with medication. **During the night.***

Go through the steps in the daytime box above, only now writing about what help your child needs at night. It's very important that you fill this box in carefully – a relatively small amount of help at night can entitle your child to a higher rate of DLA.

In addition, to the help detailed in the daytime box:

- does your child need soothing back to sleep after taking medication at night.

*How many nights a week does the child need this help?*

If your child always has difficulties then the answer is seven nights. If not then give an average which takes into account bad or worse spells. Under 5 days is less likely to count.

*How many times a night does the child need this help?*

If this varies, give an average or a range.

*Roughly how long does it take each time?*

Remember to include any time spent making medication more palatable.

## **Part 17 - Therapy**

*Does the child need therapy?*

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.

*Tell us about the child's therapy. **During the day.***

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.

*How many days a week does the child need this help?*

Include the days on which your child has therapy and any additional days on which you help them with exercises related to the therapy.

*How many times a day does the child need this help?*

If this varies give an average or a range.

*Roughly how long does it take each time?*

State how long they spend with the therapist and how long you spend helping them.

*Tell us about the child's therapy. During the night.*

This may not be a section that is relevant to your child. However, if your child does have difficulties in this area, give details in the same way as the daytime section above.

## **Page 18 - Help with medical equipment**

*Does the child need help with medical equipment?*

Tick **Yes** if your child needs any help at all with medical equipment.

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

*Tell us about the help and encouragement the child needs with medical equipment. **During the day.***

**Step 1 Say what problems your child has with medical equipment, giving specific instances if you can.**

For example, does your child need help with:

- emptying or changing a stoma appliance;
- dressing wounds or administering enemas or eye drops;
- tube feeding.

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

Explain in detail what help you provide with medical equipment, including:

- ordering or collecting it;
- helping your child to use it;
- monitoring it whilst it is being used;
- cleaning, refilling or disposing of it safely;
- offering your child support, reassurance and encouragement in connection with using the equipment.

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

For example:

- would they be physically unable to manage without it;
- would they become emotionally distressed if they did not receive it;
- might they come to harm if they did not receive it.

*How many days a week does the child need this help?*

If your child always has difficulties then the answer is seven days. If not then give an average which takes into account bad or worse spells. Under 5 days is less likely to count.

*How many times a day does the child need this help?*

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

*Roughly how long does it take each time?*

Include any time spent preparing and cleaning equipment.

*Tell us about the help and encouragement the child needs with medical equipment. **During the night.***

Go through the steps in the daytime box above, only now writing about what help your child needs at night, include any help your child needs with settling back to sleep again. It's very important that you fill this box in carefully – a relatively small amount of help at night can entitle your child to a higher rate of DLA.

*How many nights a week does the child need this help?*

If your child always has difficulties then the answer is seven nights. If not then give an average which takes into account bad or worse spells. Under 5 nights is less likely to count.

*How many times a night does the child need this help?*

If their condition varies give an average or a range.

*Roughly how long does it take each time?*

If their condition varies give an average or a range.

### **Part 19 - Blackouts, fits, seizures or something like this**

*Does the child have, blackouts, fits, seizures or something like this?*

This may not be a section that is relevant to your child. However, if your child does have difficulties in this area, complete the box below using the four step system.

### **Part 20 - The child's mental health**

*Does the child have difficulties because of the way they feel?*

Like adults, children with UC or Crohn's have to deal with the emotional effects of the condition as well as the physical ones. Give details in the box below of the effects the condition has had on your child emotionally.

Only tick No if you have read the examples on the form and read the box below and decided you don't have any such problems.

*Tell us about the help the child needs and the things the child does because of their mental health problems.*

**Step 1 Say what emotional effects the condition has had on your child, giving specific instances if you can.**

For example,:

- does it make them anxious, depressed, angry, afraid;
- have they lost their self confidence;
- do they have nightmares;
- have they tried to hurt themselves.

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

For example,:

- do you offer them comfort, support or reassurance when they are upset
- do you find ways to try to boost their self confidence
- do you encourage them to do things when they are depressed and unable to motivate themselves
- do they see a counsellor, psychiatrist or someone similar

**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;
- 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**

Do other children who do not have this condition need the same amount of emotional support as your child?

*Tell us roughly how often this happens and how long the child needs help when this happens*

Does your child need more emotional support than other children every day or most days? How much more time a day do you think you spend supporting your child emotionally, because of the effects of their condition?

**Part 21 - Movement and co-ordination**

*Does the child have difficulties with movement and co-ordination?*

Tick **Yes** if, for example, your child experiences pain when they move or can only move slowly.

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.

*Tell us about the help your child needs with movement and co-ordination.*

We have not come across co-ordination problems in connection with UC or Crohn's, but many children do have problems with movement because of stiff or painful joints.

**Step 1 Say what problems your child has with movement or co-ordination, giving specific instances if you can.**

For example:

- does your child suffer from joint pains which are made worse by movement;
- do your child's limbs get very stiff;
- is your child very easily exhausted by even small amounts of movement, perhaps because of the effects of frequent bouts of diarrhoea; malnourishment because they can't digest food properly; anaemia caused by continual blood loss or iron deficiency; the side effects of their medication.

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

For example:

- do you offer your child comfort, support or reassurance to help them deal with the problems they have with movement;
- do you make sure your child does not over-exert themselves;
- do you massage your child's limbs when they are stiff or painful.

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

- 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**

Do other children of the same age have similar problems, or need the same amount of help with movement.

## Part 22 - Moving about indoors

*Does the child have difficulties moving about indoors?*

Tick **Yes** and give details in the main box below if, in connection with moving about indoors:

- 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.

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.

*Does someone have to tell or encourage the child to move about indoors?*

If most children of the same age would need telling or encouraging, tick **Yes**. If your child needs more telling or encouragement, or needs to be told or encouraged in a different way to other children, also tick **Yes**. Give details in the main box.

*Tell us about any help or encouragement the child needs moving about indoors. Tell us about any ways the child's home has been adapted, or about any equipment they use to help them move about indoors. This could be a wheelchair, a frame, a stairlift, or something like this.*

**Step 1 Say what problems your child has with this activity, giving specific instances 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 lavatory.

**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.

*Equipment*

If your child uses any equipment to help with this activity, give details here.

**Part 23 - When the child is in bed at night**

*Does the child need help when they are in bed at night?*

***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. **(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 read the box below and decided they don't have any such problems.

*Tell us about any help the child needs when they are in bed at night.*

Go back through the form and find any information about your child's care needs, repeat them here. Add any other information you may not have already included elsewhere. For example:

**Step 1 Say what problems your child has during the night, giving specific instances 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 medication, 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?
- 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 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.

*Equipment*

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

*How many nights a week does the child need help?*

If you always have difficulties then the answer is seven days. If not then give an average which takes into account bad or worse spells. Under 5 days is less likely to count.

*How many times a night does the child need help?*

If this varies, give an average or a range. To qualify for middle rate care it needs to be either at least two (and preferably three or more) times a night or for a period of at least twenty minutes.

*Roughly how long does it take each time*

If this varies, give an average or a range. To qualify for middle rate care it needs to be either at least two (and preferably three or more) times a night or for a period of at least twenty minutes.

**Parts 24 - Help the child needs when they go out during the day or in the evening**

**Please note:** in spite of the title, these pages are about help your child needs with social and leisure activities *at home*, as well as when they go out. What used to take up nine pages in the old DLA form has now been shrunk down to two very cramped and confusing pages. But these two pages can be very important if your child needs support and encouragement with play, socialising or other leisure activities. Use separate sheets if you need to.

**What they do or would do if they had the help they need**

*When they go out during the day or in the evening*

This box may be easier to complete if you read it as asking 'Where does your child go, or where would they go if they had the help they needed?'

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, doctors, hospital, physiotherapist, counsellor, library, going shopping for pleasure (rather than for necessities), holidays, cinema, church, evening classes, local park, clubs, day-trips, visiting friends and relatives, swimming, gym, sports centre.

*How many days a week?*

If this is something they do, or would do, every day if they had the help, then the answer is 7 days. Otherwise, how many days a week would they like to do it?

*How many times a day?*

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

*How long do they usually need help for 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.

*What help do they need from another person?*

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 lavatory, to help them get to and from the lavatory? 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?

### **What they do or would do if they had the help they need**

*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, because they are too fatigued to do it themselves.

*How many days a week?*

If this is something they do, or would do, every day if they had the help, then the answer is 7 days. Otherwise, how many days a week would they like to do it?

*How many times a day?*

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

*How long do they usually need help for each time?*

Do they need help all the time they are doing this activity or just for part of it, such as setting things up and putting them away?

*What help do they need from another person?*

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

### **Part 25 - Who would you like to tell us about the child's illness or disabilities?**

Give details of the professional person who you think knows most about the way your child's condition affects their everyday life. This can be their medical specialist, GP, occupational therapist, health visitor, community nurse, stoma nurse, etc. Make sure you tell the person that you have given their name on the form and that you have explained to them in detail the problems that your child has in relation to everyday activities.

However, you need to be aware that, in spite of asking the question above, the DWP hardly ever contact anyone other than your child's GP, and they may not even do that. If there are people you

think could support your child's claim you need to contact them yourself. See *Including supporting evidence*).

## **Part 26 – Anything else about the way the child is affected by their illness or disabilities**

*Tell us about any ways that the child's illnesses or disabilities affect them that you have not been able to put anywhere else on this form.*

Use this space to tell the Decision Maker anything else that will help to give a clearer picture of the effects 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 medication 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 appliance or have special treatments such as TPN that you have not already covered fully, give details here.

### **Middle rate care**

Although the claim pack 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. But if they need attention 'frequently throughout the day' they may receive the middle rate of the care component instead.

'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: it may be helpful if you make those facts as clear as possible. So, if you wish, you can use this page to list when you 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 medication.
12.30pm	encouragement to eat and help taking medication.
4.00pm	encouragement to spend time with other children outside school hours, because my child has become quite withdrawn and isolated because of 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 medication.
9.30pm	help with washing, undressing and getting into bed.

### **Part 27 - About the child's condition**

*If the child has problems getting around, tell us when they started to have the problems you have told us about.*

*If the child has problems with personal care, tell us when they started to have the problems you have told us about.*

This may be many months or years before they were actually diagnosed. DLA is only payable when the condition has lasted for at least 3 months.

### **Part 28 - About nights in hospital**

Complete this section if your child is currently an in-patient, otherwise tick No.

### **Part 29 - About nights in a care home or similar residence**

Complete this section if your child is currently in care home or similar residence, otherwise tick No.

### **Part 31 - About nights in hospital and nights in a care home or similar residence**

If your child has been an in-patient in hospital or in care home or similar residence in the last six weeks give details here, otherwise tick No.

### **Part 31 - For children on kidney dialysis**

Only complete this if it applies to your child.

### **Part 32 - The child's school or nursery**

If your child attends school or nursery, give details here. Bear in mind that the DWP may contact the school or nursery, so you may wish to talk to them about the grounds on which you are making a claim for DLA for your child.

### **Part 33 - The child's hospital doctor or specialist**

Give details of all the hospital doctors or specialists your child has seen in the last 12 months, for any of the conditions they have. If there isn't room to list all of them here put them on an extra sheet.

### **Part 34 - The child's family doctor or health centre**

Please don't assume your child's GP knows all about the problems your child has with things like walking, dressing or washing – you may never have told them or they may not have made notes at the time. If possible make an appointment to give your GP an up-to-date picture of your child's problems as soon as you've completed this form, so that you contact them before they are contacted by the DWP. You may want to look at the section on *Including Supporting Evidence* and complete the *Health Professionals' Sheet* at the back of this guide before you see your child's GP. You should also warn your child's GP that the DWP may contact them.

### **Part 35 - Consent**

Some people are unhappy with how widely this consent is drawn, allowing the DWP to contact absolutely anyone at all. Not giving consent, however, may give the DWP an excuse to refuse your child's claim. If you are unhappy with giving such wide consent try to get advice from an advice agency before ticking the '*I do not consent box*' or adding extra conditions to your consent.

## **Part 36 - Statement from someone else who knows the child**

*How often do you see the child this form is about?*

Try to ensure it is someone who has seen your child recently and reasonably often.

*Please tell us what their illnesses and disabilities are, and how they are affected by them.*

Photocopy this sheet and give the copy to the person you want to complete it. If you are happy with what they write, fasten the sheet to this page. If not give them another blank copy and ask them if it would be possible for them to change what they have written. If this is not possible get someone else to fill in the statement instead. Make an appointment to see the person so you can answer any questions they might have and take the completed Health Professionals Sheet at the back of this guide with you. Ask the person 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. Don't delay returning the form if you don't receive a statement in time, send any additional evidence afterwards if necessary.

*Tell us your job or profession or relationship to the child this form is about.*

If possible the person who completes this statement should be a professional involved in your child's care, such as their GP, specialist or a nurse.

## **Part 37 - About Income Support, Jobseeker's Allowance or Pension Credit**

You may be entitled to additional amounts of these benefits if your child receives an award of DLA.

## **Part 38 – About tax credits**

You may be entitled to additional amounts of tax credit if your child receives an award of DLA.

## **Part 39 - Making payments to you**

The DWP now prefers to pay all benefits direct into a bank account and this section asks for details of your bank account. If you are not happy with this, or it would be a problem for you, tick Box 2 in part 40 C '*I would like information about how I can be paid by other means*', return the form and get advice from an advice agency.

## **Part 40 - Declaration**

Read the declaration carefully before you sign it.

## **Part 41 What to do now**

List any additional evidence you are enclosing with the claim pack, including how many – if any – additional sheets.

## **Part 42 - How we collect and use information**

This tells you what the DWP will do with the information you provide. There is nothing for you to complete.

**Congratulations! You've done it. The claim pack is complete. Photocopy this pack before you send it and you'll probably never have to spend so long filling in a form again in your entire life.**

## Including Supporting Evidence

As well as your claim pack 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

This can make an enormous difference to whether your child's claim succeeds. Detailed evidence from health professionals, such as your child's nurse, GP or specialist may also mean that your child's claim is dealt with more quickly and that they are less likely to have a visit from a DWP doctor. (**Always** inform your GP that you are making a claim for DLA as it is quite likely the DWP will contact him or her without telling you first, even if she has very little to do with dealing with your child's condition).

Ask the doctors, consultants or other health workers 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 might have and take the Health Professionals Sheet at the back of this guide with you. Ask them to send any 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, friends or relatives who help to look after your child can also submit letters as supporting evidence, but they should give them to you so that you can keep a copy. If it says things that you think are unhelpful then ask the writer to change them or simply do not submit the letter. 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 very damaging to your claim.

### Keeping a diary

A diary kept for about seven days detailing all the difficulties your child encounters and all the help they receive is very useful. If you keep a diary before you fill in the claim pack it can make the job a lot easier. In addition, you can send it in with your child's claim form as additional evidence. But **beware**: if theirs is a fluctuating condition then don't keep a diary when they're having a much better or worse spell, because it may give a very misleading impression. 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. Also, tribunals are generally very keen on hearing a day by day account of the sort of help you provide and the things your child finds difficult.

**Don't forget:** you must send your form before the deadline runs out, 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 be able to send it to them.

### What happens next

You should receive an acknowledgement within five working days of the DWP receiving your claim pack. 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 he requires more. He may contact your child's GP, or more rarely their specialist, for further information and/or he may ask the DWP to send a doctor to visit your child for a medical. We tell you in the next section how to prepare for a medical.

## Dealing with a medical visit

After you send in your claim pack, you should receive an acknowledgement within five working days from the DWP, at least that's what it says in the Charter Standard Statement.

Your claim pack will be looked at by a decision maker who may make a decision based just on the information you have sent or may decide he requires more. He may contact your GP for further information and/or he may ask the Medical Services department to send a doctor to visit your child.

### Who gets a medical visit?

There's no way of knowing when you make your claim whether your child will have to have a medical or not. The first you will know about it is when you receive a letter, or possibly a phone call, telling you that the DWP wish to send a doctor to your home. If you refuse to have a medical your child's claim for DLA will automatically be turned down. However, you can ask for the appointment to be made, or changed to, a time when you can have someone else present, (see below). You can also ask to be visited by a female doctor if your child would find a visit from a male doctor distressing, or vice versa.

### Who visits?

Some people are visited at home by a polite and interested doctor who takes the time to listen and who writes an accurate account of his visit. Sadly, not everyone is so fortunate. Doctors, who are often either retired GPs or local GPs squeezing these visits in with their other work, are paid a fee of over £100 for each visit. Many people we've spoken to reported that the visiting doctor seemed in a rush, stayed only a very short time and wasn't interested in what they had to say. Some found the doctor positively rude. Others reported that although the doctor seemed sympathetic and encouraging, they later discovered that the medical report was very dismissive of their needs.

### Having someone with you

Having a friend, relative, carer or support worker with you can make it much easier to deal with difficult situations, it can also provide you with a witness to what happened at the medical. If possible, tell the DWP that you intend to have someone with you, but don't worry if you don't have chance to inform them.

### Getting an appointment

You may be phoned by the doctor who is going to examine you to arrange an appointment. Doctors are warned in their handbook *Guidance for Examining Medical Practitioners* (which can be downloaded from the Members area of the Benefits and Work website) that '*arrangements for making appointments are one of the major sources of complaints against examining doctors particularly about insufficient notice of the visit. It is very important to follow the recommended practice . . .*'

In spite of this some doctors still don't follow the recommended practice, so here's what you should be able to expect.

The appointment may be arranged by telephone or letter but '*it is vital to offer sufficient (7 days) notice*'. If a date less than 7 days in advance is agreed this should be recorded on the report that the doctor writes and should be signed by you.

The doctor may be keen to arrange an appointment at short notice, perhaps because they already have another visit arranged in your area or because they are trying to fit you in around some other engagement. But if you want time to prepare or need to arrange for someone else to be present

then please don't allow yourself to be pressured into agreeing to short notice. Remember, the doctor is getting paid over £100 to visit you, so it's only fair that they set aside sufficient time to do their work for the DWP, not just try to squeeze you in between other engagements.

If necessary tell the doctor that you will have to consult with the person you want to have with you before you agree a time.

If the appointment is arranged by telephone the doctor is told it is good practice to confirm the appointment by letter. They are also told that telephone calls should be made at reasonable times, that they should allow themselves a maximum of a 1 hour window and they should call you if they are running late.

If the doctor turns up too early or too late and, for example, your accompanying person is not present, you can politely refuse to let the doctor come in and tell them that they will need to arrange a new appointment. Doctors are told by their handbook that in these circumstances they should ensure that you are given '*reasonable notice*' for a second visit.

If the doctor calls at the correct time and you are not in, they are told by their handbook that they should leave a form giving you a new appointment and that this time they do not have to give you seven days notice, but that they should still give you '*reasonable notice*' in case you wish to have a representative present.

### **Being asked to attend a Medical Examination Centre**

Since early in 2006 some DLA claimants have been invited to have a medical at a Medical Examination Centre rather than in their own home. The medical may be carried out by a nurse rather than a doctor and whoever carries out the medical will be assisted by computer software. There may be disadvantages for some claimants in such an examination as the software appears to rely almost entirely on externally verifiable factors - such as the use of prescribed aids and adaptations, involvement of health professionals and visible signs or symptoms - for decision making and seems to take very little account of the claimant's own evidence of how their condition affects them.

At the time of writing all claimants who are asked to have a medical in connection with their DLA still have the right to ask for it to take place in their own home rather than at a medical centre. In general, until more is known about the way examinations are conducted at Medical Examination Centres, we would suggest you ask for a home visit.

### **Medical Visit Record sheet**

At the end of this guide there is a medical visit record sheet for you to record what happened at the medical. Look through it before you have your medical and fill it in *immediately* afterwards, if you want to have a record of what happened. Remember to make a note of the time the doctor arrived and left: if they only stay a short time you can use this as evidence that the report is less likely to be reliable.

The Medical Visit Record sheet will provide very valuable evidence if you later decide you wish to make a complaint about the doctor or if your child doesn't get the award of DLA you consider appropriate and you decide to challenge the decision. (Do read the section below about 'Taking notes' if you intend to complete one of these sheets)

### **The medical**

Until mid 2006 the medical report form completed by the visiting doctor was divided into two parts. The first part was a statement of the claimant's needs taken by the doctor and signed by the

claimant. However, this practice has now ended and you will not be asked to sign anything as part of your child's medical. Nor will you be given the opportunity to read anything the doctor has written. However, you will automatically receive a copy of the whole report if you appeal against the decision in your child's case and we advise you to ask for a copy for your records even if the claim is successful. (See *The decision* for more about this).

The new medical report form used by doctors is 32 pages long and, in theory, the doctor has to record a lot more information and justify their opinions in much more detail than was the case in the past.

One of the most important features of the new medical report is the section on how you spend a 'Typical day'. Questions on this will usually come early on in the medical, after you've been asked about:

- your child's main medical conditions
- your child's medical history
- your child's medication
- your child's impairments and functional restrictions (how your condition affects you)

Try to ensure that the information you give relates to what you consider to be a 'typical day'. If your child's condition varies and they don't have such a thing as a 'typical day' then make this clear to the doctor. It's also very definitely worth completing the Medical Visit Record sheet if you have expressed concerns to the doctor about the idea of a typical day – just in case the doctor hasn't made a note of these concerns.

Beware of leading questions like '*They don't have any trouble with ... do they?*', or '*They can manage ... can't they?*'. Try not to be persuaded, or feel pressured, into giving an answer that isn't correct. If you do have problems with an activity, or can't manage it at all, say so and explain why.

As well as asking questions, the doctor may carry out a brief physical examination and ask your child to perform simple activities such as standing up and walking across the room. They may also ask them to walk outdoors. However, they should not ask them to do anything that you tell them would be painful.

## **Preparing for the medical**

So, if possible, before the medical:

read through the photocopy of your child's DLA claim pack to refresh your memory about the most important things you need to tell the doctor;  
have a look through the Medical Visit Record sheet so you know the kind of problems you need to be looking out for during the medical.

## **Examining your home**

We've been hearing from an increasing number of people who were very unhappy that the doctor appeared to feel they had a right to go into every room in their home. Some people said the doctor had told them that they were "*Checking to see what aids or adaptations you might need*". This is clearly not true, the doctor has no power to recommend to anyone that you be provided with aids or adaptations.

If the doctor says they wish to look round your home it may be worth asking them what they are looking for and requesting that they ask you about anything they see which they consider

significant. If there are rooms which you consider private, for example because they are used solely by a lodger or by you or another child, it seems reasonable to say that you do not wish them to go into those rooms. If the doctor ignores your wishes you should complain very strongly indeed – we'd suggest going straight to your MP.

## **Taking notes**

If you, or someone with you takes any notes whilst the doctor is actually present, visiting doctors have been instructed to issue an “oral warning” as follows:

*1 It is your right to take notes for your own use and benefit*

*2 The notes will not be included in the Report I make save for the fact that notes were taken and further, they are not accepted by myself or the DWP as an official record of this examination.*

*3 If the notes are subsequently produced at any time for any purpose, such as part of appeal process, I the Examining Doctor, my employer and the Department for Work and Pensions reserve all rights to challenge anything in the notes in the event we are asked to comment on the content of the notes at a future time.*

*4 You are free to use the notes as you choose but if you choose to publicise the notes (other than in connection with correspondence with the DWP or under any appeal procedure) I would ask that you do not publicise my name.*

It makes good sense not to publicise the doctor's name other than in appeal or a complaint, as this might leave you open to action for defamation. But that aside being given an ‘oral warning’ should not affect your actions in any way: it simply tells you that the DWP won't necessarily agree with what you write should your notes be used as part of an appeal. (The oral warning used to be much more threatening until a Benefits and Work member challenged it using information supplied by Benefits and Work).

## **Be prepared**

We don't want to leave you feeling terrified about having a visit from a DWP doctor. But many people say they had no idea what to expect before they had their medical and that they were very disappointed with how quick and irrelevant the whole thing seemed to be. We also know that very many DLA claims are turned down because of the visiting doctor's report. By being properly prepared for your medical you can reduce the chances of this happening to you.

## The Decision

Eventually 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 what 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 fixed number of years or whether it will continue until your child reaches the age of 16, (when they will have to apply again as an adult). If you are happy with the award then you need do nothing else, though there may be other benefits you can apply for or have increased as a result of receiving DLA. Try to get advice about this.

If the award is for a fixed number of years you should be sent another claim pack to complete several months before it runs out. NACC produces a guide to completing the renewal claim pack which is available from our website. If the award is until the age of 16 you may still receive forms to fill in every few years and the award can still be reduced or stopped depending on what you write in them. That's why 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

If you are not happy with the decision you can apply for it to be looked at again. But you must do this **within** one month of the date of the letter giving you the decision. You also need to be aware that the decision can be changed to increase or **decrease** your award, (though this is obviously not a problem if your child has been awarded nothing at all). You should try to get help if you wish to challenge a decision.

NACC produce a detailed guidance document called *Revisions and Appeals: a guide for children with Ulcerative Colitis and Crohn's Disease* which explains how the system works. You can download a copy from the NACC website at [www.nacc.org.uk](http://www.nacc.org.uk)

# Help!

## Help From NACC

### Benefits

Support for people with Colitis and Crohn's Disease in claiming Disability Living Allowance is provided through the Information Service. Anybody wishing to obtain our Guide on Claiming Disability Living Allowance should ring the NACC Information Line on **0845 130 2233**.

Information Officers can also direct you to other sources of help, when needed, with claiming DLA and other benefits.

### NACC-in-Contact Support Line 0845 130 3344

Even if you feel entirely able to complete the claim pack without help, you may well find the process emotionally disturbing. You may have to think hard about all the ways in which life is more difficult or more restricted for your child. What may be worse, if your child's claim is not successful, you may feel that you have not been taken seriously or believed. Contacts are NACC members who are trained to give supportive listening over the telephone. They are not there to deal with any questions to do with DLA, but if you find that the process of claiming is causing you distress they can offer support.

### Smilie's People Network 01727 830038

Smilie's People provide support and information for families in which a child has Crohn's disease or ulcerative colitis. Information is available on IBD in childhood and there are guides for teachers on how to help children with Crohn's disease or ulcerative colitis. Smilie's People produces a newsletter to keep families in touch with NACC activities and holds occasional educational/support meetings for families, publicity and fundraising events. There is a link from the NACC website to the Smilie's People website.

**Family, friends, carers and other NACC members.** If you can arrange emotional support from amongst your family and friends it may make claiming DLA easier to cope with. Bear in mind that if you are unhappy with the decision and choose to appeal, the process may take many months (or even years).

### Advice agencies and advice workers.

These may be able to help with filling forms and with challenging the decision if you're unhappy with it. However, advice agencies may be almost impossible to get through to on the phone, have no appointment system, long queues and no public lavatory. If you can't get through to your local agency on the phone, try writing to them explaining your child's health problems and asking if they do home visits, or if they can telephone you at home and offer advice. You can usually find numbers for advice agencies in your local Yellow Pages in one or more of the following sections: disability information and services; information services; social service and welfare organisations; counselling and advice.

**Please note:** you may have to try repeatedly before you can get through to advice agencies on the telephone. You should also be aware that help from advice agencies is very much in demand, so the sooner you seek help the better.

### CLS Direct helpline and website

The Community Legal Service offers free initial (30 minutes) advice from a qualified legal adviser about Welfare Benefits between 9am and 5pm weekdays. And if you call outside office hours, just leave a message and they say they'll call you back. If you are eligible for Legal Aid you can then get further free legal help with your case by phone and post. To use the helpline call **0845 345 4345**. After you choose the welfare benefits option you will be

advised to listen to recorded messages about benefits. We recommend that you don't, the messages are long, sometimes confusing and you can read them at your leisure on the CLS website at [www.clsdirect.org.uk](http://www.clsdirect.org.uk) if you wish to. Instead go straight for the option of speaking to an adviser.

You can also get information about your nearest CLS funded advice providers by visiting the CLS website at: [www.clsdirect.org.uk](http://www.clsdirect.org.uk) or calling the CLS Directory Line on **0845 608 1122**.

### **Citizens' Advice Bureaux (CAB)**

There are over 750 bureaux in mainland Britain. Look under Citizens Advice Bureau in your phone book for details of your nearest one. You can also find details of your nearest bureau at: [www.citizensadvice.org.uk](http://www.citizensadvice.org.uk)

### **Citizens Advice Scotland**

To find your nearest bureau, look under Citizens Advice Bureau in your phone book or visit the CAS website at: [www.cas.org.uk](http://www.cas.org.uk)

### **AdviceUK**

Over 900 advice agencies are members of AdviceUK. Details of your nearest ones are available from AdviceUK's website at [www.adviceuk.org.uk](http://www.adviceuk.org.uk)

### **Association of Independent Advice Centres (Northern Ireland)**

AIAC is the umbrella body for independent advice centres in Northern Ireland. You can get details of your local independent advice centre in Northern Ireland from their website at: [www.aiac.net](http://www.aiac.net)

### **Disability Information Advice Line**

There are over 140 local DIALs, all staffed by disabled people and all offering telephone advice. If you have a local line it should be listed in your telephone directory under DIAL UK. Alternatively, call the national office on **01302 310 123** or visit their website at [www.dialuk.info](http://www.dialuk.info) where you can find a directory of DIAL offices.

### **Housing Associations**

Some housing associations employ a welfare rights worker. If you live in a housing association property contact your local office.

### **Doctor's surgeries**

An increasing number of surgeries and health centres have a welfare rights worker on the premises, part-time or full-time. Check with the receptionist.

### **Local Authority**

Your local council may employ Welfare Rights Workers who can help you with your claim. Start by asking your council's main switchboard if they can put you through to a Welfare Rights Worker. If the operator doesn't know of one ask to be put through to the Social Services Department and if they can't help try the Housing Department, either department may employ Welfare Rights Workers.





# Medical Visit Record Sheet

Date of doctor's visit

Time doctor arrived

Time doctor left

Who else was present

Did you feel you had time to answer questions fully? Yes / No  
If no, please give details.

Did the doctor phrase questions in a way that suggested a particular answer? Yes / No  
If yes, please give details.

Did anything the doctor did, or asked your child to do, cause your child pain? Yes / No  
If yes, please give details including whether your child told the doctor they were in pain.

Anything else you wish to record (continue overleaf if you need to).

Signed (your signature)

Date

Signed (friend or carer who was present)

Date

# Health Professionals' 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.

1. The Agency wishes to know:
  - The length of time over which the patient has been treated.
  - Confirmation of the 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 resulting 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 reminding to take medication and safely carry out activities of daily living such as locking doors and turning off appliances.'

2. In order to assist the health professional supply this evidence, on the reverse of this sheet is a check list 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.
3. 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 their child is in connection with non-medical activities such as school, social activities, washing, dressing, etc.
4. It is important to bear in mind that Ulcerative Colitis and Crohn's Disease are largely 'hidden' conditions, in that the disabilities which arise from them, are not usually obvious. The evidence from health professionals can help to make it clear that this does not reduce their importance.

### Components and rates of DLA

**Higher rate mobility:** for children aged 3 or over who are unable or virtually unable to walk because of a physical health condition. Often taken to mean children who cannot walk more than 50 yards at a reasonable pace without pain, fatigue or breathlessness– although children who can walk further may be eligible.

**Lower rate mobility:** for children aged 5 or over who need someone with them when walking outdoors in unfamiliar places. For example, because they are partially sighted, experience sudden attacks of acute fatigue or have panic attacks.

**Higher rate care:** for children who reasonably require **help** (even if they don't get it) frequently throughout the day **and** at least twice or for at least twenty minutes at night **or** who need someone **to keep an eye on** them throughout the day **and** for at least twenty minutes or at least twice at night.

**Middle rate care:** for children who reasonably require **help** (even if they don't get it) frequently throughout the day **or** help at night at least twice or for at least twenty minutes. Alternatively for children who need someone **to keep an eye on** them throughout the day **or** for at least twenty minutes or at least twice at night.

**Lower rate care:** for children who reasonably require help (even if they don't get it) for at least an hour a day.

In addition, 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.

**Check List – for you to complete concerning your child**  
**to help the Health Professionals’ understanding of the problems your child is experiencing.**

Activity	Very brief details of the problem your child had with this activity, including variability. <i>‘Wakes up in night because of abdominal and joint pains. At least once a night, sometimes four or more times’</i>
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 medication	
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 and the evening	