Claiming Disability Living Allowance

A Guide For Adults With Ulcerative Colitis And Crohn's Disease

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Contents

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The information in this guide is intended as general information only and is not intended to be relied upon by any individual in relation to their specific circumstances. It is not intended as a replacement for appropriate professional advice.

Welcome

We are a team of welfare benefits specialists who were asked by the National Association for Colitis and Crohn's Disease (NACC) 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 NACC members. We do hope that you find the guide helpful.

Deborah Gubbay, Steven Donnison, Holiday Whitehead.

"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 NACC 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 NACC members 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 NACC members. 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 **NACC Information Service** for more information or to make an appointment for a **DLA Support Line Volunteer** to call you to help with any questions or problems you have with your DLA claim and **NACC-in-Contact Support Line** to talk over any emotional difficulties that claiming DLA 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, the new name for what used to be the Department of Social Security) medical. (For more about this see *Preparing for a Medical*).

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

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

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

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 NACC members:

Some NACC members who are eligible for Disability Living Allowance haven't made a claim because they don't consider themselves to be disabled. In reality, you don't have to be disabled at all to claim DLA. It may be enough 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.

For DLA purposes, 'disabled' simply means that you have a long term illness which affects your everyday activities.

Some NACC members 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 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.

NACC members 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 Incapacity Benefit, Income Support or Jobseekers 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:

Bodily functions

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 DLA True or False 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 Help!). 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 *Part 16: 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, means after the adult household has gone to bed, rather than when it gets dark.

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 had one client who was able to claim thousands of pounds in backdated benefits because he had kept copies of letters right from the beginning of his claim).

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

E.g. *16.02.06 Spoke to Gemma Watson at the DLA Unit. She said they have received my consultant's letter.* Don't feel embarrassed about this. In the very unlikely event that anyone refuses to give you at least their first name and the section they work on, insist on speaking to their Supervisor.

2 Arrange support

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

We suggest you take a break before starting the form.

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 freephone call to the Benefits Enquiry Line on 0800 882 200 (8.30 am to 6.30 pm Monday to Friday and 9.00 am to 1.00 pm on a Saturday) and ask them to send you a DLA claim pack.

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. (Which means you have to post it several days before that date). If they receive it after the six weeks your claim is still valid, but it starts from when the DWP get your form back instead of the date when you first asked for it.

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

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 NACC Information Service and DLA Support Line 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: Handy Hints And Legal Advice

This section gives you some general tips about completing the claim pack. It will help you make sure you give all the information needed in the most effective way you can.

Is your form different from the one we describe?

The DWP have been running various pilots, trying out different forms in different areas of the country. One such pilot DLA claim pack provides just 4 boxes for you to give all the information needed about your attention, supervision and mobility problems. Unfortunately NACC cannot produce a separate guide for every different form the DWP try out, especially as some pilots may only last a few months.

If you are sent a form that is different from the one we describe you could phone the office that sent it out and ask to be sent a standard form instead. If necessary, when you get the standard pack, tear off the date stamped sheet from the front of the pilot pack you were sent and staple it to the front of the standard claim pack to show what date your claim should be from.

Unfortunately, the DWP may say that taking part in the pilot is obligatory. If that's the case, and you have access to the internet, you might want to download a standard claim pack from the DWP website and print off parts 7-24, the pages that deal with the difficulties you have with mobility and everyday activities. Complete these pages using the NACC guide and attach them as additional sheets to the pilot claim pack.

Evidence.

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

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 NACC 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 disgorges pus. Blood sprays out from the 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 and 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, that doesn't matter, 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).

Please take the time to fill in the form in as much detail as you possibly can. Many claims are rejected simply because there wasn't enough evidence for benefit to be awarded. If you don't fill in the claim pack fully and have to appeal you will also have to explain to the tribunal why you are now saying you have problems that you didn't mention in your claim pack. Below we describe a simple four step system that may help you with completing parts 7-24 of the claim pack.

How to fill in the main boxes.

Parts 7-24 of the form ask about various everyday activities. On most pages there is a main box for describing the problems you have and smaller boxes for saying how long you need help for, how often each day or night and how many days a week. You don't have to fill in pages relating to activities you don't have problems with – but please check what we have to say about each page before deciding that you needn't complete it.

For many, though not all, of the main boxes we recommend you use our four-step system to ensure you give detailed and relevant information. We tell you which pages we think you should use the four-step system on as we go through parts 7-24 of the claim pack. 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:

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.

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.

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 smaller boxes

Parts 7-24 also ask you to say how many days or nights a week, how often each day or night and how many times a day or night you need help with each activity. Your answers will affect what rate of the care component you may be eligible for. 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 lower 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 *Part 16: Preparing a cooked main meal for yourself*.

How many times a day do you need help
For lower rate care it doesn't matter how many times, but for the middle rate it needs to be '*frequent*' which has, rather unhelpfully, been defined as several times.

How many times a night 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 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 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. Sadly, 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 anymore. 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.

Completing the claim pack – getting started

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

Part 1 – About you

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

Part 2 – For people signing this form for someone else

There are very few circumstances in which anyone other than the person making the claim should sign the form at Part 36. 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 in part two apply then you can sign the form on behalf of someone else.

Claiming under the Special Rules

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

Part 3 – About where you live

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. If this proves to be a problem, get advice from one of the agencies listed in the *Help!* section.

Part 4 – About your illnesses or disabilities

What are your illnesses or disabilities?

List **all** your health problems, not just Crohn's 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.

What medicines, tablets or other treatments have been prescribed for your illnesses or disabilities?

List all the medication you have been prescribed, how much you take and how often. If you wish, also list other, non-prescribed, medication that you use. In addition list any treatment such as physiotherapy, or parenteral nutrition or special diets or diet supplements. If in doubt, mention it.

Have you had a medical examination in the last six months, in connection with any other social security benefit?

If you have had a medical examination in connection with a claim for incapacity benefit, for example, the decision maker may get a copy of the medical report and use it as part of the evidence when considering your application for DLA.

Part 5 - For people on kidney dialysis

Only complete this if it applies to you.

Part 6 – More about you

Tick the last box in the double column: *You have some other problem not on this list*
If you suffer from depression, anxiety or something similar tick the box saying*: You have a mental health problem.*
Tick any of the other boxes that apply to you.

Have you been assessed for things such as home help, meals on wheels or disability aids, or do you have a care plan or an occupational therapy report?
Assessment reports may provide very useful information about the difficulties you have with everyday activities. But bear in mind you are not obliged to submit such reports if you do not wish to. Read through any report you are considering submitting. If you decide that, for example, your care plan sets out an unreasonably optimistic assessment of how well you are likely to progress then you may decide you do not wish to submit it. You must still tick the box to say *Yes* you have been assessed if this is the case. You should also be aware that the DWP may obtain a copy of your assessment directly from whichever organisation carried it out.

About parts 7-24

Parts 7-24 deal with how your condition affects almost every aspect of your daily life. You may want to complete them a bit at a time over a period of days.

Don't forget that the effects of Inflammatory Bowel Disease vary a great deal from person to person and you may have very few of the symptoms or problems we list, this does not mean you are not eligible for DLA. But please do try to check what we say about each page on the form, you may be surprised at how much applies to you

Part 7 - Walking outdoors

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

Describe in your own words the problems you have and the help you need with walking
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.
If you suffer from fatigue describe it: 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?
Describe any pain you suffer: where is the pain, how intense is it, what does it feel like, does it get worse the more steps you take? Do you have osteoporosis so that a stumble or fall might lead to a broken limb? Has this ever happened? If so, give details.

Tell us about anything you use to help you walk
Do you use a walking stick or walking frame? Do you need someone to lean on, do you lean on walls?

If the effort of walking would be dangerous for you, tell us about this
Might you stumble, fall, collapse with exhaustion or become, dizzy or disoriented?

Tell us roughly how far you can walk 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. As a last resort count how many paces you can take and then measure your pace.

Tell us how long on average it takes you to walk this far
Try actually timing yourself (and don't rush) rather than just guessing. Remember this is an average, so take into account your worse days.

How many days a week do you have this amount of 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.

Part 8 - Having someone with you when you are outdoors

Do you need someone with you when you are outdoors?
Only tick No if you have read the examples on the form and read the box below and decided you don't have any such problems.

Describe in your own words the problems you have and the help you need when you are outdoors
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?
A change in the law in April 2002 means that 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, 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 using words like frightened or anxious and to concentrate on the practical ways in which someone can help you.

How many days a week do you need someone with you when you are outdoors?
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.

Part 9 - Falls or stumbles

Do you sometimes fall or stumble, even in places you know well because of your disability or the effects of your medication?
Only tick No if you have read the examples on the form and read the box below and decided you don't have any such problems.

Why do you fall or stumble?
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?

Tell us where you might fall or stumble
E.g. uneven pavements or road surfaces; crossing roads; getting up or down kerbs; in and out of doorways; in crowded shops or streets; on or off buses; up and down stairs; getting out of chairs or out of the bath.

Describe in your own words the problems you have and the help you need when you fall or stumble
You may already have explained about falls and stumbles outdoors on page 4. (If not please see the preceding page). I'm afraid you now have to do it all again. In addition you now need to explain about falls and stumbles indoors. What makes you fall or stumble? When and where might you be most likely to fall or stumble? E.g. hurrying to the toilet. What help you might need? What might happen if there was no-one there to help?

Tell us roughly how often you fall or stumble
Remember to include falls and stumbles indoors and outdoors. Think back to the last time this happened.

Part 10 - Moving about indoors

Do you have problems moving about indoors?
Only tick No if you have read the examples on the form and read the two boxes below and decided you don't have any such problems.

Does someone have to tell you or encourage you
Does someone have to remind you, jolly you along or spur you on to move around to do things?

Describe in your own words the problems you have and the help you need

Moving around: 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?

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

Bending: can you bend and pick up things if you drop them on the floor? Is it painful?

Remember the four steps.
Step 1 Say what causes the problems with this activity.
Step 2 Say what the problems are. Give details of: pain; fatigue; stiffness; breathlessness; lack of strength; slowness; mobility problems; being in danger.
Step 3 Give an example.
Step 4 Say how someone can help.

Tell us about any ways your home has been adapted or any equipment you use to help you move about indoors. Tell us if someone helps you use the equipment.
This might include stair rails, raised chairs, grab bars or furniture arranged so that you can lean on it. Did you do this yourself, or did an organisation such as social services put these adaptations in for you? If they did, can you contact them and ask for a copy of the report they wrote on why you needed the adaptations? You may be able to use it as evidence for your claim.

How long …?
Give a list of the times for different activities or give a range of times to cover all the different activities, e.g. 5-10 minutes.

How many days a week …?
If you always have difficulties with at least one of these activities, e.g. going upstairs, then the answer is 7 days. If you only need help for part of each day, perhaps just the mornings or evenings, the answer is still 7 days. If you only need the help on bad days try to give the average number of bad days a week. Under 5 days a week is less likely to count.

How many times a day …?
Count all the times you need help with each activity and add them all together.

Part 11 - Getting out of bed in the morning and into bed at night

Do you have problems getting out of bed in the morning and into bed at night?
Only tick No if you have read the two boxes below and decided you don't have any such problems.

Does someone have to tell you or encourage you to get out of bed in the morning and into bed at night?
Are you sometimes too depressed or exhausted to get out of bed without someone to encourage you? Does someone – children, partner, neighbours - look in on you to make sure you have got up? If so, tick this box and give details in the box below.

Describe in your own words the problems you have and the help you need …
Are you sometimes too weak to get out of bed on a 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?

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?

Remember the four steps.
Step 1 Say what causes the problems with this activity.
Step 2 Say what the problems are. Give details of: pain; fatigue; stiffness; breathlessness; lack of strength; slowness; mobility problems; being in danger.
Step 3 Give an example.
Step 4 Say how someone can help.

Tell us about any equipment you use to help you get out of bed in the morning and into bed at night. Tell us how the equipment helps you and how useful it is. Tell us if someone helps you use the equipment.
E.g. motorised bed raiser, walking frame by the bed.

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. Under 5 days is less likely to count.

How long on average …?
This is a tricky one, but next time you get out of bed try timing it, or if someone helps you ask them to time it. It should include the time from when you wake up and want to get up to the time when you feel able to begin getting out of bed.

Part 12 - When you are in bed

Do you have problems when you are in bed?
Only tick No if you have read the examples on the form and read the box below and decided you don't have any such problems.

Describe in your own words the problems you have and the help you need
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 need help changing position or rearranging the bedding? 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?

Remember the four steps.
Step 1 Say what causes the problems with this activity.
Step 2 Say what the problems are. Give details of: pain; fatigue; stiffness; breathlessness; lack of strength; slowness; mobility problems; being in danger.
Step 3 Give an example.
Step 4 Say how someone can help.

Tell us about any equipment you use to help you when you are in bed. Tell us how the equipment helps you and how useful it is. Tell us if someone helps you use the equipment.
This might be a bed raiser, special pillows or an alarm to summon help, for example.

How long …?
Think about each of the problems you have and how long it takes to help you with them, then add them together. Or give a range of times that covers normal and bad nights.

How many nights 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. Under 5 days is less likely to count.

How many times a night
If this varies give an average or a range.

Part 13 - Help with your toilet needs

Do you have problems coping with your toilet needs?
Only tick No if you have read the examples on the form and read the three boxes below and decided you don't have any such problems.

Does someone have to tell you, remind you or encourage you to deal with your toilet needs?

Describe the problems you have and the help you need during the day
(The boxes in his section are very small, remember to use a separate sheet if necessary). Do you need help getting to and from the lavatory, (this may include using the stairs)? 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? Even if you do make it to the toilet in time 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 have to apply creams such as Anusol after a bowel movement?
The DWP very often argue that people who suffer from urgency or incontinence could use a commode (a chamber pot in a chair, alternatives would be a bedpan, a potty, a portaloo or a bucket) rather than trying to get to the lavatory in time. Would you need help to use a commode? Would you need help to empty a commode? Is there a danger that you might have an attack of incontinence whilst trying to carry the commode up (or down) the stairs potentially causing an even more distressing situation? Are there other reasons why it would not be practical to use a commode? For example: your condition may mean that your motions have a very strong smell

and it would be extremely unpleasant to use a commode in a room that you use to sit in; there may not be room for a commode in the rooms you use. Do you need to wash or shower after a bowel movement so that you would have to go to the bathroom afterwards anyway?

Remember the four steps.
Step 1 Say what causes the problems with this activity.
Step 2 Say what the problems are. Give details of: pain; fatigue; stiffness; breathlessness; lack of strength; slowness; mobility problems; being in danger.
Step 3 Give an example.
Step 4 Say how someone can help.

If you have a stoma appliance: if you need help changing the bags during the day or if you have problems with leakage during the day, give details of them in this section.

Describe the problems you have and the help you need at night
All the above also applies at night. The DWP are particularly keen on people using commodes at night, so do point out any reasons why this would not be practical. As well as all the above you may have prolonged, frequent or noisy bowel movements which you would find distressing to have to experience if you share your room with a partner.

If you have a stoma appliance: if you need help changing the bags at night or if you have problems with leakage at night, give details of them in this section.

How long … during the day/night?
Include time getting to and from the lavatory, time needed to wash yourself and to clean the toilet if necessary.

How many days/nights a week …?
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/nights is less likely to count.

How many times a day/night …
If this varies give an average or a range.

Please tell us where the toilet is in your house and about any special equipment you use to help you with your toilet needs. For example, rails by the toilet, a commode, a bottle or something else. Tell us how the equipment helps you and how useful it is. Tell us if someone helps you use the equipment.
See *Describe the problems you have and the help you need during the day* for more about bottles and commodes.

Part 14 - Washing, bathing and looking after your appearance

Do you have problems washing, having a bath or shower, or looking after your appearance?
Only tick No if you have read the examples on the form and read the two boxes below and decided you don’t have any such problems.

Does someone have to tell you, remind you or encourage you to wash or take a bath or shower?
Are you sometimes too depressed or exhausted to wash or bathe? If so, tick this box and give details in the box below.

Describe the problems you have or the help you need washing, bathing or showering or looking after your appearance. If you need to wash or bath or shower more than once a day, please tell us why. If you have bed baths, tell us how long they take.

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, your back? Are you sometimes too fatigued to wash or bathe? Do you have problems or pain standing to wash or shave?

Do you have problems because you have dressings, a line into a vein or a stoma appliance that needs to be kept dry or sterile?

Remember the four steps.

Step 1 Say what causes the problems with this activity.
Step 2 Say what the problems are. Give details of: pain; fatigue; stiffness; breathlessness; lack of strength; slowness; mobility problems; being in danger.
Step 3 Give an example.
Step 4 Say how someone can help.

Tell us about any equipment you use to help you with washing, bathing or showering or looking after your appearance. Tell us how the equipment helps you and how useful it is. Tell us if someone helps you use the equipment.

For example: bath hoist, bath seat, grab rails.

How long …?

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

How many days a week …?

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.

How many times a day …?

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.

Part 15 - Getting dressed or undressed

Do you have problems getting dressed or undressed?

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

Does someone have to tell you, remind you or encourage you to get dressed or undressed?

Do you sometimes feel too depressed to bother dressing and need encouragement? If so, tick this box and give details in the box below.

Describe the problems you have and the help you need

Do you have problems or pain reaching down to put on underwear, socks or shoes? Problems or pain with using zips, buttons and bra fastenings? 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?

Remember the four steps.

Step 1 Say what causes the problems with this activity.
Step 2 Say what the problems are. Give details of: pain; fatigue; stiffness; breathlessness; lack of strength; slowness; mobility problems; being in danger.

Step 3 Give an example.
Step 4 Say how someone can help.

Tell us about any equipment you use to help you get dressed or undressed. Tell us how the equipment helps you and how useful it is. Tell us if someone helps you use the equipment.

How long …?
Try timing yourself next time you get dressed and undressed. Remember to include any time spent resting if you need to do so.

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. Under 5 days is less likely to count.

How many times a day …?
If you have to change during the day remember to include all these times as well. If your condition varies give an average or a range.

Part 16 - Preparing a cooked main meal for yourself

Would you have a problem because of your illness or disability if you prepared a cooked main meal for yourself?

This is a very important page. If you can't prepare a cooked main meal for yourself then this by itself entitles you to the lower rate care component of DLA.

Don't forget that this is a hypothetical test: this means it doesn't matter whether you can 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 listed on the form.
And remember it's a traditional meat (or soya) and two veg. type of meal, not reheating something, making a sandwich or chucking something in the microwave. It also has to be done safely. (But it doesn't include doing the shopping, you have to imagine that's already been done).
Only tick No if you have read the examples on the form and read the box below and decided you don't have any such problems.

Describe the problems you would have and the help you would need
Because of fatigue or poor concentration would you find it difficult to choose the ingredients for a meal, work out and remember seasoning and timing, keep an eye on things when they were cooking?
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?
Do you have problems, pain or fatigue: opening tins; peeling and chopping vegetables; turning taps and knobs; lifting hot pans; standing at the cooker; stirring things; draining vegetables.
Does the smell of food make you nauseous, so you avoid cooking meals or can't complete them?

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.

Part 17 - At mealtimes

Do you have problems at mealtimes?
Only tick No if you have read the examples on the form and read the two boxes below and decided you don't have any such problems.

Does someone have to tell you, remind you or encourage you to feed yourself or have a 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 and give details in the box below.

Describe the problems you have and the help you need
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?
Does pain in your joints mean you are unable to cut up food? Do you have pain or problems holding cutlery? (*Continued on the next page*).
If you are on parenteral nutrition or tube feeding: describe the process involved and any help you need with feeding yourself, keeping equipment sterile or supervising the process.
Remember the four steps.
Step 1 Say what causes the problems with this activity.
Step 2 Say what the problems are. Give details of: pain; fatigue; stiffness; breathlessness; lack of strength; slowness; mobility problems; being in danger.
Step 3 Give an example.
Step 4 Say how someone can help.

Tell us about any equipment you use to help at mealtimes. Tell us how the equipment helps you and how useful it is. Tell us if someone helps you use the equipment.
If you are on parenteral nutrition describe the equipment involved.

How long …?
If someone helps you, how long do they spend doing this?

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. Under 5 days is less likely to count.

How many times a day?
Remember to say if you have to eat frequently throughout the day. If your condition varies give an average or a range.

Part 18 - Help with medical treatment

Do you have problems coping with medical treatment?
Only tick No if you have read the examples on the form and read the two boxes below and decided you don't have any such problems.

Does someone have to tell you, remind you or encourage you to take your 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? If so, tick this box and give details in the box below.

Describe the problems you have and the help you need during the day
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?

Remember the four steps.
Step 1 Say what causes the problems with this activity.
Step 2 Say what the problems are. Give details of: pain; fatigue; stiffness; breathlessness; lack of strength; slowness; mobility problems; being in danger.
Step 3 Give an example.
Step 4 Say how someone can help.

Describe the problems you have and the help you need during the night
See the daytime box.

How long each time during the day/night?
If someone helps you, time how long it takes. If you have problems but manage alone, time how long it takes.

How many days/nights a week?
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.

How many times a day/night?
If your condition varies give an average or a range.

Part 19 - Someone keeping an eye on you

Do you need someone to keep an eye on you?
Only tick No if you have read the examples on the form and read the two boxes below and decided you don’t have any such problems.

Describe why you need someone with you during the day?
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 keep an eye on you because you are on parenteral nutrition? Do you need someone to monitor your food intake throughout the day?

Remember the four steps.
Step 1 Say what causes the problems with this activity.
Step 2 Say what the problems are. Give details of: pain; fatigue; stiffness; breathlessness; lack of strength; slowness; mobility problems; being in danger.
Step 3 Give an example.
Step 4 Say how someone can help.

Describe why you need someone to be awake to watch over you during the night
See the box above. In addition, do you need someone to be awake when you go to the lavatory because you are unsteady on your feet due to medication, weakness or fatigue.

How long …?
During the day the supervision needs to be continual, which means that you need someone available for most of the time, though not necessarily without any breaks.
At night the supervision needs to be for at least twenty minutes or at least twice a night to count.

How many days/nights a week?
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.

How many times a day/night?
If your condition varies, give an average or range.

Part 20 - Dizzy spells, blackouts, fits, seizures or something like this

Do you have dizzy spells, blackouts, fits, seizures or something like this?
Only tick No if you have read the examples on the form and read the two boxes below and decided you don't have any such problems.

Describe the problems you have and the help you need during the day
Quite a number of NACC members seem to suffer from dizzy spells. If this applies to you, give details of them here. Do you lose your balance getting up to hurry to the toilet, for example? Do you get any warning of dizzy spells? Do you have to sit or lie down when you have one? Do you need someone to help you, steady you or watch over you when you do things that make you feel dizzy or faint?

Describe the problems you have and the help you need during the night
As above. Does someone stay awake until you come back from the toilet?

How long each time during the day/night?
Include the time that someone stays awake or is on hand in case you need them.

How often during the day/night?
If your condition varies, give an average or a range.

Part 21 - The way you feel because of your mental health

Do you have problems because of your mental health?
Only tick No if you have read the examples on the form and read the box below and decided you don't have any such problems.

Describe the things you do or cannot do, or the experiences you have had
If you suffer from depression, anxiety, stress, irritability, anger, sudden mood swings or suicidal thoughts describe them and the effect they have on your everyday life here. Have you been prescribed any medication for these sort of problems or talked to your GP, a counsellor or someone else about them? Do they prevent you meeting people, going outdoors or looking after yourself properly? What help can other people be when you are feeling anxious, depressed, stressed etc? Can they calm you down, encourage you to get up, dress, eat, go out etc.?

Tell us roughly how often this happens and how long you need help for when this happens
Think back over the last few weeks and talk to anyone who helps you, you may not be aware of how often someone gives you support or encouragement.

Part 22 - Communicating with other people

Do you have problems communicating with other people?
Only tick No if you have read the examples on the form and read the two boxes below and decided you don't have any such problems.

Describe the problems you have and the help you need
Has your condition caused you to lose your self-confidence? Do 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 get 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 steroids caused hair loss, excess facial hair, weight gain, skin problems?
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?

Remember the four steps.

Step 1 Say what causes the problems with this activity.
Step 2 Say what the problems are. Give details of: pain; fatigue; stiffness; breathlessness; lack of strength; slowness; mobility problems; being in danger.
Step 3 Give an example.
Step 4 Say how someone can help.

Tell us about any equipment you use to help you communicate with other people. Tell us how the equipment helps you and how useful it is. Tell us if someone helps you use the equipment.
Do you use the telephone to communicate with people because you don't have the confidence to meet them in person?

How long each time?
Ask anyone who helps you.

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. Under 5 days is less likely to count.

How many times a day?
If your condition varies give an average or a range.

Part 23 - Help you need when you go out during the day or in the evening

Please note: in spite of the title, these pages are about help you need with social and leisure activities *at home*, as well as when you go out. What used to take up nine pages in the old DLA form has now been shrunk down to two very cramped and confusing pages. But these two pages can be very important if you need support in order to take part in social leisure activities. The boxes are very small, so use separate sheets if you need to.

What you do or would do if you had the help you need

When you go out during the day or evening
This box may be easier to complete if you read it as asking: '*Where do you go, or where would you go if you had the help you needed?'*
Examples include: going shopping for pleasure (rather than for necessities), holidays, cinema, theatre, restaurant, pub, nightclub, library, bingo hall, post office, doctors, hospital,

physiotherapist, counsellor, church, evening classes, local park, day-trips, taking the children to and from school, visiting friends and relatives, swimming, gym, sports centre.

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

How many times a day?
Is this something you would do more than once a day?

How long do you usually need help for each time?
Include the time needed to accompany you there, stay with you throughout the activity and accompany you back.

What help do you need from another person?
Describe what help you get or would need in order to carry out this activity. Do you need someone to drive you to and from places? Do you need someone to carry things for you, to lean on, to help you find a lavatory, to help you get to and from the lavatory? Do you need someone to offer you support and reassurance because of the possibility of an episode of incontinence? Do you need someone with you in case you have a dizzy spell or a fall?

What you do or would do if you had the help you need

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? Is your concentration too poor to read but you would like someone to read to you?

How many days a week?
How often would you like to do these things or how often do you do them with help?

How many times a day?
If this is an activity that you would like to do more than once a day say how many times.

How long do you usually need help for each time?
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?

What help do you need from another person?
Would someone do the lifting, the hammering, climb ladders, fetch things, steady you, encourage you, get out or put away equipment?

Part 24 - More about the way your illness or disabilities affect you

Use this box 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?* 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:

<u>Help I need throughout an average day</u>

7.30am	help with getting out of bed washing and dressing.
8.30am	help with cutting up food for breakfast
12.30pm	help with cutting up 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 cutting up food for evening meal
10.30pm	help with washing, undressing and getting into bed

Part 25 - About nights in hospital

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

Part 26 - About nights in residential care

Complete this section if you are currently in residential care, otherwise tick No.

Part 27 - About nights in hospital and nights in residential care

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

Part 28 - When your problems started

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

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

Part 29 - Who would you like to tell us about your illness or disabilities?

Give details of the professional person who you think knows most about the way your condition affects your everyday life. This can be your specialist, occupational therapist, health visitor, district nurse, stoma nurse, home help, care worker, etc. Make sure you tell the person that you have given their name on the form and that you have explained to them in detail the problems that you have in relation to everyday activities. But please don't assume that the DWP will contact this person – they may well not, particularly if it is someone other than your GP.

Part 30 - Your family doctor or health centre

You are asked to include details of your GP on the form. Please don't assume your GP knows all about the problems you have with things like walking, dressing or washing – 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 possible, before they are contacted by the DWP. You may want to look at the section on *Including Supporting Evidence* and complete the *Health Professionals' Sheet* at the back of this guide before you see your GP. You should also warn your GP that the DWP may contact them.

If your GP has little to do with your treatment you might want to write a brief note in this section 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.

Part 31 - Your hospital doctor or specialist

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

Part 32 - consent

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

Part 33 - Statement from someone who knows 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 who completes 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.

Part 34 - About benefits and pensions

This section asks whether you, or someone else in your household, is getting any of a range of other benefits or tax credits (DLA will be paid in addition to all of them, with the possible exception of Constant Attendance Allowance, where there may be some overlap). It also asks whether you have been turned down for, or stopped receiving, DLA or attendance allowance in the last 3 years.

Part 35 - Making payments to you

The DWP now prefers to pay all benefits direct into a bank account and this section asks for details of your bank account. If you are not happy with this, or it would be a problem for you, tick Box 2 in part 35 C '*I would like information about how I can be paid by other means*', return the form and get advice from an advice agency.

Part 36 - Declaration

Read the declaration carefully before you sign it.

Part 37 - How we collect and use information

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

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

Including Supporting Evidence

As well as your claim pack the decision maker has to take into account any other evidence you provide, this includes additional evidence from you and evidence from other people.

Medical evidence

This can make an enormous difference to whether your claim succeeds. Detailed evidence from health professionals such as your nurse, GP or specialist 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 without telling you first, even if she has very little to do with dealing with your condition).

Ask the doctors, consultants or other health workers 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 with you. Ask them to send any letter to you so you can keep a copy (and if necessary ask them to change anything you think is inaccurate or unhelpful).

It is up to you to decide what evidence you submit. Do not feel obliged to use a letter that may not be helpful or might actually harm your case.

Non-medical evidence

Carers, friends or relatives who accompany you when you go out, give you lifts, coax you to eat, give support after episodes of incontinence, bring you food and drink if you're stuck in bed or help in other ways can write letters explaining what they do. The letter should be relevant to your DLA claim, so there's no point in writing about shopping or housework, and they should give it to you so that you can keep a copy. If it says things that you think are unhelpful then ask the writer to change them or simply do not submit the letter.

Don't feel obliged to submit a letter just because someone has been kind enough to write it. A letter that says the wrong things can be very damaging to your claim.

Keeping a diary

A diary kept for five days detailing all the things you find difficult, painful, cannot do unless you have help or cannot do at all is very useful. (We have included a sample day's diary near the end of this guide. 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 a 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 .

Don't forget: you must send your form before the deadline runs out, you can send other evidence later if necessary. Enclose a letter with your claim form telling the DWP that you intend to send further evidence and when you hope to be able to send it to them.

What happens next

You should receive an acknowledgement within five working days of the DWP receiving your claim pack; at least that's what it says in the Charter Standard Statement.

Next it will be looked at by a decision maker who may make a decision on the information you have sent or may decide he requires more. He may contact your GP, or more rarely your specialist, for further information and/or he may ask the DWP to send a doctor to visit you for a medical. We tell you in the next section how to prepare for a medical.

Preparing For A Medical

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 wish 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 tell the DWP that you want to have a friend or relative present and make sure that the visit is arranged for a time when they can be there. We very strongly advise you to do this for reasons we're about to explain.

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, we know from your questionnaires that not everyone is so fortunate. Doctors, who are often either retired GPs or local GPs fitting these medicals in with their other work, are paid a fee of £104 per visit by the DWP. Many members 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 a friend or relative with you can make it much easier to deal with these situations.

Having someone else present not only provides moral support, it can also provide you with a witness to what happened at the medical. Please also use the Medical Visit Record Sheet at the end of this guide to record what happens. You may be able to use it as evidence at an appeal hearing. Look through it before you have your medical and fill it in 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 he stays only a short time you can use this as evidence that his report is less likely to be reliable.

The medical and the medical report itself are divided into two parts.

Part One of the examination

This is supposed to be a statement of *your* needs in *your own* words. The doctor should ask you about a number of things including what problems you have with:

Walking
Going outdoors
Getting up
Moving about indoors
Falls
Bathroom and toilet needs
Help with medication and related activity

Help at mealtimes
Preparing a cooked meal
Using a wheelchair
Going to bed
Awareness and recognition of dangers
Blackouts, fits, comas etc
Help needed when in bed
Help with toilet needs
Help with medication
Any other needs not described above that are told to the doctor

Read through your photocopy of the DLA form and refresh your memory on all these points before the doctor arrives. 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 trouble with something or can’t manage something say so and explain why. The doctor should write down what you tell him and then either read the statement back to you or give it to you to read. You then sign to say that you agree with what has been written.

Do not sign unless you are completely happy with what is written.

This is a signed statement saying what your problems are. If it differs from what you’ve written in your claim pack it may be used by the DWP as grounds for refusing your claim.

If you need to read the statement, or have it read to you, two or three times in order to check it fully then do so. *Don’t be hurried*, the doctor is being well paid for his time. If there is anything you disagree with, ask the doctor to change it. If there is anything missing, ask the doctor to put it in. Carry on until you are completely happy with the statement. If the doctor won’t write what you ask then politely refuse to sign, but still co-operate in every other respect with the medical. If the doctor tells you that you must sign or your claim will fail tell him politely that he is mistaken and show him this page if you wish. Point out that it was written by a team of benefits specialists and that you consider it best to follow their advice. If the doctor says he’s running out of time and has to be somewhere else, politely suggest that he arranges a further appointment to come back and finish the medical. But whatever you do, **don’t sign until you’re satisfied**.

We do understand how difficult disagreeing with a doctor can be. That is why we strongly recommend you have someone with you to give you support.

Part 2 of the Examination

In the second part of the medical the doctor will ask you more questions, may carry out a brief physical examination and may ask you to carry out simple activities such as standing up and walking across the room. If you know that something will cause you pain you have two choices:

i) politely explain to the doctor that it will cause you pain and don’t do it. Unfortunately, the doctor may then write on his report that you were uncooperative and that in his opinion you could have carried out the activity if you’d tried.
ii) attempt the activity but stop as soon as you feel any discomfort and explain to the doctor why you have stopped.

If anything the doctor does causes you pain, tell him.

While the doctor examines you he fills out his own report stating what, in his opinion, your needs are. This is his part of the report, he is entirely free to disagree with everything you have told him and he does not show you what he has written. (Though you will receive a copy of the whole report if you appeal against the decision in your case).

We don’t want to leave you feeling terrified about having a visit from a DWP doctor. But many NACC members said 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 doctors 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 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. NACC produces a guide to completing the renewal claim pack, *Disability Living Allowance Renewals*, which is available from our website. 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 - your condition improves or deteriorates - you should tell the DWP as it may mean that your DLA should be reduced or increased.

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

NACC produce a detailed guidance document called *Revisions and Appeals: a guide for adults with Ulcerative Colitis and Crohn’s Disease* which explains how the system works. You can download a copy from the NACC website at **www.nacc.org.uk**

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 lay 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 - 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 lay 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!

Help From NACC

Benefits

Information and support for people with Colitis and Crohn's Disease in claiming Disability Living Allowance is provided through the Information Service. Anybody wishing to have more information about a DLA claim should ring the NACC Information Line on **0845 130 2233**. Information Officers can make an appointment for you to be rung by a DLA Support volunteer or direct you to other sources of help, when needed, with claiming DLA and other benefits.

NACC-in-Contact Support Line 0845 130 3344

Even if you feel entirely able to complete the claim pack without help you may well find the process emotionally disturbing. You 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 NACC members who are trained to give supportive listening over the telephone. They are not there to deal with any questions to do with DLA, but if you find the process of claiming is causing you distress they can offer support.

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

Advice agencies and advice workers.

These may be able to help with filling forms and with challenging the decision if you're unhappy with it . However, advice agencies may be almost impossible to get through to on the phone, have no appointment system, long queues and no public lavatory. If you can't get through to your local agency on the phone, try writing to them explaining your 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.

CLS Direct helpline and website

The Community Legal Service offers free initial (30 minutes) advice from a qualified legal adviser about Welfare Benefits between 9am and 5pm weekdays. And if you call outside office hours, just leave a message and they say they'll call you back. If you are eligible for Legal Aid you can then get further free legal help with your case by phone and post. To use the helpline call **0845 345 4345**. After you choose the welfare benefits option you will be advised to listen to recorded messages about benefits. We recommend that you don't, the messages are long, sometimes confusing and you can read them at your leisure on the CLS website at www.clsdirect.org.uk if you wish to. Instead go straight for the option of speaking to an adviser.

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

Citizens' Advice Bureaux (CAB)

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

Citizens Advice Scotland

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

Association of Independent Advice Centres (Northern Ireland)

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

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.

Doctor's surgeries

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

Local Authority

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

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.

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.

Getting DLA makes it easier for me to travel a lot more because I can go by taxi.

I couldn’t afford to buy or keep a car since losing my full-time job, so DLA has been a godsend to me.

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 has got me to Turkey, France, Wales, Scotland , London, etc. In other words – a new life.

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.

Getting high level mobility allows me to get a blue badge and free car tax.

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.

Claim File Record sheet

Date	Letter		Phone		Name and section	Details
	to	from	to	from		
28/02/06	✓				Disability Benefits Unit, Flowers Hill, Bristol	Sent claim pack and supporting letters from GP and consultant
14/03/06			✓		Jenny in Claims Section, Disability Benefits Unit, Flowers Hill 0117 949671	Said they had received my form and an acknowledgement had been sent out.

Date	Letter to from		Phone to from		Name and section	Details

Medical Visit Record Sheet

Date of doctor's visit ☐

Time doctor arrived ☐

Time doctor left ☐

Who else was present ☐

☐

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

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

Did anything 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.

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

Signed (your signature) Date

Signed (friend or carer who was present) Date

Health Professionals' Sheet

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

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

1. The Agency wishes to know:
    - The length of time over which the patient has been treated.
    - Confirmation of the diagnoses (not just IBD diagnosis).
    - Likely future clinical course.

    However the most important information is a description of the <u>consequences</u> 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 For Health Professionals' Sheet – for the patient's completion to help the Health Professionals' understanding of the problems you are experiencing.

Activity	✓	Very brief details of the problems you have, including variability, with this activity. For example 'Pain in back and legs. Fatigue. It takes me 10 minutes to get out of bed. Sometimes I can't'.
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 and into bed at night		
When you are in bed		
Toilet needs – including stoma problems		
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		
Mental health		
Communicating with other people		
Social and leisure activities		