

DLA

Changes of Circumstances

A Guide for Adults and Children

With

Ulcerative Colitis and Crohn's Disease

Last updated: June 2010

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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.

**DLA: Changes of Circumstances
A Guide for Adults with Ulcerative
Colitis and Crohn's Disease
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Summary

You should inform the DWP of any change of circumstances which might affect your DLA award, particularly if it might mean it should be reduced. This includes things like an improvement in your condition or having a stoma device fitted, if this leads to your having fewer difficulties with everyday activities.

If your condition improves

- If your condition fluctuates wait until the improvement has continued for longer than usual before informing the DWP.
- Consult with your GP or specialist about the likelihood of the improvement lasting.
- If you have an operation, wait until your convalescent period is over before deciding whether there has been an improvement in your condition.

Starting work

This shouldn't generally count as a change of circumstances in relation to DLA but you may wish to inform the office dealing with your DLA, (usually Blackpool), anyway. In addition, bear in mind the following:

- If you are receiving benefits other than DLA and you start work you **must** notify the DWP and, if you receive tax credits, Her Majesty's Revenue and Customs (formerly Inland Revenue).
- If you get housing benefit or council tax benefit you should also notify your local authority.
- If you're considering starting work, try to get a copy of your DLA form and see whether the work you are doing fits in with what you said on the form. If you will be doing things at work, without pain, difficulty, or help from another person, that you said you had difficulty doing, then you need to consider whether your condition has now improved.
- If you will actually need more attention or supervision when you start work than you currently get, then it may be that you will be entitled to a higher rate of DLA.

If your condition deteriorates

- If your condition has deteriorated and you think you might be entitled to a higher rate of DLA, try to get assistance from an advice agency before asking for your award to be looked at again. The DWP will look at your award again (technically called a supersession) and there is the possibility that it could be reduced.
- The deterioration in your condition needs to have lasted for at least three months.
- If you decide to go ahead, ask for a supersession in writing, explaining in detail the changes in your condition and the increased amount of difficulties you face in carrying out everyday activities.
- Include as much supporting evidence, such as letters from health professionals, relatives or carers, as possible. Keep a copy of the letter and evidence.
- If you're not happy with the result of your supersession request you have a right to appeal. There are strict time limits and again a possibility of your award being reduced, so get advice.

Backdating of changes in award

If your DLA is increased it is not likely to be backdated (see page 8). However, any reduction in your DLA will start from the date when you knew, or could reasonably have been expected to know, that there was a change in your circumstances which should be reported. You should not have to worry about being prosecuted for fraud, as long as you act reasonably in deciding when to notify the DWP of a change in your circumstances.

For further sources of help and support, see page 10.

DLA and changes of circumstances

One of the big worries for people who claim DLA because of fluctuating conditions like IBD, is knowing when they should tell the Department for Work and Pensions (DWP) that their condition has changed, either for the better or for the worse.

- On the one hand you probably have no idea how long the change is going to last. You may have had a very long struggle to get DLA in the first place, so you're very reluctant to do anything to jeopardise your award unnecessarily.
- On the other hand, you definitely don't want to find yourself having to pay back large amounts of benefits, or even face the remote possibility of a fraud charge. You also don't want to miss out if a change in your condition means you are entitled to more money.

It is very difficult to give clear guidance. There are few hard and fast rules in this area. There is no rule which says that you must tell the DWP after your condition has improved for a week or a month or any other fixed period. We'll do our best to help you come to a decision by trying to answer some of the questions most frequently put to Information Officers at Crohn's and Colitis UK.

What counts as a change of circumstances?

The law says that you should inform the DWP of any 'relevant' change of circumstances. A relevant change of circumstance is one which has the potential to change your DLA award, even if in the end it doesn't do so. Improvements or deteriorations in your condition can both be relevant changes of circumstances.

In practice the DWP don't mind if you fail to report a deterioration in your condition in relation to a DLA claim, because you're the only one who's losing out. But you must report a 'relevant' improvement in your circumstances. However, because IBD is known to be a fluctuating condition, an improvement in your condition lasting a few days or weeks should not be regarded as a 'relevant' change. We cover this in more detail in the questions below.

As well as a spontaneous improvement in your condition, relevant changes might include:

- having a stair lift, bath hoist, bed raiser or other aids or appliances fitted if these mean that there has been a reduction in your need for attention from another person;
- having a stoma, if this results in you having fewer difficulties with everyday activities;
- embarking on a long-term course of medication which significantly improves your condition.

Does starting work count as a change of circumstances?

Starting work does not generally count as a 'relevant' change of circumstances for DLA because DLA does not depend on whether you are working and is not affected by how much you earn, so you don't have to inform the office dealing with your DLA, (usually Blackpool), if you start work, unless working means you now need less – or more – help in connection with everyday activities. (But you must notify the DWP if you start work and you are receiving benefits other than DLA. If you get housing benefit or council tax benefit you should also notify your local authority).

However, decision makers are told that when they are informed, either by the claimant or another part of the DWP, that a claimant who receives DLA has started work, they should consider whether this suggests there may have been a change of circumstances, such as the claimant's condition having improved. If they think there may have been a change they will investigate further.

So if you do start work you may wish to write to the office dealing with your DLA, (usually Blackpool), and explain why starting work doesn't show that there has been a change in your condition. For example, you may only be working part-time or special adjustments may have been made, such as allowing you to work from home when necessary.

In any case, at some point your award is likely to be looked at again or come up for renewal. It's wise, therefore, to compare the activities listed in your claim pack with the activities required to carry out the work you are interested in.

If you will be doing things at work, without pain, difficulty or help from another person, that you said in your DLA claim pack that you had difficulty doing, then you need to consider whether your condition has now improved. If you will actually need more attention or supervision when you start work than you currently get, then it may be that you will be entitled to higher rate of DLA.

If you haven't got a copy of your claim pack, contact the Disability Benefits Unit on 0845 712 3456 and ask for one to be sent to you - if they still have it – it's likely to take some weeks but there is no charge.

Try to get advice from an advice agency about the possible effects on your benefits before starting work.

My condition has deteriorated and I'm wondering about asking for my DLA award to be looked at again. What things do I need to think about?

Asking for your award to be looked at again always involves an element of risk because it's possible for your award to be reduced or taken away altogether, even though you are certain your condition has got worse.

1 Will the deterioration make any difference to your award?

Even though your condition has deteriorated markedly, this may not mean that you are eligible for a higher award. For example, you may already be getting the middle rate of the care component because you need attention throughout the day. Your condition has got a lot worse and you now need a lot more help during the day, but you are still OK at night. In this case your care component award cannot be increased because you can only move onto the higher rate if you have needs at night as well as throughout the day. It's worth getting advice from an advice agency about whether the change in your condition is likely to entitle you to a higher award.

2 What are the risks to your current award?

Is the evidence to support the award that you have been given so strong that there is little likelihood of any of it being taken away? You may need to get advice about this.

3 How long has the deterioration lasted?

The deterioration in your condition needs to have lasted for three months before it can be taken into account by a decision maker.

4 How long is the deterioration likely to last?

If yours is a condition that fluctuates a good deal, you may wish to be sure as you can be that this is a long-term deterioration before asking for your award to be looked at again. Or if you are waiting to go into hospital for an operation, you may wish to wait and see if the operation makes a difference rather than disturb your DLA award for what could be a relatively short-term increase.

On the other hand, if it is likely to be many months before the operation and there will be a lengthy period of convalescence, you may think it worthwhile asking to have your award looked at again now.

5 What evidence do you have to show your condition has deteriorated?

In theory, the decision maker can just accept your word that your condition has deteriorated. In practice, the more supporting evidence you can get, particularly from health professionals such as doctors, nurses and specialists, the better your chances. Evidence from friends, relatives and carers is also valuable.

Crohn's and Colitis UK produces guides to claiming DLA for adults and for children; these include information about collecting supporting evidence. You can download the guides from our website at www.crohnsandcolitis.org.uk or telephone the Information Line and ask for one to be posted to you. If you can't get any supporting evidence at all, you need to think carefully about whether to ask for your award to be looked at again. Try to get advice.

I am feeling better but I know my condition fluctuates and I don't know how long this current improvement will last. Should I contact the DWP?

As we said above, there are no easy answers to how long you should leave it before reporting an improvement in your condition. If in doubt, the best advice is to report a change of circumstances. That way, you're much less likely to face having to repay overpaid benefits or face accusations of fraud.

But if you often have periods when you improve for a few weeks or a month or so, and this was the case at the time you made your claim, then your circumstances haven't changed until the improvement has lasted longer than this. It might be reasonable to consult with your GP or specialist – provided you don't have to wait months to see them – about the likelihood of the improvement lasting.

I am going to have an operation and I am expecting that my health will improve as a result of this; when should I inform the DWP - before I go into hospital?

The first thing to be aware of is that going into hospital can affect all your benefits. The effect will depend on how long you are in hospital for, and which benefits you are receiving. You should inform the DWP and, if you get housing benefit or council tax benefit, the local authority, and give them the date you are being admitted and the date you expect to leave. Let them know if there are any changes to this. If you haven't been able to inform them before you go into hospital, try to do so as soon afterwards as you are able.

However, there is no need to inform the DWP that you expect your condition to improve. Wait and see. You are likely to have a period of convalescence when you leave hospital and it would be sensible to wait until you know if your condition has actually improved before asking for your DLA award to be looked at again.

Reporting changes in circumstances

How do I report a change of circumstances if my condition has improved?

You should report the change of circumstances in writing to the Disability Benefits Unit in Blackpool and keep a copy – don't rely on the telephone. Bear in mind that just because your condition has improved, that doesn't mean that your award must be reduced or stopped. For example, if you used to need approximately two hours' help in the morning and evening and were getting lower rate care, but now you only need an hour's help you should still be eligible for lower rate care.

So, if you are reporting an improvement in your condition, you should give as much information as possible about the help you still need and, if you can, back this up with supporting evidence. Crohn's and Colitis UK produces guides to claiming DLA for adults and for children which include information about collecting supporting evidence. You can download the guides from our website at www.crohnsandcolitis.org.uk or telephone the Information Line and ask for one to be posted to you.

You may well receive another claim pack to complete as a result of contacting the DBU. You should receive a letter from the decision maker telling you whether as a result of your letter they decided to look at your claim again and if so, whether they have now made a new decision about your award. This process of making a new decision is called a **supersession**. The letter will tell you about your right to appeal if you are unhappy with the supersession decision.

How do I report a change of circumstances if my condition has deteriorated?

When you report a change of circumstances because your condition has deteriorated and you think you may be eligible for a higher award, you are technically requesting a 'supersession' of the original decision on your claim. You should apply for a supersession in writing and keep a copy of your letter and of any supporting evidence, such as letters from health professionals, relatives or carers.

Remember, you're inviting the DWP to examine your award again and there's always an element of risk involved in this, so give as much detail as you can about the change in your circumstances and support it with as much evidence as possible. If you're happy with the award of one component and only want the other looked at, say so, although the Decision Maker may still decide that there are grounds for looking at the whole award.

There is strong possibility that you will be sent another claim pack to complete as part of the supersession procedure. Fill this in with as much care as possible, using an up to date copy of the Crohn's and Colitis UK guide to help you.

If the decision maker decides to increase – or reduce - your award they will issue a new decision telling you what your new award is. If the decision maker decides that the change in your circumstances doesn't make any difference to your award they will issue a decision 'superseding at the same rate'. In this case you will receive a letter telling you that your DLA will continue to be paid at the same rate as before.

Can I appeal if I'm unhappy with the result of my supersession request?

Yes. The decision letter will tell you that you have a right to appeal. There are strict time limits: you must challenge the decision within one calendar month of the date on the letter giving you the result of your supersession request.

Remember that the appeal tribunal can look at your whole award and can reduce or end it as well as increasing it, or leaving it the same. Use the Crohn's and Colitis UK guide to DLA appeals, which you can download from our website, and get advice from an advice agency.

The only circumstances in which you do not have a right of appeal is if you request a supersession for a reason that can have no effect on your DLA. For example, if you asked to have your DLA award looked at again because you have a new carer, that would have no relevance to the rate of your DLA award and the decision maker would refuse to issue a new decision against which you could appeal.

Will any increase in my DLA award be backdated?

You will not be eligible for an increase in your award until the deterioration has lasted for three months. As long as your application is received within a month after that it will be backdated to the first day after the end of the three months.

This is a one month window of opportunity between the third and fourth month when you can have your award backdated. After that one month window, no backdating is allowed – apart from in exceptional circumstances.

So if you have waited a year before deciding to report a change in your circumstances, any increase in the award is only likely to be paid from the date on which you reported the change.

Will any decrease in my DLA award be backdated?

The award will be reduced from the date when you knew, or could reasonably have been expected to know, that the change should have been notified. This may be the date when you actually did notify the DWP of a change or may be earlier if the DWP thinks you should have told them sooner.

However, because IBD is a fluctuating condition it would not be reasonable to backdate the reduction to the first day on which you were aware of an improvement. Instead, it should be from the point when you were aware that the improvement was unusually prolonged or was likely to continue for some time because, for example, you had changed to more effective medication or had surgery.

If the reduction in your award is backdated it may not only lead to you being asked to repay any overpaid DLA, but also other money such as premiums on your income support, that have been paid as a result of the DLA award.

If you do get a letter asking you to repay benefits get advice immediately from an advice agency. You may be able to appeal the decision that you have been overpaid and also to challenge the amount of the overpayment. If money does have to be repaid, there are rules about the maximum amount that can be taken out of your benefits each week to do so.

Could I be prosecuted for fraud for failing to report a change of circumstances?

To successfully prosecute someone for fraud in these circumstances, it has to be proved beyond reasonable doubt that you failed to notify promptly the DWP of a change of circumstances which you knew affected your entitlement to benefit.

Because IBD is a fluctuating condition it is clearly going to be difficult for you to 'know' when a change in your condition affects your entitlement.

So, provided you behave reasonably, it is very unlikely that you will be prosecuted for failing to report a change of circumstances. A great deal will depend on the facts of the case.

If you have had a stoma appliance fitted and, having left hospital and recovered from the operation, it quickly becomes obvious that you now feel a great deal better and need a lot less attention then clearly you should inform the DWP.

On the other hand, if you are put on a short course of steroids which does have a considerable effect on your health, but your specialist has told you that there is no way of knowing whether it will last once the medication stops, then we would argue that that is not yet a change of circumstances which would affect your entitlement.

In many cases what will happen is a slow and gradual improvement in your condition over a period of months. This is the hardest to judge, but as long as you act reasonably in making your decision – perhaps consulting a health professional about the probability of it being long-term – then you shouldn't worry about prosecution for fraud.

In the very unlikely event that you are informed that you are being investigated for fraud, get advice immediately.

Under no circumstances agree to repaying large amounts of benefit on the understanding that the fraud investigation will then be dropped, unless you have had independent advice that it is in your interests to do so.

Help, Support and Information

Crohn's and Colitis UK

Disability Benefit Support: 0845 130 2233

Information and support for people with Colitis and Crohn's Disease in claiming DLA is provided through the Information Service. Anybody wishing to have more information about DLA can ring the Crohn's and Colitis UK Information Line on **0845 130 2233**. Our Information Officers can direct you to various sources of help, when needed, with claiming DLA and other benefits.

Information Officers can also make an appointment for you to speak to a trained Disability Benefit Service Volunteer. Our volunteer will call you on the telephone, at a pre-arranged time, to talk over any questions or concerns you may have about your application.

Our guides to DLA are available on our website, www.crohnsandcolitis.org.uk or if you prefer, we can post one to you.

NACC-in-Contact Support Line: 0845 130 3344

Even if you feel entirely able to appeal without help, you may well find the process emotionally disturbing. As your claim was not successful, you may feel that you have not been taken seriously or believed. Contacts are Crohn's and Colitis UK members who have been trained to give supportive listening over the telephone. They are not there to deal with any questions to do with DLA, but if you find the process of appealing is causing you distress, they can offer support.

Family, friends, carers and other Crohn's and Colitis UK members

If you can arrange emotional support from amongst your family and friends it may make appealing against your DLA decision easier to cope with. Bear in mind that the process may take many months, or sometimes, even years.

Advice agencies and advice workers

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

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

Legal Services Commission: Direct helpline and website

The Community Legal Advice Service offers free initial (30 minutes) advice from a qualified legal adviser about Welfare Benefits between 9am and 8pm weekdays, 9am-12.30pm Saturdays. And if you call outside office hours, just leave a message and they say they'll call you back. If you are eligible for Legal Aid you can then get further free legal help with your case by phone and post. To use the helpline, call **0845 345 4345**. After you choose the welfare benefits option, you will be advised to listen to recorded messages about benefits. We recommend that you don't; the messages are long, sometimes confusing and you can read them at your leisure on the CLA website if you wish to. Instead go straight for the option of speaking to an adviser.

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

Citizens' Advice Bureaux (CAB)

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

Citizens Advice Scotland (CAS)

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

AdviceUK

Over 900 advice agencies are members of AdviceUK. Details of your nearest ones are available from AdviceUK's website at www.adviceuk.org.uk

AdviceNI

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

Disability Information Advice Line

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

Housing Associations

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

Doctors' surgeries

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

Local Authority

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

Benefit Enquiry Line: 0800 88 22 00

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

Internet

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

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

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