
When your condition changes

Posted by laravie - 2008/05/14 09:05

I'm currently on DLA - high rate mobility and low rate care and I have a premium added to my incapacity benefit because of this. Well I've improve in my mobility recently and I'm not certain I should be on the high-rate any more. However I'm anxious about the next step. If I contact DLA and tell them this, what will happen? Will they take away the whole of the DLA? Will I have to do a completely fresh application?

I'm about to send of the incapacity for work forms and doing that has brought home the fact that I am better than I was a few months ago....Will I lose that premium too? To tell the truth I wouldnt care as I get so upset and depressed at the medicals I'd rather go without the extra few pounds.

=====

Re:When your condition changes

Posted by pete17971 - 2008/05/14 09:56

Hi,

Just a quick reply, Jim will probably expand on it as he is the real expert on DLA.

Technically if your condition improves (or worsens for that matter)you should inform the DLA unit who will probably then carry out a review of your claim. This may mean having to fill out a new form, possibly having a new medical etc.

However before doing that, it is probably better to get face to face advice from a Welfare Rights Adviser who will try to assess whether your current care award is 'safe' and indeed whether or not you still would qualify for the Mobility Component.

You can get details of a local adviser from such as Community Legal Advice on 0845 3454345 or via their webiste:

<http://www.clsdirect.org.uk/>

Nothing beats face to face advice as they will be able to physically see you and discuss your care/mobility needs then assess whether or not you are likely to qualify.

Regards

Pete

=====

Re:When your condition changes

Posted by laravie - 2008/05/14 12:25

Thanks for your reply. The problem is that my disability is M.E. so is extremely variable from day to day hour to hour and seeing me in the flesh on one occasion can be very misleading. The other factor is that even though I am walking better, I still have the M.E reaction and am exhausted and unable to do anything for some time after. This can be an immediate reaction or the next day. Its this variability that makes me dread the medicals. I almost hope to have a flare up so that they can see what its like but its not that predictable.

The other thing that worries me is that if my DLA is reassessed, will they try to take back money they've already paid me? I couldnt give a date that my mobility improved because its been a subtle and gradual improvement. Plus I could be kidding myself and be back to square one in a month or two!

Anyways, I'll look that that link you gave, thanks again.

=====

Re:When your condition changes

Posted by jima1 - 2008/05/14 18:37

laravie wrote:

I'm currently on DLA - high rate mobility and low rate care and I have a premium added to my incapacity benefit because of this. Well I've improve in my mobility recently and I'm not certain I should be on the high-rate any more. However I'm anxious about the next step. If I contact DLA and tell them this, what will happen? Will they take away the whole of the DLA? Will I have to do a completely fresh application?

I'm about to send of the incapacity for work forms and doing that has brought home the fact that I am better than I was a few months ago....Will I lose that premium too? To tell the truth I wouldnt care as I get so upset and depressed at the medicals I'd rather go without the extra few pounds.

Hi,

I can understand your dilemma. I now have chronic progressive MS, which started as remitting/relapsing MS over 22 years ago. For the first few years i never claimed DLA, but when I did I was awarded HRM & LRC. When I received my award letter I was rather surprised that I'd been awarded HRM, because at times I could walk more than 50 metres without 'severe discomfort' which is the 'yardstick' the DWP use, although legally there is no set distance to be awarded HRM, since other factors have to be considered which include speed and manner of walking, and the time taken to walk x metres.

I rang the DWP and spoke to the Decision Maker who had adjudicated on my claim and expressed my concerns that I had been awarded HRM. The response I received was that they were aware that MS was a fluctuating condition and that had been taken into consideration when awarding me DLA HRM.

I also know a fair bit about ME as I have a close relative who has had it for over 15 years and she receives HRM & LRC. Also, I was a Welfare Rights Specialist for over 25 years and also sat on Social Security Appeal Tribunals, mainly for DLA until I retired in 2005.

I have seen many clients and appellants with ME (aka CFS) and some were as bad as people I know who have MS. The point I'm trying to make is that it's a well known fact that ME can 'wax and wane' and I've known some with ME who have been well for a few weeks or so, only to suffer a relapse later and certainly would have met the conditions for DLA HRM at that time.

Whilst Pete is of course correct in stating that you are obliged to inform the DLA Unit in Blackpool of any improvement in your condition, that only applies to a permanent improvement. It is quite possible that you are in a phase of remission with your ME, and it's quite possible, indeed it happens quite often with ME, that you could suffer a relapse.

Are you being treated by a consultant for your ME, or just by your GP ? I think before you inform the DWP of any improvement in your condition, you should discuss this with whoever is treating you and seek their opinion about your prognosis and also as Pete has suggested consult 'face to face' with a welfare rights adviser who will be fully aware of the conditions for an award of HRM.

Of course, if it's thought that your improvement is permanent, then of course you must notify the DLA Unit who will then review their decision on entitlement to mobility component, but if your care needs haven't changed your LRC should remain.

However from what you stated in your reply to Pete, it really sounds to me there is a daily variability in your walking ability, especially as you state you feel exhausted often, so it's obvious that you still have ME, and all the problems it can cause.

With fluctuating conditions like MS, ME etc etc, it's always difficult to decide whether your improvement is temporary, if it is, then that's not a change of circumstances and IMO shouldn't be reported to the DLA Unit until you've sought medical advice and seen a welfare rights adviser.

That's about the best advice I can give you in an open forum.

Let us know how you get on.

Best wishes

Jim

=====

Re:When your condition changes

Posted by Fred - 2008/05/14 21:48

I've had CFS/ME on and off for a number of years. At the moment it is improving, but I do not know how long this will last. I would be careful about informing anyone at DWP about improvement, as you could find that condition might get worse due to stress or medicals, etc.

The guidance given to doctors, that the public does not see, is to treat CFS/ME as a psychological condition, any specialist that you see via the NHS will recommend CBT, if your condition is mild to moderate. The research work that has been done into CBT and CFS/ME indicates that it will make the condition worse. You can see old posting about CFS/ME and benefits if you do a search on this site.

I used to be in a group for people with this condition and it usually improves in the summer, due to the fact some of the viral conditions associated with CFS/ME tend to improve in warmer weather. If you want to know about current treatment protocols go to the www.prohealth.com or type CFS/ME adrenals or CFS/ME Mitochondria.

=====

Re:When your condition changes

Posted by laravie - 2008/05/15 09:39

Thanks Jimal,

I'm not really treated by anyone now for my M.E. Its gone on for so long. I see my GP only when I need help with something not obviously related to my M.E. because nothing I've ever been on has really helped, so I just get on with it now.

I think my doubt comes in because most or the worst part of my pain and discomfort comes after the walking. On some days I will look as though walking is easy for me but people don't see what happens behind closed doors when I get home.

The biggest problem I have is with the fatigue and I find the effort of filling out these forms, getting in contact with people and so on is ridiculously difficult at times.

Fred wrote:

I've had CFS/ME on and off for a number of years. At the moment it is improving, but I do not know how long this will last. I would be careful about informing anyone at DWP about improvement, as you could find that condition might get worse due to stress or medicals, etc.

The guidance given to doctors, that the public does not see, is to treat CFS/ME as a psychological condition, any specialist that you see via the NHS will recommend CBT, if your condition is mild to moderate. The research work that has been done into CBT and CFS/ME indicates that it will make the condition worse. You can see old posting about CFS/ME and benefits if you do a search on this site.

I used to be in a group for people with this condition and it usually improves in the summer, due to the fact some of the viral conditions associated with CFS/ME tend to improve in warmer weather. If you want to know about current treatment protocols go to the www.prohealth.com or type CFS/ME adrenals or CFS/ME Mitochondria. Thanks very much Fred. I was sent for CBT a few years ago and I only lasted 2 sessions. It was totally the wrong thing for me - I couldnt do any of the exercises I was given and felt more depressed afterwards!

Thanks for the link, I'll take a look at that.

=====

Re:When your condition changes

Posted by jima1 - 2008/05/15 10:46

Hi,

Based upon what you've said about fatigue and discomfort after walking, in my opinion you still satisfy the criteria for DLA HRM, and again in my opinion, you don't need to inform the DWP of a change in circumstances.

As I'm sure Fred will bear me out, that what you describe is typical of the way ME affects many ME sufferers.

Best wishes.

Jim

=====

Re:When your condition changes

Posted by Fred - 2008/05/15 12:53

I had a look at the prohealth web site and it can be a bit confusing with regard to treatment protocols, as the site now seems to be promote a lot of supplements in conjunction with articles: a bit biased! It got a great notice board with some UK members, so you can post and get support.

The best product that I've used from this site is called Mitochondria Ignite. This is the only supplement that gets rid of the fatigue, low motivation and brain fog. I think it is essential to treat the cause of CFS/ME, as it is easy to be drawn into treating the symptoms for years: a mistake that I made.

Lyme Disease and Epstein Barr Virus have both been implicated in a large majority of people with joint problems and chronic fatigue (and even MS), according to a doctor who specialises in treating people with CFS/ME. See; 'Fibromyalgia: Understanding and Getting Relief from Pain That Won't Go Away' (2002) by Dr. Don L. Goldenberg. You can see the reviews for this book on Amazon. If possible, I would avoid any info from UK (books or organizations) as it is about 10 to 15 years out of date.

In the past I have avoided tests on the NHS as they are not very reliable: they did not detect that I had Klebsiella pneumoniae, which was the main cause of my CFS. The test for Lyme Disease on the NHS has not got a good reputation for reliability, according to postings that I read about 4 years ago.

=====

Re:When your condition changes

Posted by j.watson - 2008/08/07 21:11

jima1 wrote:

laravie wrote:

I'm currently on DLA - high rate mobility and low rate care and I have a premium added to my incapacity benefit because of this. Well I've improve in my mobility recently and I'm not certain I should be on the high-rate any more. However I'm anxious about the next step. If I contact DLA and tell them this, what will happen? Will they take away the whole of the DLA? Will I have to do a completely fresh application?

I'm about to send of the incapacity for work forms and doing that has brought home the fact that I am better than I was a few months ago....Will I lose that premium too? To tell the truth I wouldnt care as I get so upset and depressed at the medicals I'd rather go without the extra few pounds.

Hi,

I can understand your dilemma. I now have chronic progressive MS, which started as remitting/relapsing MS over 22 years ago. For the first few years i never claimed DLA, but when I did I was awarded HRM & LRC. When I received my award letter I was rather surprised that I'd been awarded HRM, because at times I could walk more than 50 metres without 'severe discomfort' which is the 'yardstick' the DWP use, although legally there is no set distance to be awarded HRM, since other factors have to be considered which include speed and manner of walking, and the time taken to walk x metres.

I rang the DWP and spoke to the Decision Maker who had adjudicated on my claim and expressed my concerns that I had been awarded HRM. The response I received was that they were aware that MS was a fluctuating condition and that had been taken into consideration when awarding me DLA HRM.

I also know a fair bit about ME as I have a close relative who has had it for over 15 years and she receives HRM & LRC. Also, I was a Welfare Rights Specialist for over 25 years and also sat on Social Security Appeal Tribunals, mainly for DLA until I retired in 2005.

I have seen many clients and appellants with ME (aka CFS) and some were as bad as people I know who have MS. The point I'm trying to make is that it's a well known fact that ME can 'wax and wane' and I've known some with ME who have

been well for a few weeks or so, only to suffer a relapse later and certainly would have met the conditions for DLA HRM at that time.

Whilst Pete is of course correct in stating that you are obliged to inform the DLA Unit in Blackpool of any improvement in your condition, that only applies to a permanent improvement. It is quite possible that you are in a phase of remission with your ME, and it's quite possible, indeed it happens quite often with ME, that you could suffer a relapse.

Are you being treated by a consultant for your ME, or just by your GP ? I think before you inform the DWP of any improvement in your condition, you should discuss this with whoever is treating you and seek their opinion about your prognosis and also as Pete has suggested consult 'face to face' with a welfare rights adviser who will be fully aware of the conditions for an award of HRM.

Of course, if it's thought that your improvement is permanent, then of course you must notify the DLA Unit who will then review their decision on entitlement to mobility component, but if your care needs haven't changed your LRC should remain.

However from what you stated in your reply to Pete, it really sounds to me there is a daily variability in your walking ability, especially as you state you feel exhausted often, so it's obvious that you still have ME, and all the problems it can cause.

With fluctuating conditions like MS, ME etc etc, it's always difficult to decide whether your improvement is temporary, if it is, then that's not a change of circumstances and IMO shouldn't be reported to the DLA Unit until you've sought medical advice and seen a welfare rights adviser.

That's about the best advice I can give you in an open forum.

Let us know how you get on.

Best wishes

Jim

=====

Re:When your condition changes

Posted by Kelpie - 2008/08/12 19:37

Can you explain more about the addition to Incapacity Benefit because you get DLA? I have never heard of this, although know I had a supplement to ICB carried over from the old sickness benefit/through invalidity benefit which was because of my earnings before starting the IC benefit. When I started on DLA HRMC first, then LRC added some years later, to MRC now, ICB didn't alter. Thanks.

=====