



Claiming Disability Living Allowance

A Guide for Adults

with

Ulcerative Colitis and Crohn's Disease

Last updated: June 2010

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**Claiming Disability Living Allowance:
A Guide for Adults with Ulcerative
Colitis and Crohn’s Disease
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Welcome

We are a team of welfare benefits specialists who were asked by the National Association for Crohn's and Colitis (NACC), now known as **Crohn's and Colitis UK**, to produce the guide. The purpose of the guide is to help people aged at least 16 but under 65, with Inflammatory Bowel Disease (Ulcerative Colitis or Crohn's Disease), to complete an application for Disability Living Allowance. As part of the process of devising the guide we consulted widely, including receiving 1,000 questionnaires from Crohn's and Colitis UK members. We do hope that you find the guide helpful.

Deborah Gubbay, Steven Donnison, Holiday Whitehead.

First published 2002

“If anything is available to make my life more comfortable then I can buy it, that's what this benefit is for.”

That's what one Crohn's and Colitis UK member told us about Disability Living Allowance (DLA).

DLA can definitely make a big difference to people's lives. It can give members back some of their feelings of independence and control. It can help meet the cost of a car and give entitlement to a blue badge, pay for an improved diet, meet extra heating bills and pay for much-needed holidays. Needing a better diet, extra heating or a holiday are not grounds for claiming DLA, but if you are awarded the benefit you are free to spend it as you wish – you don't have to spend it on paying for care.

But making a claim can be a long drawn-out and emotionally draining process with no guarantee of success at the end. Many members of Crohn's and Colitis UK told us what a struggle it had been claiming DLA. Some told us how they felt they were not being listened to. Others even felt that they were treated like frauds or liars. This booklet is intended to reduce your chances of having such an unpleasant experience and to increase your chances of making an effective claim. We can't offer any guarantees as to success, but if you follow this guide we *can* promise that you will present a clear and accurate picture of your condition and avoid many of the pitfalls. We are confident about this promise because

we know

how difficult it is to explain your condition to other people and we know how hard it is to complete the claim pack when your symptoms can fluctuate so unpredictably. We know because we've studied over **one thousand** questionnaires, letters, diaries and e-mails sent to us on the subject by members of Crohn's and Colitis UK. We've also carried out extensive telephone interviews with members and we've helped some of you complete DLA claim packs. The things that other members found out by experience, you will know before you begin.

we understand

how complex making a claim for DLA can be. As one member said, '*The forms are so complicated that you have to be a lawyer to fill them out*'. Well, you may not be a lawyer, but you do have one on your side: this guide was written by a team of three welfare benefits specialists, one of whom is a barrister.

and you're not alone because in the **Help** Section there are details of how to:

- contact the **Crohn's and Colitis UK Information Service** for more information.
- make an appointment for a **Disability Benefit Service Volunteer** to call you to help with any questions or problems you have with your DLA claim.
- contact the **NACC-in-Contact Support Line**, to talk over any emotional difficulties that completing the DLA claim form might cause you.

There are also 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 you have a Department of Work and Pensions (DWP) 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, page 5*, for further details).

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

You can also include the Crohn's and Colitis UK booklet on *Understanding Colitis and Crohn's Disease* to help the decision maker with your application.

Download a copy from the Crohn's and Colitis UK website at www.crohnsandcolitis.org.uk or ring the Crohn's and Colitis UK Information Line on 01727 830038 and ask for one to be sent to you.

Am I eligible?

In this section we do our best to explain simply and concisely what the qualifying conditions for DLA are. But first, two facts we learnt from our research with members of Crohn's and Colitis UK:

Some members of Crohn's and Colitis UK, **who are eligible for Disability Living Allowance, haven't made a claim because they don't consider themselves to be disabled.** However, for DLA purposes, 'disabled' means that you have a long term, chronic illness which adversely affects your everyday activities.

It may be that your condition stops you preparing a cooked main meal *or* means that everyday activities such as washing, dressing or walking are painful for you. You can also claim DLA if you don't need help with anything, but you do need someone to keep an eye on you, for example, in case you have a fall, because you are having special medical treatment, or because you need someone to make sure you are getting proper nourishment throughout the day.

Some members of Crohn's and Colitis UK, who are eligible for DLA, haven't made a claim because their GP, nurse, social worker or someone else told them they were not ill enough.

If you've been told by anyone, including the Department for Work and Pensions (DWP), that you won't qualify, we would strongly advise you to consult a professional welfare rights worker (see the *Help!* section) before abandoning the idea of claiming.

Members of Crohn's and Colitis UK offered all sorts of other reasons why there was no point in them making a claim for DLA. Most of them were wrong. So, remember, **you can claim DLA even if:**

- you are working
- you are claiming any other benefits (such as Employment And Support Allowance, Income Support or Jobseeker's Allowance)
- your partner works
- you have savings
- you live alone and no-one is providing care for you
- you already have someone, a partner for example, providing care for you
- you don't want anyone to provide care for you

You **do** need to have a health problem that has lasted for at least three months and is likely to last at least another six and you do need to be under 65 when you first apply.

In addition, because of the health problem, you must 'reasonably require' help with 'bodily functions'. *Or* you need to have a health problem that means you need someone to keep an eye on you.

If this is starting to appear complicated, please don't be concerned, we are about to explain on the next page:

DLA 'True or False' test

For the purposes of DLA, 'bodily functions' are things like:

- walking
- eating
- drinking
- sitting
- sleeping
- breathing
- hearing
- seeing
- getting in or out of bed
- dressing and undressing
- washing
- having a bath
- showering
- going to the lavatory
- taking medication
- communicating

(Shopping, housework and cooking are not counted as bodily functions, but cooking is still important – see the Cooking Test in *What rate might I qualify for?*).

It doesn't matter if you normally manage all these bodily functions by yourself and don't want any help. The question the law asks is, 'Do you 'reasonably require' help?', not do you want it or get it. So, it might be less confusing if you forget about the idea of help for a moment and try the **DLA 'True or False' Test** instead. This is not a legal test, it's one we have created which may help you decide whether to make a claim.

The test

Pick any bodily function from the list: walking, dressing, having a bath, whatever you like. Now answer the questions below:

- I can do it, but it hurts *True or False?*
- I can do it, but only slowly *True or False?*
- I can do it, but not really safely *True or False?*
- I can do it, but only because I've developed a special technique of my own *True or False?*
- I can do it, but I often need someone to remind me or encourage me to do it *True or False?*
- I can do it, but I need someone with me just in case things go wrong *True or False?*
- I can't do it at all anymore *True or False?*

If the answer is *True* to *any* of those questions in relation to *any* bodily function then you may be entitled to DLA, because they are all reasons why you might 'reasonably require' help or supervision with a bodily function, even if you don't get it or want it.

If the answer is *True* in relation to walking then you may be entitled to the **mobility component** of DLA. (We explain the components below).

If the answer is *True* in relation to any of the other bodily functions you may be entitled to the **care component** of DLA.

The more bodily functions you can answer *True* to, the more likely you are to be eligible for DLA. If your condition is a variable one, so the answer is sometimes *True* and sometimes *False* then you may still be eligible for DLA. (We explain how to deal with fluctuating conditions in *Completing the Claim Pack*).

What rate might I qualify for?

This section may appear very complicated, but it's still a simplification of the rules of entitlement to DLA. It's intended to help you decide whether to make a claim, not to tell you whether you definitely qualify for a particular rate. If, after you've read this section, you think you may qualify for any rate, then you should complete a claim pack. If you don't think you would qualify then please consult a welfare rights worker before giving up on the idea entirely. (See the Help section on page 51.)

If you find this section too confusing to follow then either fill in a claim pack anyway or contact an advice centre for further help.

DLA is paid at different rates, depending on how great your needs are judged to be. Trying to work out which rate you might qualify for can get very confusing. The most important thing is to make sure you put every bit of information you can into the claim pack and then worry about whether you've been awarded the right rate when you get a decision. But here's our attempt to explain how the rates are decided.

Mobility component

There are two rates for the mobility component.

Higher rate mobility

This is for people who are unable, or virtually unable, to walk because of a physical health problem. As a *very approximate* guide, if you are unable to walk more than about 50 yards without stopping or severe discomfort then you may qualify. So, if you suffer from such extreme fatigue that you can only walk 50 yards before needing to stop for a rest you may qualify.

The test is how far you can walk without *severe discomfort*. So even if you can walk 100 yards before you absolutely must stop, if you suffer severe discomfort after 50 yards, perhaps because of soreness around the anus, then you may still qualify. Other matters, such as the speed at which you walk, the way in which you walk and the length of time you need to rest, should also be taken into account.

Lower rate mobility

This is a very different test. It is for people who can walk but need someone with them when they are outdoors in unfamiliar places. So, for example, if you need someone with you when you go to a new place, perhaps to help find lavatories for you, help you cope if you suddenly become very fatigued or have an episode of incontinence, then you may qualify.

Care component

There are three rates for the care component: lower, middle and higher depending on how much help or supervision you need. Broadly speaking you can get:

the **lower rate** if you pass the cooking test (see below) or you need help for *at least an hour a day*. People who need help first thing in the morning and last thing at night with things like bathing, dressing, undressing and getting in and out of bed will often qualify for the lower rate.

The cooking test: if your condition means that you are unable to prepare a traditional main meal for one person, you pass the cooking test and qualify for lower rate care. The law says the test is a 'hypothetical' one, which means it doesn't matter whether, in reality, you ever do try to cook a meal or whether you even know how to cook. Instead, the question is: if you had all the ingredients would you physically be able, safely and without pain, to carry out all the activities involved in cooking a meal? For example, you may suffer from joint pains and poor grip so that it is unsafe for you to hold hot pans or too painful to peel and chop vegetables or you may suffer such extreme fatigue that it would be too exhausting for you to prepare and cook food. (See *Question 48, Preparing a cooked main meal for yourself*)

The **middle rate** is for people who need attention frequently throughout the day, rather than just in the morning and evening. So if you need the help above but, for example, also need help changing and washing during the day because of incontinence you may qualify for the middle rate.

At night, if you need help for at least twenty minutes or at least twice you can also qualify for the middle rate. 'Night', for the purposes of DLA, is from approximately 11pm to 7am in most cases.

Alternatively, if you need 'continual supervision throughout the day', i.e. someone to watch over you, keep an eye on you or be on hand in case of emergencies, then you may also qualify for the middle rate. So, for example, if you have osteoporosis and are prone to falls or stumbles you may need continual supervision because the consequence of even a minor fall could be a broken limb.

If you are in need of help or supervision throughout the day and at night you may qualify for the **higher rate**. More technically, you qualify if you require:

frequent attention throughout the day *or* continual supervision throughout the day
and

help for at least twenty minutes at night or at least twice a night *or* someone to be awake to watch over you for at least twenty minutes a night or at least two or three times a night. (You may need someone to watch over you because you are receiving total parenteral nutrition (or tube feeding) throughout the night or because you may fall going to and from the lavatory).

Well, that's the descriptions of the components and rates. Don't worry if you didn't follow it all, the important thing is:

"If you think you may be eligible, make a claim."

Before you begin . . .

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

1 Make sure you're organised – 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. It can save you months of frustration and lost benefits.

Many sections of the benefits system are understaffed and overstretched. Mistakes can easily happen. For example, if your claim is refused you may send in an appeal form and even phone the DWP a few days later to check they received it. A month later you've heard nothing more so you phone again, only to be told that there's no record of your form or your phone call and it's now too late to appeal. You can apply for permission for a late appeal but there's absolutely no guarantee you'll be granted one and you may lose benefits as a result.

If, on the other hand, you've kept a claim file then when the DWP say they have no record of your form or your call, you can reply:

I sent the form first class on the 16th of October. I have a copy of it in front of me now. And on the 19th of October I spoke to Karen Smith in your office, she said she had received my appeal and would be writing to me within 14 days.

In these circumstances the DWP are likely to just ask you to send them another copy of your appeal form. Even if you are forced to apply for permission to appeal late the fact you've kept such careful records will count very strongly in your favour. A claim file can save you a great deal of time, frustration and money. It's also invaluable evidence if you wish to complain about the way your claim has been dealt with.

What to put in your claim file

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

- Your claim form may be lost by the DWP – it does happen.
- Even if your 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 indefinitely, but it may still be reviewed every few years. In either case you'll have to fill out more claim forms and having your original form to look at may be very helpful.
- If you're not happy with the result of your claim you will have difficulty challenging the decision effectively without a copy of your original form.

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 are aware of 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).

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

For example, 16.02.07: 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 on page 54 now, before you start your claim.

We suggest you take a break before starting the form. Then, when you're ready,

Start your claim!

You've decided you may be eligible? No point in hanging about. Send for that claim pack. The best way to get one is to:

- Make a free phone call to the Benefit 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) (Text phone: 0800 24 33 55) (Non-BT landlines and mobile service providers may charge you.)
- Ask them to send you a DLA claim pack.

If, after asking you a few questions, the operator suggests you won't be eligible to claim DLA, thank them for their opinion, but insist that they send you a form anyway.

You should then be sent a DLA claim 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. (This 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. 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 the date when the DWP receives your completed form.

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.

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 who might provide supporting evidence (see *Including supporting evidence*);
- making appointments to see your 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 the problems you have with everyday activities.

The form has arrived

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 you also have the support of the Crohn's and Colitis UK Information Service along with their Disability Benefit Service volunteers. And if you have got a date stamped pack, you should also have over a month to complete it, depending on how long it took the DWP to post it out to you. But before you actually put pen to paper, please read the next section.

Completing the claim pack

The decision about whether to award DLA is based on evidence. The application form you are about to complete is evidence and so are any letters from doctors, carers or relatives.

An effective claim is made up of evidence that is 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. The inclusion of the Crohn's and Colitis UK booklet *Understanding Colitis and Crohn's Disease* can help to explain these conditions to decision makers at the DWP. It is genuinely difficult for people to understand (and perhaps to believe) that such ordinary activities as eating and going to the lavatory can have such powerful effects. It's no good just saying it's painful or tiring, you have to try to use words to explain what it's like being inside your body.

Compare:

Using the toilet is very painful. I have to go very frequently and end up feeling exhausted.

with

On most mornings I have to rush to the toilet repeatedly. I often visit it five times within an hour. Sometimes I do not make it in time and I have to change and shower. My anus is constantly very sore and there is a burning sensation that gets more painful with every bowel motion. I also have a fistula in my rectum that throbs painfully and discharges pus. Blood sprays out from my rectum during bowel motions and it's got to be cleaned up quickly or it stains the toilet bowl. I am often so weak that I can only do this very slowly and painfully, and sometimes I don't manage to do it at all. When I feel that my bowel motions have passed (for the time being) I gently wash and dry the area around my anus and apply Anusol cream or Preparation H to the anus passage and lower rectum to try and calm the painful fistula and raw flesh around the anal sphincter muscle. By the time I leave the toilet I am weary and exhausted, my head is muggy and my legs are shaky and unsteady. I can't think straight or talk to anyone. All I can do is lie down and wait for the next attack.

The second account is much clearer, more detailed and much more effective as a result. Of course your condition may not be as severe as this; the important thing is that you describe it clearly and in detail. We do realise how difficult it is to write about such personal things on an official form; sadly there is no way round it. (It may make it a little easier if you use formal terms like bowel movement and anus rather than everyday terms and it will also make your evidence sound more authoritative).

Beware the tick boxes!

The DLA claim pack relies a great deal on tick boxes and small boxes for numbers and leaves very little space for you to explain how your condition actually affects you personally.

We very strongly advise that you give additional information other than just the tick and number boxes.

If you don't do so you not only make it much easier for the decision maker to turn you down, you may also make it harder to succeed if you appeal against the decision on your application.

The four-step system we describe below has been used by tens of thousands of claimants and support workers, many of whom had failed in previous attempts to claim DLA, but succeeded using this system.

It does take a lot more time and thought than just ticking boxes, but the potential increase in your household income is undoubtedly worth the effort.

Providing additional information

On most pages of the forms there are set questions about your mobility and care needs which are accompanied by tick-boxes, followed by a box asking, 'Is there anything else you want to tell us about . . . ?' We strongly recommend that you use these boxes, plus additional sheets of paper, to give more details about how your condition affects you.

For many of the pages, we recommend you use our four-step system to ensure you give detailed and relevant information. You may not always use the four steps in the same order as we suggest, but do try to make sure you include all the information.

Step 1: Say what causes the problems with the activity

Decision Makers are very fond of saying that claimants could do things if they chose, they just prefer not to. So make it clear, in your own words, that the reason you have problems is not about personal choice, but because of your health condition or because you are disabled. For example:

*I have problems with this activity because of my ulcerative colitis.
I have problems with this activity because I have Crohn's disease.*

If there is more than one reason why you have problems then say so:

*I have problems with this activity because of colitis and the medication that I have to take.
I have problems with this activity because of my Crohn's disease and my angina.*

You might get fed up with having to repeat the same thing on every page you complete, but it really is worth doing.

Step 2: Say what the problems are – in detail

Give as much information as you can about the problems you have. For example:

I have problems with washing and bathing because of pain and stiffness in my limbs. I can't stand for long in the shower because of pain in my legs, feet and back. I have tried putting a stool in the shower to sit on but it was too cramped and I almost fell trying to stand up again.

I need help getting in and out of the bath because it is painful stepping over the edge of the bath and I am very unsteady on my feet.

Washing my hair causes a great deal of pain in my arms and shoulders and there are many days when I cannot do it at all.

Washing my feet causes pain in my lower back and I cannot reach behind me to do my back, even with a long brush, because of the pain in my arms shoulders and neck.

Drying myself is extremely painful, I cannot bend enough to do my calves and feet.

Step 3: Give an example

This could be:

1. When you tried to carry out the activity and it went badly wrong:

About three months ago I tried to have a bath when there was no-one else at home. I managed to get in the bath but I slipped and fell while trying to stand up to wash my torso. I was not badly hurt, but it left me feeling terribly shaken thinking how much worse it could easily have been.

2. A recent attempt to carry out the activity which was not successful:
Last week I tried to wash my hair by myself because I didn't want to disturb my partner. I was in so much pain by the time I finished that I had to take extra pain killers and I was unable to do anything for the rest of the day.

3. If you never attempt the activity alone anymore, say how long it has been since you did so:
I have not a bath or shower without someone to help me since I fell in the bath about three months ago.

Step 4: Say how someone could help

To get DLA you need to show that you 'reasonably require' help or someone to watch over you. You don't have to show that you actually get, or want, help, just that it would be reasonable for you to have it. But if you have problems with activities and there's nothing anyone can ever do that would make the slightest bit of difference, then you may not be entitled to DLA. So always try to show a way in which someone could help.

If someone is with me they can help me in and out of the bath and wash my hair and back and feet for me.

How to fill in the number boxes

Many of the pages also ask you to say how long you need help, how often you need help and how many days or nights a week you need help with each activity. Your answers will affect what rate of the care component you may be 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 and without underestimating the problems you face. If the amount of help you need varies, see 'Fluctuating conditions' below.

How long on average do you need help for during the day?

Remember, when we talk about help you 'need', you don't actually have to be getting help - or even want to get help - what is important is whether it would be 'reasonable' in view of your health condition, for you to receive this help. If you need help for *at least an hour* a day in total you may qualify for the lowest rate.

How long on average do you need help for at night?

You have to need help for *at least 20 minutes* a night, or at least *twice* a night, for it to count.

How many days / nights a week?

As a general guide, if you need help less often than *four or five days / nights* a week you will be less likely to qualify for DLA. One exception to this is the 'cooking test': see *Question 48: Would you have difficulty preparing and cooking a main meal for yourself?* .

How many times a day do you need help?

For lowest 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 do you 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.

Dealing with fluctuating conditions

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

In addition, if you are not awarded DLA, challenge the decision and 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 you did and how you felt. If the previous week was one of your 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 your claim form that you will have no credibility at all and your appeal will probably fail.

So what do we advise you to do?

We suggest that you explain how you are on your bad days and then how you are on your '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 you have no problems whatsoever. So, for example you might say:

On bad days I cannot get out of bed at all because of fatigue and pain in my large joints and back. On better days I can only get out of bed slowly and painfully, resting several times. The pain is in my ... (etc.)

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

Be careful not to underestimate your condition. Are your 'better days' actually free of pain and discomfort, or just relatively so by your standards? It may be that, for the purposes of claiming DLA, you have to accept that you don't really have any 'good days' at all – you've just learnt to deal positively with your 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 you do have periods when you are pain free then average them out as follows:

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

If your condition varies from week to week, again average it out. If you have about one good week a month that's a bit less than a quarter of the time, so you still need help on an average of 5 to 6 days a week.

If your condition varies from month to month and you have long periods of remission then you should decide whether you have no problems during the periods of remission or whether you still suffer from pain, discomfort or fatigue.

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

What were you like before you became ill?

Before you start filling in the form ask people who know you well what things you do differently or are unable to do since you became ill. Alternatively, compare the way you do things with the way they are done by somebody who doesn't have any health problems. You may have grown so used to holding on to furniture when you move around the house that you don't even notice any more. Or your partner may have been doing things for you, such as washing your hair, for so long that you have forgotten that you used to do it yourself.

Review what you've written

We don't advise you to try to fill in the form all in one go. We suggest you do it bit by bit over a period of days or even weeks. Each time you come back to the form try to reread the part you did last time to check if there's anything you want to add or alter.

Things you shouldn't worry about when filling in the form:

Handwriting, spelling, punctuation, grammar or staying inside the boxes. Write in sentences, note form, bullet points or anything else that suits you and if you can't fit everything inside the box write outside it if you can find space. The important thing is to make the form fit your condition, rather than trying to make your condition fit the form. If necessary continue on a separate sheet, but if you do so **always**

- write your name and national insurance number across the top of each extra sheet;
- give the page numbers of the questions you're answering;
- staple it to the last page of the claim pack.

Repeating yourself. Whoever designed the DLA forms obviously felt that if a thing's worth saying it's worth saying at least half a dozen times. So repeat yourself as many times as the form requires. It's very boring, but it *is* necessary.

Whenever you're ready, get out the form and we'll finally begin.

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.

About you

This guide refers to the claim forms issued in November 2009. There are several pages of notes before the actual questions; these are intended to help you fill out the form. The questions are all numbered, and the first heading is 'About You'. It contains 12 questions, most of which are straightforward, factual questions about your name, address, contact details, etc. We'll only comment on the ones we think raise any particular issues.

6 Daytime phone number

The form asks for a daytime contact number. You may, however, prefer not to be contacted by phone for any one of a number of reasons:

- You may be at work during the day.
- Your IBD may sometimes make it difficult for you to concentrate and answer questions accurately, so you would rather have questions in writing so that you can deal with them when you are well enough.
- You may feel that it is best for both parties if everything is in writing so that there can be no dispute about what questions were asked and what answers were given.

If you have email or a fax machine then you could choose this as your preferred method of contact. Alternatively, you can write in the phone number box 'See page 37 (this and page 39 ask for 'Extra Information') or 'See additional sheet'. On page 37 or the additional sheet explain why you don't wish to be telephoned.

You should bear in mind that the DWP may well already have a telephone number for you, however, and also that if they have to write to you rather than phoning it may well take longer to deal with your claim.

8 Do you normally live in Great Britain?

If you do not normally live in Great Britain, or if you have been abroad for a long period, this may affect your entitlement to benefits. See the Guidance notes that come with the claim pack for more information about this. If this proves to be a problem, get advice from one of the agencies listed in the 'Help, Support and Information' section on page 51.

10 What type of accommodation do you live in?

The type of accommodation you live in, for example a care home or a nursing home, can make a difference to whether you are eligible for DLA. It may also be taken into account by the decision maker when deciding how severe they consider your condition to be.

11 Where is there a toilet in your home?

If there are toilets upstairs and downstairs you will need to tick both boxes. However, if you are only able to use one, for example because it has been specially adapted, then write 'See page 37' or 'See additional sheet'. On page 37, or the additional sheet, explain this.

Where do you sleep in your home?

If you sometimes sleep downstairs and sometimes upstairs you will need to tick both boxes then write 'See page 37' or 'See additional sheet'. On page 37 or the additional sheet explain how often you sleep in each place and why.

12 Signing the form for someone else

There are very few circumstances in which anyone other than the person making the claim should sign the form's Declaration. Even if you fill in this form for someone else, your partner for example, they should still read it and sign it. If you have power of attorney or any other special circumstances listed here apply, such as that you are making a claim for someone under the Special Rules, then you can sign the form on behalf of someone else.

About your illnesses or disabilities and the treatment or help you receive

The information you give in this part of the form could have a dramatic effect on your award because the DWP is attaching more and more importance to factors such as whether you see a specialist and what medication and treatment you receive when deciding how severe your condition is. So do take the time to fill this section in carefully.

13 Please list separately details of your illnesses or disabilities

Read the notes on the preceding page before completing this table.

Column 1: Name of illness, disability or diagnosis

List **all** your health problems, not just Crohn's Disease or Ulcerative Colitis. Remember any related problems such as arthritis, osteoporosis, anaemia and skin problems. Also list any other completely unrelated ones such as heart disease or asthma. In addition, include any emotional or mental health problems such as depression or anxiety. Your entitlement to DLA is based on the combined effects of ALL your health problems, so make sure you put them all down.

Column 2: How long have you had this illness or disability?

Think carefully about how long you have had IBD and any other conditions: many people go for years with symptoms before they seek help or get a proper diagnosis. The length of any award you receive may be based on how long you have had IBD: the longer you've had it, the longer the award.

Column 3: What medicines or treatments (or both) have you been prescribed?

You need to list all the medication you are taking. If you are sending in a prescription list then you don't need to complete this column in relation to medication, but you may want to put down medication you no longer receive (see next paragraph) and you will need to put down any treatment you have had.

Have you been prescribed medication in the past which you are no longer taking but which demonstrates the seriousness of your condition? We think you should put it down in this table and explain why you are no longer taking it on page 37 or an additional sheet.

For example, you may have been prescribed steroids in the past but only take them when your IBD flares. Or you may have been on a strong painkiller but decided to stop using it and put up with the pain, or seek alternative remedies, because of side-effects you were experiencing or the risks associated with long-term use of the medication. We think this is important because if you only take over the counter painkillers such as paracetamol, the decision maker may assume that your condition cannot be very serious.

In the same way, if you have had treatment in the past which shows the seriousness of your condition then list it here, even if it was years ago. For example, you may have had to have parenteral nutrition (tube feeding) in the past.

Column 4: What is the dosage and how often do you take each of the medicines or receive treatment?

In this column you need to list the dosage and how often you take each of your medications. If you are submitting a prescription list you don't need to complete this column.

14 Apart from your GP, in the last 12 months, have you seen anyone in connection with your illnesses or disabilities?

There is a list of health professionals on this page of the form, plus a social worker is also mentioned. If you see anyone else who could be regarded as a 'professional' give their details here. This is another of the ways in which the DWP are likely to decide how severe your condition is. So if you see a consultant or a specialist nurse, make sure you give their details here.

15 Does anyone else help you?

We really don't like this question. You may get help from a friend or a neighbour but you may not want them to know your personal or financial business or you may simply not like the idea of having to ask them if they mind you passing on their contact details to the DWP. You might even be concerned that it could put them off helping you because they won't want to get involved with officialdom. If they are claiming benefits, they might even be concerned that it could affect their claim if the DWP knew they were helping you.

On the other hand, if you tick No, then not only is that not true, but it suggests you need less help than you really do.

If your friend or relative is happy to be included on the form then there's no problem. But if you don't want to ask them, or if they're not happy to have their details given then tick Yes and then write 'See page 37' or 'See attached sheet' in the 'Their name' box. Then on page 37 or the additional sheet, say that they are a friend and explain the help that they give. But also explain that you do not wish to give their details and explain why – for example, you don't wish people to be privy to your financial affairs or you are worried they might stop helping.

If there is more than one person who helps you, you may need several sheets to give their details – or explain why you are not going to.

16 About your GP

The frequency with which you see your GP may also be taken into account as an indicator of how serious your condition is. However, you may not see your GP about your Crohn's Disease or Ulcerative Colitis, perhaps because you have a specialist who you see. If your GP has little to do with your treatment you might want to write a brief note in this section, or on an attached sheet, explaining why your GP is not the right person to seek further evidence from and tell the decision maker who they should contact instead. This may be useful if your GP gives unhelpful evidence which you later wish to challenge.

In addition, please don't assume, even if you see them regularly, that your GP knows all about the problems you have with everyday activities – you may never have told them, or they may not have made notes at the time. People are often astonished by what their GP writes about them. So make sure you make an appointment to give your GP an up-to date picture of your problems as soon as you've completed this form and **BEFORE** they are contacted by the DWP. You should also warn your GP that the DWP may contact them.

17 Consent

On this page you are asked to sign to give your consent for the DWP to contact other people about your claim.

18 Special rules

If your death can reasonably be expected within six months because of a progressive disease your claim is dealt with under the Special Rules. The DWP aims to deal with such claims in just eight working days.

You do not need to complete the whole claim pack if you are claiming under these rules as, if your claim is accepted, you will automatically qualify for the highest rate of the care component for 3 years even if you don't currently need that level of care. You will still have to prove any entitlement to the mobility component, however.

A claim under the Special Rules can also be made on the claimant's behalf by somebody else, their carer or GP for example, if they are not well enough to do so or have not been told the prognosis.

Please read the notes about the Special Rules on page 9 of the guidance notes very carefully. It is also **extremely important** that whoever completes the claim pack **ticks the box in question 18** to say that you are claiming under the special rules, as decision makers have refused to apply the Special Rules in the past simply because this box was not ticked.

Along with the claim pack you should also include a form DS1500 which your GP completes. You shouldn't need to actually see your GP to get this form completed, but if there is any delay send off the claim pack straight away and send the DS1500 afterwards.

If you are certain that your GP or other health professional believes that your death can reasonably be expected within six months then **you do not need to complete the section on help with your care needs**.

20 Are you on a waiting list for surgery?

Being on a waiting list for surgery may be strong evidence of the seriousness of your condition. It might, however, also be evidence that your care needs may reduce in the future, after surgery and any necessary period of convalescence.

21 Have you had any tests?

There doesn't seem to be any guidance as to how far back you should go with test results. So, even if the results are some years ago, if they support your claim and demonstrate how serious your condition is then include details here. If you don't have the test results, you may be able to get copies from the hospital that carried them out. But don't miss the deadline for returning your form if you don't receive them in time. You can always send them afterwards.

22 Aids and adaptations

Column 1: Aids and adaptations

There is a comprehensive list of aids and adaptations on this page of the form; look through them and see if you have any or if you have others that are not on the list.

Column 2: Tick boxes

You are asked to tick next to any aids or adaptations that have been prescribed for you by a health professional. This is because decision makers are told not to take into account any aids or adaptations that you have provided yourself – presumably on the grounds that if you really needed them you would have been prescribed them. If there is a reason why this is not the case, for example because you are still on a waiting list to be assessed, then you need to make this clear on the form.

Column 3: How does this help you?

Explain what you use the aid or adaptation for – even if it should be obvious.

Column 4: What difficulties do you have using this aid or adaptation?

Aids and adaptations can work both ways – they may support your claim by showing how severe your condition is, but they may undermine it by suggesting that help from the aid or adaptation means that you don't need help from another person. So, if you have an aid or adaptation, but still have difficulties with the activity then it's vitally important that you say so. For example, you may have a stair lift which means that you no longer need help with getting up and down the stairs. But you may need someone to help you get onto the stair lift and get off it again and to make sure that you are safe while going up or down in the stair lift. So, although you have a stair lift, you still need attention from another person when going up or down stairs.

Getting around outdoors

This section of the claim pack is about your mobility needs. It is your answers in this section which the decision maker will use to help decide whether you meet the criteria for an award of the higher rate or of the lower rate of the mobility component.

Make it clear if you are unable to walk at all because of, for example, a spinal injury. We suggest that you also explain briefly in the 'anything else' box at question 33 why you are unable to walk rather than taking it for granted that the decision maker will understand why. If it is accepted that you are unable to walk at all then you will qualify for the higher rate of the mobility component.

If you have no legs or feet you qualify for the higher rate of the mobility component even if you can walk with prosthetic legs. If you are both deaf and blind you may also qualify for the higher rate. In both these cases, give full details in the 'anything else' box at question 33.

23 Do you have physical problems that restrict your walking?

If you have a physical problem that makes walking difficult for you then you may qualify for the higher rate of the mobility component on the grounds that you are 'virtually unable to walk'. For example, this could be due to one or more of the following: abdominal pain; fistulas; soreness around the anus; fatigue, breathlessness; the fact that movement increases the likelihood of incontinence or any other physical problem. Give details in question 27, or in the 'is there anything else you want to tell us' box, at question 33. If you suffer from fatigue describe it carefully; is it a general feeling of weariness or is it strongest in particular parts of your body; do you get dizzy or unsteady on your feet; what happens if you keep on walking?

24 How far can you normally walk?

See the guidance notes for information about the lengths of cars, buses and shoes, intended to help you work out how far you can walk. The walking in question needs to be outdoors, but on level ground, not steep hills.

The question that needs to be answered here is how far you can walk, including any short stops, before you feel **severe discomfort**. There is no precise definition of severe discomfort, except that the law says it is less than severe pain. Can you walk at all on your worse days? Are you in severe discomfort all the time when you walk or does it begin after a certain distance? People tend to have difficulty estimating distances so, if possible, actually measure how far you can walk before you are in pain or severe discomfort. As a last resort, count how many paces you can take and then measure your pace.

The case law on what distance you can walk and still be eligible for higher rate mobility is constantly changing as different Upper Tribunals make different decisions. For a long time people who couldn't walk more than 100 yards stood a good chance, but more recently awards were unlikely for people who could walk more than 50 yards. However, Appeal Tribunals are not supposed to just consider how far people can walk, but also other factors including, the speed at which you walk, the manner in which you walk and how long you have to rest for before you can walk again. Legally, there is no set distance for eligibility for higher rate DLA – you might be able to walk 400 yards and still qualify if, for example, it took you a very long time to do so. So if you have difficulties walking, no matter what the distance, complete this section – by the time your claim is decided the law might have changed again.

25 How many minutes can you walk for before you feel severe discomfort?

Try actually timing yourself (and don't rush) rather than just guessing. Remember this is an average, so take into account your worse days. If you have to stop after walking this distance, how long do you have to stop for before you can carry on walking? Include this information alongside this box or amongst the extra box in question 33. For example, "5 minutes, but then I have to stop and rest for another 5 minutes before I can carry on."

26 Your walking speed

Read this question very carefully before you answer. The walking speeds given in the tick-boxes are not the same as the walking speeds given to doctors who carry out DLA medicals for the DWP and we are very doubtful about the whole idea of average walking speeds. The danger of this question is that it seems to be more a test of your mathematical abilities than your walking abilities. The answers you give to questions 24 and 25 allow the decision maker to calculate your walking speed independently from the figures you have given at question 26. If these don't match this could be grounds for refusing you an award.

We suggest that, if you have answered both questions 24 and 25, you simply ignore the tick boxes at question 26. There is a box at the bottom of the page in which you can write a more detailed, answer to question 26. For instance:

'I can walk 40 metres in one and a half minutes.'

Remember you may also want to use this box or the extra box at question 33 to explain what it is that limits your walking speed.

27 The way you walk

When deciding whether you are 'virtually unable to walk' decision makers should take into account the way in which you walk, as well as how far you can walk and how long it takes. However, once again we suggest that you ignore the tick boxes and instead describe in detail the way you walk.

28 Do you need physical support?

If you need to lean on someone when you walk, because your legs give way without warning, tick the Yes box. If one of the three tick boxes accurately describes your difficulties then tick it, but we would definitely advise you to give further details in the 'If there is not a box that describes the help you need' box.

29 How many days a week do you have difficulty walking?

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

30 Do you fall or stumble outdoors?

Why do you fall?

Do you get dizzy or disoriented because you are tired or exhausted, possibly after bouts of diarrhoea? Does your medication make you drowsy or dopey? Are you unsteady on your feet due to joint pains? Do your legs get shaky and give out due to weakness or exhaustion?

How often do you fall?

Explain roughly how often it happens and when the most recent event was.

Do you need help to get up after a fall?

Can you get up without help after a fall and if so, how long does it take you?

If any of the following apply, add them in to the extra box at question 33, or on an additional sheet:

Is there anything that means you are at greater risk if you fall?

Is there anything that makes falling particularly dangerous for you? For example, do you have osteoporosis, so that even a minor fall could lead to broken bones?

Have you ever injured yourself as a result of falling or stumbling?

Is there any supporting evidence you can provide for your falls? For example, have you ever had to go to the doctor or to casualty as a result of a fall? If so, give details and, if available, a copy of the record of your visit there. Alternatively, has anyone seen you fall or had to help you up after you've fallen? If so, would they be prepared to write a letter confirming what happened?

Do you use any aids or equipment?

Do you use a walking stick or a walking frame or something like this?

Why would aids or equipment not prevent you falling or stumbling?

Decision makers are fond of suggesting that if you fall because, for example, your knee gives way, you should use one or two walking sticks and this will prevent you falling. Would sticks prevent you falling? Do you get enough warning and could you support your weight on your arms? If sticks would not help, say so.

31 Do you need someone with you to guide or supervise you when walking outdoors in unfamiliar places?

This page is about entitlement to the lower rate of the mobility component. Only tick No if you have read the examples on the form and read the details below and decided you don't have any such problems.

Remember, this is about when you are in **unfamiliar** places, not places that you know well.

It is important not just to describe the problems you have, but also to say what someone else can do to help you. So if you need someone with you because you get very fatigued describe what that person can do to help. Do they support you so you can walk a little further, find you somewhere to sit and rest, help you back to a car?

Do you need someone with you who has a car in case you get tired, or need to get home to your own toilet, because you cannot use public transport?

Do you need someone with you in case you fall or stumble? Why do you need someone in these circumstances? Is it because you would have difficulty getting to your feet again? Or do you have osteoporosis, so that any fall could result in very serious injury and you need someone to keep an eye on you and try to prevent you from falling in the first place?

If you don't have someone to help you and you have to manage on your own try to think how having someone with you would make things less difficult. Remember, you don't have to actually get this help, you just have to 'reasonably require' it.

Do you need someone with you because you suffer from bowel urgency or incontinence? What can they do to help? Do they go ahead and find a lavatory for you? Do they carry a change of clothing and a washing kit for you? Are they there to help you cope practically and emotionally if you do have an episode of incontinence?

To avoid danger

For example, if you sometimes have falls and are unable to get up without help.

I may get lost or wander off

This is less likely to apply where Crohn's Disease or Ulcerative Colitis is your only health condition.

I have anxiety or panic attacks

If you don't walk outdoors alone in unfamiliar places because of 'fear or anxiety' related to your physical (rather than mental) health, this will not entitle you to an award of lower rate mobility. So, for example, if you don't go to unfamiliar places alone because you are afraid of having an episode of incontinence or an attack of breathlessness, this won't count. If, however, your fear or anxiety is so severe that your doctor's diagnosis is that it amounts to a mental health problem, such as agoraphobia, then you may be eligible for lower rate mobility on the basis of fear or anxiety related to your mental health. But if this is not the case, then it's best to avoid references to anxiety and panic attacks in relation to walking outdoors and to concentrate on the practical ways in which someone can help you.

To make sure I am safe

As above, this may apply if you sometimes have falls and are unable to get up without help or if you need someone to help you find lavatories, or cope with the distress of an episode of incontinence, whilst you are outdoors in an unfamiliar place.

If there is not a box that describes the help you need . . . Remember the four steps!

Remember: don't just rely on tick boxes to prove you're entitled. Consider using our four-step system for giving additional information about your difficulties with this activity. (See: *Completing the claim pack, page 13*)

32 How many days a week?

If you don't go out much because of your condition, that's not the point. If you would like to go out every day, then the question you should answer is, how many days a week would you need help in order to do so? If you would need help every day, then the answer is 7 days. If there are some days when you would not need help, then give an average.

33 Is there anything else you want to tell us?

Use this page to give information you haven't had room for elsewhere. Continue on an additional sheet if necessary.

Reminder

Do you use any aids or appliances to help you with walking? If so, make sure you have given details at question 22.

34 When your walking difficulties started

Your walking difficulties need to have lasted for at least three months before you will be eligible for any payment of DLA mobility component.

Your care needs during the day

These questions are designed to collect evidence about your entitlement to the care component of DLA. It's worth reading through the notes, which set out briefly who qualifies for each of the three rates of the care component. Even if you are claiming DLA primarily because of mobility problems, these are likely to affect your care needs too. For example, you may have difficulty moving around indoors, getting up and down stairs or preparing a cooked main meal because of difficulties with walking or standing. You may also need help to attend social or religious functions, or to pursue hobbies because of mobility problems.

Even if you don't think your needs will be sufficient to qualify for an award of the care component, it is worth completing any pages relating to activities that you do have problems with. This is because your claim may otherwise look inconsistent: you have said you have problems with mobility and yet you also say you have no problems with stairs, moving around indoors or pursuing hobbies and pastimes.

35 Do you usually have difficulty or do you need help getting out of bed in the morning or getting into bed at night?

Only tick No if you have read the examples on the form and the details below and decided that you don't have any difficulties with this activity.

I have difficulty or need help:

- **getting into bed**

Do you need help getting into bed or with arranging the bedding and pillows once you are in bed?

Do you have periods when you are confined to your bed so that you have to have help in and out of bed frequently throughout the day to go to the lavatory?

- **getting out of bed**

Are you sometimes too weak to get out of bed in the morning? Is getting out of bed painful? Do you need someone to help you? Do you have to get out in stages, taking rests because of stiffness and to gather your strength as you do so? Do you have to hold onto things to get out of bed? Do you need medication, or tea, or something else brought to you before you can get out of bed? Remember, someone without health problems can get out of bed in a few seconds; how long does it take you?

I have difficulty concentrating or motivating myself and need:

- **encouraging to get out of bed in the morning**

Are you sometimes too exhausted or in too much pain or discomfort to get out of bed without someone to encourage you? Does someone – children, partner, friend or neighbour - look in on you to make sure you have got up? If so, tick the box and give more information in the box at the bottom of the page.

- **encouraging to go to bed at night**

As with getting out of bed, are you sometimes too exhausted or in too much pain or discomfort to get up the stairs and into bed at night? If so, tick the box and give more information in the box at the bottom of the page.

How often/ for how long each time?

Next time you get out of bed and into bed try timing it. Or if someone helps you, ask them to time it. If you have to wait for your limbs to become less stiff or for medication to wear off enough for you to become properly awake, then getting out of bed should include the time from when you want to get out of bed to the time when you are actually able to begin getting out of bed. Bear in mind that people without health conditions can get out of bed as soon as the alarm clock goes off. This is what you should be comparing your time to.

If you always have difficulties then the answer to 'how often' is daily (seven days a week) If this is not the case then give an average which takes into account bad or worse spells. Under 5 days a week is less likely to count.

Is there anything else you want to tell us . . . ? Remember the four steps!

Remember: don't just rely on tick boxes to prove you're entitled. Consider using our four-step system for giving additional information about your difficulties with this activity. (See: *Completing the claim pack, page 13*)

Reminder

Do you use any aids or appliances to help you with getting in and out of bed? For example, motorised bed raiser, or walking frame by the bed. If so, make sure you have given details at question 22..

36 Do you usually have difficulty or do you need help with your toilet needs?

Only tick No if you have read the examples on the form and the details below and decided that you don't have any difficulties with this activity. (Note: coping with periods is listed on the following page, under *Washing, bathing, showering and looking after your appearance.*)

I have difficulty or need help:

- **with my toilet needs**

Do you need help getting to and from the lavatory - this may include using the stairs. Are your bowel motions very violent, bloody or accompanied by a lot of mucus so that you have to wash or shower afterwards? Do you find this painful or do you need help doing so? Do you need help cleaning the toilet afterwards? Do frequent bowel movements leave you exhausted and in pain so that you have to rest afterwards? Do you need help to apply creams, such as Anusol, after a bowel movement?

- **with my incontinence needs**

Do you have difficulties with continence pads or a colostomy bag or something similar? For example, if you need help changing the bags during the day or if you have problems with leakage during the day, give details in the box below. Do you sometimes have episodes of incontinence because you do not make it to the toilet in time? Do you have problems cleaning up or cleaning yourself afterwards?

I have difficulty concentrating or motivating myself and need:

- **encouraging or reminding about my toilet or incontinence needs**

If you need encouraging to use the toilet, because it is painful or distressing for you, tick the box and give more details in the box at the bottom of the page.

How often?

To work out how often you need help you need to make an estimate of how many times a day you use the toilet or have to change bags, etc. If this varies according to your condition then either give a range: for example, 4 - 8, or give an average, for example, 6. If you always have difficulties, then make clear you need help seven days a week. If not, then give an average which takes into account bad or worse spells. Less than 5 days is less likely to count.

How long each time?

When working out how long each time, include time getting to and from the lavatory, time needed to wash yourself and to clean the toilet if necessary. If you use a bottle or commode, but need someone else to empty and clean it immediately afterwards, include the time taken to do that here. Again, if the length of time varies, then give an average or a range.

Is there anything else you want to tell us . . . ? Remember the four steps!

Remember: don't just rely on tick boxes to prove you're entitled. Consider using our four-step system for giving additional information about your difficulties with this activity. (See: *Completing the claim pack, page 13*)

Caution!

The DWP very often argues that people who have difficulty getting to the lavatory, or who suffer from urgency or incontinence, could use a bottle or a commode (a chamber pot in a chair; alternatives would be a bedpan, a potty, a portaloos or a bucket) instead. Would you need help using or emptying and cleaning a bottle or a commode? How would you wash and dry your hands afterwards? How long would you have to sit in a room with a used commode during the day and would it be reasonable to expect you to do so? If you don't think it would be reasonable to expect you to use a bottle or commode, say so and, if possible, explain why. For example:

"Please do not suggest that I should use a bottle or commode. I would find it deeply embarrassing and undignified have to sit in a room with a used commode or urine bottle during the day or night. It is accepted that prisoners in jail should no longer be forced to do such things and I do not believe I should be either. I would feel the same about having to use a commode or urine bottle in front of my partner or having someone empty a commode or bottle that I have used. I understand that, for DLA, attention to help someone carry on an ordinary life is attention that is reasonably required. Using a toilet is 'ordinary life' for an adult; using bottles and commodes is not. As long as I am able to use a toilet with help then I reasonably require that help."

Reminder

Do you use any aids or appliances in connection with your toilet needs such as a rail to hold onto when you get on and off the toilet? A bottle or commode also count as special equipment. If so, make sure you have given details at question 22.

37 Do you usually have difficulty or do you need help with washing, bathing, showering or looking after your appearance?

Only tick No if you have read the examples on the form and the details below and decided that you don't have any difficulties with this activity.

I have difficulty or need help:

- **looking after my appearance**

This may include things like cleaning your teeth, shaving, doing your hair, getting in and out of the bath, washing and drying yourself, looking after your personal hygiene or using a shower

Tick as many of the boxes as you think apply – if in doubt, tick the box - and we'll deal with the how often and how long below.

The kinds of things you need to consider are these:

- Do you have problems or pain getting in and out of the bath?
- Do you have problems bending in the shower?
- Does hot water make you dizzy?
- Do you have problems or pain washing or drying your feet, your hair or your back, for example?
- Are you sometimes too fatigued to wash or bathe?
- Do you have problems or pain standing to wash or shave?

If so, give details in the box at the bottom of the page.

I have difficulty concentrating or motivating myself

- I need encouraging or reminding about washing, bathing, showering or drying.

Are you sometimes too depressed or exhausted to wash or bathe? If so, tick this box and give details in the box below. Are you sometimes too depressed or exhausted to **care** about your appearance or hygiene?

How often?

If you have to wash or bathe after using the lavatory, or following episodes of incontinence, remember to include all these times. If your condition varies give an average or a range: for example, 2 - 4 times a day, or give an average, for example, 3. Explain how many days a week you 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 long each time?

Remember this includes the time to get undressed, bathe or shower, dry and dress again and includes any time spent resting in-between or recovering afterwards. If you're not sure how to separate, for example, time needed to wash and dry yourself and time needed for help to shower then add all the times together and just put a single time in one box, with the word 'in total' below.

Is there anything else you want to tell us . . .? Remember the four steps!

Remember: don't just rely on tick boxes to prove you're entitled. Consider using our four-step system for giving additional information about your difficulties with this activity. (See: *Completing the claim pack, page 13*)

Reminder

Do you use any aids or appliances in connection with washing and bathing? This could include rails to help you get in and out of the bath, a seat in the bath, a bath hoist or a walk in bath. If so, make sure you have given details at question 22.

38 Do you usually have difficulty or do you need help with dressing or undressing?

Only tick No if you have read the examples on the form and the details below and decided that you don't have any difficulties with this activity.

I have difficulty or need help:

- **with putting on or fastening clothes or footwear / with taking off clothes or footwear**

Think about all the different sorts of clothing that you may wear; it should include putting on and fastening your bra, blouse, shirt, coat, hat, underwear, skirts, trousers, socks and tying shoelaces, for example. In addition, consider any difficulties you have with taking off all of the above and putting on or taking off nightclothes. Think about any problems you have with buttons, zips, laces and braces. Do you have to wear loose-fitting clothes or ones that are easy to get on and off, such as ones with velcro or elasticated waists?

- **choosing the appropriate clothes**

For example, do you have a visual impairment which makes it difficult for you to select clothes to wear, including making sure that they are clean, matching and appropriate to the weather and the occasion and that nothing is inside out or back to front?

I have difficulty concentrating or motivating myself and need:

- **encouraging to get dressed or undressed / reminding to change my clothes**

Do you sometimes feel too depressed to bother dressing and need encouragement?

How often?

Do you need to dress or undress more than once a day because of, for example: continence problems; changing dressings or other medical procedures; needing to sleep during the day? Do you go outdoors several times a day and need help putting on and taking off outdoor clothing? If your condition varies give an average or a range: for example, 2 - 4 times a day, or give an average, for example, 3

How long each time?

Try timing yourself next time you get dressed and undressed. Remember to include any time spent resting if you need to do so. The separation into upper and lower clothes is not very helpful: most people don't completely dress their lower half, including their shoes and then start on their top half, or vice versa. Instead, put the time needed in one box and write 'in total' below'. Again, if the length of time varies then give an average or a range. If you want to give separate times for dressing and for undressing or for putting on outdoor clothes, then it's probably easiest to do this in the 'anything else' box at the bottom of the page.

Is there anything else you want to tell us . . .? Remember the four steps!

Remember: don't just rely on tick boxes to prove you're entitled. Consider using our four-step system for giving additional information about your difficulties with this activity. (See: *Completing the claim pack, page 13*)

Reminder

Do you use any aids or appliances in connection with dressing and undressing? This could include such things as button hooks and shoe horns. If so, make sure you have given details at question 22.

39 Do you usually have difficulty or do you need help with moving around indoors?

This is a very important activity. If you need help frequently and throughout the day with moving around indoors then you may be entitled to the middle rate of the care component. Only tick No if you have read the examples on the form and the details below and decided that you don't have any difficulties with this activity.

Note: 'indoors' means anywhere indoors; this can include your home and your workplace, school or college if you attend one. If you need help moving around indoors when you are pursuing leisure activities, such as going to the cinema or a restaurant, give details of these on the '*hobbies and interests*' page (question 44).

I have difficulty or need help:

- walking around indoors

Do you have to hang onto furniture to steady yourself? Do you suffer discomfort or pain if you stand for any length of time? Does standing make your bowel urgency worse?

- going up or down stairs

Is it difficult/painful/exhausting going up or down stairs? Do you need someone to help you? Do you need someone with you in case you become dizzy or unsteady on your feet? Do you have to go very slowly, one step at a time? Do you need to hold on to the handrail? Remember to include all the times you go up and down the stairs, including all the times you go up or down stairs to the toilet. If you don't have problems with stairs simply because you avoid using them at all, perhaps you have even moved into a bungalow, then explain why it is you avoid stairs.

- getting in and out of a chair

Do you take a long time to get in or out of chairs? Do you stiffen up if you sit or lay too long? Do you need someone to help you off chairs and sofas? Have you developed special techniques such as rolling off sofas onto your knees? Do you have to hold onto things to get upright? Are

you sometimes too exhausted to get up? Is rising from sitting painful? Do you have to get up and down a lot because of pain and soreness around the anus or because of frequent trips to the lavatory? Do you ask people to fetch you things like books, cups of tea or sweaters because it is too difficult or painful to get up yourself? Do you only sit on firm chairs with arms so that you can push yourself up?

- **transferring to and from a wheelchair**

It may not take long to transfer you to and from a wheelchair, but if you need help frequently and throughout the day with transfers then this may get you an award of the middle rate of the care component. So make sure you think of all the times it may happen on an average day.

I have difficulty concentrating or motivating myself and need encouraging or reminding to move around indoors

Do you need encouragement to move about because you find it painful to do so? If so, tick this box.

How often?

Do you have to get up and down a lot because of pain or stiffness? If you need help frequently and throughout the day with things like getting in and out of chairs and moving around then this alone may get you an award of the middle rate of the care component. So make sure you think of all the times you may need this sort of help on an average day. If this varies according to your condition then either give a range: for example, 12 - 18 or give an average, for example, 15. You may need to keep a record for a day to discover just how many times you do need help to carry out all these activities. If this is too difficult you may wish to give an answer such as 'Frequently', 'At regular intervals throughout the day', or 'As often as possible'.

Is there anything else you want to tell us . . . ? Remember the four steps!

Remember: don't just rely on tick boxes to prove you're entitled. Consider using our four-step system for giving additional information about your difficulties with this activity. (See: *Completing the claim pack, page 13*).

Reminder

Do you use any aids or appliances in connection with moving around indoors? This could include such things as a stair lift, raised chair or rails. If so, make sure you have given details at question 22.

40 Do you fall or stumble because of your illnesses or disabilities?

If you do have falls and stumbles indoors and there is not sufficient room on this page for full details, we suggest you use a separate sheet and give the information below. If you experience falls, you may be eligible for DLA on the basis of needing continual supervision to avoid danger. Alternatively, you may need attention with specific activities such as using stairs, getting out of chairs or getting out of the bath which will count towards your DLA entitlement.

What happens when you fall or stumble?

Explain what health condition causes the falls. For example, is it a visual impairment which means you don't see obstructions, pain and stiffness in your knees which means they sometimes give way, extreme fatigue caused by Ulcerative Colitis or Crohn's Disease, or dizzy spells?

If you haven't had any falls, but are worried that you might, you need to explain very clearly the reasons for your worries.

Can you get up without help after a fall and if so, how long does it take you? If you can't get up at all without help, or it takes a long time, then you are more likely to need attention or supervision.

Is there anything that makes falling particularly dangerous for you? For example, do you have osteoporosis, so that even a minor fall could lead to broken bones? If this is the case, you are more likely to be judged to need help or supervision even if the risk of falling is a small one.

Have you suffered any injuries as a result of falls indoors? If so give details.

Do you need help to get up after a fall?

It does not matter if there is no-one available to help, if you would benefit from help you should explain the help that you need. For instance could they steady you so you don't fall in the first place? Help you to your feet if you do fall? Help you recover from the effects of falling?

How often do you fall or stumble ?

The more frequently you fall and stumble and the more recently it has happened, the more likely you will be considered to need attention or supervision.

Other things to consider: You may wish to give extra details to cover the following:

- **Supporting evidence**

Is there any supporting evidence you can provide for your falls or stumbles? For example, have you ever injured yourself and had to go to the doctor or to casualty? If so, give details and, if available, enclose a copy of the record of your visit there. Has anyone seen you fall or had to help you up after you've fallen? If so, would they be prepared to write a letter confirming what happened? (See *The importance of supporting evidence, page45.*)

- **Is there a pattern to your falls?**

For example, do they occur mostly in the morning when you first get up, only when you reach up to high shelves or are they entirely unpredictable? The less predictable your falls, the more likely you are to need attention or supervision. So if your falls can happen anywhere, at any time, then it's important that you say so.

If your falls are predictable, the decision maker is likely to argue that you can avoid the activities that cause falls or take precautions to reduce the likelihood of injury. For example, if you only fall when reaching into high cupboards the decision maker is likely to say that you should simply avoid this activity. However, the decision maker should not suggest that you take unreasonable precautions, such as staying in the same chair or same room all day, or wearing a crash helmet.

- **Are there precautions you can take?**

Decision makers are fond of suggesting that if you fall because, for example, your knee gives way, you should use one or two walking sticks and this will prevent you falling. Would sticks prevent you falling? Do you get enough warning and could you support your weight on your arms? If sticks would not help, say so.

The decision maker may argue that you should remove or pad all sharp or hard edges so that the risk of injury if you fall indoors is small. Is this a reasonable requirement in your case? If not, explain why. For example:

"I cannot make my home safe to fall in because there are there too many sharp edges on walls, work surfaces, fireplaces, furniture, television set, windowsills, sinks, toilet cistern, doors, door handles, fridge, cooker, chairs, tables, etc. for it to be practical to pad them all and I cannot remove these items because I need them. I don't know what materials I could use for padding, particularly on surfaces that get hot or wet or need cleaning regularly for hygiene reasons. I don't know who would carry out the work to a sufficient standard for free and I could not afford to have it done."

41 Do you usually have difficulty or do you need help with cutting up food, eating or drinking?

Only tick No if you have read the examples on the form and the details below and decided that you don't have any difficulties with this activity.

I have difficulty or need help:

- **eating or drinking**

Does pain in your joints mean you are unable to cut up food? Do you have pain or problems holding cutlery? If you are receiving parenteral nutrition or tube feeding, describe the process involved and any help you need with feeding yourself, keeping equipment sterile or supervising the process.

- **cutting up food on my plate.**

As well as cutting up food this could include removing bones, fat or rind.

I have difficulty concentrating or motivating myself and need encouraging or reminding to eat or drink.

Do you need encouraging or coaxing to eat because you associate food with pain, discomfort and illness? Do you get too depressed to be able to face eating? Do you have special dietary regimes that you need encouragement to stick to? If so, tick this box.

How often?

If you have to eat frequent small meals throughout the day, make sure you include them all. If this varies according to your condition then either give a range, for example, 3 - 5 or give an average, for example, 4.

How long each time?

Again, if the length of time varies then give an average or a range.

Is there anything else you want to tell us . . . ? Remember the four steps!

Have you suffered from malnutrition or weight loss as a result of not eating? Does it help if someone prepares food for you? Do you need help monitoring what you eat, or reminding to eat or drink supplements? Do you have to eat frequent small meals?

Remember: don't just rely on tick boxes to prove you're entitled. Consider using our four-step system for giving additional information about your difficulties with this activity. (See: *Completing the claim pack, page 13.*)

Reminder

Do you use any aids or appliances in connection with eating and drinking? This could include such things as special cutlery or a feeding cup. If so, make sure you have given details at question 22.

42 Do you usually have difficulty or do you need help with taking your medicines or with your medical treatment?

Only tick No if you have read the examples on the form and the details below and decided that you don't have any difficulties with this activity.

I have difficulty or need help:

- **taking my medicine**

This could include things such as: taking the right medication at the right time, including reading labels, opening containers, measuring amounts;
swallowing pills;
using an inhaler;
applying creams or lotions;

- **with treatment or therapy**

Do you need help with emptying or changing a stoma appliance?

Do you need help with dressing wounds or administering enemas or eye drops?

Do you need medication brought to you when you are ill?

Are you receiving parenteral nutrition or tube feeding? If so what problems does this cause you and what help do you need from another person?

I have difficulty concentrating or motivating myself and need:

- **encouraging or reminding to take my medication.**

Do you need reminding to take your medication or food supplements because your concentration is poor, or because you get very tired and forgetful? Do you need someone to monitor what you take?

- **encouraging or reminding about my treatment or therapy.**

If you need encouraging or reminding about treatment or therapy because, for example, it is painful or exhausting tick this box and give details in the box at the bottom of the page.

How often?

If your treatment or medication varies according to your condition then either give a range: for example, 4 - 8 times a day or give an average, for example, 6.

How long?

Again, if the length of time varies then give an average or a range

Is there anything else you want to tell us . . . ? Remember the four steps!

Remember: don't just rely on tick boxes to prove you're entitled. Consider using our four-step system for giving additional information about your difficulties with this activity. (See: *Completing the claim pack, page 13.*)

43 Do you usually need help from another person to communicate with other people?

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

I have difficulty or need help:

- **understanding people I do not know well**
- **being understood by people who do not know me well**
- **concentrating or remembering things**
- **answering or using the phone**
- **reading letters, filling in forms, replying to mail**
- **asking for help when I need it**

There are tick-boxes covering these subjects, but remember not to rely on these alone. Consider using our four-step system for giving additional information about your difficulties with this activity. (See: *Completing the claim pack, page 13.*)

Is there anything else you want to tell us?

Has your condition caused you to lose your self-confidence? Have you become anxious and self-conscious around other people? Do you avoid people, perhaps even friends and family? Do you avoid answering the phone or answering the door? Do you avoid social situations or new situations because of lack of self-confidence or fear of incontinence?

Or do you feel so exhausted that you can't find the energy to hold a conversation?

Do you find it hard to meet and talk to people because of the effects of your medication? For example, have the side effects of steroids caused problems for you, such as weight gain, skin problems or mood swings?

What help can other people give you? Do they encourage you to meet people, accompany you and reassure you in social situations, answer the telephone or the door for you?

44 Do you usually need help from another person to take part in hobbies, interests, social or religious activities?

Decision makers tend to take little, if any, account of help with social and leisure activities even though the law says that they should. One of the difficulties with these activities is that they may be sporadic and this makes them difficult to include in calculations of how much help you need on average. However, if you do engage in social and leisure activities, or would like to if you had help, on most days, then they may have a considerable influence on your DLA award because, even if decision makers ignore them, tribunals do not. They may be particularly important in showing attention needs throughout the day, for example, which could make the difference between getting lower and middle rate care.

At home

This can be hobbies, or pastimes or activities that you used to do, still do, or would like to take up. For example, could you do gardening, decorating or DIY if you had someone to help with the bits that require heavy lifting, bending, stretching or kneeling? Do you have a visual impairment or poor concentration, which means you need help with reading newspapers, magazines, books or letters?

Although you're not asked, it's also a good idea to explain what help you get, or would need, in order to carry out this activity or activities. Would someone, for example: lift things; climb ladders; fetch things; steady you; encourage you; get out or put away equipment; read to you; tell you what's happening in a TV programme or video; read crossword clues to you?

How often?

If it is something you would do more than once a day then say how many times a day as well as how many times a week.

How long?

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

When you go out

This could include: going shopping for pleasure (rather than for necessities), walking, holidays, cinema, theatre, restaurant, pub, nightclub, library, bingo hall, post office, doctors, hospital, physiotherapist, alternative therapists, counsellor, church, evening classes, local park, day-trips, taking the children to and from school, visiting friends and relatives, swimming, gym, sports centre.

Although you're not asked, it's also a good idea to explain what help you get or would need in order to carry out this activity or activities. Do you need someone to help you walk to and from places? Do you need someone to carry things for you, to lean on, to help you get to and from the toilet? Do you need someone to offer you support and reassurance because of the possibility of a fall or an episode of incontinence?

How often?

If it is something you would do more than once a day then say how many times a day as well as how many times a week.

How long?

Include the time needed to accompany you there, stay with you throughout the activity and accompany you back, if this is what is required.

45 How many days a week do you have difficulty or need help with the care needs you have told us about?

This question seems to refer to all your care needs; it may be difficult to answer as the facts may vary. It is a good idea to provide additional details for each activity at the end of each question, or on page 37, or on a separate sheet.

46 Do you usually need someone to keep an eye on you?

This is a very important page because you may be entitled to the middle rate of the care component if you need someone to keep an eye on you during the day. Only tick No if you have read the examples on the form and read the information below and decided you don't have any such problems.

How long can you be safely left for at a time?

During the day the supervision needs to be continual, which means that you need someone available for most of the time, any breaks would have to be very short. If you cannot predict when help might be needed, for example because you have fits or falls without warning, then the answer should be 'Zero'.

- **To prevent danger to myself or others**

Do you need someone with you during the day in case you fall because you are unable to get up again or because you have osteoporosis so that the result of a fall could be very serious?

Do you need someone to monitor your food intake throughout the day?

- **I am not aware of common dangers**

This is less likely to apply where Crohn's or Ulcerative Colitis is your only health condition.

- **I am at risk of neglecting myself**

This is less likely to apply where Crohn's or Ulcerative Colitis is your only health condition.

- **I am at risk of harming myself**

This is less likely to apply where Crohn's or Ulcerative Colitis is your only health condition.

- **I may wander.**

This is less likely to apply where Crohn's or Ulcerative Colitis is your only health condition.

- **To discourage antisocial or aggressive behaviour**

This is less likely to apply where Crohn's or Ulcerative Colitis is your only health condition.

- **I may have fits, dizzy spells or blackouts**

This is less likely to apply where Crohn's or Ulcerative Colitis is your only health condition.

- **I may get confused**

This is less likely to apply where Crohn's or Ulcerative Colitis is your only health condition.

- **I may hear voices or experience thoughts that disrupt my thinking**

This is less likely to apply where Crohn's or Ulcerative Colitis is your only health condition.

Is there anything else you want to tell us . . . ?

The reason you need someone with you must be to avoid substantial danger to yourself or to others. Describe here what the danger to you or someone else would be. Have things happened in the past that posed a substantial danger to you because you weren't supervised? For example, have you had a fall and been stuck for a long time because there was no-one to help you up? Or has a substantial danger only been averted because there was someone there? If so, give details here. If you have tube feeding or some other treatment which requires someone to monitor the equipment, mention this here. If this is the only time you need supervision during the day, then it is less likely that you will qualify for an award on supervision grounds.

47 How many days a week?

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. Less than 5 days is less likely to count.

48 Would you have difficulty preparing and cooking a main meal for yourself?

If, because of your Ulcerative Colitis or Crohn's Disease, you can't prepare a cooked main meal for yourself, then this by itself entitles you to the lower rate care component of DLA.

Remember, this is a hypothetical test: this means it doesn't matter whether you know how to cook or ever do cook. What matters is whether, if you had the ingredients, you would be physically and mentally able to carry out all the activities connected with cooking a main meal. And it's a traditional meat, fish or soya and two veg. type of meal.

Reheating something, making a sandwich or putting something in the microwave doesn't count as preparing a cooked main meal.

But you can't include problems with doing the shopping in this test; you have to imagine that's already been done.

Read what we've written below, and if there are any reasons connected with your condition that mean it would be difficult for you to prepare a cooked main meal tick the Yes box.

I have difficulty planning a meal, for example, measuring amounts, following a logical order of tasks, or telling when food is cooked properly.

This could be because of fatigue or poor concentration.

I lack the motivation to cook

If you associate eating with pain and discomfort you may not be able to motivate yourself to cook most of the time.

I have physical difficulties, for example;

- **coping with hot pans, peeling and chopping vegetables**
- **using taps, switches, knobs, kitchen utensils or can-openers**
- **carrying, lifting, standing or moving about to perform tasks.**

Does pain or fatigue cause problems with any of these activities?

Because of bowel urgency, would you have to keep hurrying to the lavatory, leaving things to burn or switching them off, which might cause them to spoil because you never know how long you will be?

Have you ever left pans to burn dry, causing a potential fire risk?

I would be at risk of injury preparing a cooked main meal for myself.

Is it safe for you to handle hot pans or sharp knives? Are you at risk of falling whilst cooking? Does heat in the kitchen make you dizzy? Give details in this box.

How many days a week would you need this help?

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

Is there anything else you want to tell us . . . ?

For example, does the smell of food make you nauseous so you avoid cooking?

An Upper Tribunal has now decided that nausea is relevant in deciding your ability to prepare and cook a main meal.

Remember: don't just rely on tick boxes to prove you're entitled. Consider using our four-step system for giving additional information about your difficulties with this activity. (See: *Completing the claim pack, page 13.*) However, you can skip step 4 if you wish, as you don't need to show that you reasonably require help with cooking, only that you have sufficient difficulty.

Caution!

Decision makers may argue that if you can't safely drain vegetables because, for example, you have pain and stiffness in your hands and you are liable to drop a hot pan, then you should use a slotted spoon (a serving spoon with holes in it to allow water to drain away). The idea is that you put the vegetables in a pan of cold water on the hob and once they are cooked you can remove them from the pan to the plate with a slotted spoon without needing to handle the pan.

If you would have any trouble with doing this, for example because you can't grip a slotted spoon either, then you need to say so.

Caution!

It has previously been decided that the main meal does not include using an oven or a grill; any problems you have with these are likely to be ignored. However, we would still recommend that you give details of problems with ovens and grills as many decision makers do still take these into account.

Caution!

Decision makers may argue that if you can't safely stand at the cooker for any length of time, you should use a perching stool. This is a stool with the seat sloping forwards so that your weight is partly on your feet and partly on your buttocks.

However, while it may be reasonable to suggest that people should buy a slotted spoon for a pound or two, a good quality perching stool is likely to cost at least £30 for a basic model and well over £50 for one with back and arm rests. You may wish to say on your form that you cannot use a perching stool because you don't own one (assuming you don't) and it is not reasonable to require you to buy one.

You should also explain if there are any reasons why you would have problems using a perching stool. For example, you might have problems getting on or off the stool; you might have dizzy spells or fits and would be in danger of falling off the perching stool; you might have difficulty putting the perching stool in position or there might not be room to use it safely in your kitchen.

If you are not sufficiently agile or mobile to cook a meal, the presence of a perching stool may be neither here nor there.

Help with your care needs during the night

This is a very important section because help you need at night, if it meets the criteria, leads to an award of the middle rate of the care component even if it is for much shorter periods than during the day. 'Night' is taken to begin when your household closes down for the night, or an average time of between 11pm and 7am.

49 Do you usually have difficulty or need help during the night?

Only tick No if you have read the examples on the form and the details below and decided that you don't have any difficulties with these activities.

I have difficulty or need help:

- **turning over, or changing position in bed**

Do you need help changing position or rearranging the bedding and pillows?

- **sleeping comfortably**

Do you need someone to bring you medication, drinks or anything else during the night? If so explain why they can't just be left within reach in case you need them.

Do you sometimes have an episode of incontinence and need someone to strip the bed, put on fresh bedding and put the soiled bedding on to soak or wash?

Do you need a hot water bottle making for you during the night or painful areas of your body massaged?

Do you become distressed and need comfort and reassurance to help you go back to sleep?

- **with my toilet needs**

See the information at question 36 in this guide. In addition, you may need someone with you when you go to the toilet at night because you have to walk past the stairs and there is a danger that you could fall.

Alternatively, you may use a commode during the night – in which case do you need help with this?

- **with my incontinence needs**

See the information at question 36 in this guide. In addition, do you sometimes have an episode of incontinence and need someone to strip the bed, help you wash and change, put on fresh bedding and put the soiled bedding in to soak or wash?

Do you need help with changing pads or a bag?

- **taking medication**

See the information at question 42 of this guide

- **with treatment or therapy**

See the information at question 42 of this guide

I have difficulty concentrating or motivating myself and need:

- **encouraging or reminding about my toilet or incontinence needs**

See the information at question 36 in this guide.

- **encouraging or reminding about medication or medical treatment**

See the information at question 42 of this guide

How often?

To work out how often you have difficulties you need to make an estimate of how many times at night you use the toilet or have to change bags at night, etc. If this varies according to your condition then either give a range: for example, 2-4, or give an average, for example, 3. If you need help less than twice a night in total, then it is less likely to count towards your DLA entitlement

How long each time?

If this varies, give an average or a range. If you need help for less than twenty minutes or less than twice a night in total, then it is less likely to count towards your DLA entitlement.

When working out how long each time, include time getting to and from the lavatory, time needed to wash yourself and to clean the toilet if necessary. If you use a bottle or commode but need someone else to empty and clean it immediately afterwards, include the time taken to do that here. Again, if the length of time varies then give an average or a range. If you need help for less than twenty minutes or less than twice a night in total, then it is less likely to count towards your DLA entitlement

Is there anything else you want to tell us . . . ? Remember the four steps!

Remember: don't just rely on tick boxes to prove you're entitled. Consider using our four-step system for giving additional information about your difficulties with this activity. (See: *Completing the claim pack, page 13.*) If you say that you need someone to bring you medication, drinks or anything else during the night the decision maker may suggest that these things can just be left within reach in case you need them. If there is a reason why this would not be practical you should explain why in this box. For example, you may not be able to take the medication or the drink without physical help or you may be too confused or distressed to do it for yourself.

Reminder

Do you use any aids or appliances in connection with changing position in bed? For example, a bed raiser, special pillows. If so, make sure you have given details at question 22.

50 How many nights a week do you have difficulty or need help?

If you always have 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.

Caution!

Decision makers are particularly keen on people using commodes at night, so do point out any reasons why this may not be practical or why you consider it unreasonable. As well as the issues listed at question 36, you might find having to empty your bowel or bladder distressing if you share a bedroom with your partner. This may be particularly the case if you have prolonged, frequent or noisy bowel movements.

51 Do you usually need someone to watch over you?

This is a very important page because you may be entitled to the middle rate of the care component if you need someone to watch over you to avoid substantial danger to you or someone else, even for short periods at night. Only tick No if you have read the examples on the form and read the information below and decided you don't have any such problems.

- **To prevent danger to myself or others**

This is less likely to apply where Crohn's or Ulcerative Colitis is your only health condition.

- **I am not aware of common dangers**

This is less likely to apply where Crohn's or Ulcerative Colitis is your only health condition.

- **I am at risk of harming myself**

This is less likely to apply where Crohn's or Ulcerative Colitis is your only health condition.

- **I may wander**

This is less likely to apply where Crohn's or Ulcerative Colitis is your only health condition.

- **To discourage antisocial or aggressive behaviour**

This is less likely to apply where Crohn's or Ulcerative Colitis is your only health condition.

- **I may get confused**

This is less likely to apply where Crohn's or Ulcerative Colitis is your only health condition.

- **I may hear voices or experience thoughts that disrupt my thinking**

This is less likely to apply where Crohn's or Ulcerative Colitis is your only health condition.

How many times a night does another person need to be awake to watch over you at night?

This needs to be at least twice, and probably three times, a night or for at least twenty minutes to count.

How long, on average, does another person need to be awake to watch over you at night?

This needs to be for at least twenty minutes, or at least twice and probably three times, a night to count.

Is there anything else you want to tell us . . . ?

It's important that you give as much information as possible if you're hoping to get an award on 'watching over' grounds. See the information about question 46 - someone keeping an eye on you during the day- for more about the kind of evidence you need to provide. Also, think about additional night time needs - for example, do you need someone to be awake when you go to the lavatory because you are unsteady on your feet due to medication, or because of your weakness or fatigue? Or do you need help with treatment such as parenteral nutrition (tube feeding)?

52 How many nights a week do you need this help?

If you always have 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.

53 Please tell us anything else you think we should know about the difficulty you have or the help you need

Use this box for any information about night-time needs you haven't managed to include elsewhere.

54 When your care needs started

This may be many months or years before you were actually diagnosed. DLA is only payable when your problems have lasted for at least 3 months.

About time spent in hospital, a care home or a similar place

For example, a residential care home, nursing home, hospice, boarding school, residential college, school or similar place.

55 Are you in hospital, a care home or similar place now?

Complete this section if you are currently an in-patient, otherwise tick No.

56 Have you come out of hospital, a care home or similar place in the past six weeks?

If you have been in residential care or an in-patient in hospital in the last six weeks give details here, otherwise tick No.

57 Have you been in hospital in the last two years?

If yes, give details here.

58 About other benefits

This section asks whether you are getting or waiting to hear about other benefits such as War Pensions or Industrial Injuries, Constant Attendance Allowance or War Pensions Mobility Supplement.

59 How we pay 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, give full reasons on page 37 (or 39 or an additional sheet) and get advice from an advice agency.

60 Statement from someone who knows you

You don't have to get anyone to complete this page, but good supporting evidence always helps a claim.

We suggest that you photocopy this sheet and give the copy to the person you want to complete it. Or if you prefer, take several copies and give them to a number of different people to complete. If you are happy with what they write staple the sheets to this page.

If you are unhappy with what someone has written, 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.

If possible one of the people completing this statement should be a professional involved in your care, such as your GP, specialist or a nurse. Make an appointment to see that person so you can answer any questions they might have and take the *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.

You may also want your partner or main carer to complete one of these sheets.

61 Extra information (page 37) and extra information continued (page 39)

Use these pages for anything you haven't managed to include but you think might be relevant, particularly for explaining more about your condition.

For example, if you have written about dizziness or exhaustion and there are specific reasons for these problems, such as:

- the effects of frequent bouts of diarrhoea
- malnourishment because you can't digest food properly
- anaemia caused by continual blood loss or iron deficiency
- the side effects of your medication

explain about them here. You could begin with something like: 'One of the main reasons I am so exhausted all the time is ... Another reason is ...'

If your condition fluctuates or you have flare-ups you can give details here of how long they can last, how serious they can be, how often you have them or just how completely unpredictable they are.

If you have had hospital admissions or surgery you can give more details here.

If you have a stoma appliance or have special treatments, such as TPN, give details here.

Or you can give an account of the way your life has changed as a result of your condition – what did you used to be able to do that you can't do anymore?

Middle rate care

Although the claim pack asks lots of questions about how often you need help and how long for, it doesn't ask you about *when* in the day you need help. However, this information can be very important. If you need 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 – you are likely to qualify only for the lower rate of the care component. But if you need attention 'frequently throughout the day' you may receive the middle rate of the care component instead. (See *What rate might I qualify for?* page 8, for more about this).

'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 I need throughout an average day

7.30am	help with getting out of bed, washing and dressing.
8.30am	help with cutting up food for breakfast
12.30pm	help with preparing food for lunch
2.30pm	(or thereabouts) help with putting on shoes and coat and help to get either to the library, to visit friends or relatives, or to visit the park or the shops for leisure and just to get out of the house.
4.00pm	help removing outdoor clothing
6.00pm	help with preparing and cutting up food for evening meal
10.30pm	help with washing, undressing and getting into bed

62 Declaration

Read the declaration carefully before you sign it.

What to do now

It's worth working through the checklist on this page before putting your pen down for the last time.

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.

The importance of 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 claim succeeds. Detailed evidence from health professionals such as your GP, or consultant if you have one, may also mean that your claim is dealt with more quickly and that you 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 her or him without telling you first, even if s/he has very little contact with you).

So, ask the health professional(s) most involved in your care if they will write a letter supporting your claim. Make an appointment to see them so you can answer any questions they might have and take the health professionals sheet at the end 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). Remember: 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.

Caution!

Doctors are under no obligation to provide you with a letter of support for your claim. Some may refuse to supply you with a letter, others may only do so only if you pay. If you are eligible for Legal Aid, some solicitors and advice agencies may be able to pay for medical evidence for you. See the *Help!* section for more about this.

Obtaining a PCA or WCA report

If you have had a medical recently (for Income Support, Incapacity Benefit or Employment and Support Allowance) – say in the last six months – as part of your Personal Capability Assessment or Work Capability Assessment, to decide if you were capable of work, it may be worth obtaining a copy of the doctor's report. Phone, or preferably write, to the office that deals with your Incapacity Benefit / Income Support / ESA and tell them that you wish to be sent a copy of the medical report and any other evidence used to make a decision in relation to your work capability. (Other evidence might include, for example, a report from your GP or other health professional.)

You do not have to give any explanation as to why you want the documents: under the Data Protection Act, the DWP has a duty to provide you with the documents you ask for.

If the report supports what you are saying in your claim pack, then there is nothing to prevent you submitting it as supporting evidence for your claim. However, you need to read it very thoroughly before you do so, as it's quite possible that some of the evidence in it will be supportive and some of it will not. If at all possible get advice from a welfare rights specialist about whether to submit the report. If you can't get professional advice and you're in any doubt, it's probably best not to submit it.

However, bear in mind that the claim pack asks if you had a recent medical for any other benefit, so it's entirely possible that the decision maker will get a copy and use it as evidence in any case.

Non-medical evidence

Carers, friends or relatives who accompany you when you go out, help you up and down stairs, accompany you to social occasions or give other sorts of support, can write letters explaining what they do. They should give the letter 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.

Whatever you do, 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 five days, detailing all the things you have problems with, cannot do unless you have help or cannot do at all, is very useful. If you keep a diary before you fill in your claim pack, it can make the job a lot easier. In addition, you can send it in with your claim form as additional evidence. But beware: if yours is a fluctuating condition, then don't keep a diary when you're having a better spell; it'll give a very misleading impression.

A diary may also prove invaluable if you need to attend an appeal tribunal, as it will be evidence of what problems you had at the time you made your claim. Also, tribunals are very keen on hearing a day by day account of the sort of tasks you perform and the things you find difficult, you *will* be asked about these if you have a hearing.

See page 50 for a sample diary.

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 you.

Who gets a medical visit?

There's no way of knowing when you make your claim whether you 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 wishes to send a doctor to your home. If you refuse to have a medical your 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 you 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 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 that 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 you don't get the award of DLA you consider appropriate and decide to challenge the decision.

Please 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 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 case and we advise you to ask for a copy for your records even if your claim is successful. (See *The decision*, page 50, 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 main medical conditions
- your medical history
- your medication
- your 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 condition varies and you 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 '*You don't have any trouble with ... do you?*', or '*You can manage ... can't you?*' 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 you to perform simple activities such as standing up and walking across the room. They may also ask you to walk outdoors. However, they should not ask you to do anything that you tell them would be painful.

Preparing for the medical

If possible, before the medical:

- read through the photocopy of your 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, (page 55), 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.

In fact, the doctor is probably doing two things.

The first is answering a question in the medical report which asks that they '*Describe any features of the current accommodation that cause increased problems for the customer e.g. upstairs toilet, steep steps.*'

The second is, in accordance with their training, checking to see if you are genuinely living the life of a disabled person. This means they will be looking out for things which they consider do not fit in with what you have said. For example, is your inhaler on a high shelf and covered in dust, looking as if it hasn't been used? Is there a heavy bolt which you have to draw to open the back door, even though you've said you can't manage to turn taps on and off because of poor grip strength? Of course, there may be very good explanations for these things: the inhaler is a spare one; you never bolt the door. But the doctor may simply observe and not ask.

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 your child or parent, 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, take 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 the 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 you have been awarded DLA. If your claim has been successful, the letter will tell you what components, care and/or mobility, you have been awarded and at what rates. It will also tell you whether your award is for a fixed number of years or for an indefinite period. 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 your award is for a fixed number of years you should be sent another claim pack to complete several months before it runs out. Crohn's and Colitis UK produces a guide to completing the renewal claim pack, *'Disability Living Allowance Renewals'*.

If your award is an indefinite one you are still likely to receive forms to fill in every few years and your award can still be reduced, or stopped, depending on what you write in them. That's why you should always keep your original claim form for reference, whatever length of award you receive.

If your circumstances change, for example, your condition improves or deteriorates, you should tell the DWP as it may mean that your DLA should be reduced or increased. Crohn's and Colitis UK produces a detailed guide called *'DLA and changes of circumstances: a guide for adults with Ulcerative Colitis and Crohn's Disease'* which explains how the system works.

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 calendar 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, although this is obviously not a problem if you've been awarded nothing at all. You should try to get help if you wish to challenge a decision.

Crohn's and Colitis UK produces a detailed guidance document called *'Revisions and Appeals: a guide for adults with Ulcerative Colitis and Crohn's Disease'* which explains how the system works.

All the guides mentioned above are available on the Crohn's and Colitis UK website at: www.crohnsandcolitis.org.uk
You can download them, or telephone the Information Line if you would like to have a paper copy posted to you.

If you would like to talk over your options with a Crohn's and Colitis UK Disability Benefit Service Volunteer, please call the Information Line, on **0845 130 2233**, to arrange a telephone appointment.

Sample Diary

Saturday Morning

Bad day today. Woke up feeling totally exhausted - had a bad night, woke up lots, needed to go down to toilet, couldn't get back to sleep for a long time each time.

My neck is stiff and painful and my hands and shoulders hurt. My hands are not very flexible. I feel extremely depressed. I can't think straight, I can't find the strength to communicate with my partner except 'Yes', 'No' and 'Please don't talk to me now'.

Get out of bed to go to the loo. My body is very stiff and tired. My feet hurt. Get down to the loo slowly. Sit for ages but just wind and pain in stomach. Go back upstairs, getting pains in my thighs by the time I get to the top of the stairs. I need to lie down. Go back to bed. Partner brings me cup of tea. Drink it, doze off for a while. 10.30, get up again. Partner reminds me to take medication - I hadn't remembered.

Have a bath. Takes a long time, as I feel very sluggish and slow. Try to get out, feel faint and light-headed. Pull plug out immediately, call to partner to come and help me. Dry myself, feel totally exhausted, need to lay down for 15 minutes. Get dressed. Hands are still stiff, need some help with buttons and laces. Partner helps to dry my hair as my arms become tired and painful holding hairdryer and trying to brush.

Have breakfast, feel very bloated and uncomfortable, have to change clothes to something looser.

Partner takes me shopping in car. By the time we get to town I need to get to the loo fast - explosive diarrhoea. No disabled loo with sink inside in the covered market so I can't clean myself up properly. Need to change underwear. No soap in loos, I'm feeling very dirty and not able to get clean. Ask partner to take me home, am very depressed. Partner is very reassuring, calms me down. We go home. Need to lie down, am upset and very tired.

Afternoon

Partner makes lunch, but I can't eat much. Back in the toilet soon after. Have to clean the toilet and myself. This leaves me feeling very tired and more depressed.

Watch TV in the afternoon till 5.30 on couch with feet up. Take dogs for walk up lane. Come back too tired to cook dinner. Sit in kitchen and tell partner how to do it. Too tired to sit up to table so meal brought to me laying on couch.

Evening

Watch TV till 10ish, get up to go to bed very tired and stiff, partner helps me upstairs, helps me undress and into bed. Checks I've remembered my medication. Helps me put on skin treatment to upper arms neck and shoulders as my arms hurt too much to stretch to these places.

During the night

Stomach is feeling bloated, uncomfortable and painful. My neck is also very stiff and painful. Can't get to sleep. Partner has to get up for medication for my tummy pain. Also makes me a hot water bottle and rubs some Ralgex into my neck for me.

Help, Support and Information

Crohn's and Colitis UK

Disability Benefit Support: 0845 130 2233

Information and support for people with Colitis and Crohn's Disease in claiming DLA is provided through the Information Service. Anybody wishing to have more information about how to claim DLA should ring the Crohn's and Colitis UK Information Line on **0845 130 2233**. Our Information Officers can direct you to various sources of help, when needed, with claiming DLA and other benefits. Information Officers can also make an appointment for you to speak to a trained Disability Benefit Service Volunteer. Our volunteer will call you on the telephone, at a pre-arranged time, to talk over any questions or concerns you may have about your application. Our guides to DLA are available on our website, www.crohnsandcolitis.org.uk or if you prefer, we can post one to you.

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 will have to think hard about all the ways in which life is more difficult or more restricted for you and have to pass on very personal information to strangers in the benefits system. What may be worse, if your claim is not successful, you may feel that you have not been taken seriously or believed. Contacts are Crohn's and Colitis UK members who have been 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 the process of claiming is causing you distress, they can offer support.

Family, friends, carers and other Crohn's and Colitis UK 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 sometimes, 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 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 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.

Legal Services Commission: Direct helpline and website

The Community Legal Advice Service offers free initial (30 minutes) advice from a qualified legal adviser about Welfare Benefits between 9am and 8pm weekdays, 9am-12.30pm Saturdays. 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 CLA website if you wish to. Instead go straight for the option of speaking to an adviser.

You can also get information about your nearest CLA funded advice providers by visiting the CLA website at: www.communitylegaladvice.org.uk

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

Citizens Advice Scotland (CAS)

To find your nearest bureau, look under Citizens Advice Scotland in your phone book or visit the CAS website at: 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

AdviceNI

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.adviceni.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 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.

Doctors' 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.

Benefit Enquiry Line: 0800 88 22 00

This is a DWP line for general questions about benefits for 'disabled' people and carers.

Internet

www.dwp.gov.uk This is the website of the Department of Work and Pensions.

www.direct.gov.uk This is the website of the UK government.

www.disabilityalliance.org This website has a great deal of up to date information

Quotes from people who have IBD

If you are lucky enough to be awarded high rate mobility you can even choose to have a car, which is definitely a huge help. Getting high level mobility allows me to get a blue badge and free car tax.

The only exercise I can do is swimming, so the extra money has helped me to do this.

Getting DLA enables me to pay helpers so I can continue to go to work, keep my house clean, maintain a small garden and not be too exhausted to enjoy some free time at weekends.

Since getting DLA I feel much more independent and worry less about having to rely on family to help me all the time.

Since getting DLA I feel more dignified being able to pay for help.

I couldn't afford to buy or keep a car since losing my full-time job, so DLA has been a godsend to me. Getting DLA makes it easier for me to travel a lot more because I can go by taxi.

Since getting DLA I'm much more (nicely, I hope) assertive, much happier and it's been wonderful having the cash to share household costs with my spouse.

Since getting DLA my confidence has definitely improved.

Since getting DLA I do feel more in control financially and not so guilty about paying out for things like taxis.

Since getting DLA I have bought various bits of disabled equipment and found the courage to get a wheelchair to get out and about more.

DLA pays for me visiting the hairdresser once every six weeks and has made me 'rich' enough to be generous i.e. the odd bunches of flowers for friends.

Getting DLA makes it easier to make the most of the life that I have. I can afford to have a healthier, better diet and use convenience foods when I am unable to prepare a meal.

I have been unable to work due to Crohn's and an accident, plus another illness, so DLA makes life possible.

The knock-on effect of getting DLA has been lower levels of stress and anxiety about everyday necessities. My general condition has certainly improved and my outlook is more positive.

Since getting DLA I feel more independent as I don't have to rely on other people to take me out or collect my son from school.

As a result of getting DLA I also qualified immediately for Income Support, so I now get the free prescriptions for all my medication.

Since getting DLA I have felt less stressed with constant money worries.

Before I got DLA I didn't have enough to live on, so it has made an enormous difference to my life.

Since getting DLA I feel more independent and money worries are a lot easier. My overall condition remains the same, but I can cope a lot better.

Since getting DLA I can be independent and this has had really positive effects: I have reduced the amount of steroids I need for the first time since diagnosis.

Before, I did not have enough to live on so DLA has made an enormous difference to my life. I now feel more independent too and life has become less of a struggle.

Since getting DLA my confidence has definitely improved. I've started a part-time college course plus I do one day a week therapeutic work in a clothing shop.

Medical Visit Record Sheet

Date of doctor's visit

Time doctor arrived

Time doctor left

Who else was present

Did the doctor arrive at the agreed time?

Yes / No

If no, please give details.

Did you feel relaxed and able to talk freely to the doctor?

Yes / No

If no, please give details.

Did the doctor listen to what you had to say and give you 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 you discuss with the doctor whether you have such a thing as a 'Typical day' and give a clear idea of the variability of your condition?

Yes / No

If yes, please give details.

Did the interview distress or upset you in any way?

Yes / No

If yes, please give details.

If you had a physical examination, did anything you did or the doctor asked you to do cause you pain?

Yes / No

If yes, please give details, including whether you told the doctor you were in pain.

Did the doctor go into rooms in your house without your permission or without adequately explaining why they were doing so?

Yes / No

If yes, please give details.

Anything else you wish to record

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 applying for benefit may have already completed this form. You may wish to go through it with them.
3. Patients may not have previously revealed to their health professional the extent to which the disease affects the 'ordinary' aspects of their life. One reason for this is that living a restricted life has become the norm, and facing up to that can be distressing.
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 people who are unable or virtually unable to walk because of a physical health condition. Often taken to mean people who cannot walk more than 50 yards at a reasonable pace without pain, fatigue or breathlessness— although people who can walk further may be eligible.

Lower rate mobility: for people 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 people 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 people 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 people 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 people who reasonably require help (even if they don't get it) for at least an hour a day or who are unable to prepare a cooked main meal for themselves.

Checklist

Activity	✓	Very brief details of the problems you have with this activity. For example 'I am in pain and unsteady when I use the stairs. It helps to have someone to lean on'.
Walking outdoors		
If you need someone with you when you walk outdoors		
Falls or stumbles		
Moving about indoors		
Getting out of bed in the morning		
Getting into bed at night		
When you are in bed		
Toilet needs.		
Washing and bathing		
Getting dressed and undressed		
Preparing a cooked main meal		
Problems at mealtimes		
Help with medical treatment		
Someone keeping an eye on you		
Dizzy spells, blackouts, fits and seizures		
Communicating with other people		
Social and leisure activities		